



# Managing the HCV Epidemic

A PRACTICAL AND COST-EFFECTIVE  
APPROACH FOR BC COMMUNITIES

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HEPATITIS C COUNCIL OF BRITISH COLUMBIA

## HCV IN BC

**A RENEWED FOCUS**

MARCH 2005





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# Managing the HCV Epidemic: A Practical and Cost-effective Approach for BC Communities

## Introduction

The BC Hepatitis C Collaborative Circle\* is a province-wide network of organizations and individuals involved with addressing the hepatitis C virus (HCV) epidemic in B.C. We offer this paper as a contribution to the ongoing discussion about how British Columbia should proceed in the absence of a clearly defined provincial or national strategy.

Burgeoning HCV-related health costs, a lack of clear direction at the national level and the recent subsuming of the national Hepatitis C Prevention, Support and Research Program within the new Public Health Agency of Canada all place B.C. at an important juncture. We can continue with a disjointed, half-hearted response that leaves HCV-positive individuals in progressively poorer health, new infections rising, and taxpayers ill-served, or B.C. can show leadership, by meeting HCV head-on with a coordinated, multi-leveled response.

We believe the latter is desirable, possible and necessary, not only for humanitarian reasons but because prudent management of healthcare resources demands it.

This paper will show that, far from being over, the medical and financial burdens of the HCV epidemic are increasing dramatically and creating a situation that urgently demands a response. It will also set out considerations intended to inform that response.

We will set the stage by situating HCV within a national/international context (I), and describing the unique characteristics that make this disease particularly challenging for individuals (II) and epidemic management (III). This will be followed by a brief examination of how HCV has been handled in B.C. to date (IV), and a discussion of some of the shortcomings of that response (V).

\* Note: The BC Hepatitis C Collaborative Circle is presently amalgamating its constituent organizations and members into the Hepatitis C Council of BC.

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This document will then outline relevant disease management options currently being explored (VI), and suggest considerations that all stakeholders ought to bear in mind when doing so (VII). These emphasize the important contributions that community-based organizations can make. We will conclude with recommendations for practical and cost-effective measures that can be instituted by government (VIII).

### I

## Background

The hepatitis C virus was only identified in 1989, but this hasn't slowed it from swelling into an epidemic that has eclipsed HIV/AIDS<sup>1</sup> by five times in terms of total infections, and which may become three times as deadly in North America. Worldwide, an estimated 170 million people have HCV; three to four million more are infected annually.<sup>2</sup> In Canada, 250,000<sup>3</sup> people live with HCV<sup>4</sup>; 5,000<sup>5</sup> to 8,000 more contract it each year. B.C. is particularly hard hit: an estimated 65,000 British Columbians already live with HCV, with 1,500 to 2,400 new infections occurring annually. Having double the national rate, B.C. accounts for almost 30% of Canada's infections.

Despite the growing burden, HCV barely registers in the public consciousness—accounting for its apt nickname, “the silent epidemic.” Its low profile is partly due to its insidious, stealthy nature: symptoms often go undiagnosed for years, and complex HCV-related conditions, especially those affecting the liver, develop over decades.

Visible or not, HCV is already costly. The Canadian Institutes of Health Research estimates that Canada spends about \$500 million annually on HCV-caused health problems.<sup>6</sup> In 1999, the Vancouver/Richmond Health Board estimated the total cost of HCV to be \$1 million per patient from the time of diagnosis to death, including medical costs and lost productivity.<sup>7</sup>

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Today's costs are, as one study<sup>8</sup> calls it, the tip of the iceberg. The majority of Canadians with HCV have been infected for over 10 years. By 2008, disease progression among this cohort will manifest in a dramatic rise in costly complications, such as a:

- > 92% increase in cirrhosis (scarring of the liver that can lead to liver failure and death)
- > 102% increase in hepatocellular carcinoma (liver cancer)
- > 126% increase in liver failure
- > 126% increase in liver-related deaths
- > 300% increase in the need for liver transplants<sup>9</sup>

The escalation of costly health complications among this group (a phenomenon we will call the Double Decade Demographic), together with new infections, is predicted to double Canada's HCV costs to \$1 billion annually by 2010.<sup>10</sup> Statistical modeling in the U.S. suggests that this upward trend could continue beyond 2030.<sup>11</sup>

The impact of the Double Decade Demographic should not be underestimated. It is like a time bomb where we know the approximate time of detonation and size of the blast area but we haven't yet developed the technology to disarm it. The prudent and responsible approach in these situations is to reduce the damage and loss of life by taking action before it explodes.

Close to 60% of cases in BC are among those aged 40-59.<sup>12, 13, 14</sup> In what would normally be their peak earning and family raising years, these people are, in increasing numbers, stricken with the pain, disability and death resulting from a viral infection that occurred, without their knowledge, at some point in their youth.

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The convergence of several factors is contributing to the seriousness of this situation:

- > a disease process with few, if any, early warning signs,
- > and one where, on average, 20 years pass before the liver is unable to regenerate sufficiently to keep up with the damage caused by the virus and the body's immune response,
- > a large number of people who have been infected for many years,
- > expensive and difficult to tolerate drug treatments that have only recently surpassed 50% effectiveness,
- > much more expensive but very limited numbers of available transplants,
- > and a healthcare system that has not yet fully grasped the tremendous impact of this situation.

To respond appropriately, we must consider the unique challenges that HCV presents to individuals and to epidemic management.

## 2

### HCV challenges individuals

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

In about 15% of people, HCV infections clear spontaneously within a few months.<sup>15</sup> Most such people are unaware of the infection and their successful immune response.

For the majority, chronic hepatitis C can mean debilitating fatigue, pronounced difficulty with concentration and memory, muscle and joint pain, nausea and other gastrointestinal upsets. Between 20 and 30% of chronic infections progress to cirrhosis, liver failure or liver cancer.

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The liver performs more than 500 important biochemical functions in the body. When badly damaged, it cannot remove toxins from the blood. As these accumulate to overwhelming levels, the horrific symptoms of end stage liver disease result. Patients become emaciated and jaundiced, - painful swelling and cramping of the abdomen and legs occurs, sometimes accompanied by unbearable itching. Mental confusion and unreasoned aggression take hold. Death can follow a massive spontaneous bacterial infection, bleeding from veins in the throat, or coma.

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.<sup>16</sup>

The physical challenges of living with HCV are compounded by additional obstacles, some of which are systemic.

For example, about 15% of British Columbians do not have a family physician<sup>17</sup>. It's not unreasonable to assume that newly diagnosed HCV-positive people, among whom B.C.'s most marginalized groups are over represented, figure highly among those without regular medical care. Securing care from a well-informed physician is arguably more difficult because B.C.'s fee-for-service medical billing structure, which allows physicians to bill equally for a five-minute consult as for a 55-minute one, creates a financial disincentive for doctors to commit to the complex and time-consuming needs of HCV patients.

