
The Hepatitis C Prevention, Support and Research Program: Health Canada Initiatives on Hepatitis C

Health Canada

In September 1998, Health Minister Allan Rock announced new federal hepatitis C funding of \$50 million over five years for initiatives relating to community-based support, research, and disease prevention. Since then, broad cross-country consultations have taken place with individuals and their caregivers who are infected, or affected, by this disease; non-governmental organizations; provinces and territories; and health care professionals. The result is a relevant, compassionate and targeted new Health Canada Hepatitis C Program with a four-point action agenda, that encompasses five components – prevention; community-based support; care and treatment support; research; and ongoing management, evaluation and public involvement.

Federal Health Minister Allan Rock introduced a comprehensive set of initiatives in September 1998 to build a pan-Canadian capacity to prevent the further spread of hepatitis C, to build a research capacity and to provide care and treatment support for those with the disease.¹ These new initiatives included the Hepatitis C Prevention, Support and Research Program. This Program was developed in consultation with those who had contracted hepatitis C through the blood system and their representatives, and those who had contracted hepatitis C outside the blood system, as well as other non-governmental organizations and professional groups with an interest in this disease. The Program is a five-year initiative with funding totalling up to \$50 million.

Through an extensive consultation process, the new Program has developed a **4-Point Action Agenda**.² Its goals are to:

- contribute to the prevention of hepatitis C infection;
- support persons infected with, and affected by or at risk of contracting hepatitis C through the development and availability of tools and mechanisms;
- provide a stronger evidence base for hepatitis C policy and programming decisions and advance prevention, treatment and cure options by expanding the body of available research and research capacity; and,

- strengthen the response of the Canadian population to hepatitis C through increased awareness and capacity.

Hepatitis C (or Hep C as it is commonly known) has not traditionally received much public attention. The hepatitis C virus (HCV) was not identified until 1989 and prior to that, had been characterized as non-A, non-B hepatitis. In 1990, a specific test to detect the presence of HCV in blood became available, but at present scientists are still unable to culture the virus *in vitro* – a requirement which would facilitate the development of a vaccine and new treatments.

In Canada, it has been estimated that approximately 240,000 Canadians, or 0.8% of the population, are infected with hepatitis C and, of those, only about 30% are aware of their infection. Research indicates that individuals infected with HCV may not experience symptoms for up to 30 years.

Worldwide, hepatitis C is a significant health problem with an estimated 170 million people infected.³ Studies have shown an anti-hepatitis C positivity rate in the US of about 1%; in the Middle East 1-2%; and in Western Europe 1-1.5%. Certain countries have a much higher prevalence (as high as 18%) mainly due to past mass immunization programs that did not use sterile equipment.

Some populations also have a much higher prevalence. In Canada, these include past recipients of blood, blood

products or organs; injection drug users; prisoners and immigrants from areas in the world with higher hepatitis C prevalence. Hepatitis C has also been identified as the most common cause of post-transfusion hepatitis worldwide, accounting for approximately 90% of this disease in Japan, the US and Western Europe.⁴

Hepatitis C has not attracted significant research funding in Canada. This has been due, in large part, to a need for a critical mass of research which, in the past, has been difficult to attain because of the highly competitive nature of research and the scarcity of hepatologists doing research. There are only about 25 trained liver specialists practicing in Canada, a number of whom are internationally renowned in their field and are only located in major cities. This lack of specialists and experienced physicians gives rise to significant treatment challenges including long waiting lists for patients to be seen.

Following Minister Rock's September 1998 announcement, Health Canada staff were assigned the task of designing, implementing and delivering the new Hepatitis C Program. A new organization was soon formed within the department. The staff recognized the need to consult with a wide variety of stakeholders to ensure that many varied and sometimes contradictory views and opinions could be expressed and discussed in open fora. They also understood the need to address both research and

research capacity around hepatitis C as a matter of urgency in Canada.

In the fall and winter of 1998, the staff from the new Program undertook a broad set of consultations across the country on the potential design of the new Program.⁵ What they heard from numerous stakeholders was not always complimentary about the past role and leadership of governments. It did, however, offer a promise that partnerships could be undertaken in the future and that strides could be made over the next five years in the areas of: prevention; community-based support; care and treatment support; research; and ongoing management, evaluation and public involvement in the Program.

FIVE COMPONENTS

Prevention is targeted programming aimed at preventing the transmission of hepatitis C among those who are currently uninfected, particularly those who are at high risk, such as injection drug users. Some programming will also be targeted, in the form of information and education, to those who face a marginal risk of infection, such as partners of hepatitis C individuals and health care workers.

Increasing public awareness and knowledge about an issue as complex and sensitive as hepatitis C can only be done in partnership and collaboration with many other agencies, organizations, community groups and dedicated individuals. In developing and stimulating efforts in this area, the Program is encouraging and funding the development of tools and information materials to support activities at the national and local levels. For those at greatest risk of contracting this disease, risk reduction behaviour will be profiled. Finally, pilot projects will be funded and evaluated to assess their effectiveness.

Community-Based Support includes programming to support both a strong community-based response to the needs of individuals and their families who are infected with or affected by hepatitis C, and emphasizing a strong role for community organizations in the Hepatitis C Program.

