

# **A Proposed Strategy to Address Hepatitis C in Ontario 2009 - 2014**

**Prepared for the  
Honourable Minister David Caplan  
by the Ontario Hepatitis C Task Force**

**September 2009**

## Table of Contents

Letter to the Minister.....	2
Members of the Ontario Hepatitis C Task Force .....	3
Executive Summary .....	4
1. Introduction.....	5
1.1 Hepatitis C in Ontario.....	6
1.2 Ontario’s Response to Hepatitis C to Date.....	7
1.3 Ontario Hepatitis C Strategy – Why Now? .....	9
1.4 First Principles .....	10
2. Framework for Action .....	13
2.1 Treatment.....	13
2.2 Prevention.....	19
2.3 Education.....	23
2.4 Support.....	30
2.5 Surveillance and Research.....	34
3. Coordination and Implementation .....	38
4. Conclusion.....	40
5. Endnotes and References.....	41

Dear Minister Caplan;

It is a pleasure to offer to you on behalf of your Ontario Hepatitis C Task Force, the enclosed *Proposed Strategy to Address Hepatitis C in Ontario: 2009-2014*. This document reflects the knowledge gathered through an extensive community consultation process, dialogue and discussion with relevant groups within the Ministry of Health and Long-Term Care and other ministries of the Government of Ontario, and the experience and expertise of the dedicated women and men that make up your Hepatitis C Task Force.

Hepatitis C is an insidious disease that has taken far too many lives in Ontario. If left unchecked in its spread, hepatitis C will continue to impact the lives of Ontarians and cost millions of dollars to Ontario taxpayers annually. While Ontario has done much to assist those infected through the blood system, our consultations across Ontario have made clear that a comprehensive strategy is needed to manage this disease. By investing in effective targeted community programs and services, more integrated models of health care delivery, and education and prevention programs, it is our belief that Ontario can control this disease and improve health outcomes for thousands of Ontarians currently infected with, or at risk of being infected with, this deadly disease.

In this report, your Task Force has provided you with a template for action which we feel will go far to achieving a comprehensive approach to disease management for hepatitis C. We have noted that to control and manage this disease cooperation and coordination will be required, not only within the health care system, but across systems and jurisdictions. You will also note that our recommendations respond to the reality that the impact of hepatitis C is increasingly being felt by the most vulnerable among us.

As a person living with hepatitis C, I have been given a great opportunity to work with the wonderful group of people on the Task Force, in your ministry, and across Ontario who are all dedicated to making Ontario a better and healthier place for everyone to live. I thank you for this opportunity and encourage you to continue to listen to the voices and the experiences of people living with hepatitis C, who come from all walks of Ontarian life.

We look forward to continuing to serve you and the people of Ontario, both individually and as your Task Force on hepatitis C.

Yours truly,

A handwritten signature in black ink, appearing to read 'John C. Plater', written in a cursive style.

John C. Plater  
Chair, Ontario Hepatitis C Task Force

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# Executive Summary

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The hepatitis C virus (HCV) is transmitted through exposure to infected blood. Individuals can remain asymptomatic for many years after initial infection. HCV is a major cause of acute hepatitis and chronic liver disease, including cirrhosis and liver cancer. It is estimated that 110,000 Ontarians are infected with HCV. Of those, one-third are undiagnosed, are unaware they are living with the virus, and unwittingly may be passing it on to others. The progression of this largely curable disease among people infected over the past 30 years – including those who have not been diagnosed or treated – is expected to result in an explosion of costly liver-related complications.

The majority of those infected (54%-56%) are current or former Injection Drug Users (IDUs). Eleven per cent to 13 per cent were infected through blood transfusions, and 30%-35% through unknown or other possible risk factors.

Higher risk populations include: prisoners, street involved youth, those who share drug-using equipment, those use unsafe tattooing and piercing practices, and those from countries with prevalence rates higher than that in Canada. Aboriginal people also are a higher risk population as a result of their over-representation in the prison system and among the drug-using population.

Although over the years Ontario has invested in HCV responses, the challenge of hepatitis C requires a strategic and coordinated approach. There is an urgent need for more focused programs that reach marginalized populations – those most affected by and at risk for HCV. Active intervention in disease management – including education, prevention, comprehensive assessment, provision of harm reduction resources, supported treatment, and coordination of services – makes sound economic sense. The information and recommendations in this proposed Strategy are based on data gathered from 13 community consultations held across Ontario in 2007-08, reports and recommendations from provincial and national agencies involved in hepatitis C, and input from the Ontario Hepatitis C Task Force (OHCTF) Research Working Group and Clinical Issues Working Group.

Implementing this proposed Strategy's recommendations would strengthen both Ontario's response to HCV and the health services for people who use drugs and other populations at higher risk for HCV, HIV and other blood-borne pathogens. It also would have a broader impact on reducing other communicable diseases.

The recommendations in this proposed Strategy build on existing work undertaken by ministry program areas, local public health units, and local health and social service agencies to move Ontario to a more comprehensive and integrated response to hepatitis C, both inside and outside the health sector. Strengthening the response to HCV is required urgently to reduce the future disease burden and associated costs to Ontario's health care system. Investing in the goals, objectives, and activities outlined in this proposed Strategy – and the stewardship required to implement this Strategy – would capitalize on existing programs and make Ontario a Canadian leader in responding to HCV.

# 1. Introduction

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A recent report from the Canadian HIV/AIDS Legal Network and the Centre for Addictions Research of B.C. (CARBC)<sup>1</sup> notes that the World Health Organization (WHO) has referred to HCV as a “viral time bomb” because it can spread quickly and quietly for some time before the force of its explosive impact hits health care systems. WHO adds that “hepatitis C already weighs heavily on the health care system. Its public health and economic impact is expected to double in only a few years.”

HCV is a major cause of acute hepatitis and chronic liver disease, including cirrhosis and liver cancer. HCV is the leading cause for liver transplants worldwide.<sup>2</sup> “Out of every 100 people infected with HCV, 75 to 85 may develop chronic infection, 10 to 20 may develop cirrhosis over a period of 20 to 30 years, and one to five may die from the consequences of long-term infection including liver cancer.”<sup>3,A</sup>

We can respond to hepatitis C because it is largely preventable. It is not spread through casual contact and compared with HIV and hepatitis B, the risk of sexual transmission is low. Most new cases can be traced to specific risk factors, which can be addressed through prevention, education, and the comprehensive distribution of safer drug-use equipment to encourage social and behavioural change. Between 42 per cent and 80 per cent of those who undergo a single course of drug therapy will clear the virus, with a significant number actually reversing liver damage.<sup>5</sup> Improved treatment outcomes are associated with early detection and access to treatment. Expert analysis shows that strategic investments could reduce projected costs and result in future savings.<sup>6</sup>

It is with a strong sense of urgency that the Proposed Strategy to Address Hepatitis C in Ontario 2009-2014 was developed by the Ontario Hepatitis C Task Force (OHCTF), in consultation with the Hepatitis C Secretariat, (both of which were established to guide the provincial response to this growing epidemic), and the Ministry of Health and Long-Term Care (MOHLTC).

Responding to hepatitis C in Ontario requires a strategic plan to achieve positive long-term outcomes for those at risk for/infected with HCV as well as for the health care system. This document outlines a strategy which uses a systems approach<sup>B</sup> to respond to hepatitis C in Ontario. The Strategy makes several recommendations to build a solid foundation and a focused and coordinated effort to address all HCV-related issues in Ontario.

The proposed Strategy uses a broad, evidence-based approach to coordinate and build on existing programs to increase the quality of care and to target development of a patient-centred, results-driven, long-term strategy.

<sup>A</sup> It is important to note that in mortality statistics most of the above-mentioned deaths are not classified as being caused by hepatitis C. Desai and Peltekian report that appropriate representation of data impacts on the public perception of the leading causes of death in Canada. This reporting variance may also influence the design and delivery of health services by regional health authorities and influence the prioritization of these patients with respect to referral and treatment.<sup>4</sup>

<sup>B</sup> A systems approach is the application of systems thinking. “...systems thinking is a way of helping a person to view systems from a broad perspective that includes seeing overall structures, patterns and cycles in systems, rather than seeing only specific events in the system. This broad view can help you to quickly identify the real causes of issues in organizations and know just where to work to address them.” (Adapted from “Field Guide to Consulting and Organizational Development” – available at <http://www.authenticityconsulting.com>)

This document has three major sections: Section 1 focuses on the background of hepatitis C in Ontario, including the provincial response to date, and the principles underpinning Ontario's approach to addressing HCV. Section 2 outlines a framework for action with strategic initiatives for the next five years in the following priority areas:

- Treatment
- Prevention
- Education
- Support
- Research and Surveillance

Section 3 outlines the role and responsibilities of key stakeholders in coordinating the proposed Strategy and reporting on its implementation. This approach is consistent with MOHLTC's shift to a stewardship model in managing the province's health care system under which Local Health Integration Networks (LHINs) assume more operational activities and the ministry provides strategic, system-level direction and coordination, and ensures accountability.

## 1.1 Hepatitis C in Ontario

It is estimated that 110,000 Ontarians – or slightly less than 1 per cent (0.85%) of the total population – are infected with HCV. The majority (54%-56%) are current or former Injection Drug Users (IDUs). Eleven per cent to 13 per cent were infected through blood transfusions, and 30%-35% through unknown or other possible risk factors including:

- Sexual, vertical [mother to child], or nosocomial (infections originating in a hospital or a health care service unit, but secondary to the patient's original condition) transmission as a result of non-sterile invasive procedures completed outside of Canada
- The sharing of drug preparation and inhalation equipment and/or the use of unsterilized tattooing and piercing equipment<sup>7,8,9,10</sup>

First identified in 1989, HCV is one of the most common causes of acute hepatitis and chronic liver disease worldwide.<sup>11</sup> “An estimated 250,000 people in Canada are infected with HCV, and more than 3,200 to 5,000 individuals are newly infected with HCV every year.”<sup>12</sup> HCV is transmitted through exposure to infected blood. Individuals can remain asymptomatic for many years after they are first infected. By 1990, when a serologic test for the virus was first licensed, Ontario already had a large reservoir of chronically infected individuals. Diagnostic testing on a broad scale did not begin until the mid-1990s and it wasn't until 1998 that all Canadian provinces made reporting hepatitis C diagnoses to local public health units mandatory.