In B.C., people with HCV also face unnecessarily restrictive criteria for access to the combination of drugs that, for many, represent a cure.<sup>18</sup> Patient eligibility for the current standard of treatment (pegylated Interferon with Ribavirin) is ultimately determined not by treating physicians or specialists, but by Pharmacare-imposed criteria. Some of these are no longer supported by current knowledge about best practices<sup>19</sup>: for example, requirements that patients show elevated liver enzymes twice over six months (an imprecise indicator of damage to liver cells), be treatment-naive, age 18 or over and not actively using injection/intranasal drugs.<sup>20</sup>

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For many patients who are deemed eligible, the expenses associated with drug therapy put it out of reach. On top of a deductible which, depending on income and when in the calendar year treatment is begun, can amount to thousands of dollars, patients endure grueling drug therapy-related side effects. These play out in lost days of work (i.e. income) and costly over-the-counter remedies for effects such as diarrhea, upset stomach and skin conditions. Other common side effects such as depression, dental problems, neutropenia (loss of white blood cells, which fight infections), and anemia (loss of red blood cells, which carry oxygen) also demand expensive medications which have little or no Pharmacare coverage.

For many patients, B.C.'s geography, weather and dearth of local clinical expertise means expensive and exhausting travel for treatment when they are least able to expend the money or energy expected of them.

Co-infection with HIV, a reality for about 7% of HCV patients (about 4,500 British Columbians) makes matters worse. Each disease intensifies the progression of the other and complicates the treatment of both. For example, liver damage advances more rapidly in patients co-infected with HIV and can be worsened by some of the drugs used to treat HIV. Liver disease has now become a leading cause of death for people with HIV.<sup>21</sup>

Finally, people with HCV typically require additional supports at the time of diagnosis, when making decisions about treatment, throughout treatment or clinical trials, and during severe HCV-related complications such as cirrhosis, liver failure or cancer. Important additional supports in all of these situations include timely access to clear, comprehensive and accurate information, psychosocial supports in individual and group settings, as well as help in navigating the unfamiliar and complex medical world. One of the most profoundly disturbing aspects of unmet support needs is the suicides that occur following treatment. It appears that during this time of transition the prolonged depression-inducing effects of the treatment medications can combine with either the despair of a treatment failure or an inability to adapt to the changed expectations and self-image which can follow successful treatment. Paradoxically, when most people are thinking that the worst is over, patients may be at greatest risk.

As we will see below, such supports are seriously lacking in B.C.



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### 3

## HCV challenges epidemic management

HCV is an incredibly resilient virus that remains viable outside the body for up to four days.<sup>22</sup> It is about 10 to 15 times more infectious than HIV<sup>23</sup>, and there is no preventative vaccine for it.

Infection is largely preventable by avoiding blood-to-blood contact with an infected individual. Transmission can occur through the sharing of equipment used for drug injection/snorting/smoking, piercing, tattooing, nail care, electrolysis, shaving, and acupuncture, as well as sexual activity, particularly if blood is present (for example, unprotected sex during menstruation, or when tissue trauma or lesions may be present). In addition, approximately 25,000 young Canadian athletes are at risk from injectable steroid use.<sup>24</sup> Infections can also be passed *in utero* from mother to child, and result from needlestick injuries and contaminated equipment used in medical procedures such as hemodialysis. Prior to 1992, many people were infected through Canada's blood system.

But prevention is confounded by HCV's low profile, its frequent confusion with Hepatitis A & B (both vaccine-preventable) and the fact that more than a third of those infected are unaware of their status<sup>25</sup> and may be unknowingly passing the virus to others.

Misinformation or lack of information about HCV is not limited to the general public. Most doctors practising today did not receive HCV-specific training in medical school, and knowledge about HCV is rapidly evolving. Community-based organizations report that as recently as five years ago, newly diagnosed patients were advised that little could be done for them. It has since become clear that in addition to treatment advances, patient education about nutrition, weight control and alcohol intake can have a positive impact on disease progression.

HCV challenges health planners by eluding easy categorization: it is variously considered a carcinogen, a sexually transmitted infection, an infectious disease, a blood-borne pathogen, a preventable disease, a (for a minority) curable disease and a chronic disease. As we shall see below, this means it is sometimes subsumed

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with other diseases into ill-fitting management strategies or worse, left out altogether.

HCV also challenges our capacity to deliver information, treatment and support to populations where new infections primarily occur. This is partly because more research is needed about transmission routes, risk factors and risk levels, particularly about the 40% of infections that occur by means other than shared drug ingestion equipment. This challenge is also due to the diversity of groups experiencing new infections: First Nations people, incarcerated individuals, immigrants from numerous HCV-endemic countries, marginalized youth and middle-class retirees. This diversity, in tandem with language, culture and geographic barriers, makes it clear that effective messaging demands an alternative to a one-size-fits-all approach.

### ● STIGMA

No discussion of HCV challenges, both to epidemic management and to individuals, would be complete without special attention to one of its most problematic and amorphous aspects: stigma.

Because 60% of new diagnoses are attributed to the sharing of contaminated equipment to ingest drugs, HCV's limited public image is associated with illegal behaviour and all of the social ills that accompany addiction. By and large, addiction is still viewed as a character flaw at best and a criminal trait at worst, rather than as a health issue which springs from a complex interplay of social, economic, psychological, and genetic factors. Most people wouldn't dream of denying care to patients who suffer a health toll from legal and socially accepted habits, such as inactivity, high-fat diets, or alcohol consumption, but many are quick to judge HCV patients as undeserving of treatment or care because they are thought to have brought HCV onto themselves.

Such attitudes, which are found commonly among the general public and healthcare providers, tar all HCV-positive people with the same dehumanizing brush—be they people who continue to struggle with addictions, or those whose

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experimentation with drugs were brief or distant departures from otherwise productive, law-abiding lives. They also obscure the reality that 40% of HCV infections in Canada were contracted by means other than drug use.

Stigma around HCV fuels real and common experiences of discrimination, fear of job and insurance loss, guilt, isolation, and ostracization by family, friends and community upon disclosure of HCV-positive status. Stigma is sometimes internalized by HCV patients themselves. It hinders delivery of effective prevention education and appropriate care, and it makes HCV less likely to be recognized, or championed, as the pressing public health concern that it is.

The following two sections examine B.C.'s response to HCV, and some of the shortcomings of that response.

### 4

## The HCV response in BC

In 1998, the **Government of Canada** responded to the infection of thousands of Canadians with HCV through our blood system with an initiative<sup>26</sup> which provided compensation for those who contracted HCV between 1986 and 1990, \$300 million over 20 years to provinces/territories for care and treatment services, and \$50 million over five years for prevention, community-based support and research. This latter amount was intended for short-term purposes, but also to lay the groundwork for a longer term strategy for improved health outcomes for people with HCV, a network of community-based organizations involved in addressing HCV, broader and more timely treatment options, greater awareness of risk factors and fewer new infections.

