A National Hepatitis C Strategy in Canada

A Discussion Paper

Prepared by the
Canadian AIDS Society

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The Canadian AIDS Society

The Canadian AIDS Society (CAS) is a national coalition of 115 community-based AIDS organizations across Canada. CAS is dedicated to increasing response to HIV/AIDS across all sectors of society, and to enriching the lives of people and communities living with HIV/AIDS.

Since 1986, the Canadian AIDS Society has served as the national voice for the community-based AIDS movement. The national office advocates on behalf of people and communities affected by HIV/AIDS, develops programs, services and resources for its member organizations, and provides a national framework for community-based participation in Canada's response to AIDS.

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1.0 Background

Health Canada estimates that 210,000 - 275,000 people are infected with the hepatitis C virus (HCV) in Canada.[1] If resources and efforts remain the same, the numbers of people living with HCV will continue to rise dramatically in this country. Globally, an estimated 170 million persons, or 3% of the world's population, are chronically infected with HCV, with 3 to 4 million persons are newly infected each year. [2]

The major causes of HCV infection worldwide are use of unscreened blood transfusions, and re-use of needles, syringes, tattooing and piercing equipment. No vaccine is currently available to prevent Hepatitis C. Drugs, such as interferon taken alone or in combination with ribavirin, can be used for the treatment of persons with chronic hepatitis C, but the cost of treatment is very high. Treatment with interferon alone is effective in about 10% to 20% of patients. Interferon combined with ribavirin is effective in about 30% to 50% of patients. Ribavirin does not appear to be effective when used alone. Thus, from a national and global perspective, the greatest impact on Hepatitis C disease burden will likely be achieved by focussing efforts on reducing the risk of HCV transmission from nosocomial exposures (e.g. blood transfusions, unsafe injection practices) and high-risk behaviours (e.g. injection drug use). According to Health Canada, up to 70% of infected Canadians are unaware of their status.[1] Therefore, they are unable to take steps to protect their health and the health of others. Greater public awareness of risk factors and access to testing is needed. In order to deal with the demand for support and information, community-based programs need to be in place to assist people to take the steps required to slow disease progression and stay as healthy as possible for as long as possible. For those considering treatment (those who qualify under today's restrictive criteria) there is a need for education regarding the risk and benefits of treatment and support to attain successful treatment outcomes when undergoing this expensive and difficult-to-tolerate regime. The new pegylated interferon is currently only available to treatment-naïve patients. People who have had to discontinue treatment because of side effects and those who didn't respond to treatment, or who did respond but later had the virus rebound, often have no further options. Failing treatment can be a death sentence.

In September 1998 the Government of Canada declared its commitment to preventing the further spread of HCV and to the treatment and care of people living with the disease. Along with this commitment came an allotment of $50 million over five years for hepatitis C prevention, community-based support and research. This funding was intended as a means to meet our short-term goals and set the ground work for long-term results. Health Canada indicated that these longer term results would include an improved health and quality of life for people living with or affected by HCV; the establishment of a network of community organizations involved in HCV; an increase in treatment measures; efforts to ensure early diagnosis; increased awareness of HCV risk factors, community-based support and research; and increased adoption of risk reduction behaviours by those at greatest risk of infection. The five year allotment of funding was

[1]Hepatitis C: Hepatitis C Prevention Support & Research Program; Health Canada, Health Canada's website, available at http://www.hc-sc.gc.ca/hppb/hepatitis_c/pdf/hepcMidterm/i_problem.html , November 2003.
[2]Hepatitis C; Fact Sheet Number 164, October 2000, World Health Organization website, available at http://www.who.int/inf-fs/en/fact164.html .

established largely in response to the infection of thousands of Canadians through the blood system. Today's improved blood screening techniques have virtually eliminated this route of HCV transmission. Many of the people who were infected in this way however, are still in need of care, treatment and support.[3]

