

**Rationale and Recommendations
for a
Canadian Hepatitis C Strategy**

2004

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Preface

This document is the result of consultation and collaboration among community-based organizations across Canada during 2003-2004. These organizations face the challenges of hepatitis C on a daily basis.

The undersigned agree that urgent, immediate action is needed and it must be part of a comprehensive, multi-year, national Strategy coordinated and led by strong federal action. Without such a Strategy, their ability to continue to work in this field and to mitigate the grave consequences of this epidemic is severely threatened.

(Insert names/organizations here)

The full document can be accessed at:

Canadian Hemophilia Society, <http://www.hemophilia.ca>

Canadian Hepatitis C Network, <http://www.canhepc.net>

Hepatitis C Society of Canada, <http://www.hepatitiscsociety.com>

Rationale and Recommendations

for a

CANADIAN HEPATITIS C STRATEGY

Executive Summary

The proposed Canadian Hepatitis C Strategy is based on the premise that hepatitis C is treatable, the transmission of the virus is largely known, and the number of new infections can be minimized. The objectives of the proposed strategy are to:

- Reduce new cases of hepatitis C to near zero.
- Clear the virus among those infected.
- Reduce impacts among those infected.
- Address the social and economic conditions that affect prevention and treatment.
- Integrate hepatitis C programs with other public health initiatives, where appropriate and effective.

Between 1960 and 1992, up to 160,000 Canadians were infected with hepatitis C through blood or blood products.¹ Currently about 250,000 Canadians are infected with hepatitis C, and an estimated 5,000 to 8,000 more are infected every year.²

The majority of new infections are due to the sharing of injection drug equipment, however, up to 40% of new infections are caused by other risk factors.³

Treatment is Cost-Effective

According to the Canadian Institutes of Health Research, hepatitis C costs the Canadian healthcare system about \$500 million, annually. This figure is estimated to double to \$1 billion by 2008 and may skyrocket to \$3.2 billion annually by 2021. These costs could be reduced to just a fraction with appropriate treatment. Hepatitis C can be successfully treated with the new therapy combination of pegylated interferon and ribavirin. Overall, approximately 55% of patients achieve a sustained viral response (SVR), that is, the virus is reduced to undetectable levels and, in most cases, is unlikely to return.⁴ A significant minority experiences the added benefit of reversing liver damage; those who are treated and do not clear the virus may minimize liver damage until more effective treatments are available.

Early detection and treatment are associated with better treatment outcomes. However, only one- to two-thirds of infected Canadians have been diagnosed. An additional barrier has been the requirement in some provinces that treatment is available only if patients have elevated liver enzyme levels and have never been treated before. Studies have shown that a significant number of patients can have advanced liver disease without elevated liver enzyme levels.^{5, 6} The newer 'pegylated' formulations are showing efficacy in patients for whom the older treatment has failed yet they are being denied access to potentially lifesaving medications.⁷

Approximately 20%, or 50,000 Canadians, either now have or will soon develop the most serious consequences of HCV infection; cirrhosis (scarring of the liver), liver failure and hepatocellular carcinoma (liver cancer).⁸ Treatment and medical care then becomes much more difficult and expensive. The experience of end stage liver disease is not a pleasant one. The abdomen and lower extremities can become painfully distended with fluid susceptible to spontaneous infection. Breathing can become difficult. The liver cannot filter toxins and blood flow is blocked by scar tissue. Veins in the throat can suddenly burst, causing potentially fatal, uncontrolled bleeding. Confusion, aggression, and finally, irreversible coma results. The number of people affected will place a substantial burden on the healthcare system and may even negatively impact access to care for patients with non-HCV related illness.

By 2008 current Canadian cases of hepatitis C will result in a 92% increase in cirrhosis, decompensated cirrhosis will increase by 126%, the number of patients requiring liver transplantation will rise by 246%, and hepatocellular carcinoma (HCC) will increase by 102%.⁹ While it is difficult to find specific Canadian death statistics, in the United States, between 1993 and 1998, hepatitis C-related deaths increased by 220%.¹⁰ That trend is expected to increase further.

Treatment is cost effective. Every \$1 spent on HCV combination therapy can result in medical cost savings of about \$4.¹¹ Even when the percentage of those who do not clear the virus is taken into consideration, the investment in treating every eligible patient would be repaid in ten years. Moreover, the savings in associated disability loss could be as high as \$400 million.

Problems with Current Hepatitis C Approaches

In 1998, the Canadian government set up a five-year \$50 million Hepatitis C Prevention, Support and Research Program, which has allowed for important first steps and pilot projects. However, there has been a lack of an overall strategy, coordinated surveillance, and coordination of services across the different levels of government and within healthcare districts.

The effectiveness of surveillance to predict and monitor the spread of disease has been limited by the lack of baseline data, the lack of pro-active testing of at-risk populations, and the lack of a national database that links public health information with treatment and other health-related data. The undercounting of deaths attributable to hepatitis C, for example, is due to the lack of consistent reporting criteria.

Similarly, the lack of research into routes of transmission has hampered appropriate interventions with specific populations such as injection drug users, Aboriginal people, youth, and incarcerated persons. Hepatitis C-specific projects have not been linked to other databases or epidemiological studies, and this has limited understanding of their effectiveness and impact on reducing new infections and improving disease outcomes.

To date, effective prevention and support for essential care and treatment have been hampered by the lack of large-scale, coordinated, sustained, public awareness campaigns and the general lack of public support for programs serving people with mental illness, substance users, prison populations, and other stigmatized individuals.

Without adequately funded treatment and support programs, treatment is inaccessible to many people. Medication for the 48-week treatment program is expensive and causes significant side effects such as depression, anemia, autoimmune disorders and susceptibility to infections. Without adequate medical, psychosocial, and essential living support (housing and nutrition), many people would not be able to complete this arduous regimen. Issues of stigmatization, discrimination and lack of peer support create additional barriers to accessing and successfully

completing treatment, especially among street-involved youth, those in prisons or other custodial settings, rural communities, and Aboriginal communities. Community-based organizations, which provide these valuable, cost-effective services, have been hampered by grossly inadequate funding, lack of capacity-building resources and uncertainty about future directions.

Recommendations for Canadian Hepatitis C Strategy

Prevention

Programs to reduce risks of HCV transmission should build upon the harm reduction and prevention programs that exist federally, provincially, and locally to address HIV transmission, other blood borne diseases, and other infectious diseases. Increased support for needle exchange programs and safe injection sites that are accessible and “user-friendly” are a first line of action.

It is important to remember that people who use injection drugs are not a homogeneous group nor do they all fit the usual urban stereotype. Many have jobs and families, a significant number live in smaller communities. Injection drug use is often transitory or experimental. It needn't be an inadvertent death sentence. The shorter ‘window of opportunity’ for preventing HCV infection, due to its high infectivity, will require concentrated and innovative approaches.

Equally important is treatment for drug dependency with a range of options that are readily available across the country, including withdrawal management (detox), treatment on demand, methadone programs, outpatient and peer-based counseling, daytime and residential treatment, and other support services.

At least 50% of the prison population is at risk for hepatitis C as a result of drug use.¹² Needle and syringe programs, treatment for drug dependency, confidential testing, counseling and treatment services within the prison system are essential. Access to sterilized tattoo and piercing equipment is also recommended.

While transmission of hepatitis C through blood and blood products, person-to-person transmission in healthcare settings, and exposure through accidental needle stick are all very low, education and adherence to infection control, standard precautions and follow-up on occupational exposure are very important to minimize risk.

Similarly, transmission between sexual partners is very low but it is important promote awareness of guidelines on “safer sex” practices (use of condoms and dental dams) and other standard precautionary practices such as not sharing toothbrushes, razors or nail care equipment. In addition to minimizing the risk of HCV transmission, it is important to protect those who are HCV positive from dangerous co-infections.

There is currently no drug to reduce the risk of transmission from mother to child. The best options are education to promote healthy pregnancy, testing during the child's first two years, and supportive care. More knowledge is needed about the mechanisms of viral clearance in children, breastfeeding, vertical transmission and the treatment of children with rapidly progressing HCV infection.

We must provide HCV-specific school-based curricula, as well as prevention education targeted for street-involved, drug using, or incarcerated youth. There must be education on safer tattooing/piercing, drug use (including steroids) and harm reduction techniques, including refusal/negotiation skills, as well as initiatives to encourage youths to be tested for HCV status and learning about access to treatment options. Finally, broad-based prevention campaigns for HCV must include youth, and these must take place in conjunction with campaigns through venues and approaches that are specific to youth.

Public Awareness

Sustained public awareness campaigns directed to the general public as well as targeted messages to persons who may have had previous exposure to HCV or who are currently at increased risk are needed. These include those who may have received blood products prior to HCV screening, past injection or intranasal drug users, and those who have received tattoos or body piercings.

These must take into consideration difficult-to-reach populations such as those in rural areas, those with low literacy, and those of varied cultural and language backgrounds. They must accommodate the stigma around hepatitis C and its association with drug use and alcohol abuse (liver damage, particularly cirrhosis, is often solely equated with alcohol abuse).

Finally, education should be developed in collaboration with those in the target communities, including drug users and at-risk youth.

Care and Treatment Support

There must be a full spectrum of health promotion initiatives and healthcare services accessible to persons with hepatitis C that proceeds seamlessly from diagnostic testing to specialist care in a comprehensive care setting to extended care in the community (family practice, mental health services, social support and hospice). Healthcare includes access to treatment and related supportive services.

Currently there are only about 40 hepatologists to treat nearly a quarter of a million HCV patients in Canada. The solution is multifaceted, including training for specialists, the education and inclusion of other healthcare professionals (e.g., nurse practitioners and general practitioners) as part of the clinic care team, and linkages to family physicians to support management of the patient before, during, and following anti-viral treatment.

There are a number of excellent clinic programs that can serve as models for developing a network of Hepatitis C Comprehensive Care Clinics that would adhere to standards of care based on evidence and expert consensus and assure that each patient has a managed care plan and access to a full complement of treatment and care services.

Finally, there is a need to provide services for those not considered eligible for drug treatment and those who choose not to treat with medication.

Community-Based Support

Community-based peer support networks connected to and providing services to the local community are an essential, effective, and cost-effective component of prevention and care and treatment programs. Staffed by peer counselors, educators and volunteers who come from the target community, these groups can serve as the point of entry into harm reduction, diagnostic, and treatment programs. These groups have an unparalleled understanding of their community's culture and ability to reach 'hidden populations' of infected persons and those at risk.

Community-based organizations can play a key role in mobilizing, educating and coordinating a community-wide response that improves health outcomes and treatment responses. For example, up to 20% of patients experience treatment failures due to discontinuation because of side effects.¹³ Assisting just 50 patients to successfully complete treatment could result in over \$1million saved in medication costs, alone. Community-based activities that prevent new

infections can be even more cost-effective. Resources, training, and support are needed to assure that these organizations are able to do this important work and are connected to one another and to other services in their communities.

Many Aboriginal communities have HCV infection rates several times the national average. The current tendency to ‘silo’ funding allocations and program responsibilities has led to inequities in access to treatment, care and support. There is a pressing need to find avenues of collaboration and cooperation so that Aboriginal people living both on-reserve and off reserve benefit equitably, while respecting cultural and autonomy issues.

Research

The recommendations for a comprehensive research strategy are taken from the Recommendations on the Renewal of the Health Canada/CIHR Research Initiative on Hepatitis C put forth by the Joint Advisory Committee of the Health Canada/CIHR Research Initiative on Hepatitis C.

We support the development of a National Hepatitis C Prevention/Care Research Outcomes Network (HCV-PRO-NET) to guide prevention and care best practices. This network will be used to develop and evaluate innovative prevention, care and treatment strategies for at-risk populations (e.g., aboriginal peoples, substance users, incarcerated individuals), HIV co-infected individuals, infants and children, and promote vaccination against hepatitis A and B viruses among hepatitis C infected persons. This network will also support community-based research.

The ultimate goal of the HCV-PRO-NET will be to serve as a knowledge broker between researchers, policy makers, healthcare providers and community to translate prevention, care and treatment knowledge into clinical practice.

(A listing of all recommendations can be found on page 47)

Linkage to Other Strategies and Programs

While a comprehensive Hepatitis C Strategy must be linked to other public health and infectious disease strategies to assure effectiveness and cost-effectiveness, it cannot be subsumed within other strategies because of the epidemic’s unique qualities and enormous potential impact on the health of Canadians. By 2030, in the United States, it is estimated that hepatitis C will kill three times as many people as AIDS.¹⁴ Canada faces a similar scenario if concerted action is not taken.

Why does Canada need a Hepatitis C Strategy?

Approximately one quarter of a million Canadians are infected with hepatitis C, and an estimated 5,000-8,000 more Canadians are infected every year. The good news is that Canada has never been in a better position to control the spread of hepatitis C. Unlike cancer, diabetes, or hypertension, hepatitis C is not a disease whose incidence increases as a result of aging. Unlike influenza or SARS, it is not spread through casual contact; transmission is limited almost exclusively to blood. Compared to HIV and hepatitis B, the risk of sexual transmission is low. While the incidence continues to be high, the majority of new cases can be traced to a few primary causes, which can be addressed by a sustained community effort in conjunction with

other public health initiatives. Also, in contrast to many other chronic diseases, with new treatments and appropriate support, the hepatitis C virus can be reduced to undetectable levels in a significant number of those already infected. The time is now for Canada to invest in an aggressive national hepatitis C strategy.

