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Hepatitis C Prevention, Support and Research Program Health Canada

Mid-term evaluation report

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Hepatitis C Prevention, Support and Research Program
Health Canada

Mid-term evaluation report

April 2003

Prepared by the
Hepatitis C Section, Community Acquired Infections Division
and the Departmental Program Evaluation Division

For the Audit and Evaluation Committee, Health Canada
and the Treasury Board Secretariat

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Chronology

Terms of reference approved	September 2001
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Draft report	September 2002
Evaluation Advisory Committee meeting	October 2002
Completion of revised draft report and working documents	December 2002
Submission to Audit and Evaluation Committee	March 2003

** Please note that since the completion of the report, the name of the Division has been changed to Community Acquired Infections Division, Hepatitis C Section. The former name has been kept throughout the report to reflect the context for the period covered by the report.*

Executive Summary

Hepatitis C in Canada

The World Health Organization estimates that as much as 3% of the world population, or 170 million people, are infected with the hepatitis C virus. In Canada, the estimates are that more than 240,000 people, or 0.8% of the Canadian population, have been infected. Many infected people have no symptoms and are unaware of their condition; they are at risk of chronic liver disease and even liver cancer. Serious effects of this disease may not appear for decades after the initial infection.

Injection drug use has been documented as the primary risk factor in Canada. There is no vaccine for hepatitis C; however it can be treated and, today, treatment can result in sustained viral suppression for approximately 40% to 80% of cases, depending upon viral strain.

The Hepatitis C Prevention, Support and Research Program

The Hepatitis C Prevention, Support and Research Program was created following release of the report of the Krever Commission, which explored the safety of Canada's blood supply. In 1998, the Government of Canada announced a comprehensive package of initiatives which included $50 million over five years to develop new disease prevention and community-based support programs and support research on hepatitis C. The Program has five components: Management, Policy, Evaluation and Public Involvement; Research; Care and Treatment Support; Prevention; and Community-based Support.

The Program aims to reach both primary and secondary clients: primary clients are those infected with, affected by or at risk of contracting hepatitis C; secondary clients are those individuals or organizations providing services to primary clients.

The Program Evaluation

An evaluation of the Program was completed in 2002 as part of a commitment to the principles of evidence-based program investment and the need to maintain accountability to the public. Planning for the evaluation began in June 2001 with development of the terms of reference; following that, the Program contracted with a consulting firm specializing in evaluation.

Methodology

The evaluation process involved a set of questions and indicators as developed in a customized Data Collection Matrix. These indicators were developed in the evaluation framework for the Program and were further refined for the actual evaluation. Both qualitative and quantitative data were collected from a wide variety of sources, including surveys, interviews, and reviews of documents and relevant literature.

The design of the evaluation was based on the use of a logic model, which represents the means by which the Program is expected to achieve outcomes. The model identifies the main components of the Program and depicts links between the main activities, outputs, and immediate, intermediate and long-term outcomes. To assess program performance the evaluation focused on four key areas: Scope of the Problem, Program Implementation, Achievement of Program Outcomes, and Program Lessons Learned.

The strengths of the process include the use of multiple sources to obtain data on the Program and the high response rates to all surveys and interviews. The chief limitation of the evaluation is that, at mid-point, the best that can be accomplished in a single examination is a general understanding of the Program outcomes and outcome achievement; it is not appropriate to expect a definitive statement about the success of the Program.

Findings

- The program has demonstrated a broad strategic approach to program development at the the national level in response to hepatitis C.
- Research capacity and knowledge about hepatitis C has increased with Program funding.
- Research has been of high quality.
- More behavioural and social science research is needed.
- A large number of materials (e.g. patient information resources, training resources, resources for health professionals and others) were developed and disseminated.
- There appear to be some challenges in accessing hepatitis C information that is appropriate in terms of literacy level and cultural appropriateness. As well, information needs to be consolidated in a central location.
- Key partnerships have been developed with the Program at the national level, and evidence of partnerships and collaborative arrangements (e.g. partnerships with public health organizations, HIV/AIDS organizations and hepatitis C organizations) exists throughout all components of the Program.
- Training was delivered to physicians, nurses, other health professionals and staff and volunteers.
- Capacity to respond to hepatitis C at the community level has been improved; the number of projects, and staff and volunteers has increased.
- High-priority populations are involved in project development.
- Access to care and treatment is not uniform and continues to be an issue. Efforts have been developed by the Program to provide care and treatment support through the training of health professionals and at the local and regional level through community-based funding.
- Public awareness of hepatitis C remains low.

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Evaluation Conclusion: Overall Assessment

The contaminated blood tragedy was the genesis of the Hepatitis C Program. Three years into its mandate, the Program has been successful in the implementation of numerous program activities to strengthen the Canadian response to hepatitis C. Surveillance data, however, show high hepatitis C rates among populations such as Aboriginal peoples, street youth, inmates and drug users. Addressing the multiple health determinants and disease challenges of diverse populations demands a coordinated strategy that promotes a multi-disciplinary approach, linkages and partnerships.

Evaluation Recommendation(s)

1. In the context of federal government priorities, it is recommended that continued federal leadership be considered in the broad areas of capacity building, research, surveillance and project/model evaluation. The knowledge generated from these activities will set the foundation for a coordinated, multi-disciplinary approach to hepatitis C that is able to meet the diverse needs of people infected through the blood supply and marginalized populations.

Program Response

Current Status	Action Required	Time Line	Lead
The Program is developing a rationale and plan to have the Program renewed.	**In current Program cycle**: Integrate the findings of the mid-term evaluation into the renewal and the strategic planning processes of the Division.	Work in progress. Jan 2003 and ongoing	Director Mgr, Policy and Evaluation Mgr, Program

Evaluation Conclusion: Generation of Knowledge in the Area of Hepatitis C

The findings of the evaluation demonstrated the Program's ability to leverage funds from the Canadian Institutes of Health Research (CIHR) for research mainly in the areas of biology, pathogenesis and treatment of the disease. More is required to support behavioural and social science research. Research worthy of international presentation and publication has been encouraged and funded through the Program.

Evaluation Recommendation(s)

2. With regard to research, it is recommended that
   - Hepatitis C research continue to be a major focus of the Program.
   - The Program continue to monitor the joint Health Canada/CIHR research initiative on hepatitis C and guide CIHR to include an increased focus on behavioural and social science research while maintaining its current support for clinical/biomedical research.
   - The Program retain a portion of research funds within the Hepatitis C Division to fund directed research for the purpose of answering those research questions critical to the development of effective hepatitis C policies and programs.
   - The Program and CIHR work together to resolve the problem of mismatched funding cycles, communication and decision-making.

Program Response

Current Status	Action Required	Time Line	Lead
The Program has an allocation of $14.1 million in research funds over 5 years. Of that amount, $12.25 million is transferred to CIHR under a special research initiative on hepatitis C. This initiative is funded on a cost shared basis, with CIHR contributing $6.125 million over 5 years. Findings from the consultation process conducted between October 2002 and January 2003 indicate that there is strong support for research in areas of treatment, prevention, and behavioural and social science.	**In current Program cycle:** Continue funding hepatitis C research through present Memorandum of Understanding (MOU) with CIHR. Program to exercise stronger role in the management of the MOU through improved financial and progress reporting and multi-disciplinary discussions on research priorities.	Ongoing	Director Mgr, Program Research Coord.
	The CIHR and HC initiative on hepatitis C research targeted a call for proposals on prevention, and care and treatment in September 2002.	Ongoing	Research Coord.
	Study on knowledge, attitude and behaviour of physicians dealing with hepatitis C.	Ongoing	Research Coord.
	Support increased links with international researchers through attendance at international symposia and sharing of research findings.	Ongoing	Research Coord.

Evaluation Conclusion: Partnerships

The outlook for the continued development of effective partnerships and collaborations is good. The evaluation reported evidence of continued efforts and work with a broad spectrum of partners at all levels of programming within each of the program components. The relevance of partnership with some organizations needs to be re-assessed, and other partnerships need to be strengthened (e.g. at risk populations).

Evaluation Recommendation(s)

3. It is recommended that the Program be more strategic about partnership development at the inter-governmental, national, regional and community levels as identified below:
    - Re-examine the current funding relationship with the national NGOs in terms of relevance, responsiveness, accountability and intra-organizational linkages.
    - Strengthen linkages at the national level with the Office of Canada's Drug Strategy, the Canadian Strategy on HIV/AIDS, Correctional Service Canada and, in particular, develop a strategic partnership with First Nations and Inuit Health Branch to ensure that programming is seamless for Aboriginal peoples on and off reserve.
    - In order to strengthen and coordinate the federal, provincial and territorial response, the Program should establish a Federal/Provincial/Territorial coordinating mechanism (e.g. Working Group on hepatitis C).

Program Response

Current Status	Action Required	Time Line	Lead
The evaluation and the discussions arising out of the November 2002 National Program Meeting identified the need to review and clarify the role of the national organizations and their regional chapters. As well, the national NGO operational funding applications must be examined for relevance to prevention in at-risk populations.	**In current Program cycle:** National office to determine reporting, funding and support mechanisms (e.g. development and sharing of generic resource materials) between national organizations and their chapters.	March 2003 onwards	Prog. Consultant Mgr, Program
	Review and reassess partnerships with national NGOs to ensure that prevention activities are conducted at the national level. This will be done in the review of NGOs 2003-2004 work plans.	March 2003 onwards	Prog. Consultant Mgr, Program

Current Status	Action Required	Time Line	Lead
The evaluation results highlighted the need to foster a stronger and broader response to the disease. The Program should particularly look to partners working with populations at greatest risk of HCV. The November 2002 National Program Meeting supported a stronger relationship with FNIHB and Correctional Service Canada (CSC). Past efforts have been limited to collaborative surveillance and/or research studies.	**To encourage a coordinated approach between PPHB and FNIHB the Program will:** a) engage in systematic discussions with FNIHB. Issues of mobility on and off reserve make it important to coordinate funding and programming to best meet the needs of Aboriginal peoples.	April 2003 onwards	Mgr, Program Regions FNIHB
	b) share materials and information related to hepatitis C and involve FNIHB in project review committees.	April 2003 onwards	
	To support collaborative work in Corrections the Program will:		
An MOU is currently being developed between the Community Acquired Infections Division and CSC to enable collaboration on training, surveillance and prevention of infectious diseases.	a) Develop stronger links with CSC and provincial/territorial correctional staff.	Ongoing	Chief, TB & Bacterial Respiratory Diseases Mgr, Program Regions
	b) Document regional initiatives in Corrections and promote these initiatives with other regions.	May - Sep 2003	Regions
The membership list for F/P/T Heads of Corrections Working group on Infectious Diseases has been shared with regions.	c) Maintain membership on F/P/T Heads of Corrections Working Group on Infectious Diseases and continue to invite Corrections to collaborate on common issues of interest and relevance.	Ongoing	Mgr, Program
The need was identified for a stronger level of cooperation and coordination between federal and provincial/territorial governments to address the prevention and care needs of persons infected with and at risk of HCV.	The Program will engage in discussions with F/P/T representatives to determine the interest in establishing an F/P/T collaboration mechanism.	January 2003 onwards	Director Mgr, Program Policy Analyst
The Program has made ad hoc presentations to the Federal/Provincial/Territorial Advisory Committee on AIDS (F/P/T AIDS). There is no equivalent for hepatitis C.	The P/T consultation held January 9 2003 identified interest in a P/T infectious disease working group.	Ongoing	Mgr, Program Policy Analyst Mgr, Policy and Evaluation
	In the absence of a working group or other collaborative mechanism, the Program will continue to consult with P/Ts in an ad hoc manner on issues of mutual interest and will enhance the role of regions in these ongoing consultations.		Various Prog. Consultants Regions

Evaluation Conclusion: Care and Treatment Support

Most gastroenterologists and hepatologists are located in large urban centres and are associated with research or teaching centres. Primary clients at case study locations often reported long waiting times to see a specialist, long distance travel to major cities to receive care and excessive caseloads of treating physicians as barriers to care and treatment. Individuals seeking care, treatment and support for hepatitis C indicated a need for a more sensitive and informed approach to care by some health professionals.

Evaluation Recommendation(s)

4. In order to address the need for additional health professionals who provide hepatitis care and treatment, it is recommended that the federal government collaborate with P/Ts and professional associations in the development of capacity in the medical field. This would be accomplished through the provision of scholarships and fellowships to train specialists and through the provision of ongoing support for continuing medical/health education for family physicians and other health professionals.
5. It is recommended that the Program continue to strengthen care, treatment and support for marginalized and under-served populations (including Aboriginal people, street-involved youth, people who inject drugs and inmates) by educating health professionals about how to address the specific needs of these populations.

Program Response

Current Status	Action Required	Time Line	Lead
Funded initiatives have included the development of guidelines and materials for health professionals, the development of information on care and treatment, and the education and training of nurses and family physicians. In its review of the evaluation report and recommendations, the Program Advisory Group overwhelmingly supported the development of capacity in the medical and health care fields. During the Nov 2002 National Program Meeting, the regional staff discussed ways to enhance response to marginalized groups. This was also identified in the evaluation.	**In current Program cycle**: Recent fellowship program was initiated for nurses through the Canadian Nurses Foundation.	Ongoing	Prog. Consultant
	Expand/maintain training opportunities on hepatitis C through continuing medical education workshops.	April 2003 onwards	Prog. Consultant
	Support 2nd annual HIV/HCV co-infection workshop.	completed	Prog. Consultant
	Support of a 2nd Canadian conference on hepatitis C.	2003-2004	Prog. Consultant
	The Program is collaborating with professional associations to update the guidelines for the management of viral hepatitis.	Ongoing	Prog. Consultant
	Expand and enhance the dissemination of guidelines and materials to other health care professionals aside from physicians and liver disease specialists (e.g. nurses, social workers, outreach workers).	Ongoing	Prog. Consultant
	Identify and disseminate regional examples of successful work with marginalized populations such as injection drug users, street youth, Aboriginal people and inmates.	April 2003 - March 2004	Regions

Evaluation Conclusion: Communication, Engagement and Information Exchange

Ongoing dialogue and consultation with stakeholders and priority populations is required to ensure that program objectives and interventions are relevant and appropriate. In addition, it is important that the Program be able to draw upon a broad base of well-informed hepatitis C representatives to bring concerns, advice and direction to the Program.

Communication of Program priorities, directions and the exchange of information is paramount to improved access to hepatitis C information, capacity-building and the achievement of key Program outcomes.

Evaluation Recommendation(s)

6. It is recommended that the Program, at the national, regional and local levels, strengthen the voices of priority populations (e.g. Aboriginal people, street-involved youth, drug users and inmates).
7. In order to ensure that the Program remains accountable, transparent and relevant, it is recommended that the Program specify a clear role for the Program Advisory Group (PAG) that defines an increased ability for the PAG to influence program delivery, and the composition of the PAG be augmented to include representation from priority populations (e.g. injection drug users, individuals in the corrections system, Aboriginal groups, youth, researchers and ethno-cultural communities).
8. It is recommended that the Program implement mechanisms to facilitate communication and the exchange of information across program components, across regions and between national, regional and local levels.
9. It is recommended that a central repository or clearinghouse for hepatitis C information be established and, further, that efforts be made to make culturally appropriate hepatitis C information readily available.

