

**Hepatitis C Prevention, Support and Research
Program
Hepatitis C Division
Health Canada**

**Community Consultation
on Program Renewal**

**December 12 & 13, 2002
Ottawa**

Meeting Summary

Draft Report, January 14, 2003

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1.0 Introduction

On December 12 & 13 2002, the Hepatitis C Division, Health Canada, held a consultation meeting with community groups and persons infected and affected by the hepatitis C virus on future activities for hepatitis C in Canada. (Meeting Agenda attached in Appendix A). This consultation meeting was one of a series of discussions that are being undertaken and was an opportunity for community groups and infected/affected persons to provide input on priorities for a renewed hepatitis C initiative and to identify current activities which may no longer be needed. This report summarizes the presentations that were made, the small group discussions, and the key themes which emerged.

1.1 Context of the Consultation Meeting

Since the discovery of the hepatitis C virus in 1989, Canada has taken a number of important steps in prevention and in the care of those infected, affected, and at risk of contracting the hepatitis C virus (HCV). In December 1994, the Laboratory Centre for Disease Control held a national conference discussing the prevention and control of hepatitis C. In 1997, the Krever Commission explored the issue of blood safety in Canada after many people became infected with blood-borne diseases through transfusion of blood or blood products. In March 1998, federal, provincial, and territorial (F/P/T) governments announced an offer of financial assistance to those infected with HCV through the blood system between 1986 and 1990. In September 1998, the Minister of Health announced a commitment of \$525 million dollars to provide care; including a \$50 million Hepatitis C Prevention, Support and Research Program. The Program, of a 5 year duration, is currently in its fourth year and work is commencing to renew the Program. Consultation with key stakeholders is an integral component of this renewal process.

1.2 Meeting Objectives

The objectives of the consultation meeting were:

- To provide input for the direction of a potentially renewed hepatitis C program;
- To determine if any key strategic directions (themes) were overlooked;
- To explore what form future hepatitis C initiative programming should take in a renewed Program.

Fifty one participants representing both individuals infected and affected by hepatitis C and community groups from across Canada working in the area of hepatitis C attended this two-day meeting. A participant list is appended.

2.0 Current Status of the Hepatitis Prevention, Support and Research Program: Where We Began, What We've Accomplished, and What We've Learned

After introductions, William Murray, Manager, Policy and Evaluation Unit, Hepatitis C Division, provided an overview of the Program, achievements to date and future directions.

2.1 Overview of 1998 Comprehensive Plan to Address Hepatitis C

On March 27, 1998, the federal, provincial, and territorial governments agreed to offer financial assistance to those Canadians who were infected with hepatitis C through the blood system between January 1, 1986 and July 1, 1990. The value of the settlement is approximately \$1.1 billion, plus interest, which represents the largest class action settlement in Canadian history.

In September 1998, the Minister of Health announced a \$525 million strategy to address hepatitis C in Canada. This strategy included:

- ▶ \$300 million over 20 years transferred to the provinces and territories to be used to augment HCV services provided by provincial/territorial health care programs;
- ▶ \$125 million over five years to strengthen blood regulation and disease surveillance;
- ▶ \$50 million for provincial and territorial "look-back/trace-back" initiatives to identify both recipients and donors of infected blood; and
- ▶ \$50 million to develop new HCV disease prevention, community-based support programs and research.

The \$50 million allotted for new programs and research would ultimately result in the Hepatitis C Prevention, Support and Research Program; a five-year initiative, running from 1999/00 to 2003/04. The program is in the fourth year of its mandate

2.2 Hepatitis C Program Components

To address hepatitis C issues in prevention, support and research, 5 components were established:

Prevention: initiatives aimed at preventing the transmission of hepatitis C among those who are currently uninfected. (\$4.9 million over 5 years)

Care and Treatment Support: targeted national-level initiatives aimed at supporting the needs of people infected with and affected by hepatitis C. (\$8.4 million over 5 years)