In 2001, the B.C. government created **BC Hepatitis Services** (BCHS). As a division of the B.C. Centre for Disease Control, BCHS was tasked with developing a provincial strategy for prevention and care for all forms of hepatitis, including HCV, and creating an interdisciplinary team to work collaboratively with clinicians, scientists, educators, consumers, health and social service agencies.

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BCHS partially funds the **B.C. Hepatitis Program**. Located in the Vancouver General Hospital, this program provides treatment, care, support, primary prevention and outreach for patients within the Vancouver Coastal Health Authority. It also provides public education in the form of conferences and science fairs, and partners on research and clinical projects with UBC, St. Paul's Hospital and others. The B.C. Hepatitis Program co-ordinates with the HIV Centre for Excellence to manage treatment for HIV/HCV co-infected patients, and, in conjunction with BC Hepatitis Services, develops and delivers HCV education for medical students, physicians, nurses and allied health professionals—such as 3 day Interdisciplinary Viral Hepatitis Workshops, which have been conducted for 200 health professionals from around BC.

Between 2001 and 2003, BCHS launched four modest<sup>27</sup> pilot projects aimed at integrating hepatitis/liver-related prevention and care activities in Kamloops, Campbell River, Prince George and Surrey. These clinics employ part-time hepatology nurses, offer limited access to specialists, and liaise to some extent with social workers, mental health and addictions services. BCHS also undertook a youth education project in the greater Vancouver area in 2003.

**The Pender Community Health Centre** (Vancouver Downtown Eastside) and the **Cool Aid Community Health Centre** (Victoria) have recently partnered to improve access to HCV treatment for inner city residents with a history of injection drug use. Building upon their experience in treating HIV using a Directly Observed Therapy (DOT) approach, they are beginning to apply this to HCV infection within a multidisciplinary 'one-stop shop' approach that includes a research team, nutritionist, nurses, infectious disease specialists, as well as mental health and addiction services. Given that injection drug users in these cities have a higher than usual percentage of genotype 2 or 3 infections, which respond well to treatment and are less expensive to treat because they only require six months of medication, the staff project an eventual 30% reduction in inner city cases of HCV, if a concerted approach to case identification and treatment is backed up by adequate supports. To that end, they are pursuing funding sources and partnerships with local community-based organizations.

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Additionally, there are a small number of individual specialists who, with short-term funding from the pharmaceutical industry for nursing support, are attempting to increase their ability to treat more patients.

**B.C.'s Public Health Units** provide confidential testing, information, and data collection, as well as hepatitis A/B, influenza and pneumococcal vaccinations. Some units have been very proactive in educating nurses, providing information and follow-up around HCV.

There have been recent efforts to address rampant HCV (20-40%) among prison populations: federal inmates in the Lower Mainland are now being treated by Dr. John Farley. Some educational sessions have begun in Lower Mainland prisons during the past year, and discussions are now in progress to establish safer tattoo practices. Despite international evidence supporting their effectiveness, harm reduction measures for drug use have yet to be initiated in B.C.'s prisons.

**Community-based organizations** (CBOs) have also responded to HCV, by providing prevention information, harm reduction options (such as needle exchanges), peer supports, community education, advocacy, and referrals to related services such as mental health and addictions services.

In 1999 four such projects in B.C. were funded by Health Canada. In 2000, nine B.C. projects were funded, while eight organizations received small grants for support group development and capacity-building. At present, with a 38% reduction in funding for the BC region, only seven CBOs receive modest<sup>28</sup> federal funding for prevention, support and education<sup>29</sup>.

By mobilizing volunteer power and trustful relationships with at-risk populations, CBOs have created efficiencies in overcoming barriers such as language, marginalization and geographic isolation, and delivering prevention information in a credible, culturally appropriate format.

Their work has also helped maximize existing healthcare resources: for example, by attending to patients' needs for basic information, referrals, and emotional support, CBOs free up physician time for higher level medical care. By linking researchers to HCV-

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affected populations and testing conclusions “on the ground,” CBOs enhance the viability and relevance of ongoing scientific inquiry.

### 5

## Problems with this response

All of the above represent important steps forward. However, several factors seriously constrain the effectiveness of B.C.’s response to HCV.

To begin with, Health Canada’s five-year HCV initiative, while achieving much, allocated too little, for too short a time for a critical strategy component: HCV-dedicated community support and education. The Canadian AIDS Society calculates that at its height, Health Canada support for this work amounted to \$14 per HCV-positive Canadian, annually.<sup>30</sup> To put this into perspective, the corresponding amount for HIV will be 50 times greater: \$708 per HIV-positive person by 2008.<sup>31</sup>

Unfortunately, many of the projects that were funded in 1999 and 2000 were just hitting their stride with innovative and highly cost-effective services, utilizing partnerships and existing expertise in their communities, when Health Canada changed its funding priorities. Work that had been nationally and internationally acclaimed had to either be dropped or attempted on a 100% volunteer basis. Trying to meet the growing demand with few resources resulted in widespread burnout.

During the past two years, only a handful of projects have been funded by the federal government. The majority, while doing what they can to reach out to the rest of the province, are based in the Lower Mainland. Most B.C. communities, and entire health regions such as Interior Health, which covers almost half the province, have had no funded community-based HCV services at all. After many unsuccessful approaches to foundations and private sources, it has become obvious that HCV is not considered a sexy cause and private funders expect to see government solidly at the table. To our knowledge, despite having the

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constitutional jurisdiction for health care and the most to gain from improved health outcomes, the provincial government has not invested any money in HCV-focused community-based services.

Despite scarce resources, personal hardship, illness and the deaths of key members, most CBOs have continued to provide some basic support and education, but at a level far below demand and their potential to provide.

It must be noted here that AIDS Service Organizations (ASOs) have played a major role in providing community-based services for HCV from the beginning, an outcome of the fact that 30% of their HIV/AIDS clients are co-infected with HCV. Because they have often been the only funded service in many communities, an expectation of services has been created among both co-infected and HCV mono-infected populations.

This has created a peculiar funding advantage for ASOs: with a longer history, expertise in HIV/AIDS, recognition by their program funders of the importance of infrastructure development, capacity-building, and social marketing, ASOs attract more appropriate funding levels than do CBOs which primarily focus on HCV.

However, it has become increasingly clear that ASOs face significant challenges in trying to carry out HCV work.

In the absence of HCV-specific funding, ASOs must choose between turning desperate people away or providing minimal service “off the side of one’s desk”, which also diminishes the resources available for people with HIV/AIDS.

