

EVALUATION SUMMARY REPORT



Hepatitis C Prevention and Community-Based Support Fund Alberta/NWT

2003 - 2005



Public Health
Agency of Canada

Agence de santé
publique du Canada

Canada 

ABOUT THE PUBLIC HEALTH AGENCY OF CANADA

Strengthening its ability to protect the health and safety of Canadians, the Government of Canada has delivered on its commitment to establish a new Public Health Agency of Canada. When the Agency was formed in September 2004, the Population and Public Health Branch of Health Canada officially became a part of the Public Health Agency of Canada.

The creation of the Public Health Agency of Canada marks the beginning of a new approach to federal leadership and collaboration with provinces and territories to renew the public health system in Canada and support a sustainable health care system.

Focused on more effective efforts to prevent chronic diseases, like cancer and heart disease, prevent injuries and respond to public health emergencies and infectious disease outbreaks, the Public Health Agency of Canada works closely with our partners to keep Canadians healthy and help reduce pressures on the health care system.

The Agency is headed by the Chief Public Health Officer, Dr. David Butler-Jones, who reports to the Minister of Health. Health Canada also reports to the Minister of Health. Although separate, both are members of the health portfolio and will work together to improve and protect the health of Canadians.

For more information on activities of the Public Health Agency, Alberta/NWT Region, please request a copy of the Annual Report (see contact information on next page).

Public Health Agency of Canada

Mission:

To promote and protect the health of Canadians through leadership, partnership, innovation and action in public health.

Vision:

Healthy Canadians and communities in a healthier world.

ABOUT THIS REPORT

I am pleased to introduce this report on the results of the Hepatitis C Prevention and Community-Based Support Fund in Alberta. This report highlights key results and learnings from 18 projects funded during April 2003 - March 2005. The 18 projects explored various approaches to hepatitis C prevention and support, and included a diverse range of stakeholders, target populations and settings. I hope that this effort to disseminate evaluation results will benefit both regional and national hepatitis C prevention and support stakeholders.

On behalf of the Agency, we would like to acknowledge work of the members of the Alberta Hepatitis C Advisory Committee and representatives of community-based organizations throughout Alberta who have contributed to the results documented in this report. The value of their time, interest and expertise goes well beyond the limits of these pages.

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Background on hepatitis C

WHAT IS HEPATITIS C?

Hepatitis C is an infection of the liver caused by the hepatitis C virus (HCV) that was first identified in 1989. The virus is spread by direct exposure to the blood of those infected with HCV. Compared to HIV, HCV is 10 to 15 times more transmissible by blood.¹

Hepatitis C infection is classified in two stages: acute and chronic. In the acute stage, symptoms such as loss of appetite, nausea and vomiting, stomach pain, extreme fatigue and a yellowing of the skin and eyes (jaundice) may appear six to seven weeks after infection. However, 60% to 70% of people in the acute stage have no symptoms and are still infectious to others. About 85% of people infected with HCV will progress to the chronic stage to carry the virus for the rest of their lives. Serious effects of the disease such as liver scarring (cirrhosis), liver cancer, and liver failure may not appear for decades after the initial infection. Drug therapy can clear HCV in 40 to 80% of patients; however, it is a long course of treatment and often has debilitating side effects. Currently, there is no vaccine available.² Overall, hepatitis C costs the Canadian healthcare system about \$500 million every year. This is expected to double to \$1 billion by 2010.³

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PREVALENCE OF HEPATITIS C

In Canada, 240,000 people are estimated to be infected with HCV, of whom only 30% know they have the virus. That is, more than 170,000 people do not know they are infected with HCV.⁴ About 23% of the 49,600 Canadians living with HIV are also co-infected with HCV.⁵ More than 5,000 new HCV infections occur in Canada every year: about 60% of which are due to injection drug use. In 2004, 1418 new hepatitis C cases were reported in Alberta.⁶

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The most common ways of HCV transmission are:⁷