The proposed Canadian Hepatitis C Strategy is achievable and the goals to reduce new cases and treat those currently infected are realistic. Those at risk are those who have direct blood-to-blood contact with those already infected. The first step is to identify and treat those who are already infected. Between 50 and 80% of those treated (depending on HCV genotype), will clear the virus and will no longer be able to infect others. Second, we must invest in harm reduction programs, such as needle exchange, education, and standard precautions, to reduce the likelihood of the virus being transmitted from one individual to another. Third, by providing education and support, we can ensure that people stay as healthy as possible until more effective treatments become available. In order to succeed we need to invest in the economic and social supports necessary for the success of the steps 1,2 and 3. Investing strategically in research is also a key component to success in each of these areas.

The federal government must assume a leadership role. Disparities exist provincially in many areas, such as prevention and access to treatment. In all jurisdictions, there are multiple communities of stigmatized and marginalized people living with or vulnerable to HCV infection. Public awareness, risk reduction, community-based support and education, and research are all areas that will benefit from a coordinated national response.

Certain populations and responsibilities are clearly under federal jurisdiction or fall within existing areas of federal policy, notably: prison populations, First Nations, Metis and Inuit peoples, immigration, international development, federal disability and human rights protection, approval of clinical trials and the medicines generated by clinical research, and research funded through the Canadian Institutes of Health Research.

There are many areas where a range of actions, objectives and strategies are required. Take for instance the fact that there are only about 40 hepatologists in the country. It takes years to train a hepatologist and the shortage of such specialists will not be solved overnight – this is a long-term problem. There needs to be immediate short-term responses to this shortage, intermediate longer-term objectives and strategies, as well as long-term solutions.

Effective prevention requires not only access to safe equipment but education and behaviour change. Modifying behaviour requires sustained, on-going support that reinvents itself with each succeeding generation. Effective prevention efforts adapt to deal with issues such as ‘prevention fatigue’ and continually innovate in order to reach the most vulnerable segments of society while maintaining and building upon those approaches that prove successful. This requires local action, often in a face-to-face setting, peer empowerment, and creative social marketing that is devised in close collaboration with people in vulnerable and affected communities. Hence, the need for a coordinated nation-wide, long-term hepatitis C strategy

Work on HCV is still very much at the beginning stages in this country and a structured framework is needed in the diverse fields of public health, direct community support, prevention, care & treatment support, and research, for the documentation and sharing of information, best practices, evidence-based outcomes and evaluated results across jurisdictional boundaries.

These jurisdictional boundaries are not only within Canada but extend to the international community as well. Canada is one of the few countries poised to assume an international leadership role and reputation for excellence in dealing effectively with hepatitis C. Canada’s expertise in this field can contribute significantly to HCV responses worldwide- particularly in developing countries where the impact is expected to be particularly devastating.

Canada must make a commitment to act now. As a result of the first five-year federal program on hepatitis C, we have made important advances but the program ends on March 31, 2004. Already, many organizations, whose funding ended in 2003, have had to close their doors or drastically reduce services. After doing all they can to meet the demand for services and submitting dozens of grant applications, they have learned the painful lesson that hepatitis C, because of low awareness levels, is not a priority for private funders, particularly without partnership from government. Now, we risk even further loss of accumulated community expertise.

The federal government must immediately commit to sustained funding at a substantially increased level, in order to meet the challenges that the disease presents today and those it will increasingly present in the years to come.

Required Resources

Program	Annual amount	Five Year Total
Interdisciplinary research -CIHR	\$5.0 million	\$25 million
National Hepatitis C Prevention/Care Research Outcomes Network (HCV-PRO-NET)	\$4.0 million	\$20 million
Disease Prevention*	\$5.0 M	\$25.0 M
Community-Based Support and Education**	\$18.0 M	\$90.0 M
Community Capacity Building***	\$5.0 M	\$25.0M
Care and Treatment Support	\$8.5 M	\$42.5 M
Program Management	\$4.5 M	\$22.5 M
Annual Totals	\$50.0 M	\$250.0 M (five years)

*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.

**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.

***It is important to structure the funding so that organizations involved in community capacity-building during the first two years have the funding available to transition into Community-Based Support and Education project funding in subsequent years.

Background

How Widespread is Hepatitis C?

Worldwide, over 170 million people are infected with the hepatitis C virus (HCV) and up to 4 million new infections occur each year¹⁵ but this epidemic that has only recently been recognized as a major public health threat. In Canada, HCV is the most frequently reported viral infection in the National Reportable Disease Surveillance System.¹⁶ During 2001 and 2002 there were approximately 16,000 cases reported each year. The official estimate is that approximately 0.8% of the population is now infected. Approximately 5,000 new infections are believed to occur each year, although the incidence could be as high as 8,000.

However, awareness among both the general population and those at highest risk remains low and, shows signs of declining. In two national surveys commissioned by the Health Canada Hepatitis C Prevention Program in 1999 and again in 2001, Canadians' self-reported knowledge of hepatitis C decreased considerably between 1999 and 2001.¹⁷

Estimates of the percentage of those currently infected who have been diagnosed, range from 30%¹⁸ to 70%. Either way, there are a significant number of Canadians who are unaware of their status and their potential risk to others. These estimates are extrapolated from epidemiological data and several features of the disease suggest that these figures considerably under-represent the true incidence and prevalence. First, many people when initially infected experience no symptoms or only nonspecific systems, such as general fatigue and weakness, which may be discounted or misdiagnosed. Second, some people, perhaps up to 20%, will clear the virus with no treatment required; however, spontaneous clearance is unlikely for those who are still HCV-positive after six months. Third, the period from time of infection to symptomatic hepatitis C can be very long, as long as 20 to 30 years, so many infected in the late 1970's and early 1980's are only now being identified. According to one recent study, 20% of patients are not diagnosed until cirrhosis occurs, which severely limits treatment options and success.¹⁹

How Serious is Hepatitis C?

Hepatitis C is a serious viral infection that can destroy the liver through a combination of viral activity and the body's immune response. In the absence of complicating factors, this process can take many years. The liver's ability to regenerate and its absence of pain receptors are part of what makes hepatitis C a 'silent epidemic', often progressing without well-defined symptoms until the disease has become life threatening. Over time, the accumulation of cellular damage and scar tissue can overwhelm the liver's regenerative capacity and ability to function properly.

The liver performs over 500 important biochemical functions and is essential to life. Hepatitis C is 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. In attempting to destroy a constantly mutating virus, the body's immune system can become disordered and attack healthy cells and tissue.

In approximately 20% of cases, chronic hepatitis C leads to cirrhosis (scarring of the liver), liver failure, or hepatocellular carcinoma (liver cancer). In Canada, this means that over 50,000 people either now have, or will soon develop these grave conditions.

Clinical data show that, even before the onset of cirrhosis, some people experience symptoms and deteriorating medical conditions related to HCV infection. Debilitating fatigue and chronic pain are daily challenges for many people with hepatitis C.

In the absence of effective treatment, the impact of hepatitis C will place considerable strain on the healthcare system. By 2008 current Canadian cases of hepatitis C will result in a 92% increase in cirrhosis, decompensated cirrhosis will increase by 126%, the number of patients requiring liver transplantation will rise by 246%, and hepatocellular carcinoma (HCC) will increase by 102%.²⁰

Hepatocellular carcinoma (HCC) is on the rise in North America primarily as a result of increases in hepatitis B and hepatitis C infections. Worldwide, there are over 1 million new cases of HCC annually and it is the third most common cause of cancer death. In the U.S., it is estimated that more than 17,000 people are diagnosed with HCC annually. Hepatocellular carcinoma is a particularly aggressive cancer with a six-month survival rate from time of diagnosis of only 50%, a one-year survival rate of 24% and a five-year survival rate of less than 5%.

The rate of disease progression in chronic hepatitis C is variable. The risk of cirrhosis appears to be at least 20% within 20 years and may approach 30% within 30 years.²¹ There is no correlation with ALT (alanine aminotransferase) levels, viral load, or HCV genotype. However, later age at infection, alcohol consumption, fatty liver, obesity, male gender, increased liver iron, and co-infection with HIV and hepatitis B, have been associated with more rapid disease progression.²²

Early detection and treatment are associated with better treatment outcomes; however, there are several important barriers to Canadian patients receiving appropriate treatment. First, the criteria to access treatment under some provincial formularies require that the patient demonstrate elevated ALT levels, despite the fact that treatment guidelines dispute the usefulness and accuracy of ALT levels as a basis for determining disease progression.

Second, while the combination of pegylated interferon and ribavirin is recognized as the 'gold standard' for HCV treatment, patients for whom the older therapies have failed are deemed ineligible. The consequence is that their disease can continue to progress to liver failure when the only option becomes a transplant, if available.

How is Hepatitis C Spread?

Between 1960 and 1992, an estimated 90,000 to 160,000 Canadians were infected with hepatitis C through infected blood or blood products.²³ Currently, the sharing of injection drug equipment accounts for the majority of new infections, although up to 40% of new infections are attributed to other routes of transmission, some of which are not well understood.

Even using the same surface to prepare an injection may pose a risk. The virus can remain infective on environmental surfaces at room temperature for between 16 hours and 4 days.²⁴ Compared to HIV, HCV is 10 to 15 times more highly transmissible by blood.²⁵ Harm reduction measures such as needle exchange/distribution programs have had a demonstrated impact on the spread of HIV; however, more intensive efforts will likely be required to effectively reduce the transmission of HCV. Sharing needles, syringes, swabs, filters, spoons, tourniquets and water for injection drug use are all risks for transmission.

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

<i>Risk factor</i>	<i>%</i>
<i>Injection Drug Use</i>	60.6
<i>Unknown</i>	13.3
<i>Others</i> <i>(Includes drug snorting, blood contact, hepatitis C carrier in family*, institution associated, and incarceration)</i>	12.8
<i>Health Care Acquired</i> <i>(Includes transfusion, blood product, haemodialysis, hospitalization, history of surgery, organ transplant, history of dental visit)</i>	6.4
<i>Other Subcutaneous**</i> <i>(Includes tattooing, body piercing, acupuncture)</i>	3.7
<i>Sexual</i>	3.2

Source: Enhanced Hepatitis Surveillance System, Health Canada

*may include shared razors and toothbrushes

**some nail care practices carry a risk of blood to blood transmission

Unsafe Drug Practices

Research has shown high rates of HCV among short-term users of injection drugs who share drug-injecting equipment.^{26 27} Approximately 60% of injection drug users carry the hepatitis C virus, with estimates in some cities ranging as high as 90%. Measures that have shown success in reducing HIV infection have not had the same impact on HCV infections, in part, because of the hardiness and greater infectivity of the hepatitis C virus through blood. However, investment in harm reduction education, needle exchange and safe injection sites continue to be the most effective strategies for reducing risk.

In addition, 29.4% of young steroid users, or approximately 25,000 Canadians, report injection use.²⁸ Currently there are no prevention campaigns targeting these youth.

In Canadian penal institutions, up to 40% of incarcerated individuals have hepatitis C,²⁹ often as a result of shared injection equipment. A significant number began injection drug use for the first time while in prison. The stressful living conditions and lack of access to adequate healthcare and harm reduction measures, along with issues of availability and a greater ease of avoiding chemical detection by using injectable drugs that degrade relatively quickly rather than drugs such as marijuana, which remain in the body longer, are all factors in commencing injection drug use in prison.³⁰ Other possible routes of hepatitis C transmission in prisons include the mandated sharing of personal hygiene materials (nail clippers, razors) amongst prisoners.

Finally, the sharing of crack pipes has been implicated as a possible source of transmission due to the heat of the pipe causing cracked and bleeding lips, in addition to a tendency for dehydration among users. The potential for transmission also exists when drug-snorting equipment is shared.

Hospital Acquired Infection

Person-to-person transmission of hepatitis C via contaminated equipment has occurred when there has been a breakdown in infection control procedures, for example, the use of multidose vials, contagion following colonoscopy and contact with contaminated anaesthetic equipment. Significant numbers of transmissions have also been reported among patients in renal dialysis units.

Skin piercing and tattooing

Tattooing and piercing practices carry a potential risk for transmission if contaminated inks and equipment are used. Although some provinces have guidelines for sterilizing equipment and safe practice, there appears to be no enforcement and no national standards. The practice of amateur tattooing and piercing is a particularly high risk for HCV transmission among youths and those in correctional institutions.

Vertical transmission

Approximately 2700 HCV positive Canadian women give birth annually. Vertical transmission from mother to child carries an estimated risk of 5 to 10%. If the mother is co-infected with HIV, the risk of HCV transmission increases by up to 60%. Because the incidence of new infections is rising most rapidly in those 20 to 45 years old, HCV infection will occur more commonly in women of childbearing years.³¹

Unlike HIV, there are currently no drugs that can be offered to reduce the risk of mother to infant transmission of hepatitis C. While HCV has been found in breast milk, women are generally not counseled to abstain from breastfeeding unless the nipples are cracked or bleeding.