When HCV-related activities conflict with a HIV/AIDS-focused mandate, ASOs face a dilemma. As the Canadian AIDS Society asks, “What would it be like if the majority of HIV/AIDS services were delivered by the Canadian Diabetes Society or the Arthritis community?”<sup>32</sup> When funding is tight and commitment, expertise, client comfort, and organizational priorities are at stake, an organization’s primary mandate usually prevails.

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ASOs long ago realized a crucial principle: involving a target population in the planning, delivery and evaluation of services ensures programs are responsive and relevant, and builds capacity within the affected community. Work with those affected by HCV invokes the question: is the need for expediency overriding that crucial principle? Some ASOs which have considered broadening their mandate have been told that this could put their HIV/AIDS-dedicated funding in jeopardy.

It is also clear that ASOs are, in many ways, ill-positioned to serve those mono-infected with HCV. Although there is some overlap in risk factors and vulnerable populations, the two diseases exhibit important differences<sup>33</sup> in both—requiring differing approaches to prevention, education, care and support. This has been a challenge not only in Canada but internationally. Australia, which is at least five years ahead of Canada, in the official review of its first Hepatitis C Strategy, determined that a more sophisticated approach is required—one which uses integrated approaches where effective but recognizes these important differences and allocates resources based upon these differences, measured outcomes and ongoing input from affected populations.<sup>34</sup>

In addition to the shortcomings experienced in developing an effective, sustainable community-based response, unfortunate challenges arose in other areas, particularly those involving Federal/Provincial/Territorial inter-jurisdictional issues. Despite some progress, there has not yet been full implementation of comprehensive and standardized data collection practices, with the result that, decades into this epidemic, large data gaps remain in areas such as the true incidence of new infections, risk factors and accurate cause of death reporting. There are serious concerns about the lack of long-range measures to address the acute shortage of expertise: at present, fewer than 50 hepatologists exist in Canada—hardly enough to cope with the oncoming Double Decade Demographic.

Moreover, the critical mass of expertise and infrastructure created by this five-year federal initiative risks being lost. Funding was scheduled to end in March 2004, but on the eve of the second Canadian Conference on Hepatitis C, Health Canada granted an 11th-hour, one-year funding extension. At that time, proposals were invited only from organizations that had been funded in the previous year.



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This effectively froze out most organizations, regardless of the importance or cost-effectiveness of their approach. Once again, there will be another one-year extension for 2005-06.

For its part, BC Hepatitis Services has done important work. However, more than two-thirds of its annual budget is spent on hepatitis A vaccinations, hepatitis B vaccinations for school children, diagnostic testing, surveillance and informatics—which, while beneficial to the province as a whole, does relatively little for 65,000 HCV-infected British Columbians. Without provincial funding, four out of B.C.'s five health regions have one or no funded community-based hepatitis C projects and there is an obvious need for improved linkages, collaboration and partnerships with the liver clinic pilot projects. A recent BCCDC review of BC Hepatitis Services-funded liver clinic projects suggests that barriers such as distance and stigma continue to impede service delivery, while burgeoning demand has barely been addressed: for example, the Liver Information and Treatment Clinic project in Kamloops receives far-flung patients who cannot sustain the four-year wait<sup>35</sup> for service from a small liver clinic in Kelowna General Hospital.

B.C.'s Public Health Units are commendably providing vaccinations for hepatitis A and B, some HCV education and referrals to related services, but member organizations of the BC Hepatitis Collaborative Circle observe that HCV testing services and follow-up for this reportable disease are not at all consistent throughout the province.

In the midst of inconsistency, uncertainty and unacceptably limited funding, HCV continues its silent advance—most alarmingly, among populations least equipped, in terms of other determinants of health, to cope. For example, infection rates among First Nations people have soared to 10 to 12 times the national average<sup>36</sup>.

The unfortunate result of all this is that B.C. remains under prepared for the costly Double Decade Demographic. It is against this backdrop that several approaches to disease management, each with implications for HCV, are being formulated or considered. We will briefly describe these in the following section.

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### 6

## Approaches under consideration or development

In January 2005, the **Health Canada/Canadian Institutes of Health Research (CIHR) Research Initiative on Hepatitis C** proposed a renewed national initiative on HCV.<sup>37</sup> It would use HCV as a demonstration project for a collaborative approach to infectious disease prevention and control under Canada's newly created Public Health Agency. It would create a national network of HCV Co-ordinating Centres or Alliances, comprised of existing organizations, programs and infrastructure, to establish collaborative interdisciplinary and interjurisdictional links between provincial, territorial and national stakeholders.

**BC Hepatitis Services** is currently refining a proposal for an expanded BC Hepatitis Program to provide centralized co-ordination for all aspects of diagnosis, clinical guideline development, treatment expertise, professional education, research and data collection in B.C. The Vancouver-based program would link to B.C.'s Centre for Excellence in HIV/AIDS, and complement HCV prevention and surveillance activities of the B.C. Centre for Disease Control. BC Hepatitis Services envisions a neat fit between the BC Hepatitis Program and the Health Canada/CIHR proposal above.

**B.C.'s Interior Health Region** will soon release a plan for management of communicable diseases. Although early planning focused on blood-borne pathogens, namely HIV/AIDS, HCV and HBV, there are indications that plan will be expanded to include tuberculosis and sexually transmitted infections. Some stakeholders<sup>38</sup> have already expressed concern that the obscure term "blood-borne pathogen" risks lowering the public profile of HCV even further, increasing confusion about what it is, and complicating delivery of public and patient education. Adding air-borne and sexually transmitted infections could compound those risks.

In March 2004, close to 40 **Canadian national level and community-based organizations**, including 12 who focus their activities in B.C., offered their *Rationale & Recommendations for a Canadian Hepatitis C Strategy*.<sup>39</sup> This document proposes a multi-leveled, interdisciplinary approach to HCV. It emphasizes capacity-building among CBOs, key roles for HCV affected people in

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the planning, delivery and evaluation of services, well-planned public awareness campaigns, expanded harm reduction initiatives, and augmented services for testing, treatment and addictions. The needs for strategic cross-sectoral linkages, enhanced training for health professionals, a comprehensive research agenda, alternative physician billing structures and investment in specialist expertise are also highlighted.

During the fall of 2004, the **BC Hepatitis C Collaborative Circle** brought together a broad range of stakeholders across the province, through a series of capacity-building meetings funded by the Public Health Agency of Canada and industry sources. The meetings, which were held in each of B.C.'s five health regions, produced a comprehensive inventory both of B.C.'s existing services and service gaps, with a view to informing the future planning and delivery of coordinated HCV care and services. Documents produced by these meetings have been posted on the Hepatitis C Council of B.C. web site, which also serves as a forum for province-wide communication about HCV.