Anti-HCV is the antibody screening test used to determine prior HCV exposure. In Ontario, hepatitis C is a reportable disease under the Health Protection and Promotion Act, 1990.<sup>13</sup> The current case definition requires confirmation of a positive anti-HCV antibody result using two Enzyme-linked Immunoassay (EIA)<sup>c</sup> laboratory tests. Once the antibody has been confirmed, results are forwarded to local public health units for investigation and follow up in accordance

<sup>c</sup> EIA – Enzyme-linked Immunoassay is a biochemical technique used mainly in immunology to detect the presence of an antibody or an antigen in a sample.

with the Ontario Public Health Standards, 2008.<sup>14</sup> Case definitions in Australia, the U.S., and U.K. distinguish between acute and chronic HCV infections. Case definitions in Canada and Ontario do not.<sup>15</sup>

Laboratory technology and process enhancements – specifically through the use and improvement of Polymerase Chain Reaction (PCR)<sup>D</sup> testing – have made it possible to go beyond determining prior exposure to HCV to:

- Confirm the presence of an active viral infection
- Determine the amount of active virus and the genetic variation or genotype of the disease

These advancements play a critical role in determining the actual status of HCV infection. While spontaneous viral clearance occurs within the first three months of diagnosis in approximately 20 per cent of those who acquire HCV, the mechanisms responsible for this clearance – or the persistence – of the disease remain uncertain. It is important to note, however, that the rates of spontaneous clearance cited in the literature range from 10%-50% with higher rates in females and Aboriginal populations, and lower rates in people who use illicit drugs and those co-infected with HIV.<sup>16,17,18</sup>

About four times more Ontarians are infected with HCV than are infected with HIV.<sup>19</sup> An estimated 96 per cent of co-infected (HIV and HCV) individuals have a history of past or current injection drug use.<sup>20</sup> Despite the scope of HCV infection in Ontario, no comprehensive network of clinics, community-based organizations or other services have been established similar to those serving people with HIV. Consequently, existing services that engage those who are higher risk – such as the street-involved, those who use drugs or tattoo parlours, and those who have body piercing done in unregulated facilities – are addressing hepatitis C beyond their current mandate and without additional funding.

Ontario's Aboriginal population has a disproportionately higher rate of incarceration, drug use, and HCV risk. When considering this it is important to understand the social context, including the issue of stigmatization and marginalization of Aboriginal peoples in Ontario and the historic oppression, marginalization, and colonization that have contributed to their low health and socioeconomic status in Canada. As the Canadian Aboriginal AIDS Network emphasizes, it is important to understand the many reasons why Aboriginal people are at higher risk for HCV and over-represented in the prison system.<sup>21</sup>

## 1.2 Ontario's Response to Hepatitis C to Date

To date the MOHLTC has supported a number of initiatives in response to HCV:

- Ontario opened the first Needle Exchange Programs (NEP)<sup>E</sup> in 1989 as a designated public health program. The Needle and Syringe Programs (NSPs) provide needle and syringe exchange services across Ontario and help to reduce the risk of HCV (and other blood-borne viruses) transmission by increasing access to sterile needles and syringes, removing used needles from community circulation, and educating clients on the risk of needle reuse. Currently, NSPs

<sup>D</sup> PCR – Polymerase Chain Reaction is used to reproduce (amplify) selected sections of DNA or RNA.

<sup>E</sup> “NEP” is an evolving term. The current term used is Needle and Syringe Programs.



distribute a small proportion of the sterile needles required. It is estimated that annually every person who injects drugs needs approximately 1,000 needles.<sup>22</sup> The Ontario Public Health Standards, 2008, state that the board of health “shall ensure access to a variety of harm reduction program delivery models which shall include the provision of sterile needles and syringes and may include other evidence-informed harm reduction strategies in response to local surveillance.”

- The Injection Drug User Outreach Program has been in operation since 1997/98. The AIDS Bureau of the MOHLTC provides funding for local community-based prevention workers to provide HIV prevention, education, support and referrals to Injection Drug Users at risk of contracting HIV and HCV.
- Since 1998, the Ontario Hepatitis C Assistance Plan (OHCAP) has provided financial assistance to individuals infected through the Ontario blood system on or before December 31, 1985 or between July 2, 1990 and September 28, 1998. As of June 2009, OHCAP has received more than 7,773 applications, accepted more than 4,032 for assistance, and distributed more than \$100M in financial aid under the program. In October 2004, Ontario announced the hepatitis C prevention and treatment action plan. This includes:
  - Publicly reporting on how Ontario spends federal funding to provide treatment to people living with hepatitis C acquired through the Canadian blood supply before 1986 and after 1990
  - Creating the Hepatitis C Secretariat and Ontario Hepatitis C Task Force<sup>23</sup>
- The Ontario Harm Reduction Distribution Program (OHRDP) has operated since 2005/06. Today, the program also includes knowledge transfer and the dissemination of research. The program purchases and distributes additional harm reduction materials – sterile water, vitamin C, tourniquets, alcohol swabs, filters, and steri-cups – used in drug and injection preparation to complement the needles and syringes supplied through Ontario’s 34 participating NSPs and their partner agencies. The goal of this program is to reduce equipment sharing and thereby the risk of HCV, HBV, and HIV.
- In 2006/07, the MOHLTC launched a province-wide public awareness campaign encouraging at-risk individuals to talk to their doctors about hepatitis C and be tested. It also provided options for those previously diagnosed with HCV. This campaign consisted of television and newspaper ads, posters, and a pamphlet – all of which directed viewers/readers to the [hepcontario.ca](http://hepcontario.ca) website to assess their risk of exposure to the disease.
- In February 2007, the publicly funded Ontario Hepatitis Nursing Program (OHNP) was announced by then Minister of Health and Long-Term Care, the Honourable George Smitherman.<sup>24</sup> OHNP is mandated to:
  - Increase Ontario’s hepatitis C treatment capacity, with a focus on underserved communities that have a high hepatitis C prevalence
  - Reduce the rate of serious liver disease such as cirrhosis, liver failure and hepatocellular carcinoma

- In 2007/08, the Hepatitis C Secretariat of the MOHLTC funded the development of a comprehensive toolkit consisting of prevention, education, and harm reduction resource materials for use with high-risk populations such as those who use drugs, youth, Aboriginal communities, and those within the prison system. The website and toolkit communications vary in content, format, language level, and intended audience, allowing service providers to select the most appropriate materials for their communities.

The Federal Hepatitis C Undertaking Agreement signed in January 2002 is focused on:

- Understanding and addressing the unique circumstances of those infected with HCV through the blood system before January 1, 1986 and after July 1, 1990
- Increasing the capacity of publicly financed health care programs to ensure that all Canadians infected with hepatitis C through the blood system have reasonable access to health care services for treatment

To date, Ontario has received \$88.4 million from the Government of Canada – out of a total of \$132.6 million it will receive over a 20-year period – as part of the Federal Hepatitis C Undertaking Agreement.<sup>25</sup> The purpose of this agreement has been to provide provinces and territories with funding for programs and services for people with hepatitis C, unlike other programs which have focused on compensation.

### 1.3 Ontario Hepatitis C Strategy – Why Now?

One-third of those with HCV are undiagnosed, are unaware they are living with the virus, and may unwittingly pass the virus on to others.<sup>26,27</sup> The progression of this largely curable disease among those infected over the past 30 years – including those who have not been diagnosed or treated – is expected to result in an explosion of costly liver-related complications.<sup>28</sup>

Ontario can prepare for this, with a well coordinated, multi-year strategy to:

- Prevent new infections
- Provide timely care for persons living with hepatitis C

Active disease management – including education, prevention, comprehensive assessment, provision of harm reduction resources, supported treatment, and coordination of services – makes sound economic sense. The B.C. Centre for Disease Control estimates that the average per patient lifetime cost for HCV – from the time of diagnosis to death, including medical costs and the individual's economic loss – is \$1 million.<sup>29</sup>

#### First Nations

To date, Ontario's stand is that the federal government has the primary responsibility of providing health care services to First Nations people. While it is essential to recognize provincial and federal jurisdictional boundaries, the distinct needs and realities related to mobility of First Nation communities must be considered to achieve a comprehensive, effective Ontario Hepatitis C Strategy. It is time for the provincial government to recognize that First Nations people are also Ontario citizens and must be considered in all HCV strategic plans, priorities, and initiatives.

The Proposed Strategy to Address Hepatitis C in Ontario: 2009-2014 presents an inclusive approach to align with the principles of harm reduction and equity. One of the strategy's main principles involves ensuring "equal access to high-quality treatment, prevention, support, and educational interventions" for all Ontarians at risk of/living with HCV, including First Nations individuals accessing the provincial health care system. This could include greater focus on improving access to harm reduction programs among Aboriginal people living on reserve, while simultaneously respecting Federal, Provincial and Territorial (F/P/T) jurisdictions.

Although over the years Ontario has responded to HCV, the current challenge requires a strategic and coordinated approach to develop a comprehensive and effective strategy emphasizing treatment, prevention, intervention, education, support and research, and surveillance. Today, there is an urgent need for more focused programs that reach marginalized populations – those most affected by and at risk for HCV.<sup>30</sup>

The establishment of Local Health Integration Networks (LHINs) and their strong emphasis on planning for their communities has set the stage for more coordinated and flexible programming and service provision. LHINs could be identified as a vehicle for HCV treatment and education with accompanying prioritized funding.

There is a synergy in the MOHLTC now to bring together a coordinated strategy to respond to HCV in Ontario. While several pieces are in place, there is, however, no coordinated hepatitis C focus.

## **1.4 First Principles**

The Proposed Strategy to Address Hepatitis C in Ontario 2009-2014 is based on an integrated approach and would inform relevant activities of the five major areas: treatment, prevention, education, support, and surveillance and research.

### **Access Equity**

- All Ontarians at risk of/living with HCV should have equal access to high-quality treatment, prevention, support, and education interventions, regardless of where they live or how they contracted the disease, individual linguistic or cultural barriers, socioeconomic or education level.

### **Harm Reduction Approach**

- Harm-reduction is an evidence-based, pragmatic approach to drug use that aims to reduce or mitigate the harmful impacts of drug use on individuals and communities by reducing transmission of blood-borne pathogens through the provision of sterile needles and other drug-using equipment without requiring individuals to quit using drugs. While helping people to stop using drugs is an appropriate long-term goal for some, harm reduction strategies put the emphasis on the most immediate, achievable and positive changes, whether or not they can be shown to reduce consumption.

## **Effective Partnership and Collaboration**

- Effective implementation of the Strategy would require collaboration between different sectors of health services delivery, including community-based, clinical, and hospital-based care, and between relevant provincial program areas within the MOHLTC and other ministries, and with different levels of government.

## **Reducing Stigma and Discrimination**

- The stigma and discrimination associated with injection drug use that those living with hepatitis C suffer can be barriers for those at risk for HCV infection accessing appropriate programs and services. All HCV programs and services in Ontario should be delivered in a non-judgmental, non-discriminatory manner.