The natural history and clinical significance of hepatitis C in children is variable and poorly defined. Little research has been conducted on treating children.

Sexual transmission

The risk of HCV sexual transmission is considered to be fairly low, although there is some controversy due to study limitations such as small sample sizes, exclusion of non-sexual routes and failure to test for genotype discordance among partners, which has sometimes suggested source/routes of infection other than sexual transmission. Further research is needed to answer important questions, such as: are certain types of sexual contact more likely to transmit HCV than others? Is gender related to susceptibility to HCV transmission? Does age impact one's likelihood of contracting HCV?

The HCV Partners Study³² shows a sexual transmission rate of 2.2% among monogamous heterosexual couples. The majority of couples infected with the same HCV genotype had no other significant risk factors for transmission, suggesting sexual activity may be the route of transmission but further DNA analysis of viral strains will ultimately determine whether sexual transmission occurred.

There is some evidence that existing infection with HIV or other sexually transmitted infections, practices such as fisting and unprotected receptive anal intercourse; where the risk of tissue trauma is increased and unprotected sexual activity during menstruation may increase the risk of transmission.

Number of new infections each year and at-risk populations

Unfortunately we have no reliable data on the overall rate of new infections because of the lack of active diagnosis and reporting. However, some populations are clearly at a higher risk compared to others.

Aboriginal Peoples

The most recent data suggest that aboriginal populations in Canada, both urban and rural, have a 15 to 20 percent positive rate for anti-HCV antibodies compared to an infectivity rate of less than 1% for the general population.³³

Recent Immigrants

Canadians from areas of the world where both hepatitis B and C are endemic face a higher risk of co-infection and its complications than those born in Canada.³⁴

Youth

Sharing of injection equipment puts young, street-involved youth at particularly high risk for hepatitis C infection. A 1995/96 Montreal study of street-involved youth (aged 15 to 22 years) showed that 36% had used injection drugs and 12.6% were infected with HCV. The majority (67%) of those who injected had shared injecting equipment.³⁵

Similarly, a 1998 Winnipeg study found that at the time of their first injection, 49% of injection drug users were under 20 years of age, and 22% had injected with a “used” needle.³⁶ Moreover, young women may be at even high risk since they begin injecting at an earlier age than males and are more likely to be in situations where they are sharing equipment or drugs.³⁷ Due to the rapid acquisition of HCV infections following initiation into use of intravenous drugs, young IDUs or recent injection initiates represent an important HCV demographic. This may be particularly important in urban areas experiencing a high prevalence of blood-borne infections among IDU populations. Studies have shown that younger IDUs engage in high-risk behaviours to a greater extent than established users, which increases their vulnerability to blood-borne infections.

Contributing Factors

Clearly, contributing factors in all high-risk populations are environmental factors and determinants of health (income, education, housing, nutrition, support, and access to medical care). Physiological factors may make some groups, defined by ethnicity, age, and gender, more difficult to identify and treat.

Co-infection

Twenty to thirty percent of people with HIV are also co-infected with hepatitis C. Liver disease has recently become a leading cause of death in HIV-infected individuals.³⁸ HIV infection has profound effects on the severity and course of HCV-related liver disease. In several studies, HIV/HCV co-infected individuals had higher HCV viral loads, accelerated development of hepatic fibrosis, increased prevalence of cirrhosis, and a more severe clinical course compared with HCV mono-infected individuals. Co-infection with HIV and HCV has emerged as a significant public health concern because these viruses may act synergistically to accelerate the progression of HCV-related liver disease.³⁹ Because of the significant interaction of these two

infections, HCV/HIV co-infection needs to be understood as a issue in and of itself. There is a pressing need for co-infection specific research and better coordination of expertise and treatment.

Costs

While there is no consensus as to the exact cost of hepatitis C, medically and socially, by all estimates the financial burden of hepatitis C is huge.

The C. Everett Koop Institute at Dartmouth College has estimated the average lifetime cost for hepatitis C, in the absence of a transplant, to be approximately \$100,000 per patient.⁴⁰ The BC Centre for Disease Control has done an analysis in which they estimate the cost at \$1 million per patient from time of diagnosis to death, including the medical costs and the economic loss for that individual. A single course of anti-viral treatment medications can cost \$20,000. The cost of treating liver failure is about \$50,000⁴¹ and a transplant exceeds \$100,000⁴² with a subsequent lifelong need for expensive anti-rejection drugs. Last year, Canada spent up to \$30 million on hepatitis C-related liver transplants. Based on current infection statistics and cases of cirrhosis, liver failure and need for transplant are generally expected to triple over the next 10 to 15 years.

Overall, according to the Canadian Institutes of Health Research (CIHR), hepatitis C costs the Canadian healthcare system about \$500 million annually, and this figure is estimated to double to \$1 billion by 2008. Based on studies in the U.S.A., which project even further ahead, the cost of hepatitis C in Canada may balloon to \$3.2 billion annually by 2021. Clearly, Canada is facing an increasingly expensive epidemic, which, while modest in comparison to some chronic illnesses, could be reduced to only a fraction of the estimated cost if appropriate strategies and investments in prevention, education and treatment are put in place now.

Costs of Medical Care (year) US	
	Costs in billions of dollars
Hepatitis C	5.46
Asthma	5.80
Rheumatoid Arthritis	7.10
Epilepsy	11.10
COPD	23.90
Cancer	107.00

Source: Leigh et al. Arch Int Med. 2001;161: 2231

Only HCV mortality is predicted to increase (2-3 fold by 2020)

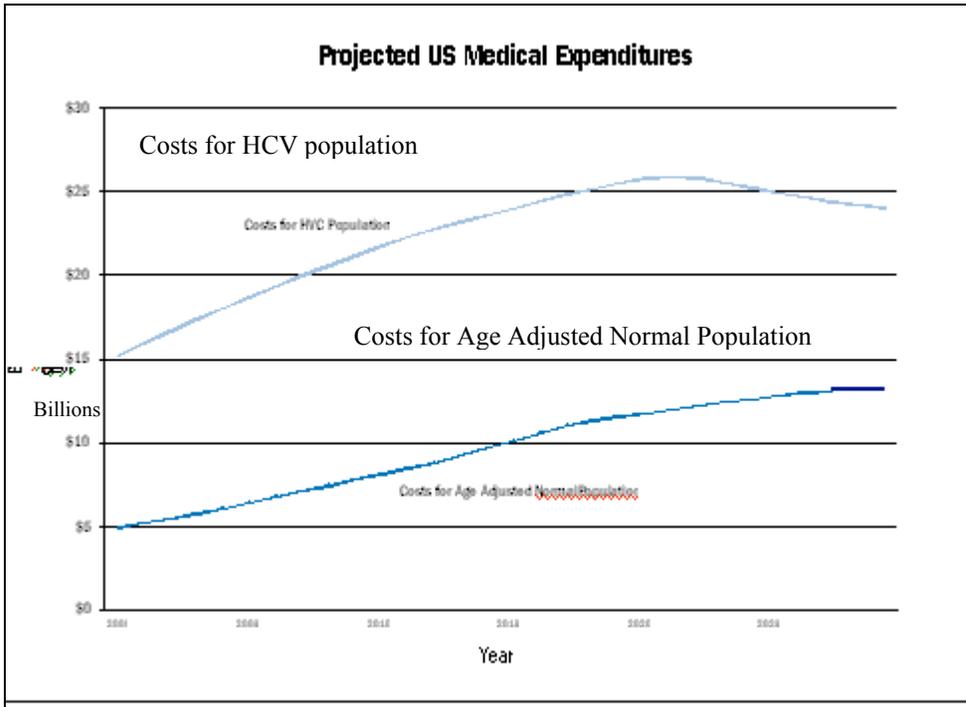
Cost-Effectiveness of Hepatitis C Treatment

A Milliman and Robertson Inc. research report entitled, “The Hepatitis C Epidemic: Looking at the Tip of the Iceberg” came to the following conclusions:

- Our cost-benefit analysis shows that 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.
- People with HCV currently consume at least \$15 billion per year for all their medical care.
- Without effective curative treatment, total healthcare costs for patients infected with Hepatitis C will peak at an estimated \$26 billion (in current dollars) per year in about 2021.
- For a typical patient, curative treatment (combination therapy) pays for itself within 10 years—before considering avoided disability costs and lost productivity costs. This considers the total healthcare costs of both patients who respond and patients who do not respond to treatment, as well as the present value of future healthcare spending.
- The disability losses associated with HCV will cost employers billions of dollars. If all of the eligible population were working and were treated with combination therapy,

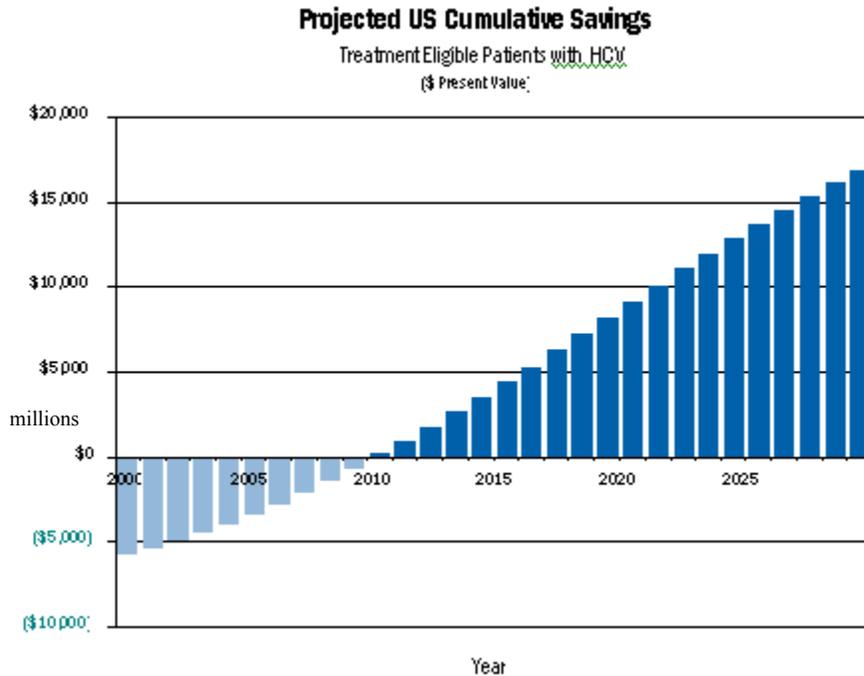
employers would save at least \$4-5 billion (present values) in lost work-time costs over the course of the epidemic.⁴³

Costs for all medical care of HCV population (excluding those with normal ALT levels) compared to a normal population with the same age mix, years 2000 to 2030.



Source: The Hepatitis C Epidemic: Looking at the Tip of the Iceberg, Milliman and Robertson Inc.

The increase in expenditures reflects increasing disease severity and aging balanced by the accelerated mortality of the affected population.



Source: The Hepatitis C Epidemic: Looking at the Tip of the Iceberg, Milliman and Robertson Inc.

The above graph shows that the initial high cost of treatment is offset by reduced healthcare costs over subsequent years. The costs are completely offset at about year nine and the return on investment (ROI) becomes positive after that.

Treatment of hepatitis C is complicated by the fact that there are numerous strains of the virus, with genotypes 1a and 1b being the most common in North America (about two-thirds of all cases) and genotypes 2 and 3 accounting for the majority of the rest. With the exception of duration, treatment is the same for all types but tends to be more effective for non- genotype 1.

Unlike many other chronic diseases, hepatitis C is considered a “curable” disease. Over the past decade, treatment has progressed from interferon to interferon combined with ribavirin to pegylated interferon with ribavirin. Success, defined as a sustained viral response (SVR) in which the virus is undetectable six months after treatment, has steadily increased from approximately 10% with interferon monotherapy to between 50% (for genotype 1) and 80% (for genotypes 2 and 3) with pegylated interferon combination therapy. Fortunately, in most cases, the SVR appears to be permanent. Even with the increased cost of pegylated interferon combination therapy over monotherapy interferon, the current “gold standard” treatment has proven to be extremely cost effective.

Cost Effectiveness of Treatment Comparisons	
Treatment or other interventions	Dollars/quality-adjusted life-years gained
<i>IFN Monotherapy 12 mos.</i>	\$5,000
<i>Pneumococcal vaccination</i>	\$9,000
<i>Screening mammography</i>	\$20,000
<i>Screening for colorectal cancer</i>	\$86,000
<i>Treatment of hypertension</i>	\$88,000

Source: Bennett WG et al. Ann. Int Med. 1997; 127:864, Kim WR et al. Ann Int Med. 1997; 127:871.