Program Response

Current Status	Action Required	Time Line	Lead
Program staff consulted broadly with numerous stakeholders and individuals at the onset of the Program, and an environmental scan was conducted. Recent consultations conducted as part of the renewal process for the Program included representatives from Aboriginal groups, drug users and individuals infected with and affected by hepatitis C. Locally, priority populations participate on project peer review committees and at regional priority setting meetings for the Program.	**In current Program cycle:** Continue the involvement of priority populations on regional review committees.	Ongoing	Regions
	Involve drug users and their organizations in national level programming.	April 2003 onwards	Regions
	Investigate new ways and mechanisms, such as representation on the Program Advisory Group, to enhance representation of priority populations nationally.	April 2003 onwards	Regions Mgr, Program

Current Status	Action Required	Time Line	Lead
The PAG presently consists of nine members representing the Canadian Liver Foundation, the Canadian Hemophilia Society, the Hepatitis C Society of Canada, the Canadian Public Health Association, the Canadian Centre on Substance Abuse, the Canadian Association for the Study of the Liver, the infected/affected community and Heath Canada.	Regional staff to identify organizations representing marginalized populations not represented directly on PAG (e.g. injection drug users, individuals in the corrections system, Aboriginal groups, youth, researchers and ethno-cultural communities).	January 2003 - in progress	Mgr, Program Prog. Consultant Regional staff
	Schedule meeting with current PAG members to discuss representation and expanded role.	Completed	Mgr, Program
	Revisit terms of reference and invite new members to take part in future PAG meetings.	November 2003	Prog. Consultant Regional staff
Current mechanisms for communication include a monthly program teleconference call with both regional and national staff; two program meetings per year; a specialized hepatitis C database for communicating program developments and disseminating materials on hepatitis C; and a web site.	Planning for a second Canadian conference is under way and includes a strong community component as an effective means of sharing lessons learned between community groups.	Planning under way since Feb 2003 for early 2004	Prog. Consultant
There is no central repository for hepatitis C information. Strong support exists from the community and program staff to consolidate information. Identified as a gap in the evaluation.	The Canadian Public Health Association (CPHA) will launch a hepatitis C clearinghouse in June 2003. This will improve the tracking and dissemination of program products, lessons learned and activities.	March 2003-2004	Prog. Consultant
Culturally appropriate information is being developed at the local level through funded community organizations. Cultural appropriateness can relate to numerous groupings such as ethnicity, literacy and language.	Regions to continue working with community groups for the development of culturally appropriate materials.	Ongoing	Regions
A needs assessment conducted by the Canadian Liver Foundation (CLF) in 2001 identified the need for translation of basic materials into six other languages.	Program is proceeding with consultations with third language communities to determine most effective format (e.g. video, written materials) for educational and awareness resources.	In progress	Prog. Consultant

Evaluation Conclusion: Building Capacity

The outlook for the further development of hepatitis C capacity is favourable as a result of significant efforts made to date in the Community-based and Care and Treatment Support components of the Program. Community capacity is essential to sustain the early successes of community groups and organizations involved in serving populations infected with/affected by or at risk of hepatitis C.

Evaluation Recommendation(s)

10. It is recommended that the Program support community groups for continued capacity building.
11. It is recommended that the Program continue to support community development through its regional offices, and support initiatives aimed at disseminating lessons learned, especially as they relate to interventions with marginalized populations.

Program Response

Current Status	Action Required	Time Line	Lead
The evaluation identified a common request for provision of funding to support ongoing operations and infrastructure of local community groups (rather than project funding). Currently, operational funding is limited to national NGOs and is not provided at the local level.	**In current Program cycle:** Continue funding of local and community-based projects to encourage partnerships at the local and P/T levels. Investigate with other federal programs and with Treasury Board Secretariat the feasibility of supporting infrastructure needs of organizations in future.	Ongoing March 2003 onwards	Mgr, Program Mgr, Program Mgr, Policy and Evaluation
Regions benefit from funding to hold priority setting/capacity building workshops in each respective region. Themes covered include evaluation, proposal writing, lessons learned and strategic planning.	The program is planning to support similar workshops in 2003-2004. The Program will share lessons learned through the dissemination of the evaluation case studies and other initiatives developed in the regions.	March 2003 - 2004	Prog. Consultant Regions

Evaluation Conclusion: Program Monitoring and Evaluation

Measurement of success was not possible for all program outcomes. It is advisable that key initiatives be appraised and the extent of their effectiveness measured. Strategic action plans and evaluation tools will need to be developed and are likely to improve the Program's ability to chart the Program's success and ability to achieve objectives.

Evaluation Recommendation(s)

12. It is recommended that the Program design awareness activities with priority populations and measure the impact of these initiatives.
13. It is recommended that implementation of the care and treatment guidelines that have been developed through funding by the Program be measured to determine the extent to which they are being adopted.
14. As the Program moves forward, it is recommended that
    - strategic directions and action plans be developed that clearly link Program components and funding to Program objectives
    - progress toward objectives be reported annually in a streamlined, standardized manner
    - the Evaluation Logic Model and Data Collection Matrix be modified, and
    - Program outcomes and impacts be identified that can 1) be measured, 2) be attributed to the Program, and 3) be reasonably expected to occur within the five-year time period.

Program Response

Current Status	Action Required	Time Line	Lead
The Program has baseline data on some of its outcomes: an environmental scan (2000); two public opinion polls(99/01); and a research agenda drafted in 1999. The data collected as part of the evaluation will form the baseline for measurement of progress for outcomes where no previous data existed.	Develop plan and strategy for the collection and analysis of data and measurement of program outcomes for final evaluation due in 2004.	April 2003-June 2003	Policy Analyst
	Develop strategy to measure use and uptake of care and treatment guidelines and effectiveness of planned awareness initiatives:	Feb 2003 onwards	Prog. Consultant Policy Analyst
	a) In the short term, develop survey to evaluate co-infection guidelines developed with the Canadian Infectious Disease Society.	Completed	
	b) Explore ways to expand current evaluation of physician practice-based learning module to other training initiatives.	March - June 2003	Prog. Consultant Policy Analyst
Work plans have been developed since 2000 although not consistently for each program area. Recent integration of the Hepatitis C Program with the Sexual Health/STI and tuberculosis areas will require a co-ordinated set of strategic directions.	Division work planning session took place April 2003. Coordination is ongoing.	April 2003 and ongoing	Director Mgr, Program

Current Status	Action Required	Time Line	Lead
A standardized reporting format was developed for the 150 funded community-based projects. Year 2001 was its first year of implementation. The mid-term evaluation looks at years 1,2,3 for all program areas.	Progress in the Community-based support component of the Program is tracked annually through the project progress reports. Explore the development of similar annual or bi-annual reporting mechanism for other areas of the Program. Review and ensure consistent application of reporting requirements across regions.	April 2003	Policy Analyst
The initial Program evaluation framework had five logic models, one for each program component. A simplified version was developed for the purposes of the evaluation.	Engage in discussions with the Departmental Program Evaluation Division (DPED) to perform modifications to the Logic Model, program indicators and Data Collection Matrix. (A logic model is a work in progress and it is good practice to revisit a model as a program evolves.) Then implement data collection process and analytical strategy.	June 2003	Mgr, Policy and Evaluation Policy Analyst

Introduction

This document is a summary of the findings of an evaluation conducted on the Hepatitis C Prevention, Support and Research Program.

The problem of hepatitis C in Canada is described, and this is followed by an outline of Health Canada's Hepatitis C Prevention, Support and Research Program. Details on the evaluation process of the Program include information on the purpose, methodology and findings. A discussion of the strengths and limitations of the study is also included. The report concludes with a summary and a set of recommendations.

This report is based on information provided in the evaluation process, which was completed for the Program by an independent, third-party evaluation specialist consulting firm. The evaluators relied upon input from the primary clients of the Program, as well as Health Canada staff and a wide array of stakeholders; their input is gratefully acknowledged.

I. The Problem: Hepatitis C in Canada

In this section is a brief overview of hepatitis C as a threat to public health in Canada.

Hepatitis C: the virus

Hepatitis C is a disease of the liver caused by the hepatitis C virus (HCV). The World Health Organization estimates that as much as 3% of the world population is infected with HCV and that there are more than 170 million people worldwide who have chronic hepatitis C and are carriers. Many infected people have no symptoms and are unaware of their condition; they are at risk for chronic liver disease, cirrhosis and even liver cancer. Progression of the disease is slow. Because many HCV-infected people are in the 30-49 age group, the number of deaths due to HCV could increase significantly over the next two decades.[1]

In Canada, the estimated prevalence of HCV-infected people is 240,000, or 0.8% of the population. Of these people, approximately 70%—more than 170,000 people—are unaware that they have been infected, and yet they may be carriers of the virus. The infection is newly diagnosed in an estimated 3,000 to 8,000 people each year.

Canada's rate compares with 0.9% in the European Community and an estimated prevalence of 0.3% to 1.0% in the United Kingdom. In the United States, hepatitis C has been identified as the most common blood-borne infection with an estimated prevalence of 1.8%, or 3.9 million people.[2]

According to the Population and Public Health Branch of Health Canada, the highest incidence of HCV diagnosis occurs among people aged 20 to 49 years of age, and incidence is higher among males.

Hepatitis C infection is classified in two stages: acute and chronic. In the acute stage, symptoms may appear six to seven weeks after initial exposure; however, 60% to 70% of people in the acute stage have no symptoms, or symptoms are so mild that they are unaware of the infection. An important characteristic of hepatitis C infection is the fact that in a high proportion of infected people (75% to 85%) the acute infection progresses to chronic infection, which is associated with slowly progressing liver disease; serious effects of the disease may not appear for decades after the initial infection. Twenty percent of chronically infected people will develop cirrhosis or scarring of the liver, which can lead to liver failure. [3] A proportion of chronically infected people will develop liver cancer.

Hepatitis C is spread most commonly by direct blood-to-blood contact with an infected individual. Injection drug use is the major mode of transmission of HCV in Canada. The virus is transmitted through transfer of infected blood in the sharing of needles, syringes or other drug paraphernalia.[4] A person can become infected after a single event of drug use.

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[1] World Health Organization, Hepatitis C. Fact Sheet No 164, Geneva: WHO,1997.

[2] J. Frankish, G. Moulton, B. Kwan, M.D. Waters, et al., Hepatitis C prevention: an examination of current international evidence. Hepatitis C Division, Hepatitis C Prevention, Support and Research Program. 2001, p.3.

[3] S. Zou,S., M. Tepper, A. Giulivi, Viral hepatitis and emerging blood-borne pathogens in Canada, *Canada Communicable Disease Report*. Vol 27S3, September 2001.

[4] Ibid

Between 1960 and 1992, an estimated 90,000 to 160,000 Canadians were infected with hepatitis C through infected blood or blood products. Hemophiliacs were particularly at risk for HCV. Since implementation of universal blood screening, this risk has been substantially reduced; risk of infection currently is one in 500,000 units.[5]

Risk of transmission through sexual activity is low, but people who have multiple partners face an increased risk of infection. Vertical transmission of HCV, from mother to baby, occurs in less than 5% of cases, and increases where the viral load in the mother is high, and when the human immunodeficiency virus (HIV) is also present.[6] Health care providers who may be exposed to blood in the workplace are at risk for HCV infection, but the prevalence of the disease at present as documented is no greater than in the general population. HCV infection has been reported through other means of exposure, such as use of contaminated devices used in tattooing, body piercing and electrolysis.[7] Household contact (sharing toothbrushes and other items that might be contaminated with infected blood) is considered a possible, but low, risk. A significant number of cases of hepatitis C occur in people who have no known risk factors.

Injection drug use is the primary risk factor and has been documented as the factor in 60% of the newly infected cases reported between 1999 and 2001. In Canada, approximately 25% of people who inject drugs report that they were incarcerated at the time they first injected drugs; the prevalence of hepatitis C infection in Canada's federal correctional facilities is estimated to be between 25% and 40%.[8]

Table 1.
Primary risk factors for acute hepatitis C cases, 1999-2001

Risk factor	%
Injection Drug Use	60.6
Unknown	13.3
Others	12.8
Health Care Acquired	6.4
Other Subcutaneous	3.7
Sexual	3.2

Source: Enhanced Hepatitis Surveillance System, Health Canada

Note. 2001 data preliminary. *Sexual* includes sex with hepatitis C carriers. *Health care acquired* includes blood transfusion, blood product, hemodialysis, hospitalization, history of surgery, organ transplant, history of dental visit. *Others* includes drug snorting, blood contact, hepatitis C carrier in family, institution associated, and incarceration. *Other subcutaneous* includes tattooing, body piercing, acupuncture.

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[5] L. Cranston, Building a better blood system for Canadians. *Canadian Journal of Public Health*, 2000, Vol. 91: Supplement 1. P. S41.

[6] Canadian Association for Study of the Liver, Management of Viral Hepatitis, Proceedings of 1999 consensus conference, 2000, p. 12.

[7] S. Zou, M. Tepper, A. Giulivi, Current Status of Hepatitis C in Canada, *Canadian Journal of Public Health.*, 2000, Vol 91: Supp. 1, p.S4.

[8] Correctional Service Canada, 1995 National Inmate Survey, 1996.

A number of people infected with hepatitis C are also infected with hepatitis B or HIV/AIDS. As of December 1999, more than 11,000 Canadians were co-infected with these viruses.[9] The hepatitis C and B viruses and HIV are all blood-borne pathogens and share similarities in modes of transmission, except that sexual transmission is a stronger risk in hepatitis B and HIV. Hepatitis C is estimated to be 10 to 15 times more likely than HIV to be transmitted through contact with infected blood.[10] Risk is considered to be present for all three viruses to varying degrees in these situations: sexual contact, mother-to child, occupational exposure (such as needle stick), sharing injection equipment, unsterile procedures that involve piercing the skin such as tattooing and body piercing, and use of unsterile equipment in medical or other procedures.

How Canada Tracks the Infection

In Canada, viral hepatitis incidence and prevalence data are collected through both routine and enhanced surveillance as well as through targeted studies of specific populations and groups at risk of contracting viral hepatitis.

The routine collection of data on viral hepatitis, including hepatitis C, is achieved through a national surveillance system. Health Canada's National Notifiable Disease Reporting System regularly reports on diseases under national surveillance. Between 1992 and 1998 there was a dramatic increase in the number of reported cases due to increased reporting by provinces and territories. This was likely due to increased awareness and testing as well as access to federal transfer payments to cover 50% of the look-back, trace-back studies. The vast majority of these cases are those chronically infected as opposed to acutely infected. The completeness of notifiable disease reporting varies over time and by province or territory.