Community-Based Support: programming which supports both a strong community-based response to the needs of persons infected with, affected by, or at risk of contracting hepatitis C, and mechanisms for effective input from community-based organizations. (\$18.1 million over 5 years)

Research: initiatives intended to encourage and support the research, development and dissemination of knowledge about hepatitis C. (\$14.1 million over 5 years)

Management, Policy, Evaluation and Public Involvement: strategic management of the program using public involvement and evidence-based decision making. The delivery of the program is guided by a population health framework to ensure coordinated, integrated and long-term sustainable investments for the benefit of those persons infected with, affected by or at risk of hepatitis C infection and the Canadian population at large. (\$4.5 million over 5 years)

2.3 Risk Factors

From 1960 to 1992, an estimated 90,000 to 160,000 individuals were infected with HCV through infected blood or blood components. Since the implementation of universal blood screening for hepatitis C in 1990, the risk of contracting HCV through blood exposure in Canada has been substantially reduced. The most important risk factor identified for acute hepatitis C cases for years 1999-2001 is injection drug use. The distribution of risk factors are presented in Appendix B. Several of the participants asked for clarifications. It was determined that more accurate information was required around the risks of infection through sexual transmission.

Research is showing that the populations at greatest risk are:

People injecting drugs: Behavioural risk factors such as the sharing of contaminated needles and other instruments among people who use drugs is becoming a major population and public health issue. Injection drug use was the highest reported risk factor (> 60%) for the years 1999-2001 amongst acutely infected hepatitis C cases.

Incarcerated: In Canada, approximately 25% of those who inject drugs report that they were incarcerated at the time when they first injected drugs. The prevalence of HCV within prisons in Canada is estimated between 25% and 40%.

Aboriginal people: It is estimated that the incidence of acute hepatitis C infection among the Aboriginal population was on average 7.6 times higher than that observed in the Non-Aboriginal Canadian-born population.

Street Youth: Recent studies have shown that reported rates of HCV infection are also very high among street youth with injection drug use being a key factor. The Centre for Infectious Disease Prevention and Control conducted a study with street youth in seven large urban centres across Canada and found that out of 1200 street youth, 22% had injected drugs and of those who injected drugs, 15.9% tested positive for HCV.

2.4 Mid-term Evaluation of the Program

The sunset date of the Hepatitis C Prevention, Support, and Research Program is March 31, 2004. A mid-term evaluation has recently been completed for the Program to provide future direction and to identify successes and unmet needs. A series of successes and challenges were identified for each of the five program components. This midterm evaluation report will serve as a starting point for the preparation of a paper to renew the Program. Consultations such as this one, will fill the evaluation gaps and serve to broaden the justification for renewal.

2.5 Consultation Themes Working Group

In early October, a meeting was hosted of an external working group whose role was to help define the themes for the consultations on the Program's renewal. These themes will be discussed throughout the consultation meetings to ensure that any gaps in the evaluation are filled and to round out some of the issues that may not have been well addressed by the evaluation.

Four consultation themes were identified: research, prevention, care and treatment and partnerships. Cross cutting these themes were the issues of target groups, capacity building and information sharing.

2.6 Consultation Schedule

Five consultations with a series of groups and stakeholders have been planned. Some have already taken place.

NGO Consultation	November 13 2002	Ottawa
Drug Users Consultation	November 21 2002	Toronto
Aboriginal consultation	December 9 2002	Winnipeg
Community Groups and Infected/Affected Individuals	December 12&13 2002	Ottawa
Provincial/Territorial	January 9 2002	Ottawa

Researchers in the field of hepatitis C will be consulted throughout the month of January though teleconference or by mail and will be asked to identify emerging research gaps and priorities.

2.7 Next Steps

Lastly, the next steps following the series of consultations were outlined. All the information from the consultations and the evaluation results will provide the evidence to write a paper for renewal of the Program. In early 2002, the paper will be vetted within Health Canada and with other government departments. At the end of April, it will be considered by senior decision-makers and if approved, a contract with Treasury Board will be prepared. We may not know until February 2004 if the Program is renewed.