For some individuals, successfully eliminating viremia may have an added benefit of reversing damage caused by the hepatitis C virus, including cirrhosis. In one study, approximately 16% of treated cirrhotic patients had undetectable levels of virus following treatment; in the follow-up period of up to 7 years, hepatocellular carcinoma was detected in 4% of those treated compared to 38% of control patients⁴⁴ However, even for those patients in whom the virus is not totally eliminated or those who may experience a relapse following treatment, (potentially up to 10%, although some of these cases may actually be a new infection rather than a recurrence of the original virus), interferon may still be cost-effective. Treatment may slow down the progression of the disease, until more effective treatments are available. It may also delay liver decompensation. The probability of survival after decompensation is about 50% at 5 years with the only remaining option being a liver transplant.⁴⁵

While liver transplants are an important component in the treatment of hepatitis C, it is an unfortunate fact that in Canada at the present time only 400 livers are available for transplantation on an annual basis. The need far outstrips the supply, and there are other downsides. Liver transplants are expensive, carry significant risks and usually result in HCV infection of the transplanted liver. Moreover, recent research suggests that the disease, when it recurs, tends to progress more rapidly among a significant percentage of transplant recipients.⁴⁶ Transplant units are then faced with the dilemma of whether to offer a second organ to someone whose liver has fails in as little as five years.

Despite the very strong case for treating hepatitis C, patients face significant barriers in gaining access to treatment in Canada. Several studies have shown that patients whose biopsies show significant liver disease may nevertheless have normal liver enzyme levels. Despite these findings, some provinces, like British Columbia, will deny treatment to patients unless their enzyme levels test at more than 1.5 times normal, twice over six months. This has led to reports

of desperate patients using dangerous methods, such as drinking large quantities of alcohol, to raise enzyme levels. For patients with mild, slowly progressing disease, there are some experts who consider this the optimal time to treat since the likelihood of tolerating treatment and clearing the virus may be greater. However, this benefit must be weighed against the severe side effects of treatment and the possibility that the disease may progress slowly without treatment. As with other life-threatening diseases, the decision to treat should be made by the physician and patient.

Unfortunately, in every province, funding for treatment services is grossly inadequate. The result has been long waiting lists. For example, in BC, which has initiated five viral hepatitis treatment pilot projects, there are waiting lists of up to three years. In Ontario, patients may wait up to a year to see a specialist and then months longer to get into a treatment program.

Problems with Current Hepatitis C Approaches

In 1998, the federal government allocated \$50 million over five years to support hepatitis C disease prevention, community-based support, and research. The Hepatitis C Prevention, Support and Research Program has allowed for some very important initiatives, including collaborative initiatives with local and provincial services. However, the program and funding were not guided by an overall vision and strategy for hepatitis C prevention and management nor by clearly articulated goals and outcomes. There has been a lack of coordinated surveillance and monitoring so that five years after the start of the program, we still lack good data on prevalence, incidence, and impact of programs. Overall, there are many gaps in existing program services and a lack of coordination among initiatives at various government levels, across provinces, and within healthcare districts.

Prevalence and at-risk populations not clearly defined

National surveillance for hepatitis C suffers from a lack of consistent reporting criteria. In the absence of hepatitis C–defining illnesses, even though HCV may be considered the underlying cause of death, other causes are often listed on the death certificate. Thus, many deaths that should be attributed to hepatitis C are not counted. Finally, the International Classification of Diseases (ICD10) has a specific code (Z22.51) for a “carrier of viral hepatitis C” which should be used nationally for birth and death statistics as well as for HCV-associated morbidity and mortality.

More research into routes of transmission and the associated risks is needed to improve surveillance and to develop appropriate interventions with specific “at-risk” populations. For example, some research has shown that people who use psycho-stimulant drugs have different risk factors than opiate users and, therefore, may benefit from different programs and approaches. Similarly, until specific research was conducted, it was not known that the majority (52%) of parents with children who had received care in a neonatal intensive care unit prior to 1992 were, in fact, unaware that their children may have received blood products. Consequently, most in these high-risk populations have never been screened for HCV infection.

Lack population baseline measures

Surveillance is an integral part of disease prevention and control. It can provide the needed data for policy and program development, implementation and evaluation to guide public health action. Although hepatitis C is the most frequently reported, notifiable viral infection in Canada, the effectiveness of current surveillance efforts are severely hampered by a number of factors which require attention. For example, there is a lack of baseline data, pro-active testing of all at-risk populations, and an integrated national database that links public health information with treatment and other health-related data.

For example, in 2001, the British Columbia Centre for Disease Control published an evaluation of its surveillance program and made recommendations for improvement. *'To enhance the value of HCV surveillance in B.C., four key initiatives have been proposed:*

Promote surveillance for acute cases of HCV:

- *Develop and implement a standard case definition for acute HCV.*
- *Collect enhanced epidemiologic data (including risk factors) on all new acute HCV cases.*
- *Promote testing of all persons at high risk of HCV as an important secondary prevention measure.*

Establish HCV seroprevalence baseline rates using periodic surveys that include population-based studies and target high-risk populations (e.g., incarcerated persons, First Nations people, and persons who inject drugs).

Enhance the flexibility and utility of HCV surveillance by integrating the capacity to enter, analyze and report on epidemiologic factors beyond the core data set into the existing public health information system.

*Develop indicators linked to program objectives and incorporate and integrate additional sources of data, such as administrative databases and epidemiologic studies, to measure the burden of illness and disease outcomes more effectively.'*⁴⁷

There is a need to enable the sharing and coordination of advances across provincial and territorial boundaries.

Lack of Awareness

'While there are identified groups whose behaviours or environmental conditions put them at higher risk, hepatitis C affects people from diverse backgrounds; ethnicity, race, education, occupation, age, gender and social status do not act as barriers to transmission.'⁴⁸ However, to date, there has been a lack of large-scale, coordinated, sustained, public awareness campaigns delivered through the public media (television, radio, billboard, print).

Moreover, it has been difficult to raise public and provider awareness about the need for essential care, treatment and support. These difficulties are compounded by the general lack of public interest in, and support for, programs serving people with mental illness, substance users, prison populations, and other stigmatized individuals.

In addition, those providing hepatitis C services experience significant categorical and programmatic restrictions that make it difficult to integrate hepatitis C into existing STD and

HIV/AIDS programs.⁴⁹ Finally, those at risk represent many different cultures, languages and literacy levels. These factors pose an additional set of challenges to the development of appropriate prevention and community-based programs.

Lack of Support for Treatment

Without adequately funded treatment and support programs, treatment is inaccessible to many people. The drugs used to treat hepatitis C are expensive, costing over \$20,000 for a 48-week course of treatment, making them unaffordable for patients without private insurance or full provincial coverage. But the cost of the medication is only one component. Treatment can be a grueling process. At best, taking interferon/ribavirin can be similar to having a recurring, mild flu (fatigue, aches, chills, fever) that lasts for up to twelve months. There can also be more serious side effects such as increased vulnerability to other infections, dental problems, hemolytic anemia, renal dysfunction, and cardiovascular and neuropsychiatric complications. Depression, in some cases, has been severe enough cause cessation of treatment and, in other cases, has resulted in suicide. Lack of access to psychiatric services in tertiary settings is emerging as a problem for people with hepatitis C, particularly those undergoing treatment.⁵⁰

There are many other issues faced by people living with hepatitis C that exacerbate the difficulties of accessing or completing treatment. The provision of adequate nutrition, housing and other support is essential to treatment success. For example, malnutrition is common when the liver is diseased and it can have a significant impact on morbidity and mortality. In addition, the anorexia, nausea and vomiting associated with liver disease can lead to reduced dietary intake, furthering the potential for malnutrition.⁵¹ People with hepatitis C often require a diet that is both palatable and high in nutrition, which can be more expensive.

Those who are incarcerated face issues of access to prevention and peer support programs, the availability of competent health care professionals and sympathetic custodial staff, concern about the confidentiality of health information, complex diagnostic and treatment issues, movement in and out of custodial settings, and the lack of continuity, once released back into the community.

In smaller communities disclosure of an individual's health status can easily lead to public identification. Disclosure can occur by simply describing a situation, without the use of names, in the presence of others. Pharmacies, labs, hospital hallways, waiting rooms and community services are all places where confidentiality has been inadvertently broken. As stated in the Australian Hepatitis C Strategy,

*'Any consequent discrimination can limit a person's participation in the community, limit their employment opportunities, and affect the provision of goods and services, including health care. Experiences of social isolation can be exacerbated by the lack of specific hepatitis C health care services or advocacy and support groups in rural, regional and remote areas.'*⁵²

It is common for HCV infected people to state that they experience the greatest level of stigmatization and discrimination in health care settings. There is a need for community-based

programs that provide support and education to patients as well as sensitization and education for healthcare providers on these issues.

Infected healthcare workers experience this troubling issue in both a personal and professional sense. The prevalence of hepatitis C among health care workers is no higher than that in the general population. In spite of this, health care workers themselves also experience stigma, isolation and prejudicial behavior, including inappropriate responses from the health system when (potentially) exposed to a blood borne virus such as hepatitis C and HIV via an accidental needlestick injury or some other form of exposure. This experience, or witnessing a colleague's experience, may then deter health care workers from reporting possible exposures to blood borne viruses because of the potential impact on their employability.⁵³

Some people are choosing to use complementary and alternative therapies (CAT) to relieve the symptoms of hepatitis C infection or reduce the side effects of conventional treatment. There is a clear need for good research into the effectiveness of complementary and alternative therapies for hepatitis C as well as support for access to CAT where desired and useful.

According to the BC Centre for Disease Control, treatment is indicated for only 20% of HCV infected persons⁵⁴. The treatment that is currently available and covered by provincial drug plans is effective in reducing HCV to undetectable levels (sustained viral response) in approximately 55% of patients treated. Therefore, in practical terms, almost 90% of persons infected with hepatitis C do not have access to effective treatment.

The Canadian Hepatitis C Strategy must incorporate support and education, both general and peer to peer, to assist people to stay as healthy as possible for as long as possible. It must also provide for those who may not be considered eligible for treatment (e.g., non-response to previous therapy, active drug use, relapse or re-infection, incarceration for less than duration of treatment, or 'normal' ALT levels, and those who choose not to treat because of depression, comorbidities, or concern for side effects, etc.). The healthcare system has a responsibility to develop and implement strategies for living with chronic hepatitis C without viral therapy for the reasons of compassion, humanity, and good public health.

Recommendations for a Canadian Hepatitis C Strategy

Recommendations for Prevention

Prevention must be directed toward reducing the incidence of new infections and preventing disease progression among those already infected. Recommended strategies are based on the knowledge that over 60% of new infections are due to injection drug use; other drug use, tattooing, and skin piercing account for about 15%; transmission in healthcare settings could be 6% or higher, and estimates of sexual transmission range from 1% to 3%. In addition, there are factors specific to high-risk populations that need to be addressed if prevention strategies are to be successful.

- 1. Prevention strategies must be linked to other programs of harm reduction, health promotion, and social and economic support as well as programs that**

address the risk factors for specific populations (e.g. prison populations, Aboriginal communities and street-involved youth).

- 2. Health Canada should, with new money, enable the participation of hepatitis C Community-based Organizations (CBOs) in the Strategy for Building Capacity Around Preventive and Therapeutic Vaccines against HIV, HCV and Cancer.**

Harm Reduction

There is currently no preventive vaccine for hepatitis C, nor is there likely to be one in the near future. The most immediately effective means of reducing the likelihood of disease transmission among injection drug users is to promote safe practice, by providing sterile syringes and needles, supplying other equipment as needed and making safe injection sites accessible and “user-friendly.” Programs to reduce risks of HCV transmission should build upon the numerous harm reduction and prevention programs that exist federally, provincially, and locally to address HIV transmission, other blood borne diseases, and other infectious diseases. Many of these have been in existence for years building resource networks, credibility, and successful approaches with high-risk populations.

Health Canada has a responsibility to:

- 3. Ensure that effective harm reduction programs are identified, supported and promoted as models for implementation in similar circumstances.**
- 4. Utilize the strengths of injection drug using communities to develop innovative strategies for peer support and education that reduce acute infections among ‘new’ users.**
- 5. Address the determinants of health that lead to risk behaviours and sub-optimal health status. (e.g., it is more difficult to maintain safe practices when you’re homeless, hungry and sick.)**

Needle Exchange

Needle exchange/distribution-harm reduction programs have been proven to be effective and cost-effective approaches for prevention of HIV and HCV in Canada and other countries. For example, the 2002 review of Australia’s needle exchange/harm reduction programs concluded that approximately 46,000 infections of HCV and HIV had been prevented. From 1988 to 2000, the estimated return on investment of the Australian program was \$7.75 billion in avoided treatment costs for HIV and HCV.⁵⁵ Indeed, the cost-effectiveness of the programs has been so significant that these initiatives have been called a ‘blue-chip investment’, offering significant health gains, financial savings, and other benefits.⁵⁶ Similarly, an independent national review in New Zealand has calculated that each \$NZ spent on needle and syringe programs (NSPs) yields a \$NZ20 saving in lifetime treatment costs.⁵⁷

- 6. Existing needle exchange/distribution programs across Canada should be maintained and expanded where indicated. Access should be provided in areas that are currently not served.**

Safe Injection (Consumption) Sites

There is considerable evidence demonstrating the importance of providing safe injection/consumption rooms as part of a harm reduction program (Nadelmann et al., 1999).

These sites are effective in contacting hard-to-reach or vulnerable drug users (including those already infected, homeless, or foreign nationals), promoting safe injection practices, providing for safe disposal of needles, reducing the risks of overdose, and reducing use of drugs in public places.

