



Responding to the Epidemic

Recommendations for a Canadian Hepatitis C Strategy

Developed in collaboration by the

Anemia Institute for Research and Education
Canadian AIDS Society
Canadian AIDS Treatment Information Exchange
Canadian Harm Reduction Network
Canadian Hemophilia Society

Canadian Hepatitis C Network
Canadian Liver Foundation
Hepatitis C Council of BC
Hepatitis C Society of Canada
Prisoners' HIV/AIDS Support Action Network

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For more information

This document is accessible online at www.hepc.cpha.ca.

Ce document est également disponible en français sous le titre :

Vers une réponse à l'épidémie : Recommandations pour une Stratégie canadienne sur l'hépatite C

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Introduction

The hepatitis C virus (HCV) was identified in 1989, but didn't register with Canadians as an important health concern until the early 1990s when it became apparent that up to 160,000 Canadians¹ had contracted HCV through contaminated blood products. Today, HCV has mostly faded from the headlines, and public awareness about this frequently fatal virus has plummeted.

Experts estimate that 250,000² Canadians are infected with HCV, for which there is no vaccine. Up to 80,000 are destined for liver scarring, cancer, and failure. One-third of those with HCV still do not know they have it,³ and may be unwittingly passing the virus to others. More than 5,000 new infections occur in Canada per year,⁴ most frequently among those least equipped to access prevention education, effective intervention and treatment supports.

At the same time, HCV-related costs are about to soar. The slow progression of this largely curable disease among people infected over the past 30 years, including those who have not yet been diagnosed or treated, is expected to result in an explosion of costly liver-related complications.

In 1998, the Government of Canada introduced a \$50-million, five-year Hepatitis C Prevention, Support and Research Program. Important progress was made; however, the program lacked critical components, including sufficient funding, and ended in March 2004. Single-year funding has twice been extended, but there has been no indication that this funding, or a multi-year strategy, will be extended beyond the program's end-date of March 31, 2006.

The Government of Canada, in partnership with the provincial and territorial governments, can prepare for the projected surge in HCV-related complications, with a well-coordinated, multi-year strategy to prevent new infections and provide timely care for infected individuals. Such preparation is not only the right thing to do, but fiscally responsible.

This paper represents the contribution of Canada's HCV community to the formulation of an effective Canadian Hepatitis C Strategy. It draws on the insights of 10 community-based organizations involved in HCV-related activities, the latest international research from the Canadian Institutes for Health Research (CIHR) and the BC Centre for Disease Control, and other expert opinion to identify critical strategy components. Its recommendations fully support and complement those offered in January 2005 by the Joint Advisory Committee (JAC) to the federal Hepatitis C Program.⁵

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1. Health Canada, *Hepatitis C Prevention, Support and Research Program: Get the Facts: Mid-term Evaluation Report* (Health Canada, 2003), 3. Available at www.phac-aspc.gc.ca/hepc/hepatitis_c/pdf/hepcMidterm/
 2. Public Health Agency of Canada, *About Hepatitis C: Virus Information*. Available at www.phac-aspc.gc.ca/hepc/hepatitis_c/aboutvirus.html
 3. Remis, R.S. *A Study to Characterize The Epidemiology Of Hepatitis C Infection In Canada, 2002. Final Report*. (Ottawa: Health Canada, 2004).
 4. Public Health Agency of Canada, *Hepatitis C: Frequently Asked Questions*. Available at www.phac-aspc.gc.ca/hepc/hepatitis_c/drhepc.html
 5. Joint Advisory Committee of the Health Canada/CIHR Research Initiative on Hepatitis C, *Hepatitis C As A Roadmap for Integrated Communicable Disease Prevention and Control: A Strategy for the Renewal of the Health Canada/Canadian Institutes of Health Research (CIHR) Research Initiative on Hepatitis C* (Ottawa: 2005).

I. Background

What is HCV?

HCV is a blood-borne virus that can destroy the liver.

