

Hepatitis C: Intervention Programming for Youth at Risk

Final Consolidated Report



This document was initiated/prepared by the former Population and Public Health Branch of Health Canada before the creation of the new Public Health Agency of Canada on September 24, 2004. The new Agency is now responsible for its release and dissemination.
Published by authority of the Minister of Health
This publication can be made available on computer diskette or in large print upon request.
This report can also be accessed through the Public Health Agency of Canada website at: http://www.phac-aspc.gc.ca/hepc/hepatitis_c/index.html and through the Canadian Hepatitis C Information Centre at: http://www.hepc.cpha.ca/english/res_e/index.htm
The opinions expressed in this paper are those of the author and do not necessarily reflect the official views of the Public Health Agency of Canada.
© Her Majesty the Queen in Right of Canada, represented by the Minister of Health 2004 Catalogue No. H39-4/51-2004E ISBN 0-662-38025-8
PDF: H39-4/51-2004E-PDF 0-662-38026-6
HTML: H39-4/51-2004E-HTML 0-662-38027-4

Hepatitis C: Intervention Programming for Youth at Risk

Final Consolidated Report

Prepared for:

Hepatitis C Prevention, Support and Research Program
Community Acquired Infections Division
Centre for Infectious Disease Prevention and Control
Population and Public Health Branch
Health Canada

Prepared by: The Alder Group

2004

Table of Contents

1.	Introduction	1
2.	Information Review	1
	2.1 Research Methodology	2
	2.2 Initiatives for Youth at Risk	3
	2.3 Intermediary Programs	4
	2.4 Materials	8
3. I	Interviews with Intermediaries	11
	3.1 Communications – Issues and Vehicles	11
	3.2 Successful Programs	16
4. F	Report on Focus Groups with Youth	21
	4.1 Methodology	21
	4.2 Awareness of Hepatitis C	23
	4.3 Communicating the Hepatitis C Message	25
5. (Conclusions and Recommendations	30
	5.1 Broad Parameters of Success	30
	5.2 Most Promising Programs	31
	5.3 Key Messages and Messengers	32
	5.4 Support Resources Required	33
Арр	pendix A – Interview Guide Intermediaries	34
App	pendix B – Intermediaries Interviewed	36
App	pendix C – Facilitators' Guide: Focus Groups	37
App	pendix D – Key Fact Sheet	42
Арр	pendix E – Detailed Results of Focus Groups (by city)	43
Apr	pendix F – Focus Groups: Partnering Organizations	49

1. Introduction

In the mid-term program evaluation of the Hepatitis C Prevention, Support and Research Program, Health Canada identified several at-risk populations in need of information about hepatitis C, particularly youth at risk. Youth at risk can be defined as "alienated and marginalized youth who are characterized by: adopting the street lifestyle, dropping out of school or failing academically, being involved in alcohol and/or other drug use, and being involved in illegal behaviour." (Health Canada, 1997) As these youth are among the populations at greatest risk of contracting hepatitis C, effective means must be found to provide them with targeted information on how to prevent the acquisition and/or transmission of the hepatitis C virus (HCV).

This research project aims to answer the question, "What do people need, in their hands and in their heads, to act on hepatitis C prevention?" The research will gather information to:

- identify the needs of youth at risk with regard to the prevention of hepatitis C;
- identify the needs and effective approaches, including vehicles and language, for use by intermediaries, including peer intermediaries; and,
- provide recommendations for the development of preventative approaches and materials.

The project is based on the assumption that the most effective approach to reach youth at risk will be via intermediaries, including youth intermediaries, and not directly to the youth at risk. This project encompassed three phases:

- 1. An information review, which included analysis of programs and materials directed to youth at risk;
- 2. Interviews (12) with intermediaries dealing with youth at risk; and,
- 3. Focus groups (six) conducted in cities across Canada.

This report represents the results of these three elements separately, then provides recommendations for future programming directed to youth at risk.

2. Information Review

A review of current programs and materials regarding hepatitis C directed specifically to youth was conducted, covering the following elements:

- programs delivered via intermediaries, including peer intermediaries;
- promising materials to raise awareness of the issue among youth at risk; and,
- websites of interest to intermediaries and youth.

2.1 Research Methodology

To conduct this review, the following activities were undertaken.

- ➤ A review was completed of programs and materials of Health Canada-funded hepatitis C projects across Canada, with information as provided by Ottawa staff.
- ➤ A literature search of published research on effective programs was conducted. The programs and studies used in this information paper were found through targeted Internet searches with different search engines (Google[™], Yahoo®, Altavista[™]), periodical searches at the Health Canada library using SydneyPlus and through the Medline/Publine online database of health-related periodicals, supplied by the US National Library of Medicine and the National Institutes of Health.
- An Internet search was done for programs listed on reputable websites, as found using the search engines cited above.
- ➤ Information provided through health promotion list serves was reviewed.

Overall, there was little information available on evaluated programs targeting youth at risk and hepatitis C prevention; however, some Australian studies were found to have examined the role of peer intermediaries in reaching youth at risk and providing them with prevention information. These study results will be discussed in a subsequent section of this document. Many of the programs found were closely linked with AIDS programming, based on a common method of transmission for these two infections (i.e., injection drug use/IDU).

Secondary searches were also conducted to determine what programming options currently exist for youth at risk in relation to other health behaviours such as substance abuse and tobacco usage. Some different programming options were found as means to encourage the cessation of tobacco use among teens and youth at risk.

These programming options included some of the more traditionally focused youth at risk options such as outdoor education programming ("Outward Bound" types of initiatives, weekend retreats, etc.) and community-supported programming where smoke-free, alternative environments (e.g. community centres, dances, playgrounds) were set up and which youth were encouraged to use.

Attempts were also made (unsuccessfully) to contact via phone and e-mail the program managers and researchers related to the programs and studies found.

This report outlines effective approaches and materials aimed at preventing the spread of infections among youth at risk. These issues were further explored via interviews with intermediaries and focus groups with youth.

Note: A series of reports has been developed by Health Canada relating to youth and substance abuse. Their findings are not repeated here. They can be accessed via Health Canada or on its website at

http://www.hc-sc.gc.ca/hecs-sesc/cds/publications/index.htm#public_youth

2.2 Initiatives for Youth at Risk

Programs

Programming targeted to youth at risk was often found to include the use of peer intermediaries/peer educators to reach the intended audience. In some instances, the intermediaries (peer and otherwise) involved in the programming activities were former injection drug users who may also have been diagnosed with hepatitis C. These types of intermediaries, who have experienced the same circumstances and faced the same risks as the target youth audience, may share a common perspective with the youth.

Current hepatitis C programming activities in use that target youth at risk include the following.

- ➤ Needle exchange programs, often staffed by peer intermediaries/peer educators, which may also offer health screening services.
- > Drop-in centres with peer counsellors and other intermediaries on staff. Telephone hotlines are also available through some centres, as are support groups for youth infected with hepatitis C.
- ➤ Theatre productions used to convey information on sex, sexuality, risk factors and self-esteem, which encourage audience interaction (asking questions, etc.).

Much of the traditional programming around issues such as drug use and sexually transmitted diseases (STDs) has been done in school settings. Often, however, these programs miss youth who may have dropped out of school, or they use approaches that do not engage this particular population.

New programming options, such as the activities listed above, in non-traditional venues (i.e., at needle exchange programs rather than school assemblies) and in non-traditional formats (i.e., theatre productions rather than lecture formats) are being used to attempt to reach youth at risk in settings they may be more familiar with. These options employ formats that are more appealing to this group, and are not dependent upon youths' literacy skills.

Materials

In conjunction with programming initiatives, hard copy materials are also being produced and distributed to youth at risk to further "bring home" the programming messages. Materials used in targeting this population make use of plain language approaches, including the use of common street or slang terms for drug use and sexual contact. These materials

make good use of graphics and images to combat issues of literacy and the lack of familiarity with medical terminology.

Much of the material produced is in the form of pamphlets, stickers, post cards, key chains and other materials that can be easily distributed to youth on the street. This facilitates the distribution of these materials in settings other than schools.

In addition, several youth-oriented websites exist, but may need to be combined with other programming approaches (such as designated terminals in drop-in centres) as access to the Internet may not be readily available for this population, especially homeless youth.

Program and material messaging

Overall, these programs and the accompanying materials aim to get across specific messages of hepatitis C prevention to youth. The target messages being conveyed include:

- > the risk factors for contracting the hepatitis C virus (through injection drug use, non-sterile application of body art and piercing, unprotected sex with multiple partners, or other risk factors);
- ➤ the means of preventing hepatitis C, including use of clean needles, use of hygienic tattoo/piercing practices, safe sexual practices, etc.;
- > the symptoms of suspected hepatitis C infection (fatigue, changes in urine/feces colour, jaundice); and,
- ➤ where further information and help is available to youth.

2.3 Intermediary Programs

Two recent initiatives in Australia examined the efficacy of peer-based education/counselling programs for youth at risk. A pilot project and a study were conducted using grants from Australia's Federal Health and Aged Care department.

Dr. S. Sawyer, as cited in the *Report on the Strategic Research Development Committee's Program of Social and Behavioural Research into Hepatitis C* (See references, at the end of Section 1) indicated that much of the information available to young injection drug users about blood awareness, such as how blood-borne viruses may be transmitted, was not appropriate, i.e. language used, tone, etc.

For the study, 65 youth were recruited from needle exchange programs and given basic education on HCV. After receiving the education, the recruits were asked if they would in turn be interested in recruiting other youths to the program and educating their peers.

The significant findings of this study were twofold. First, participants in the program reported that they had learned new information that resulted in a change to some aspect of their behaviour, with regard to HCV prevention (again, details were not given as to what

specific behaviours changed). Second, the youths found that becoming a peer educator had a "significantly greater effect on knowledge" of HCV risks, preventative measures, etc., than when they had only received peer education. However, both groups (peer educators and the recipients of the peer education) did indicate that they had learned from being part of the study.

This study seems to suggest that peer education or peer intermediary programs hold benefits for the youth who receive peer education, but that more significant gains may also be obtained through increased recruitment and training of the peer intermediaries themselves. This study also suggested that the use of peer intermediaries was a more appropriate means of transferring information to youth at risk than some of the current materials available. It did not specify, however, what materials had been used.