Due to limitations in the National Notifiable Disease Reporting System, an enhanced sentinel site surveillance system for acute hepatitis B and C was established in 1998. The enhanced surveillance began with two sites and at the time of this report, had expanded to seven sites across the country covering approximately 16 % of the population. The sentinel sites contribute data on acute and chronic hepatitis B and C infections, risk factors associated with infection and genotype information.

There is no vaccine available to prevent hepatitis C. Treatment is available for patients, usually through drugs such as a combination of interferon and ribavirin. The treatment regimen and duration of treatment depends upon the virus type (there are six types of hepatitis C virus). Research findings indicate that today, treatment can result in sustained viral suppression for approximately 40% to 80% of patients.

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[9] R.S. Remis, et al. Estimating the number of people co-infected with hepatitis C and human immunodeficiency virus. Report to Health Canada, 2001.

[10] T. Heintges, J.R. Wands. Hepatitis C virus:epidemiolgy and transmission, Hepatology, 1997, 26:521-526.

The Economic Burden to Canada

Documented health costs due to hepatitis C are high and rising quickly. For example, treatment with the ribavirin/interferon alfa-2b combination can cost up to $30,000 per course of treatment for an infected person. In 1998, the average cost of a liver transplantation performed in Ontario was $121,732, but costs could range up to more than $600,000.[11] Using the average cost above, the 217 liver transplants for hepatitis C in Canada in 1998 cost $26 million. From 1998 to 2008, the need for liver transplants is expected to triple.

There are only limited data on direct costs, but studies from other countries suggest that there may be costs associated with detecting the infection, managing and treating hepatitis, and managing associated or resulting conditions such as liver cancer and liver transplants, and, finally, providing terminal care.[12]

Indirect costs associated with hepatitis C represent productivity losses due to premature mortality, reduced work performance or absenteeism from work due to sickness or the effects of treatment, and missed days of work for family or friends who are providing care for the infected person. It is estimated that there will be added pressure on Canada's social support systems because of hepatitis C; there are already indications that infected individuals are relying on permanent disability pensions as a source of primary income.

Personal costs may be significant as well; individuals report that hepatitis C results in a notable and negative effect on quality of life as a result of stigmatization and the physical symptoms of the disease.

Focus of Prevention Efforts

Injection drug use is the primary risk factor for new infections of hepatitis C. A review of the literature has identified research gaps in several areas, such as understanding the root cause of injection drug use, evaluation of harm reduction programs, and understanding which prevention interventions are the most effective for groups at risk for HCV infection.

Key Points

- Hepatitis C has already been diagnosed in tens of thousands of Canadians.
- Many people have been infected and are unaware that they have the infection; they have the potential, however, to transmit it to others.
- The majority of people with hepatitis C infection progress to a chronic or lifelong infection, and some develop serious liver disease over several decades after the initial infection.
- The cost of treating people with hepatitis C and their long-term health problems is estimated to be significant.
- Injection drug use is the most common risk factor among newly diagnosed cases of hepatitis C.
- Prevention is key: targeting people at risk is required to slow the spread of hepatitis C significantly.

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[11] Canadian Journal of Surgery, 2002, Vol 45 (6), pp 425-434.

[12] A. Sheill,M. Law, The cost of hepatitis C and the cost-effectiveness of its prevention. *Health Policy*. 2001,S8:121-131

II. Genesis of the Hepatitis C Prevention, Support and Research Program

Since the hepatitis C virus was isolated and characterized in 1989, Canada has responded to this threat to public health through various levels of government. Actions have been aimed at preventing the spread of the infection and supporting care initiatives for those infected with, affected by, and at risk of contracting hepatitis C.

In 1997, the Krever Commission reported on the issue of the safety of Canada's blood supply; after the publication of the commission report, the Government of Canada announced a comprehensive strategy to address hepatitis C. The strategy would, specifically, protect the health of Canadians by improving blood safety and by building knowledge about hepatitis C, and would ensure that Canadians who have been infected with hepatitis C through the blood system do not pay out-of-pocket expenses for medical treatment. This $525 million package included $50 million over five years to develop new disease prevention and community-based programs and support research on hepatitis C. The result, the Hepatitis C Prevention, Support and Research Program, was designed, implemented and managed by Health Canada.

The Hepatitis C Prevention, Support and Research Program (hereafter referred to as "the Program" in this document) is a five-year initiative spanning fiscal years 1999/00 to 2003/04. It was developed in consultation with a wide range of stakeholders, including people who have contracted HCV. This consultation process was instrumental in outlining the following goals for the Program:

- To contribute to the prevention of hepatitis C;
- To support people infected with and affected by hepatitis C through the development and availability of tools and mechanisms;
- To provide a stronger evidence base for hepatitis C policy and programming decisions and to advance prevention, treatment and care options by expanding the body of available research and research capacity; and
- To strengthen the response of the Canadian population to hepatitis C through increased awareness and capacity.

Program Components

To address hepatitis C issues of prevention, support and research, a program with five inter-related components was conceived. The five components are as follows.

Management, Policy, Evaluation and Public Involvement	◗ The Program will be managed strategically using public involvement and evidence-based decision-making. A population health framework will guide Program delivery. ($4.47 million)
Research	◗ Initiatives will encourage and support research, and the development and dissemination of knowledge about hepatitis C. ($14.13 million)
Care and Treatment Support	◗ Targeted national-level initiatives will be aimed at supporting the needs of people infected with and affected by hepatitis C. ($8.43 million)

Prevention	◗ Initiatives will be aimed at preventing the transmission of hepatitis C. ($4.9 million)
Community-based Support	◗ This component covers programming that supports community-based response to the needs of people infected with, affected by, or at risk of contracting hepatitis C, with mechanisms for input from community groups to ensure effectiveness. ($18.06 million)

More detailed information on the activities planned in each of these components is discussed together with findings from the evaluation in the Implementation section of this report.

The goals of the Program are community-based and aim at effectiveness at the local level; as a result, the Program is best administered through a regional Program structure. The Program is administered by Health Canada regional program staff located in seven regions: British Columbia, Alberta, Manitoba/Saskatchewan, Quebec, Ontario, Atlantic, and the Northern Secretariat (Northwest Territories, Nunavut and Yukon). (The Northern Secretariat was formed in 2002.)

The reach of the Program was intended to be primary and secondary clients: primary clients are those infected with, affected by and at risk of contracting hepatitis C; and secondary clients are those individuals or community organizations providing services to primary clients.

Key Points

- The Program was established for five years, from fiscal year 1999-2000 to fiscal year 2003-2004.
- The Program was allotted $50 million in resources.
- There are five components to the Program: management, research, care and treatment support, prevention, and community-based support.
- Primary clients of the Program are people infected with, affected by, or at risk of contracting hepatitis C.
- Secondary clients are those individuals or community organizations providing services to primary clients.

III. The Program Evaluation

Purpose

The Hepatitis C Prevention, Support and Research Program is based on a number of key principles, including the use of evidence-based programming investment decisions and the need to maintain accountability to the public. The evaluation of the Program conducted in 2002 was initiated as part of a commitment to these principles, and the need to report to the Treasury Board Secretariat on implementation, delivery issues and concerns, and the progress toward desired outcomes.

The evaluation process was intended to meet three objectives:

- Contribute to better decision-making on how to deliver the Program most effectively, and to provide strategies for continuous improvement;
- Provide an assessment of the progress under the Program toward achievement of planned outcomes (in particular, the goal of supporting the primary clients); and
- Provide objective information to assist with decisions on Program priorities and future activities.

Timing of Data Collection

Planning for the mid-term evaluation began in June, 2001, when terms of reference for the study were developed in consultation with the regions and the Evaluation Advisory Committee. The Program contracted with Barrington Research Group to assist with the evaluation. The work was carried out between January and December 2002. This report is based on data from that work.

Methodology

A summary of the evaluation methodology is presented in the Data Collection Matrix (Appendix 1). Both qualitative and quantitative data were collected from a wide variety of sources (Appendix 2).

The design of the evaluation process was based on a logic model, which was developed as part of the Program evaluation framework. The framework was a collective effort involving both national and regional staff, members of the Program Advisory Group and other key stakeholders. For the purpose of the mid-term evaluation the logic model was simplified and reduced from five separate logic models to one integrated model. The Program Evaluation Logic Model (Figure 1) represents the means by which the Program is expected to achieve outcomes. The model identifies the main components of the Program and depicts links between the main activities, outputs, and immediate, intermediate and long-term outcomes.

To assess the Program performance, the evaluation focused on four key areas: Scope of the Problem , Program Implementation, Achievement of Program Outcomes, and Program Lessons Learned.

Scope of the Problem

The intent in this key area was to review the magnitude of the hepatitis C problem in Canada. An attempt was made to compare the scope of hepatitis C with that of hepatitis B (HBV) and the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), but many obstacles were encountered. Significant differences in how data are collected for the three diseases made comparison difficult. Expert advice from epidemiologists indicated that in light of this situation, comparisons could result in information or interpretations that could be misleading. Any attempt to draw similarities and differences between infectious diseases should be discussed in a multidisciplinary group setting and be grounded in scientific evidence.

Interviews with the primary clients of the Program provided a human perspective on the disease, as part of providing a comprehensive and balanced picture of hepatitis C in Canada.

Program Implementation

The intent in this area is to focus expressly on program delivery and, in particular, to compare what was planned and what was actually achieved. Information was gathered from diverse sources: a review of Program documents; interviews with Program staff and other stakeholders; surveys on implementation from the community-based support projects and care and treatment support organizations; progress reports from community-based support projects; and case studies. This information was compared with goals identified in the activity and output components of the Evaluation Logic Model.

Achievement of Program Outcomes

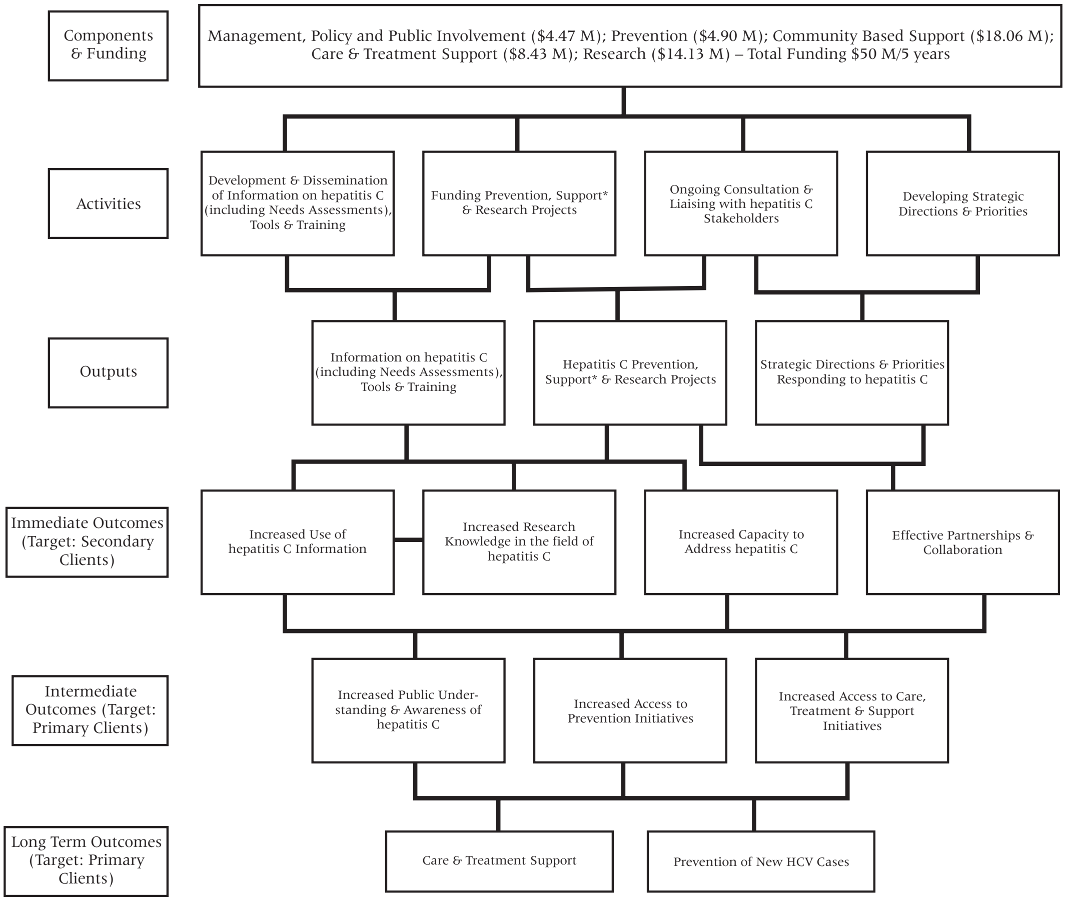
The intent of work in this area was to determine whether the Program has made progress toward the achievement of outcomes identified in the Logic Model.

Program Lessons Learned

Work in this area was intended to identify issues that could be used by Program stakeholders and by Health Canada to improve Program delivery, reach and impact. This information was collected informally through use of all other methods and instruments developed for the evaluation.

Surveys and interviews were designed in consultation with Health Canada staff, health experts and researchers. Participants were identified by Health Canada staff and the evaluators, and in the case of the Health Expert Survey and the Researcher Implementation and Outcome Achievement Survey, peer reviewers were consulted in the process of participant selection.

Figure 1. Hepatitis C Prevention, Suuport and Research Program Evaluation Logic Model



**Support refers to hepatitis C care and treatment support and community-based support.*

The interviews and surveys completed are listed below. (For more detail, please see Data Collection Matrix, Appendix 1.)

- Community Case Study–Primary Client Interview
- Community Case Study–Secondary Client Interview
- Community Case Study–Board and Advisory Group Interview
- Community Case Study–Staff/Volunteer Interview
- Other Stakeholder Interviews
- Researcher Implementation and Outcome Achievement Survey
- Community-based Support Program Implementation and Outcome Achievement Survey
- National Staff and Regional Staff and Advisory Group/Committee Interview
- Health Expert Survey.

As well, a review of pertinent documents was conducted, and a scan of published literature originating in Canada was completed (see List of Technical Reports, Appendix 9).

Case studies were developed, based on the methodology in the work of Robert K. Yin (Yin 1989) and Eleanor Chelimsky (United States General Accounting Office, 1990). Interviews for this segment of the evaluation were conducted with community projects across the country: YouthCo AIDS Society in Vancouver, BC; Lethbridge HIV Connection in Lethbridge, AB; Kamamakus Theatre Troupe in Prince Albert, SK; Winnipeg Hepatitis C Resource Centre in Winnipeg, MB; Kingston Street Health Centre in Kingston, ON; Hepatitis C Foundation of Quebec in Montreal, QC; and Hepatitis C Moncton Inc. in Moncton, NB.