Q&A

-Further clarifications were required on how the consultations feed in the renewal process.
-Several participants were interested in finding out more about the work that has been done with health care professionals, physicians in particular. The lack of knowledge on the part of family physicians, the lack of knowledgeable physicians in remote communities and the difficulty marginalized populations such as IDUs have in obtaining hepatitis C medical care were identified as important barriers to care and treatment.

-A suggestion was made to obtain the names of the physicians and nurses trained through the fellowships offered in the area of hepatitis C and to communicate this information to communities. The issue of a proper fee structure to reimburse physicians for the care provided to hepatitis C patients was also discussed.

3.0 What Work Remains to be Done in the Area of Hepatitis C?

Participants were divided into six (6) groups for a discussion about what needs to be done in the area of hepatitis C. Highlights of the discussions were reported in plenary session.

3.1 Care and Treatment – What work remains to be done?

Participants were provided with a series of questions to aid discussion:

- Are the original goals for this Program component still relevant? If not, how should it be adapted?
- Are there additional gaps in care and treatment you feel need to be addressed?
- What needs to be done to address each of the challenges outlined, including new gaps raised?
- Are there specific care and treatment programs you feel Health Canada should support?

Care and treatment goals of the program: *To support persons infected with and affected by hepatitis C through the development and availability of tools and mechanisms and to strengthen the response of the Canadian population to hepatitis C through increased awareness and capacity.*

While these goals are still relevant, it was felt that the terms “tools and mechanisms” and “support” were ambiguous and needed to be better defined. The goals must clearly state what services the Program is supporting and through which mechanisms it intends to do so. Examples given include: through better informed physicians and frontline workers, through better communication and additional research, through support groups and peer education. Community groups made it clear that Health Canada should not support patients directly but help those who do.

The issue of “increased capacity” was also discussed. While there are service organizations that are well established in communities (i.e. AIDS Service Organizations [ASO]) there are other groups that are membership driven and which focus on care for those infected through the blood system or those who feel uncomfortable using an ASO. These community groups tend to be smaller, and funding is often difficult to obtain. Support must be offered to those smaller organizations and the requirement for showing partnerships at the funding application stage revisited.

It was also identified that the goals should be framed within the perspective of a broader national strategy or response which would ensure that the support and treatment needs of all those infected with hepatitis C are met, including those in remote areas and those with specific needs.

Challenges identified in the mid-term evaluation:

- a. Need to continue to address care, treatment and support issues for marginalized, underserved and at-risk populations
- b. Need to assess relationship with national NGOs in terms of relevancy and responsiveness to emerging needs

- c. Community agencies need more support/capacity-building
- d. Need examples of successes with at-risk populations

The groups felt that care, treatment and support are still needed for all Canadians in addition to the at-risk populations. Additional gaps and special emphasis was placed on the following:

- Need for improved access to care and treatment programs/initiatives for all people with hepatitis C.
- Need for more treatment options for people presenting alcohol and drug issues including support for harm reduction services and initiatives and increased services and care for people injecting drugs. Gaps in care and treatment were also identified with specific populations such as Aboriginal people, youth and co-infected individuals.
- Lack of coordination between provincial/territorial and federal governments. There is a need for better communication and coordination to eliminate some of the barriers to access to treatment. Provincial accountability and greater transparency for funds transferred to provinces/territories for care and treatment support for those infected by HCV is also required.
- Funding structure for community organizations is not conducive to integrated, long term programming. There is a need to address both the source of funding (across HC programs) and explore the availability of funds for infrastructure as opposed to project funding.
- Greater emphasis required on determinants of health (addressing basic needs and social issues such as housing, income support, food security).

Other gaps identified include a need for a more open screening process and increased peer support and support groups for those infected and affected by the disease.