The second study, conducted by Dr. Nick Crofts (cited in the same Report on the Strategic Research Development Committee's Program of Social and Behavioural Research into Hepatitis C) had similar results to the Sawyer study, based on pilot-testing of a peer-based hepatitis C counselling and testing service at a needle and syringe program. This study placed trained peer counsellors at needle/syringe exchange programs to provide HCV testing and counselling services to injection drug users. It concluded that the counselling provided helped to decrease risk-taking behaviour or recipient injection drug users, and that "the delivery of these services by a trained and experienced peer ... is an appropriate and effective model."

Canadian programmers are also employing a peer intermediary model in their hepatitis C programs targeted to youth at risk. The following are examples of two Canadian peer intermediary programs.

YouthCo

http://www.youthco.org

YouthCo is a Vancouver-based non-profit organization that works with youth on HIV/AIDS programming. Included in their repertoire is the HEPCats program (Hepatitis C Advocacy and Treatment), that uses peer-counselling initiatives to provide support and information to youth infected with AIDS and HCV or youth at risk of contracting HIV and/or HCV.

The Teen Health Centre

http://www.teenhealthcentre.com/teens/programmes/pro02.htm

The Teen Health Centre in Windsor-Essex County, Ontario, has a hepatitis C division with several programs targeted to youth dealing with HCV either personally or in their families. In particular, the Speakers' Bureau program is aimed at youth at risk, including recovering injection drug users. The program aims to help these youth increase their decisions-making capacity surrounding healthy lifestyle choices. The program concludes with participants making presentations about the program to other youth and peers in the community.

Intermediary programs

The intermediary programs available to youth, including programs targeted to youth at risk by organizations with programs focused on hepatitis C issues, run the gamut from informal drop-in centres staffed by intermediaries to formal education and counselling sessions, workshops, medical screening and referral services. The intermediary programs may be offered on the organization's premises, but many also operate through mobile outreach units that work at youth-oriented venues (concerts, raves, demonstrations) and at needle exchange programs in order to make themselves visible to youth who may be in need of their services.

A less traditional approach being used by intermediaries to address issues of risk-taking behaviours including substance abuse and sex, is interactive theatre group performances. These performances encourage audience participation through questions related to the issues being presented onstage.

This type of initiative also makes use of peer intermediaries, as youth in the community are recruited to help create and stage the theatre performances. YouthCo of Vancouver, HIV Edmonton (http://www.hivedmonton.com/link/theatre.html), and Rossbrook House in Manitoba, are all currently employing this type of programming in their organizations.

A second programming approach being employed by these organizations is the establishment of "Dinner Clubs". Having found a low response rate and buy-in for traditional support group settings in the at-risk population, and particularly among injection drug users, YOUTHLINK Inner City in Toronto instead established informal dinners where youth at risk could gather and speak to one another and available counsellors, without the setting confines of a group support session. YOUTHLINK reported that this program had to be re-examined and reworked on a couple of occasions in order to find the format that would best accommodate the non-traditional lifestyles of their clientele. They found that holding the suppers at the end of a traditional "workday" when many of the youth were already at the centre for other programs, meant that the youth would stay for the dinner club program. Scheduling the suppers later in the day, which would require the participants to potentially leave for a few hours and then return, proved ineffective, as the participants' lifestyle, including drug use, would often prevent them from returning later.

YouthCo of Vancouver also provides dinner club type programming, as well as monthly events programming and a yearly retreat for program participants.

The Alberta Alcohol and Drug Abuse Commission (AADAC) (http://www.aadac.com) has established a youth advisory council, in order to help inform intermediaries making programming decisions. AADAC intermediaries work with the Youth Council members to garner opinions on AADAC's print materials, television campaigns and website content, as well as providing suggestions on programming needs.

Other intermediary programming options being offered by various organizations include:

- ➤ "Train the Trainer" type initiatives provided by organization intermediaries to volunteers, youth workers and other health care workers (e.g. YouthCo and HIV Edmonton);
- ➤ Educational workshops for both youth and front-line youth workers, to expand general hepatitis C knowledge (risk factors, transmission, symptoms, etc.) (e.g. YOUTHLINK, ACCESS The AIDS Committee of Sudbury, Rossbrook House, Get Together to Get Better in Cape Breton);
- ➤ Traditional support groups (e.g. HIV Edmonton, ACCESS, Wabano Centre for Aboriginal Health http://www.wabano.com); and,
- ➤ Telephone "Helplines" staffed by intermediaries offering support to individuals affected by hepatitis C (e.g. Hepatitis C Support Project of San Francisco).

Intermediaries

Some of the organizations currently supplying hepatitis C programming have also tried to find other intermediaries in the community who may have contact with individuals at risk of contracting HCV. As such, these organizations have instituted educational programs in order to reach other possible community-based intermediaries. One example is the development of community workshops specifically for pharmacists, prepared and delivered by Hep C – CB (Cape Breton). In response to the pharmacists' organization identifying an increase in prescriptions for injection pharmaceuticals, Hep C – CB was planning a daylong session for pharmacists surrounding injection drug use in general and HCV in particular.

In addition, a study out of Australia, entitled "An intervention to improve compliance with skin penetration guidelines in tattooists, beauty therapists and hairdressers" (See Strategic Research Development Committee Report) suggests that, despite introduction of health guidelines, tattoo artists, and body piercers (as well as hairdressers and beauty therapists) are still lacking knowledge of how to prevent blood-borne diseases such as hepatitis C , and that education of this population could be done through intermediaries such as public health officials who are already doing premise inspections.

This could be a future direction for some Canadian intermediaries — to provide additional prevention counselling to a group that is working first-hand with youth at risk in an area where prevention is a key issue. Educated tattoo artists and body piercers would then, in a sense also become secondary intermediaries, working with youth to prevent blood-borne transmission of HCV through the promotion of clean tattooing and piercing practices. Social and outreach workers, youth corrections officers and others who work with youth would also fall into this category of intermediaries.

2.4 Materials

For youth

The materials being produced by various organizations targeting youth at risk tend to be comprised of pocket-sized pamphlets, brochures, stickers, key chains, etc., that are easily distributable from a variety of locations such as street corners, needle exchange programs, concerts, malls, etc.

A good example of a materials based initiative, is the distribution of "party packs" at local area raves by the Youth ESsential (YES) project, administered by AIDS Calgary Awareness Association. The party packs contain stickers, temporary tattoos, lubricant, condoms and lollipops, much of which is branded with the YES program logo. This has raised awareness and increased the visibility of the YES program.

The following is a list of some of the materials in production (at the time of writing) for youth listed by subject matter.

Hepatitis C, AIDS and safe sexual practices

- ◆ YouthCo HEPCats pocket guide produced by YouthCo on hepatitis C information
- Straight up on Hep C pocket guide produced by Youthlink Innercity on hepatitis C information
- ◆ Sex, Drugs & Prevention: Hepatitis C pamphlet produced by Sexuality Education and Resource Centre (SERC) one of a series which includes HIV/AIDS, Hepatitis B, Herpes, Chlamydia & Gonorrhea, Genital Warts
- ◆ What is Hepatitis C? postcard produced by AIDS Calgary one of a series which includes What is an STD?, What is HIV/AIDS?, What is Harm Reduction? Safer Partying Tips, Youth Empowerment You can make a difference
- ◆ Fun Ways to F*!k Around Safer C pocket guide produced by Youthlink Innercity with information and instructions on safe sexual practices (also mention of body piercing and HIV/AIDS)
- ◆ Condoms...Your best bet for safer sex pocket guide with information and instructions on condom use, originally produced by the AIDS Committee of Toronto, reproduced by the Village Clinic (Manitoba)
- ◆ Dam It: Facts about safer oral sex pocket guide with information on oral sex instructions on dental dam use, produced the Village Clinic (Manitoba)
- Germs: How to Stay Healthy on the Street booklet produced by StreetWorks with information on hepatitis C, AIDS, other STDs and communicable diseases
- Harsh Reality booklet produced by Kali Shiva AIDS Services and SERC with information on hepatitis C, AIDS, and other STDs

- pBe Street Smart booklet produced by Love Lives Here with information on hepatitis C, AIDS, and other STDs
- ◆ Condom key ring from Think Again

Tattooing and Piercing

- ◆ Safe Tattooing and Piercing: Finding a studio that's right for you pamphlet produced by The Wellington-Dufferin-Guelph Health Unit
- ◆ Safe Body Art: Are you thinking about getting a Tattoo or Body Piercing pamphlet produced by HIV Edmonton
- Tattooing and Piercing: Make it safe pamphlet produced by the Region of Peel
- Body Art, Body Smart pocket guide produced by YouthCo
- Why get a body piercing or a tattoo? postcard produced by AIDS Calgary one of a series (see above)

Drugs and Needle Use

- Injection Drug Use pocket guide produced by Youthlink Innercity, information and instructions on safer injection practices and associated risk factors
- Harsh Reality booklet produced by Kali Shiva AIDS Services and SERC with information on drug use including safer injection practices
- Be Street Smart booklet produced by Love Lives Here with information on drug use including safer injection practices
- What You Need To Know About Using Steroids pamphlet produced by The AIDS Committee of Guelph & Wellington County – information on safe injecting practices and risks for contracting HCV
- Hi Dad Public service announcement (30 seconds) produced by the Alberta Community Council on HIV

Others

 Hepatitis C: Manitoba's Hepatitis C Support Guide – booklet produced by the government of Manitoba – information for people living with hepatitis C

For Intermediaries

For intermediaries working with youth at risk in the area of hepatitis C prevention, there are several resources that have been produced that may be of use in establishing peer training programs and in finding available services.

- ➤ Hepatitis C Peer Education Model—guide produced by Kali Shiva AIDS Services as an introduction to peer education principles
- ➤ A Peer Training and Resource Manual for HIV + Injection Drugs Users guide produced by Kali Shiva AIDS Services as resources for peer educators

- ➤ Harm Reduction: Considered and Applied guide produced for Health Canada dealing with the application of harm reduction principles in dealing with HIV and hepatitis C in Aboriginal communities.
- ➤ HIV/AIDS: Can you provide me with information that does not distort the facts? pamphlet produced by YouthCo with information on the HIV/AIDS programs they offer to schools, community groups etc.

Youth-oriented websites

As stated previously, several organizations have also created websites directed to youth with specific information on hepatitis C. For this type of material to be effective, however, accessibility barriers must be overcome. As such, some organizations may find it useful to provide access to these types of websites at drop-in centres, though mobile terminals, etc., in order to remove access barriers.

The following is a list of some youth targeted health and information sites.