## **Monitoring and Evaluation**

- Regular monitoring and evaluation are required to guide Strategy implementation, track progress in each of the five areas, and to provide opportunities for revising goals and objectives based on:
  - The results of the evaluations
  - Emerging issues
  - New technologies and treatment advances
- It would also ensure transparency and accountability via annual progress reports.
- Monitoring and evaluation will focus on a key factor in the role of stewardship – whether programs are delivering the intended services to the intended populations.

## **Greater Involvement of People Living with Hepatitis C**

- The Greater Involvement of People Living with HIV/AIDS (GIPA)<sup>31</sup> demonstrated that people living with this virus brought a unique perspective to the development of policies and programs and the successful response to HIV/AIDS.
- This proposed Strategy involves people living with hepatitis C having a larger role in developing policies and programs that respond to the disease. This may bring a personal experience perspective to the development of policies and programs while public acknowledgement of living with HCV may help reduce the stigma and discrimination.

This proposed Strategy's recommendations build on existing work undertaken by ministry program areas, local public health units, and local health and social service agencies to move Ontario to a more comprehensive and integrated response to hepatitis C, both inside and outside the health sector.

The proposed Strategy information and recommendations are based on:

- Data gathered from 13 community consultations<sup>F</sup> held across Ontario in 2007-2008
- Reports and recommendations from provincial and national agencies involved in hepatitis C
- Input from both the OHCTF Research and the Clinical Issues working groups

Community consultations involved all major stakeholders, including:

- People living with HCV
- Health care providers
- Addictions and mental health professionals
- Public health officials
- Corrections nurses
- Pharmaceutical industry representatives
- Housing programs/shelters
- Researchers
- Community-based organizations including AIDS Service Organizations, community health centres (CHCs) and organizations serving Aboriginal communities
- Other agencies that deliver education, treatment, and support to people living with HCV/at risk for HCV infection, including staff of NSPs and harm reduction programs
- Ontario Hepatitis C Task Force members

Implementing the proposed Strategy's recommendations would not only strengthen the HCV response in Ontario, but would have a broader impact on reducing other communicable diseases and play a role in strengthening health services for those who use drugs and those at higher risk for HCV, HIV and other blood-borne pathogens.

The proposed Strategy's initiatives would build on the successes and existing infrastructure and support established for both provincial and local programs, including the increasing volume of programmatic research being used to shape policy development and service delivery in this field. The recent evaluation of the Ontario Harm Reduction Distribution Program (OHRDP), for example, has underscored the extent to which uptake in the program – i.e., changing the risk environment – has a positive impact in reducing the drug equipment sharing practices that increase the risk of HCV infection.

At least 80 per cent of those living with HCV are current or former IDUs.<sup>32</sup> There are others, including those infected through the blood supply. Ontario has set aside up to \$200 million to provide financial assistance to individuals infected with HCV through the blood supply before 1986 and after 1990. Of this amount, slightly more than \$100 million has been spent to date. In contrast, funding to deliver community-based HCV programs and services to all other at risk/living with HCV populations stands at only \$4.4 million.

<sup>F</sup> Multi-stakeholder consultations were held in Thunder Bay, Sudbury, Windsor, London, Hamilton, Ottawa, Kingston, Peterborough, Mississauga, Toronto, Sault Ste. Marie, Kitchener and Owen Sound. Representatives from the following stakeholder groups were invited: AIDS service organizations, Roche and Schering Pharmaceutical, Needle Exchange Programs, people living with or affected by HCV, Community Health Centres, tattoo and piercing parlours, Ministry of Community Safety and Correctional Services, housing/shelters, Aboriginal services, psychiatry, methadone clinics, Public Health Agency of Canada (PHAC), Public Health Units, university researchers, treating physicians, Hemophilia Ontario, Nurses, support group leaders, Canadian Liver Foundation, and addiction treatment centres.

## 2. Framework for Action

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Community consultations identified activities required for an effective HCV response in five priority areas. These are not listed in order of priority and should be developed and delivered concurrently for optimal impact. Where relevant and available, these activities would leverage existing programs and resources to ensure the most cost-effective approach. In developing this proposed strategy, the OHCTF recognized that not all activities recommended through the consultation process are feasible within the five-year time frame, even with additional resources. It has, therefore, included goals, objectives, and actions for only the most urgent priorities. Additional activities recommended through consultations should be considered for implementation.

The following framework aims to deliver a comprehensive and integrated response to hepatitis C in Ontario in treatment, prevention, education, support, and research/surveillance, based on the aforementioned principles.

### 2.1 Treatment

**Goal: Improve access to the treatment continuum; including pre-, during, and post-treatment for people living with HCV.**

While no vaccine prevents hepatitis C, there is an effective antiviral treatment, consisting of pegylated interferon and ribavirin, now available. Undergoing a full recommended treatment dosage increases the rate of successful outcomes.<sup>33, 34, 35</sup> Current cure rates for HCV vary according to the genotype of the virus and range from 42%-80%.<sup>36</sup> Even if HCV is not completely cleared, a 24- or 48-week course of antiviral treatment, which can be extended to 72 weeks if clinically indicated, significantly improves liver function and reduces progression of the disease.<sup>37</sup> Studies have also indicated that such treatment is cost-effective, given the gains in life expectancy and economic productivity for people living with HCV.<sup>38</sup> However, there currently are many treatment-eligible patients who do not access treatment or discontinue treatment for a range of reasons, including poor access to appropriate care and psychosocial support during treatment, debilitating adverse events, and concurrent disorders such as mental health and addiction issues.<sup>39, 40</sup>

Treatment outcomes also are influenced by social determinants of health such as homelessness, poor nutrition, poverty, stress, and lack of education, income, and social support. Social determinants of health have a significant impact on the predisposition of individuals and groups to illness, as well as the ways in which they experience and recover from illness. The impact of social determinants of health can affect a person's susceptibility to illness and result in more complications and longer recovery times.<sup>41</sup>

## **Objective 1: Increase the access to HCV treatment and care for higher risk individuals and groups.**

People who use drugs often have poor access to health services. They require additional support services to ensure treatment readiness and to increase the likelihood of adherence during treatment.<sup>42</sup> Although 42%-80% of those who complete treatment are able to clear the virus, existing approaches often do not address important underlying factors – such as addiction, mental health, nutritional status, concurrent disorders, and poverty – that have a significant impact on both treatment readiness and adherence. Early testing and counselling are critical parts of the care and treatment continuum. Increasing access to treatment for higher risk populations by addressing the continuum of health and social service needs would improve health outcomes and reduce new infections by reducing the number of people with active HCV in Ontario.

The primary risk factors for acquisition of hepatitis C are the practices and behaviours associated with injection drug use. People who use drugs also are at risk for alcoholism, psychiatric illness, and psychosocial instability.<sup>43</sup> In light of all these factors, historically this marginalized group has not been considered a viable candidate for hepatitis C treatment. Yet studies have shown that with close supervision, clients with complex social and mental health issues have treatment success rates similar to those of the general population.<sup>44,45,46</sup> Nursing support also has been shown to increase treatment adherence from 30%-90%.<sup>47</sup>

The Ontario Hepatitis Nursing Program (OHNP) was established to increase hepatitis C treatment capacity in Ontario's underserved, high-prevalence communities. The care provided by OHNP nurses is intended to ensure that more of those living with HCV have access to treatment which can help improve their quality of life and mitigate or prevent serious complications. The program focuses on support and close monitoring of clients throughout the treatment continuum and results in client readiness and increased adherence to treatment, thereby improving clinical outcomes.

OHNP nurses also record standard hepatitis C and treatment outcomes data – much needed information that will provide guidance on future prevention and treatment initiatives and help in the further development of standards of care.

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**Recommendation:** Expand the Ontario Hepatitis Nursing Program to 35 treatment nurses.

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The *Management of Chronic Hepatitis C: Consensus guidelines 2007* recommended adopting a multi disciplinary team approach to the care and treatment of people living with HCV as a strategy to increase treatment adherence. This also was one of the most pressing priorities identified in community consultations. The health human resources required to deliver an appropriate continuum of care and treatment include:<sup>6</sup>

- Specialist physician (e.g., gastroenterologist, hepatologist, and infectious disease specialist)
- Primary care physician
- HCV treatment nurse
- Nutritionist
- Psychiatrist or psychologist

<sup>6</sup> The list of health human resources is not in order of priority.

- Mental health and addiction counsellor
- Case worker/manager
- HCV outreach workers
- HCV community coordinators

Section 2.4 identifies the additional supports required to address the social determinants of health. The MOHLTC has decentralized key components of the health care system through Local Health Integration Networks (LHINs) and encouraged the grouping of clinical practices into Family Health Teams (FHTs) that include physicians, specialists, and allied health professionals. The proposed model for the higher risk HCV population is “one-stop shopping.” These teams would be located throughout the province and would supplement a core staff team of physicians, infectious disease specialists, hepatologists, gastroenterologists, nurses, mental health and addiction professionals, case managers and administrative staff, and other staff required to deliver services to a patient population with complex health and social service needs.

These multidisciplinary teams would be similar to those found in CHCs, FHTs, Diabetes Clinics, and HIV Outpatient Clinics. Establishing them to deliver care, treatment, and support is consistent with proven models of health care delivery for complex health conditions and would expand access to a range of health care providers. In addition to medical services, most people living with HCV require access to a range of social services. A holistic approach to delivering care and treatment to these people, many of whom have concurrent disorders, would ensure optimal treatment outcomes. For example, higher risk populations need assistance in acquiring health cards, drug coverage, and access to mental health and addiction services.

Expanding this holistic approach to include assistance with housing and other social services would be facilitated where primary health care services – such as the integrated teams described above – were coordinated with other services, including vocational counselling and housing assistance. Expanding the use of broad assessment tools such as those being piloted in mental health would assist these teams in understanding the needs of people living with/at risk for HCV infection.

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**Recommendation:** Adopt a holistic approach, including a multidisciplinary model and a range of support services, to deliver comprehensive care and treatment for people with HCV in acute care, community-based, and institutional settings, such as provincial correctional facilities.

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Optimal hepatitis C care should be accessible throughout Ontario. The physical size of the province and the distribution of health care services throughout Ontario present a problem to those who live in rural/remote areas who cannot access required care locally.

The ministry’s Northern Health Travel Grant Program (NHTGP) helps defray transportation costs for eligible residents of northern Ontario who must travel long distances within Ontario or to Manitoba to receive medically-required, insured specialty services that are unavailable locally.



Unless advance funding is provided through NHTGP designated third-party agencies, eligible persons incur the cost of transportation and later are reimbursed. Travel grants are based on the two-way road distance a client travels, less a 100-kilometre deductible. The grants do not cover meals or accommodation. In the event a designated third-party agency advances funds to an eligible client, that agency claims the grant on behalf of their client.