Approximately 15% of people infected with HCV will spontaneously clear the virus within a few months. For the rest, it can mean a lifetime of debilitating fatigue, pronounced difficulty with concentration and memory, muscle and joint pain, nausea and other gastrointestinal problems. Up to 25% of chronic HCV infections result in cirrhosis, liver failure or liver cancer.⁶

Such complications cause horrible suffering. Patients often become emaciated and jaundiced. Painful swelling and cramping of the abdomen and legs occur, sometimes accompanied by unbearable itching. Advanced cases include mental confusion and unreasoned aggression, massive spontaneous bacterial infection, bleeding from veins in the throat, coma and even death.

HCV is also associated with a number of extra-hepatic conditions such as diabetes mellitus, non-Hodgkin's lymphoma, arthritis, porphyria cutanea tarda, lichen planus, autoimmune thyroiditis, essential mixed cryoglobulinemia, Sjogren's syndrome, membranoproliferative glomerulonephritis, fibromyalgia, neuropathy and osteoporosis.

How is HCV contracted?

HCV is passed through blood-to-blood contact with infected individuals. Such contact occurs most often in the following situations:

- sharing of any blood-contaminated equipment, including that used for drug injection/snorting/smoking, piercing, tattooing, nail care, electrolysis, shaving, acupuncture;
- blood transfusions or other medical procedures, where flawed infection control procedures allow use of blood-contaminated equipment;
- some sexual activities (for example, during unprotected sex during menstruation, or when tissue trauma or lesions are present);
- needle-stick injuries; and
- vertical transmission (in utero, during childbirth and possibly breastfeeding).

To avoid HCV infection, people must be aware of HCV and its routes of transmission; however, their ability to translate that knowledge into practice is strongly related to environmental and social factors (also known as determinants of health). These include effective access to medical care, freedom from addiction, functional literacy, adequate income, secure housing, safe domestic environments, respectful and abuse-free relationships, robust self-esteem and the sense of belonging to a broader community.

6. Joint Advisory Committee, 5.

When these critical determinants of health are in place, and given adequate information, people can make healthful choices. Without these basics, such choices become difficult, if not impossible.

Due in part to the complex interplay of these factors, HCV has made its most destructive inroads into the following populations:

- people who inject, snort or smoke drugs (including steroids) with contaminated equipment such as syringes, spoons, filters, tourniquets and crack/crystal meth pipes;
- people (frequently youth, and those in prisons) who engage in tattooing or piercing with virus-contaminated equipment;
- Canada's Aboriginal peoples ;
- incarcerated Canadians; and
- street-involved youth.

II. The Challenge

Several aspects of HCV make it a complex disease to prevent, monitor and treat.

Perhaps most challenging is the insidious nature of the disease. Its slowly developing symptoms typically go undiagnosed or misdiagnosed for years; meanwhile, the virus may be unknowingly transmitted to others. When HCV escalates undetected, serious and costly liver complications follow — and opportunities to maximize health outcomes and minimize resource expenditures are lost.⁷

The diversity of at-risk populations also presents challenges, particularly for prevention and early diagnoses. Their varying languages, socio-economic status, cultures, education levels and geographic locations require HCV information to be delivered in multiple and innovative formats.

Co-infection with HIV and HCV is also a concern. About 23% of the approximately 49,600 Canadians living with HIV are also co-infected with HCV.⁸ Liver disease has recently become a leading cause of death among those who are co-infected.⁹ In addition to an increased rate of liver-related death, some research suggests that mortality for co-infected individuals is higher than for people infected with HIV alone.

7. According to one recent study, 20% of patients are not diagnosed until cirrhosis occurs, which severely limits treatment options and success. Reported at American Association for the Study of Liver Diseases 2003 Conference Boston, MA Oct 24-28, 2003. See www.natap.org/2003/AASLD/day6_5.htm for article about paper presented by Beth P. Bell, Centers for Disease Control and Prevention, Andre N Sofair, Connecticut Emerging Infections Program and Yale University School of Medicine.

8. R.S. Remis, *Estimating the Number of Persons Co-infected with Hepatitis C Virus and Human Immunodeficiency Virus in Canada*, (Toronto, Health Canada: 2001).

9. I. Bica, B. McGovern, R. Dhar, D. Stone, K. McGowan, R. Scheib, D.R. Snyderman, "Increasing mortality due to end-stage liver disease in patients with human immunodeficiency virus infection" in *Clinical Infectious Diseases* 32 (2001), 492-497.