It is important to remember that even with sustained virologic response, the underlying damage and disability remains. In addition, the number of people with hepatitis C who, either now or in the near future, have cirrhosis, liver cancer or liver failure exceeds the total number of HIV and AIDS diagnoses in Canada. These numbers are expected to increase dramatically. Based on the estimate of 240,000 persons infected with HCV in Canada in 1998, it is projected that the number of hepatitis C cirrhosis cases will increase by 92% by 2008, the number of liver failures will increase by 126%, the number of hepatocellular carcinomas by 102%, and the number of liver-related deaths associated with HCV by 126%.[4] The need for liver transplants is expected to triple between 1998 and 2008.[1] Thus, despite the decreasing incidence of HCV infection, the future healthcare burden attributable to HCV-related liver disease will be quite significant. There are too few hepatologists to meet the coming demand. Not enough specialists and general practitioners have sufficient knowledge in treating and managing hepatitis C. Developing cost-effective multi-disciplinary team approaches that incorporate both healthcare providers and community services providers (including hospice, peer supports, financial assistance, housing, home care, mental health, addiction services, etc.) is essential.

2.0 Purpose

At their meeting in May, 2003 the Canadian AIDS Society's Board of Directors adopted the position of advocating for a Canadian Hepatitis C Strategy funded by the Government of Canada.[5] The Canadian AIDS Society believes that the Government of Canada has a responsibility to respond to the growing Hepatitis C (HCV) epidemic in Canada. The Canadian AIDS Society feels that the current Hepatitis C epidemic requires a Strategy that ensures a coordinated, integrated and multi-level approach by all governments in Canada that will be in place until the Hepatitis C epidemic is under control. It is projected that by 2030, HCV mortality in the US will be triple that of HIV.[6]

We are now well into the last year of funding for the Hepatitis C Program. However, there has been no indication from the Government of Canada as to how it plans to continue to support people living with HCV or to ensure continued and improved efforts to prevent the further spread of this disease. This issue calls for a coordinated, integrated and multi-level approach by all governments. Our federal government needs to display leadership on this issue and ensure that the programs and services that have been developed across this country are sustained and improved upon. Community-based organizations such as AIDS service organizations (ASOs) have been providing services to people infected with or affected by Hepatitis C for the past five years, despite being woefully underfunded. Even at its height, funding amounted to only $14 per infected person, annually. In 2003, most communities still do not have access to funded services.

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[3] Hepatitis C Strategy, Canadian AIDS Society Position Paper, CAS website at www.cdnaids.ca, 2003.
[4] Zou S, Tepper M, El Saadany S. Prediction of hepatitis C burden in Canada. Canadian Journal of Gastroenterology, July/August 2000;14(7):575-580.
[5] Hepatitis C Strategy, Canadian AIDS Society Position Paper, CAS website at www.cdnaids.ca, 2003.
[6] Internet Conference Reports. 54th Annual Meeting of the American Association for the Study of Liver Diseases. October 24-28, 2003. Boston, MA., available at http://www.hivandhepatitis.org/hep_c.html#111403b .

These organizations have been stretched to their limits and beyond in order to provide the necessary services while staying within the financial limits established by the Government of Canada in 1998. They are now facing an uncertain future accompanied by an ever growing number of clients. It is unacceptable to see community-based organizations that have come to be relied upon having to close their doors, end their programs, or work towards the inevitable closures of those programs and services.

The purpose of this paper is to examine possible approaches to the strategy that the government might take, based on examples from other national strategies world-wide and from the experience of ASOs and those organizations already providing HCV prevention and care throughout Canada.

The paper examines three possible approaches to implementing an HCV strategy in Canada, and examines the pros and cons of each approach. These approaches are 1) full integration of a new HCV strategy with the current Canadian Strategy on HIV/AIDS (CSHA). 2) Complete segregation of the two strategies and 3) Partial integration of the new HCV strategy and the CSHA.

In addition, this paper provides recommendations that the government should take to inform the development of the strategy regardless of the approach chosen. It should be noted that this paper does not examine the pros and cons of integration with Infectious Diseases (as recommended by CIHR), Bloodborne Pathogens (Interior Health, BC), Drug Strategy, nor sexually transmitted infections (STIs).

