Health Canada
Santé Canada

Hepatitis C

Hepatitis C Prevention Support & Research Program

Canada

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INTRODUCTION

It has long been known that a form of viral hepatitis distinct from hepatitis A and B existed, but it was only in 1989 that the hepatitis C virus was first identified.

Hepatitis is a disease characterized by inflammation of the liver. Although some people may experience symptoms, such as fatigue and jaundice, following initial infection, many others have no symptoms.

In Canada, it is estimated that between 210,000 and 275,000 people are currently infected with hepatitis C, of whom only 30% know they have the virus.

The Hepatitis C Prevention, Support & Research Program intends to increase awareness, promote positive prevention behaviours, expand research activity and augment the government's capacity to respond to this health threat.

THE COMMITMENT

The Government of Canada is fully committed to hepatitis C prevention as well as treatment and care for those living with the disease.

In September 1998, the federal government announced initiatives to improve hepatitis C disease prevention and treatment; to strengthen measures to ensure the safety of Canada's blood supply; and to help all Canadians infected with or affected by the hepatitis C virus.

Among these initiatives is a commitment of $50 million over five years for hepatitis C disease prevention, community-based support and research.

CONSULTING CANADIANS

Between November 1998 and March 1999, Health Canada officials met with a number of individuals and organizations to fulfill the government's promise to consult with Canadians on the design of the proposed Hepatitis C Program. The stakeholders most involved in the consultation process from the outset included:

- Hepatitis C Society of Canada
- Canadian Hemophilia Society
- Canadian Liver Foundation

These organizations, which were later joined by the Thalassemia Foundation of Canada, used input from their local chapters to provide insight into hepatitis C issues from both a national and regional perspective. The on-going advice and assistance of these organizations has been invaluable, particularly with respect to organizing a series of community focus groups and helping to shape the goals and objectives of the Program.

More information on the consultation process is available in Annex C.

THE HEPATITIS C PREVENTION, SUPPORT & RESEARCH PROGRAM

Following the Minister's announcement in September 1998, Health Canada staff were assigned the task of designing, implementing and managing the Hepatitis C Prevention, Support & Research Program. The Program is part of the Hepatitis C Division located within the Population and Public Health Branch of Health Canada.

The consultations with Canadians were instrumental in helping the Division design a federal program which both fulfills Health Canada's commitments and meets the needs identified by stakeholders.

The goals of the Program are to:

- contribute to the prevention of hepatitis C infection;
- promote the development and availability of tools and mechanisms in support of persons infected with or affected by hepatitis C;
- expand research availability & capacity and;
- strengthen the response of the Canadian population to hepatitis C through increased awareness.

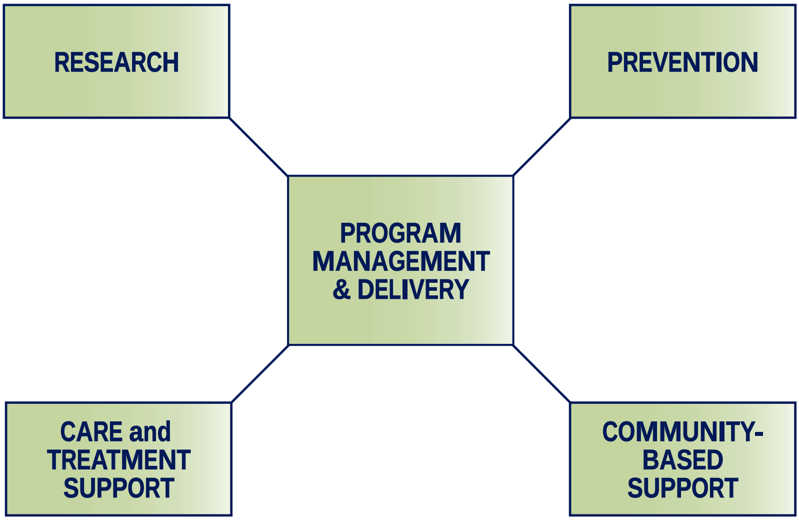
The Guiding Principles are to:

- use **the best available evidence** for programming investment decisions;
- adopt a **Population Health** approach – by acknowledging the impact factors such as income, culture and education have on the health of Canadians, and taking them into account for program design, implementation and evaluation;
- focus on the **needs and priorities** of the infected and affected populations, and those at greatest risk;
- emphasize **practical, immediate measures** shown to enhance the quality of life for those infected, affected and at risk;
- meet **ongoing needs on a sustainable basis**;
- ensure **equitable, responsive and compassionate consideration and support** to all persons infected with, affected by or at risk of hepatitis C infection, regardless of mode, source or time frame of infection;
- minimize program overhead in order to **maximize program impact and benefits** for the intended populations;
- engage the **commitment and support of key sectors and stakeholders** to assume responsibility for, and take initiative on appropriate research, prevention and community support measures;

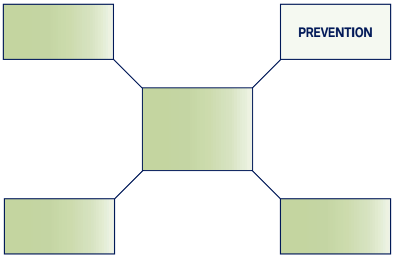
- emphasize **complementarity and coordination** of all efforts; and,
- **encourage public accountability** – in order to ensure that the Hepatitis C Program remains relevant and responds properly to changing realities, decision-making will be evidence-based and accompanied by ongoing performance review and monitoring.

Program Components

The Program's five year, $50 million budget will be allocated to five major components. Each component is further described below.



Prevention



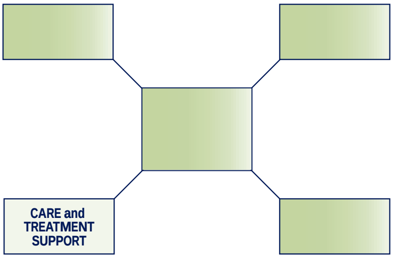
This component includes targeted programming aimed at preventing the transmission of hepatitis C among those who are currently uninfected, particularly those who are at high risk, such as injection drug users. Programming will also be targeted to those people who face a lower risk, such as health care workers and partners of hepatitis C positive individuals.

In collaboration with key sectors and institutions such as community groups serving marginalized populations, addictions agencies and health care practitioners, Health Canada will improve the general public's awareness and knowledge of hepatitis C and contribute to efforts to prevent its spread in Canada.

Some of the activities planned under this component of the Program include:

- the development of tools, training and information materials to support national, regional and local prevention activities;
- activities aimed towards those who are at greatest risk which will reduce their vulnerability to infection by encouraging them to adopt risk reduction behaviours; and,
- funding pilot projects and programs, evaluating their effectiveness and sharing results with others.

Care and Treatment Support



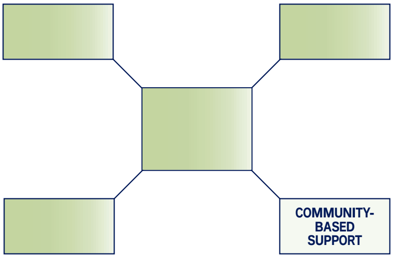
National-level activities undertaken under this component of the Program aim to support the needs of those who are already infected with or affected by hepatitis C. Activities also contribute to enhancing the health and well-being of these persons by delaying the progression of the disease and improving their awareness of and access to care, treatment and support.

As in other components, building the commitment and capacity of key organizations and institutions to provide better care, treatment and support is critical to the success of this part of the Program.

Activities under the Care and Treatment Support component include:

- education and training;
- treatment guidelines;
- information dissemination; and,
- network development.

Community-Based Support

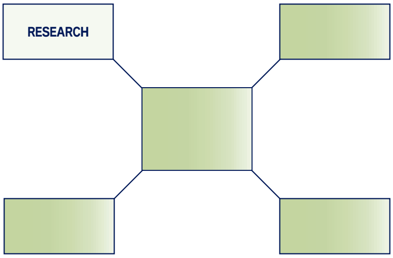


This component will include programming to support both a strong community-based response to the needs of persons infected with or affected by hepatitis C, as well as a strong role for community organizations in the national Hepatitis C Program. The activities under this component will contribute to 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 or at increased risk of hepatitis C.