- http://www.health.qld.gov.au/istaysafe/default.asp The Queensland (Australia) Sexual Health and Hepatitis C website for young people
- ➤ http://www.teenhealthcentre.com/teens/index.htm The Teen Health Centre Website, based in Windsor, Ontario
- ➤ http://www.youthresource.com/index.cfm A sexual health website aimed at gay, lesbian, bisexual, transgender, and questioning (GLBTQ) young people, based in Washington, DC
- http://www.zoot2.com/ AADAC's youth website (focus is on drugs, alcohol and gambling)

References cited in this section

Health Canada. 1997. Meeting the Needs of Youth at Risk in Canada: Learning from a National Community Development Project. Ottawa, ON: Health Canada, p.2.

Strategic Research Development Committee. No date. Report on the Strategic Research Development Committee's Program of Social and Behavioural Research into Hepatitis C. http://www.health.gov.au/nhmrc/research/srdc/hepc.pdf

3. Interviews with intermediaries

To determine the best way to reach youth at risk of contracting hepatitis C, interviews were conducted with intermediaries who deal with such youth on a regular basis. Most of those interviewed work for youth social service organizations. Interviewees also include some Health Canada employees responsible for funding hepatitis C programs.

The objectives of the interviews were:

- > to determine the needs of youth with regard to hepatitis C;
- > to identify key messages that resonate most with youth;
- ➤ to determine what means or approaches intermediaries find effective in communicating the risk of hepatitis C to youth;
- > to highlight current programs and materials that are particularly effective; and,
- > to determine the needs of intermediaries, with regard to hepatitis C.

Twelve telephone interviews were conducted. (See Appendix A for the interview guide; Appendix B for the list of those interviewed.)

3.1 Communications – Issues and Vehicles

Health issues for youth at risk

Intermediaries were asked for their opinions on key health issues for youth at risk. A number of people did not feel that the youth they deal with consider their health to any degree. They pointed out that for some, meeting their need for drugs or alcohol was paramount, followed by the basic needs for food and shelter. Personal safety and transportation were also mentioned as concerns, particularly for youth in the north.

For many, a feeling of invincibility or else hopelessness for the future means that health issues do not figure greatly in their thinking.

"The youth we deal with don't have specific health concerns. They don't think they will live that long."

Specific health issues mentioned include the following.

➤ Information about safe drug injection – how to inject, where not to inject, etc.

- Mental health issues, including self-esteem and abusive relationships. Lack of acceptance is a key factor to their mental outlook, and this is closely tied to their drug use and street culture. Their peer group helps them "connect" and feel like they belong.
- Having access to health services, the information and resources to make healthy choices
- > Infection that can arise from piercing
- Sexual health, including STDs, teen pregnancy, AIDS
- Physical abuse, both in their past and current living conditions

AIDS Calgary conducted a survey of youth in their programs in 2000, and received 200 responses. The key topics the youth identified as relevant (from the choices provided) included sexual health and negotiating safer sex. Hepatitis C was not mentioned.

Awareness of the risks of hepatitis C

A wide range of opinion exists regarding awareness of hepatitis C. Some intermediaries reported high awareness among the youth they deal with, usually because of personal experience (youth in their immediate peer group have hepatitis C). They understand the main transmission methods, and know the long-term impact of hepatitis C. Others report little or no awareness of the disease among the youth they interact with. In the middle are those youth who are aware of the disease, but have only the most basic information.

When first being told about the disease, many youth think of hepatitis C as "scary" and fear getting tested, even where free testing is available. At the next level are those who are aware of hepatitis C and understand that it is transmitted primarily through sharing injection drug and piercing equipment. They are less aware of other methods, such as sharing toothbrushes, razors or equipment for snorting/smoking drugs. Those who seek more information seem to want very practical advice about the issue, including:

- ► How and where can they get tested?
- ➤ How is it transmitted? (They particularly concerned about whether hepatitis C is transmitted sexually.)
- ➤ Is it treatable? (Many believe it is not.)

One element that may be important in reaching youth is the question of whether they identify themselves as being at risk. For example, first-time or infrequent injection drug users are considerably less aware of the risks of hepatitis C than longer-term users. They tend to feel (even when informed about risk factors) that this is a disease of the hardcore, of which they are not a part. This may actually make this group at higher risk for infection.

There appears to be much lower awareness of hepatitis C than HIV/AIDS, although those who are aware of hepatitis C think of them as similar diseases.

Key messages

Intermediaries felt that messages about hepatitis C must address youth in their current situations, and that the harm reduction approach is the only viable one with this target group. The messages intermediaries felt were most important for youth to hear were:

- ➤ What is hepatitis C?
- > You may be at risk.
- You have the power to prevent hepatitis C. (Information on how to prevent it)
- > You may have it and not know.
- ➤ If contracted, hepatitis C will have a major effect on your life.

It was felt that there should also be a focus on transmission methods such as shared toothbrushes and razors, positioned perhaps in public washrooms, youth shelters and other areas where youth at risk may see them. There appears to be very little awareness of these transmission methods, and intermediaries are confident that knowledge in this area would significantly alter behaviour like sharing toothbrushes and razors.

The way messages are positioned and delivered was also felt to be very important to their effectiveness. Messages must respect youth, and impart the feeling that they are valued. Messages must also be geared to specific risk behaviours and the age groups to be relevant to that target audience. For example, young teens are more likely to be involved in piercing or tattooing than injection drug use.

"It is essential that the feeling that they are important and special be built into the message. Only if that is done will they be receptive to any information about prevention."

Story telling was described as a particularly powerful vehicle to get messages across. Hearing how hepatitis C affects a peer was felt to be the most powerful message possible. This is consistent with effective processes identified for the prevention of smoking among youth.

It was noted that some youth may be resistant to messages about hepatitis C, just because they hear so much about AIDS that they tune this type of messaging out.

The best messenger

The source of the message is felt to be at least as important as the message itself. While some people felt strongly that youth are the most effective communicators with other youth, others felt that credible adults could be equally successful. Attitude, not age, was felt to be a key factor in credibility.

Youth rule – Many people cited another youth as the person most likely to be effective in reaching youth at risk. The credibility and transparency that youth have with each other cannot be replicated. Youth who are themselves affected by hepatitis C are felt to be the best messengers. One of the most useful things the peer educators do is give referrals to other youth, as to where they can get other help and information. Their references are credible, where those from an adult might not be.

Youth should also be directly involved in the development of messages to ensure that they are consistent with street culture and acceptable to youth. Unconventional methods of getting the messages out may also be required. (See the next section, Formats, for more on this.)

Intermediaries noted, however, that youth-to-youth programs can be difficult to organize and maintain. A significant amount of staff time must be devoted to organizing and nurturing youth as leaders. The stigma of becoming part of the "establishment" is a problem, and often youth may participate in a program, but don't want to be perceived as leaders among their peers.

In addition, proper screening and training are required to ensure the youth intermediaries are properly prepared. In sensitive areas, when dealing with youth involved in the sex trade for example, great care must be taken to ensure the youth intermediary is trained to deal with difficult or dangerous situations. In the case of the sex trade, there could be situations in which the youth intermediaries might be mistaken for prostitutes themselves.

A prior history in the area, while providing the youth with a clear understanding of what to expect, may also put the youth in a precarious position where situations may act as "triggers" to resume high-risk behaviours. For example, seeing drug paraphernalia may induce a past user to resume injection drug use, if they are not fully free from the psychological, as well as the physical ties to drug use.

It was noted that people who do outreach, whether as youth or adults, must not only be able to get a message out, but also to process and respect the feedback they receive. Skills and training are required to do this effectively.

Adults with empathy – Adults from a wide range of backgrounds can be successful intermediaries, as long as they approach the task with honesty, respect for the youth and an open, non-judgmental attitude. Adults who themselves have an alternative lifestyle, such as artists, extreme athletes or tattoo artists, or those who come from street culture, can be

extremely effective. Those who work in shelters and food banks may also relate well to street youth, although doctors, nurses and other professionals can have the same success, with the right approach. An open and accepting attitude, respect and no sign of being patronizing were cited many times over as the key attributes of people who work effectively with youth at risk. It was noted that it tends to take longer for an adult to make a connection with youth than it would for another youth; however, once a relationship is established it can be equally effective.

A joint effort – Partnerships between youth and adults can also work well. A middle-aged nurse cited her success in joining with a youth to go into areas that had never received outreach services. Paramount to success was the fact that she presented herself as nothing other than what she was, a researcher. Acting falsely "cool" or "hip" is spotted and immediately shunned by youth.

Formats

The intermediaries interviewed noted that different communications vehicles appeal to different types of youth. Generally, visual materials like posters or postcards, work better than written ones. Understanding the prime audience, and making sure the products fit the program, are keys to success. As with all communications vehicles, literacy and cultural context are key issues. Again, materials produced by youth for youth are most effective. Some other general rules of communicating with youth were also provided.

Language is important – Anything preachy, too wordy, or with too many statistics must be avoided. Language must be clear, but not "dumbed down." It must be empowering, and provide the youth with the information and the questions to ask so they can take this health issue into their own hands. For example, kids contemplating a tattoo must feel it is in their power to ask for proof that a new needle is being used.

Materials must be developed specifically for youth, and not for a general audience. Intermediaries noted a real void in materials for youth aged 12 to 16. Scarce resources will often drive an attempt to reach all groups with one vehicle, but this approach rarely, if ever, works, particularly with marginalized groups.

Size matters – As a general rule, any information that cannot easily be put in someone's pocket is of no use to this audience. Posters may attract attention, but youth are more likely to read something if they can do so by themselves, in a quiet spot, and that means they need to take it with them. Very small pamphlets and postcards with eye-catching pictures were used quite effectively in this way.

A combination of the two types of media may be best, for example, a poster to attract attention on a toilet stall door, and a small pamphlet or postcard placed elsewhere in the washroom where people could take them away.

Innovative formats attract attention – A new approach may be required to get the attention of youth at risk. Examples include putting messages about risk on packages of needles, condoms, matchbooks, toothpaste and bars of soap. Stick-on tattoos were also popular among the youth. A music CD was also suggested, whereby the youth write and perform the music, create the cover design and have hepatitis C messages on the sleeve and as part of the theme of the songs (lyrics/stories) as well.

Electronic vehicles reach some – Drop-in centres, group homes and other places youth at risk gather will often make computers available to them, and youth who have access make good use of e-mail and the Internet. E-mail becomes an easy way to connect with a group of youth through things like rave chat groups, which are used by promoters to let people know a party is coming up. This may be a good venue for delivering informationabout hepatitis C, and upcoming programs or events. It is best done, however, from the inside, from a youth already part of the chat group.