The activities of this component contribute to gaining a better understanding of the nature and effects of hepatitis C

infection and how communities can provide support to those who are infected with, affected by or at increased risk of hepatitis C infection. As of March 2000, over 40 community-based projects have been funded that are wide-ranging in scope and impact and include the following: an educational conference and roundtables on hepatitis C for front-line workers (New Brunswick); the production of a bilingual information newsletter on hepatitis C (Québec); the development and distribution of a brochure for pregnant women who are infected with hepatitis C (Ontario); the development of harm reduction tools and mechanisms to reach injection drug users and their families (Saskatchewan); the development and distribution of a comprehensive, user-friendly booklet that assists people to make decisions regarding treatment, housing, employment and related issues (Manitoba); the development of a *Safe Body Art* pamphlet to provide young people with information about the increased risks of hepatitis C associated with body piercing and tattooing (Alberta); and support for hepatitis C and HIV co-infection education and outreach activities, including the development of targeted educational material (British Columbia).

Care and Treatment Support emphasizes national-level initiatives aimed at supporting those already infected with or affected by hepatitis C. Activities focus on increasing the health and well-being of individuals who are infected by delaying the progress of the disease and improving their access to the care and treatment support they require.

Activities under this component include professional education and training; treatment guidelines; information dissemination and network development. In developing programming in this critical area, the Program is merging existing tools with new approaches. For example, the University of Manitoba has been funded to assess an existing CD ROM-based medical software program to determine if this application would be useful to rural physicians in identifying, diagnosing and counselling patients with hepatitis C infections. The results of this pilot project will be shared across regions and communities. As well, the Dietitians of Canada was funded

to develop and conduct a needs assessment on nutritional guidelines for patients infected with hepatitis C. Other notable examples include funding to the Canadian Liver Foundation to develop two information documents, one targeted to patients, the other to doctors. The Society of Obstetricians and Gynaecologists of Canada has also been funded to produce clinical guidelines for the treatment of pregnant women who are infected with hepatitis C.

Research will encourage and support the research, development and dissemination of knowledge about hepatitis C, as well as build the commitment and capacity of the Canadian research community to conduct research which will contribute to a better understanding of the hepatitis C virus and its epidemiology, treatment and prevention, to decrease its burden on infected and affected populations.

In July 1999, the Program and the Medical Research Council of Canada announced the allocation of \$18.4 million to further hepatitis C research. In announcing this program, Minister Rock indicated clearly his hopes and expectations. "This initiative," he stated, "targeted to Hepatitis C and its potentially devastating effects on people, will build much needed knowledge. Ultimately, this crucial work will benefit all Canadians, particularly those living with the virus." Dr. Henry Friesen, the President of the Medical Research Council, also added, "This program will help train more scientists and enable the scientific community to fill the numerous gaps in Hepatitis C-related knowledge, such as prevention, clinical research and treatment."⁶

This collaborative five-year research partnership will fund scientifically meritorious projects in the following areas: the biology, pathogenesis and epidemiology of the virus; screening and diagnostic technologies; the natural history of the disease; treatment strategies; quality of life issues and preventive measures. In February 2000, the first 13 projects under this initiative were funded.

A Joint Advisory Committee, composed of scientists, physicians and stakeholders, has been established to advise Health Canada and the Medical Research Council

on research priorities and the management of the partnership, and to ensure transparency and accountability to all stakeholders and the general public. This initiative has been grandfathered into the new Canadian Institutes of Health Research (CIHR).⁷

Management, Evaluation and Public Involvement is the component in which several activities will be undertaken to ensure that the Program is well-managed, transparent to the Canadian public and is accountable for the effective use of the resources dedicated to it.

Although not as visible as the other components, these elements are critical in developing and maintaining the strategic partnerships that will advance and support the goals of the Program. A Program Advisory Group (PAG) has been established with representatives from stakeholders and the Program to assist with setting directions; responding to emerging issues; ensuring coordination of key sectors and organizations involved in Program initiatives; and fostering citizen engagement in ongoing implementation. Current membership of the PAG includes the Canadian Hemophilia Society, the Canadian Liver Foundation, the Hepatitis C Society of Canada, the Canadian Centre on Substance Abuse, the Canadian Association for the Study of the Liver and the Canadian Public Health Association.

THE WAY FORWARD – ONGOING COMMITMENT AND CONSULTATION

The success of any national program aimed at preventing hepatitis C infection, stimulating research and caring for those already infected, relies heavily on involving all partners throughout its design, development and delivery.

The five components of the Hepatitis C Program outlined above provide a unique combination of research, community-based support, education and outreach activities. This multi-faceted approach has been developed in consultation with a wide range of stakeholders, including researchers, provincial governments, health care professionals, non-governmental organizations working in this area and, of course, individuals and their families who have been infected with and affected by this disease.

How to Contact Us: The Hepatitis C Prevention, Support and Research Program at Health Canada looks forward to updating you periodically on the progress and outcomes of these initiatives. We are currently working on developing our own website. In the meantime, if you require further information on any of the five program components or the Four-Point Action Agenda, please visit us on the Health Canada website at [\[sc.gc.ca\]\(http://sc.gc.ca\), where you can search under the topic of hepatitis C.](http://www.hc-</p>
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2. Health Canada. Health Promotion and Programs Branch. Health Canada, Hepatitis C Care and Awareness: National Guidelines for Proposals. Ottawa: October, 1999.
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7. Health Canada. Legislation to create the Canadian Institutes of Health Research receives Royal Assent. [News release 2000-38]. Ottawa: April 14, 2000.

Web-based reference sites:

Alberta Health
Association of Ontario Health Centers
Canadian Institutes of Health Research
Canadian Liver Foundation
Health Canada
Hepatitis C Society of Canada
Medical Research Council of Canada
World Health Organization