Another barrier-creating issue is the lack of hepatitis C treating physicians in rural/remote areas of Ontario. Solving this issue requires the integration of innovative models of health care delivery, such as telemedicine, which can virtually connect local physicians and clients in remote areas with hepatitis C treatment experts in urban centres.

The Ontario Telemedicine Network (OTN) provides the delivery of health care services and education via two-way videoconferencing systems and uses the latest telediagnostic instruments including digital stethoscopes, otoscopes, high-resolution patient examination cameras, endoscopic equipment and digital imaging facilities that transfer data between users in urban, rural and remote sites across the province.<sup>48</sup>

Telemedicine is changing the way health care and education is delivered in Ontario by bringing patients and health providers face-to-face no matter how far apart they are. Telemedicine clinical appointments are becoming as easy to arrange and carry out as traditional health care professional office visits.<sup>49</sup>

More than 2,000 health care professionals deliver care using OTN in more than 615 sites across the province. In 2008, more than 42,000 telemedicine clinical consultations were conducted in Ontario.<sup>50</sup>

Using innovative models of delivery would help ensure health care is accessible to all Ontarians affected by hepatitis C, regardless of where they live. Such models can serve as effective cost-savings measures if they use existing infrastructure to increase access to health care services. Additionally, if a model like Telemedicine becomes more widely adopted, there would be an expected decrease in the use of the NHTGP which would cut costs further.

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**Recommendation:** Increase the use of innovative models of health care delivery to reduce geographic barriers associated with hepatitis C care and treatment.

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## **Objective 2: Implement guidelines for clinical management of HCV infection and an expanded treatment algorithm for health care providers.**

Although the consensus guidelines on managing chronic HCV infection were updated in June 2007, not all health care providers are aware of them or the important changes related to clinical decision-making. The treatment algorithms in the current guidelines also need to be expanded to include HCV testing, additional queries during treatment, and post-treatment clinical care up to and including palliation for non-responders/those in relapse.

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**Recommendation:** Provide continuing support for the ongoing development, adoption and regular updating of National Consensus Guidelines<sup>51</sup> as required to reflect treatment advances.

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The question of liver transplants for people living with HCV (or co-infected with HIV) who are on methadone maintenance therapy, or have other indicators that previously precluded them from becoming viable liver transplant candidates, has been an issue in the past and requires clear guidance based on current clinical evidence.

Although the need for liver transplants would not be eliminated through improved treatment outcomes, for those with HCV, it would be reduced. Thus, there would be more donated livers which would improve access to those who still require transplants. This may result in those previously rejected as transplant candidates because of behaviours common in HCV-infected people, being given access to liver transplants.

In its review of literature and recommendations for actions on issues related to organ transplantation in patients who are HIV positive, the Ontario Advisory Committee on HIV/AIDS (OACHA) recommended: “The Minister of Health and Long-Term Care publicly endorse the principle that HIV-positive individuals, including persons co-infected with hepatitis B or C, who meet eligibility criteria and for whom there are effective antiretroviral options available for treatment following surgery, must be considered viable candidates for organ transplantation.”<sup>52</sup>

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**Recommendation:** Review best practices and current clinical evidence regarding liver transplantation for people living with HCV who have advanced liver disease. Communicate those findings to health care providers and community-based organizations serving those living with HCV and/or HIV.

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The Clinical Issues Working Group of the OHCTF can continue working with treating physicians, relevant specialists – including gastroenterologists, hepatologists, and infectious disease specialists – and develop an expanded standard treatment algorithm and HCV management tool for health care providers throughout Ontario. This would include providing advice to relevant external stakeholders (such as the Ontario Medical Association, College of Physicians and Surgeons of Ontario, and the Registered Nurses Association of Ontario, and the College of Nurses of Ontario) and ministry program areas on incorporating these documents into planned health care provider education programs.

The expanded treatment algorithm can identify each step in the treatment process, from HCV antibody testing to HCV PCR RNA testing through treatment counselling and decisions regarding the appropriate length of treatment through to post-treatment assessment and beyond.

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**Recommendation:** Work with relevant specialists and treating primary care physicians to implement updated guidelines and a related standard treatment algorithm to assist health care providers in managing HCV infection in treatment-ready patients.

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### **Objective 3: Improve access to HCV treatment that reflects current clinical practice and emerging evidence.**

The existing process for accessing HCV treatments through the Ontario Drug Benefit (ODB) program's Exceptional Access Program (EAP) is time- and labour-intensive. To improve access to treatment and collected hepatitis C treatment data we require:

- Greater flexibility
- A mechanism for acquiring the drugs efficiently
- The ability to track hepatitis C related treatment outcomes

The Ontario Public Drug Programs (OPDP) recently completed a review of the eligibility criteria for approving medications for the treatment of chronic hepatitis C. The review included an assessment by the ministry's expert committee – the Committee to Evaluate Drugs (CED) – advice from experts in the treatment of viral hepatitis and took into consideration the 2007 Management of Chronic Hepatitis C: Consensus Guidelines, and the opinions of experts submitted by the OHCTF's Clinical Issues Working Group.

Unfortunately, many of the changes proposed by the OHCTF's Clinical Issues Working Group were not incorporated into the revised criteria. The new criteria continue to make it difficult for those clients who are infected with genotype 1 and 4 to qualify for funding.

Current criteria require clients to have at least two elevated ALT values (more than 1.5 times the upper limit of normal values) within the previous six months, OR fibrosis on biopsy (Metavir stage 2 or greater). The difficulty with this is that if a client has normal ALT values, the criteria require an invasive biopsy to confirm stage 2 or greater fibrosis.

The criteria should ensure that they do not discriminate against those who have barriers to accessing biopsies and thus eliminate their eligibility for EAP approval.<sup>53</sup> Criteria based on liver biopsy results can delay or exclude Northern Ontario clients with genotype 1 from treatment.

It is important to note that genotype 1 is prevalent among past/current people who use drugs in Canada. Sharing of drug using equipment is also the primary risk factor for acquiring hepatitis C. Many people who use drugs are part of a marginalized community that does not have private insurance or the financial means to personally cover the cost of their HCV treatment. If those comprising the largest HCV infection pool do not have access to treatment, the reservoir for further transmission will continue to rise.<sup>54</sup>

Providing equal access across the province to biopsies/biopsy alternatives would ensure all clients have the opportunity to apply for EAP coverage.

The revised criteria also do not address the opportunity to extend treatment to "slow responder" patients, defined as those with genotype 1 who decrease their viral loads by 2 logs after 12 weeks of treatment and who achieve viral negativity by week 24. A review of related studies has shown that extending treatment from 48 weeks to 72 weeks increases slow responder chances of attaining a sustained virological response (SVR). One such study cites SVR rates in 38 per cent of clients on

48 weeks of treatment versus 63.5 per cent of clients attaining an SVR on 72 weeks of treatment (P=0.068). Slow responders comprise 22 per cent of HCV-infected clients and require their therapy to be extended to 72 weeks to achieve the higher SVR rates.<sup>55</sup>

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**Recommendation:** Continue discussions between the OHCTF's Clinical Issues Working Group, the Hepatitis C Secretariat, and the OPDP to address barriers relating to the current EAP criteria to ensure equal access to HCV treatment for all Ontarians living with hepatitis C.

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A facilitated access mechanism would provide greater flexibility for those treating physicians with established, recognized HCV practices to use their clinical judgement and current evidence to guide treatment – bearing in mind current criteria and guidelines – to ensure quality assurance.

The implementation of a facilitated access mechanism would aim to provide timely access to hepatitis C treatment, thereby improving health care delivery for those embarking on hepatitis C treatment.

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**Recommendation:** Establish a facilitated access mechanism through the Ontario Drug Benefit (ODB) program for hepatitis C treatment.

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A commitment to track treatment outcomes could be included in new listing agreements. Better data collection on outcomes could assist in developing policy and treatment delivery. It is imperative to identify and track prior to treatment the mitigating factors that lead to more successful treatment.

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**Recommendation:** Establish OPDP listing agreements with drug manufacturers that include commitments to track treatment outcomes.

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## 2.2 Prevention

### **Goal: Reduce HCV transmission in Ontario.**

Ontario has effective, evidence-based prevention initiatives, such as NSPs, available to reduce HCV transmission, but they are not always accessible for higher risk populations. Reducing HCV transmission will require the consistent, coordinated implementation of HCV-related harm reduction/prevention initiatives across Ontario. NSPs and other harm reduction programs to reduce the incidence of HCV and other blood-borne pathogens should be available and accessible in every public health unit in the province.

## **Objective 1: Increase access to harm reduction materials.**

Scientific evidence indicates that a harm reduction approach to drug use is effective in reducing transmission of HCV, HIV and other blood-borne pathogens, and in improving health outcomes. The OHRDP currently purchases drug preparation and injection preparation equipment and distributes them on request free of charge to local harm reduction programs across Ontario. However, many individuals at risk for HCV infection either have no access or limited access to these proven prevention tools.<sup>56</sup>

A comprehensive harm reduction program, including increased participation in the OHRDP and improved access to these materials in a variety of settings, would be developed in collaboration with public health units, NSPs, and community-based agencies – including CHCs – which provide services to people who use drugs. Included in the program would be measures to ensure the appropriate disposal of harm reduction materials.

The OHRDP would be linked to local harm reduction initiatives so that HCV prevention and education activities are delivered in a more coordinated, comprehensive, and consistent manner across Ontario. It would also draw on local research and evaluation activities that provide the evidence base for policies and programs.

Increasing access to these materials not only provides effective tools for reducing HCV transmission, but has been proven to strengthen access to other necessary care, treatment, and support services for this population, many of whom face barriers in accessing health services through more traditional health care settings.<sup>H</sup>

- For example, a comprehensive and independent outcome evaluation of Ottawa Public Health's Safer Crack Use Initiative, involving personal interviews with 550 male and female crack smokers completed six months pre-implementation and at one month, six months, and 12 months post-implementation, revealed several positive impacts associated with the program. These included: A statistically significant decline in the frequency of engagement in the multi-person use or sharing of crack-smoking equipment – a practice epidemiologic evidence associates with HIV and HCV transmission and acquisition
- A trend away from injecting drugs to smoking – a much less risky route of drug administration

Providing safer crack-smoking resources resulted in more than 4,000 contacts between women and men who smoke crack and a program offering a comprehensive range of resources to enable this group to increase control over their own health.

Following cancellation of this program by Ottawa's Board of Health in July 2007, MOHLTC provided funding to continue providing safe inhalation materials to people who use drugs in Ottawa. The current evidence-based program is housed at Somerset West Community Health Centre and has been operational since June 2008.