In late 2003, the **B.C. Ministry of Health Planning** tabled a framework for a Provincial Chronic Disease Prevention Initiative.<sup>40</sup> This framework focuses on a set of diseases prioritized by B.C. physicians, which includes liver disease. However, apart from one reference to HCV as an example of a communicable disease that can become chronic, the framework gives HCV no further mention. It's not clear why this is, given HCV's commonalities with other prioritized diseases, for example: although the virus may be reduced to undetectable levels in some patients, HCV *is* undeniably chronic for most. It is preventable, and many chronic disease management strategies can be usefully applied to HCV.

Although the framework appears to omit HCV, its general approach has been endorsed by some stakeholders who took part in the regional strategy meetings facilitated by the BC Hepatitis C Collaborative Circle. They emphasize the potential utility for HCV of the disease-specific structured collaborative model, comparable to those recently initiated for heart disease and diabetes. This model utilizes practice guidelines, patient registries, performance measures, web-based and PDA technology, public/private partnerships, shared care models, professional development and self-management training for patients.

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### 7

## The opportunity

Facing a costly, oncoming Double Decade Demographic, B.C. has an opportunity and an obligation to develop a coordinated strategy to manage HCV. Each of the approaches above offers valuable elements, which ought to be carefully considered by all stakeholders.

The B.C. Hepatitis Collaborative Circle submits that any effective strategy, or combination of strategies, must also reflect B.C. values of compassion, equal opportunity, and equitable access to healthcare. Realizing these values requires clear commitment to the fundamental principle that all citizens deserve:

- > A reasonable level of funded services for HCV prevention, support and education, treatment and care, consistent throughout B.C.
- > Accurate, appropriately presented and readily available information about HCV.
- > Treatment and care for HCV in a respectful, confidential manner.
- > Treatment regimes which are supported by current best practices knowledge.
- > Meaningful input into the design, delivery and evaluation of programs meant to benefit them.
- > Recognition that addiction is a health issue, with implications for individuals, their families and communities.

British Columbians also recognize that the long-term viability of our healthcare system depends on careful management of healthcare resources today. For HCV epidemic management, this means:

- > A co-ordinated, multi-leveled approach which involves all levels of government, jurisdictions, academic disciplines and social sectors.
- > Building upon successful pre-existing infrastructure, such as regional hepatitis and liver clinics established by BC Hepatitis Services,

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community-based organizations, productive linkages between organizations such as the B.C. Centre for Excellence in HIV/AIDS, BC Hepatitis Program and universities.

- > Long-range planning to address B.C.'s scarce supply of and rising demand for hepatologists and other appropriately trained healthcare providers.
- > Significant utilization of proven means of reducing numbers of new HCV infections, multiple-genotype infections, and co-infection with HIV and/or HBV: obvious measures include harm-reduction initiatives such as needle exchanges and safe consumption sites.
- > Prevention, treatment and care regimes which consider and address all determinants of health for at-risk groups.
- > Concerted effort to address obstacles of stigma and lack of awareness around HCV, among the public, healthcare providers and HCV-positive people themselves.
- > Recognition that HCV can and should be incorporated into other disease management strategies where appropriate, but that its unique characteristics sometimes require an HCV-specific approach—and dedicated funding resources. For example, prevention efforts need to recognize and reflect the greater infectivity of HCV through blood and how this impacts on the need for greater availability of harm reduction materials and the need for innovative approaches to behavior change around sharing equipment and the initiation of inexperienced users. Treatment support and education are also areas where an HCV-specific approach is needed.

Cost-effective HCV management also demands expanded access to state-of-the-art drug therapy and treatment supports now, not only to reflect current best practices knowledge, but to avert downstream costs incurred by complications.

Consider end-stage liver disease (ESLD), an expected complication for up to 20% of untreated HCV patients. Each case of ESLD costs B.C. taxpayers about

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\$500,000 per person in direct healthcare costs alone; the lucky few who receive liver transplants incur another \$200,000 each, not including a lifetime supply of costly (\$10,000 to \$30,000 annually) anti-rejection drugs and the medications that deal with their side effects.

Treatment with pegylated interferon with ribavirin costs \$10,000 to \$20,000 per patient, and effectively cures more than 60% of those treated.<sup>41</sup> It's also frequently successful for people who have failed to respond to an older drug regimen (up to 40%) or who did respond, but later suffered a relapse (up to 70%). Even when drug treatment fails to eradicate the virus, it can slow, stabilize or improve fibrosis progression, and reduce risks of liver failure, liver cancer or the need for a liver transplant.

BC Hepatitis Services conservatively estimates that, if 500 patients are given this treatment, half will achieve a sustained viral response, in which the virus level has been reduced to undetectable levels. Even if 30% of those who don't experience a sustained viral response were to progress to ESKD, ESKD rates for the entire group will have dropped by one quarter. As a consequence, total downstream costs would be reduced by 40 per cent over not treating the group. For 500 treated patients, that represents a savings of \$30 million.

Additional supports can make treatment even more cost-effective. As noted in Section I, grueling side effects range from diarrhea, fever, rashes, hair loss, insomnia and nausea to potentially life threatening anemia, neutropenia, thrombocytopenia and depression. For at least one in five patients, these side effects are severe enough to cause withdrawal from drug therapy. With the availability of growth factors, anti-depressants, over-the-counter remedies and psychosocial supports, more patients complete treatment, however. According to BC Hepatitis Services, even if such supports were offered to 25% of 500 treated patients at a cost of \$10,000 each, treatment success rates overall would climb an additional 12%—resulting in a total healthcare savings of 51% over not treating.

This example underscores the need for:

- > Recognition that expanded access to state-of-the-art treatment and related supports today can realize significant cost savings tomorrow.

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An effective HCV strategy must also prioritize a tremendous, under-recognized asset: British Columbians affected by HCV. Each one is a crucial ally, better positioned than any service provider or health planner to advance prevention. Disenfranchised or ill-informed, the daily burdens of HCV-positive people can play out as high-risk behaviours—and new infections which sabotage epidemic management efforts. Their meaningful engagement in a broader effort is extremely valuable, as is their hard-won, collective knowledge about how to manage life with HCV.

When the HCV-affected community is viewed in this light, key strategic questions emerge: how can people be engaged in epidemic management? How might every HCV-positive individual, including those who are as yet are unaware of their status, be equipped and motivated to relay messages of prevention? How may their unique positions in, and intimate knowledge of, cultures and settings where HCV transmission occurs provide opportunities for public education, research and ongoing monitoring of program effectiveness? How may individuals with HCV be empowered to manage HCV more effectively, for themselves and each other, thereby helping to optimize precious healthcare resources?

The answer lies beyond treatment regimes, expanded liver clinics and research agendas. Although vital, these do not promote engagement in that broader effort. We must look instead to those best positioned, through geography, culture and trust, to cut through counterproductive stigma and strengthen links between HCV-affected people and epidemic managers: community-based organizations.