Other benefits include facilitating access to treatment and providing opportunities for social reintegration among those already infected and marginalized. The establishment of safe injection sites in collaboration with national, provincial, and local harm reduction programs is an essential element of a comprehensive strategy of HCV prevention.

- 7. The federal government must continue its leadership role and support the establishment of safe consumption sites and ensure that barriers to use by marginalized populations (e.g. youth, women, Aboriginal persons) are addressed.**

Drug Dependency Treatment

Equally important in addressing HCV infection are programs to treat drug dependency, thus reducing the risk of infection or re-infection and improving the chances of successful treatment for HCV. Thus, treatment is one of the four pillars of Vancouver's innovative "Four Pillars" drug strategy. These interventions include withdrawal management (detox), treatment on demand, methadone programs (including low threshold programs), outpatient and peer-based counseling, daytime and residential treatment, housing, ongoing medical care, and other support services.

- 8. A range of drug dependency treatment options needs to be readily available across the country.**

Prison Populations

Drug use in prisons is very high, with more than 50% of prisoners reporting active drug usage and up to 40% infected with HCV. Thus, jurisdictions worldwide are recognizing the importance of promoting safe drug use in prisons as part of any program to contain the spread of HCV. Experts have stressed the importance of implementing harm reduction and prevention measures, confidential testing, counseling and treatment services within the prison system. In recent years, there have been an increasing number of NSPs (needle and syringe programs) available within prisons. The first of these was piloted in Switzerland in 1992 and evaluations of this and subsequent programs have documented reductions in sharing rates, no new acquisitions of HIV, HBV or HCV and no serious unintended consequences.⁵⁸ There are currently no NSPs active in any of Canada's prisons.

In addition to human rights and ethical considerations, it is in the best practical interest of Canadians to ensure that prisoners receive the same standard of health care, as prisons are part of the community, and most prisoners will be returning home eventually.

- 9. Health Canada must work with Corrections Canada and similar Provincial or Territorial Ministries to fund effective harm reduction programs that address the needs of both prisoners and correctional systems. Consistent implementation of current policies concerning harm reduction pilot projects should be encouraged.**
- 10. Concomitant with clean injection equipment and treatment programs to reduce drug dependency is the need for education among prison workers to ensure**

there is appropriate understanding of hepatitis C risk factors and the need for support for harm reduction initiatives.

- 11. Reducing transmission risks by providing access to appropriate tattoo and piercing equipment, along with access to appropriate sites for performing these practices is also recommended.**

Public Health Services

In order to make effective health policy decisions a coordinated, nationwide system that can identify, monitor and report on the prevalence, incidence, demographics, risk factors, disease outcomes and burdens of hepatitis C in a consistent and uniform manner is needed. The system needs to develop the flexibility and utility to incorporate additional sources of data and analyze epidemiologic factors while respecting individual privacy rights.

Public Health Units can serve an important role in prevention efforts by providing disease surveillance, access to testing, and information, thereby reducing the number of new infections and the negative health consequences of HCV. Some units have done an excellent job of ensuring that the public health nurses, trained in drawing blood and providing pre/post test counseling, are also available for nonjudgmental support services, such as referral to community-based hepatitis C services, finding an appropriate physician, ensuring that appropriate immunizations are up to date and providing patient resource materials.

Public Health Units can also provide a degree of public anonymity that is sometimes not available in doctor's offices.

Public Health services need to be adequately resourced to conduct coordinated disease surveillance, testing and prevention, which should include:

- 12. An improved national surveillance database.**
- 13. The ability to conduct enhanced surveillance interviews for acute hepatitis B and C cases.**
- 14. The capacity to provide testing and immunizations.**
- 15. Targeted immunization programs and education for individuals at risk.**
- 16. Ongoing collaboration between Federal, Provincial and Territorial Public Health and other relevant provincial agencies (e.g. BC Hepatitis Services).**
- 17. Develop, implement and enforce a uniform set of regulations for tattooing, piercing, body modification and nail care businesses that prevent the risk of infection without being so prohibitive that businesses and customers are driven underground.**

Health Care Settings

Since 1990 transmission of HCV through blood and blood products has been reduced considerably through the implementation of donor screening and testing. With current nucleic amplification testing (NAT), the risk of HCV in donated blood in Canada is less than one in a million. Similarly, all organs and tissues are tested for HCV.⁵⁹ Person-to-person transmission in healthcare settings is also very low, with the current risk of HCV infection to a healthcare worker

as the result of exposure to HCV through accidental needle stick or other subcutaneous exposure being less than 3%. Education and adherence to infection control, standard precautions and follow-up on occupational exposure are nevertheless very important to minimize any risk.

The risk of HCV transmission to patients from infected healthcare workers is possible during certain procedures.

- 18. Guidelines for occupational exposures and healthcare workers with hepatitis C infection need to be clearly written and updated on a regular basis. These guidelines should also be clear for healthcare workers infected with HCV who have been successfully treated and demonstrate no detectable viral activity.**
- 19. There is a need to implement education, practice and equipment modification strategies in healthcare settings to improve infection control practices and reduce occupational exposure risks such as needle stick injuries.**

Sexual Partners

Understanding the true risk of HCV transmission through sexual intercourse is problematic because of the limited research that eliminates other risk factors, such as drug use, sharing of toothbrushes or razors, and any tearing or bleeding during sexual activity. The data suggest the incidence is very low, accounting for less than 5% of all infections.

- 20. The development and promotion of guidelines on 'safer sex' practices, such as the use of condoms and dental dams is highly recommended as well as the promotion of other standard precautions, including not sharing toothbrushes or razors and/or engaging in unprotected sexual activity where blood may be present. In addition to minimizing the risk of HCV transmission, it is important to protect those who are HCV positive from dangerous co-infections.**

Mother to Child (Vertical Transmission)

There are substantiated cases of children born to mothers with hepatitis C who become infected, primarily, it is believed, during delivery. Unlike HIV, there is no evidence-based drug protocol for reducing the risk of a child being born with HCV to an infected mother. The best options are education to promote health pregnancy, testing during the child's two years, and supportive care.

- 21. Continued research and widespread dissemination of knowledge is needed about the mechanisms of vertical transmission, viral clearance in children, breastfeeding, and the treatment of children with rapidly progressing HCV infection.**

Women

There are a number of areas where further research and education on prevention and how female gender and age affect disease progression and treatment are needed. As with many diseases, women are often underrepresented in clinical trials.

- 22. Further research and public information are needed on transmission risks, natural history, symptomology, the role of hormone levels, contraceptive use, screening strategies, pregnancy care, and assisted reproduction.**

Youth

Adolescence provides a unique opportunity to target youth at a time when they are developing communication, negotiation, and decision-making skills. Engaging youth concerning their participation, or potential participation, in risk activities for HCV is key to preventing new infections among youth, as well as encouraging those newly infected to get tested, seek treatment and otherwise safeguard their health in order to prevent progression of the disease.

- 23. Sustainable human and financial resources need to be designated for capacity building, skills sharing, and networking for youth, in order to ensure that peer education and support initiatives continue to be viable across a diverse set of youth communities (i.e. urban, rural, Aboriginal, street involved, incarcerated, etc.). This includes establishing or increasing resources for train-the-trainer programs, peer education and awareness building, and peer support and treatment information programming for HCV+ youth.**
- 24. Youth also need to be engaged in policy and program development, which includes proactively addressing the stigma and lack of resources (i.e. financial, stable housing and others) that often act as barriers to youth voice and participation.**

Recommendations for Public Awareness

Public awareness refers to the education of the general public as well as targeted messages to persons who may have had previous exposure to HCV or who are currently at increased risk. Increased risk may result from injection drug use and other activities that increase the likelihood of exposure to HCV. Living conditions, such as the lack of stable housing, inadequate nutrition, and lack of social supports increase the likelihood that people will not take precautions. Lack of access to professional healthcare services can delay the detection and treatment of infection. The goal of public awareness for those either currently or previously at risk is to encourage people to come forward for testing and further information. Those that test positive need to be informed of the steps they can take to protect their health, the health of others, and to obtain treatment.

A large-scale, coordinated, comprehensive media campaign is needed to increase public awareness of hepatitis C risk factors and the need for testing among the high number of Canadians who are unknowingly infected and unlikely to be currently involved in risk activities. This campaign should make extensive use of radio and television. Additional efforts that target specific risk activities need to be implemented with the involvement of those most at risk in order to tailor effective prevention messages and prevent new infections. Reducing the stigma associated with infection must be a priority.

At-risk Population Testing

Testing for HCV infection should be offered to those with risk factors for infection.⁶⁰ Risk factors should include:

- History of injection drug use (including those who may have briefly experimented with injection drugs years ago)
- Sexual activity with an injection drug user or HCV positive partner
- Blood transfusion before May 1992 (regardless of symptoms) and up to 1999 (if history of symptoms suggesting potential HCV).
- Receipt of organ transplant prior to 1992
- Infants in neonatal units prior to 1992
- Haemodialysis patient
- Immigrants in receipt of medical services that could involve transmission of hepatitis C in countries where HCV infection rates are high
- Employment in health care
- Tattoos and body piercings
- Intranasal or crack cocaine use
- Having an HCV infected mother
- History of incarceration

To be effective, public awareness campaigns encouraging testing must take into consideration factors that may influence whether messages are heard and acted upon. Many of Canada's at risk population live in rural areas where access to information may be more difficult. Another barrier is the stigma around hepatitis C and its association with drug use and alcohol abuse (liver damage, particularly cirrhosis, is often solely equated with alcohol abuse).

25. Campaigns targeted at encouraging people with HCV risk factors should be developed and delivered by Health Canada in partnership with provincial/territorial governments, healthcare professionals and community-based organizations.

26. When mounting public awareness/testing campaigns, issues of varying literacy levels, age-appropriateness, and the need for materials in a variety of languages are important factors to plan for.

Youth

Using peer education models that avoid scare tactics and stereotyping have proven to be successful approaches to raising awareness, increasing knowledge, and building skills. This includes HCV specific school-based curriculum, as well as additional targeted prevention education for youth further at risk, such as street involved, drug using, and incarcerated youth. It is essential that such curriculum go beyond the basics of HCV transmission and prevention to address issues of drug use (including steroids) and harm reduction techniques. Further education initiatives should focus on decreasing the number of youth who are unaware of their HCV status, as well as informing youth who are HCV+ that treatment can be 50-80% effective with early detection and appropriate treatment.

HCV education for youth needs to happen not only in classroom or youth group settings.

- 27. Broad-based public awareness campaigns for HCV must also specifically address the needs of youth, in particular in the area of stigma and discrimination. Reaching youth through public campaigns must also take into account venues and approaches that most appeal to youth in order to be effective (i.e. public services announcements on Much Music, use of the Internet, music festivals, and messaging in public places frequented by youth). Most importantly, campaigns that are developed for youth should be primarily designed by youth.**
- 28. Health Canada should fund the development and delivery of a standardized HCV prevention curriculum to be delivered to all youth prior to them engaging in risk activities and address their early decision making patterns. This curriculum should be peer developed and delivered.**

Rural Issues

Access to information, support, needle exchange/distribution, harm reduction materials or Methadone maintenance therapy (MMT) can be difficult for those in rural areas. The transfer of program models from urban settings, where they are often developed and piloted, must take into consideration the challenges of small communities, remote locations and the lack of public transportation, and extreme weather conditions.

- 29. Federal/provincial/territorial support must be in place to develop rural alternatives to 'safe consumption sites' and continue to expand the reach of harm reduction programs, including mobile and fixed site needle exchange/distribution programs, methadone maintenance therapy (including low threshold programs), prescription alternatives to street drugs, and other disease prevention measures such as outreach programming that is developed specific to the needs of people who are now engaging in risk behaviours.**

Stigma

Conservative values common to many communities, both rural and urban, can be a barrier to providing school-based prevention education. These communities may adopt an attitude of "we don't have a hepatitis C/ drug/ homelessness problem" which precludes their willingness to openly address the problems and to provide the necessary information to their children and others.

Among infected middle-class Canadians, often labeled the 'hidden epidemic', the stigma of hepatitis C is related to concerns about loss of jobs, insurance, mortgages, friendships, and community standing and even greater concerns about prejudice and discrimination directed at their children. Some of these individuals represent "closeted" past or current injection drug users who are afraid of legal and social sanctions, including loss of healthcare coverage and access to other services which are not available to those with a chronic, progressive, potentially life-threatening disease.

Among injection drug users (past and present), the key barriers to disclosure and seeking help are the perceived negative moral judgments and discrimination from healthcare providers and others in the community. Many report the experience of "moral judgment" that is directed at

those who are regarded as 'drug-seeking' or 'unclean' and, therefore, deserving illness. Perceived stigma can limit association with accessing hepatitis C services through AIDS Service Organizations, STD clinics or single-purpose clinics. In a small community, patients report that simply being seen talking to a "Hep C Support" person can lead to gossip and assumptions about one's health status, behaviours and worth. Conversely, once a community has replaced assumptions and fear with facts and understanding, it can be a very supportive place to live.

30. Public awareness campaigns aimed at reducing such stigma are critical to ensuring that people will access needed services.