Analysis and Presentation of Findings

Specific data from the variety of sources used were analyzed as follows.

Quantitative Data

Prior to analysis, data were entered into SPSS version 10.0 for analysis, using a double-entry validation technique.

Qualitative Data from Case Studies

All qualitative data were entered into NVivo for analysis; initial codes were determined in consultation with the Data Collection Matrix. Use of this conceptualization to code data strengthens the validity of the findings, as they can be compared directly with data obtained from other sources and through other methods. In addition, case study reports were reviewed by the research team for accuracy; this collaborative approach provided opportunities to discuss interpretation of the findings, reinforcing their validity. Case study reports were also sent to Health Canada regional program staff for review, and to confirm the reliability and validity of the findings.

The consultant provided findings in a two-part report. The first part documented findings related to Program implementation and progress toward achievement of Program outcomes, followed by comment and conclusions. The second part consisted of seven case study reports, providing detailed information of activities in seven locales.

Strengths and Limitations of the Findings

Strengths

The fact that multiple sources of data were used reduces the potential for bias and provides greater opportunity for a balanced picture of the Program. Evaluators further took steps to reduce bias by balancing stakeholder information with Program documentation and input from primary clients wherever possible. This strategy has been documented as a means to enhance validity (Silverman, Ricci and Gunter, 1990).

Another strength is the high response rates achieved in the surveys done and the high degree of participation in interviews with Program staff and stakeholders.

Limitations

Across all methods of data collection, a purposeful sampling strategy was employed (Paton, 1990). The complex nature of the Program, timelines and available resources presented many challenges for the application of quasi-experimental techniques. As well, because the population is unknown in most cases (the total number of health experts, primary clients, etc.), a random probability sampling strategy was not feasible. The purpose was to collect data from sources that were most likely to be the most informative.

Another limitation of the evaluation is that at this point, the best that can be accomplished in a single examination is a general understanding of the Program outcomes and outcome achievement; it is not appropriate to expect a definitive statement about the success of the Program or about what work has yet to be done—it is a given that challenges remain ahead for the Program.

It is acknowledged that a complete program impact analysis has yet to take place and will be important to future evaluations of the Program.

Key Points

- The evaluation process is linked to the Logic Model.
- Evaluation is a one-time look at the Program, which is in development; a complete impact analysis is part of the overall strategy of the Hepatitis C Program.
- The evaluation focused on four areas: scope of the problem, program implementation, achievement of outcomes, and lessons learned.
- The methodology incorporated data collection from a variety of sources.

IV. Program Details and Implementation

In this section is a discussion of the key activities undertaken under the Program (as per the Logic Model, page 11). Information is provided with specific details for each of the five Program components. The key activities are as follows:

1. Consulting and collaborating with hepatitis C stakeholders;
2. Developing strategic directions and priorities;
3. Funding projects for prevention, support and research; and
4. Developing and disseminating information.

1. Consultation and Liaison with Hepatitis C Stakeholders

Engaging hepatitis C stakeholders—primary clients, health care providers and the public—in delivery of the Program has been a key guiding principle. By involving stakeholders, Health Canada ensures that the Program is relevant, responsible and transparent, and, most important, that the needs of primary clients are met.

Before the Program was designed, Health Canada officials met with various stakeholders including the Hepatitis C Society of Canada, the Canadian Hemophilia Society, the Canadian Liver Foundation, and the Thalassemia Foundation of Canada. Focus groups were held throughout Canada, in which people infected with or affected by hepatitis C participated. Health Canada also sponsored a national Consensus Conference and a researcher agenda workshop, and meetings with federal, provincial and territorial health officials. In addition, multiple meetings were held to discuss program design with representatives from Aboriginal peoples' organizations and non-governmental organizations.

Stakeholder input was encouraged throughout Program implementation, with the inclusion of a consultation or feedback mechanism in each of the five Program components.

Management Component

This component is responsible for leadership and direction for the Program; a Program Advisory Group was established in 2000 with a mandate to

- assist the Program management team with direction setting;
- foster citizen engagement in Program implementation; and
- ensure complementarity and coordination of work by key sectors, organizations and institutions undertaking activities related to Program objectives.

The advisory group is a nine-member body with representatives from a variety of organizations (the Canadian Public Health Association and the Canadian Centre on Substance Abuse, for example), who represent the interests and needs of people infected with, affected by, and at risk of contracting hepatitis C.

Evaluation review: Minutes of Program Advisory Group meetings demonstrate direct consultation and discussion with representatives of the Program's primary group on key issues in a timely manner; it is less clear, however, how the dialogues influenced implementation of the Program in practical terms.

Research Component

A Joint Advisory Committee is responsible for overseeing the granting of research funds, and relies on broad stakeholder representation. Members of this committee include individuals in clinical or biomedical practice and research, representatives of non-governmental organizations, an epidemiologist, plus representatives of Health Canada and the Canadian Institutes of Health Research. The committee reviews research grant applications against priorities set in June 1999 at a national research agenda meeting.

Evaluation review: The needs of the hepatitis C infected/affected community are well-represented on the committee. It was less clear that the committee represents the research needs of priority populations that are at risk of hepatitis C, such as injection drug users, street youth, Aboriginal peoples and people incarcerated in Canada's prisons.

Care and Treatment Support Component

Mechanisms to determine the requirements for care and treatment support projects include needs assessments, focus groups and environmental scans.

Evaluation review: A survey of groups funded by the Program to do care and treatment support indicated that before the design of a project, consultations took place with a variety of groups including stakeholders and partners, government representatives and individuals infected with or affected by hepatitis C. Most organizations surveyed (82%) indicated that their priority population was involved in project development. A high-profile example of how the Program worked to consult widely and foster partnerships with stakeholder groups was the First Canadian Conference on Hepatitis C, which brought together more than 900 participants, including liver specialists, researchers, physicians, nurses, community workers, representatives of government health departments and non-governmental organizations, and people infected with or affected by hepatitis C. In the words of one presenter, the result was that "participants took the opportunity to move beyond listening and learning ... into planning and strategizing as a team, in the true spirit of synergy... the conference marked an important point in how our country has approached issues related to HCV."[13]

Prevention Component

In this component, the purpose of consultation and liaison is to lead to partnerships and collaborations among government and non-government organizations that are doing, or could be doing, work toward prevention of the spread of hepatitis C.

Evaluation review: A document review identified that a scan of all organizations involved in hepatitis C initiatives was conducted early in the Program, including the identification of key players and potential partners. Consequently, many activities have been undertaken to further partnership development, including

- a partnership with the Canadian Centre on Substance Abuse to address knowledge gaps and, in particular, to address the issue of injection drug use;
- prevention-focused partnerships established with several agencies at the national level (e.g. Office of Canada's Drug Strategy, Correctional Service Canada), and meetings held to establish partnerships within Health Canada and between Health Canada and national organizations; and

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[13] Minuk,G. 2001. Proceedings. First Canadian Conference on Hepatitis C. P.4.

- a link established with the First Nations and Inuit Health Branch of Health Canada to work collaboratively in surveillance and research.

Community-based Support Component

In this component, ongoing consultation with stakeholders is intended to determine funding priorities for projects; in particular, consultations are held at the regional level with staff from community-based support projects and at the individual project level with priority groups.

Evaluation review: Interviews were conducted with Hepatitis C regional program staff and other stakeholders. The findings were that, in the main, staff consult with regional reference groups such as committees or networks (63%), community groups within their region (63%) and provincial/territorial agencies (38%). Individuals infected with or affected by hepatitis C and individuals who have injected drugs were also identified as groups consulted by program staff. Stakeholders interviewed were of the opinion that priority groups tend not to be involved in consultations beyond the project level, as these groups are difficult to reach. There appears to be a difference of perception between the groups interviewed in relation to the level of involvement of priority populations, and this may require future exploration by the Program.

At the local level, community project staff indicated that they do involve people infected with or affected by hepatitis C and injection drug users before designing a project (63%) and in the development of projects (69%), mostly through involvement in the community group's board or advisory committee or in community consultation/focus groups.

2. Developing Strategic Directions and Priorities

Each program component has objectives designed to assist in setting priorities and strategic direction. The Management component determines direction for the Program overall.

Management Component

Objectives in this component are to

- provide leadership and strategic direction for the Program at a national level;
- promote horizontal integration and develop strategic partnerships to support Program goals; and
- ensure responsible, cost-effective management, promotion, delivery and evaluation of the Program.

Evaluation review: It has already been noted that the Program has successfully developed and sustained relationships with stakeholders and partners. Engaging priority populations has been more difficult because of the challenges in reaching out to these populations. It is also noted that there is no evidence that discussions held within the Program Advisory Group have any impact on the development of strategic direction. The Hepatitis C Division of Health Canada (which is responsible for administering the Program) has successfully developed horizontal linkages, and has kept the regions and other Health Canada departments informed; the Division has collaborated with stakeholders and built alliances to support Program objectives. Stakeholders who were surveyed commented that more challenges lie ahead in terms of the need for a clear national strategy, greater leadership and increased organizational capacity to deal with the disease.

The Program has demonstrated an ability to respond to emerging priorities at the regional and project levels through community groups. National progress reports from community-based support projects are used to inform strategic direction. Reporting was inconsistent in the first two years, and a standardized format was developed in the third year. Community groups have indicated that reporting based on diseases is burdensome. A review of reporting requirements might be warranted.

Research Component

As discussed, a list of research priorities was developed at a special meeting in June 1999 involving Health Canada and research agencies, including the Medical Research Council, now the Canadian Institutes of Health Research. The objectives in this component are to

- encourage and support research and the development and dissemination of knowledge about hepatitis C; and
- build commitment and capacity to conduct research in the research community in Canada to promote better understanding of hepatitis C.

Evaluation review: The Program sponsored high level events such as the Hepatitis C Open Forum and the First Canadian Conference on Hepatitis C; the Joint Advisory Committee has also advised Health Canada and the Canadian Institutes of Health Research on emerging issues, particularly those related to priority populations (injection drug users, youth, Aboriginal peoples and people in Canadian prisons).

Research in priority areas such as the biological nature of the virus and treatment of the disease have been funded. Behavioural and social science research, which are disciplines integral to effective prevention and treatment interventions, have been largely overlooked.

Care and Treatment Support Component

Objectives of the Care and Treatment Support component are to

- contribute toward efforts to enhance and promote the health and well-being of people infected with, affected by and at risk of contracting hepatitis C, to delay disease progression, and to improve their awareness and access to care, treatment and support; and
- build the commitment and capacity of key organizations and institutions to provide better care, treatment and support.

The goal of this component is to enable health care professionals and non-professional caregivers to provide care and treatment. This is accomplished by working with national professional organizations, professional associations and institutions such as the College of Family Physicians of Canada, the Canadian Nurses Association and the National Association of Friendship Centres, to name a few.

Evaluation review: Projects of broad national significance have been developed and implemented through Program associations and partnerships. Initial consultations with national organizations resulted in the development of an important list of required program activities, such as the development of hepatitis C care and treatment guidelines. (For more details, see Appendix 4.)

Prevention Component

Objectives of work ongoing in this component are to

- contribute to measures that will prevent the spread of the hepatitis C virus; and
- build the commitment and capacity of key sectors and institutions to pursue and support prevention measures in an integrated, collaborative way.

Strategic direction for this component was first determined by a national environmental scan undertaken to identify community and national-level HCV-related activities. At that time (late 1999 to early 2000) very few hepatitis C-specific activities were present in Canada. Strategic direction was also formulated through ongoing communication and consultation with partnering agencies such as the Office of Canada's Drug Strategy and Correctional Service Canada. As well, key issues in prevention have been identified and explored through research, discussion papers, epidemiological studies and stakeholder input at the Hepatitis C Forum and the First Canadian Conference on Hepatitis C.

Evaluation review: As research and feedback from stakeholder groups identified and confirmed injection drug use as a primary risk factor for HCV, the Program strengthened its focus on injection drug use. Discussions with the First Nations and Inuit Health Branch resulted in the identification of the problem of injection drug use in Aboriginal populations. While on-reserve programming is a First Nations and Inuit Health Branch responsibility, it is recognized that collaboration and communication is important to achieve program objectives. The Program has demonstrated an ability to respond to changing priorities and unexpected developments.

Community-based Support Component

Building a strong, community-based response to the needs of people infected with, affected by and at risk of contracting hepatitis C is the focus in this component. Objectives are to

- contribute to a better understanding and appreciation of the nature and effects of hepatitis C among Canadians; and
- enhance the capacity of national, regional and local community organizations to provide support.

Evaluation review: Funding priorities are determined at the regional level and revised annually. The Program contributes funds for annual consultation/capacity building workshops which are integral to Health Canada's approach to population health planning. These workshops may include information sessions, networking opportunities and group processes aimed at identifying lessons learned and future needs. This has helped regions to establish projects that reflect regional priorities and community needs.

3. Funding for Prevention, Support and Research Projects

The Program funds projects involved in research, care and treatment support, prevention and community-based support activities. Funding guidelines and criteria developed and applied, and the funding process and resulting activities will be discussed for each of the five components of the Program.

Research Component

Funding guidelines and criteria

Three major activities have been funded in this component.

i. Funds allocated to the Canadian Institutes of Health Research for hepatitis C research. This involves a memorandum of understanding between the Program and the Institutes wherein Health Canada provides funds to the Institutes that are then granted to researchers whose projects have met Health Canada/Institute standards and priorities. Over the five years of the Program, $12.34 million from Operations and Management funds have been allocated.

ii. Program-driven epidemiological data-gathering not funded under other initiatives. This activity is intended to "top up" other surveillance activities, in particular those used to investigate special populations at risk of HCV, including injection drug users and Aboriginal peoples. Over the five years, $900,000 has been allocated.

iii. Funds for special research initiatives. Funding is also provided for special research initiatives such as workshops or symposia; over five years, $496,000 was allocated for these initiatives.

Funding process and resulting activities

Health Canada provides the Canadian Institutes of Health Research with research funding at the beginning of each fiscal year. Between September 1999 and September 2001, 33 out of 86 applications for operating grants and 14 out of 15 career awards were approved for funding. Approval is based on scoring in a peer review process; high-scoring proposals are forwarded to the Program's Joint Advisory Committee. (See Appendix 3 for list of key research accomplishments.)

Evaluation review: Funded researchers were surveyed as part of the evaluation process. The majority stated that the application process was clear (72%), that the time allowed for proposals was sufficient (64%), and peer reviewer comments were constructive (63%). National staff, regional staff and Program Advisory Group members as well as other stakeholders interviewed noted that the funding process has been problematic. The Canadian Institutes of Health Research have had difficulty forecasting expenditures. Funds are allocated in December, leaving the Program with a short time frame to disburse unallocated funds before the end of the fiscal year. Nevertheless, respondents were satisfied that the amount of funding available is significant. Eighty percent said that the funding was the prime factor facilitating their research; 24% said their projects would not have gone ahead without such funding.