In addition to an unparalleled reach within target populations, these organizations can serve a vital role in the optimal use of healthcare resources. Armed with appropriate resources and accurate information, CBOs can meet patients' needs for basic treatment support and education more cost-effectively than health professionals can. By lightening the load on liver clinic nurses, specialists and primary care physicians, these organizations further enable healthcare professionals to do what no one else can: provide high-level medical care. By

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providing prevention education, co-ordination of community services, and peer support, CBOs help create healthier, more responsive communities, which reduce the burden of HCV on our health system as a whole.

For HCV management, this logically implies:

- > Recognition of the critical role of community-based organizations in epidemic management.
- > A focus on optimal utilization of HCV-related resources, through policies and programs which enable service providers to focus on what they are most economically positioned to do.
- > A well-designed research agenda with mechanisms for wide and timely dissemination of research findings, and active links between academia and community-based organizations for both collaboration and community-based research.



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## Conclusion & recommendations

British Columbia cannot afford to neglect or postpone an effective response to HCV: every five hours, another person in B.C. contracts this disease. Equally disturbing, many of these are young people. Quite apart from the toll this exacts in human potential, the medical cost from time of diagnosis to death, including economic loss for that individual, is estimated at \$1 million per patient<sup>42</sup>

The B.C. Hepatitis C Collaborative Circle firmly believes that working within a provincial framework presents the greatest opportunity for a coordinated approach that ensures uniformly high standards and equitable access. Informed by the considerations set out above, such an approach would include the following actions by government:

- 1 Develop a collaborative HCV, Co-infection and Liver Disease Treatment Program for B.C., situated within the Provincial Health Services Authority, involving BC Hepatitis Services, the BC Hepatitis Program, and the Centre of Excellence for HIV/AIDS, which both supports and is supported by regional hepatitis/liver clinics with links to community-based organizations. For an illustration of this model, see **Figure 1** (p26).
- 2 Identify and utilize means to integrate this program with HCV prevention, research, education, and support programs at the federal level.
- 3 Identify and implement links between this provincial HCV program and other relevant initiatives, such as the Canadian Strategy on HIV/AIDS, Canada's Drug Strategy, Four Pillars approaches and Aboriginal health initiatives.
- 4 Augment funding for existing hepatitis clinic pilot projects, and establish additional clinics throughout B.C.
- 5 Support and extend the effectiveness and work of this provincial body and its regional clinics with a province-wide network of community-based organizations, providing outreach, prevention, harm reduction, support and education services. Depending on the needs identified in

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each region, these services may be located both in larger communities where clinics are located and in more remote communities where needs for basic education and supports are even more pressing. For an illustration of how CBOs can support and extend the effectiveness of liver clinics, see **Figure 2** (p27).

- 6 Allocate resources to support the creation of this province-wide HCV network, comprised of community-based organizations and groups organized into local and regional networks, and fund opportunities for capacity-building among these organizations and communities.
- 7 Explore opportunities for interdisciplinary, multi-sectoral pilot projects which improve access to HCV treatment and support throughout B.C. and among diverse populations. Projects should emphasize solutions to barriers such as geographic location, confidentiality concerns and demands of travel on HCV patients with already compromised health.
- 8 Support and expand harm-reduction measures such as needle exchanges, peer-based outreach and education, safe-consumption sites, prescribed alternatives to street drugs, and other, lower risk drug delivery methods. Ensure availability of harm reduction measures for incarcerated individuals.
- 9 Address the lack of awareness and stigma around HCV, through targeted, culturally appropriate public awareness campaigns, developed with input from members of HCV-vulnerable populations.
- 10 In co-operation with the provinces, territories and the Government of Canada, standardize and enhance HCV surveillance and data collection.
- 11 Establish a centralized site for easy access to reliable and relevant HCV information.
- 12 Working with HCV stakeholders, identify gaps in HCV knowledge; develop and fund a research agenda that addresses these gaps.
- 13 Implement a comprehensive research agenda, with mechanisms for disseminating new knowledge about HCV to stakeholders throughout B.C. in a timely fashion and for strengthening productive links to community-based organizations.

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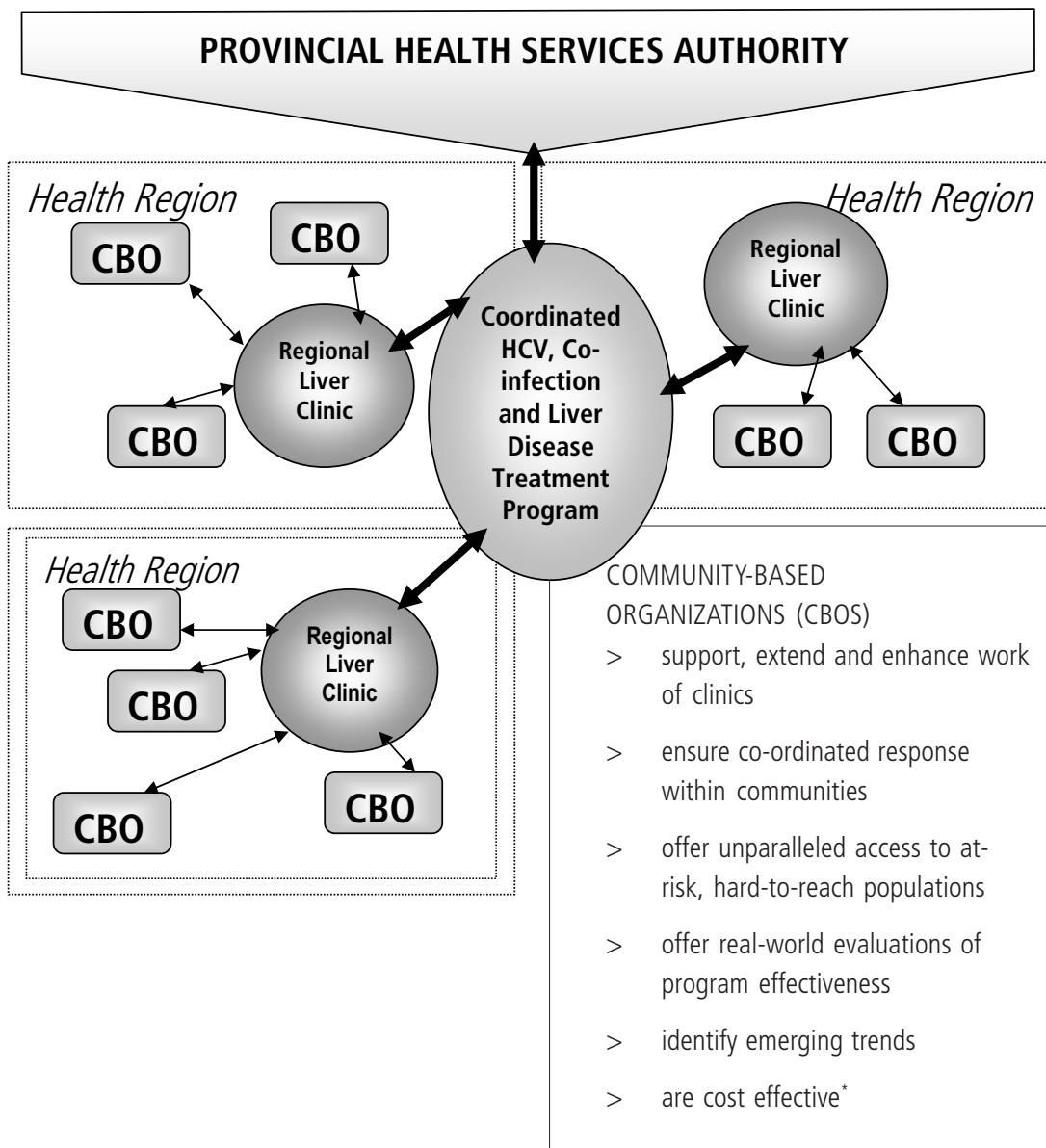