- Sharing needles, straws, pipes, spoons and other drug-related equipment
- Getting a tattoo, body piercing, electrolysis or acupuncture from an operator who does not use sterile equipment or techniques
- Getting pierced by a needle or sharp equipment that has infected blood on it, as in a workplace situation

- Receiving a blood transfusion before the testing of blood donations became universal in 1992 (between 90,000 and 160,000 people are estimated to have been infected this way)

Some low-risk ways of HCV transmission are:

- Being born to a mother with hepatitis C
- Sexual intercourse – however, having multiple sexual partners may increase the risk
- Sharing personal household articles such as a razor or toothbrush with an infected person

HEPATITIS C PREVENTION AND HARM REDUCTION: MAKING THE LINK

Because the majority of new HCV infections are due to injection drug use, prevention strategies in Canada have included a “harm reduction” focus on injection drug use. Harm reduction refers to the policies and programs that aim to reduce the harms associated with non-prescription drug use such as HCV and HIV transmission. Harm reduction strategies may also act upon the social and economic harms that impact an individual, community or society. A defining feature of harm reduction is the focus on the prevention of drug-related harms rather than the prevention of drug use. Harm reduction initiatives such as community-based outreach, needle exchanges, and methadone programs are proven means of reducing behaviours that put people at risk of HCV infection.^{8,9}

People Who Use Drugs

For this report, the term “people who use drugs” will refer to people who use or inject illicit drugs.

Hepatitis C Prevention, Support and Research Program

In September 1998, the federal Minister of Health announced a wide-ranging initiative to address hepatitis C. The aims of the initiative are to build knowledge about hepatitis C, and to support all Canadians who are infected with, affected by or at-risk of developing hepatitis C.

The Hepatitis C Prevention, Support and Research Program is one component of a federal response to hepatitis C. The \$50 million, five year program was established in 1999 and was set to end in March 2004. The Program was extended for one year to March 2005 and then again to March 2006. The goals of the Program are to:

- Contribute to the prevention of hepatitis C infection
- Strengthen the public's potential to respond effectively to hepatitis C, by raising awareness and building the required capacity
- Support Canadians who are infected with, affected by, or at-risk of developing hepatitis C, by encouraging the development and dissemination of useful tools and mechanisms
- Foster research initiatives and increase research capacity to both strengthen the evidence base guiding policy/program development, and expand the options for prevention, treatment and cure

The Hepatitis C Prevention, Support and Research Program is divided into five components which are described below.

Prevention	Care & Treatment Support	Community-based Support	Research	Management, Policy, Evaluation, Public Involvement, & Emerging Issues
Supports activities that help prevent the spread of HCV, especially among those at greatest risk.	Supports activities that contribute to the health and well-being of those already infected or affected by HCV.	Supports activities that strengthen local capacity to respond to the needs of persons infected or affected by HCV.	Supports activities that further hepatitis C related knowledge.	Supports activities to ensure the overall program is well managed and accountable.

The Hepatitis C Prevention and Community-based Support Fund in Alberta

Since 2000, the Alberta/NWT Region has provided project funding to non-profit community organizations within Alberta through the Prevention and Community-based Support components. The purpose of the funding is to strengthen community participation to:

- Prevent the spread of hepatitis C
- Increase awareness and capacity to respond to hepatitis C
- Support persons infected with, affected by, or at risk of developing hepatitis C
- Provide evidence for hepatitis C policy and programming decisions

The delivery of the Hepatitis C Prevention and Community-based Support Fund (referred to as the ‘Fund’ for this report) is based on the population health approach.* Priority is given to initiatives that use a “community development approach” to ensure people that are affected by hepatitis C and/or populations that are at-risk of HCV infection play a meaningful role throughout the project – for example, by identifying needs, developing, and carrying out activities and tracking results. At-risk populations include people who use drugs, street-involved youth, people in prisons, and Aboriginal peoples.