Suggestions for Future Action:

Access:

- Facilitate access to hepatitis C care and treatment for all Canadians by increasing the number of health care professionals who can provide hepatitis C care and treatment
- Continue to provide guidelines and training to physicians and nurses and expand training to social workers and mental health workers who provide support and care to those affected with hepatitis C
- Expand treatment coverage so that more provinces cover the cost of treatment (this would require changes in relevant provincial drug assistance plans). Because care and treatment falls strictly within provincial/territorial jurisdiction, the federal role could only be one of encouragement
- Increase support during treatment course (i.e. information on side effects, counselling and support during treatment, support for visits to physicians or clinic)
- Support harm reduction initiatives, including low threshold methadone programs
- Encourage support groups and peer-based support. The support for peer education must be accompanied by appropriate funding

- Consider “travelling” practitioners to serve patients located in remote areas and northern communities.

Education/Awareness:

- Support public education efforts to raise the awareness of the Canadian population and to reduce the stigma associated with the disease. Consider the needs of the various targeted populations in developing the educational messages
- Demonstrate leadership in the development of culturally-based and culturally-appropriate materials
- Support increased research in the field of hepatitis C, including social/behavioral and community-based research. Emphasis must also be placed on developing accurate and consistent information

Information Sharing/Networking:

- Facilitate the sharing of examples of projects/initiatives and foster opportunities to showcase what is being done (through conferences, improved web site)
- Support a clearinghouse to store and disseminate all hepatitis C material developed
- Encourage and support the formation of advisory groups which would represent the needs of specific populations (i.e. IDU s)
- Consider the creation of a broad-based advisory committee which would include representation from several departments and several areas such as Corrections, Mental Health, Addictions, Aboriginal communities and Social Services. A multi stakeholder committee would help foster a more coordinated approach to hepatitis C
- Facilitate inter-provincial communication and communication between regions to identify successful programs, to identify what has been done by provinces/territories in hepatitis C programming and to share examples of successful projects

Role of Health Canada

Activities that could be supported by Health Canada include:

- Demonstrate national leadership to ensure the care and treatment for all Canadians infected/affected by hepatitis C
- Support hepatitis C programming at the community level
- Support research that addresses the cost effectiveness and quality of care of treatment programs
- Recognize the important role of medical and social service practitioners and further continue to support hepatitis C training and fellowships

3.2 Prevention – What work remains to be done?

Prevention goal of the program: *To contribute to the prevention of hepatitis C*

The group felt that this goal remained relevant but said a renewed program should strive to go beyond a “contribution” to the prevention of hepatitis C. There should be clearer targets and a strong will and commitment to prevention. Prevention goal must include a distinction between primary and secondary prevention.

Challenges identified in the mid-term evaluation:

- a. Need a clear national strategy to prevent the spread of hepatitis C
- b. Work more closely with at-risk groups (IDU, Aboriginals, inmates, street youth)
- c. Need to pursue more work with institutions (hospitals, public health, health regions)

While the group recognized that these are key challenges to meeting the Program's Prevention goal, the group felt that the Division should increase its efforts in public education, education of youth through schools and peer-driven education. There is a need to further develop the harm reduction programs and broaden the scope of prevention efforts to other health care settings/professions such as, aestheticians, tattooist, the dental profession as well as with correctional officers and mental health workers. Successful prevention must address systemic barriers that keep transient and marginalized and geographically isolated individuals from receiving services and prevention messages.

In addition to the need to work more closely with institutions, the group gave strong support to supporting the grassroots and frontline organizations who are often the first point of contact for people infected with hepatitis C. In particular, the support and funding for community groups and organizations could be improved. Finally, lack of access to screening and testing was identified as an important gap to effective prevention.