This component will strengthen links between organizations through:

- funding and capacity-building support for organizations and initiatives on behalf of persons infected with, affected by and at risk of hepatitis C; and,
- funding support for the development and evaluation of community-based programming which responds to the needs of those who are infected with, affected by or at risk of hepatitis C.

Research

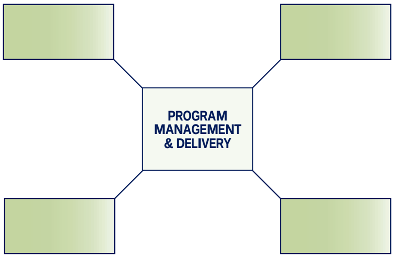


Research is required to bridge the gap between what is currently known about hepatitis C and what has yet to be discovered to be effective in prevention and treatment. The goals of this component are to further hepatitis C-related knowledge, transfer and disseminate it, and apply research findings to the activities taking place under the other components of the Program.

The following are some of the activities supported under the Research component:

- furthering the development of Canada's research capacity by supporting investigator- initiated research and training scientists to work in the hepatitis C research field;
- encouraging targeted workshops and conferences to promote research activities and identify priorities;
- identifying and responding to emerging and changing priorities;
- working together with partners to identify other sources of funding to advance hepatitis C research; and,
- communicating research results and outcomes so that all may benefit from the new knowledge.

Program Management & Delivery



Health Canada is undertaking several activities to ensure that the Program is well-managed, coordinated with others who are interested and involved, as well as transparent and accountable for the effective use of the resources devoted to it.

Specific activities under this component include:

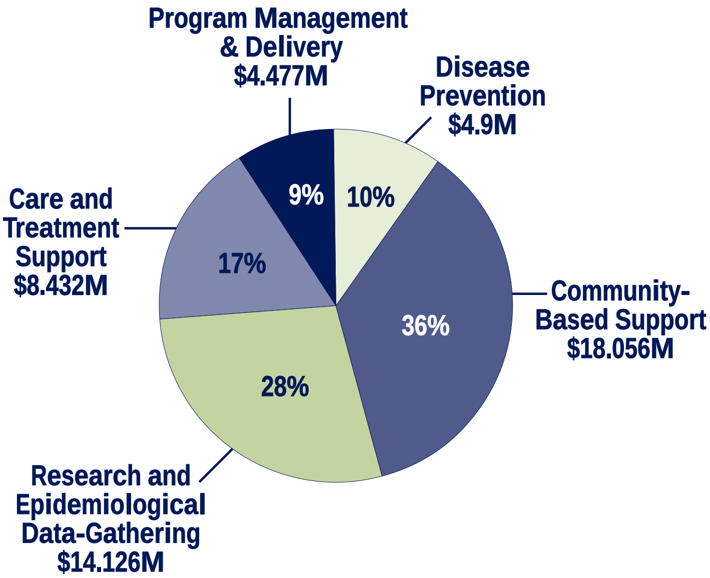
- developing strategic partnerships to support and advance the Program's goals;
- communicating with interested parties and the general public about the Program;
- launching a public awareness campaign;
- keeping the Program flexible so that it can adapt to emerging needs as knowledge is gained about hepatitis C;
- conducting a mid-term and five year review of the Program; and,
- fostering a population health approach to hepatitis C programming.

The Program Management & Delivery component provides leadership for the overall Program. It is the focal point for international linkages and inter-sectoral partnerships and collaborations. To assist in this endeavour, an advisory body has been formed with representatives from stakeholder groups and the Hepatitis C Prevention, Support & Research Program.

The Program Advisory Group (PAG)'s role is to:

- assist the program management team with direction setting;
- foster citizen engagement in the implementation of the Program; and,
- ensure complementarity and coordination of key sectors, organizations and institutions assuming responsibilities and/or taking initiatives relevant to the Program's objectives.