<sup>H</sup> Several barriers to access were identified in the 13 community consultations across Ontario, including stigmatizing attitudes and behaviours of health care providers, the reluctance of health care providers to treat people living with HCV due to concerns regarding HCV treating competency, and coordination with other health and social service providers to address the complex health and social service needs of many people living with HCV.

Providing a full range of harm reduction materials to prevent the transmission of disease and other harms complies with the *Ontario Needle Exchange Programs: Best Practice Recommendations, March 2006*. This document references the many studies that support the distribution of safer inhalation equipment and is well respected nationally and internationally.

In order to support safer injection preparation and injection practices, NEPs should be expanded in areas of the province where injection drug use is a problem. Distribution of safe inhalation equipment should be a routine practice by Public Health Units across Ontario and other local community organizations that support prevention efforts for HCV.

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**Recommendation:** Expand access to harm reduction tools (including safer inhalation equipment and educational materials) for people who use drugs.

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Policies and practices in force in correctional facilities present significant barriers for prisoners to access and consistently use harm reduction materials, such as sterile needles, drug preparation equipment, and safer inhalation equipment. For example, the prohibition against the possession of needles in correctional facilities precludes access to the most important HCV prevention tool for IDUs.<sup>57</sup> Collaboration between the Ministry of Community Safety and Correctional Services (MCSCS), AIDS Bureau, the Hepatitis C Secretariat, and Public Health Division may foster discussions and best practices on expanding the outreach and education activities required to deliver all evidence-based harm reduction materials in sufficient quantities to drug using and other higher risk populations in correctional facilities. These groups also could work with corrections staff to address workplace safety concerns regarding these programs, such as prisoners who use unsafe tattooing practices.

The HIV and Corrections Working Group<sup>1</sup> already have developed an infectious disease brochure to raise the awareness of HCV in provincial correctional facilities. We encourage continuation of this work.

Routine screening for HCV and other possible infections or diseases is not mandatory in prisons. Testing is available to those prisoners who request it. Testing may lead to diagnosis and possible treatment of any disease and ultimately reduce the potential of further transmission in the prison population. In addition, with treatment, other support and education services could be provided that may result in other positive social and health outcomes.

As most prisoners eventually move back into the community, both individuals and the community benefit by addressing the high rates of HCV prevalent in those incarcerated in Ontario's correctional facilities. Countries that have implemented NEPs and other harm reduction measures in prisons have substantially reduced HCV transmission. However, Canadian correctional settings have not introduced many of these evidence-based prevention interventions.<sup>58</sup> Barriers to delivering NEPs, other drug preparation equipment and tattoo and body piercing kits will be addressed – including workplace safety concerns – in collaboration with the MCSCS. The goal is to ensure prisoners have

<sup>1</sup> The HIV and Corrections Working Group includes: the AIDS Bureau, MCSCS, the Hepatitis C Secretariat, Public Health Agency of Canada, Federal Corrections, and various community agency representatives who work closely with clients in corrections.

the same access to harm reduction materials and information as other Ontarians, in keeping with the recommendations of the Canadian Medical Association, the Ontario Medical Association, the Registered Nurses' Association of Ontario, and the Canadian Nurses Association.

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**Recommendation:** Encourage further collaboration between the Hepatitis C Secretariat, the Ministry of Community Safety and Correctional Services, AIDS Bureau, and Public Health Division to facilitate the availability of harm reduction tools (including educational materials) through the use of best practices for delivering HCV prevention, testing, and treatment interventions to inmates in correctional facilities.

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The ministry should begin discussions between MCSCS and police services on policing experience to find common ground on policies and practices related to overdose protocols, bad drug cautions, and police complaints procedures. These discussions should also include practical skills training with police to provide them with tools to respond more effectively to people who use drugs.<sup>59</sup>

Policing practices in seizing drug-using equipment also present barriers to ensuring people who use drugs are able to use safe practices to prevent HCV acquisition and transmission. Policing practices, laws, and other structural barriers that might impede access to harm reduction materials for populations at higher risk of HCV infection should be assessed and corrected if necessary.

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**Recommendation:** Collaborate with the Ministry of Community Safety and Correctional Services (MCSCS) to review policing practices in the community and relevant legislation and implement strategies to remove structural barriers to HCV prevention.

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## **Objective 2: Develop, expand, and support outreach services for clients with a higher risk of acquiring HCV.**

Outreach services for people at higher risk of acquiring and transmitting HCV and other blood-borne pathogens is a key component of harm reduction. Outreach workers with experience in working with this population could ensure that prevention information, service and support is accessible and being delivered.

Outreach programs are particularly critical to delivering HCV prevention and education interventions to populations at highest risk for HCV. Prevention and intervention remains the most cost-effective way of responding to HCV in Ontario.

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**Recommendation:** Expand funding, to increase current outreach services and develop and provide information and support to agencies currently working with higher risk populations to support hepatitis C prevention.

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## 2.3 Education

### **Goal: Increase knowledge and awareness of HCV.**

An estimated one-third of those living with HCV are unaware of their status, since many individuals remain asymptomatic for years after infection. Community consultations identified the need to increase the level of knowledge about HCV prevention, treatment, and care among health care providers, other relevant stakeholders and higher risk populations (such as people who use drugs) as an urgent priority. The development and delivery of education programs also need to address the barriers faced by ethnocultural communities in accessing culturally relevant information about HCV prevention and other care, treatment, and support services.

The ministry launched two separate public education campaigns. Television and newspaper ads were used to increase awareness of HCV. The ads focused on increasing public understanding of hepatitis C infection and associated risk factors, as well as prevention and treatment options. The TV ads ran for six weeks and included a self-completed personal risk assessment tool on a MOHLTC website. Advertising was geared to the general population. During the campaign people were drawn to the website, however, visits declined when the advertising stopped.

The second education campaign involves a comprehensive toolkit consisting of prevention, education and harm reduction resource materials for use with high-risk populations such as people who use drugs, youth, Aboriginal communities, and inmates. The toolkit website and materials vary in content, format, language level, and intended audience. This range of options allows service providers to select the materials most appropriate for their communities.

The most pressing education needs are for health care providers, the HCV infected, people immigrating from, or who have travelled in, countries with high HCV prevalence rates, and those at higher risk of HCV infection, including people who use drugs and individuals and businesses involved in high-risk activities, such as non-professional tattooing and body piercing.

Consideration should be given to a broader public education program focusing on increasing awareness of the impact and scope of HCV in Ontario, reducing the stigma associated with HCV infection, and strengthening public support for the expanded investments required to reduce HCV transmission. The existing HCV prevention toolkit and website includes resources aimed at both health care providers and people at risk of/living with HCV. These resources can be expanded with additional HCV education materials and local resources for the specific audiences identified in this section.



## **Objective 1: Increase HCV awareness among higher risk populations, which include people who use drugs.**

The vast majority of new HCV infections result from unsafe drug injecting and smoking practices and other drug equipment sharing practices. Targeted education and harm reduction materials for people who use drugs are required to:

- Increase awareness of how HCV is transmitted
- Increase awareness of how to prevent HCV transmission
- Identify how to access local testing and counselling services
- Identify other local care, treatment, and support resources, including mental health and addiction services

The population of those using drugs in Ontario is not homogenous. People who use drugs come from culturally, linguistically, and socioeconomically diverse backgrounds. Thus, an HCV awareness campaign must include clear, standardized messages that are relevant or adaptable for the variety of communities that are part of Ontario's drug-using population.

Reaching people who use drugs with educational materials can be challenging due to the illicit nature of drug use and the associated social stigma. Thus, to ensure education programs and materials have the maximum impact, they should be delivered in conjunction with evidence-based prevention interventions, such as NEPs, with a strong focus on peer education and train-the-trainer sessions.

The overarching goal of the HCV awareness campaign should be to change the risk environment. This includes making the materials relevant and available in a wide range of settings, including:

- Needle and Syringe Programs
- Public Health Units
- Community Health Centres
- Medical Clinics and other Primary Care Settings
- Community-based Organizations, including those delivering outreach and other support programs for people who use drugs and people who do not have adequate housing.
- AIDS Service Organizations
- Addictions and Mental Health Agencies
- Provincial Correctional Facilities

Although HCV awareness campaigns will focus on sharing injection and drug preparation equipment as the primary mode of HCV transmission, the campaign messages also should include information on the risk of unsafe drug-smoking practices, sexual transmission, and tattooing and body piercing.

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**Recommendation:** Develop and implement an HCV awareness campaign for people who engage in higher risk activity, people who use drugs and those involved in unsafe tattooing and body piercing activities, in collaboration with NEPs, public health units, community-based agencies, and mental health and addictions agencies.

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## Aboriginal Peoples

Aboriginal peoples are a higher risk population due to their over-representation in the prison system and among the drug-using population.

Statistics Canada reports that Aboriginal people are over-represented in both federal and provincial correctional facilities populations and suggests that although this may be due in part to less access to education and employment opportunities, “other factors could include income, housing and criminal justice processes.”<sup>60</sup> The Canadian Aboriginal AIDS Network has also cited racism and the impact of colonization as reasons for this over-representation.<sup>61</sup>

A 1998 Health Canada literature review noted that “substance abuse has been described as a manifestation of ‘alienation’ of Aboriginal people.”<sup>62</sup> Although the review referred to a lack of information on drug use in this population as compared to alcohol, increased narcotic use was noted.<sup>63</sup> The Assemblies of First Nations has indicated that illicit drug use may be double that of the general population.<sup>64</sup> This places those Aboriginal people at greater risk of HCV exposure through the higher risk behaviours associated with incarceration and drug use.<sup>65</sup>

Ontario does not systematically collect data on the ethnicity of those with hepatitis C. This makes it difficult to determine the prevalence of HCV in the Aboriginal population.<sup>66</sup> Studies suggest that Aboriginal populations may have an increased rate of spontaneous clearance.<sup>67</sup> However, a population-based study suggests the HCV infection rate is higher in the Aboriginal population (ranging from 1 per cent to 18 per cent) compared with the remainder of the Canadian population (0.5 per cent to 2 per cent).<sup>68</sup>

Therefore, it is essential to emphasize prevention in the Aboriginal population with educational programs and materials designed to resonate with diverse Aboriginal populations across Ontario and raise awareness of hepatitis C in a culturally appropriate way. Targeted educational programs created in partnership with existing networks serving Aboriginal peoples would foster capacity building, help prevent the further transmission, reduce stigma associated with hepatitis C, and improve access to care in a culturally appropriate manner that recognizes the unique history and circumstances of this population.