Recommendations for Support, Education and Health Promotion

Support

Community-based hepatitis C organizations and support groups provide invaluable group and individual support. They have an unparalleled understanding of their community's culture and an ability to reach 'hidden' populations. With proper training and resources, they can expand the ability to serve greater numbers of people at any given time, expand the hours of support available, reduce unnecessary office visits, phone calls, and emergency room visits and reduce the workload of healthcare providers.

Community-based organizations play a key role in ensuring that services are accessible, cost-effective and responsive to changing needs.

From 1960 to 1992, an estimated 90,000 to 160,000 individuals were infected with HCV through infected blood or blood components. A significant number of infected persons are concerned about the potential for public disclosure and stigma and do not access groups. The experience of living with hepatitis C needs to be normalized while respecting and addressing concerns about privacy and confidentiality. Because of this reality, community-based organizations need to develop expertise in outreach – off site or remote dissemination of information and support. This work tends to be highly specialized, targeted and quite labour intensive. It involves a wide range of communications expertise and techniques. For this reason, it will be necessary that the Canadian Hepatitis C Strategy support an extensive, flexible and broad range of community-based outreach.

Health Canada needs to invest in Community Based Organizations that will:

- 31. Provide outreach, education and support programming that is community-based, community driven and community evaluated.**
- 32. Foster peer-based support and mentoring programs that address the diverse needs of urban, suburban, and rural communities.**
- 33. Utilize, support and further develop existing expertise within community-based hepatitis C organizations.**
- 34. Ensure close collaboration with Needle Exchange Programs, AIDS Service Organizations, other disease organizations, Public Health, Aboriginal organizations, youth organizations, Addiction Services, prisoner advocacy/Corrections, Mental Health and anti-poverty groups.**

Additionally, Health Canada should:

- 35. Fund and support the development of regional and national bodies that represent local and regional concerns, produce common resources, collaborate with other national initiatives and advise policy makers. These organizations need to be inclusive, accountable and representative of people affected by hepatitis C.**
- 36. Fund and support capacity building at the community level.**
- 37. Work with CBOs, Provincial and Territorial Ministries of Human Resources and Canada Pension Plan to ensure that chronic hepatitis C is recognized as a medically and functionally valid basis for Disability Benefits status.**
- 38. Work both independently and collaboratively with other F/P/T Ministries to address the determinants of health that can positively impact health status before, during and after treatment. (e.g. Ensure safe housing needs are met for HCV positive youth and youth “at risk” [i.e. street involved youth]).**

Health Promotion

Health promotion is the process of enabling people to increase control over their own health and to make healthier lifestyle choices. The five mandates for effective health promotion as outlined in Canada’s Population Health approach are:

- Build healthy public policy;
- Create supportive environments;
- Strengthen community action;
- Develop personal skills and;
- Re-orient health services.

All Federal, Provincial and Territorial governments have endorsed the Population Health approach. It is designed to focus on the health of populations, invests upstream, bases decisions on evidence, applies multiple strategies to act on the determinants of health, collaborates across levels and sectors, engages citizens and increases accountability for outcomes.

Evidence for impact of self- management programs on service use

Health promotion and patient self-management programs have been shown to be successful in a number of health areas.

Health Problem	Impact of self-management programmes on care services
Chronic Pain Arthritis	Reduction in number of visits to health professionals up to 80% ^{12,16}
Arthritis Insomnia Asthma	Reduction in number of general practitioner visits up to 44% ¹⁷⁻²¹
Sickle Cell Disease Asthma	Reduction in number of hospitalisations (up to 31%) and length of stay (up to 50%) ^{22,23}
Insomnia	Reduction in number of visits to specialists by 15% ²¹
Sickle Cell Disease Asthma	Reduction in number of accident and emergency department visits up to 39% ^{22,23}

Source: *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*, http://www.doh.gov.uk/healthinequalities/ep_report.pdf

BC Hepatitis Services is developing a patient self-advocacy guide and the University of British Columbia School of Nursing is researching best practices in hepatitis C self-management. Efforts should be made to integrate these and other resources into a national Expert Patient education program.

Community-based hepatitis C support groups/organizations can play a key role in providing this training and ensuring ongoing continuity of training cycles through a train-the-trainer process. It is important that community expertise be appropriately valued, both in terms of content and commitment of time.

39. Health Canada should fund community-based organizations (CBOs) to develop and deliver an Expert Patients program to assist people with hepatitis C to better navigate the healthcare system and improve their capacity for self-care.

Outreach and Peer Education

Education, including key messages that promote prevention, harm reduction, pro-active self care, and treatment knowledge should be developed in collaboration with those in the target communities, including ethnic communities, newly diagnosed people, those who have been infected for years, drug users and street-involved youth. Information developed and delivered by members of the community is more likely to be better received, understood and believed. There are numerous examples of effective harm reduction and health promotion programs developed and delivered in collaboration with community-based projects involving people infected with, affected by or at risk for hepatitis C.⁶¹ Unfortunately, the number of projects and the resources available to them are woefully inadequate relative to the number of persons at risk.

40. Health Canada should fund CBOs to develop and deliver outreach and peer education projects/programs.

41. To be effective, appropriate peer supports and resources, needle exchange services, safe injection sites, and access to adequate nutrition and shelter must support outreach and peer education programs.

Given the limited number of hepatologists and trained specialists, education efforts will need to focus on both increasing the number of trained physicians and nurse-practitioners as well as increasing the capacity of affected individuals, communities and community service providers to provide education, support and care services.

Education initiatives need to incorporate information on prevention, nutrition, treatment issues, and actions that can minimize disease progression, co-morbidities, and stigma.

Health Canada must provide the resources to enable CBOs to:

- 42. Collaborate with health educators on the design and provision of medical/nursing/dental school curricula and Continuing Medical Education sessions on hepatitis C and associated conditions for physicians, nurses and dental professionals.**
- 43. Educate healthcare providers on issues such as working with people who use injection drugs, addictions medicine and pain management, and the realities of the issues faced by those who live with HCV prior to, during and after treatment.**
- 44. Provide education and orientation to allied service providers (mental health, addictions, social workers, hospice, peer supports etc.)**
- 45. Coordinate with existing chronic illness health education/promotion programs on the development and delivery of 'Expert Patient' programs.**
- 46. Provide train- the- trainer education to hepatitis C community support group leaders**
- 47. Deliver patient education/ self-advocacy/ wellness programs through a combination of face to face (one to one and group) and distance education utilizing telemedicine and high-speed Internet facilities.**
- 48. Provide access to phone support/information services for patients and the general public.**
- 49. Educate community service providers about support needs.**
- 50. Partner in the development of a substantial nation-wide media campaign that publicizes risk factors and the need for testing, including youth-specific messaging and input.**
- 51. Contribute to the continued development of a Canadian Hepatitis C Information Centre.**
- 52. Incorporate prevention education into school curricula, beginning with basic, age-appropriate 'Standard Precautions' education in primary school, followed by prevention/harm reduction and negotiation/refusal skills in high school. Within this, include a train-the-trainer curriculum in order to establish networks of peer educators, particularly in rural areas.**
- 53. Develop peer education initiatives for youth groups outside of the mainstream school system, in order to target more at-risk youth – i.e. incarcerated youth, street involved youth, and youth participating in higher risk activities such as drug use and body art.**
- 54. Ensure that materials are culturally appropriate and available in a range of literacy levels, learning styles and languages.**

Recommendations for Care and Treatment Support

There must be a full spectrum of health promotion initiatives and healthcare services accessible to persons with hepatitis C that proceeds seamlessly from awareness and diagnostic testing to specialist care in a comprehensive care setting to extended care in the community (family practice, mental health services and social support). Healthcare includes access to treatment and related supportive services.

Diagnostic Testing

55. Ensure that adequate resources are in place to provide testing, pre/post test counseling and diagnostic analysis of blood samples.

Comprehensive Care

Comprehensive care is a model of care with the goal of providing the best quality of life for those infected with hepatitis C. This includes a managed care plan supervised by a specialist, access to appropriate antiviral treatment, and community-based supportive care.

Currently there are only about 40 hepatologists to treat nearly a quarter of a million HCV patients in Canada, in addition to those patients requiring specialized care for other liver diseases. It is estimated that about 60% of patients receive their care for an often-complex disease with new treatment protocols from a non-specialist. Many patients do not even have a regular family physician these days. The solution is multifaceted, including recruiting and training more specialists, inclusion of other healthcare professionals (e.g., nurse practitioners and general practitioners) as part of the clinic care team, and linkages to family physicians to support management of the patient before, during, and following anti-viral treatment.

There are a number of excellent clinic programs that can serve as models for developing a network of Hepatitis C Comprehensive Care Clinics that would adhere to standards of care based on evidence and expert consensus. Comprehensive Care Clinics would also assure that each patient has a managed care plan and access to a full complement of treatment and care services to treat the disease and provide for the best possible quality of life. The Medical Director for each clinic would supervise operation of the clinic, oversight and education of staff, and maintenance of a patient registry or database. The treating specialist would be responsible for diagnosis, medical assessment, therapeutic services, and follow-up. The nurse coordinator would supervise patient education, evaluation of family and other social supports, counsel on management of therapy including side effects, evaluate capacity for self-management, and provide support during follow-up. Clinic team specialists that may include a psychologist, psychiatrist or mental health specialist, infectious disease specialist, immunologist, hematologist, dentist, nutritionist, and social worker would provide additional core services.

Based on experience with other diseases, such as hemophilia, muscular dystrophy, cancer, and arthritis, the success of comprehensive clinics depends on availability of training to attract specialists, funds for recruiting and training nurses and general practitioners, adequate resources for laboratory testing and support staff, access to state-of-the art treatment including supportive

care, and availability of research and operational funding to set up a range of pilot projects, collect data, and do evaluations.

With the implementation of an effective public awareness campaign, sufficient resources need to be in place to meet the need for testing and treatment. Organ donations and transplant services will also need to meet the anticipated increase in demand.

In addition, patients should be involved in the planning and evaluation of services to assure that they are meeting the needs of individuals and their families. Education of staff should also focus on understanding the challenges faced by patients and reducing the experience of ‘judgmental’ treatment. Finally, outreach is needed to ensure that “hard-to-reach” populations are aware of and willing to access clinic services.

In conjunction with Provincial and Territorial Ministries of Health, and healthcare profession governing bodies, Health Canada should:

- 56. Establish and regularly update protocols/guidelines for assessment, testing/workup, record keeping and referral.**
- 57. Establish and regularly update treatment and follow-up guidelines.**
- 58. Identify and establish telemedicine satellites in rural and remote communities.**
- 59. Develop alternative care management (multidisciplinary teams, nurse practitioners, core team/extended team, etc.) and alternative physician billing models for the care and treatment of chronic diseases such as hepatitis C.**
- 60. Fund and recruit physicians to train as hepatologists.**
- 61. Improve the coordination of care and sharing of expertise on co-infection issues through the development of ‘co-infection centres of excellence’.**
- 62. Build more robust hepatitis C prevention, education, support, care management and research into Chronic Disease Management and Primary Care Reform initiatives.**
- 63. Improve organ donation rates and ensure that transplant services develop the capacity to meet the increasing demand for liver transplants.**
- 64. Ensure equitable access to drug therapy, care and treatment across all jurisdictions.**

Community-Based Care and Support

Treatment can be difficult for the patient, carries significant risks, and requires careful management. Ongoing patient education, counseling and support in coping with the effects of treatment are key to the successful completion of treatment. Recent research indicates that adherence to the dosing regimes play an important role in achieving sustained viral response (SVR). Treatment discontinuation and failure due to side effects occurs in up to 20% of cases. Considering the substantial direct and indirect costs of treatment, strategies for improving the likelihood of SVR outcomes are important components of treating hepatitis C.

There are a number of ways that the percentage of treatment failures can be reduced. Some of these require medical expertise. Others, such as treatment-induced depression, addiction relapse, anxiety, nutritional and dental issues can be largely dealt with, less expensively, by other

resources in the community if they understand hepatitis C, its treatment, and the importance of timely, coordinated interventions.

Expedited referral pathways are necessary so that patients with hepatitis C are able to access, in a timely manner, the care, services and support needed to ensure that these results are optimized and resources are utilized in a cost-effective manner.

Clinics, where they exist, are open for limited hours. People live with the effects of hepatitis C and treatment 24 hours per day, seven days per week. Trained community services providers and peer supports who understand the effects of hepatitis C and treatment and are knowledgeable about the resources available, can assist in achieving better treatment outcomes and increase the capacity for self-care, especially among special populations. Systems for identifying, supporting and increasing access to such services should be developed.

Health Canada should provide the resources to enable CBOs to:

- 65. Establish mutual education and referral pathways for mental health, addictions, nutritional, and dental health counseling/services.**
- 66. Establish education and pathways for community nursing, homecare and hospice services.**

Rural Issues

Many people with hepatitis C are also choosing either to return to their home towns or move to rural communities because of lower costs of living, a slower pace of life, and the perception of greater local support. Unfortunately, many do not access treatment or have difficulty in managing a full course of treatment because of the lack of medical and support services in these communities.

The geographic and physical locations of treatment services create significant hardships for people living in rural areas. Weather, terrain and distances make travel to specialists living in distant or urban areas uncertain, expensive and exhausting. A 10-minute appointment can require three days of travel, accommodation, childcare and meal expenses. It is not an overstatement when patients report being exhausted for days and weeks afterwards.