3.0 A Look at Other National Strategies

The following is a brief examination of existing HCV strategies in other countries which similar social, economic and civil infrastructures as Canada.

3.1 Australia

Australia was the first country to develop a national strategy for HCV[7]. *The National Hepatitis C Strategy 1999-2000 to 2003-2004* was launched in June 2000 by the Commonwealth Department of Health and Aged Care, Australia's federal minister. The Strategy has two primary aims:

- to reduce the transmission of hepatitis C in Australia;
- and to minimise the personal and social impacts of hepatitis C infection.

It identifies four priority areas for future public health activity:

- To reduce the transmission of hepatitis C in the community;
- To improve treatments for hepatitis C infection;
- To assist people with hepatitis C to maintain their health and provide care and support to those affected by hepatitis C; and
- And to prevent discrimination against people affected by hepatitis C and reduce the stigma and isolation experienced by them.

[7]Commonwealth Department of Health and Aged Care. The National Hepatitis C Strategy 1999-2000 to 2003-2004. Australia, June 2000.

The Strategy is based on six essential components that are considered fundamental to developing effective responses in the four priority areas. These components are: developing partnerships and involving affected communities, access and equity, harm reduction, health promotion, research and surveillance, linked strategies and infrastructures.

Eight papers entitled *Hepatitis C: Informing Australia's National Response* were also commissioned from the community and other government departments to inform the Strategy's development. The strategy builds and links with other policies and strategies within the Australian government, including the National HIV/AIDS Strategy and those implemented to reduce the impact of illicit drug use. In relation to the former, The Australian HCV Strategy is partially integrated with the national HIV/AIDS strategy where over-lap was naturally and successful occurring in the community already – such in areas of testing and prevention information delivery – while areas of treatment required a different approach and thereby strategy segregation.

3.2 England

England's infectious disease strategy, *Getting Ahead of the Curve*[8] developed in 2002 identified hepatitis C as an important public health issue requiring action. Consequently, a separate strategy for hepatitis C was developed: *Hepatitis C Strategy for England*[9]. The aims are to prevent new cases of hepatitis C infection, identify those who are chronically infected by increasing testing for hepatitis C and to offer specialist advice and appropriate treatment via co-ordinated pathways of patient care. A strengthened effort specifically targeted at injection drug users will aim at improving health promotion activities, including improving needle exchange services, the provision of harm reduction information and activities to prevent initiation into injecting. Treatment for drug dependency falls under the *Government's 10-year Drug Strategy*, and the newly established *National Treatment Agency for Substance Misuse.*

Health promotion campaigns are proposed in the hepatitis C strategy to raise awareness amongst the general population and to avoid infection. Further information will also be provided to primary care health professionals. Good practice guidelines are available for skin piercing and tattooing establishments and will be promoted, as will infection control guidelines in clinical settings. The strategy will increase the offer of testing in clinical settings and improve health services for those diagnosed by developing managed clinical networks and co-ordinated pathways of patient care, with accessible specialist treatment centres across the country. The strategy also recognizes the need for social care and support for those living with and affected by hepatitis C.

England's report highlights the relationship of the hepatitis C strategy to its other public health strategies. It ties the hepatitis C strategy into its government-wide public health strategy entitled Saving Lives: Our Healthier Nation as both strategies share goals of improving health and reducing the health inequalities, and to action to combat cancer, as HCV infection may cause

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[8]Department of Health, Getting Ahead of the Curve: a strategy for combating infectious diseases (including other aspects of health protection), England, 2002.