Although there is the potential to reach a lot of people with a website, it should be noted that many youth at risk do not have access to computers. It may be that service providers and students use these sites more heavily than those to whom they are directed.

Comic books or magazines still work – Publications developed and written by youth for youth can be effective, as long as adults avoid the desire to editorialize or censor the material. In successful magazines, youth are paid a small honorarium for their contributions. Distribution to group homes, youth agencies, stores and restaurants that youth frequent will get them into the right hands.

3.2 Successful Programs

Intermediaries were asked about programs they currently run regarding hepatitis C prevention, and what elements make them particularly effective.

A wide range of formal and informal programs were discussed, including:

- > outreach to raves and other events where youth gather;
- theatre, street theatre or video production involving youth in all aspects, from script-writing, to acting, set design and technical elements;
- events with speakers, workshops, displays, hepatitis C testing, etc. (such as Tracks of Y's "What's blood got to do with it?" [Winnipeg], and others);
- discussion of hepatitis C within other programs, such as needle exchanges, sexual health displays or HIV/AIDS workshops;
- peer health education program, where youth are trained to become facilitators and communicators – giving information to younger kids;

- teen health centres, drop-in centres, supper clubs, etc.; and,
- > mobile information units or vans, that go to where youth gather.

"The type of program doesn't seem to be that important, as long as the kids are the ones in charge. They need to make the decisions and make the program work."

Intermediaries pointed out that a lot of good work is accomplished on the streets, without benefit of a formal program. Mobile units (vans or displays) can be effective as identifiers, drawing kids in because they go to where the youth gather. A display that is visually stimulating and interactive can help to open lines of communication. Drawbacks to mobile units or vans are the expense and, in the case of the display, difficulty in transporting it.

A Montreal program trains youth intermediaries, who have themselves come from the streets, to work with youth to build self-esteem through physical fitness and life skills, like learning how to purchase and prepare healthy food, budgeting, etc. The youth transfer the lessons they learn about taking care of their health to harm reduction and prevention. For example, they see first-hand that if they don't eat well, they won't have the energy to participate in a workout, and so on.

Some intermediaries mentioned programs designed specifically for service providers. Rave 101 was one such course being used by AIDS Calgary. It was developed for service providers to increase understanding of the rave culture, dispel its myths and spread the word that health and wellness are promoted through the YES program.

Elements of success

Although the successful programs described by intermediaries varied greatly, they had a number of common elements. Those that involved youth talking to other youth were cited as most successful, when done well. One-on-one contact with a skilled counsellor was also seen as extremely beneficial. Youth at risk need to be heard, and providing them with undivided attention is a clear way for them to know that they have been heard, that they are important. A team approach in which an adult was paired with a youth facilitator was also cited as being effective.

In terms of programming itself, common elements of success used the following approaches.

Led by youth – Key among the elements of success was the need to involve youth in every aspect of a program, from its inception to every step of its operations. Ideally, programs support youth talking to other youth. This ensures that the program will have the credibility and transparency required to be effective in reaching out to youth. It also has the long-term benefit of teaching youth a variety of skills they can then apply to their lives in general.

Programs developed by youth tend to draw out their creativity and build confidence in skills youth themselves may not have known they had. The key to youth involvement is that they maintain control over decisions. In some youth organizations, youth form part of the boards of directors. Adults can assist in providing a venue or forum for the youth to operate, but the youth must be in charge.

"The program picked up considerably once it was youth-driven, after a false start with adults leading the program."

One issue that needs to be handled with care in programs involving youth to youth intervention is the need to set clear boundaries on the youth volunteer's role during outreach. At raves or other party environments, youth volunteers must follow guidelines established by the program and not engage in risky behaviours such as drug use themselves. A Calgary program, Rave Safe, has established such guidelines. Clearly, youth cannot be put into a situation where they may put themselves in danger of any kind, which can happen whether they come from and are well-versed in that culture or not.

Go to where the kids are – Programs, whether formal or informal, that reach out to youth where they already are will be easier to run and more effective than trying to gather youth to an unfamiliar spot. Simply walking the streets where kids hang out will create important connections. Drop-in centres, coffee shops, raves and street clinics are common points of contact. Other locales, like food banks and tattoo parlours are used less often, but are seen as promising outreach points.

Speaking respectfully, but in a way youth can relate to, is also "going to where they are," and an important part of making connections. When dealing with youth at risk, there is no place for censorship or genteel couching of terms. Kids must feel like they can say or ask whatever they want.

Give them what they need – When trying to attract the attention of youth, it helps to entice them with practical or useful items. The YES program provided youth with "love kits." They contained fun and practical products like lollipops, sticker tattoos, condoms and lubricant, along with information cards and stickers that raised awareness about the YES program and its messages. Other programs used coloured condoms as a way of drawing in youth. They were seen as fun and different, and created an opportunity to open lines of communication. Providing food, i.e., meeting basic needs, can also be an attraction. Kids will often come for the food, but stay because of the open, accepting approach of the environment. Learning comes as part of the package.

Make them welcome – As mentioned previously, innovative programs may attract youth, but it is the atmosphere and approachability of the coordinator that works to keep them there. A trusted, credible individual, regardless of age, is key to maintaining productive relationships with youth at risk.

Give them anonymity – When the subject is difficult, such at hepatitis C, it can be hard or awkward to open lines of communication. One program offered an interesting approach to encouraging all youth in an information session to ask questions. The coordinator handed out a number of slips of paper to everyone in attendance. During the session, a bag was passed around and everyone had to put a slip of paper in, whether they wrote anything on it or not. The process allowed youth to ask the most difficult or embarrassing questions they wanted, without fear of identification.

What doesn't work?

Intermediaries were quite clear on the fact that traditional education programs do not work with youth at risk. Pamphlets and posters, in themselves, will do little to prevent the spread of hepatitis C. Websites are accessible only to youth with computers, and videos require a television. Although these vehicles can be used within a program, they must be an integral part of the approach to be valuable. Intermediaries need to have established a respectful relationship with the youth before written materials will be read, never mind acted upon.

They also cited other elements to be avoided with dealing with youth at risk.

Deadlines can kill – It is important to recognize that when programs are driven by youth at risk, meeting deadlines in a conventional government or business environment can be more than challenging. Results may take longer than one fiscal year. While youth often learn about meeting responsibilities through this type of programming, this is often a gradual process. They need time for ideas to percolate, in an environment where it is okay to make mistakes, safely. Because a project has not met its deadlines, does not mean that it was not successful.

Resources rule – Involving as many kids as may require a successful program is often impossible due to limited funding. Often new members simply cannot be added to a group, because resources are already stretched to the limit. This is particularly true in Canada's north, where everything, such as food, heat and travel, costs more. Ongoing funds for staff is also an issue cited by almost all the intermediaries. Promising programs are sometimes cut before results can be demonstrated.

In addition, intermediaries pointed out the long-standing challenge of measuring long-term effectiveness of attempts to change behaviour.

New program approaches

Intermediaries were asked where they would put any resources they were given for hepatitis C prevention. Although many noted that they would simply augment current successful operations, some presented new concepts they would like to pursue.

Train youth – A number of possible programs focused on involving youth to a greater extent. As a basis, they all required appropriate materials and training for youth to provide effective outreach. In order to ensure the youth have the right personal skills, it was suggested that a screening tool be developed as part of a detailed recruitment process. Knowledge of hepatitis C and courses in facilitation and effective listening were felt to be basic requirements. Beyond that, training in conflict resolution, suicide prevention and mental health issues was felt to be important, so that trained youth could identify and refer youth at risk to the appropriate health or social service professionals. Once established, this training could be disseminated as a "train-the-trainer" course, with experienced youth participating in training of other youth across Canada.

In its application, youth would work in pairs, so that trained, experienced youth would be twinned with those in training in a mentorship arrangement. The youth could work in existing programs, including AIDS outreach and needle exchange programs, to create multifaceted prevention programs, building on effective links already created.

Training for credible intermediaries – A number of people who interact with youth have very little information about hepatitis C. Sessions geared to service providers, involving and at least partially led by youth, would help raise awareness and knowledge of youth culture and hepatitis C throughout the health and social services sectors, and beyond. Involving doctors, nurses, teachers, mental health workers, parole and corrections officers would address the traditional professions that deal with youth at risk. Training could be spread beyond these circles, however, to tattoo artists, servers at coffee houses and hairdressers to bring the message to the wider street community. Given a broad enough scope, it could also include training in conflict resolution, how to resource programs and participatory evaluation research.

The end result of such a training session would be a strategic plan, developed jointly between the youth and the service providers to put into action in the community. This format could be used to assist programs across Canada by providing models on how to nurture youth-driven programming.

Involve the business community – Tattoo artists and piercers tend to be held in high esteem by youth at risk. A number of concepts were suggested to involve them in education regarding hepatitis C, from simply distributing written information through these businesses, to arranging for discounts for youth who present a certificate showing they have been tested for hepatitis C.

One stop shopping – One concept suggested providing a range of services to youth and others at risk under one roof. A food bank, medical services, needle exchange program, a shelter and showers, along with counselling services would be provided.

Rural focus – Intermediaries who work in rural areas of Canada noted the need for basic information on harm reduction, and how it applies to hepatitis C. In the Atlantic provinces, for example, there continues to be a need to lay the groundwork on harm reduction approaches. Fewer opportunities for information exchange exist, and anonymity remains an issue in small, mainly rural provinces.

Focus on all risk behaviours – Currently, most information on harm reduction focuses on drugs. A common precursor to drug use, however, is drinking alcohol. It is often a pre-condition for drug use and other high-risk behaviours such as tattooing and piercing. Intermediaries felt there was a need to give kids better information about drinking, particularly among younger and rural youth.

4. Report on focus groups with youth

4.1 Methodology

The third and final part of this project to determine the best way to reach youth at risk of contracting hepatitis C consisted of focus groups conducted in six cities across Canada (Halifax, Toronto, Calgary, Vancouver, Whitehorse and Montreal). From 10 to 21 youth attended each session, for a total of 73 participants. All the participating youth lived in urban areas.

Due to logistical issues, the group in Montreal consisted of youth intermediaries, rather than youth at risk. The four intermediaries, part of a program called Pairs-Aidants, were youth who had been at risk in the past, but had overcome serious lifestyle issues and become part of a peer-to-peer outreach program operated through a youth service organization.

The objectives of the focus groups were to determine:

- the awareness levels of youth at risk regarding hepatitis C;
- ➤ the types of approaches to information dissemination that would appeal most to youth at risk (written, spoken, combination approaches);
- the most appropriate messengers to convey information on hepatitis C to youth;
- > formats of information (written and electronic) that would be most effective, including size, graphics, language, etc.; and,
- programs that youth themselves would endorse as being effective in reaching them.