- 67. The use of Telehealth and Internet consultations should be expanded to increase access to specialized knowledge and reduce the burden and expense of long distance travel.**

Some jurisdictions have recognized the scope and impact of hepatitis C and have established multidisciplinary teams. In large, urban areas this approach has the advantage of being a convenient, one-stop shop where expertise and resources can be shared. However, they are expensive and seldom able to incorporate all the disciplines required to meet the full spectrum of needs. Smaller communities and rural areas face particular challenges.

A number of different models need to be piloted and evaluated. One model that may provide a cost-effective, capacity building alternative to expensive, dedicated-purpose, centralized, multi-disciplinary teams is the “Core/Extended Team” concept. By building upon existing expertise and partnerships with health and community service providers to ensure that consumers can access a wide range of health and social services at all points of illness progression, in communities throughout the region, it will assist existing Liver Clinics to focus on best utilizing the high level skills of their staff members.

The 'Core Team' consists of nurse-clinicians and a primary care physician(s), who consult with and are supervised by a specialist. The 'Extended Team' consists of associated healthcare professionals, community service providers and peer supports within the communities of the region. This decentralized approach has the advantage of minimizing overhead and staffing costs while building capacity and maintaining the key advantages of a multidisciplinary team approach.

Aboriginal Communities

Many Aboriginal communities have HCV infection rates several times the national average. The current 'silo' approach to funding allocations and program responsibilities have led to inequities in access to treatment, care and support.

68. There is a pressing need to find avenues of collaboration and cooperation so that Aboriginal people living both on-reserve and off reserve benefit equitably, while respecting cultural and autonomy issues.

Youth

There are many barriers that affect the way youth access treatment, care and support services. Unemployment, a distrust of adults, limited access to safe and stable housing, and high rates of mobility and drug use are just some of the factors that both put youth at increased risk and hamper their access to care and support once infected. Compounding the situation is the widespread societal stigmatization of youth and an overall lack of age appropriate and peer delivered services.

Avoiding HCV infection or accessing appropriate treatment becomes that much more difficult for youth if they are experiencing unemployment or underemployment. For street involved, incarcerated, sex trade worker and other marginalized youth, the struggle to meet basic needs is the priority.

Furthermore, there is often a strong distrust of adults among marginalized youth, which is reinforced through lived experience. This distrust often leads to a decreased access to sterile drug equipment, healthcare, and much needed support.

Drug use among marginalized youth remains high, and active drug use remains a major barrier to undergoing HCV treatment as well as adversely affecting the health of infected youth. Treatment options are few.

69. There is a need for increased resources to specifically treat youth with addiction issues.

Injection Drug Users

Very few people who inject drugs enter hepatitis C treatment programs. Meeting other needs on a daily basis may be a higher priority. Some people dread the barriers and judgments that they encounter. Some do not understand the implications of HCV infection. The current criteria, which demand the cessation of drug use (which may not be practical without some therapeutic replacement), make accessing treatment difficult. The limited research on people who have either injected regularly 6 months prior to treatment and those who injected intermittently during treatment has shown SVR rates similar to other patients, given appropriate supports and access to other services. If harm reduction supplies/materials/education are easily available, concerns regarding re-infection also need not be a contraindication to treatment.

Methadone Maintenance Therapy has been shown not to be a contraindication to treatment.

- 70. Given the large number of HCV infected active drug users, further research and clinical trials are needed to investigate the possible interactions of anti-viral and illicit drugs and the successful treatment of injection drug users.**

Recommendations for Research

Research is critical to increasing our understanding of the basic science, natural history, epidemiological issues, treatment advances and effectiveness of various interventions as they relate to hepatitis C.

The recommendations for a comprehensive research strategy are taken from the Recommendations on the Renewal of the Health Canada/CIHR Research Initiative on Hepatitis C put forth by the Joint Advisory Committee of the Health Canada/CIHR Research Initiative on Hepatitis C.

Recommendations:

- 71. Continue funding research in partnership with CIHR.**

- 72. Develop a National Hepatitis C Prevention/Care Research Outcomes Network (HCV-PRO-NET) to guide prevention and care best practices.**

This network will be used to develop and evaluate innovative prevention, care and treatment strategies for at-risk populations (e.g., Aboriginal peoples, substance users, incarcerated individuals), HIV co-infected individuals, infants and children, and promote vaccination against hepatitis A and B viruses among hepatitis C infected persons. This network will also support community-based research.

The HCV-PRO-NET will use a “clinical trials” model, where, for example, interventions are applied and tested in a controlled fashion and outcomes are measured to generate new knowledge on best practices. We propose that a representative team of interdisciplinary experts and stakeholders including researchers, clinicians, social and behavioural experts, nurses and consumers pilot the use of the HCV-PRO-NET to design, develop and evaluate interdisciplinary prevention and treatment studies for those most in need. This network will use science-based principles to guide integrated prevention and care best practices at national, provincial and local levels.

Key aspects of the HCV-PRO-NET include:

1. The community groups affected by hepatitis C are very diverse and many are marginalized. Many, such as drug users and blood donor recipients, have not worked together for a common purpose. Community groups must have input and involvement in every aspect of the renewed initiative to ensure that the diverse needs of those infected with and affected by hepatitis C are taken into consideration.
2. A focus primarily on those most at risk and hard to reach/treat populations. Examples include: Aboriginal peoples, substance users, incarcerated individuals, HIV co-infected individuals, infants and children.

3. The unique feature of this network will be its mandate to bring the systematic approach that has already been applied to treatment trials networks and apply it to the evaluation of preventive interventions.
4. Support for community-based research.
5. A requirement to use existing resources where feasible. For example, a CIHR sponsored Canadian HIV Trials Network is in existence and certain components could be shared to minimize duplication and reduce costs.
6. Development of partnerships between CIHR, Health Canada, the Canadian Network for Vaccines and Immunotherapeutics (CANVAC) and other agencies (e.g., Canadian Association for the Study of the Liver [CASL], Canadian Infectious Disease Society [CIDS], Canadian Viral Hepatitis Network [CVHN]) will be encouraged to allow stakeholders to share knowledge, expertise and infrastructure. For example, a therapeutic HCV vaccine trial is imminent and could be carried out in Canada under the auspices of CANVAC in partnership with the HCV-PRO-NET. Such studies would put Canada at the forefront of scientific research in this area, and could help those most impacted by hepatitis C. These types of studies hinge not only on the scientific development and assessment of the therapeutic vaccine but also depend on the ability to maintain existing at-risk population cohorts (e.g., the Vancouver Injection Drug Study; St. Luc cohort in Montreal; OPICAN multi-site cohort of illicit opiate and other drug users in Quebec City, Montreal, Toronto, Edmonton and Vancouver (since 2001)). Tracking these high-risk populations or devising new strategies to track at-risk populations will be key to evaluating novel prevention, care and treatment programs in those at greatest risk of being infected including vaccines to prevent infection if developed.
7. The recently CIHR funded National Hepatitis C Research Training Program Grant will bring together inter-disciplinary experts to train tomorrow's leaders in prevention, care, treatment and education. The HCV-PRO-NET will provide the infrastructure to test and evaluate the effectiveness of inter-disciplinary interventions at national, provincial and local levels (i.e., provide knowledge translation).

The ultimate goal of the HCV-PRO-NET will be to serve as a knowledge broker between researchers, policy makers, healthcare providers and community to translate prevention, care and treatment knowledge into clinical practice.

- 73. Additionally, because ongoing evaluation and evidence-based decision-making should be built into all aspects of the Strategy, CBOs recommend that Health Canada support partnerships between community-based organizations and university programs for research and the development of appropriate evaluation tools.**
- 74. Patient, peer and community evaluation should be incorporated into all activities that affect individuals or the community.**
- 75. Health Canada should fund research on stigma and its effects on people with hepatitis C.**
- 76. Research and action strategies are needed to improve post-marketing approval surveillance and adverse events reporting.**

Recommendations for Program Management

In order to ensure a cost-effective, responsive Canadian Hepatitis C Strategy, it is recommended that Health Canada:

- 77. Increase overall funding to \$50 million annually with a strong capacity-building component.**
- 78. Provide opportunities for capacity building among community-based organizations, such that they will acquire the practical knowledge and skill sets needed for mobilizing themselves to effectively manage their concerns and issues. Ensure access to full project funding (based on a positive evaluation of capacity-building work and an appropriate application/work plan) within any 3 year funding cycle for organizations involved in capacity building.**
- 79. Provide a mix of project and multi-year operational funding (based upon positive evaluation results).**
- 80. Fund innovative pilot projects.**
- 81. Ensure transparency, timely communications and evaluation of program management by funding recipients.**
- 82. Support cooperation and collaboration with related strategies and initiatives (e.g. Canadian Drug Strategy, Canadian AIDS Strategy)**
- 83. Develop mechanisms for partnerships with Federal, Provincial and Territorial Ministries of Health, Solicitors General, Social Services, and Mental Health and First Nations and Inuit Branch.**
- 84. Reduce duplication of effort by maintaining user-friendly access to developed resources.**
- 85. Recognize and support a range of partnership models and development processes.**
- 86. Provide regular opportunities for skills building, sharing of best practices, and networking on both regional and national levels.**

Linkage to Other Strategies and Programs

Hepatitis C affects such a large number of people and has such an economic impact and unique qualities that it is important that it not be subsumed within other strategies. Rather, a comprehensive Hepatitis C Strategy must be linked to other public health and infectious disease strategies and share approaches and resources when addressing the same populations.

Because the risk is considered very low, hepatitis C is not defined as a sexually transmitted infection, although transmission is possible during sexual activity.⁶² Therefore, hepatitis C prevention efforts must be addressed uniquely from those addressing sexually transmitted infections.

Independent Hepatitis C Strategy

The concerns expressed by the Australian Hepatitis C Strategy Review Team can be applied to the Canadian situation. Specifically, the Review Team found that the evolutionary process for hepatitis C from being a ‘related disease’ to achieving a degree of autonomy within the established HIV infrastructure has been supportive but conditions attached have limited its effectiveness. They suggest that the hepatitis C infrastructure has been allowed to grow on the condition that it did not compete for HIV funding or seek an equitable power base. Several submissions to the Review argued that hepatitis C establish an independent framework distinct from the HIV infrastructure rather remain than tied to the HIV programs and activities.⁶³

Overall, to ensure that services are appropriate and responsive to changing needs of the hepatitis C community, capacity building, infrastructure development, systemic advocacy and expertise in the areas of human and legal rights must be developed and owned by the hepatitis C community. To these ends, cooperation and collaboration with current HIV/AIDS and related programs are highly desirable and will allow hepatitis C to build on the experiences and expertise that exist in the consumer communities.

Linkage to Harm Reduction Programs (needle exchange, drug treatment, methadone maintenance, standard precautions)

As stated by Leonard et al., ‘High HCV prevalence and incidence rates have been reported in a number of studies despite apparent widespread implementation of risk reduction strategies that appear to have been adequate to maintain a low or lower prevalence of HIV. Public health measures to reduce HIV risk-related injection behaviours have had an impact on HIV transmission. However, in view of the documented large reservoir of existing HCV infection in the IDU population and the high degree of infectivity and transmissibility of HCV per episode of blood contact compared with HIV, research should be conducted to examine the feasibility of modifying existing programs or developing new ones that target the elimination rather than reduction of HCV risk-related injection behaviours. For instance, research could be carried out to examine the utility of interventions aimed at encouraging transitions to relatively less risky forms of drug ingestion such as smoking, snorting and swallowing. Similarly, research could be conducted to examine the effectiveness of implementing MMT programs that administer methadone at dose levels associated with complete cessation of injecting, rather than simply reducing HCV risk-related injection practices.’⁶⁴ Continued research is needed into safer prescription alternatives to other ‘street drugs’ with their inherent problems of unknown purity, dangerous additives and the high costs of black market pricing and the subsequent crimes committed to obtain them. Establishing that HCV infection among IDUs is an important and high priority public health issue is fundamental to further interventions to control the spread of HCV.⁶⁵

Anticipated Mental Health Strategy

A number of studies have shown high rates of HCV infection among people with mental illnesses, particularly among those with a history of institutionalization. Conversely, hepatitis C and the drugs used in its treatment are associated with increased incidence of depression. The Australian Hepatitis C Strategy Review Team notes recent research into hepatitis C's effects on the brain and the links to depression (Foster et al. 1998; Forton et al. 2001). This research should be closely monitored, to guide mental health services for people with hepatitis C. As more people undergo hepatitis C treatment, the need for accessible counseling and mental health support will become even more critical.

Where appropriate, both mental health and drug services should be encouraged to participate in the development and delivery of hepatitis C-related prevention interventions.

Canadian Strategy on HIV/AIDS

Co-infection with HCV has become an increasingly serious problem for people with HIV. Close collaboration on issues related to prevention, care and support, treatment, and research need to continue.

Other Strategic Linkages

Linkages to other strategies should be explored and developed where they can increase awareness and effectiveness. These include strategies to address:

Determinants of health (housing, nutrition, medication, psychosocial support, education).