## Prison populations

In Ontario, the prevalence rate of hepatitis C infection among prisoners in provincial institutions was estimated at 17 per cent, and in prisoners with a history of injection drug use was estimated at 54.7 per cent. The prison setting presents an opportunity to deliver HCV education, harm reduction, treatment and care; reducing the risk of spreading the infection during incarceration and after release.<sup>69</sup> A variety of studies of Canadian prisons indicate rates of injection drug use of between 11 per cent and 24 per cent, with overall drug use as high as 73 per cent.<sup>70</sup> Public Safety Canada says prisons have the highest proportion of people with substance-use issues in Canada.<sup>71</sup> This setting also represents an important opportunity to deliver HCV awareness messages – such as the risks associated with tattooing and body piercing in prison – and harm reduction materials to a key population.<sup>72</sup>

## Youth

Drug use is particularly high among street involved youth – children and adolescents who become socially dislocated from their mainstream counterparts and who experience marginal or chronic homelessness.<sup>73</sup> A Canadian study suggests an average of 20 per cent of street youth have injected drugs at some point. Rates of HCV infection among street youth was 4%- 17%,<sup>74</sup> well above the 0.8 per cent prevalence estimated within the general population.<sup>75</sup>

In Ontario, new HCV infections are highest among those aged 20-39. Rates are approximately twice as high in males than females.<sup>76</sup> Since sharing drug-using equipment is the primary risk behaviour for hepatitis C transmission, along with unsafe tattooing and piercing practices, it is important to develop targeted education and prevention messaging that appeal to youth.

The Hepatitis C Secretariat should work with the Public Health Division with regard to HCV prevention education to ensure it is provided in accordance with the Public Health Standards.

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**Recommendation:** Develop appropriate educational materials and intervention programs that target higher risk populations, particularly Aboriginal peoples, prison populations, and street involved youth and ensure these materials and programs are accessible to these populations.

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## Countries with Higher HCV Prevalence

Some countries have higher prevalence rates than Canada. In these countries, certain cultural and medical practices may lead to higher risk for blood-borne diseases. The Canadian Association for the Study of the Liver (CASL) 2007 consensus guidelines on the Management of Chronic Hepatitis C state that: “The annual estimated hepatitis C-related mortality and the rate of cure on therapy is exceeded by the number of new infections and the number of infected persons immigrating to Canada, so that the prevalence of hepatitis C virus (HCV) infection is increasing and will continue to increase for the foreseeable future.”<sup>77</sup>

There is a need to provide education and awareness programs that are relevant and culturally appropriate for people who arrive in Ontario from these countries so these people will have better access to hepatitis C information.

In 2006, the Canadian Liver Foundation (CLF) and the Canadian Ethnocultural Council (CEC) partnered to conduct the project entitled “Engaging Ethnocultural Communities on Hepatitis C.” Information gathered in focus groups provided insights into the social environments, culture, and social support networks in each identified ethnocultural community. These insights, in turn, contributed to identifying the best ways to engage each community in developing, designing, and delivering culturally appropriate hepatitis C education materials. Specifically, the project increased the understanding of:

- Best ways to deliver public health education messages about hepatitis C to the identified Chinese, Egyptian, Filipino, and Vietnamese ethnocultural communities
- Barriers to obtaining information on hepatitis C
- Role of ethnocultural communities in public health education

- Attitudes towards blood-borne diseases (hepatitis C)
- Obstacles to understanding disease transmission, progression, long-term effects, and prevention measures for those infected with, and affected by, hepatitis C in the Chinese, Egyptian, Filipino, and Vietnamese ethnocultural communities

The project also identified community champions willing to advance knowledge and awareness of this important public health issue. The project received an overwhelmingly positive response from individuals in identified communities and has succeeded in generating an enormous interest in hepatitis C. This is a strong contrast to the lack of interest in, and knowledge about, hepatitis C displayed by participants at the onset of the focus group discussions.

The communities are strongly motivated to become more engaged on this issue. They have specifically expressed an interest in obtaining more and up-to-date information on hepatitis C and a desire to share the information in their communities. It is important to keep the momentum going and not to lose the interest in hepatitis C that has been generated through these focus group discussions. Communities have clearly indicated that they require help from the government if they are to be engaged meaningfully in addressing the challenges that hepatitis C poses to their communities and to the health of all Canadians.

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**Recommendation:** Develop and implement relevant hepatitis C education and awareness campaigns for people who have travelled or lived in countries with a high hepatitis C prevalence rate (higher than the Canadian rate) and/or developing countries.

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## **Objective 2: Increase knowledge of HCV treatment/care issues among health care providers, including those in the mental health and addictions field.**

There are limited numbers of HCV treating health care providers in Ontario (e.g., hepatologists, infectious disease specialists, and gastroenterologists), and it is important to:

- Strengthen the existing knowledge and clinical expertise of primary care physicians and other health care providers who deliver HCV care and treatment
- Expand the number of health care providers capable of delivering HCV care and treatment
- Assist health care providers in delivering HCV care and treatment in a supportive and culturally sensitive manner

It is equally important that mental health and addictions staff (including drug rehabilitation program staff) review intake protocols and confirm that counselling regarding HCV testing and treatment is included so that clients have the earliest possible opportunity to access treatment and increase the likelihood of a sustained virologic response (SVR) to treatment.

Treating physicians have also recommended establishing an education program aimed at increasing the level of knowledge within the medical community through initiatives such as a clinician-scholar fellowship program, which would train physicians to manage chronic viral hepatitis and become leaders in their local community. At the end of the one-year program, it is expected that the trained physicians would be experts in all aspects of the management of individuals with viral hepatitis,

from initial evaluation, through initiation of therapy, the assessment of response, and the management of side effects. This approach would progressively expand the number of HCV-treating physicians in Ontario and reduce the requirement for specialists to assume the care of patients living with HCV.

Ontario should expand existing accredited CME education sessions aimed at increasing awareness of HCV care and treatment issues among physicians to include nurses and other health care providers in both acute and community-based settings beyond the existing HCV treatment nurse program. Education sessions should include reference to the development of a multidisciplinary, team approach, treatment algorithm (outlined in the treatment section of this proposed Strategy), and address current issues related to HCV, including:

- Early identification and referral of individuals at risk for HCV infection to testing and counselling services
- Management of HCV and HIV co-infection
- Screening and referral of patients with HCV to appropriate local mental health and addiction programs, harm reduction programs (such as NEPs) and other support services
- The impact of drug and alcohol use on disease progression, treatment readiness and adherence
- Early detection of other complications such as carcinoma

The HCV counselling and testing guidelines currently in development will provide the basis for an important component of this initiative.

Consultations also identified an urgent need to increase knowledge of the HCV testing process among health care providers to ensure that HCV-positive antibody results for patients are followed up with PCR RNA testing to confirm active infection and viral genotype. Developing and disseminating a testing protocol, including pre- and post-test counselling guidelines for providers is required to ensure that:

- Initial HCV antibody screens and follow-up PCR RNA tests are ordered more routinely
- Providers understand that antibody screens only identify the presence of HCV antibodies, i.e., previous exposure and not necessarily active infection
- Providers understand that having HCV-positive antibodies following successful clearance of the virus does not confer protection against any future infection
- Advice from experienced HCV-treating physicians is sought only when PCR RNA results confirm active infection and genotype
- Providers know what information to include on laboratory requisition forms
- Providers know how to interpret test results and follow up consistently on those results

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**Recommendation:** Provide family physicians and other health care providers with continuing medical education (CME) and other educational opportunities aimed at increasing their understanding of HCV care and treatment in collaboration with community organizations doing similar work.

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Individuals living with HCV report facing stigma and discrimination from health care providers and others involved in delivering services.<sup>78</sup> Education sessions should include a diversity training component to increase awareness of the stigma and discrimination faced by people living with HCV (particularly those with a history of injection drug use) and to ensure health services are provided in a non-discriminatory and non-judgmental manner.

The Ontario Medical Association, The College of Physicians and Surgeons of Ontario, and The College of Nurses of Ontario, and other relevant colleges and associations of allied health professionals will be consulted regarding strategies to ensure maximum uptake of HCV educational programs targeting health care providers.

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**Recommendation:** Include diversity training as a component of overall education for health care providers that addresses how to work with these patients using a non-judgmental, non-discriminatory approach.

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Many individuals living with HCV/at risk for HCV infection have concurrent mental health and addiction issues. Individuals at higher risk for HCV infection should be offered testing and counselling at multiple entry points within Ontario's health care system, whether they enter it through a drug rehabilitation program, CHC, community-based organization or via a family physician.

Drug rehabilitation programs in particular can provide an important avenue for reaching clients at higher risk for HCV infection. Programs should ensure that counselling regarding HCV testing and treatment is included in their intake procedures so that clients are aware of their HCV status and, if positive, have access to treatment.

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**Recommendation:** Work with Mental Health and Addictions so that all addictions and mental health professionals include HCV counselling and testing as part of their intake process, including referral as required to local treating physicians.

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### **Objective 3: Increase awareness and implementation of infection prevention and control practices for skin penetration in settings identified in the Infection Prevention and Control Best Practices for Personal Services Settings.<sup>79</sup>**

Some tattoo/body piercing parlours and other settings in which skin penetration occurs (such as detention centres and correctional facilities) do not have adequate infection prevention and control practices in place and may be contributing to blood-borne infections such as HCV. This is particularly relevant for correctional facilities, where access to sterilization equipment or sterile needles is unavailable or insufficient and inadequate cleaning, disinfecting, and routine practices are the norm. While such practices are standard in health care delivery settings, anecdotal information suggests that Best Practices Guidelines are not followed consistently in other skin penetration settings and are contributing to new infections.

## Tattoo and body piercing businesses

Tattoo parlours and piercing studios should be advised to use single-use disposable needles, sterilized equipment, and single-use ink caps. The Infection Prevention and Control in Personal Services Settings Protocol 2008, developed under the Ontario Public Health Standards 2008, require that local boards of health perform routine inspections of these facilities, including a risk assessment at least once a year; and respond to any complaints they receive. The frequency of inspections is increased based on compliance results from inspections.<sup>80</sup> Public Health could monitor practices at tattoo parlours and body piercing locations more frequently with additional monitoring to prevent the transmission of viruses through instruments and supplies used at these facilities.

The Public Health Division, MOHLTC has developed information regarding the risk of HCV acquisition and transmission and the need to consistently use best practices for all piercing and tattooing equipment and supplies (e.g., ink).