Suggestions for Future Action:

Prevention/Awareness:

- Although priority populations are important, a broad national, prevention/awareness campaign should be undertaken that focuses on the general population and which urges the general population to be tested. Health Canada could consider a Public Service announcement (PSA) or a National Testing Day.
- There is a need for targeted approaches for at-risk populations. Examples given were street youth, homeless, individuals in correctional facilities. Level of literacy is important and must be adequate.
- Community groups can play a key role in the specialized campaigns for at-risk populations. Thinking needs to be put into getting information to places the at-risk groups frequent i.e. drop-in clinics, bars, coffee-houses. Individuals that are frontline workers are well positioned to spread the message of hepatitis C prevention. The Division can support community groups in doing this work rather than undertaking these projects themselves.
- Prevention work should be started early in the schools. A curriculum on hepatitis C could be developed which could be adopted by the schools.
- Research into other risk factors such as the use of "crack" was suggested as well as a research on modes of transmission.

Access:

- Availability of clean needles around the clock and in alternative public settings i.e. pharmacies or other commercial establishments would go a long way to support prevention efforts in the injection drug using population.

Finally, participants were asked to identify particularly successful prevention projects as well as any activities which are no longer required. Peer education and the adoption of multi-pronged, holistic approach to prevention were identified by the majority of participants as successful mechanisms to hepatitis C prevention.

3.3 Summary

Despite the various interests of the stakeholders present at this meeting, a number of underlying themes consistently emerged from day one:

Equal Access:

- There is a large range of groups who need and will continue to require assistance and support from the Program.
- Those who provide care and treatment services must be informed and have the resources necessary to care for the disease or address the needs of those infected, affected or at-risk of Hepatitis C - transfused, IDU, people, youth, street-youth, homeless and transient populations.

Networking/Sharing of Information:

- There is a lot of work being done by various groups across Canada but the information is not being shared and disseminated from region to region.
- There is support for the sharing of successful initiatives, teleconferences and national conferences, and for the development of a clearinghouse to coordinate the knowledge base, and existing information materials developed by various groups.
- There is support for the expansion of the HC website and use of the web to disseminate information.

Education/Awareness:

- Support for a broad national awareness campaign.
- There is a need to work with youth and develop educational prevention messages for youth in schools.

4.0 What is the best way to accomplish the work that remains to be done in hepatitis C?

On day two, participants were again divided into small working groups. During the morning session these small group discussions were focussed on the processes, partnerships and activities required to complete the work set out in the previous day discussions.

The areas examined by the groups were:

Information sharing–

- What information do you need to better carry out your work?
- What is the best way to share information to benefit everyone?

Partnerships –

- What role do partnerships play in your work?
- How are successful partnerships forged and sustained?
- What are some examples of partnerships that have worked for you?

Program management –

- What can Health Canada do to support you, through the development of information, research and/or processes?
- How can Health Canada be most helpful in helping you do your work?

4.1 Information/ Sharing of information

Suggestions for Action:

Information for newly diagnosed:

- Develop information package for newly diagnosed including treatment options, support referrals, nutrition guidelines, information on alternative medicines)
- Train peer counsellors to answer critical questions and address initial crisis/shock
- Plain language information: the CLF materials were quoted as being helpful
- Nurses in Health Units to contact newly diagnosed
- More 1-800 info lines

Enhanced Web Site:

- Post information on new drug trials, fast tracking on new medications on the internet
- Increased release of important research studies
- Improve access to the internet: not youth friendly or accessible to the marginalized populations. Other means of dissemination are required for these groups
- Accurate and regularly updated information

Conferences/Meetings:

- Support for another national conference which would include community/grassroots focus
- Provincial/regional information sessions which would bring together a broad representative of health care workers such as, nurses, physicians, social workers, mental health workers, frontline workers, peer educators

- Development of networks such as the newly formed Canadian Hepatitis C Network (CHCN) and support of existing networks
- Teleconferences and satellites workshops would support more frequent opportunities for sharing of information

Materials:

- Sensitivity to literacy levels and cultural appropriateness
- There is also a need for more user-friendly resources and resources in additional languages
- Involvement of target populations in the development of the information materials
- Development of “basic tool kits and basic resources” to be adopted by others. This would help to reduce some of the duplication currently occurring
- More effective sharing and dissemination of information. Strong support for a clearinghouse
- Disseminate best practices, lessons learned, what works.