Care and Treatment Support Component

Funding guidelines and criteria

The goal in this component is to enable health care professionals and non-professionals to provide the care and treatment necessary to support Canadians infected with, affected by or at risk of contracting hepatitis C. Over five years, $8.43 million was allocated to this component. Within the work of this component are four key activities.

i. Professional and non-professional education and training

ii. Development of guidelines (best practice and health care)

iii. Hepatitis C information dissemination

iv. Hepatitis C networks

Funding process and resulting activities

The care and treatment of people infected with hepatitis C are in the jurisdiction of the provinces and territories; the program activities here are directed at national organizations that could potentially develop tools and training for caregivers. (See Appendix 4 for a list of key care and treatment support accomplishments.)

Evaluation review: Eleven of 15 funded organizations provided feedback. The majority indicated that the primary focus of their organization was education and awareness (82%), followed by prevention (55%), research (36%) and care and treatment support services (36%). All indicated that they are active in developing resources and tools such as training manuals, treatment guidelines or brochures. Most were also funded to do training and skill development (82%). One hundred percent of the organizations responding said that receiving the funding was the factor that facilitated their project; 82% indicated that their project would not have been realized without it. Respondents noted that delayed funding was a factor that hindered implementation of their project.

The evaluation did not include an assessment of these activities.

Prevention Component

Funding guidelines and criteria

The aim of funding here is to contribute to measures that will prevent the spread of hepatitis C, with particular emphasis on those at greatest risk.

Funding process and resulting activities

Identification of prevention initiatives was based on directions in the Treasury Board Submission and on the basis of gaps identified in the environmental scan done at the outset of the Program. (See Appendix 5 for list of key prevention accomplishments.)

Evaluation review: Multiple initiatives have been enacted, including fact sheets and brochures produced for the general public and priority populations, surveys conducted to assess knowledge on risk factors and at-risk populations and discussion papers presenting the international perspective on HCV prevention and harm reduction to guide the advancement of prevention and treatment of hepatitis C in Canada. As well, inter-sectoral collaborations have been developed, and prevention-focused partnerships have been created at the national level.

In case study locations, early outcome results have included: improved knowledge of risk factors, prevention and harm reduction strategies as reported by primary clients; the improved ability to follow a full course of treatment as a result of support and information provided; the adoption of better nutritional habits and the opportunity to make referrals to other services for marginalized and street involved populations.

Community-based Support Component

Funding guidelines and criteria

Overall funding ($18.06 million) in this component is aimed at strengthening the participation of communities with two categories of funding: operation funding for national organizations and project funding for regional and local community-based groups. Operational funding provided a total of $2.7 million over five years, which was given to three national organizations: the Hepatitis C Society of Canada, the Canadian Hemophilia Society and the Canadian Liver Foundation. Project funding for regional and local community-based groups was administered regionally;149 projects were funded throughout Canada.

Funding process and resulting activities

Three objectives for providing operational funding to national organizations under the Program were to

- strengthen the capacity of community-based groups to respond to the needs of people infected with, affected by or at risk of hepatitis C;
- strengthen communication with the membership, other community-based groups, and other sectors; and
- strengthen collaboration with local chapters, other community-based groups and other sectors.

Project funding for regional and local community-based groups was administered regionally. Through a calculation based on population and estimated prevalence of HCV, each region received an allocation of funds for the purposes of supporting local and regional community-based groups working in the area of hepatitis C. (See Appendix 6 for summary of activities.) Detailed information on the activities are also presented in the various technical reports.

Evaluation review: The three national non-governmental organizations were funded for some similar activities; respondents to the National Staff, Regional Staff and Advisory Group Interviews indicated that there had been some duplication of activities. Participants in the Other Stakeholder Interviews, however, said that the duplication was more a matter of a lack of collaboration among the organizations than actual duplication, and that each organization deals with a different but possibly overlapping priority group. The other stakeholders added that efforts to establish partnerships have been resource-intensive and at times counter-productive to their organization. Representatives of the non-governmental organizations supported the idea that the funding had worked toward building capacity across Canada.

At the local and regional level, respondents in the Community-based Support Program Implementation and Outcome Achievement Survey were satisfied with the application process (63%); the majority of projects focused on education and awareness (62%). The most common factor that allowed the project to proceed was the Program funding (90%). Key accomplishments listed were as follows: resources and tools developed; training and development activities; information and awareness activities; support activities; networking partnership activities; activities to strengthen organizations; and needs assessments.

4. Developing and Disseminating Information on Hepatitis C

Developing and sharing information on hepatitis C is a part of the work of each of the five Program components. The objectives are to guide the work done in all Program components; to inform physicians, nurses and other caregivers as well as people infected with and affected by hepatitis C about treatment options; and to inform Canadians generally about hepatitis C.

Management Component

Developing a public awareness campaign for hepatitis C involved development of key messages, testing the messages and then launching a public campaign (Get the facts) in 2002.

Evaluation review: There were many changes in the plans to enact a public information campaign as a result of the challenges in getting agreement on what the priority messages should be.

Research Component

Evaluation review: More than two-thirds (68%) of those who completed the Researcher Implementation and Outcome Achievement Survey had shared information about hepatitis C through 109 presentations. Most of these were at international conferences or symposia (76%), and 64% reported presenting at a Canadian research event. In addition, 32% of respondents said they had published the results of their research, mostly (63%) in peer-reviewed journals, including respected international journals such as *Clinical Biochemistry*, *Journal of Medical Virology*, and the *Journal of Viral Hepatitis*.

Care and Treatment Support Component

Evaluation review: Funded activities included resource or tool development (100% of the organizations surveyed), and training and skill development (82% of organizations). Specific materials developed were brochures/pamphlets; journal articles and special supplements to journals; training manuals; Web sites; learning modules; Web course; and a desk reference text for physicians. More than half the organizations involved in treatment and support provided hepatitis C-related training; a desk reference was provided to 35,000 physicians and training was offered to 12,000 individuals infected with, affected by or at risk of contracting hepatitis C.

Prevention and Community-based Support Components

Evaluation review: Of the 68 projects responding to the Community-based Support Program Implementation and Outcome Achievement Survey, the vast majority (97%) indicated active involvement in hepatitis C development activities and reported that the majority (80%) of activities were implemented exactly as planned. Brochures or pamphlets were the most common resource produced in these projects and covered the following areas: awareness information (89%); prevention information (81%); general information on hepatitis C (80%); issues associated with hepatitis C (59%); and populations at risk (56%).

Results of the Other Stakeholder Interview showed that duplication of efforts could occur in this specific area of resource development; there is a need for coordination. Health Canada staff noted that there are plans to create a "clearinghouse" to consolidate hepatitis C-related materials.

Dissemination activities were widely reported by organizations surveyed: 91% had distributed prevention information, and 89% had made presentations at the community level and project level (69%). Dissemination of information took various and sometimes innovative forms including

- theatre performances to nearly 10,000 people at 36 different venues in 2001-2002. Presentations were given at educational conferences, in correctional institutions, in high schools in the Prince Albert area, in over 20 northern communities and at the Aboriginal Winter and Summer Games.
- outreach services for the Aboriginal population in south western Alberta and the dissemination of educational material to raise awareness at the Aboriginal Conference on HIV/AIDS, HCV and harm reduction.
- the development of resources for youth at risk and the distribution of 1,200 HCV prevention resources during 24 street sweeps conducted in the course of one year in the downtown Vancouver area.

Needs assessments have already been noted as a common research activity; some survey respondents found this to be a duplication, whereas representatives of the community-based support projects said they found the activity useful in targeting their activities.

Training processes were also reported frequently in the surveys and interviews: 96% of the projects reported providing hepatitis C-related training. Recipients of training were staff, health professionals, and volunteers.

Key points

- Consultation and liaison: there are many indications of the involvement of priority populations in strategic direction and project development; less clear is evidence of how discussions at the Program Advisory Group level influenced implementation, and there is ambiguity in stakeholder, staff and project perception about involvement of priority populations.
- Developing strategic direction: stakeholders cited the need for a clear national strategy, stronger leadership and increased organizational capacity; the Program sponsored several high level planning events and projects of broad national significance; and, research and feedback confirmed injection drug use as a primary risk factor for hepatitis C.
- Funding for prevention, support and research: a mismatch between funding cycles for the Canadian Institutes of Health Research has resulted in some examples of lapsed funding; the majority of organizations have been active in creating resource materials, but the effectiveness of these materials has yet to be assessed; and some duplication has been observed among the three non-governmental organizations, but in general, capacity has been built.
- Development and dissemination of information: the majority of funded researchers have shared knowledge, and the majority of community-based support groups have prepared resources; there appears to be a need for coordination of resources; and the majority of funded projects delivered training on hepatitis C.

V. Program Outcome Achievement

Implementation of Program activities is expected to result in planned Program Outcomes. In this section, outcome achievement (in response to evaluation questions) and Program successes and challenges are discussed.

1. Outcome Achievement

In this section, the evaluation results related to progress toward achievement of the outcomes identified in the Logic Model (page 11) are reported. Progress toward immediate outcomes was assessed, and intermediate outcomes were assessed where possible. The assessments presented here are a synthesis of findings related to Program outcomes.

Knowledge Generation

Evaluation question: *To what extent has knowledge been generated through research about hepatitis C, as a result of the Program?*

Results

Research capacity and knowledge has increased

- In partnership with the Canadian Institutes of Health Research, the Program funded 33 research projects and 14 training and salary awards, as of September 2001.
- Respondents to the Researcher Implementation and Outcome Achievement Survey indicated that the Program had attracted new researchers; 24% said that without Program funding they would not have conducted their research projects.
- Researchers said that "the Program stimulated research, increased publications and raised Canada's international stature in hepatitis C research."
- 87% of health experts surveyed identified two areas in which the Program has had an impact: clinical research and basic research.

Research is of high quality

- Funded researchers reported that there had been 18 publications of Program-funded research, most frequently (63%) in peer-reviewed journals.
- Funded researchers reported presenting research findings at conferences and workshops, for a total of 109 reported presentations.
- The breakthrough development reported was development of the "supermouse" model to study vaccines and new treatments of hepatitis C, published in 2001.

Some research on hard-to-reach populations

- A few research projects funded by the Program were completed outside the partnership with the Canadian Institutes of Health Research: six completed and two ongoing research projects on risk factors and injection drug use related issues, four completed surveys and five surveillance-related initiatives were completed in collaboration with the Health Care Acquired Infections Division.

- Some of the projects deal with priority at-risk populations—street youth, injection drugs users and Aboriginal peoples—who are not generally targeted in other research projects.

More social science research is needed

- Gaps in research were noted in the survey results: of 33 grants awarded, only one related to quality of life, which suggests that social science has been overlooked. Health experts surveyed noted that there was a lack of information in Canada in the areas of prevention (51%), care and support (43%) and harm reduction strategies (43%).

Use of Information

Evaluation question: *To what extent has there been increased use of hepatitis C information by people infected with, affected by, or at risk of contracting hepatitis C, caregivers, and organizations providing support and care, as a result of the Program?*

Results

Early results

- 66% of funded researchers reported that their research had been completed and 12% knew of cases where their findings had been applied.

Evidence of information use

- Needs assessments were key to the identification of where information needed to be targeted.
- A large number of materials were developed and disseminated; numerous requests were also received for reprints as an indication of reach and level of use.

Obstacles to accessing information exist

- One-third of respondents in the Community Case Study–Primary Client Interview reported difficulty in locating information on hepatitis C. They noted that Internet access and the ability to perform Internet searches seemed necessary.
- Other comments reported were related to language (materials were in English only and/or were American in content), and suggested that text was culturally inappropriate for Aboriginal people, and that the literacy level was too high, especially for inmates.
- Fewer than a third of respondents to the Community Case Study–Secondary Client Interview felt that there was enough hepatitis C information. Topics requiring additional research included prevention, Aboriginal people and youth, disease transmission, risk factors and harm reduction strategies.
- There is a need to further assess the ability of the Program to encourage greater use of hepatitis C information both at the individual and organizational level, and to confirm accessibility of this information.

Development of Partnerships and Collaborative Arrangements

Evaluation question: *To what extent have effective partnerships and collaborations been developed in response to hepatitis C issues as a result of the Program?*

Results

Partnerships have been developed at the national level

- To increase Program reach, the Program has formed partnerships and collaborated with many different government departments, agencies and organizations.

Partnerships are part of most Program components

- There is widespread evidence of the development of partnerships and collaborative arrangements.
- Partnerships have been developed for a variety of purposes; the most common was for the purpose of sharing information.
- Program-funded researchers report partnerships with hospitals/health centres, educational institutions, and pharmaceutical companies. Respondents involved in care and treatment support reported a total of 44 partnerships; the majority of community-based support representatives reported partnerships for a total of 474. Community partners included public health units, HIV/AIDS organizations, the Canadian Liver Foundation and the Hepatitis C Society. Most said they planned to continue these relationships.
- Community networks were among the successes reported by community-based support projects, as a result of funding. Examples from case study locations include information exchange, with dissemination of materials and referrals through hospitals, partners working in schools and with street youth, and local community centres, in order to increase reach (Montreal); the importance of learning how to work with the Aboriginal community to develop an adequate response to HCV (Lethbridge); and the realization that partnerships can lend credibility, bring mutual benefits, and foster collaboration for the achievement of common objectives with a shared client group (Moncton).
- Partnerships promote increased capacity to address hepatitis C, but it is unknown whether this improved capacity will survive if funding ends.

Development of Capacity to Address Hepatitis C

Evaluation question: *To what extent have the community-based groups, partners in program delivery, and researchers developed the capacity to address hepatitis C issues, as a result of the Program?*

Results

The findings of the regional environmental scans conducted in 1999-2000 found that most community-based groups were at an early stage of development, volunteer-driven and had received little or no funding or formal training.

Survey results have shown that a significant effort has been made across all program components to increase the capacity of communities across Canada to address hepatitis C. There are specific areas where capacity has increased.

Training of professionals and non-professionals

- Training and development opportunities were provided frequently, at varying levels, and in different components of the Program.
- Training was most commonly related to the care and treatment of patients with hepatitis C (basic information on the disease, progression of the disease).
- Training was presented most often to nurses, family physicians/general practitioners, other health professionals, and staff/volunteers, in descending order.
- Training serves to build capacity at both the organizational and individual levels; the impact of training initiatives has yet to be assessed. This information would be valuable at the national level.
- The perception of primary clients and stakeholders is that physicians' level of knowledge and training on hepatitis C remains limited. Areas where this knowledge could be improved include diagnosis, general understanding of the disease and treatment.