More than 55% of those who receive state-of-the-art drug therapy are effectively cured of HCV.¹⁰ However, access criteria are restrictive, and sometimes contradict current science.¹¹ Only 20%¹² of HCV patients are indicated for treatment; for the approximately 8%¹³ who actually get it, drug therapy frequently entails debilitating side effects¹⁴ which demand expensive interventions¹⁵ not covered by provincial/territorial drug plans. Without critical supports to manage side effects, up to 20% of patients abandon treatment before it is completed. In some provinces and territories, access restrictions mean that patients who fail to complete drug treatment will be ineligible to try again.

People who complete drug therapy often require prolonged assistance and support¹⁶ even after clearing the virus, because the liver has been damaged by years of infection. However, as with those deemed ineligible for treatment and suffering progressively deteriorating health, there are few, if any, social supports available — particularly in rural areas.

Those needing liver transplants are perhaps most desperate. At present, need far outstrips the supply of only 400 livers available annually in Canada. Transplants are expensive, risky and almost always subject to recurring HCV infection. Accelerated disease progression may occur as a result of the need to use immunosuppressants.

There is also concern about the phenomenon known as the “double decade demographic”: the very large cohort of individuals infected through Canada’s blood supply and other modes of transmission before 1990. Disease progression among this population, as it moves into its second decade after infection, is expected to result in a surge of HCV-related complications.

At least as challenging as the medical aspects of HCV are Canadians’ attitudes surrounding it.

Only nine years after legal settlements arising from Canada’s tainted blood scandal, HCV has almost disappeared from the headlines. Research shows public awareness about HCV is declining markedly.¹⁷ HCV

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10. *Hepatology Watch, Special Issue: Highlights of Roche Satellite Symposia*, Oct. 19, 2001 ACG Annual Meeting: Progress in the Management of Hepatitis C. 2001 AASLD Annual Meeting: Pegylated Interferons in HCV-Treatment Outcomes Dallas, Texas, Nov.12, 2001. Available at www.hepwatch.com/Special%20Issue.htm.
 11. In some provinces, such as B.C., drug therapy is available only if patients have elevated liver enzyme levels (an indicator of advanced liver disease) and have never been treated before. However, new research shows significant numbers of patients have advanced liver disease without elevated liver enzyme levels, and newer ‘pegylated’ formulations showing efficacy in patients for whom older treatment regimes have failed. See, for example: P. Pradat, T. Poynard, A. Alberti, J. I. Esteban, P. Marcellin, O. Weiland, S. Badalamenti, C. Trepo, “Predictive Value of ALT Levels On Histological Findings in Chronic Hepatitis C: A European Collaborative Study,” *Hepatology*, (Hotel-Dieu, Lyon, France, 2001). Paper presented at the 36th Annual Meeting of the European Association for the Study of the Liver, April 18-22, 2001. Abstract available at www.natap.org/2001/36theasl/alt_levels050101.htm See also I.M. Jacobson, F. Ahmed, M.W. Russo et al. “Pegylated Interferon Alfa-2b Plus Ribavirin in Patients with Chronic Hepatitis C: A Trial in Prior Nonresponders to Interferon Monotherapy or Combination Therapy and in Combination Therapy in Nonresponders: Final Results,” in *Gastroenterology* 124 (2003): A-714.
 12. BC Centre for Disease Control, *A Hepatitis Strategy for British Columbia* (Vancouver, B.C.,1999): 3.
 13. Estimation by Dr. Morris Sherman, July 19, 2005, via email. A hepatologist in the University of Toronto’s Department of Medicine: Gastroenterology Division, Sherman is current chair of the Canadian Viral Hepatitis Network and president of the Canadian Association for Study of the Liver.
 14. Side effects include depression, anemia, autoimmune disorders and susceptibility to infections.
 15. These include drugs, psychosocial supports such as counseling, and supports related to social determinants of health such as nutrition and housing.
 16. See note 15.
 17. Two national surveys commissioned by the Health Canada Hepatitis C Prevention Program show Canadians’ self-reported knowledge of hepatitis C decreased considerably between 1999 and 2001 (Health Canada, 2003).

is often confused with hepatitis A and B, for which vaccines exist. Ironically, ignorance and confusion prevail at the same time that the double decade demographic is expected to produce a dramatic increase in HCV-associated health costs.