Peer Networks/peer education:

- Further develop and support peer networks/educators
- Peer networks are a very effective mechanism to share information in marginalized populations

Research:

- Need for additional research on modes of transmission. Comprehensive research and greater clarity around sexual transmission and research into risks associated with use of drugs other than through injection (e.g. sharing of crack pipes) is required.

4.2 Partnerships

Suggestions for Action:

Role of partnerships:

- Important to be realistic in terms of demands for partnership. Health Canada funding is strongly linked to ability to demonstrate partnerships. Sometimes, there are no “true” and useful partnerships at the beginning of a project. Partnerships build over time and this should be better recognized by Health Canada and reflected in funding applications
- Emphasis should be on new partnerships formed
- Partnerships bring reliability, support and stability
- Sometimes partnerships do not work due to competition for funding

Integrated/Comprehensive approach to care:

- There needs to be greater coordination between government programs: hepatitis C, HIV/AIDS, Mental Health, Addictions, Justice, Corrections and the First Nations and Inuit Branch. If the government works in silos, it is difficult to foster cross-disease partnerships and offer comprehensive, holistic care
- Fostering of relationships between groups i.e.hemophilia, HIV/AIDS, IDU to help build informal, and formal support systems
- Encourage inter-governmental committees and information sharing

Funding:

- Funding structure is not conducive to effective partnering. Difficult to develop true, effective partnerships with uncertainty of funding
- Higher awareness of other projects/programs funded through dissemination of projects/programs funded at regional and national level
- Increase funding for the development of opportunities for grassroots community groups to meet , get on-line, cover transportation costs and other barriers faced by remote communities

4.3 Program Management

Suggestions for Action:

Role of Health Canada:

- Health Canada should not be “doing” but “supporting” the majority of the work . More autonomy and decision-making must be given to regions and to community groups. The group supported a shift in perspective with a greater role to be played by community groups in the implementation of hepatitis C related care and support. Health Canada must support the community not lead it.

National Strategy:

- A National Strategy should be developed and coordinated by the Program. It should be broad-based, involve multi-stakeholders, local/community groups as well as provincial, territorial and federal levels of government.

5.0 Priorities

In the afternoon session of day two, participants were asked to identify their top priorities for inclusion in a renewed Program. The gaps and suggestions for action identified in day one were summarized in five categories; principles/cross-cutting elements, program management, care and treatment, prevention, research. Participants were asked to rate the elements presented (see Worksheet #4 - Appendix C) according to whether they determined them to be “must “do” “good to do” or “nice to do”. A plenary session followed and identified the following priority items:

Program management:

Funding:

Wide support for making it easier for community groups to obtain funding. Under funding, participants indicated the funding method has to change; attempts have to be made to provide operational, not just project funding; and finally, support was given to encourage HC to consider multi-year funding and funding for advocacy initiatives.

Research:

Community-based research was given broad support, followed by the need to: fund more psycho-social research; provide accurate and consistent information on hepatitis C; and continue to research modes of transmission. Specific research topics included clear statement around sexual transmission and exploration of issues specific to injection drug use.

Care and Treatment:

National hepatitis C strategy

The participants voiced clearly that they want to see a national strategy for hepatitis C with:

- Uniform access to drugs, care and treatment
- Programs that address all Canadians, no matter how they were infected or where they reside, including prisons
- A national screening program

Better informed and trained professionals

Several groups identified a strong support for continued educational work and training for health professionals (doctors, nurses, social workers, mental health workers etc..) who treat and care for patients with hepatitis C.

Support was also provided for peer support programming, programs addressing relapse/non-respondents, comprehensive treatment, including pain management, psycho-social as well as physical symptoms and programs addressing co-infection issues.

