Canadian Coalition of Organizations Responding to Hepatitis B and C

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2011 Hepatitis Strategy Report Card Executive Summary
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Introduction:

Hepatitis B and hepatitis C are both infectious diseases of the liver, which can lead to serious liver damage including liver cancer and the need for liver transplantation. The viruses that cause hepatitis B (HBV) and hepatitis C (HCV) are both transmitted through blood-to-blood contact. HBV can also be transmitted through bodily fluids other than blood (saliva, anal or vaginal fluid and semen). The World Hepatitis Alliance estimates that 1 in 3 people worldwide have been exposed to viral hepatitis, with over 1 million deaths each year related to hepatitis B and / or hepatitis C[1]. It has been estimated by the Public Health Agency of Canada that approximately 600,000 Canadians are living with hepatitis B and / or hepatitis C;[2] the cost to the Canadian public health care system will continue to soar unless there are more effective strategies implemented to address the epidemic.

In 2008, as part of World Hepatitis Day, the World Hepatitis Alliance (WHA), comprised of organizations from various countries, came together with the goal of expanding World Hepatitis Day awareness activities. Another goal of the WHA was to develop 12 Asks, a series of requests for governments to take action on hepatitis prevention, treatment and support which was to be presented to governments for action by 2012. Six global asks were developed by the WHA and six were to be developed by each country to reflect their specific needs around hepatitis B and C. A committee of Canadian organizations collaborating at planning World Hepatitis Day 2008 discussed, developed and arrived at a consensus on 6 national Asks specific to Canada. These were presented as part of World Hepatitis Day 2008. In 2009, recognizing that Canada did not have a national strategy or comprehensive system for addressing hepatitis B and C, the Canadian Coalition of Organizations Responding the Hepatitis B and C ("The Coalition") was born. The Coalition set out to ask provincial, territorial and federal governments to respond to these Asks by the year 2012 by actively advocating for our national Asks.

[1] World Hepatitis Alliance (2011). About Viral Hepatitis. http://www.worldhepatitisalliance.org/AboutViralHepatitis.aspx. Retrieved: July 16 2011.
[2] Public Health Agency Canada (2011). Hepatitis - Infectious Diseases. http://www.phac-aspc.gc.ca/hep/index-eng.php. Retrieved: July 16, 2011.

In 2010, the Coalition identified the need to assess the successes and gaps in provincial, territorial and federal strategies as a step towards a fully funded, coordinated national approach to address hepatitis B and C. Over the past year, The Coalition developed a Report Card which looks at each of the 6 national Asks in detail and assesses the strategies implemented by each province and territory as well as the federal government. Please let it be emphasized that the Report Card is a commentary on the activities of the governments, and not the work of independent organizations that work tirelessly, often in isolation and with very limited resources at their disposal.

Method:

For each of the 6 Asks, a number of 'issues' were developed, each accompanied by a series of expectations for how The Coalition defines success at addressing the issue. Further, for each expectation, a measurement was identified to indicate whether the expectation is being met. The activities of each province and territory, as well as the federal government, were explored and documented over a period of approximately five months. Input was sought from key stakeholders in each region, including health authorities, government officials, and community organizations. Information was not readily available for PEI, Nunavut or the Northwest Territories; we consider this evidence of a serious gap in resources, funding and support for those living with hepatitis B and C in those communities.

Each of the 6 Asks will be discussed briefly in this executive summary; please refer to the complete Report Card for additional detail, explanations and comments.

Ask 1: Promote prevention of hepatitis B and C through expanded education, immunization and harm reduction programs across Canada.

The first Ask requests expanded prevention activities, including vaccination for hepatitis B and harm reduction programs, to lower the spread of both HBV and HCV.

Analysis of this Ask suggests that although governments are doing relatively well in providing HBV vaccinations to infants, school-aged children and at risk populations, a universal vaccination program in all regions is necessary. Pregnant women are generally offered screening for HBV, although a more proactive screening process, accompanied by counseling and support, is still necessary in many regions. Universal maternal screening for HCV should be further explored for its potential as a recommended practice; although it cannot prevent transmission, it can benefit women, their families and their care providers.

All regions need a more comprehensive harm reduction strategy which addresses the needs of populations regardless of geographic region, in order to decrease the spread of diseases. Safer injection facilities, methadone and needle exchanges should be available in all regions, while all governments need to adopt a broader perspective on the determinants of health if they are to be able to address the harms associated with drug use and drug use policy.

Governments are essentially failing in terms of the prison population; this is an opportunity to treat, prevent transmission among and educate a very high-risk population, thereby limiting the spread of viral hepatitis and other infectious diseases. There is no consistency from one institution to the next; harm reduction measures, resources and equipment must be available and accessible in all provincial and federal institutions. It is critical that policies in place at correctional facilities promote and not hinder harm reduction activities.