Equally problematic is the destructive stigma which surrounds HCV. It is associated with Canada's least politically viable causes: the addicted, incarcerated, street-involved, mentally ill and poor, as well as immigrants from HCV-endemic countries. Misinformed, discriminatory, and dismissive messages are pervasive. HCV-positive individuals experience shame, isolation, hopelessness, and fear of increased ostracization. They become reluctant to even access care, or to be engaged in prevention.

III. Canada's Response

At present, Canada's HCV-positive population is served by about 300 treating physicians (which includes infectious disease specialists, internists, gastroenterologists, and family physicians, and fewer than 50 hepatologists). If all of Canada's HCV-positive individuals were to be diagnosed and appropriately referred, the available specialists would be utterly overwhelmed.¹⁸ Treatment costs continue to rise, as does the demand for liver transplants.

Most Canadian communities have no access to HCV-related services. Community-based organizations, which have proven to be well positioned to offer cost-effective prevention, education, support and referral services, have been forced to shut their doors, or remain hamstrung by chronically inadequate and uncertain funding.

Consequently, much organizational capacity and momentum have been lost, and volunteers have burned out. Many have died of this disease. Undiagnosed and untreated HCV cases progress to much costlier complications, and expensive treatment regimes fail due to lack of necessary supports. Stigma and discrimination continue to plague those who are infected and those most at risk of infection. Every year, another 5,000¹⁹ Canadians become newly infected.

Canadians pay dearly. Consider the following HCV-associated costs:

- one course of anti-viral treatment medication: \$20,000²⁰
- average lifetime cost for HCV per patient, without a liver transplant: \$100,000²¹
- average lifetime cost for HCV per patient, from time of diagnosis to death, including medical costs and the economic loss for that individual: \$1 million²²
- estimated medical cost of death from liver failure: \$50,000²³

18. *ibid.*

19. Public Health Agency of Canada, *Hepatitis C: Frequently Asked Questions*. Available at www.phac-aspc.gc.ca/hepc/hepatitis_c/drhepc.html

20. Joint Advisory Committee, 3.

21. BC Centre for Disease Control, 9.

22. *ibid.*, 3.

23. *ibid.*, 3.

- cost of one liver transplant: \$121,732 to \$250,000²⁴ plus a subsequent lifelong need for expensive anti-rejection drugs
- Canada's expenditures on HCV-related liver transplants in 2000: between \$14.9 million and \$30.5 million²⁵
- Canada's medical expenditures on HCV per year: \$500 million²⁶

These costs are only the tip of the iceberg. Epidemiologists expect the progression of disease among Canadians who are currently infected to play out in an imminent and dramatic cost spike:

- By 2008, current Canadian cases of hepatitis C will result in a 92% increase in cirrhosis, a 126% increase in decompensated cirrhosis, a 246% increase in the number of patients requiring liver transplants, and a 102% increase in liver cancer over 1998 levels.²⁷
- Overall, HCV costs the Canadian healthcare system about \$500 million annually. This is expected to double to \$1 billion by 2010.²⁸

When the already underfunded Hepatitis C Prevention, Support and Research Program ended in March 2004 an outcry from Canada's HCV community led to a one-year funding extension until 2005, and once again until March 2006. There has been no indication that funding will continue beyond that, much less be augmented to include critical missing elements or sustained long enough to realize lasting benefit.

IV. The Opportunity

Clearly, Canadian taxpayers are playing catch-up to an increasingly expensive epidemic – but there is good news. HCV is distinguished from other costly diseases in that:

- Hepatitis C is 100% preventable.
- Its incidence does not increase with age.
- It is not spread through casual contact.
- Compared to HIV and hepatitis B, the risk of sexual transmission is low.
- Most new cases can be traced to a handful of risk factors which, through education, social and behavioral change, can be addressed.
- Between 50 and 80% of those who undergo a single course of drug therapy will clear the virus; a significant number actually reverse liver damage.²⁹
- Better treatment outcomes are associated with early detection and treatment.