[9]Department of Health, Hepatitis C Strategy for England[9]: Implementing 'Getting Ahead of the Curve': action on blood-borne viruses. August 2002.

primary liver cancer. The hepatitis C strategy relates to the 10-year strategy for tackling drug misuse (Tackling Drugs to Build a Better Britain) by strengthening prevention activities and by identifying ID users already infected with HCV. Finally, the hepatitis C strategy relates to the infectious diseases strategy as mentioned above, which has identified the need to intensify measures to control serious infectious disease problems. Hepatitis C is an important component of the blood-borne virus action plan. This plan also ties into the action taken as a result of the *National Strategy for Sexual Health and HIV.*

3.3 United States

Hepatitis C is an emerging public health problem in the United States. The Centers for Disease Control (CDC), in collaboration with various partners, has developed The *National Hepatitis C Prevention Strategy*[10]. This plan is a public health strategy for prevention and control of HCV infection, for providing credible information to enhance health decisions, for the promotion of healthy living through strong partnerships with national, State and local organizations. Its aims are to lower the incidence of acute hepatitis C and reduce the disease burden from chronic HCV infection. To achieve its goals, the strategy proposes: harm reduction programs directed at persons at increased risk of infection to reduce the incidence of HCV; counselling, testing, and medical evaluation and management of infected persons to control HCV-related chronic liver disease; surveillance to evaluate the effectiveness of prevention activities; and research to provide answers to questions pertinent to the prevention and control of hepatitis C. The principle components of the strategy include education of health care and public health professionals, education of the public and persons at risk, clinical and public health activities, outreach and community-based programs, surveillance, and research.

The strategy offers that the most effective way to prevent HCV infection and its consequences is to integrate hepatitis C prevention activities into existing clinical services and public health programs, such as those for the prevention and treatment of HIV/AIDS, sexually transmitted infections (STIs), and drug use. The CDC strategy to lump HCV with HIV and STIs may be an expediency that takes advantage of existing state HIV and STI infrastructure. It may be an attempt to monopolize funding under the CDC umbrella. However, the focus on sexual diseases and transmission is troublesome as other expert sources see those linkages and risks as being of relatively minor significance for HCV.

3.4 Other Countries

Countries such as the Netherlands, Germany, Canada and Brazil are all in the process of developing strategies to address issues of HCV. However, what does not remain clear is the approach that these strategies will take in linking and connecting with related strategies and existing infrastructures, such as those addressing the issues of HIV/AIDS and other blood-borne pathogens and strategies addressing the issues of illicit drug use.

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[10]Centers for Disease Control and Prevention. National Hepatitis C Prevention Strategy: A Comprehensive Strategy for the Prevention and Control of Hepatitis C Virus Infection and its Consequences. United States of America, Summer 2001.

4.0 Approaches to Implementing a National Canadian HCV Strategy

Based on recommendations from the community and examples of other countries in dealing with HCV, it is believed that Health Canada is in the process of looking at ways to develop and implement a national HCV strategy in Canada. Although governments and communities groups alike agree that a strategy is needed, it is uncertain how an HCV strategy will link with other national strategies, specifically the Canadian Strategy on HIV/AIDS.

Many AIDS Service organizations have begun providing HCV prevention information as part of their HIV prevention programs, in the absence of this information being readily available from other sources. Issues of co-infection are also high on the agendas of many ASOs, and many medical clinics have introduced regular testing for HCV among their HIV positive patients so that routine issues of care and treatment can be addressed in the event of co-infection. However, the resources available for this work are limited, and many ASOs have taken this on as a matter of necessity rather than choice, stretching already limited human and financial resources. A national HCV strategy in Canada would begin to address these issues and provide much needed, long term resource support for HCV work in Canada.

One of the greatest strengths of the AIDS movement has been a sustained insistence that affected people play a central role in the planning, delivery and evaluation of services. This has built capacity within the community and ensured that programs and services are relevant and responsive. Some questions remain to be answered: Will Canadian ASOs be taking the position, either explicitly or through passive acceptance of the status quo, that a principle essential to their existence be denied to the hepatitis C community?

Principles aside, what would it be like if the majority of HIV/AIDS services were delivered by the Canadian Diabetes Society or the Arthritis community? These diseases, because of their autoimmune nature, are closely associated with hepatitis C. Many people with HCV develop all three. An argument could be made that, other than transmission risks, they have much more in common than HCV and HIV do. How would people with or at risk for HIV feel about receiving services from the Arthritis Society? Would they have confidence in the expertise or understanding of the challenges of living with hepatitis C? How would they perceive the Arthritis Society's commitment to their well-being? What would it be like to receive services from an organization with a different primary mandate and focus? What would likely happen during a time of funding shortage? Would these organizations be at risk of consciously or unconsciously making resource allocation decisions that favour their primary mandate and constituency?