## Correctional facilities

An HCV education program, which includes information on:

- The risk of HCV transmission through incorrect reprocessing of equipment
- Appropriate infection prevention and control practices for body piercing and tattooing in provincial correctional facilities should be developed in collaboration with the Ministry of Community Safety and Correctional Services and Public Health Division

This initiative also should include information on:

- The risk of blood-borne disease transmission such as HCV through unsafe injecting practices and other drug equipment sharing practices
- How to reduce the risk of transmission through appropriate harm reduction strategies, including the use of tattoo and body piercing kits

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**Recommendation:** Increase awareness and implementation of appropriate infection and prevention control practices in settings where tattooing and skin penetration is performed.

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## 2.4 Support

**Goal: Strengthen the support for people living with HCV and higher risk populations so they access services available to them.**

Support includes access to drug treatment, psychosocial supports such as counselling, and supports related to social determinants of health such as nutrition and housing. Support should also be provided for community capacity building in order to provide community-based education.

Socioeconomic, environmental, cultural, behavioural, and biological factors determine health status. The social determinants of health should be addressed through support services that address housing needs, peer support, financial support, transportation (particularly in rural areas), and other factors that affect risk reduction behaviour, treatment readiness, adherence and post-treatment care for people living with HCV and high-risk populations.

## **Objective 1: Increase the availability and accessibility of support for those living with/at risk for hepatitis C.**

Hepatitis C is most prevalent among hard-to-reach and underserved populations, and is compounded by co-morbidities such as chronic alcoholism, mental health issues, socioeconomic factors, and high-risk behaviour.

An important component of this proposed Strategy's multidisciplinary care model is support services – to address unstable housing, the need for peer support and counselling, and the need to refer those living with HCV/at risk for HCV infection to local social services and community-based organizations. These services would address environmental and socioeconomic factors contributing to poor health outcomes for those at risk for HCV infection and those living with HCV, including those who do not respond to treatment, relapsers, and those who choose not to be treated. End of life/palliative care services should be available for people living with HCV whose health status deteriorates to the point where these are required.

Community-based organizations can provide services to those at risk for/infected with hepatitis C. Such coordination would aid in linking community organizations into a network accessible and available to those who need these services but who are not aware of their existence or availability.

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**Recommendation:** Encourage development of a regional network consisting of agencies and community-based organizations currently responding to hepatitis C related issues.

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Community consultations all identified the need for local HCV coordinators and outreach workers. HCV coordinators would help facilitate local networks and assist both clients and agencies in navigating the health care system.

Ontario should provide sustainable funding so communities can hire HCV coordinators to maintain reliable and dependable services throughout the province. Additionally, HCV information must be developed and delivered using different communication tools such as the Internet and phone, and other in-person support and education services for patients and the general public.

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**Recommendation:** Increase the number of HCV coordinators who will assist clients and agencies to navigate the health care system, improve access to available local services, and reach those infected with/at risk for HCV with education, support and referrals.

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Outreach workers are able to provide direct support, education, and referrals to people infected with/at risk for hepatitis C in their own environment, providing clients with greater access to available community services. Outreach workers provide the critical link between marginalized clients and health and social services. This way of connecting with clients is a proven and effective engagement strategy. The community consultation process consistently raised the need to support the introduction of outreach workers.

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**Recommendation:** Expand the number of HCV outreach workers who will assist and provide services to people living with/at risk for hepatitis C in familiar environments.

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Many clients have difficulty reconnecting with support services in the community when they are discharged from provincial correctional facilities. Outreach workers can play a critical role in addressing this issue.

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**Recommendation:** Dedicated HCV outreach workers will liaise with provincial correctional facilities to provide support and follow up when people re-enter the community.

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The ministry should continue developing its website as a resource available across Ontario for those with hepatitis C. It is important to recognize that people with hepatitis C have a multitude of needs including stable housing, nutrition, mental health and addictions support, and may suffer from poverty. Providing a simple and easy-to-access link to all services required to address this vast array of needs would improve access and availability, and will increase recognition of a comprehensive Ontario approach to supporting people at risk and with hepatitis C.

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**Recommendation:** Develop an electronic navigation tool for local and provincial programs including mental health, addiction, and housing services.

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Collaborate with local health care providers and services to offer patient education programs to those with/at risk for hepatitis C to empower themselves in seeking care, treatment and services and possibly providing peer support to those in the same environment.

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**Recommendation:** Develop peer support programs in collaboration with local HCV coordinators to enable HCV-positive individuals to improve their capacity for self-care.

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## **Objective 2: Increase collaboration between different levels of government to bring about a coordinated approach to support and care.**

The Public Health Agency of Canada's (PHAC) mandate is to:

- Provide a new approach to federal leadership and collaboration with provinces and territories on efforts to renew the public health system in Canada
- Support a sustainable health care system

The Surveillance and Epidemiology Section of the Community Acquired Infections Division is responsible for routine and enhanced Sexually Transmitted Infection (STI) and community-acquired hepatitis C surveillance, epidemiology and research. It:

- Contributes to broader initiatives, within the Centre for Infectious Disease Prevention and Control, for enhanced surveillance of populations vulnerable to sexually transmitted and blood-borne infections
- Collaborates with provincial and territorial representatives, international agencies and other partners to improve behavioural and disease surveillance for public health action

The Hepatitis C Prevention, Support and Research Program (the Hepatitis C Program), launched in 1999 as part of the federal response to the report of the Commission of Inquiry on the Blood System in Canada, was renewed in 2008 with ongoing annual funding of \$10.65 million to be allocated to initiatives that improve population health, decrease health disparities, and reduce the associated burden on the health care system by:

- Contributing to the prevention of hepatitis C and related infections
- Supporting those infected with, affected by, at risk for, and/or vulnerable to hepatitis C and related infections
- Providing a stronger evidence base for policy and programming decisions
- Addressing the risks associated with certain behaviours
- Addressing issues of co-infection with related sexually transmitted and blood-borne infections (STBBI) and tuberculosis (TB), common risk factors, and population health approaches to disease prevention and control

While community agencies may apply to PHAC for funds, it is important for Ontario to work in close cooperation with PHAC to fund program initiatives which integrate well with Ontario's Hepatitis C proposed Strategy. As well, close cooperation would enable the federal government to respond to Ontario priorities and ensure that funds are leveraged to achieve maximum benefit.

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**Recommendation:** Consistently collaborate with the federal government to ensure best use of resources.

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The OHCTF has consulted with health programs and other ministries to develop the Proposed Strategy to Address Hepatitis C in Ontario 2009-2014. Ongoing discussions and collaboration should be supported to inform the Strategy as needed and to bring about a coordinated, cooperative, and effective implementation.

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**Recommendation:** Support and encourage collaboration and consultation among ministries to address social determinants of health as they relate to hepatitis C.

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The ministry should also provide guidance and support to LHINs to recognize and consider hepatitis C a priority. It should do this by working with local organizations and by providing funding to services needed to respond to hepatitis C treatment, prevention, education, care, and support. LHINs should also encourage coordination in their regions by involving mental health and addiction services, housing, social services, and other organizations to address all the needs of those with hepatitis C. Support also should be given to harm reduction initiatives and outreach in the LHINs.

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**Recommendation:** Ensure that Local Health Integration Networks (LHINs) address hepatitis C as a provincial priority that includes local issues that may not be a provincial priority.

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## 2.5 Surveillance and Research

### **Goal: Improve applied research and surveillance on HCV.**

Strengthening the quality and quantity of policy- and program-relevant research in Ontario to help inform and improve education, prevention, treatment and support interventions. Ontario has a robust network of researchers involved in HIV and HCV research with strong connections to public health units, community-based agencies, treating physicians, hospitals and academic centres as well as other stakeholders responsible for delivering education, prevention, care and treatment interventions to those living with HCV/at higher risk for HCV infection. This expertise will be supported through a comprehensive HCV research and surveillance program. In addition, a Research Working Group of the OHCTF was established in July 2008 to provide ongoing advice to the OHCTF and the Hepatitis C Secretariat on issues related to HCV research and surveillance.

### **Objective 1: Improve HCV surveillance data.**

Currently, Ontario relies on three sources of information to track the rate of hepatitis C infection:

- Modelled estimates of true incidence and prevalence by an epidemiologist
- Case reports (i.e., reported incidence) gathered by local public health units and reported to the ministry
- Ontario Public Health Laboratory statistics on hepatitis C testing

Several initiatives are required to assess the quality and completeness of the HCV surveillance system in Ontario and to establish more precise estimates of HCV epidemiology that can in turn inform policy and program development. These include:

- Ongoing population-based and risk-group-specific surveys to provide up-to-date true prevalence and incidence estimates to feed into mathematical models
- Better follow-up of reported cases to ensure completeness of risk factor data, follow-up RNA testing to confirm chronic infection, an estimate of the likely onset date, and categorization into newly-acquired, chronic, and resolved cases
- Thorough and ongoing data cleaning to remove duplicates, and ensure accuracy and completeness

The current HCV surveillance system must be assessed and changes made to establish more consistent, timely, and accurate reporting of active HCV infection to and by public health units. This would help improve the response to Ontario's HCV epidemic.

The Ontario Provincial Infectious Disease Advisory Committee (PIDAC) has a subcommittee that is developing a new case definition that places hepatitis C in three categories: 1) newly acquired, 2) chronic/unspecified, and 3) resolved. This definition implies an increase in hepatitis C RNA testing to distinguish between chronic and resolved infections. These definitions were under development when this report was being written. Changing the case definition to include the types of HCV infection will capture more accurate and complete data which would provide a more precise picture of hepatitis C in Ontario.

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**Recommendation:** Evaluate Ontario’s current HCV surveillance system and make changes to improve the completeness, quality, and timeliness of reporting; endorse a case definition that distinguishes between newly acquired, chronic, and resolved hepatitis C infections.

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Any increase in the number of cases for RNA testing resulting from adoption of PIDAC’s case definition (all cases will require RNA testing), would require additional resources for public health labs. An enhanced lab study and questionnaire could be a solution for the increased need for RNA testing.

Physicians should be given guidelines that recommend every person with a positive antibody test have an RNA test. Only some physicians understand the PCR and RNA testing requirement. A detailed explanation of the additional testing requirement should be provided to physicians and public health units.

In April 2008, the Ontario Public Health Laboratory (OPHL) and the Hepatitis C Secretariat created an algorithm to inform health care providers of the steps required following the receipt of a positive or inconclusive HCV antibody test. Since it still is not widely understood that an RNA test is required to confirm active viral infection, an insert with this information accompanies all positive and inconclusive HCV antibody test results sent from OPHL back to the health care provider.

The information insert, or *Labstract*, ensures that health care providers are aware of the steps required following a positive HCV antibody test. Specifically, if the antibody test is reactive or inconclusive, additional testing for the active virus is recommended to determine the client’s accurate status and to assist with treatment.<sup>81</sup>

The PIDAC proposed case definition and the ongoing communication to health care providers is focused on ensuring Ontarians seeking hepatitis C testing obtain the correct tests and accurate results that reflect their current status of infection: negative, exposed but resolved, or positive.

