

## TERMS OF REFERENCE for MEMBERS

### 1.0 PURPOSE

Action Hepatitis Canada is a national coalition of organizations focusing on the response to hepatitis B and C – two diseases that negatively affect the quality of life of up to 600,000 Canadians and their families, friends, caregivers and communities.

Action Hepatitis Canada’s vision is a Canadian society in which persons affected by or at risk for hepatitis B and C no longer encounter discrimination, stigma, or barriers to testing, prevention, treatment and support.

We believe that better health outcomes for persons living with and at risk for Hepatitis B & C is best achieved when governments, policy makers and civil society work together to realize a commitment to Hepatitis B & C prevention, testing, care, treatment, support, surveillance and research with funding proportionate to the impact & burden of this health issue.

Our work in engaging government, policy makers, and civil society involves advocating across Canada for hepatitis B and C prevention; improving access to care and treatment; increasing knowledge and innovation; creating public health awareness; building health-professional capacity; and supporting community-based groups and initiatives.

### 2.0 BACKGROUND

Hepatitis B and hepatitis C are viruses that damage the liver, and can cause debilitating symptoms, liver disease and accelerated mortality. People living with hepatitis B and C are often unrecognized, undiagnosed and go untreated for years. Research on hepatitis B and C is inadequately funded, and prevention initiatives and access to treatment, care and support are limited. Widespread stigma associated with hepatitis compounds poor health outcomes.

In Canada, strategies to coordinate hepatitis B and C research, prevention, treatment and support have been too narrow, inconsistently adopted and inadequately funded. With new technological developments and health intervention models making better treatment outcomes and the eradication of viral hepatitis possible, it is time to refocus the Canadian response to hepatitis B and C.

### 3.0 MANDATE

Action Hepatitis Canada works to improve health outcomes for persons living with and at risk for Hepatitis B and C by working on behalf of organizations with governments, policymakers and civil society to realize a commitment to Hepatitis B and C prevention, care, treatment, support and research – with funding proportionate to the impact and burden of this health issue on quality of life.

By engaging government, policy makers, and civil society Action Hepatitis Canada seeks to achieve equitable policy and program implementation in the following areas:

- Prevention of both hepatitis B and C through expanded education, immunization and harm reduction programs across Canada
- Access to comprehensive care and treatment programs across Canada

- Increased knowledge and innovation through interdisciplinary research and surveillance that monitors and reduces the burden of both hepatitis B and C on Canadians
- Awareness about risk factors, stigma and the need for testing among the at-risk groups, as well as the general population
- Recruitment, training and capacity development of qualified service providers and health professionals.
- Support for communities and community-based groups to develop, deliver and evaluate peer-driven initiatives.

These areas complement the six global “asks” formulated by the World Hepatitis Alliance, which are:

- Public recognition of chronic viral hepatitis as an urgent public health issue
- The appointment of an individual to lead Government strategy nationally
- The development of a patient pathway for screening, diagnosis, referral and treatment
- Clear, quantifiable targets for reducing incidence and prevalence
- Clear, quantifiable targets for reducing mortality
- Clear, quantifiable targets for screening

To find further explanation of our policy positions, please visit [www.actionhepatitiscanada.ca](http://www.actionhepatitiscanada.ca)

#### **4.0 MEMBERSHIP**

Membership in Action Hepatitis Canada is open to Canadian organizations committed to addressing hepatitis B and/or hepatitis C. Action Hepatitis Canada and each organizational member agree to a Memorandum of Understanding, which outlines the following terms:

- Members agree to support the mandate of Action Hepatitis Canada as outlined in this Terms of Reference
- Members receive a report annually prior to the Annual General Meeting on Action Hepatitis Canada activities
- Members receive a work-plan outline for Action Hepatitis Canada activities in the coming year after the Annual General Meeting
- Members are encouraged to nominate representatives from their organization to vacant positions on the Steering Committee, and are entitled to one (1) vote in the Steering Committee election
- The Steering Committee commits to contact members prior to initiating public/external action, such as but not limited to lobbying elected government representatives or launching advocacy campaigns so that members are aware of actions being taken. Action Hepatitis Canada members are encouraged to promote our activities with their own members to generate additional support.

Individuals interested in engaging with Action Hepatitis Canada and supporting our activities are encouraged to join our communication list at [www.actionhepatitiscanada.ca](http://www.actionhepatitiscanada.ca).

## 5.0 STRUCTURE

Action Hepatitis Canada's work-plan is set and stewarded by a Steering Committee, which is made up of 8-12 members elected to 2 year terms. Steering Committee member selection occurs as described above in section 4.0, as well as in the Steering Committee Terms of Reference, available at [www.actionhepatitiscanada.ca](http://www.actionhepatitiscanada.ca).

CATIE, the national knowledge broker on HIV and Hepatitis C, provides the secretariat services for Action Hepatitis Canada. The fiduciary relationship between CATIE and Action Hepatitis Canada is expressed in a Memorandum of Understanding.

## 6.0 DISCLAIMER

Action Hepatitis Canada's mandate is to engage government and policy makers to make gains in the areas listed in Section 3.0. Membership in Action Hepatitis Canada demonstrates an alignment with these goals and "asks", however it is understood that from time to time, Action Hepatitis Canada may express views that are not endorsed by one or more member organizations. Similarly, member organizations may from time to time take a different stance than that of Action Hepatitis Canada.

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Approved: February 6th, 2014 by the Interim Steering Committee at a face-to-face meeting in Toronto.

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### **Action Hepatitis Canada**

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