Although health care settings and correctional facilities have up-to-date and enforced infection control policies, personal services settings (body art, beauty, acupuncture facilities) need to be regulated across the country and control / enforcement measures put into place. In a few locations the Personal Services Settings (PSS) industry is creating training and testing for practitioners and some cities are working to develop more stringent control/enforcement measures as well as public education on the risk of hepatitis transmission in these settings.

Every infant born in Canada is offered free vaccination against HAV and HBV.	C-
All pregnant women are offered screening for HBV and HCV and counseled on the benefits of prenatal detection, especially for HBV.	B+
Provinces/territories have in place a process for offering and encouraging babies born to HBV+ mothers to receive medical interventions to prevent vertical transmission.	B
Program is in place which identifies, notifies, and offers vaccinations to individuals not previously vaccinated	C-
A harm reduction strategy exists and is in operation across the province/territory.	C-
Accessible and population-appropriate harm reduction programs are in place in all correctional institutions.	F
Up-to-date infection control policies are in place and enforced in all healthcare provider settings, body art and beauty industry facilities, and at all correctional facilities.	B-

Ask 2: Improve access to comprehensive care and treatment programs in all areas of the country.

The second Ask emphasizes the need for improved access to comprehensive HBV and HCV care and treatment programs across the country.

HCV and HBV treatment is generally available across the country, but not consistently or uniformly; cost disparities need to be reduced, the availability of specialists needs to be increased, and wait times must be shortened.

Information on the number of individuals treated for hepatitis C is not effectively monitored or available in much of the country. Still, it remains clear that too many people remain undiagnosed and untreated for HCV. Screening based on age as well as risk needs to be enforced.

While liver transplants should be available to all who need them in theory, in practice, numbers of transplants are too low. This is particularly true for HIV and HCV co-infected persons. Transplanting the liver of a person who is HIV+, HBV+ or HCV+ should be

considered as a lifesaving measure for recipients who are willing to receive such livers. Furthermore, living donor transplants should be more widely promoted. The federal government should exercise leadership and take a more active role in organ donation campaigns.

Treatment management guidelines are generally up-to-date, although more coherent national guidelines are needed, as inconsistencies exist from province to province, especially regarding support provided for the complex health needs of HBV+ and HCV+ persons.

Drug coverage is available everywhere but policies are inconsistent across the nation; a uniform and universal national drug coverage program is needed. Some policies and practices are outdated or otherwise not in line with recommended guidelines, such as the not re-treating patients who were previously unsuccessful with HCV treatment.

In terms of clinical trials, increased access to these trials is needed, both in terms of geography (i.e. rural regions should have access to clinical trials as well) and the availability of information regarding how to access clinical trials. The drug approval process in Canada is acceptable, although consistency in coverage and access across the country is needed; internationally approved drugs should be considered for a fast track review by Health Canada. One national drug plan would be desirable.

All HBV+ and HCV+ individuals are given equal access to treatments, specialty care and liver transplants.	C-
HBV and HCV management guidelines are reviewed regularly to ensure they conform to medical standards, best practices and advances.	C
HBV and HCV treatment including anemia drugs and recognized alternative therapies, are covered under provincial drug plans or programs.	C
Government approval processes for clinical trials take into account different groups of populations affected by HCV and HBV.	B
Drug approval process is timely, efficient and safe.	B

Ask 3: Increase knowledge and innovation through interdisciplinary research and surveillance to reduce the burden of hepatitis B and C on Canadians.

Surveillance data on HBV and HCV is accessible in most regions, although some of it is 2-3 years old; The Coalition recommends a more comprehensive and up-to-date surveillance program.

Death from liver cancer is reported by all regions, however, data on morbidity and mortality directly related to HBV and / or HCV is not readily available.

HBV should be a reportable disease, just as HCV is, to Health Canada. Reporting parameters for both HBV and HCV should be expanded so that important indicators, such as genotype, are consistently monitored. HBV/HCV testing should be systematically included in annual check-ups, particularly for at-risk groups.

National acute and chronic case definitions are used in reporting, but these case definitions do not distinguish between active and resolved infection. A separate definition for reporting resolved infections could facilitate better management and evaluation of case reports as well as create a more accurate picture of the hepatitis epidemic in Canada.

There is currently insufficient funding both federally and provincially/territorially for research, in particular for non-pharmaceutical areas. There needs to be a greater national coordination of research and its dissemination as the current system lacks transparency.

Surveillance data and updates are published in a timely and accessible manner.	B
HBV and HCV-related hepatocellular carcinoma (HCC) morbidity and mortality data are monitored on an ongoing basis.	C
Incidence of HBV and HCV is monitored through routine surveillance, enhanced surveillance and population-based surveys.	C
Compulsory reporting is required from all health authorities.	B
Surveillance data describes HBV and HCV in terms of a case definition which reflects acute, chronic and resolved infections.	B-
Increase funding for HBV and HCV research.	C
Enhance knowledge exchange and dissemination of HBV and HCV research.	C

Ask 4: Create awareness about risk factors, stigma and the need for testing among the general population and at-risk groups.