Without actively advocating for and supporting genuine capacity building among the HCV community, will the HIV/AIDS community soon find itself in a weaker position by not having a strong community-based disease specific ally? Will the growing public perception that 'AIDS ain't serious anymore' lead to pressure to dramatically reduce future funding? A strong, committed, mobilized HCV community of 300,000 would be in the same boat and support mutual interests. Finally, let's consider the numbers; prevention activities target the approximately 5000 new infections that occur annually. Co-infection affects about 12,000 Canadians. That leaves over 250,000 HCV mono-infected Canadians in need of support, education, treatment care and management, and research activities.

The following portion of this paper examines the approaches that a national HCV strategy might take. This document looks at the potential HCV strategy and the options of development from a national government perspective. For example, arguments for segregation of the HCV and HIV strategies does not mean that ASOs that are providing HCV prevention information to their clients should immediately stop doing so. The argument is intended only to suggest that the approach the government takes in providing resources and a plan of action for providing this information should be separate from the HIV strategy is so far as it requires separate funding envelopes and not simply increases in funding to current HIV programs, as well as detailed and separate strategies for prevention, care/treatment, and surveillance. Conversely, an integrated approach does not mean that organizations specializing in HIV/AIDS work should automatically assume HCV under their mandate, but rather that the option exists for including it where necessary within the revised CSHA. Regardless of the approach Health Canada takes in developing and implementing a national HCV strategy, no strategy can operate in isolation. It must be linked to existing strategies and infrastructures, such as the CSHA and the National Strategy on Drug Illicit Use.

4.1 Integration of the National HCV Strategy with the CSHA

Because so many of Canada's AIDS Service Organizations are already providing HCV prevention, harm reduction information and other HCV services as part of their existing HIV programs, it has long been assumed that any national HCV strategy will be at least partially integrated with the Canadian Strategy on HIV/AIDS. Although the exact details of how this integration would look or be developed are unclear, the following looks at some of the broad issues of integration, in terms of the pros and cons of such a development.

Pros of Integration

- Established infrastructure for HIV program and service delivery benefits the implementation of the new national HCV strategy, resulting in more efficient delivery of HCV services to Canadian public;
- Less duplication of services, where over-lap between current HIV and HCV programs already exists, such as prevention and education;
- Broader continuum of care model for co-infected clients, and additional training for HIV specialists in HCV issues;
- In many ASOs and clinics across Canada, HIV and HCV programs and services, especially in the area of prevention and education, are already integrated as a matter of course and necessity; and
- Testing of HCV occurs earlier, as doctors and clinicians routinely testing for HIV add HCV to their testing programs.

Cons of Integration

- Reduced effectiveness of HIV programs and services that need to take on added burden of HCV programs and services;
- HIV/AIDS programs and services not designed nor equipped to deal with HCV, resulting in misinformation or confusing information, especially in the areas where prevention information is not the same or information is still being debated (ie. sexual transmission of HCV);
- Stakeholders for HCV and/or HIV may not buy in or support integration, thereby causing increased friction between stakeholders within a combined strategy;
- Fewer resources would likely be allocated to a combined HCV/HIV strategy than would be in separate strategies;
- Confusion among population and education professionals as to differing risks of exposure for each disease, making combining of prevention information difficult. The same difficulties would arise in combining treatment approaches to two very different diseases with very different treatment options. Co-infection also adds to this complexity;
- Overburdens already underfunded community infrastructure struggling with the HIV epidemic. Are we prepared for 6 times as many clients for 1/25th the funding per person?;
- HIV professionals and volunteers need to be retrained in HCV and co-infection care information;
- Transmission routes to entry for each disease can vary and can cause confusion among ASO front line workers and clients when trying to integrate education and prevention approaches;
- Information about sexual routes to entry for HIV are well established, while routes of entry around sexual transmission of HCV are still being debated;
- Stigmas associated with HIV (or STIs or illicit drugs) may deter significant numbers of people with HCV from accessing services;
- HCV has a very low public profile. Programs such as BC's Interior Health HIV/AIDS/Blood-borne Pathogens Plan further bury public awareness; and
- Hepatitis C already suffers from confusion with other form of hepatitis, both viral and non-viral.