Capacity to respond at the community level improved

- The majority of projects responding to the survey reported that they provide training and development opportunities. This was most commonly staff training, health professional training, volunteer training and counsellor/peer support training.
- Projects reported holding workshops or other events on prevention education, partnership development and networking.
- Hepatitis C information dissemination is critical for knowledge at the community level. As such, since receiving funding, the majority of surveyed community groups reported presenting information on hepatitis C to community and project audiences. Nearly 40% presented to regional audiences and 20% to national audiences.
- Innovative approaches to delivering services were observed at the case study sites: examples include a volunteer theatre group; a holistic care and treatment approach integrating primary care, needle exchange counselling and support for marginalized populations; a youth-centred organization using a peer-driven service model; and the formation of a broad-based provincial coalition to address the needs of those infected with/affected by HCV.

Priority populations involved

Involvement of priority populations in project activities is an important element of building a strong response to hepatitis C in Canada.

- The majority of project activities involved priority populations through their inclusion on boards, advisory groups or in consultations and focus groups.
- The majority of community-based support organizations reported involving priority populations such as individuals infected with hepatitis C, family and friends of individuals infected with hepatitis C, women, Aboriginal people and people who inject drugs.
- The primary clients interviewed reported receiving valuable services from the projects, including information, support or counselling, the opportunity to get involved, and referrals to other service providers.

Numbers of staff and volunteers increased

- The numbers of staff and volunteers increased—groups responding to the Community-based Support Program survey reported an average of one full-time staff, 1.6 part-time and 8.2 volunteers per project, and 66 of the surveyed community-based groups reported that more than 500 volunteers were added during 2001-2002 for a total of more than 18,000 volunteer hours of service.
- Community-based groups were observed to be employing strategies aimed at long-term sustainability.
- Capacity-building at the organizational level has not clearly translated into more access for primary clients; only 39 out of 149 community-based projects provided information on client access. Further information is required before the Program can make strong association statements between capacity and increased access.

Access to Prevention and Care, and Treatment Support

Evaluation question: *To what extent has there been improved access to prevention and care, and treatment support?*

Results

Access to care and treatment is an issue

- About two-thirds of primary clients surveyed commented that there is not enough care and treatment support available in the community; this view was shared by those responding to the other stakeholder interview.
- Other stakeholders identified access to care and treatment or a lack of expertise (among caregivers) as a barrier to care.

Demonstrated effect at the local/regional level

- Before the Program began there were few hepatitis C-related projects. At the time of evaluation 149 local/regional projects were funded. (See Appendix 7 for details on regional environmental scans.)
- The projects responding to the Community-based Support Program Implementation and Outcome Achievement Survey noted that populations targeted were individuals infected with hepatitis C, people who use injection drugs, families and friends of people with hepatitis C, youth, community organizations, people co-infected with HCV/HIV, Aboriginal people, prisoners or ex-prisoners, women, health care providers, and the general population.
- Referrals to care and treatment support resources were another indicator that accessibility may be increasing.

Public Awareness of Hepatitis C

Evaluation question: *What is the level of public awareness of hepatitis C?*

Results

The Program commissioned two national opinion polls, in 1999 and again in 2001, to survey Canadians on general awareness of hepatitis C. Six questions appeared in both survey instruments and can be used as a point of comparison. Self-reported knowledge of hepatitis C decreased considerably between 1999 and 2001: in 1999, 53% of people responding said that they were either somewhat knowledgeable or very knowledgeable about hepatitis C; in 2001, 28% said the same thing. The level of concern about hepatitis C also decreased, with 57% reporting in 1999 that they were concerned, as compared with 45% in 2001.

The evaluation did not examine why this decrease in awareness occurred. It is believed that this drop is attributable to a decrease in coverage of hepatitis C by the national media. At the time of the first survey the national media reported extensively on the issue of federal compensation to those infected with hepatitis C from the blood system. It is likely that the presence of hepatitis C in the national media at the time the first poll was taken had an effect on the level of public awareness. Hepatitis C did not have the same media profile at the time the second poll was conducted. In addition to decreased media coverage and within this time period, the Hepatitis C Program did not launch the public awareness campaign as planned and focused most program activities in selected communities.

The evaluation indicated that awareness has been raised on a small scale in selected communities where hepatitis C projects have been implemented. The case studies and several project evaluations have reported an increase of awareness of risk factors, modes of transmission and harm reduction strategies in their targeted populations (which includes incarcerated individuals) as a result of prevention messages and materials distributed in their community or environment. A systematic targeted approach to raise awareness in key groups at risk has not yet been implemented by the Program.

2. Program Successes and Challenges

Key successes and challenges identified in the technical report are listed here for each component: Management, Prevention, Community-based Support, Care and Treatment Support, and Research.

Management Component

Successes

Broad vision, national scope: The Program provides a broad strategic approach to program development at the national level in response to hepatitis C; it is evident that much has been accomplished in each component.

Understanding of population health: The Program structure demonstrates an understanding of population health principles.

Multi-pronged approach: The Program has approached the challenge of hepatitis C through its five components in varied ways.

Broad initial consultation: The extensive initial program consultation process helped identify research, practice, community and personal issues. No group declared that it had been ignored.

Partnerships demonstrated: Ample evidence was noted of established partnerships and their effect on setting direction and priorities.

Flexibility: The Program has been able to adapt to changing facts about hepatitis C and to address issues, especially those of marginalized groups, without diminishing focus on high-priority populations.

Well-managed overall: Funds have been generally well managed.

Challenges

Need for a clear strategic direction: Initial clarity of program design has resulted in success; however, concerns were expressed about future direction.

Coordination and communication functions need to be strengthened: Survey results indicated that there is a need for improved coordination both across regions and between regions and the national level.

Linkages with stakeholder groups not established: The Program Advisory Group provides representation for people infected with, affected by and at risk of contracting hepatitis C. There is no indication, however, that discussions within the Program Advisory Group have an impact on implementation.

Provincial/territorial liaison needs greater focus: More needs to be done to foster cooperation.

Ongoing consultation with priority populations limited: A number of at-risk populations have not received equal attention. Services to Aboriginal groups, for example, tend to be compartmentalized.

Documentation variable: There is a need to streamline and improve reporting and evaluation mechanisms.

Funding cycle issues need more problem-solving: Government fiscal year beginning and end dates are well known, and planning should be possible; yet project funding is often late and still must be spent before fiscal year end.

Research Component

Successes

Amount of funding: The research community sees Program funding as significant.

Training and salary support dollars: Provision of funds for training and salaries indicates an understanding of researchers' needs and serves to support new researchers.

Responsive research agenda: Communication between researchers and government has been achieved, and through feedback from the research community the Program has been able to relay to the Canadian Institutes of Health Research the need for more behavioural and social science research.

Emerging research is ground-breaking: Published research to date has been valuable.

Other potential successes: Several initiatives were noted as having potential for success where the ground has been prepared for important research findings.

Challenges

Lapsed funding: The mismatch between funding cycles of the Canadian Institutes of Health Research and Health Canada has resulted in lapses of significant amounts of funds for research, and must be resolved.

Lack of behavioural and social science research: Many social issues connected with hepatitis C warrant further exploration and should be more prominent in the research agenda.

Research findings should be integrated into Program implementation: Research findings must be communicated and shared so that they can inform and influence practice guideline development and other critical issues; knowledge generation should be accompanied by communication/dissemination strategies.

Care and Treatment Support Component

Successes

Practice guidelines: Practice guidelines, which are critical to treatment improvements, have been developed and produced in several formats.

Capacity building: Professional education activities in the form of self-guided programs, workshops and Web-based training modules have been developed to encourage access by physicians and other health professionals.

First Canadian Conference on Hepatitis C: This event continues to be the landmark in information-sharing and capacity building on a national level.

Patient/community resources: The development of resources such as fact sheets and brochures was identified as a benefit to organizations working in the field, which, prior to Program funding, had limited resources for such materials.

Challenges

Clearer priority-setting and fund-granting processes: There is a need to establish clear priorities.

Address care and treatment support issues for at-risk populations: Additional tools are required in this component: development of psycho-social guidelines, information on disability issues and information on self-care.

Measure the reach of guidelines: Knowing who is using treatment and support guidelines developed to date and what effect that has had on practice are key.

Clearinghouse: The need for a clearinghouse to coordinate and distribute hepatitis C materials is critical to enhance existing distribution methods and to ensure efficient use.

Prevention Component

Successes

Effective collaboration and consultation: Collaboration and consultation has worked well in this component, and has resulted in much needed resource development.

Significant needs assessment findings: National and regional needs assessments were useful in documenting the lack of hepatitis C-related services at the community level.

At-risk populations identified: The Program has demonstrated flexibility regarding target populations and has initiated important work in areas such as injection drug use.

Important national partnerships developed: Relationships with key departments and organizations has led to fruitful collaboration on prevention research.

Challenges

Clear strategy needed to address prevention: Development of a clear national hepatitis C prevention strategy would support collaboration with partners and stakeholder groups.

Need to work more closely with priority at-risk populations: Several populations engaging in high-risk activities (street youth, injection drug users, and inmates of correctional facilities) require a specialized approach to prevention.

Need to explore relationships with institutions: Work has proceeded with national organizations, however, future work should explore the potential of partnerships at the provincial/territorial level with institutions such as public health units and health regions.

Community-based Support Component

Successes

Funding for national non-governmental organizations: Identification of key non-governmental partners facilitated access to those infected with and affected by hepatitis C.

Community-based support projects effective: Funding has resulted in a significant number of projects meeting local needs as identified in needs assessments; the documentation review plus observations at case study sites led to the conclusion that the projects have been well managed by Health Canada.

Projects are the conduit to and from high-priority populations: Information on high-priority population needs and experiences obtained directly from these projects assist decision-makers to be grounded in the reality of life with hepatitis C.

Community-based partnerships are key to sustainability: Strong community networks are critical to ensuring a sustainable community response to hepatitis C.

Challenges

Relationship with national non-governmental organizations needs examination: Issues of duplication and efficient and effective use of resources to achieve Program objectives were outlined both in the document review and the audit of the national non-governmental organizations funded by the Program. Findings suggest that the Program should assess these relationships and explore partnerships with other national organizations.

Community groups need more capacity-building: Smaller community groups need support.

Models of best practice needed: More focus is needed on how successful projects deal with at-risk populations.

VI. Summary and Recommendations

Since the Hepatitis C Prevention, Support and Research Program was created in 1999, many steps have been taken to promote awareness of hepatitis C, to assist in the provision of care and treatment, and to further research into management and prevention.

Much of the work of the Program has been developmental in nature; what is needed now is continued support to allow growth in all the programs, projects and initiatives that have begun.

The hundreds of thousands of Canadians infected with hepatitis C will continue to need care, treatment and support, and—given the high rate of new infections reported each year—a strong focus on prevention is needed urgently.

Recommendations

The mid-term evaluation provided a timely snapshot of the Program's current status in its efforts to address the hepatitis C problem in Canada. It identified several areas of current and future direction for the Program with regard to its implementation, progress toward achieving outcomes, lessons learned, and upcoming fifth-year evaluation.

The review of the literature and Program documents along with responses from primary clients, secondary clients, staff, other stakeholders, health experts and researchers identified four key themes that characterize the magnitude and scope of the hepatitis C problem in Canada.

1. Hepatitis C infection is highest among people who have injected drugs:

Individuals who have injected drugs are at the highest risk of HCV infection. Populations such as street-involved youth, Aboriginal people, and inmates, who were identified by respondents as "hard-to-reach," appear to be particularly at risk of HCV infection because of their involvement with drug injection and other skin-piercing activities.

2. Prevention efforts are needed to reduce the rate of new infections:

It is estimated that there are between 3,000 and 8,000 new hepatitis C infections occurring every year in Canada. Prevention and harm reduction efforts are most efficient if they are targeted toward those at greatest risk of contracting hepatitis C. Injection drug use continues to be the primary mode of hepatitis C transmission, but its root causes are not well understood. Furthermore, there is a need to improve the understanding of which hepatitis C prevention interventions and approaches are most effective with at-risk groups.

3. Limited access to physicians who are knowledgeable about hepatitis C:

Respondents who are infected with hepatitis C, as well as those who provide hepatitis C support services in the community, indicated that it is not easy to obtain care and treatment services from physicians. In particular, there is a limited number of liver/hepatitis C specialists in Canada, which results in long waiting periods for those seeking treatment. The lack of available services has a negative impact on the quality of life of infected individuals.

4. Public understanding and awareness of hepatitis C is low:

> In addition to results from the polls of the Canadian public, every group interviewed or surveyed for the mid-term evaluation echoed the finding that public awareness of hepatitis C is low. Feedback from those who are infected with hepatitis C, as well as from those who provide support services to these individuals, indicates that this limited understanding on the part of the public has led to isolation and stigmatization.

Based on analysis of all the information collected during the course of this mid-term evaluation, the following recommendations are advanced with the objective of Program improvement.

Strategic Direction/Overall Assessment

The contaminated blood tragedy was the genesis of the Hepatitis C Program. Three years into its mandate, the Program has been successful in implementing numerous program activities to strengthen the Canadian response to hepatitis C. Surveillance data, however, show high hepatitis C rates among marginalized populations such as Aboriginal peoples, street youth, inmates and drug users. Addressing the multiple health determinants and disease challenges of diverse populations demands a coordinated strategy that promotes a multidisciplinary approach, linkages and partnerships.

Recommendation #1:

> In the context of federal government priorities, it is recommended that continued federal leadership be considered in the broad areas of capacity building, research, surveillance and project/model evaluation. The knowledge generated from these activities will set the foundation for a coordinated, multidisciplinary approach able to meet the diverse needs of people infected through the blood supply and of marginalized populations.

Generation of Knowledge

The outlook for the generation of knowledge about hepatitis C through research is good. The findings of the mid-term evaluation demonstrated that as a result of the Program, a significant amount of money is available for research and that high-quality research – worthy of international presentation/publication – is being produced. Overall, however, researchers have only begun to scratch the surface of understanding the biology, pathogenesis, and treatment of the disease. Research aimed at understanding behaviours related to hepatitis C transmission is at an even earlier stage of development. Stakeholders highlighted the need for the government to maintain hepatitis C as a high-priority research area and to ensure that funding remains available even if the current Program sunsets. The evaluation also revealed that the relationship between the Program and CIHR has failed to encourage and support behavioural and social science research, and has not been sufficiently flexible in supporting the research necessary to answer questions that are critical to effective policy and program development. Finally, stakeholders expressed considerable concern regarding the large amount of research funding that lapses each year.

Recommendation #2:

With regard to research, it is recommended that

- Hepatitis C research continue to be a a major focus of the Program.
- The Program continue to monitor the joint Health Canada/CIHR research initiative on hepatitis C and guide CIHR to include an increased focus on behavioural and social science research while maintaining its current support for clinical/biomedical research.
- The Program retain a portion of research funds within the Hepatitis C Division to fund directed research for the purpose of answering those research questions critical to the development of effective hepatitis C policies and programs.
- the Program and CIHR work together to resolve the problem of mismatched funding cycles, communication and decision-making.