Prevention:

Public education

Strong support was identified for public education through IDUs, schools and common points of contact (i.e. pharmacies). There were differing views with respect to the focus of public

education: some felt education on hepatitis C should reach the public at large while others felt that a targeted approach was required for those at risk because populations at risk would not be reached by conventional methods.

Harm reduction

Under prevention, participants gave their support to a harm reduction approach to drug use, which would include: needle exchanges, legalization and taxation support, continuous coverage for needle exchanges and safe injection sites.

Stronger partnerships

Support by participants to ensure stronger partnerships, including sharing of information/best practices and better links between regions

The plenary session initially called for the development of a priority list whereby key elements from the priority items listed above would be posted. However, participants decided that all items were important and that it was very difficult to begin ranking priority items at the expense of others. Some participants were strongly opposed to developing a priority list.

6.0 Closure and optional networking session

Bill Murray gave concluding remarks. Bill acknowledged that it was perhaps unfair to ask stakeholders to establish a priority list and that the final decision making and responsibility for this was ultimately Health Canada's. This would be done as Health Canada moves closer to the submission of its paper for program renewal. A summary report of the meeting will be prepared and sent to all participants. There will be an opportunity to provide feedback on the report.

A networking session attended by participants only followed. It was lead by the facilitators.

Appendix A

Hepatitis C Prevention, Support and Research Program Community Consultation Thursday and Friday, December 12-13, 2002

Meeting: Government Conference Centre
Rideau Room
2 Rideau Street, Ottawa

Accommodations: Novotel Hotel
33 Nicholas Street, Ottawa
(613) 230-3033

OBJECTIVES and AGENDA

Objectives:

- To provide input for the direction of a potentially renewed hepatitis C program
- To determine if any key areas of work were overlooked to date
- To explore what form future hepatitis C programming should take in a renewed program

Draft Agenda – Day 1

- 8:00-8:30 Registration (*Continental breakfast will be provided*)
- 8:30-9:10 Welcome, introductions and discussion of the objectives of the meeting
- 9:10-9:30 ***Where we began and what we've accomplished*** – Presentation on the current status of the program,
Bill Murray, Senior Policy Adviser, Hepatitis C Division, Population and Public Health Branch, Health Canada
- 9:30-9:50 Questions and Answers
- 9:50-10:10 ***Mid-term evaluation – What have we learned?***
Bill Murray
- 10:10-10:30 Questions and Answers
- 10:30-10:45 Break
- 10:45-12:00 ***Hepatitis C care and treatment***
Small group discussion on the work required in care and treatment: What needs to be done and what is the best way to achieve it?
- 12:00-1:00 Lunch
- 1:00-2:00 ***Hepatitis C care and treatment - plenary***

Small groups report back, followed by a plenary discussion on common issues and suggestions.

- 2:00-3:00 **Hepatitis C prevention**
Small group discussion on the work required in prevention: What needs to be done and what is the best way to achieve it?
- 3:00-3:15 Break
- 3:15-4:15 **Hepatitis C prevention – plenary**
Small groups report back, followed by a plenary discussion on common issues and suggestions.
- 4:15-4:30 Conclusion of day 1 - remarks by Bill Murray

Draft Agenda – Day 2

- 8:30-8:45 Welcome and introduction to the day
- 8:45-9:30 **Success stories** – Small group discussion of particularly successful programs or initiatives, with an eye to identifying common elements or processes that lead to success.
- 9:30-10:30 **Information sharing and partnerships**
Small group discussion on the information, research, partnerships and processes required to help participants better carry out their work.
- 10:30-10:45 Break
- 10:45-12:00 **Information sharing and partnerships**
Small groups report back, followed by a plenary discussion on common issues and suggestions.
- 12:00-1:00 Lunch
- 1:00-2:00 **Establishing priorities for continued programming** – Small group discussion to review the activities outlined over the past two days with a view to setting priorities. What are the most critical initiatives that need to go ahead?
- 2:00-2:45 **Establishing priorities – plenary** – Discussion of priorities and how they would fit into a potentially renewed program. What key elements would form part of a renewed program?
- 2:45-3:00 Conclusion of the meeting – Closing remarks by Bill Murray
- 3:00-4:15 **Optional session: next steps** – Participants will have the opportunity to network and discuss potential partnerships and activities.