- 14 Develop and implement strategies to attract and train more hepatologists, primary care physicians and nurses with enhanced knowledge of HCV treatment issues. Continue to develop shared care and alternative billing models.
- 15 Update BC Pharmacare's drug treatment criteria, and implement mechanisms to ensure B.C. Pharmacare's drug treatment criteria are reviewed and updated regularly to reflect current knowledge about HCV.

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**Fig. 1: A Model For a Province-Wide Organization**



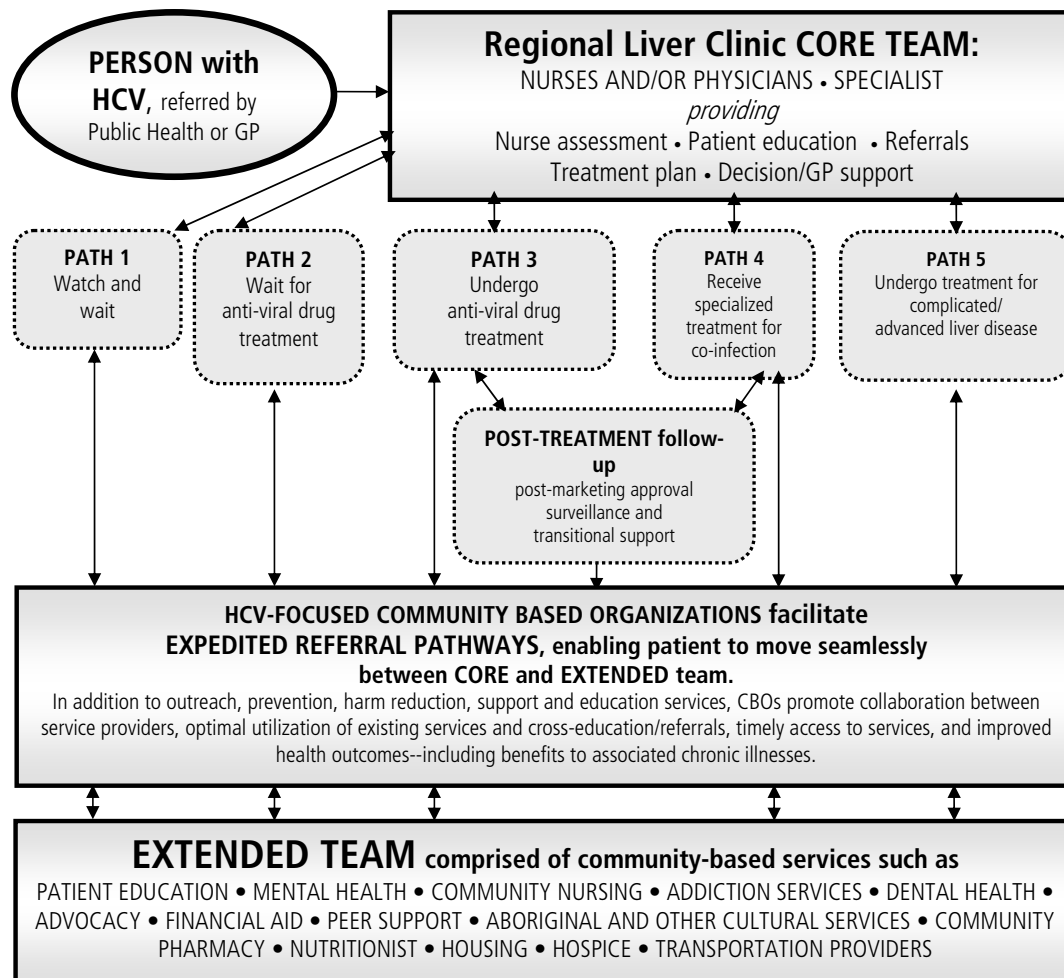
\* Note: endnotes dedicated to cost effectiveness can be referenced on p33 of this document.

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**Fig. 2: How CBOs Can Extend and Expand the Reach and Effectiveness of Regional Liver Clinics**

**Community-based organizations expedite referral pathways:** Capacity is developed in communities through the education of existing service providers about HCV, treatment issues, the roles that each can play within this extended team and the importance of timely access to these services, particularly during treatment. This collaborative, cross-educational process can not only increase the percentage of successful treatment outcomes as well as the health outcomes of HCV positive people not on treatment but it can also broaden awareness and cooperation among service providers and community groups on a range of challenges and determinants of health that affect the community as a whole.



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- > Public Health Agency of Canada Hepatitis C Fact Sheet, available at [http://www.phac-aspc.gc.ca/hcai-iamss/bbp-pts/hepatitis/hep\\_c\\_e.html](http://www.phac-aspc.gc.ca/hcai-iamss/bbp-pts/hepatitis/hep_c_e.html)
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## ENDNOTES