HBV and HCV testing is offered on a routine basis in some settings (i.e. prisons, treatment centers), but is available only by request in many other settings. Testing programs should include anonymous testing options and be offered through existing programs such as sexual health clinics. Testing trends should be studied to inform a national prevention and treatment strategy.

In terms of education and support programs around HBV and HCV, there has been relatively little concerted or coordinated effort at a national level. The Coalition recommends that a national strategy involves education and anti-stigma campaigns (which are unique from HIV-focused campaigns), increased funding for outreach programs and support for provincial and territorial governments' programs. Across Canada, individual programs and organizations are doing great work but are often forced to work in isolation and with limited and/or unreliable funding.

Establish testing programs aimed at high-risk populations.	C
Create ongoing education campaigns aimed at the general public, medical community, and patients to de-stigmatize both diseases.	C
Awareness programs about HBV and HCV risk factors aimed at youth and at-risk populations are developed and promoted.	C
Outreach programs and campaigns encouraging monitoring and treatment are regularly undertaken to reach HBV+/HCV+ diagnosed individuals who are asymptomatic, untreated or non-responders, including those in correctional facilities.	C

Ask 5: Build capacity through training and recruitment of qualified health professionals.

The fifth Ask pertains to the training and recruitment of qualified health care professionals who specialize in HBV and HCV.

HBV and HCV training and continuing education are available for various levels of healthcare providers in a variety of formats. The Coalition recommends that training be mandatory for emergency department staff, both physicians and nurses. The Coalition also recommends the provision of HBV and HCV training and education to be strongly encouraged in all healthcare settings.

There seems to be a relatively stable number of hepatologists and related specialists in the country, though these numbers could decrease in the coming years due to retirement. Simultaneously, there will be greater demand for specialists as the number of people seeking treatment and care increases. Additionally, there is currently little incentive for physicians to specialize in hepatology. Creating greater incentives for healthcare professionals to specialize in hepatology, as well as training non-specialists such as family physicians, nurses and other care providers in the areas of HBV, HCV and liver health is important for averting a potential future shortage.

Curriculum in HBV and HCV healthcare provider training is established and related continuing education programs are provided.	B
Provide incentives to encourage doctors, nurses and allied healthcare professionals to specialize in areas related to HBV and HCV.	D

Ask 6: Support communities and community-based groups in developing, delivering and evaluating peer-driven and focused initiatives.

Provincial/territorial funding has been relatively stable and supportive in some instances, but in others has been inadequate or non-existent. Federal funding has been inconsistent, and an annual delay in renewing funding agreements has been an ongoing problem, disrupting staff and program stability, preventing long-term planning and putting the very existence of many organizations at risk. The Public Health Agency of Canada has not lived up to a commitment for ongoing funding made by the Minister of Health in 2008. Resources are still scarce and difficult to access. There continues to be strong resistance at the federal level to the concept of harm reduction.

Stable funding ensures outreach programs (harm reduction and education) are accessible to at-risk communities through local frontline organizations.	F
Organizations that provide care and support to individuals infected with and affected by hepatitis B and C are provided stable funding.	F

Conclusions:

An overarching theme that emerged from the Report Card is the need for a coordinated, comprehensive, nationally supported strategy to address prevention, care and treatment for HBV and HCV. The absence of information available for PEI, Nunavut and the Northwest Territories, along with the limited information available for many of the other

provinces and territories, represents another overarching theme of limited information availability and a lack of commitment in terms of surveillance, reporting and funding. Finally, the lack of collaboration and coordination between the provinces, territories and the federal government is another important theme which needs to be urgently addressed.

The following recommendations follow from the Report Card analysis:

- Universal, publicly-funded vaccination program for HBV
- HBV testing and counseling for all pregnant women; Universal maternal screening for HCV should be further explored for its potential as a recommended practice
- Catch-up HBV vaccination programs available in all regions, at no cost
- Comprehensive Harm Reduction strategies in place in all regions, which include yearly evaluations
- Harm reduction services and equipment available and accessible in all provincial and federal correctional institutions
- HBV and HCV treatment consistently available in all regions
- Routine surveillance and reporting of HBV and HCV cases and related deaths
- HBV should be a reportable disease
- Increased organ donations and increased availability of livers for individuals living with hepatitis C
- Decreased wait times to see liver specialists; decreased wait times to receive a liver transplant
- Improved access to clinical trials, including in rural regions
- Improved drug approval process, including fast tracking of drugs approved internationally
- Increased federal funding for research and dissemination activities, especially for non-pharmaceutical funding
- Increased testing of HBV and HCV, especially in high-risk groups; anonymous testing should be incorporated into testing programs
- Increased funding for education and anti-stigma campaigns and outreach programs around HBV and HCV
- Incentives for health care providers specializing in HBV and HCV
- Increased (and stable) funding for organizations supporting individuals living with HBV and HCV