Appendix B

Incidence of Mutually Exclusive Risk Factors for Acute Hepatitis C, Aboriginal and Non-Aboriginal Canadian-Born, 1999-2000 Combined¹

<i>Risk factor</i>	<i>%</i>
Injection Drug Use	63.0
Unknown	17.0
Others	12.0
Health Care Acquired	4.0
Other Subcutaneous	2.0
Sexual	2.0

¹Sexual includes: Sex with hepatitis C carriers. Health care acquired includes: Blood transfusion blood product, hemodialysis, hospitalization, history of surgery, organ transplant, history of dental visit. Others includes: Drug snorting, blood contact, hepatitis C carrier in family, institution associated, and incarceration. Other subcutaneous includes: Tattooing, body piercing, acupuncture.

Appendix C

Hepatitis C Prevention, Support and Research Program Community Consultations

Worksheet #4 – Setting Priorities

Yesterday, you told us what was still needed in the areas of care and treatment and prevention of hepatitis C. This is a reflection of those views:

Program principles/management

- Funding
 - eliminate “stovepiping” between programs
 - ensure multi-year, secure funding of sufficient quantity
 - attempt to provide operational, not just project funding
 - ensure accountability for use of provincial funds
- All programs to be informed by infected/affected people
- Address determinants of health (adequate housing, income, food, education, self-esteem, sensitivity to comfort levels)
- Culturally-specific approaches (in multiple languages, for low literacy groups, etc.)
- Support programs specific to needs of groups and individuals
- Cross-cutting Elements
- Improved communications and sharing of information
 - between HC programs: no silos
 - between community organizations: more sharing
 - to tie all groups together: an advisory group
 - potential mechanisms: hepatitis C clearinghouse, conference
 - between governments: a federal/provincial/territorial committee on hepatitis C
- Strong political leadership
- Address systemic barriers
 - stigmatization as a result of source of infection
 - correctional system
 - isolation/transportation (rural)
 - low literacy
 - legal barriers to treatment
- Research, including
 - modes of transmission
 - effective education methods
 - psycho-social research on risk behaviours

- community-based research
- accurate, consistent information
- alternative treatments
- issues specific to IDUs
- Better informed and trained professionals (doctors, nurses, social workers, etc.)
Adequate compensation to deal with complicated issues hepatitis C presents

Care and Treatment

- A national strategy with:
 - Uniform access to drugs, care and treatment
 - Programs that address all Canadians, no matter how they were infected or where they reside, including prisons
- Better informed and trained professionals (doctors, nurses, social workers, etc.)
- Equal treatment for all people, including those who may not identify with the issue (barbers, tattooists), as well as inmates, IDUs and other marginalized people
- Comprehensive treatment, including pain management, psycho-social as well as physical symptoms
- Continuous treatment – from diagnosis forward
- More inclusive screening –
not just at-risk groups
with adequate support and treatment
- Programs that address co-infection issues
- Programs that address the re-lapse of non-respondents
- Better tools and mechanisms; and better sharing of those available

Prevention

- A harm reduction approach to drug use, including
 - needle exchanges
 - legalization and taxation
 - support
 - continuous coverage (24hours /7 days/week)
 - safe injection sites
 - other drug delivery methods (not just needles)
- Public Education, using consistent, accurate information, through
 - school curricula
 - health practitioners
 - injection drug users
 - youth

- peer-to-peer approaches
- workshops
- common points of contact (e.g. Pharmacies)

- Stronger partnerships, including
 - piggy-backing of programs, information
 - sharing of information/best practices
 - better links between regions
- Resources to reproduce and distribute good materials
- Look at international successes
- Blood-less (or reduced) surgery
- Multi-pronged approaches
- Industry support

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