The Alberta Hepatitis C Advisory Committee sets the regional Fund priorities, determines the funding process for each year, and reviews project proposals. The Alberta Hepatitis C Advisory Committee for 2003 to 2005 was comprised of representatives from Alberta Health and Wellness, the Alberta Non-Prescription Needle Use (NPNU) Initiative, Alberta Solicitor General, Capital Health, and an individual living with hepatitis C.

From 2000 - 2003 funding was available for projects one to three years in duration. A total of \$316,000 was allocated in each year for 2000-01, 2001-02, and 2002-03 to an average

* The population health approach focuses on the range of individual and collective factors that influence health, known as the determinants of health. These factors include: income and social status, social support networks, education, employment and working conditions, health services, physical and social environments, biology and genetic endowment, personal health practices and coping skills, healthy child development, gender and culture. The model also focuses on applying multiple strategies across multiple levels and sectors to act on the determinants.

of 15 projects per year. Priorities included reaching off-reserve Aboriginal communities, high-risk youth, correctional services staff and inmates, and women at-risk, as well as strengthening regional hepatitis C networks. For fiscal years 2003-04 and 2004-05, funding was targeted to the NPNU Initiative as described below.



**NON
PRESCRIPTION
NEEDLE USE
INITIATIVE**

The goal of the NPNU Initiative is to reduce the harms associated with non-prescription needle use as they relate to the transmission of blood-borne pathogens such as HIV and hepatitis C. The NPNU Initiative includes the NPNU Consortium (comprising 37 policy-makers, funders, experts and programmers who direct a shared plan of action), a steering committee, seven task groups, the Opioid Dependency Treatment Coordinating Committee, and the Harm Reduction Programmers Committee. The membership of the NPNU Initiative is province-wide and represents the following sectors: education, corrections, health care, law enforcement, human resources and employment, harm reduction, AIDS service organizations, addictions, and mental health.

FUNDING PROCESS 2003-04

In June 2002, the task groups and committees of the NPNU Initiative (see description above) were solicited for one-year projects that were scheduled to begin April 2003. Priority was given to projects that developed and sustained volunteer capacity among the priority themes of the NPNU Initiative (the Aboriginal population, the prisons population, addictions, community and professional development, mental health, public awareness, youth and surveillance). Nine projects were supported in Alberta for a total of \$254,071.

FUNDING PROCESS 2004-05

In May 2004, the task groups and committees of the NPNU Initiative were solicited for 6-month projects that were scheduled to begin October 2004. Priority was given to projects that supported the priority themes of the NPNU Initiative (the Aboriginal population, the prisons population, addictions, community and professional development, mental health, public awareness, youth and surveillance). Nine projects were funded for a total of \$257,000.

Methods – how evaluation data were collected

DATA SOURCES

Program results presented in this report are based on data provided from funded projects. Each project is required to submit quarterly monitoring reports that provide qualitative and quantitative project data.* Projects also submit a final report at the end of the project. Most projects also submit a separate evaluation report. These reports contain information on project activities, results, lessons learned, and methods used to gather evaluative data, and feedback on PHAC support.

ANALYSIS

Project activities were analysed to determine how they contributed to the Fund's objectives of:

- preventing hepatitis C
- increasing awareness and awareness of hepatitis C
- supporting persons infected with, affected by, or at risk of developing hepatitis C
- providing evidence for hepatitis C policy and programming decisions

PHAC program consultants, with the support of the PHAC evaluation consultant, summarize quantitative data using descriptive statistics and analyse qualitative data using content analysis. During the analysis, the following questions are answered:

- What were the main project activities and results and how did they contribute to the Fund's objectives?
- How many people were reached through project activities?
- How many partners and sectors were reached?
- What determinants of health were addressed through project activities?
- What have projects learned about what works and what doesn't work?
- What feedback do projects have for PHAC about support received and funding program administration?

* The Monitoring Report and Final Report forms were modified in 2004/05 to capture more quantitative data on resources leveraged and volunteer hours.