24. Joint Advisory Committee, 12.

25. Joint Advisory Committee, 12.

26. Joint Advisory Committee, 12.

27. S. Zou, M. Tepper and S. El Saadany, "Prediction Of Hepatitis C Burden In Canada," *Canadian Journal of Gastroenterology* 14 (July/Aug. 2000), 7:575-580. See www.pulsus.com/Gastro/14_07/zou_ed.htm

28. Joint Advisory Committee, 6.

29. S. Nishiguchi, T. Kuroki, S. Nakatani, H. Morimoto, T. Takeda, S. Nakajima, S. Shiomi, S. Seki, et al. "Randomized Trial of Effects of Interferon-A on Incidence of Hepatocellular Carcinoma in Chronic Active Hepatitis C with Cirrhosis," *Lancet* 346 (1995), 1051-1055. Abstract available at www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7564784&dopt=Citation

Other reasons for hope include many insights transferred from the battle with HIV in Canada and elsewhere:

- Harm reduction initiatives are proven means of reducing infections.
- With education and support, infected people stay healthier longer, and suffer fewer costly complications later.
- Investments in sustained public education pay off in terms of behaviour change.
- Involvement of at-risk populations increases program effectiveness.
- Community-based organizations show unparalleled ability to mobilize at-risk populations with messages that are effective within those populations.
- Every infected person is uniquely positioned to advance the cause of prevention, and with adequate supports, can be engaged in that cause.

Expert analysis shows that strategic investments could reduce projected costs to a fraction of current levels, and realize significant tax savings:

- Every prevented infection equals \$1 million saved in medical costs and productivity over a person's lifetime.³⁰
- Every \$1 spent on combination therapy can result in about \$4 of medical cost savings. The return includes present value considerations and considers total payments for medical care.³¹
- For a typical patient, curative treatment with state-of-the-art drug therapy pays for itself within 10 years, even before considering avoided disability and lost productivity costs. This factors in the total healthcare costs of patients who respond to treatment and those who do not, as well as the present value of future healthcare spending.³²

The Government of Canada, in partnership with provincial/territorial governments, can and should adopt an ongoing, comprehensive, co-ordinated strategy to manage HCV in Canada, both for compassionate reasons and to maximize Canada's healthcare resources. Critical components of an effective strategy include:

- Disease Prevention
- Community Engagement (including capacity-building and community-based support and education)
- Care and Treatment Support
- Interdisciplinary Research
- Creation of a National HCV-PRO-Net
- Program Management

30. BC Centre for Disease Control, 3.

31. S. Dulworth, S. Patel and B.S. Pyenson, *The Hepatitis C Epidemic: Looking at the Tip of the Iceberg*, Milliman & Robertson Inc. (Washington, D.C.: 2000), 1. Available at www.milliman.com/pubs/HRR03.pdf.

32. *ibid.*

V. Recommendations for a New Canadian Hepatitis C Strategy³³

Disease Prevention

Federal resources required: \$5 million annually / \$25 million over 5 years³⁴

The Public Health Agency of Canada (PHAC) should:

- In partnership with provincial/territorial governments, healthcare professionals and community-based organizations, develop and deliver educational programs aimed at the general public, at-risk groups, and HCV-positive individuals on:
 - HCV transmission routes, including sexual and vertical (mother-to-child) transmission,
 - co-infection with HIV,
 - the importance of getting tested,
 - prevention and treatment options, and
 - stigma around HCV, as a significant hindrance to effective prevention and treatment.

Such programs must be peer-reviewed to ensure that they are culturally appropriate and available in a range of literacy levels, learning styles and languages.