Process

The consultants partnered with youth organizations in each city that met the following criteria; they must:

- reach youth at risk, under 16 years of age, where possible; and,
- have a program (supper club, drop-in centre, etc.) that youth attend.

The criteria the youth organizations were directed to use, in selecting focus group participants, were that they:

- > must be fairly communicative and have a relatively high level of function;
- > should not be hepatitis C positive;
- > should not know whether they are HCV positive or not (as this would indicate they know enough about the disease to have been tested, which means they know much more about the disease than the average youth).

A youth facilitator led the groups, accompanied by an experienced facilitator who was able to monitor the process, ensure consistency, and co-facilitate when required. Youth were provided dinner and a \$20 honorarium for attending.

The breakdown of participants is provided below.

City	Participants	Male	Female	Age, other characteristics
Halifax	12	8	4	Ages: 17-22 4 homosexual, 1 trans-gendered, 2 couples
Toronto	10	6	4	Ages 16-23
Calgary	16	11	5	Ages: 15 (2), 16 (4), 17 (6), 19-22 (4)
Vancouver	21	8	13	Ages: 13 (2), 14 (1), 15 (5), 16 (8), 17 (4), 18 (1); a number of Aboriginal and mixed-race participants
Whitehorse	10	5	5	Ages: 15 (1), 16 (4), 17 (2), 19 (2), 25 (1); 3 Aboriginal youth
Montreal	4	1	3	Ages: 18-22 (youth intermediaries)

4.2 Awareness of Hepatitis C

Health Issues for youth at risk

After introductions, the youth were asked about issues that concern them. Very few raised health issues, with sexually transmitted diseases and smoking being the only health issues that came up, and those only at one group. Concerns that cut across all groups related to their lack of money, problems in relationships and with family, and difficulties in school. Issues that came up at individual groups included difficulties with the law or other authority figures, work, lack of shelter and food, racism, drug use, government cut-backs, and general instability in their lives.

Youth who had personal experience with hepatitis C raised that as a concern at three of the groups. Other issues raised more than once included injuries, the cost of prescription medication and BSE (bovine spongiform encephalopathy or "Mad Cow Disease"). Concerns raised only once across all focus groups included frostbite, weight problems, monkeypox, violence, lack of sleep, trouble with teeth, and "boot rot", a fungal condition that occurs when feet are constantly damp.

Knowledge of hepatitis C

Awareness of hepatitis C varied substantially among the groups, with most participants in the Toronto and Whitehorse groups quite aware, and those in Halifax and Calgary far less so. Each group appeared to have at least one person who was quite knowledgeable on the subject, generally because that person had a friend or relative who had hepatitis C. About one-third of participants in Vancouver knew about HCV. In Whitehorse and Vancouver, educational programs about hepatitis C had recently been delivered in the schools the youth attended (alternative school in Vancouver, regular curriculum in Whitehorse).

In Montreal, the youth intermediaries were well aware of hepatitis C, and felt the youth they worked with were also aware of the disease, at least superficially. They felt youth they dealt with were better informed about HCV than the general population, and this stemmed from the fact that they recognized that they were at much greater risk of contracting it. Notwithstanding their recognition of the risk, many youth minimized their concerns about the disease and its potential impact on their lives. According to the youth intermediaries, even those who were HCV positive often downplayed its seriousness, particularly if they were not experiencing symptoms. Even when symptoms were present, they would attribute them to something else (lack of sleep, a bad cold, etc.), rather than seriously address their illness.

Prior to getting information about hepatitis C from the facilitator, focus group participants were asked what they knew about the virus. The following statements emerged. (Note: This provides an aggregate of information; many groups were not aware of much of this information. See Appendix E for site-specific data.)

- > It is an infection of the liver.
- ➤ It is a viral infection.
- ➤ It is transmitted in the blood (through needles, razors, toothbrushes, piercings, tattoos).
- ➤ It can be spread through fighting, if open wounds exist on both parties.
- There is no vaccine against it (only for A & B).
- > Symptoms: flu-like, nausea, fatigue. Sometimes people don't have symptoms.
- If you drink alcohol with hepatitis C, it makes you really sick.
- > There is some form of treatment for it.

Many people compared hepatitis C to HIV, in terms of transmission and their concern over it, although most indicated that they were far more concerned about HIV.

Some also believed that:

- ➤ HCV can be spread to children, if you have it while pregnant;
- ➤ It is easily transmitted through sex with an infected person;
- > It is difficult to eatch;
- ➤ It may be airborne;
- It can live outside the body for an extended period of time (up to two weeks).

After the facilitator provided a brief overview of hepatitis C, youth were given the opportunity to ask questions. Most concerns focused on:

Methods of transmission – Although they were aware that blood was the transmitter, participants wondered how long the virus could remain alive outside the body, and whether coming into contact with standing blood through an open sore could transmit the infection.

Infection through snorting equipment – Only a few of the participants in the Toronto group knew that HCV can be transmitted through snorting equipment. This appeared to be compelling new information for many participants, with a number of them contending that it was not true.

Sexual transmission – Some participants believed that sex with an infected person created a high risk of infection.

Tattooing and piercing – Information regarding the importance of sterile equipment, ink, etc., in tattooing procedures also appeared to be compelling.

The availability of a vaccine – Many participants thought a vaccine was available, and that they had, in fact, been vaccinated. The facilitator clarified that they had most likely been vaccinated for hepatitis B, or possibly A, but that no vaccine exists for hepatitis C. This made some youth angry, feeling that as a marginalized population, their needs were not being met.

Generally, the youth in the groups felt that awareness of hepatitis C was quite low among their peers. As stated previously, the exception to this was in Montreal.

When asked what they might do to avoid infection with HCV, the youth said they would:

- > not share needles or "rigs" (injection equipment);
- > not shoot drugs;
- > not share razors or toothbrushes;
- > use condoms;
- follow the same steps as for HIV;
- ➤ "be more aware" about the risks of tattooing;
- watch where you walk (to avoid dirty needles);
- be careful who you have sex with;
- > get tested for HCV regularly;
- > talk about it to others.

A number of the youth were very candid in their discussions, calling others' bluffs when they made comments like, "Don't shoot up," or "Be careful who you have sex with." They pointed out that much depends on the state of mind and sobriety of the individual at the time, and that people often don't plan ahead regarding drug use or sexual activity. Some noted that they will probably have forgotten about the risks of hepatitis C in a few days.

4.3 Communicating the Hepatitis C Message

The best messenger

The youth were asked to whom they would talk and who they could trust regarding information on hepatitis C. All groups identified their friends as a trusted source of information. Others receiving widespread support as being knowledgeable and trusted sources include: youth counsellors (five of six groups); someone who has the disease (five of six groups); a health clinic with free, anonymous testing (three of six groups); parents or other relatives (three of six groups); doctors or nurses (three of six groups).

The youth intermediaries felt themselves very well placed to provide information, as they were intimately familiar with the lifestyles and issues of youth at risk, and had received information and training on hepatitis C, counselling and resources in the community.

Sources of information that received more than one mention are:

- ➤ an anonymous telephone health line, with trained professionals;
- Elders (sited by aboriginal participants); and,
- Reading material.

There was considerable discussion about the type of person who can be trusted, with general agreement that someone who "talks straight and knows their stuff" is acceptable. Criteria for trusted messengers included respect, tolerance, generosity, knowledge and familiarity with the person. Confidentiality was also cited as important, either from an individual or a health setting. A preachy approach was roundly panned. Knowledge based on experience, rather than education seemed more credible to these youth, including the peer intermediaries, although a combination of both was cited as ideal.

A number of youth were adamant that police officers are not good messengers. They voiced a considerable number of complaints about them and the way police treat youth on the street.

There was a lot of agreement between groups on the fact that youth such as themselves can tell who is "cool" and who is not, and that the qualities that comprise "cool" include an open, non-judgmental and respectful attitude, and open, clear language.

Formats

Print

Participants in the focus group were presented with a number of written materials — pamphlets, brochures and postcards — to review. Each participant was asked to pick one up and explain to the group what they liked and/or did not like about it.

The following elements emerged as being important in print materials:

Graphics – Bright colours, interesting graphics (particularly psychedelic, as per the FX materials), and arresting headlines attracted their attention. Graphics or colours were cited most often as the reason participants picked up a piece.

Size – The smaller items, such as the thumbnail brochures or postcards were picked up most frequently. Participants agreed they would be most likely to take away postcards and smaller sized brochures, and were therefore more likely to read them. Brochures that appear to be small but then fold out to be much larger (For example, *Sex and Prevention*, produced by Sexuality Education and Resource Centre [SERC]) were criticized for being too long and trying to "trick" people into believing they were small pieces. Some of the very small brochures were also criticized for trying to pack in too much information and for being difficult to read.

With few exceptions, participants said they would be very unlikely to take a larger booklet or book. Those who said they would tended to be people who had a greater concern over their health, for example, pregnant girls. Despite the lack of interest in taking away larger materials, a number of participants believed that there was still significant value in such publications, to have as resources in places like shelters and drop-in centres where people could read them on-site.

Language – Simple, clear language was seen as most important to getting the message across. Catchy headlines were often cited as the reason people picked up a particular piece.

Format – The one sample that had a comic book format was very popular in all groups, particularly impressive considering it was only available in French, and most participants spoke only English.

Contact numbers – A number of participants noted how important it was to have a local contact number for further information.

Behaviour tended to reinforce the participants' contention that they would take the smaller materials. Many asked if they could keep some of the post-cards and mini-brochures, and the materials that disappeared over the course of the five focus groups were all small-format pieces.

Video

One video, *Clean Points*, *Tips on Hepatitis C*, was shown to most of the groups (Calgary did not have a VCR available), and a second, *Filter*, *the Facts about Hepatitis C*, was also shown only in Vancouver. It had very recently become available, and the facilitators, after viewing it, thought it would be interesting to have participants' views on both videos.

Although some groups found *Clean Points* interesting — even compelling — many felt the individuals featured were too old and "decrepit" for youth to relate to. The group in Toronto, which appeared to include more active injection drug users than other groups, appreciated the video more. They felt it was truthful and accurately depicted "real" people, living through real issues. They said if it were shown at a drop-in centre, for example, they would watch it. Most however, felt the characters in the video needed to be younger to attract the attention of young people. They pointed out that if many of people who contract hepatitis C are young, a video on prevention should feature young people.