Partnerships

The outlook for the continued development of partnerships and collaborations is good given that the work done to date in all Program components was seen by respondents as successful. Relevancy issues have been identified, however, with some partnerships, for example, the existing partnerships with national non-governmental organizations and their ability to meet the needs of marginalized populations. In addition, other types of partnerships should be developed to enhance program effectiveness; for example, key partnerships at the intergovernmental, national and community levels.

The Population and Public Health Branch of Health Canada deals exclusively with the health issues of Aboriginal populations off-reserve, and the First Nations and Inuit Health Branch (FNIHB) supports the delivery of public health and health promotion services on-reserve and in Inuit communities. Issues of mobility tend to blur these distinctions at the community level, so it is important to coordinate funding and programming to best meet the needs of Aboriginal peoples.

Although health care services are the jurisdiction of the provinces and territories, there are many areas in which the federal government shares health care objectives, particularly in disease prevention and health promotion. It is therefore important that a strong level of cooperation and coordination exist between the federal government and the provinces and territories. The area of hepatitis C prevention, support and research is no exception, where the prevention and care needs of infected and at-risk Canadians demand an effective working relationship.

Recommendation #3:

It is recommended that the Program be more strategic about partnership development at the intergovernmental, national, regional, and community levels as identified below:

- Re-examine the current funding relationship with the national NGOs in terms of relevance, responsiveness, accountability and intra-organizational linkages.
- Strengthen linkages at the national level with the Office of Canada's Drug Strategy, the Canadian Strategy on HIV/AIDS, Correctional Service Canada and, in particular, develop a strategic partnership with First Nations and Inuit Health Branch to ensure that programming is seamless for Aboriginal peoples on and off reserve.
- In order to strengthen and coordinate the federal, provincial and territorial response, the Program should establish a Federal/Provincial/Territorial mechanism (e.g. Working Group on hepatitis C).

Care and Treatment Support

At the case study sites, primary clients often reported long waiting times to see a specialist, long distance travel to major cities and excessive caseloads of treating physicians as barriers to care and treatment support. It was also observed that when high-priority populations are reached and an attempt is made to bring them into care or to provide prevention messages, the approach of some professionals may lack sensitivity, an appreciation of a person's situation, or respect for an individual's dignity.

Recommendation #4:

> In order to address the need for additional health professionals who provide hepatitis C care and treatment, it is recommended that the federal government collaborate with P/Ts and professional associations in the development of capacity in the medical field. This would be accomplished through the provision of scholarships and fellowships to train specialists and through ongoing support for continuing medical/health education for family physicians and other health professionals.

Recommendation #5:

> It is recommended that the Program continue to strengthen care, treatment and support for marginalized and under-served populations (including Aboriginal peoples, street-involved youth, people who inject drugs, and inmates) by educating health professionals about how to address the specific needs of these populations.

Communication and Information Exchange

It is critical to engage hepatitis C stakeholders — specifically, those infected with, affected by or at risk of contracting hepatitis C; hepatitis C service providers; and the public — in meaningful dialogue, both initially and on a continuing basis, to ensure that the Program is designed and is implemented appropriately. Feedback from respondents indicated that direct consultation with high-priority populations occurs at the level of the community-based support projects. Some stakeholders, however, did not feel that high-priority populations were heard regarding the Program's delivery at the regional and national levels. Given the importance of understanding how to reach identified high-priority populations and enhance their involvement in research and prevention efforts, the following recommendation is proposed:

Recommendation #6:

> It is recommended that the Program, at the national, regional, and community levels, strengthen the voices of high-priority populations (e.g. Aboriginal people, street-involved youth, drug users and inmates).

In all aspects of its conduct, the Program Advisory Group (PAG) is to represent the needs of individuals who are infected with, affected by and at risk of hepatitis C as well as the Canadian population in general. While the PAG has been an active Program committee, the evaluation has shown that it has been used primarily as a sounding board rather than as a conduit to bring stakeholder concerns, advice and direction to the Program.

Recommendation #7:

> In order to ensure that the Program remains accountable, transparent and relevant, it is recommended that the Program specify a clear role for the Program Advisory Group (PAG) that defines an increased ability for the PAG to influence Program delivery, and that the composition of the PAG be augmented to include representation from priority populations (e.g. injection drug users, individuals in the corrections system, Aboriginal groups, youth, researchers and ethno-cultural communities).

While regional priorities helped to design regional strategies and project selection, many stakeholders indicated that there was not enough coordination either across regions or between regions and the national level. It appears that local project issues, models and/or lessons learned are rarely communicated either horizontally (to other regions) or vertically (to the national level). Similarly, the experiences within each of the five components are seldom shared. As a result, stakeholders are often uncertain about new developments.

Recommendation #8:

> It is recommended that the Program implement mechanisms to facilitate communication and the exchange of information across Program components, across regions, and between national, regional and local levels.

Materials, information and research findings are being produced in greater numbers as the Program continues to develop. Therefore, it will be important to coordinate and disseminate these products. The material should be accessible to Program staff at all levels, as well as to stakeholders, physicians and other care providers, infected/affected/at-risk populations and the general public. Further, to save time and share lessons learned, community projects should have access to materials developed by other projects that they can then adapt to the needs of their own local high-priority populations. Not only must people have the means and know-how to obtain this varied information but the information must also be presented in ways that are sensitive to literacy, language and cultural needs. The possibility of using a non-governmental organization to operate a clearinghouse should be considered.

Recommendation #9:

> It is recommended that a central repository or clearinghouse for hepatitis C information be established and, further, that efforts be made to make culturally appropriate hepatitis C information readily available.

Building Capacity

The outlook for the further development of hepatitis C capacity is favourable, given the significant efforts to date in the Community-based Support and Care and Treatment Support components of the Program. These are exemplified in the involvement of high-priority populations, the provision of training and development, and the development of staff and volunteers. The case studies, however, clearly indicate that continued community capacity building is essential in order to sustain the efforts of groups serving populations infected with/affected by or at risk of hepatitis C. The significant efforts and investment made to date will not come to fruition unless adequate time and resources are provided so that these small community groups can become embedded in local and provincial networks of care and can obtain ongoing funding.

Recommendation #10:

> It is recommended that the Program support community groups for continued capacity building.

The many lessons learned by community-based projects in working with at-risk priority populations need to be studied, shared and replicated. Training and mentoring activities can foster the transfer of these learned skills and processes.

Recommendation #11:

> It is recommended that the Program continue to support community development through its regional offices and support initiatives aimed at disseminating lessons learned, especially as they relate to interventions with marginalized populations.

Program Monitoring and Evaluation

The Program has been involved in a number of major initiatives, but this mid-term evaluation did not measure the impact of some activities. Before these initiatives are expanded or built upon, it is essential that the outcomes be appraised. Specifically, lessons learned from the first awareness campaign should be identifed and applied to any subsequent awareness initiatives, and the actual uptake and use of the practice guidelines prepared for health professionals need to be measured. Finally, looking to the future, it is important to put in place the strategic action plans and evaluation tools necessary to implement and chart the success of the work that will be occurring in the final year and a half of the Program's five-year mandate.

Recommendation #12:

> It is recommended that the Program design awareness activities with priority populations and measure the impact of these initiatives.

Recommendation #13:

> It is recommended that implementation of the care and treatment guidelines that have been developed through funding by the Program be measured to determine the extent to which they are being adopted.

Recommendation #14:

> As the program moves forward, it is recommended that
>
> - strategic directions and action plans be developed that clearly link Program components and funding to Program objectives;
> - progress towards objectives be reported annually in a streamlined, standardized manner;
> - the Evaluation Logic Model and Data Collection Matrix be modified; and
> - Program outcomes and impacts be identified that can be 1) measured, 2) attributed to the Program, and 3) reasonably expected to occur within the five-year time period.

Appendices

1. Data Collection Matrix
2. Data Collected for the Mid-term Evaluation
3. Key Accomplishments
    Research
    Care and Treatment Support
    Prevention
    Community-based Support Projects
4. The Regional Environmental Scans
5. Bibliography
6. List of Working Documents

Appendix 1

Data Collection Matrix

1.0 Scope of the Problem

Evaluation Question	Planned Approach	Indicators	Method/ Instrument
1.01 What is the current state of hepatitis C in Canada?	A review of the literature related to hepatitis C in Canada. A comparative analysis will focus on diseases that share important characteristics with hepatitis C. The analysis will compare hepatitis C with hepatitis B and HIV/AIDS on the following: • Disease epidemiology • Federal response • Risk factors and groups at risk • Social and economic costs of the disease • Care and treatment support, prevention, community-based support and research A general overview of other similar hepatitis C programs in other jurisdictions. A survey of health experts to gather feedback related to hepatitis C in Canada. Interviews with Other Stakeholders to gather feedback related to hepatitis C in Canada.	**1.01a** Incidence, prevalence, co-infection and transmission trends **1.01b** Evidence of federal response to hepatitis C situation **1.01c** Identification of social and economic costs of disease **1.01d** Evidence of risk behaviours among populations at risk **1.01e** Care and treatment support, prevention, community-based support and research	Literature review HES OSI

Legend: ***HES****: Health Expert Survey*
OSI*: Other Stakeholder Interview*
I/OS*: Implementation/Outcome Achievement Survey*
SI*: National and Regional Staff and Advisory Group/Committee Interview*
CCS-DES*: Community Case Study Descriptions*
CCS-PCI*: Community Case Study – Primary Client Interview*
CCS-SCI*: Community Case Study – Secondary Client Interview*

2.0 Program Implementation

Evaluation Question	Planned Approach	Indicators	Method/ Instrument
2.01 Has the hepatitis C Program been implemented as designed?	Review the Program documents, Program Logic Model and framework, and look for evidence (data/information obtained by Program staff, other stakeholders/ partners) of Program delivered according to planned activities and outputs. The following items will be included in the review: • development and dissemination of information, tools, guidelines • funding of prevention, support and research projects • ongoing consultation/liaison • development of strategic directions For each activity and output identified by the Program explore and note suggestions for improvement. Link information on Program Implementation to Program outcomes: • survey funded projects/ initiatives to determine if the Program is on its way to achieving its intended outcomes • interview national and regional Program staff and advisory group/committee members to determine if the Program is on its way to achieving its intended outcomes	**2.01a** Information tools, best practices, training adequately developed and disseminated **2.01b** Evidence of consultation with stakeholders, partners, regions and target groups **2.01c** Number of organizations and researchers the Program has enabled to work on hepatitis C issues **2.01d** Evidence of analysis of needs and gaps in HCV projects and initiatives funded **2.01e** Evidence of Program responsiveness to changing interests and priorities **2.01f** Evidence of consistent application of Program guidelines and delivery mechanisms **2.01g** Identified duplication in implementation	I/OS Document Review SI

Legend: ***HES****: Health Expert Survey*
OSI*: Other Stakeholder Interview*
I/OS*: Implementation/Outcome Achievement Survey*
SI*: National and Regional Staff and Advisory Group/Committee Interview*
CCS-DES*: Community Case Study Descriptions*
CCS-PCI*: Community Case Study – Primary Client Interview*
CCS-SCI: Community Case Study – Secondary Client Interview

3.0 Outcome Achievement

Evaluation Question	Planned Approach	Indicators	Method/ Instrument
3.01 To what extent has knowledge been generated through research about hepatitis C as a result of the Program?	For each of the six evaluation questions listed, a review of the extent of progress in achieving the expected outcomes will be made. To do this the following will be undertaken through a review of Program documents and the Outcome Achievement Survey: • An inventory of outcome data based on identified/ selected indicators • Time series comparisons of indicator information (newly collected data and existing data, when possible) • Funded vs. non-funded comparisons of data when possible	**3.01a** Research findings attributable to Program **3.01b** Dissemination activities	Literature review Document review I/OS
3.02 To what extent has there been increased use of hepatitis C information by people infected with/ affected by and at risk of HCV and by individuals, groups, caregivers, and organizations providing support and care, as a result of the Program?		**3.02a** Statements/evidence of research/prevention/care and awareness of treatment support information by HC, NGOs, community organizations and primary clients **3.02b** Use and integration of needs assessments, best practices and resources developed **3.02c** Community groups integrate research component into project activities	I/OS CCS-PCI CCS-SCI and OSI Document review
3.03 To what extent have effective partnerships and collaborations been developed in response to hepatitis C issues, as a result of the Program?		**3.03a** Number of partnerships and collaborations per year **3.03b** Number of new partnerships and collaborations or evidence of efforts to engage new partners **3.03c** Type and quality of partnerships/examples of working together	I/OS and CCS-SCI Document review

Legend: ***HES**: Health Expert Survey*
***OSI**: Other Stakeholder Interview*
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***CCS-SCI**: Community Case Study – Secondary Client Interview*

3.0 Outcome Achievement (*continued*)

Evaluation Question	Planned Approach	Indicators	Method/ Instrument
3.04 To what extent have the community-based organizations, partners in Program delivery and researchers developed capacity to address hepatitis C issues, as a result of the Program?		**3.04a** Number of professionals and non-professional caregivers trained by Program **3.04b** Types of capacity developed within community groups and partner organizations (degree of participation, volunteer leadership, etc.) **3.04c** Number of volunteers **3.04d** Ability of social and scientific researchers supported by the Program to contribute to HCV body of knowledge	I/OS Document review CCS-SCI
3.05 To what extent has there been improved access to prevention and care and treatment support?		**3.05a** Development of innovative care and treatment models and application of models to programming **3.05b** Availability of innovative support services for infected and affected individuals **3.05c** Referrals to care and treatment support resources **3.05d** Type and number of clients served	I/OS Document review CCS-PCI CCS-SCI
3.06 What is the level of public awareness of hepatitis C?		**3.06a** Public sensitivity to and awareness of hepatitis C **3.06b** Awareness of risk factors, transmission **3.06c** Awareness of prevention methods **3.06d** Knowledge of drug use practices and support for harm reduction programming	CCS-PCI

Legend: ***HES****: Health Expert Survey*
OSI*: Other Stakeholder Interview*
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CCS-DES*: Community Case Study Descriptions*
CCS-PCI*: Community Case Study – Primary Client Interview*
CCS-SCI*: Community Case Study – Secondary Client Interview*

4.0 Lessons Learned

Evaluation Question	Planned Approach	Indicators	Method/ Instrument
4.01 What has worked well and what has not worked well?	Through interviews, surveys and case studies, identify Program successes and best practices, Program weaknesses and areas needing improvement	**4.01a** Identified Program successes and best practices **4.01b** Identified Program weaknesses and areas needing improvement	All methods/ instruments All methods/ instruments
4.02 What are some of the Program's best practices and what are some of the recommendations for Program change and improvement?	Through interviews, surveys and case studies, identify recommendations to support the long term success and sustainability of the Program outcomes	**4.02a** Identified recommendations to support the long term success and sustainability of Program outcomes	All methods/ instruments

Legend: ***HES****: Health Expert Survey*
OSI*: Other Stakeholder Interview*
I/OS*: Implementation/Outcome Achievement Survey*
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CCS-DES*: Community Case Study Descriptions*
CCS-PCI*: Community Case Study – Primary Client Interview*
CCS-SCI*: Community Case Study – Secondary Client Interview*