- Support and expand harm reduction programs, ensuring they are adequately resourced with appropriate drug-use materials. Harm reduction initiatives include needle exchange/distribution, safer crack use programs, safe injection/consumption sites, safe tattooing practice, and programs to address barriers to access experienced by at-risk populations, particularly in Canada's correctional facilities.
- Support and expand readily available treatment for drug dependency, including:
 - withdrawal management (detox),
 - treatment on demand,
 - methadone/buprenorphine programs (including low-threshold programs),
 - outpatient and peer-based counseling,
 - daytime and residential treatment, and
 - housing, ongoing medical care, and other support services.
- Involve at-risk populations in prevention efforts by supporting the development of innovative peer support and preventive education programs which:
 - allocate human and financial resources for sustainable capacity building, skills sharing, and networking for youth;
 - build capacity among diverse target communities (including youth, rural, Aboriginal, street-involved, injection drug-using, crack/crystal meth-smoking and incarcerated people) to mobilize their strengths and social networks to design and deliver programs which resonate with those communities,

33. A table summarizing recommended strategy expenditures can be found in Appendix A.

34. If public health initiatives, public awareness campaigns and harm reduction activities are all included under this heading it may be necessary to shift some funding from other categories.

- address determinants of health (i.e. housing, nutrition, safety) which factor into high-risk behaviours and hinder HCV prevention, care and treatment; and
 - address barriers faced by marginalized at-risk groups in accessing harm-reduction programs, particularly among Canada’s incarcerated population.
- Ensure that access to information, support, needle exchange/distribution, safer crack-use materials and education, prescription alternatives to street drugs, harm reduction materials and methadone and buprenorphine maintenance therapy are available in rural as well as urban areas. These must reflect rural considerations such as at-risk population needs, extreme weather, lack of public transportation, stigma and heightened confidentiality concerns.
- Educate and sensitize service providers (workers in healthcare and prison settings, drop-ins and shelters; peer educators and street-outreach workers) who regularly deal with at-risk population about:
 - HCV risk factors,
 - prevention of needle-stick injuries in occupational settings,
 - stigma around HCV as a factor constraining effective prevention and treatment, and
 - efficacy of harm reduction initiatives.
- Link all prevention strategies to new and existing programs at the local, provincial and federal level, which focus on:
 - harm reduction,
 - safer sex practices,
 - health promotion,
 - social and economic support,
 - populations particularly at risk for HCV, and
 - HIV and other blood-borne/infectious diseases.
- Provide new funds to enable HCV-focused community-based organizations’ participation in the Strategy for Building Capacity Around Preventive and Therapeutic Vaccines against HIV, HCV and Cancer.
- Provide adequate funds for Canada’s public health units to:
 - improve the national surveillance database;
 - conduct enhanced surveillance interviews for acute hepatitis B and C cases;
 - educate, test and immunize high-risk populations against hepatitis A and B;
 - collaborate with federal, provincial and territorial Public Health and other relevant provincial agencies (e.g. BC Hepatitis Services) in disease surveillance, testing and prevention;
 - develop, implement and enforce consistent, workable guidelines and regulations for tattooing, piercing, body modification and nail care businesses.

Community Engagement (including Community Capacity-building and Community-based Support and Education)

Community-based organizations are extremely well positioned to deliver health-promoting education and support to target populations, and to the general public, in a cost-effective manner.

As key allies in epidemic management, they must be adequately resourced by the PHAC to build their capacity, and to develop, deliver and evaluate initiatives specific to their communities. Funding should be structured so that organizations who successfully build capacity can transition to project funding in subsequent years.

Community Capacity-building

Federal resources required: \$5 million annually / \$25 million over 5 years³⁵

PHAC should provide adequate, sustained funding for community-based organizations to:

- develop the capacity to utilize existing HCV-related expertise and develop it further;
- engage HCV-positive individuals and populations at greatest risk in program development, delivery and evaluation (including train-the-trainer education for HCV community support group leaders); and
- form regional and national networks of organizations which are inclusive, accountable and representative of people affected by HCV to:
 - share learning and resources;
 - represent local and regional concerns; and
 - collaborate with other national initiatives and advise policy makers.

Community-based Support and Education

Federal resources required: \$18 million annually / \$90 million over 5 years³⁶

PHAC should provide adequate, sustained funding for community-based organizations to:

- Develop and deliver HCV information using a variety of methods, including phone-, internet-based and other in-person support and education services for patients and the general public.
- Develop and deliver an Expert Patients program, wherever possible in co-ordination with existing chronic illness health education/promotion programs, to teach HCV-positive individuals to better navigate the healthcare system and improve their capacity for self-care.
- Collaborate with other relevant programs/organizations, including those focused on harm reduction, HIV/AIDS and other diseases, public health, Aboriginal, youth, addictions, prisoner advocacy/corrections, mental health and poverty.
- Collaborate with health educators on the design and provision of medical/nursing/dental school curricula and continuing medical education.