The Vancouver youth related much better to the *Filter* video, which featured two young people who had hepatitis C. They commented: "It could have been one of us in that video." They were far more attentive in watching the video, and in discussion afterwards, said they thought it was much better. The youth said it provided important information they had not been aware of, and appreciated the fact that it clearly showed both injection and tattooing equipment. They felt the messages were more specific and harder hitting, and that this made it more effective. For example, the video very clearly stated that the water shared among

injection drug users in preparing their injections probably was the source of infection for many Vancouver drug users. This appeared to be new and compelling information for the group. Another message that captured their attention was that of the young woman saying she could not drink so much as one beer without feeling very ill. This clearly resonated with the group. Another element that garnered much discussion was the detailed description of sterile tattooing equipment, and what consumers should look for to ensure a safe tattoo experience. The youth who viewed the video said it presented them with a "big reality check."

Communications approaches

Participants in the focus groups were asked about their receptiveness to various types of communications approaches. They were presented with four options.

- Make sure that people that you trust and respect know about hepatitis C, and trust them to informally educate youth. These people could be youth themselves.
- Make information products, like brochures, pamphlets, videos, websites available at places where youth at-risk hang out, and hope they pick up on the information.
- ➤ Use both of these approaches: enlist the people you trust, and give them information they can turn the youth on to.
- Use other approaches like street theatre, puppet shows, comic books, etc.

Peer-to-peer approaches

Most participants expressed support for getting the messages out via a trusted intermediary, noting that they would be more likely to listen to someone their own age than to an older person. Some expressed support for the team approach, with an older qualified person partnering with one or more young people. Some participants pointed out that they remember information much better when they hear it from people they know and trust, compared to reading written material.

An approach supported in all focus groups, including youth intermediaries, is that of teams of youth spreading the word to their peers. Word of mouth was considered an extremely strong means of communication. Youth would be trained by those knowledgeable in the subject, and would spread out to various venues, as appropriate to their cities. Participants suggested this could be done anywhere that youth gather — concerts, drop-in centres, schools, etc. A more formal, workshop-type setting was also supported. Providing marginalized youth with employment in this way, tapping into their multiple skills while providing a public service was seen as a "win-win" situation for all involved.

Participants provided a wide variety of suggestions for how this could approach could be applied.

For Groups could go into the streets, handing out sandwiches, condoms and information.

- ➤ Youth could create posters, and hang them in high-traffic areas for other youth at risk, explaining their artwork and the message behind it.
- ➤ Teams could have matching t-shirts, with a preventative message and go to "party" venues concerts, street festivals, raves, etc.
- ➤ Individuals could use a "Speaker's Corner" to spread the message.
- A "Hep C Squad" could visit schools to get the message to younger youth.
- ➤ Teams could create a video/television ads involving local youth, demonstrating a "day in the life of a young person with hepatitis C."
- ➤ Youth would create a magazine including information on both hepatitis C and HIV/AIDS.
- > Youth, working with knowledgeable adults, could produce a CD, including writing the music and lyrics to original songs, creating the cover artwork, arranging for production, etc. The packaging would provide room to print the lyrics and other health messages, while the artwork and format would clearly be directed to youth.

Clearly, there was no lack of imagination, and there was considerable enthusiasm for the types of projects the youth "ambassadors" could develop to spread the prevention message. In most focus groups, the discussion generated a great deal of interest, with some individuals offering their names as potential youth intermediaries.

Mass Media Approaches

In addition to face-to-face contact, some participants felt a combination of tactics would be best, pointing out that the information needs to be "in people's faces." Specific approaches that were supported in most groups are:

- Bus ads (inside and out), bus shelters, bench advertising;
- Posters (with public washrooms cited twice as good locations);
- > TV and radio advertising; and,
- Messages on various products: condom wrappers, beer cans, cigarette packages, rolling papers.
- One approach that received mixed response was an Internet site. Although this concept was supported in some groups, others felt it was not readily accessible to many youth at risk.

5. Conclusions and recommendations

5.1 Broad Parameters of Success

The three elements of this research project (information review, interviews with intermediaries and focus groups) point to very similar conclusions regarding programming to prevent the transmission of HCV among youth at risk. There are broad parameters for successful programs that are supported in the literature, by intermediaries and by youth themselves.

- ➤ Led by youth Whether in programming or the development of materials, youth must have a strong voice in shaping the initiative. Involvement should commence at the very beginning of the project to give youth a hand in determining what the project should be and how it should be run. Skilled adults can be important as guides and assistants, as their knowledge of hepatitis C and of processes required to move project forward will be instrumental, but youth should be in charge of the project.
- ➤ Show respect A successful program will be built upon respect for the target audience: youth at risk. Whether it is led by youth or adults, an open, non-judgmental attitude and respectful tone is paramount to opening the lines of communication required to move any initiative forward. Understanding youths' circumstances in life is key: proceeding with that insight through all steps of the project will be important, beginning with goal setting and extending to issues like the size of the project team, the creative approach used, hours of operation, deadlines and all other elements. A harm reduction approach is, of course, implicit in this process.
- ➤ Provide appropriate support Screening, training and on-going support are important to youth-centred programs. As mentioned previously in this report, initiatives run by youth at risk can be difficult to organize and maintain. Screening tools or approaches that may assist in identifying youth who have the personal skills to be effective as youth intermediaries would be useful. Training on knowledge of HCV would be a minimum requirement. Depending on the nature of the project, development of facilitation and listening skills, and training in conflict resolution, suicide prevention and mental health issues would be tremendous assets.
- ➤ Use appropriate materials Discussions with intermediaries and youth at risk supported the literature review in emphasizing that materials must be focused on the issue at hand, and appropriate to the audience. Clear language, eye-catching graphics and small size are important to have youth take materials away and read them. A fair number of good materials exist; however, there continue to be gaps. Intermediaries noted that very little exists for youth aged 12 to16. These younger youth are unlikely to be engaged in IDU, but may be drinking alcohol, a common pre-cursor to drug use or other risky behaviours such as non-sterile tattooing or piercing. Some materials exist that address tattooing and piercing separately from injection drug use, which is important as there continues to be a stigma around injection drug users. Materials that

- relate drinking to these risky behaviours were not found in the fairly extensive search conducted as part of this project. In addition, few materials focus specifically on snorting and non-IV drug paraphernalia. This void is of particular concern, as the possibility of transmission through straws and other snorting equipment was not understood, and in fact, was rejected by a majority of the youth who participated in the focus groups.
- ➤ Are targeted at specific audiences Just as materials need to be targeted to specific behaviours, programs must address specific age groups and types of behaviour. Intermediaries felt that first-time or infrequent injection drug users may be at greatest risk of infection, as they are considerably less aware of the risks. They tend to view HCV as a disease of the hardcore, of which they are not a part. Rural youth at risk are also in a precarious situation, as they have few resources available to them, and little chance of anonymity in a small community. Anonymous telephone help lines may be considered for these youth.

5.2 Most Promising Programs

This review revealed a wide variety of programs that can be effective in raising awareness of HCV, from street outreach, to workshop, to theatre. The parameters of success identified above are the threads that run through them all. Specific programs that show the most promise are as follows.

➤ Youth intermediary programs – Training youth to be ambassadors of the prevention message is seen to be most effective, both in spreading the message and in having a long-lasting effect on their own behaviour. Providing marginalized youth with employment in this way would tap into and expand their skills and abilities while they assist their peers, and was seen as an extremely constructive approach for all involved. Benefits include increased self-esteem, job experience and improved stability in their lives.

Once established, this training could be disseminated as a "train-the-trainer" course, with experienced youth participating in training of other youth across Canada. YouthCo (Vancouver) is currently using this approach very effectively. Trained youth could then determine how they want to apply their knowledge and skills. Youth suggested a wide range of options, from speakers' bureaus and workshops, to street outreach, to the development of theatre or video productions, to attendance at youth events, like raves and concerts. Examples of all of these types of programs exist currently and could be modeled. As stated above, the keys are in developing an effective training program and providing youth with the power to direct and implement the project.

In addition, it is important to recognize that the actual product resulting from this type of project is less important than the process, including the ongoing connection with a group of people. Less emphasis should be placed on tangible products, and more on skills and process. Note: For further details on involving youth at risk in community projects, refer to Health Canada's report on *Meeting the Needs of Youth-at-Risk in Canada: Learnings from a National Community Development Project* available from

Health Canada or through its web site at http://www.hc-sc.gc.ca/hecs-sesc/cds/pdf/meetingneedse.pdf

➤ Adult intermediary programs – A wide variety of adults could be drawn in as messengers of the hepatitis C prevention message. Unfortunately, many lack the skills and knowledge necessary. Training programs for service providers in the health and social services sectors, involving and at least partially led by youth would help raise awareness and knowledge of street culture and hepatitis C. Such a program could be spread to tattoo artists, servers at coffee houses, hairdressers and others who interact with youth to bring the message to the wider street community.

5.3 Key Messages and Messengers

Messengers – Both youth and adults were identified as good messengers of the hepatitis C prevention message. Knowledge of the subject, an open and non-judgmental attitude, and confidentiality were cited as key characteristics of good messengers.

Given these attributes, youth clearly are more open to messages from other young people, particularly if these messengers are personally affected by hepatitis C. The credibility and transparency they bring to the issue are clearly assets.

Adults from a wide range of professions can be effective communicators. Youth counsellors and health professionals are obvious ones. Some relatively untapped sources of the prevention message are tattoo artists, extreme athletes and artists, who themselves have an alternative lifestyle. Adults who themselves come from a street culture also have credibility.

Teams involving youth and adults also appear to have a lot of merit, combining the approachability of another youth with the knowledge and experience of an open adult. Generally, youth said they would relate better to someone who approached the hepatitis issue C based on their personal experience rather than education alone. A combination of both was felt to be ideal.

Mass media – When asked about the best approaches to reach youth, they raised mass media outlets as being effective. Along with mainstream avenues such as posters, television and radio advertising, they suggested transit ads, in buses, bus shelters and on bench advertising as sites that would catch their attention.

Key messages – Beyond general information about hepatitis C and the risks of transmission, there was general consensus among the intermediaries and youth that the most important messages to relate to younger youth at risk (ages 12 to 16) are:

- ➤ the methods of transmission of hepatitis C, including drug injection and sharing of drug equipment, but particularly snorting and tattooing/piercing, as these methods appeared far less known:
- > steps individuals can take to prevent its spread;

- > the importance of testing; and,
- > the effect that hepatitis C will have on a person's life.