- <sup>1</sup> It is estimated that by 2030, hepatitis C will kill three times as many people in the United States as AIDS. Source: Internet Conference Reports. 54th Annual Meeting of the American Association for the Study of Liver Diseases. Oct. 24-28, 2003. Boston, MA. See also a *National Hepatitis C Strategy in Canada: A Discussion Paper*, prepared February 2004 by the Canadian AIDS Society.
- <sup>2</sup> World Health Organization, cited in "Scope of Worldwide Hepatitis C Problem," *Liver Transplantation*, Vol. 9, No. 11, Suppl. 3 November 2003: S10-S13. Robert S. Brown Jr. and Paul J. Gaglio.
- <sup>3</sup> Public Health Agency of Canada fact sheet, available at [http://www.phac-aspc.gc.ca/hcai-iamss/bbp-pts/hepatitis/hep\\_c\\_e.html](http://www.phac-aspc.gc.ca/hcai-iamss/bbp-pts/hepatitis/hep_c_e.html)
- <sup>4</sup> Bloodborne Pathogens Section, Blood Safety Surveillance and Health Care Acquired Infections Division, Health Canada 2003.
- <sup>5</sup> *A Study to Characterize the Epidemiology of Hepatitis C Infection in Canada, 2002*. Final Report. Prepared for Health Canada by R.S. Remis. 2004.
- <sup>6</sup> *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. 2005: 3.
- <sup>7</sup> *A Hepatitis Strategy for BC, Vancouver/Richmond Health Board, July 20, 1999*.
- <sup>8</sup> *The Hepatitis C Epidemic: Looking At The Tip Of The Iceberg* by Sherrie Dulworth, Sunit Patel, and Bruce S. Pyenson, New York: Milliman & Robertson, Inc. 2000.
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- <sup>12</sup> 2003 British Columbia Annual Summary of Reportable Diseases, BC Centre for Disease Control
- <sup>13</sup> See [http://www.decisionresources.com/stellent/groups/public/documents/abstract/dr\\_006568.hcsp](http://www.decisionresources.com/stellent/groups/public/documents/abstract/dr_006568.hcsp)
- <sup>14</sup> Epidemiology of Hepatitis C in Canada, Bruce Gamage, RN, BCCDC, [www.cna-nurses.ca/CNA/documents/pdf/publications/Hep\\_C\\_epidemiology\\_e.pdf](http://www.cna-nurses.ca/CNA/documents/pdf/publications/Hep_C_epidemiology_e.pdf)
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- <sup>16</sup> Diagnosis and Management of Hepatitis C, [http://www.medscape.com/viewprogram/712\\_pnt](http://www.medscape.com/viewprogram/712_pnt)
- <sup>17</sup> Ensuring Excellence: Renewing BC's Primary Care System, A Discussion Paper by BC's Physicians, September 2002



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- <sup>18</sup> At present, B.C. offers drug treatment to less than 2% of HCV-infected patients annually. If more patients knew of their status, service wait times were reduced and BC Pharmacare guidelines accurately reflected current research findings, drug treatment would be offered more widely—to up to 30% of those with HCV.
- <sup>19</sup> These criteria are based on standards established by the Canadian Association for the Study of the Liver in 1999. They have been overturned by 2003/04 CASL guidelines which recommend that HCV patients be considered for drug treatment even if they do not meet the above criteria. These newer guidelines are based on recent research that suggests that: A) patients with mild liver disease show the best response to drug therapy, B) ALTs are not a conclusive measure of whether patients have progressed to fibrosis, which requires treatment, C) Up to 70% of people whose virus reappears after treatment with an older regimen show success with a second round of state-of-the art drug therapy; and re-treatment for those who failed to respond to older drug regimens show success rates of up to 40%, D) Patient's age, use of alcohol, injection or intranasal drugs should be considered therapy management challenges which should more appropriately be considered management challenges by physicians in conjunction with their patients.
- <sup>20</sup> There have been reports to CBOs that some patients, desperate for drug therapy, risk liver degeneration by consciously using alcohol to elevate liver enzyme levels to meet Pharmacare-imposed treatment criteria.
- <sup>21</sup> Bica I, McGovern B, Dhar R, et al Increasing mortality due to end-stage liver disease in patients with human immunodeficiency virus infection , *Clinical Infectious Diseases* 2001;32:492-497
- <sup>22</sup> Source: <http://www.cdc.gov/ncidod/diseases/hepatitis/c/faq.htm#2b>
- <sup>23</sup> Heintges, T. & Wands, J.R. (1997). Hepatitis C virus: epidemiology and transmission. *Hepatology*, 26, 521-526
- <sup>24</sup> *Reducing the harm associated with injection drug use in Canada*. Federal/Provincial/Territorial Advisory Committee on Population Health (2001). Ottawa: Health Canada.
- <sup>25</sup> See [http://www.phac-aspc.gc.ca/hepc/hepatitis\\_c/aboutfacts.html](http://www.phac-aspc.gc.ca/hepc/hepatitis_c/aboutfacts.html). It should be noted that this has important implications for health of infected individuals as well, in that later detection raises risks of fibrosis progression.
- <sup>26</sup> This was known as the Health Canada Hepatitis C Prevention, Support and Research Program.
- <sup>27</sup> Hepatitis & Liver Clinics were given \$25,000 in start-up funding and \$75,000 annually.
- <sup>28</sup> These organizations combined received a total of \$367,000 from Health Canada.
- <sup>29</sup> Two other organizations also received some funding late in the year.
- <sup>30</sup> A National Hepatitis C Strategy in Canada, A Discussion Paper. Canadian AIDS Society, Feb. 2004. This figure was calculated based on \$3.6 million annual funding for Community-Based Support at the height of the federal Hepatitis C Prevention, Support and Research Program. If it were to be calculated based upon the allocation for the BC region at the height of the program, the amount would drop to \$9.00 per infected British Columbian, per year. . See [http://www.bccdc.org/hepatitis/community/HealthCanadaHepC\\_CommSupport.shtml](http://www.bccdc.org/hepatitis/community/HealthCanadaHepC_CommSupport.shtml) This per-capita amount does not include those who are at risk of contracting HCV; if it did, this sum would plunge still further
- <sup>31</sup> See Figure 2, Community-based programs at [http://www.phac-aspc.gc.ca/aids-sida/hiv\\_aids/federal\\_initiative/initiative/fi/3\\_e.html](http://www.phac-aspc.gc.ca/aids-sida/hiv_aids/federal_initiative/initiative/fi/3_e.html)

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- <sup>32</sup> *A National Hepatitis C Strategy in Canada –A Discussion Paper*, prepared February 2004 by the Canadian AIDS Society.
- <sup>33</sup> For example, HCV is 10 to 15 times more infectious through blood-to-blood contact than is HIV. While HCV can be transmitted sexually where blood-to-blood contact may occur, this mode of transmission is uncommon—unlike HIV. HCV is also characterized by several different genotypes, some of which are more treatable or serious than others. It is possible to get more than one. Immigrant populations who hail from parts of the world where HCV is endemic are particularly vulnerable.
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## NOTES ON THE COST EFFECTIVENESS OF THE COUNCIL'S PROPOSED APPROACH

- 1 Five years after the Canadian Centre on Substance Abuse (CCSA) reported in 'Resources for Hepatitis C: A Needs Assessment', that Canadian literature on cost-effectiveness and many other related topics was 'quite scanty', it appears that this is an area still in need of attention. However, research in other countries and evaluations of similar approaches for HIV provide compelling evidence for the cost-effectiveness of community-based and peer provided outreach, prevention, harm reduction, education, counselling and support services. Some examples are below.
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- 7 The impact results of a peer-driven intervention to combat HIV among drug injectors. Broadhead R et al., XII International Conference on AIDS, Geneva, 1998.



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