35. If Public Health initiatives, public awareness campaigns and harm reduction activities are all included under this heading it may be necessary to shift some funding from other categories.

36. In 2000-2001, 78 community-based projects were funded. Many more were unable to access funding. If we project the funding of 100 projects/programs nationwide, at \$150,000 per annum, the total required is \$15 million.

- Educate healthcare and allied service providers (including those involved in mental health, addictions, social work, peer support, hospices and other community-based organizations) about working with people who use drugs (especially illicit injection drugs and steroids), the various addiction treatment approaches to pain management, the needs of patients undergoing anti-viral drug treatment, and realities of life with HCV.
- Help craft HCV prevention education for inclusion into school curricula, including basic, age-appropriate ‘standard precautions’ education in primary school and prevention/harm reduction and negotiation/refusal skills in high school. These should include a train-the-trainer component to establish networks of peer educators, particularly in rural areas.
- Develop peer education initiatives for youth outside of the mainstream school system, particularly those who are incarcerated, street-involved and participating in high-risk activities such as injection drug use and body art.
- Establish mutual education and referral pathways between mental health, addictions, nutritional and dental health, counseling, community nursing, home care and hospice services, with particular emphasis on improving treatment outcomes.
- Help ensure that all programs and educational materials are culturally appropriate and responsive to a range of literacy levels, learning styles and languages.
- Support the work of comprehensive HCV care clinics (see below).
- Help develop a PHAC-funded nationwide campaign that publicizes risk factors and the need for testing, including youth-specific messaging and input.
- Contribute to the continued development of the Canadian Hepatitis C Information Centre.
- Work with provincial/territorial Ministries of Human Resources and the Canada Pension Plan to ensure that chronic HCV is recognized as an episodic disability for disability benefits.
- Work with other federal, provincial and territorial ministries to address determinants of health critical to successful treatment (e.g. safe housing for HCV-positive and at-risk youth).

Care and Treatment Support

Federal resources required: \$5 million annually / \$25 million over 5 years

People with HCV need a full spectrum of health services, from diagnostic testing and specialist care, to extended care in the community. Essential health services include:

- anti-viral drug therapy for all those it will benefit;
- supports before, during and after drug therapy;
- care for people deemed ineligible and/or contra-indicated, for drug treatment;
- care for people for whom treatment fails; and
- care for people who choose not to treat with medication.

To ensure HCV services meet actual need, the provincial and territorial ministries of health, health profession governing bodies and related disease-specific non-governmental organizations should take the following measures:

- Develop a network of comprehensive HCV care clinics, offering alternative care management (multidisciplinary teams, nurse practitioners, core team/extended team, etc.), access to HCV-focused specialists, nurses, counselors, dentists, nutritionists, social workers and referrals to related services.
- Ensure adequate funding for testing, pre- and post-test counseling and diagnostic analysis of blood samples.
- Establish and regularly update protocols/guidelines for assessment, testing/workup, record keeping, referral, treatment and follow-up.
- Ensure equitable access to drug therapy, care and treatment across all jurisdictions, making appropriate use of tele-health and internet-mediated consultations in rural and remote communities.
- Look for avenues of collaboration and cooperation which respect cultural and autonomy issues, so that Aboriginal Canadians on and off reserve benefit equally.
- Develop and implement alternative physician billing models for care and treatment of labour-intensive chronic diseases such as HCV.
- Fund development and delivery of patient education/self-advocacy and wellness programs.
- Utilize appropriately trained community-based organizations to provide basic treatment support/education, medical professionals to concentrate on the complex medical issues involved, and to be able to treat more patients.
- Build more robust HCV prevention, education, support, care management and research into Chronic Disease Management and Primary Care Reform initiatives.
- Promote organ donation; help transplant services develop capacity to meet increased demand for liver transplants.
- Improve the co-ordination of care, and sharing of expertise on HCV/HIV co-infection issues.
- Fund and recruit physicians to train as hepatologists, to meet the expected surge in demand.
- Augment resources to treat youth with addictions, and for capacity building, skills sharing and networking among youth. A diversity of youth communities (including urban, rural, Aboriginal, street involved, incarcerated) must be engaged in policy and program development to ensure their viability.
- Educate primary care physicians to deliver HCV care and treatment, and link them with consulting hepatologists.