The potential risk for hepatitis C to be transmitted through snorting equipment is almost completely unknown among youth, and should be a larger focus of attention. Most youth do not view snorting drugs as risky to their health in the way that injection drug use is.

Tattooing and piercing are frequent behaviours among youth at risk. Clear direction on what to look for and ask about at tattoo parlours was one element of the *Filter* video (YouthCo) that was very much appreciated by youth. Few print materials go into the explicit detail, including pictures, required for youth to safeguard themselves.

5.4 Support Resources Required

To recap the ideas presented above, the following resources are required to develop effective hepatitis C prevention programs for youth.

Materials – Although many good materials exist today, some areas remain unaddressed, including:

- > the specific needs of younger youth; and,
- drinking, as a precursor to other risk behaviours.

In addition, the messages currently being circulated need to be reviewed for accuracy and consistency. For example, one new set of materials uses the slogan "Be aware if you share!" Messages must be clear on the fact that drug paraphernalia, razors, toothbrushes, etc., should never be shared. Being "aware" is not a strong enough message.

Training materials – A key approach being suggested in this report is a train-the-trainer method of preparing both youth and adult intermediaries to spread the hepatitis C prevention message. An effective screening tool to seek out appropriate candidates for training as youth intermediaries would be helpful to this effort. In addition, materials need to be sought out or developed that address:

- information on hepatitis C;
- facilitation methods and approaches;
- > conflict resolution;
- > suicide prevention; and,
- mental health issues.

Appendix A – Interview Guide – Intermediaries

Introductory remarks focused on the objectives of this project: determining the best means to reach youth at risk with a prevention message regarding hepatitis C.

- 1. What do you think are the main health concerns of youth at risk?
- 2. How aware do you think kids are of the risks of hepatitis C?
- 3. What facts or messages about hepatitis C do you think youth at risk are likely to take seriously enough for it to have an impact on their behaviour? Why? (or if they say "none", Why not? Any ideas on how to get around that?) If required, prompt with the following messages:
 - ➤ There are 4,000-5,000 new cases of hepatitis C each year, many of them among youth.
 - ➤ Two to three times more people will die from hepatitis C this year than from AIDS.
 - ➤ Hepatitis C infection is the leading cause of liver transplants¹.
- 4. What programs (on any subject) do you operate that are targeted to kids who are at-risk for hepatitis C? I'm not concentrating here on only hepatitis C programs we want to find out about any programs that seem to work with this target group.

If there are multiple programs:

- 5. Which do you feel is the most successful of these programs? How has success been measured?
- 6. What is it about this program that makes it work?
- 7. What programs, or element of programs, have you found to be ineffective, and why?

If there is only 1 program

Is the program successful?

- 8. What elements of it are effective?
- 9. What elements haven't worked well?
- 10. Do you actively consult/engage youth to help you make programming decisions? If yes, how?
- 11. What type of outreach do you think is most effective (peer-to-peer, adult intermediary, mobile units, theatre presentations, dinner groups, etc.)? Why?

¹ Note: New information emerged after the intermediary interviews, resulting in these messages being changed slightly for the focus groups with youth. See "Key Fact Sheet," Appendix D, for the most recent messages.

- 12. Do you know of any materials or formats that are particularly effective (brochures, videos, web sites)? What makes you say so?
- 13. Where (physical location) do you generally try to reach at-risk kids?
- 14. Based on what you know of your local street youth culture, who do these kids find credible, or cool? We're focusing here on any groups that could be harnessed for outreach, so that includes the traditional health and social service providers, but could also include tattoo artists, food bank workers, or others you can think of.
- 15. If you were given program money today, where would you spend it, and why?
- 16. Are there any particular materials or programs (training, for example) you need to improve the effectiveness of your hepatitis C programming?

Appendix B – Intermediaries Interviewed

The following people were interviewed for this report:

Diane Bailey, Director, Mainline Needle Exchange, Halifax, Nova Scotia

Lori Crozier, Executive Director and Linda Collins, Youth Worker, Blood Ties, Whitehorse, Yukon

Julie Dingwell, AIDS Saint John, Saint John, New Brunswick

Laurie Fownes, Team Leader, Community Outreach, AIDS Calgary, Calgary, Alberta

Sheila Lane, Teen Health Centre, Spryfield, Nova Scotia

Margaret Ormond, Winnipeg Youth Working Group (Tracks of Y event), Winnipeg, Manitoba

Betty Taylor, Tom Scinto and Anne-Marie Pinel, OASIS and Youth Net, Ottawa, Ontario

Johanne Tessier, coordinatrice des pairs aidants, CACTUS, Montreal, Quebec

Sarah Barber, Alberta Regional Office, Health Canada

Myrna Majano, Manitoba Regional Office, Health Canada

Colleen Wickenheiser, BC Regional Office, Health Canada

Appendix C – Facilitators' Guide – Focus Groups

Introductions (15 minutes)

Introduce yourself and your colleague and explain the role of facilitator and reporter.

Stress using our first names, and that it's OK to ask a question any time you want to.

Diana/Ellie and I are consultants for Health Canada. We've been hired to find out what the best ways might be to inform the youth who are most at-risk of hepatitis C about those risks and how to deal with them. What we're going to do today is to get your opinions and your advice on that. At the end of the session, we're going to ask you what you would do if you were in charge of designing a program to prevent the spread of hepatitis C. My job is to ask the questions, and Diana's job is to make notes about your answers and write a report that will go to Health Canada. No one will be identified in any part of the report, so feel free to say whatever you would like to.

Explain participants roles:

Your job for the next two hours is just to be open and honest. You don't have to know anything about hepatitis C, and you don't have to be concerned about getting flak for anything you say. We just want honest responses to the questions we'll ask you. There are no right or wrong answers.

Explain how the session will be conducted, and the ground rules:

I'll ask a question. But this is not like school where you have to raise your hand - we want this to be more like a conversation than a question and answer period. So if you want to talk - go ahead. I'll referee if we have a couple of people talking at once.

I've got a flipchart here, and might make notes while you talk. This is just a memory aid for me.

You should feel free to speak freely, and to express yourself the way you want to, and interact with me and with the others in whatever way you're most comfortable.

Any questions?

Orchestrate introductions:

We're going to be talking together for the next couple of hours. That's generally easier to do when you know a little bit about the people you're talking to. So let's take a minute for you to each introduce yourselves.

- Name
- Where you live.
- and just for fun, if you had a million dollars, how would you spend it?

Question 1:

What's important to you? What stresses you out? What about health issues? (15 minutes)

What kinds of things stress you out? What concerns do you have?

Are any health issues important to you? If so, what are they and why are they important to you? And listen - when I say "any health issue" – I really mean ANY issue, whether it's kind of mainstream, like safe sex, or mainline, like what are the safest injection practices.

Be ready to prompt if they want to know what a health issue is: SARS, AIDS, vegetarianism, cloning, genetically-engineered food, drug abuse, methadone programs, etc.

Do you take any actions, - do you DO anything, or NOT do some things, because of your concern? What?

If they have no health issues, ask them: What about personal safety? Are there any things that you go out of your way to do, or not to do, related to safety?

Question 2:

What Do You Know About Hepatitis C? How important is it? (15 minutes)

No one mentioned hepatitis C as a health concern. Have you ever heard of it? What have you heard?

OR

A couple of people mentioned hepatitis C. Can you tell me what you guys know about hepatitis C?

Use pre-printed flipchart to give them key facts about hepatitis C.

No lectures, **I** swear. But I need to give you a couple of key facts to get some feedback from you. Here are some key facts about hepatitis C.

Review flipcharted info.

After covering how the virus is transmitted: *I talked earlier about youth who are most at* risk of contracting hepatitis C. It's youth who are involved in this stuff that are most at risk. That means that many youth who live on the streets are at risk. But so are other youth who engage in these practices, regardless of where they live.

Complete the review of the flipcharted information.

Now that you have this information - what's your take on this? Would you go out of your way to take steps to avoid getting hepatitis C? Why, or why not?

Ouestion 3:

Good Messengers? (15 minutes)

For this and all sorts of other projects, Health Canada needs to know who youth at risk are most likely to listen to, trust, and respect, so that they can get those people involved in getting health messages out to others. Can you tell us who those people are likely to be? And this could be ANYONE youth at risk are likely to come into contact with, like:

- other youth
- staff at public health clinics
- people at food banks or soup kitchens
- staff at drop-in centres
- tattoo artists

used music dealers

- ANYONE

So: Who is both cool and trusted?

If they say they can't generalize this to a "class of person" get some of them to describe the people they DO trust, and what it is that makes them trustworthy.

Question 4:

Best Way to Package the Message? (30 minutes)

Admin instruction:

On a table to the rear or side of the room, arrange printed materials. If a video or videos are available, have that set up.

Health Canada may decide to develop some information products for youth at-risk. We'd like you to give us some advice about the kind of products they are most likely to consider.

So what I want you to do now, is just take a few minutes to look at the material we've displayed here. Feel free to talk to each other, or to grab something to eat or drink while you do this. We want to know if there's anything you see that you really like or really hate, and any insights you can give us on why you like or dislike something would be appreciated. You don't have to do a lot of note-taking, but if you could just make notes about the titles of stuff you like or dislike it would be helpful.

I'll give you about 10 minutes to schmooze through this stuff, and then we'll talk about it.

Give them 10 - 15 minutes, then reconvene.

Ask: Did any of you see anything you liked? Promote a general discussion, and probe as required to elicit this kind of information:

- Might you actually take this product if it was available to you?
- Any particular type of size, graphic design, or style of language, that works better than others?
- Note that you will probably also encounter significant information about products youth disliked during this discussion.

Ask: Did you see anything you found particularly bad? Promote the same sort of general discussion as above.

Ouestion 5:

Best Way to Carry the Message? (15 minutes)

There are a couple of ways Health Canada could use to get information about hepatitis C to youth at risk. They could: (show 4 pre-flipcharted options):

- make sure that people that you trust and respect know about hepatitis C, and trust them to kind of informally educate youth. These people could be youth themselves.
- make information products, like brochures, pamphlets, videos, websites available at places where youth at-risk hang out, and hope they pick up on the information.
- use both of these approaches: enlist the people you trust, and give them information they can turn the youth on to.
- use other approaches like street theatre, puppet shows, comic books, etc.

Which of these approaches do you think would work best, and why? Or can you think of another approach you think might be better than any of these?