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**Recommendation:** Work with the Ontario Agency for Health Protection and Promotion to ensure that its existing lab infrastructure can accommodate an increase in samples being submitted for RNA testing as a result of the changed HCV case definition. Ensure information is disseminated to physicians affected by the testing process change.

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Population-based surveys are the most accurate method of establishing information on HCV prevalence. Surveys of populations at higher risk for HCV infection is important in establishing baseline surveillance data and informing prevention and education interventions.

Enhanced Hepatitis Strain Surveillance System (EHSSS)<sup>82</sup> provides important information on the epidemiology of HCV infection in Canada that is used to support decision-making in public health. EHSSS offers an in-depth look at demographic and risk factors for HCV infection, and allows the identification of acute HCV infection. This comprehensive surveillance program currently covers more than 40 per cent of the Canadian population. However, this sentinel site approach may only be applicable to the populations covered by EHSSS.<sup>83</sup>

EHSSS data also indicate that IDU continues to be the predominant risk factor for HCV infection in Canada. This data is supported by information gathered through other surveillance programs including I-Track, the enhanced surveillance of persons who inject drugs.<sup>84</sup>

Using existing Canadian surveillance data and undertaking further surveillance research will allow the province's prevention policy and programming to be informed by Ontario-specific, evidence-based research.

Despite improvements in routine passive surveillance, many cases go undetected because of the low incidence of acute symptoms among newly acquired infections and the long latency period from the beginning of chronic infection to the appearance of liver-related problems. Currently, mathematical models are relied upon almost exclusively to estimate prevalence and these models may not be an accurate reflection of the true prevalence. Periodic population-based surveys are needed to determine actual prevalence, which, in addition to providing a point prevalence estimate, also could be used to validate and refine the mathematical models since they still would be needed to estimate prevalence between surveys.

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**Recommendation:** Work with the Ontario Agency for Health Protection and Promotion to support enhanced HCV surveillance via population-based and specific population surveys, such as HCV seroprevalence (the number of persons in a population who test positive for the disease based on serology [blood serum] specimens) studies. Use existing Canadian surveillance research and endorse further research to improve and inform prevention programming in Ontario.

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## **Objective 2: Establish data on the risk of HCV transmission in skin penetration settings, sexual activities and drug equipment sharing practices.**

Although the risk factors for HCV transmission through unsafe injecting practices are well established in the scientific literature, other factors that increase the risk of transmission, for example, other drug equipment sharing practices (such as sharing crack pipes), high-risk sexual behaviours (resulting in contact with blood from another person), and tattooing/body piercing are less well understood. Research on the available scientific evidence is required to assess HCV transmission risk via these routes and to inform education and prevention interventions.

Systematic literature reviews are required to confirm the risk – and level of risk – of HCV transmission through specific high-risk sexual behaviours and via tattooing or body piercing. Factors that increase the risk of transmission through such practices – such as the informal setting of tattooing and piercing in correctional facilities – should be considered within overall research questions. Research and policy development should include collaboration with other provincial and national organizations that have undertaken work in this area, including the Canadian AIDS Society, Canadian HIV/AIDS Legal Network and the Canadian Institutes of Health Research (CIHR), among others.<sup>85</sup>

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**Recommendation:** Support systematic reviews of the scientific and grey literature on HCV transmission risk as a result of high-risk sexual behaviour, tattooing, body piercing, and sharing of inhalation equipment (i.e., crack pipes).

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### **Objective 3: Establish policy-relevant data on treatment uptake and outcomes in specific populations.**

Data is required to assess treatment uptake and outcomes – and the factors that improve treatment readiness and adherence – in order to inform the delivery of care and treatment.

The Institute for Clinical Evaluative Sciences (ICES) and other ministry-funded research units must ensure 25 per cent of their core annual work plans involve ministry-responsive research. Data on clinical outcomes, cost-effectiveness studies and other health services research could be identified to address policy-relevant questions to inform the development and delivery of HCV programs and services in Ontario. In addition, both federal research initiatives, such as the Public Health Agency of Canada (PHAC) population survey on HCV and industry-sponsored independent investigator clinical research represent potential avenues for collaboration that will strengthen the availability of robust HCV research data in Ontario.

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**Recommendation:** Support policy-relevant applied research, in collaboration with relevant federal and pharmaceutical industry research initiatives.

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### **Objective 4: Establish data on optimal program/health service delivery models to reach higher risk populations.**

Those using drugs often face barriers in accessing the health care system and cite the stigma of drug use, or discrimination by health and social service professionals as among the barriers to accessing health care services. We need research to assess existing models of service delivery and establish best practices in delivering a range of interventions to those using drugs.<sup>86</sup>

Ontario-based research is required to supplement existing data to establish best practices in delivering education, prevention, treatment, and support interventions to populations at higher risk for HCV. These initiatives should include:

- Best practices of existing harm reduction programs
- Evaluation of NEPs to ensure they are established using Ontario Needle Exchange Programs: Best Practice Recommendations (March 2006)
- Evaluation of barriers to testing, counselling, and treatment among high-risk populations
- Evaluating operations to develop best practices

Research findings from these initiatives will inform ongoing program development and service delivery, including the comprehensive provincial harm reduction program outlined in Section 2.2.

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**Recommendation:** Conduct comprehensive program evaluation and operations research to establish the optimal model and best practices for delivering harm reduction and other HCV-relevant programs and health services to higher risk populations.

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### 3. Coordination and Implementation

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**Goal: Implement the Proposed Strategy to Address Hepatitis C in Ontario 2009-2014 in collaboration with key stakeholders.**

Stakeholders have called for a provincial strategy to implement each of the five priority areas outlined in this document. This Strategy would move Ontario's response to HCV to a comprehensive, programmatic approach with interconnected initiatives in treatment, prevention, education, support, and surveillance and research.

While stewardship for Ontario's response to HCV rests primarily with the Hepatitis C Secretariat, successfully implementing this Strategy will require collaboration and coordination across the MOHLTC, including:

- AIDS Bureau
- Public Health Division
- Research Unit
- Health Data Branch
- Mental Health and Addictions
- Aboriginal Health Strategy Unit
- Local Health Integration Networks
- Ontario Agency for Health Protection and Promotion

In implementing this proposed Strategy, the Hepatitis C Secretariat will take a leadership role, providing strategic advice and support to the other ministry program areas that will be responsible for implementing various components of this proposed Strategy. Successfully responding to HCV in Ontario requires as prerequisites that:

- The implemented policies and programs are consistent with those outlined in this proposed Strategy
- The necessary human resources to implement and evaluate them are provided

The OHCTF and the Ontario Advisory Committee on HIV/AIDS (OACHA) have established a joint working group to address areas of mutual concern. These include the need to:

- Broaden harm reduction initiatives
- Strengthen the surveillance system in Ontario
- Increase incentives for physicians to treat people living with HCV and/or HIV
- Address barriers to implementing evidence-based prevention, care and treatment programs in prisons

The Hepatitis C Secretariat and other relevant ministry program areas should collaborate with other ministries, which have key roles to play in the successful implementation of this proposed strategy to achieve a consistent approach to HCV across Ontario. These include the ministries of:

- Community Safety and Correctional Services
- Education
- Community and Social Services
- Children and Youth Services
- Aboriginal Affairs
- Health Promotion

Aboriginal communities (First Nations, Métis, and Inuit) work directly with the federal government to address health service delivery to on-reserve and Inuit populations. The province is responsible for working with Aboriginal communities to address off-reserve health issues. Ensuring programs are relevant to Aboriginal communities and accurately reflect jurisdictional issues requires close collaboration and consultation with Aboriginal leaders, service providers, and the federal government. The Hepatitis C Secretariat will work with the Ministry of Aboriginal Affairs, the AIDS Bureau, the Aboriginal Health Strategy Unit, and Ontario Aboriginal HIV/AIDS Strategy (OAHAS) to ensure HCV treatment, prevention, education, support, and research initiatives are delivered in culturally appropriate ways to off-reserve Aboriginal populations.

The proposed Strategy should be implemented in collaboration with – and complementary to – federal initiatives, including:

- The Hepatitis C Prevention, Support and Research Program
- Research funded through Public Health Agency of Canada (PHAC) and the Canadian Institutes of Health Research (CIHR)

As part of its stewardship role, the Hepatitis C Secretariat – in collaboration with other ministry program areas and stakeholders – also should be responsible for monitoring and evaluating the implementation of this Strategy, and producing an annual report that assesses both progress and challenges in achieving the Strategy objectives.

The recurring themes of the community consultations were the need for:

- Better coordination of local programs and services relevant to populations at risk for HCV infection
- Stronger links between local and provincial initiatives aimed at responding to HCV in Ontario

Several community consultation reports recommended establishing a local hepatitis C network, with a local lead agency that would be best positioned to better publicize and coordinate HCV-related programs and services in the local community.

The Hepatitis C Secretariat, relevant ministry program areas, and local networks and agencies should work with lead agencies and local hepatitis C networks to ensure the proposed Strategy is consistently implemented across the province and is responsive to – and informed by – the experience of local communities and programs.



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**Recommendations:**

- Confirm local lead agencies and contacts, including the role of the LHINs, and establish a process for ongoing communication and collaboration for implementing the Proposed Strategy to Address Hepatitis C in Ontario: 2009-2014 across Ontario communities.
  - Ensure coordination among those agencies and organizations that will require extra resources to increase their capacity in order to implement these proposed Strategy recommendations.
  - This proposed Strategy has identified gaps in the care, support, prevention, and education related to individuals infected, affected, and at risk of acquiring hepatitis C. New human resources will be required to provide the expertise necessary to bridge these gaps. These resources may be placed in a variety of settings (CHCs, service organizations, and hospital clinics), utilizing synergies that already exist and would be dependent upon the needs and resources already available in those communities.
  - Identify opportunities to clarify federal, provincial, and territorial roles and responsibilities to identify partners and maximize coordination and cooperation in implementing the Proposed Strategy to Address Hepatitis C in Ontario: 2009 -2014.
  - Involve those living with hepatitis C/at higher risk for acquiring HCV in developing programs and policies that deal with hepatitis C, including the five priority areas outlined in this proposed Strategy: treatment, prevention, education, support, and surveillance and research.
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## 4. Conclusion

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Strengthening the response to HCV is required urgently to reduce the future disease burden and associated costs to Ontario's health care system. Investing in the goals, objectives, and activities outlined in this proposed Strategy – and the stewardship required to implement this Strategy – would capitalize on existing programs and make Ontario a Canadian leader in responding to HCV.

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