Appendix 2

Data Collected for the Mid-term Evaluation

Instrument/ Method	Respondents	Procedure	Response *n*
Literature Review	—	Published literature as well as government and non-government documents related to hepatitis C	—
Document Review	—	117 national and regional Program documents for the period June 1999 to March 2002	—
National Staff, Regional Staff and PAG Interviews	Hepatitis C Division staff, Program Advisory Group members and regional Program staff	Telephone interviews	17
Other Stakeholder Interview	Members of NGOs, Health Canada staff from other departments, individuals infected with hepatitis C, representatives from provincial/ territorial ministries of health and representatives from pharmaceutical companies	Telephone interviews	24
Health Expert Survey	Physician specialists, nurses, nurse specialists and clinical researchers	On-line and mail surveys	37
Community-based Support Program Implementation and Outcome Achievement Survey	Community-based groups that received funding for community-based support hepatitis C projects	Mail survey	68 of 126 (54%)
Researcher Implementation and Outcome Achievement Survey	Hepatitis C researchers that received funding through CIHR	On-line survey	26 of 42 (62%)
Care and Treatment Support Program Implementation and Outcome Achievement Survey	National organizations that received funding for care and treatment support projects	Mail survey	11 of 15 (73%)
Community Case Study – Primary Client Interview	Hepatitis C-infected individuals who access services at the community-based support projects selected for the case studies	In-person and telephone interviews	31
Community Case Study – Secondary Client Interview	Groups (in the same community as the project selected for the case study) that provide services to those infected with, affected by or at risk of contracting hepatitis C.	In-person interviews	33
Community Case Study – Board/Advisory Group Interview	Board members of the community-based support projects that were targeted for the case studies	In-person interviews	9
Community Case Study – Staff/Volunteer Interview and Project Coordinator/ Director Interview	Staff, volunteers and project coordinators of the community-based support projects that were targeted for the case studies.	In-person interviews	32

Appendix 3

Key Accomplishments

Research

- 109 presentations by 68% of funded researchers who were surveyed
    - 76% of researchers who presented made presentations at an international conference/symposium/meeting
    - 65% of researchers who presented made presentations at a Canadian conference/symposium/meeting
- 32% said that they have published their hepatitis C research, mostly in peer reviewed journals (63% of those who have published)
    - resulting in 18 publications
- Breakthrough development of the "supermouse" model to study new vaccines and treatments for hepatitis C
- 33 funded operating grants (Results of Year 1999, 2000 and 2001 competitions)
- 14 funded training and salary awards (Results of Year 1999, 2000 and 2001 competitions)
- 6 completed and 2 ongoing research projects funded through grants, contracts and transfers outside of CIHR
    - Estimates of HIV/HCV Co-Infection
    - Aboriginal Street Youth and HCV (Bureau of HIV/AIDS, STD and TB)
    - Economic Impact of HCV
    - Manitoba Research Chair
    - Canadian Paediatric Surveillance Program (CPSP)
    - Cohort Study of Street Youth
    - Social Network Analysis of Injection Drug Users
- 4 completed surveys funded outside of CIHR
    - Angus Reid Survey of Hepatitis C Awareness
    - Baseline Survey of Hepatitis C Patients and Association Representatives
    - Environics Public Opinion Survey
    - Special Report on Youth, Piercing, Tattooing and Hepatitis C
- 5 collaborative surveillance/research initiatives with Health Care Acquired Infections Division, Bloodborne Pathogens Section
    - Enhanced Surveillance
    - Hepatitis of Unknown Cause: Exploratory Study
    - Health Canada Aboriginal Working Group
    - Aboriginal Seroprevalence Study on Viral Hepatitis
    - Canadian Viral Hepatitis Network

Care and Treatment Support

Professional education/training

- HCV CD ROM for gastroenterologists and rural physicians – pilot test (University of Manitoba/ Liver Disease Unit)
- Training needs assessment of physicians and other caregivers with priority development conducted by:
  - College of Family Physicians
  - National Association of Friendship Centres
  - Aboriginal Nurses Association
  - Society of Obstetricians and Gynaecologists of Canada
- Training workshops by:
  - College of Family Physicians of Canada
  - Canadian Liver Foundation
- Distribution of the HCV CD ROM to rural physicians (Society of Rural Physicians of Canada)
- An HCV-HIV Workshop on the assessment and treatment of HCV-HIV
- Proceedings from the 1st Canadian Conference on Hepatitis C
- Needs assessment for alternative hepatitis C treatment therapies

Guideline development

- Needs analysis of nutritional guidelines for people infected with hepatitis C (Dietitians of Canada)
- Development of Clinical Guidelines for the Reproductive Care of Women Living with Hepatitis C Virus (Society of Obstetricians and Gynaecologists of Canada)
- Development of HCV/HIV Co-Infection Treatment Guidelines (Canadian Infectious Disease Society)
- A desk reference for physicians (College of Family Physicians of Canada)

HCV information dissemination

- Reprint and distribution of the Hepatitis C Medical Information Update and Patient Hand-Out
- A volume of *The Canadian Journal of Public Health*
- A volume of *The Canadian Journal of Gastroenterology*
- The Web site (*www.healthcanada.ca/hepc*) provides information on hepatitis C, compensation, Program funded projects, resources, publications, FAQs, contact information, and a question-and-answer service

Networking of professional and non-professional caregivers

- Proceedings of the 1st Canadian Conference on Hepatitis C, which involved health care professionals, researchers, representatives from community and government organizations, pharmaceutical representatives, and people infected with/affected by HCV

Prevention

Develop knowledge and strategic direction

- Two surveys of the Canadian public about general awareness of hepatitis C, providing evidence of research undertaken to identify needs and gaps in hepatitis C knowledge
- An environmental scan that ascertained the level of community and national HCV-related activities in Canada prior to the start of the Program
- Environmental scans conducted across Canada to identify key players, existing initiatives, barriers, gaps in service and opportunities for hepatitis C prevention and community-based support
- Fact sheets and brochures developed to provide information on risk factors, symptoms, prevention strategies, and where to get more information about hepatitis C for the general public and for high-priority populations such as youth and people who inject drugs

Undertake prevention research to fill gaps in knowledge

- Surveys and discussion papers on issues such as risk factors among youth, HCV and at-risk populations, intervention issues, HCV in Canadian prisons, harm reduction frameworks, and hepatitis C resource needs; then several documents to demonstrate progress in this area

Set prevention programming agenda

- The VANDU case study, an example of "best practice"*

Establish partnerships and intersectoral collaboration

- The environmental scans identified key players, existing initiatives, barriers, gaps in service and opportunities for hepatitis C prevention and community-based support.
- F/P/T collaborative strategic planning session was held to address IDU.
- Prevention-focused partnerships were established with several agencies at the national level (e.g., Canada's Drug Strategy, Correctional Service Canada, Canadian Centre on Substance Abuse, and Health Care Acquired Infections Division, Bloodborne Pathogens Section).
- Several government staff from other departments were invited to the national Program meeting in November 2001 to explore partnerships both within Health Canada and between Health Canada and the national organizations.
- A summary of research, care and treatment support projects, and prevention and community-based support projects indicates that several have involved partnerships with various Aboriginal groups or organizations.
- Community consultation meetings and capacity-building workshops provide a networking opportunity to share project information, initiate partnerships, share strategies to prevent HCV, and provide support to those who are infected/affected, thus demonstrating that the Program is helping to establish partnerships at the regional and local levels.

**The partial funding of the VANDU project along with the case study of this organization provides some support for the description of a local prevention model; however, there was no documentation regarding how the results of the case study were disseminated or how the findings were used for strategic Program planning.*

Community-based Support Projects

- 149 projects funded to date
- British Columbia – 27
- Alberta – 33
- Manitoba/Saskatchewan – 13
- Ontario – 36
- Quebec – 23
- Atlantic – 16
- Northern Secretariat – 1

- 132 resources or tools developed
- 92 training and skill development activities
- 77 information and awareness development activities
- 72 support activities
- 72 networking/partnership activities
- 64 activities to strengthen organizations
- 58 needs assessment activities

Appendix 4

The Regional Environmental Scans

The regional environmental scans (1999-2000)

Altantic	◗ Eight community-based groups were identified with a mandate specific to HCV-related issues. Most were at an early stage, volunteer driven and had received little or no funding or formal training.
Quebec	◗ Three community organizations engaged in the fight against hepatitis C, all less than one year old, without staff or funding. All other organizations polled indicated that HCV was not a priority. The availability of French language HCV information was very limited.
Ontario	◗ Northern Ontario groups were the most underdeveloped. Human resources were limited and there was a high rate of burnout for volunteers. Lack of funding was the single most important barrier. The lack of HCV-related information in the medical community was noted.
Manitoba	◗ Two of 34 organizations reported HCV initiatives. Many devoted a small proportion of their time to HCV, generally in the context of HIV/AIDS, substance abuse and/or sexually transmitted disease (STD) programming.
Saskatchewan	◗ IDU, STDs, addictions and poverty were major areas of concern. Agencies worked with HCV as the need arose and were not aware of HCV-related resources or services.
Alberta	◗ HCV was incorporated into regular programming and organizations felt ill equipped to provide the information and support required.
British Columbia/ Yukon	◗ No conclusions were discernable in the "HCV Survey Response Project" that was provided to the Evaluators by Health Canada as the BC/Yukon Environmental Scan. From the national roll-up report, six types of community-based groups were identified. Most respondents were not part of a larger hepatitis C network or did not know if they were.
Northwest Territories/ Nunavut	◗ Programs dealt with HIV/AIDS and risk behaviours, not HCV. There was a shortage of skilled staff; transient populations increased exposure to IDU and sexual activity; anonymous testing was not possible in small communities; standards of care and treatment were not consistent; lack of access to computers/Internet hampered health professionals; and there was a lack of resources appropriate for different languages, dialects, cultures, and literacy levels.

Appendix 5

Bibliography

Angus Reid Group. (2000). *Hepatitis C: Final report*. Report to Health Canada.

Boucher, M. and Gruslin, A. (2000). The reproductive care of women living with hepatitis C infection. *Journal SOGC, 22 (10)*, 820-845.

Burak, K. W. and Lee, S. S. (2000). Treatment options in patients with hepatitis C. *Canadian Journal of Public Health,* 91.Supplement 1: 22-26.

Canadian Association for the Study of the Liver. (2000). Canadian consensus conference on the management of viral hepatitis. *Canadian Journal of Gastroenterology*, 14. Supplement B: 5B-20B.

Centre for Infectious Disease Prevention and Control. (2002). *Enhanced surveillance of Canadian street youth: Phase II* [PowerPoint presentation]. Ottawa: Division of Sexual Health Promotion and STD Prevention and Control.

Correctional Services Canada. (1996). *1995 national inmate survey: Final report*. Ottawa: Correctional Services Canada.

Cranston, L. (2000). Building a better blood system for Canadians. *Canadian Journal of Public Health*, 91 Supplement 1: S40-1, S43-4.

Environics Research Group. (2001). *Baseline survey of hepatitis C patients and association representatives: Final report.* Report to Health Canada.

Environics Research Group. (2002). *Awareness and knowledge of hepatitis C: Final report.* Report to Health Canada.

Hagedorn, C. H. and Rice, C. M. (2000). *The hepatitis C viruses*. Berlin, Germany: Springer-Verlag.

Health Canada. (1998). Report on the meeting of the expert panel on hepatitis C epidemiology. June 17–18, 1998.

Health Canada. (2000a). *Mediums to reach injecting drug using populations*. Ottawa: Health Canada.

Health Canada. (2000b). Program Advisory Group for the Hepatitis C Prevention, Support and Research Program terms of reference.

Heintges, T. and Wands, J. R. (1997). Hepatitis C virus: Epidemiology and transmission. *Hepatology*, 26: 521-526.

Jager, J. C., Limburg, L. C. M., Postma, M. J., van Ameijden, E. J. C., Rossi, C. and Wiessing, L. G. (2000). Project to analyse impact and costs of HCV, HBV and HIV infection in injecting drug users in the EU. Draft final report.

Medland, N., Grulich, A., Dore, G., Bradford, D. and Madeddu, D. (2001). Might this patient be positive? Epidemiology and transmission. In G. Dore et al (Eds.), *HIV/Viral hepatitis: A guide for primary care.* Canberra: Australasian Society for HIV Medicine Inc. National Capital Printing.

Nicole, L. E. (2001). Management guidelines for the HCV and HIV co-infected adult: Recommendations of a multidisciplinary expert panel. *The Canadian Journal of Infectious Diseases*, 12 . Supplement A: 1A-40A.

Patton, M. Q. (1990). *Qualitative evaluation and research methods.* Newbury Park, CA: Sage.

Remis, R. S. (2001). *Estimating the number of people co-infected with hepatitis C virus and human immunodeficiency virus in Canada.* Report to Health Canada.

Remis, R. S. et al. (1998). *Estimating the number of blood transfusion recipients infected by hepatitis C virus in Canada, 1960-85 and 1990-1992.* Report to Health Canada.

Rowe, W., Rowe, J. and Malowaniec, L. (2000). Hepatitis C: Mental health issues. *Canadian Journal of Public Health*, 91. Supplement 1: 42-44.

Schuler, A. and Manns, M. P. (2000). Patients with chronic hepatitis C – Who should not be treated? *Canadian Journal of Gastroenterology*, 14. Supplement B. 63B-66B.

Shiell, A. and Law, M. G. (2001). The cost of hepatitis C and the cost-effectiveness of its prevention. *Health Policy.* 58: 121-131.

Silverman, M., Ricci, E. M. and Gunter, M. J. (1990). Strategies for increasing the rigor of qualitative methods in evaluation of health care programs. *Evaluation Review,* 14: 57-74.

United States General Accounting Office (1990). *Case Study Evaluations*. (Program Evaluation and Methodology Division Transfer Paper 10.1.9). Washington, DC: U. S. Government Printing Office.

World Health Organization. (1999). Global surveillance and control of hepatitis C. Report of a WHO consultation organized in collaboration with the Viral Hepatitis Prevention Board, Antwerp, Belgium. *Journal of Viral Hepatitis*, Jan 6, 35-47.

Yin, R. K. (1989). Case study research: Design and methods (Revised Edition). *Applied Social Research Methods Series,* 5. Newbury Park, CA: Sage.

Appendix 6

List of Working Documents

Work Plan

Literature Review

Document Review

Progress Report: Literature Review Search Protocols

Progress Report: Document Review and Staff Interview Protocol, Implementation Survey Design

Progress Report: Community Case Study Data Collection Tools and Protocols

Progress Report: Health Expert Survey Data and Staff/Stakeholder Interview Data

Progress Report: Summary of Data from Implementation and Outcome Achievement Surveys

Progress Report: Primary Client and Secondary Client Interview Data Tables

Report on Case Studies

Final Analysis Report