Question 6:

Pulling it All Together (15 minutes)

Health Canada wants to design a program for youth at-risk, on hepatitis C. They'll be factoring your opinions into any program they design. But here's your shot at giving them even more direct guidance. If you were designing a program to create awareness of and help prevent the spread of hepatitis C among youth at-risk, what would your program include? How would it work?

As ideas arise, cross-reference as appropriate to clarify other opinions voiced throughout the session. Example:

- a couple of people really liked the idea of installing computers at drop-in centres, so that some key websites could be visited. But you haven't mentioned it here. Why is that?

Closing

OK guys - we've now asked all the questions we wanted to put to you.

Are there any questions you want to ask us, before we wrap up?

Many thanks to participants, and then give them whatever admin information is required.

Appendix D - Key Fact Sheet

Key Facts About Hepatitis C

Hepatitis C (Hep C) is a virus that causes liver disease. There is no vaccine. (as many as 50 % of people with acute hepatitis C may spontaneously clear the virus. A sustained response with a long-term viral clearance is achieved in 30 to 40 % of chronic cases.)

It is transmitted by blood-to-blood contact, for example through:

- sharing needles when doing drugs;
- > sharing snorting equipment like straws or bills;
- > tattoos or piercings with unsterilized needles; or
- > sexual activity (low risk).

Most infected people show no symptoms. When symptoms DO appear, six to seven weeks after infection, they may include:

- > jaundice;
- chronic fatigue;
- nausea or lack of appetite;
- discoloured pee;
- diarrhea;
- > joint pain;
- itchy skin.

Hep C can be mild and short, or chronic. Most infected people get the chronic form (70-80%).

Chronic hepatitis can take 5-30 years before it causes major problems like:

- \succ cirrhosis permanent scarring of the liver (10-20% of chronic cases)
- \triangleright liver cancer (1-5%)

Over 250,000 people in Canada have Hep C. It is the leading cause of death from liver disease.

There are approximately 5,000 new cases of hepatitis C each year, many among young people.

Appendix E – Detailed Results of Focus Groups (by City)

Please note: The information in this report should not be taken as reflective of the populations of these cities as a whole, but as an indication of the current knowledge of these particular participants. Trends across all cities may be taken as a good indication of general knowledge on the subject.

(As participants at the Montreal focus group were peer intermediaries who had received training in hepatitis C, their results are not included in this question.)

Knowledge of hepatitis C (unprompted)						
	Halifax	Toronto	Calgary	Vancouver	Whitehorse	
It is a viral infection of the liver.	✓	✓	✓	✓	✓	
It is transmitted in the blood,						
through:	\checkmark	✓	\checkmark	✓	✓	
needles	\checkmark	✓	\checkmark	✓	✓	
razors	\checkmark	✓		✓		
toothbrushes	✓	✓	\checkmark	✓		
piercing and tattoos		✓		✓	✓	
snorting equipment		✓				
fighting, with open wounds on						
both people			\checkmark			
No vaccine exists against it						
(only for A & B).				✓		
Symptoms: flu-like, nausea,						
fatigue.		✓		✓		
Sometimes people don't have symptoms.		/		_ /		
· -						
Effects of drinking alcohol by					./	
hepatitis C + people		'		•	•	
There is some form of treatment						
for it.					✓	
Compared it to AIDS, in terms						
of transmission or concern over			,			
it			\checkmark	 	✓	

		Messe	ngers			
	Halifax	Toronto	Calgary	Vancouver	Whitehorse	Montreal
Your partner	✓					
A friend	✓	✓	✓	✓		✓
A youth counsellor	✓		✓	✓		✓
A doctor or nurse	✓		✓			✓
Parents or other relatives	✓			✓	✓	
Someone who has it already – they would know	√	✓	✓	√		✓
A telephone health line, with trained professionals	√				✓	
A health clinic with free, anonymous testing	✓			✓	✓	
The Internet				✓		
The news				✓		
Elders		✓	✓			
"Some" teachers			✓			
Emergency health workers (Ambulance medics)			✓			
Reading material			✓			
Trust no one		✓	✓			

	Materials					
1.	Large – Manitoba	Bad. Really, really long. Like it because it has good information for people who are pregnant (as I am). Like book format				
2.	Postcard – orange & black	Good info, but have to think to figure it out. Like it because it's orange. Turned it over, and it gives good info – how it's transmitted. Lists what to watch out for. Good reviews because it s so straightforward. Many said they d take it - asked if we had extra copies.				
3.	FX – pamphlet	Like idea of comic book. Would sit down and read it. Could see this as a cartoon in a magazine for youth. Blunt, very open – doesn't try to hide the info, is matter-of-fact. Very cool looking – doesn't look like a book on disease. I would read it in front of other people. Can't read it, but looks good (comment from non-French reader).				
4.	FX – magazine	Good info; very high approval of graphics, colour, etc. Too big; hard to carry around. Lots of slang.				
5.	Be Street Smart	Has a lot of everything – info on being street-wise. Lots of information, on lots of topics. Would read it. Wouldn't read all that, maybe breeze through it. Pictures are good.				
6.	Postcard – Safer Partying	Not preachy; realistic. Good tips, taking account of what people really do. A bit too wordy, but catches your attention. Picked it up because of the art, colours. Looks cool. Explains things I would never think of – what you should do re the drugs you use – tell your friends, prepare yourself. Lots of teens go out partying; get drunk, pass out, don't have a ride home; don't plan ahead. Writing is a little small. Title doesn't tell you anything. Print too small, too much to read.				
7.	Postcard – Safer Body Art	Good info on going into a body art place; what to look for. Good graphics, pictures - draws your attention. Would pick it up. Like idea of postcards. Short and sweet. Easy to hand out; could even be smaller. Good basic info, not too much.				
8.	Postcard – People	Liked the colours – pretty, would pick it up. Too little info, but small, so that's good.				
9.	Postcard – Hep C (bugs)	Explains how to reduce risk; high-risk activities. Big bold letters.				

	Materials (continued)					
10.	Postcard – STDs (condoms)	Colourful, caught my eye. Tells the basic facts. Short and simple is best. Language can't be big and complicated. Needs to be really basic. Put a little more info on it. Like the fact that it has contact numbers.				
11.	Postcard – Harm reduction	Would pick it up; good quote on front.				
12.	Postcard – HIV/AIDS	Likes the message, the "trippy" colours. Agrees with the message, except for the part where they are telling you what to do. With too many messages, no one pays attention				
13.	Thumbnail – Fun ways	Very well accepted - one of the most popular and one many agreed they would take away with them, asked if we had extras. Colourful, written in "our language". Liked how it rates the risks. Good, basic, simple information that participants related to. "Tells you what to look out for."				
14.	Thumbnail – IDU	As an ex-user, this is useful. Teaches me about how to prevent AIDS. Good info. The cover clearly says what it's about: injection drug use.				
15.	Thumbnail – Hep C	It has a phone number for more info, and that's good. Don't like the fact that it is wordy. It's boring - should be brighter and bolder, more interesting looking. Too small, too many words. Small thing to read. All the information is there.				
16.	Sex and Drugs	Catchy name, but too long to read. Like the happy face. Cover grabs attention. Good that it has contact numbers. Good info on what it is, how to prevent the spread. Works because of the clear pictures. Format strange – too big to open up, wouldn't want to open it on the bus. Shows how to put on a condom - useful info. Bold cover. SEX attracts your attention. Don't like the colour. Good size; pictures; bold print. Convenient, but a little long to read. The fact that it's subtitled is useful. Well-written. Like smiley faces When I see sex and drugs on a piece of paper, it grabs my attention – my favourite thinks to do in life Colours stand out; words grab your attention. It's small, can carry it around easily. Detailed info.				

	Materials (continued)					
17.	Inside the walls	Really good. Has all the right info. Has realistic pictures showing shooting equipment. Tells you how to stay healthy if you have hep C. Has English and French. Cover is good. A bit too much text. Good reviews - particularly the look of it.				
18.	Safe tattooing and piercing	Would read it. Wouldn't really pay attention, though. Would change cover. Boring - needs more colour.				
19.	HC – Hepatitis C	Like it; would read it. Caught my eye. Looks like a guy giving you the finger. Serious message – you could have it. Didn't read it. Would read it and keep it on me. Others didn't believe he would. Others said they wouldn't read it; would chuck it. They thought the information and tone was good, but that the presentation (colour, graphics, etc.) was boring.				
20.	Safe Body Art	Wouldn't change anything. Thinking about getting more tattoos, and this tells you what to expect; what to see. How to care for your tattoos, etc. Cool.				
21.	Tattooing and piercing	Have a lot of friends who want to get tattoos. Would be good if they read this. Good info, but would add more detail. Graphics are okay, but not something that would attract my eye. Should have more colour. Don't like it. Doesn't teach you anything. Want something small and short. Artwork fine, don't mind it. Have several tattoos. 1950's picture is too old. Should have actual pictures of what disinfecting info looks like. Provide it everywhere. Too many words; use more pictures. Tattoo parlours should all be regulated.				
22.	Posters (French only) (no English-language posters available at time of testing)	Posters were generally thought a good idea to attract attention. One produced by the Canadian Liver Foundation was thought particularly good, as it addressed less known transmission methods – piercing, tattoos, razors, tooth-brushes.				

Effective Media for the Message							
	Halifax	Toronto	Calgary	Vancouver	Whitehorse	Montreal	
Bus or billboard ads, bus shelter ads; bench advertising.	✓	√		√			
Web site, as long as it had an easy name to remember	✓			Not supported	Not supported	✓	
TV ads (MTV)	✓			✓		✓	
Messages on condom wrappers, beer bottles/ cans, rolling papers, cigarette packages	√						
Posters	In bathrooms		√	Not in bathrooms	✓	In bathrooms	
A poll in the newspaper			✓				
Workshops for people		✓	✓				
Give teams of youth a job, spreading the word	✓	✓	✓	✓	✓		
Promote awareness at concerts, shows	✓		✓				
Use celebrities / put normal people in the spotlight			√				
Through schools				✓	✓		
Radio ads				✓	✓		
On skateboards					✓		
A hip song/CD	✓					✓	

Appendix F – Focus Groups: Partnering Organizations

The following organizations partnered with The Alder Group, as host of the focus groups:

- > Youth Link Toronto
- ➤ AIDS Calgary
- > Youth Net Vancouver
- ➤ Phoenix House, Halifax
- > BYTE Society Bringing Youth Towards Equality, Whitehorse
- > CACTUS Montreal

In addition, the following groups assisted by providing their insights to the facilitators:

- > YouthCo, Vancouver
- ➤ Whitehorse/Youth of Today Society (Blue Feather Youth Centre)