Budget



HEPATITIS C PREVENTION, SUPPORT and RESEARCH PROGRAM

5 year Allocation by Component (1999 – 2004)

Annual Allocation per year (in Millions)	
1999-2000	$5.846
2000-2001	$10.960
2001-2002	$11.326
2002-2003	$11.220
2003-2004	$10.648

MOVING FORWARD

The Hepatitis C Prevention, Support & Research Program's five-year funding will enable it to meet its short term objectives but most importantly, to set the ground work for long-term results. These desired outcomes include:

- improved health and quality of life for those infected with or affected by hepatitis C;
- the establishment of a network of community organizations meeting the needs of persons infected with, affected by or at risk of hepatitis C;
- an increase in clinically-proven, cost-effective treatment measures;
- the reduction of the complications of the disease through early diagnosis and more effective treatment;

- increased complementarity and integration between disease prevention, community-based support and research;
- a more informed population; and,
- reduced incidence of hepatitis C in specific measurable populations (such as injection drug users) and increased adoption of risk reduction behaviours by those at greatest risk of infection.

ACCESSING THE PROGRAM

The Hepatitis C Prevention, Support & Research Program is committed to building collaborative partnerships with various sectors in order to meet the needs of all Canadians regarding hepatitis C and particularly, the needs of those who are infected with or at increased risk of hepatitis C. A fundamental objective of the Program is to ensure that activities are both responsive and accessible to Canadians.

To obtain further information about the Hepatitis C Program, please contact the Health Canada Program Consultant in your region.

A complete list of national and regional offices is provided in Annex A.

CONTACTS

HEALTH CANADA – POPULATION AND PUBLIC HEALTH BRANCH

BC/Yukon
Regional Office
Vancouver, British Columbia

Tel.: 604-666-2729
Fax: 604-666-8986

Alberta/NWT
Regional Office
Edmonton, Alberta

Tel.: 780-495-2754
Fax: 780-495-5537

Manitoba/Saskatchewan
Regional Office
Winnipeg, Manitoba

Tel.: 204-983-2833
Fax: 204-983-8674

Ontario/Nunavut
Regional Office
Toronto, Ontario

Tel.: 416-952-1286
Fax: 416-973-4389

Quebec
Regional Office
Montreal, Quebec

Tel.: 514-496-9627
Fax: 514-283-3309

Atlantic
Regional Office
Halifax, Nova Scotia

Tel.: 902-426-2700
Fax: 902-426-9689

National Office
Hepatitis C Division
Hepatitis C Prevention, Support & Research Program
Ottawa, Ontario

Tel.: 613-941-7522
Fax: 613-941-7563

Hepatitis C Online: ***www.hepc.gc.ca***
Health Promotion Online: ***www.hc-sc.gc.ca/healthpromotion***

HEPATITIS C VIRUS INFECTION

It has long been known that a form of viral hepatitis distinct from hepatitis A and B existed, but it was only in 1989 that the hepatitis C virus was first identified.

Hepatitis C is transmitted mainly by direct contact with infected blood or blood products, such as through transfusion. Indeed there have been many reported cases of hepatitis C being transmitted through blood products before these were screened for the virus. However, modern screening techniques have virtually eliminated the risk of hepatitis C transmission to users of Canada's blood system.

Currently, the major mode of contracting hepatitis C is through the sharing of contaminated needles and other instruments among injection drug users. Other risk behaviours include using contaminated equipment for tattooing, body piercing, and acupuncture. Current research tells us that the risks of transmitting hepatitis C through sexual intercourse or child birth are low.

Hepatitis is a disease characterized by inflammation of the liver. It may be caused by a number of agents, including viruses such as the hepatitis C virus, alcohol and drugs.

Although some people may experience symptoms, such as fatigue and jaundice, following initial infection, many others have no symptoms. Because the disease progresses slowly in the body, symptoms can appear 20 – 30 years after the initial infection.

In Canada, it is estimated that between 210,000 and 275,000 people are currently infected with hepatitis C, of whom only 30% know they have the virus.