Canada's Drug Strategy.

First Nations and Inuit Health Branch, Aboriginal and Metis peoples and communities.

Canadian Strategy for Cancer Control.

National Public Health initiatives.

Relevant Provincial or Territorial strategies and initiatives.

"I don't know about other groups but I know the few people that we have are getting very run down health-wise, trying to help new people that are diagnosed with Hep C. We have no place that we can meet with them and help them understand what it is they are dealing with. I sure would not like sitting in a coffee shop talking about my new disease. I hope our government realizes just how serious the problem is before it is too late."

-Community group member, March 2004

Listing of Recommendations

Prevention

1. Prevention strategies must be linked to other programs of harm reduction, health promotion, and social and economic support as well as programs that address the risk factors for specific populations (e.g. prison populations, Aboriginal communities and street-involved youth).
2. Health Canada should, with new money, enable the participation of hepatitis C Community-based Organizations (CBOs) in the Strategy for Building Capacity Around Preventive and Therapeutic Vaccines against HIV, HCV and Cancer.

Health Canada has a responsibility to:

3. Ensure that effective harm reduction programs are identified, supported and promoted as models for implementation in similar circumstances.
4. Utilize the strengths of injection drug using communities to develop innovative strategies for peer support and education that reduce acute infections among 'new' users.
5. Address the determinants of health that lead to risk behaviours and sub-optimal health status. (e.g., it is more difficult to maintain safe practices when you're homeless, hungry and sick.)
6. Existing needle exchange/distribution programs across Canada should be maintained and expanded where indicated. Access should be provided in areas that are currently not served.
7. The federal government must continue its leadership role and support the establishment of safe consumption sites and ensure that barriers to use by marginalized populations (e.g. youth, women, Aboriginal persons) are addressed.
8. A range of drug dependency treatment options needs to be readily available across the country.
9. Health Canada must work with Corrections Canada and similar Provincial or Territorial Ministries to fund effective harm reduction programs that address the needs of both prisoners and correctional systems. Consistent implementation of current policies concerning harm reduction pilot projects should be encouraged.
10. Concomitant with clean injection equipment and treatment programs to reduce drug dependency is the need for education among prison workers to ensure there is appropriate understanding of hepatitis C risk factors and the need for support for harm reduction initiatives.
11. Reducing transmission risks by providing access to appropriate tattoo and piercing equipment, along with access to appropriate sites for performing these practices is also recommended.

Public Health services need to be adequately resourced to conduct coordinated disease surveillance, testing and prevention, which should include:

12. An improved national surveillance database.
13. The ability to conduct enhanced surveillance interviews for acute hepatitis B and C cases.
14. The capacity to provide testing and immunizations.
15. Targeted immunization programs and education for individuals at risk.
16. Ongoing collaboration between Federal, Provincial and Territorial Public Health and other relevant provincial agencies (e.g. BC Hepatitis Services).
17. Develop, implement and enforce a uniform set of regulations for tattooing, piercing, body modification and nail care businesses that prevent the risk of infection without being so prohibitive that businesses and customers are driven underground.
18. Guidelines for occupational exposures and healthcare workers with hepatitis C infection need to be clearly written and updated on a regular basis. These guidelines should also be clear for healthcare workers infected with HCV who have been successfully treated and demonstrate no detectable viral activity.
19. There is a need to implement education, practice and equipment modification strategies in healthcare settings to improve infection control practices and reduce occupational exposure risks such as needle stick injuries.
20. The development and promotion of guidelines on 'safer sex' practices, such as the use of condoms and dental dams is highly recommended as well as the promotion of other standard precautions, including not sharing toothbrushes or razors and/or engaging in unprotected sexual activity where blood may be present. In addition to minimizing the risk of HCV transmission, it is important to protect those who are HCV positive from dangerous co-infections.
21. Continued research and widespread dissemination of knowledge is needed about the mechanisms of vertical transmission, viral clearance in children, breastfeeding, and the treatment of children with rapidly progressing HCV infection.
22. Further research and public information are needed on transmission risks, natural history, symptomology, the role of hormone levels, contraceptive use, screening strategies, pregnancy care, and assisted reproduction.
23. Sustainable human and financial resources need to be designated for capacity building, skills sharing, and networking for youth, in order to ensure that peer education and support initiatives continue to be viable across a diverse set of youth communities (i.e. urban, rural, Aboriginal, street involved, incarcerated, etc.). This includes establishing or increasing resources for train-the-trainer programs, peer education and awareness building, and peer support and treatment information programming for HCV+ youth.
24. Youth also need to be engaged in policy and program development, which includes proactively addressing the stigma and lack of resources (i.e. financial, stable housing and others) that often act as barriers to youth voice and participation.

Public Awareness

25. Campaigns targeted at encouraging people with HCV risk factors should be developed and delivered by Health Canada in partnership with provincial/territorial governments, healthcare professionals and community-based organizations.

26. When mounting public awareness/testing campaigns, issues of varying literacy levels, age-appropriateness, and the need for materials in a variety of languages are important factors to plan for.
27. Broad-based public awareness campaigns for HCV must also specifically address the needs of youth, in particular in the area of stigma and discrimination. Reaching youth through public campaigns must also take into account venues and approaches that most appeal to youth in order to be effective (i.e. public services announcements on Much Music, use of the Internet, music festivals, and messaging in public places frequented by youth). Most importantly, campaigns that are developed for youth should be primarily designed by youth.
28. Health Canada should fund the development and delivery of a standardized HCV prevention curriculum to be delivered to all youth prior to them engaging in risk activities and address their early decision making patterns. This curriculum should be peer developed and delivered.
29. Federal/provincial/territorial support must be in place to develop rural alternatives to 'safe consumption sites' and continue to expand the reach of harm reduction programs, including mobile and fixed site needle exchange/distribution programs, methadone maintenance therapy (including low threshold programs), prescription alternatives to street drugs, and other disease prevention measures such as outreach programming that is developed specific to the needs of people who are now engaging in risk behaviours.
30. Public awareness campaigns aimed at reducing such stigma are critical to ensuring that people will access needed services.

Support, Education and Health Promotion

Health Canada needs to invest in Community Based Organizations that will:

31. Provide outreach, education and support programming that is community-based, community driven and community evaluated.
32. Foster peer-based support and mentoring programs that address the diverse needs of urban, suburban, and rural communities.
33. Utilize and support existing expertise within community-based hepatitis C organizations.
34. Ensure close collaboration with Needle Exchange Programs, AIDS Service Organizations, other disease organizations, Public Health, Aboriginal organizations, youth organizations, Addiction Services, prisoner advocacy/Corrections, Mental Health and anti-poverty groups.

Additionally, Health Canada should:

35. Fund and support the development of regional and national bodies that represent local and regional concerns, produce common resources, collaborate with other national initiatives and advise policy makers. These organizations need to be inclusive, accountable and representative of people affected by hepatitis C.
36. Fund and support capacity building at the community level.

37. Work with CBOs, Provincial and Territorial Ministries of Human Resources and Canada Pension Plan to ensure that chronic hepatitis C is recognized as a medically and functionally valid basis for Disability Benefits status.
38. Work both independently and collaboratively with other F/P/T Ministries to address the determinants of health that can positively impact health status before, during and after treatment. (e.g. Ensure safe housing needs are met for HCV positive youth and youth “at risk” [i.e. street involved youth]).
39. Health Canada should fund community-based organizations (CBOs) to develop and deliver an Expert Patients program to assist people with hepatitis C to better navigate the healthcare system and improve their capacity for self-care.
40. Health Canada should fund CBOs to develop and deliver outreach and peer education projects/programs.
41. To be effective, appropriate peer supports and resources, needle exchange services, safe injection sites, and access to adequate nutrition and shelter must support outreach and peer education programs.

Health Canada must provide the resources to enable CBOs to:

42. Collaborate with health educators on the design and provision of medical/nursing/dental school curricula and Continuing Medical Education sessions on hepatitis C and associated conditions for physicians, nurses and dental professionals.
43. Educate healthcare providers on issues such as working with people who use injection drugs, addictions medicine and pain management, and the realities of the issues faced by those who live with HCV prior to, during and after treatment.
44. Provide education and orientation to allied service providers (mental health, addictions, social workers, hospice, peer supports etc.)
45. Coordinate with existing chronic illness health education/promotion programs on the development and delivery of ‘Expert Patient’ programs.
46. Provide train- the- trainer education to hepatitis C community support group leaders
47. Deliver patient education/ self-advocacy/ wellness programs through a combination of face to face (one to one and group) and distance education utilizing telemedicine and high-speed Internet facilities.
48. Provide access to phone support/information services for patients and the general public.
49. Educate community service providers about support needs.
50. Partner in the development of a substantial nation-wide media campaign that publicizes risk factors and the need for testing, including youth-specific messaging and input.
51. Contribute to the continued development of a Canadian Hepatitis C Information Centre.
52. Incorporate prevention education into school curricula, beginning with basic, age-appropriate ‘Standard Precautions’ education in primary school, followed by prevention/harm reduction and negotiation/refusal skills in high school. Within this,

include a train-the-trainer curriculum in order to establish networks of peer educators, particularly in rural areas.

53. Develop peer education initiatives for youth groups outside of the mainstream school system, in order to target more at-risk youth – i.e. incarcerated youth, street involved youth, and youth participating in higher risk activities such as drug use and body art.
54. Ensure that materials are culturally appropriate and available in a range of literacy levels, learning styles and languages.

Care and Treatment Support

In conjunction with Provincial and Territorial Ministries of Health, and healthcare profession governing bodies, Health Canada should:

55. Ensure that adequate resources are in place to provide testing, pre/post test counseling and diagnostic analysis of blood samples.
56. Establish and regularly update protocols/guidelines for assessment, testing/workup, record keeping and referral.
57. Establish and regularly update treatment and follow-up guidelines.
58. Identify and establish telemedicine satellites in rural and remote communities.
59. Develop alternative care management (multidisciplinary teams, nurse practitioners, core team/extended team, etc.) and alternative physician billing models for the care and treatment of chronic diseases such as hepatitis C.
60. Fund and recruit physicians to train as hepatologists.
61. Improve the coordination of care and sharing of expertise on co-infection issues through the development of 'co-infection centres of excellence'.
62. Build more robust hepatitis C prevention, education, support, care management and research into Chronic Disease Management and Primary Care Reform initiatives.
63. Improve organ donation rates and ensure that transplant services develop the capacity to meet the increasing demand for liver transplants.
64. Ensure equitable access to drug therapy, care and treatment across all jurisdictions.

Community-Based Care and Support

Health Canada should provide the resources to enable CBOs to:

65. Establish mutual education and referral pathways for mental health, addictions, nutritional, and dental health counseling/services.
66. Establish education and pathways for community nursing, homecare and hospice services.
67. The use of Telehealth and Internet consultations should be expanded to increase access to specialized knowledge and reduce the burden and expense of long distance travel.

68. There is a pressing need to find avenues of collaboration and cooperation so that Aboriginal people living both on-reserve and off reserve benefit equitably, while respecting cultural and autonomy issues.
69. There is a need for increased resources to specifically treat youth with addiction issues.
70. Given the large number of HCV infected active drug users, further research and clinical trials are needed to investigate the possible interactions of anti-viral and illicit drugs and the successful treatment of injection drug users.

Research

71. Continue funding research in partnership with CIHR.
72. Develop a National Hepatitis C Prevention/Care Research Outcomes Network (HCV-PRO-NET) to guide prevention and care best practices.
73. Additionally, because ongoing evaluation and evidence-based decision-making should be built into all aspects of the Strategy, CBOs recommend that Health Canada support partnerships between community-based organizations and university programs for research and the development of appropriate evaluation tools.
74. Patient, peer and community evaluation should be incorporated into all activities that affect individuals or the community.
75. Health Canada should fund research on stigma and its effects on people with hepatitis C.
76. Research and action strategies are needed to improve post-marketing approval surveillance and adverse events reporting.

Program Management

In order to ensure a cost-effective, responsive Canadian Hepatitis C Strategy, it is recommended that Health Canada:

77. Increase overall funding to \$50 million annually with a strong capacity-building component.
78. Provide opportunities for capacity building among community-based organizations, such that they will acquire the practical knowledge and skill sets needed for mobilizing themselves to effectively manage their concerns and issues. Ensure access to full project funding (based on a positive evaluation of capacity-building work and an appropriate application/work plan) within any 3 year funding cycle for organizations involved in capacity building.
79. Provide a mix of project and multi-year operational funding (based upon positive evaluation results).
80. Fund innovative pilot projects.
81. Ensure transparency, timely communications and evaluation of program management by funding recipients.

- 82.** Support cooperation and collaboration with related strategies and initiatives (e.g. Canadian Drug Strategy, Canadian AIDS Strategy)
- 83.** Develop mechanisms for partnerships with Federal, Provincial and Territorial Ministries of Health, Solicitors General, Social Services, and Mental Health and First Nations and Inuit Branch.
- 84.** Reduce duplication of effort by maintaining user-friendly access to developed resources.
- 85.** Recognize and support a range of partnership models and development processes.
- 86.** Provide regular opportunities for skills building, sharing of best practices, and networking on both regional and national levels.

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