4.2 Segregation of the National HCV Strategy with the CSHA

The following looks at some of the broad issues of keeping a national HCV strategy and the CSHA separate, in terms of the pros and cons of such a development.

Pros of Segregation

- HCV gets a separate and fully-funded specific strategy to address issues and HCV stakeholders do not get lost among the HIV community;
- ASOs free to take on burden of HCV work under separate strategy, and/or develop linked but separate approaches to prevention within the same organization or set up referrals to other organizations better equipped to handle HCV;
- Resources allocated for separate strategies likely to be higher than combined strategies;
- HCV Strategy can benefit from the experience of the CSHA in that it does not inherit problems of delivery and implementation of already existing strategy;
- Gives HCV stakeholders a separate and distinct consideration from the CSHA, which was not designed with these stakeholders in mind; and
- Can clearly define links with other strategies and infrastructures without directly competing for resources.

Cons of Segregation

- Possible duplication of services;
- Many AIDS organizations already doing HCV prevention and education under current mandate. Would require organizations to split programs and apply for funding under separate envelopes thereby convoluting the funding and resource allocation process; and
- HCV strategy does not benefit as fully from established HIV strategy experience and infrastructure.

4.3 Partial integration of HCV Strategy/CSHA

The following looks at some of the broad issues of *partially* integrating a national HCV strategy and the CSHA, in terms of the pros and cons of such a development.

Pros of Partial Integration

- Services are not duplicated where there is naturally an overlap between the strategies, such as in the areas of prevention and education and harm reduction;
- HCV benefits from in-roads made with HIV strategy, and yet retains autonomy and does not get solely identified with HIV; and
- The two strategies work together and become integrated where necessary, and provide an evolutionary model for integration and segregation over time, which can be revisited during the four year evaluation.

Cons of Partial Integration

- Competition for resources in some areas may lead to friction between various stakeholders in all areas of both strategies;
- Partial integration could sacrifice the continuum model, as more attention is paid to some integrated areas by a larger body of stakeholders; and
- Confusion among what areas of the strategy are integrated and what areas are not, thereby complicating funding processes and resource allocation for the communities doing the work.

5.0 Recommendations

1. That Health Canada carefully consider the pros and cons of each of the above named models, and provide strong rationale, based on in-depth consultations with the community, before a decision is made on the final approach, while at the same time ensuring issues of HCV continue to be addressed with adequate resources across the country;

2. That following the Australian example, that Health Canada commission opinion and discussion papers from the community and other government departments to inform strategy development;

3. That these position papers should be on the topics of HCV epidemiology and surveillance, community-based research, prevention, care/treatment/support, Injection Drug Use, Harm Reduction, testing, international issues, and linking current strategies and infrastructures with the new strategy; and

4. That Health Canada provide clear links with the new HCV strategy with both the CSHA and the National Strategy on Drug Use in Canada and other relevant strategies and infrastructures, both nationally and internationally.

6.0 Conclusions

It is expected that Health Canada will recommend a national HCV strategy in Canada within the next fiscal year. As with the CSHA and the previous National AIDS Strategies, recommendations for the implementation of any strategy must start with those already doing the work in the community. As such, it is also up to that community to make sure its voice is heard, and provide strong recommendations on the direction the National HCV strategy should take. Whether integrated, segregated and linked, or partially integrated, all that is known at this stage is that such a strategy is needed, that it is needed now, and that the community it is intended for must be involved in its design, implementation and eventual delivery, while at the same time ensuring the work currently being done in these areas continues.