Interdisciplinary Research

Federal resources required: \$5 million annually / \$25 million over five years (plus additional funding to implement CFAARI, see below and original CFAARI document).

To enhance our understanding of HCV, treatment advances and intervention effectiveness, PHAC should continue funding interdisciplinary research in partnership with the Canadian Institutes for Health Research.

A comprehensive proposal has been put forward by the Joint Advisory Committee (JAC) of Health Canada/Canadian Institutes of Health Research,³⁷ for the establishment of a national Collaborative Framework for the Advancement and Application of Health Care Research and Innovation (CFAARI) to guide the development and application of best practices and facilitate the integration of activities related to HCV prevention, care, treatment and support. This would follow a separate budget line.

PHAC should fully implement those recommendations, prioritizing funds for research on:

- action strategies to improve post-marketing approval surveillance and adverse events reporting;
- stigma, and its relationship to epidemic management and health outcomes of HCV-positive individuals;
- possible interactions of anti-viral and illicit drugs, and successful treatment of people who use injection drugs;
- vertical transmission mechanisms and risks, viral clearance in children, breastfeeding, treatment of children with rapidly progressing HCV infection, transmission risks, natural history, symptomology, the role of hormone levels, contraceptive use, screening strategies, pregnancy care, and assisted reproduction; and
- relationships between gender, age, disease progression and treatment.

PHAC should also support research partnerships between university programs and community-based organizations. These partnerships should include development and application of community-based research projects and evaluation tools, to include patient, peer and community input.

37. Joint Advisory Committee of the Health Canada/CIHR Research Initiative on Hepatitis C, Hepatitis C As A Roadmap For Integrated Communicable Disease Prevention And Control: A Strategy For The Renewal Of The Health Canada/Canadian Institutes Of Health Research (CIHR) Research Initiative On Hepatitis C (Jan. 20, 2005).

Program Management

Federal resources required: \$4.5 million annually / \$22.5 million over 5 years

To maintain a cost-effective, responsive Canadian hepatitis C strategy, PHAC requires overall funding of \$4.5 million annually. This funding should prioritize:

- innovative pilot projects;
- a strong capacity-building component for community-based organizations; and
- a mix of project and multi-year operational funding, tied to positive program evaluation results.

To maximize value from public investments into HCV, PHAC should ensure access to full project funding within any three-year funding cycle for community-based organizations which demonstrate:

- appropriate capacity development and sound application/work plans;
- transparency, accountability and timely communications; and
- positive evaluation results.

A truly integrated national response to HCV will also require PHAC to:

- support collaboration between related strategies and initiatives (e.g. Canadian Drug Strategy, Federal Initiative to Address HIV/AIDS in Canada);
- develop mechanisms for partnerships with federal, provincial and territorial Ministries of Health, Solicitors General, Social Services, Mental Health and the First Nations and Inuit Health Branch;
- reduce duplication of effort by maintaining user-friendly access to existing information resources;
- emphasize, in all of its HCV-related projects, regular opportunities for skills-building, sharing of best practices, and networking on regional and national levels; and
- recognize and support a range of partnership models and development processes.

Appendix A

| Program | Annual amount | Five-year total |
|---|---|--|
| Disease Prevention | \$5 million | \$25 million |
| Community Capacity Building | \$5 million | \$25 million |
| Community-based Support & Education | \$18 million | \$90 million |
| Care and Treatment Support | \$5 million | \$25 million |
| Interdisciplinary Research - CIHR | \$5 million | \$25 million |
| Program Management | \$4.5 million | \$22.5 million |
| National Hepatitis C Prevention/ Care Research Outcomes Network (see CFAARI document) | See CFAARI document | See CFAARI document |
| Total | \$37.5 million (+ additional funding for CFAARI) | \$187.5 million (+ additional funding for CFAARI) |

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