Approximately 10 – 20% of persons chronically infected with hepatitis C develop cirrhosis of the liver. Cirrhosis is a serious degenerative disease that causes liver cells to be damaged and replaced by scar tissue. As the liver ceases to function properly, it loses its ability to perform important functions such as breaking down foods in the digestive process, regulating hormonal balance, producing proteins required for blood clotting, and cleansing the blood of toxic substances such as alcohol and nicotine. Cirrhosis can lead to liver failure and death. Among those who do develop cirrhosis, approximately 1 – 4% are expected to develop liver cancer (hepatocellular carcinoma) each year.

In Canada, there are few approved drug therapies to treat hepatitis C infection. These drugs are very expensive, costing thousands of dollars per person per year, and can induce side effects severe enough to prevent some people from using them.

CONSULTATION PROCESS

Various groups participated in activities in the consultation process.

Focus Groups

Health Canada officials worked extensively with stakeholder and community organizations to establish a series of community focus groups. Over a four-month period, 29 focus groups were held across the country. These groups brought together a broad-based and diverse group of participants who were infected with or affected by hepatitis C, to share their views regarding their experience. The objectives of these focus groups were:

- to build first hand knowledge of the needs, concerns and expectations of persons infected with and affected by hepatitis C;
- to gain an understanding of existing conditions, services, support activities, challenges and barriers; and,
- to solicit input on Health Canada's Hepatitis C Program's key design elements.

The consultation process identified important areas of consensus. There was a keen interest and a significant degree of support expressed for the development of a program dedicated to hepatitis C. Participants noted that the needs are urgent and agreed that education and community-based support are key program elements to be addressed. Stigmatization was considered a major problem, especially for children, and participants pressed the government to work toward overcoming ignorance, stereotyping and discrimination. Finally, all participants identified the critical need for consistent and reliable information for persons infected with or affected by hepatitis C.

Consensus Conference

In October 1998, Health Canada's Laboratory Centre for Disease Control (LCDC) held a conference to examine the present state of knowledge and action on hepatitis C. This consensus conference was a follow up to an earlier conference in 1994. Recommendations by participants included the need for enhanced surveillance activities to better understand the disease and where it is occurring; improved public health interventions to improve access to hepatitis C testing and to prevent the disease; improved laboratory testing of hepatitis C; relevant strategies to address injection drug use; continued identification of those who might have been infected by the blood system; and national awareness activities to educate the public.

Research Agenda Workshop

In January 1999, a workshop was held to identify a research agenda for the diagnosis, care and prevention of hepatitis C in Canada. Participants included individuals from Health Canada, the Medical Research Council, the Canadian Blood Services and Héma Québec, the hepatitis C community, as well as epidemiologists, researchers, clinicians and scientists. They discussed gaps in current knowledge, including the need for more relevant research on the biology of the virus, the pathogenesis and epidemiology of hepatitis C, screening and diagnostic technology, the natural history of the disease, treatment strategies, quality of life issues, and preventive measures, including a vaccine. Participants generally agreed that a broad-based research agenda would be needed to bridge gaps in knowledge and provide better outcomes for those infected with or at risk of hepatitis C.

Provinces/Territories

Federal officials also met with their provincial and territorial counterparts to gain their perspectives on Program priorities. Officials agreed that there needs to be a balanced framework for the new Program with emphasis on education, care, research and support and integration of hepatitis C prevention within a broad-based programming approach to blood-borne pathogens.

Aboriginal Organizations

Preliminary contacts were made with individuals from ten Aboriginal organizations representing First Nations, Inuit and Métis. These meetings highlighted the need for more information about the incidence of hepatitis C infection in Aboriginal communities. Aboriginal stakeholders noted that there may be cause for concern about the rate of hepatitis C infection in Aboriginal communities due to higher rates of incarceration and injection drug use.

Non-Governmental Organizations

Health Canada officials also met with several national non-governmental organizations (NGOs) representing the issues, populations and professions which, while not necessarily specific to hepatitis C, have direct relevance to those who are infected with or affected by hepatitis C. Concerns and views shared by NGOs included the need for greater awareness about the disease, enhanced education activities and further research.