DATA QUALITY

Many steps are taken to ensure that information presented in this report is accurate. Care is taken to report only those results that could reasonably be observed through reported evaluation methods and instruments. Funded projects typically use a variety of data collection methods, such as surveys, focus groups, participant feedback (oral and from forms), pre and post measures, and diaries. Program consultants may also compare the description provided to what they observed through site visits, meetings or events that they have attended. A draft of the report is circulated to the Program Advisory Committee prior to publication. In addition, projects provide a final accuracy check of their individual project summary and results.

LIMITATIONS

Information presented in this report is based on reports submitted by funded projects. Results described are those reported during the course of the funding period and do not reflect project impact beyond the funding period.

Project results: 2003-2005

OVERVIEW OF RESULTS

As a result of project funding in 2003-04 and 2004-05, a total of 3773 youth, social and health professionals, people affected by hepatitis C, prison inmates, people who use drugs, and the general public were reached as a result of projects in both fiscal years. In 2004-05, \$76,000 in resources were leveraged as a result of project funding and a total of 82 volunteers contributed 940 hours of work to the projects.

The following sections summarize the projects' outputs and immediate and intermediate outcomes by the determinants of health, partnerships and the objectives of the Fund. A discussion of the lessons learned about the project activities follows. For more information about each project, see the project descriptions starting on page 21.

2003-04 Projects

- \$254,071 were allocated to nine projects
- Project sponsors had 12 months to complete their projects
- A total of 2,306 people were reached

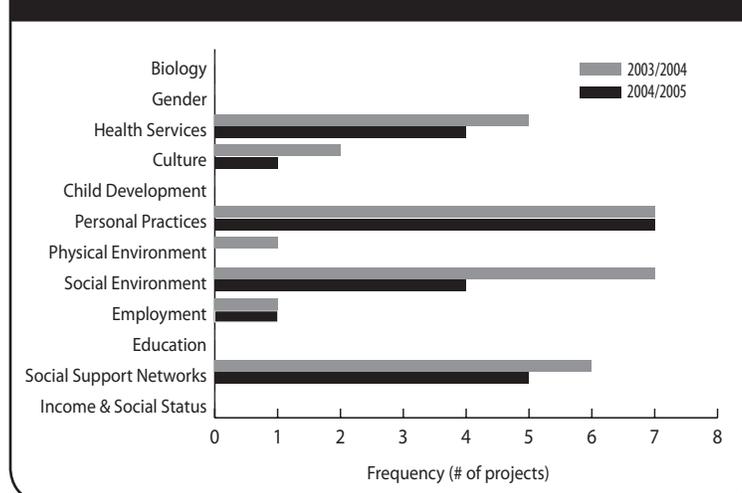
2004-05 Projects

- \$257,000 were allocated to nine projects, \$76,000 in resources were leveraged
- Project sponsors had about 6 months to complete their projects
- A total of 1,467 people were reached

The determinants of health addressed by 2003-04 and 2004-05 hepatitis C projects

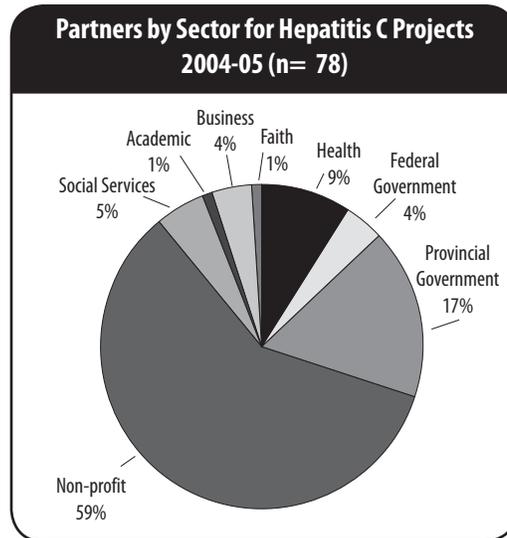
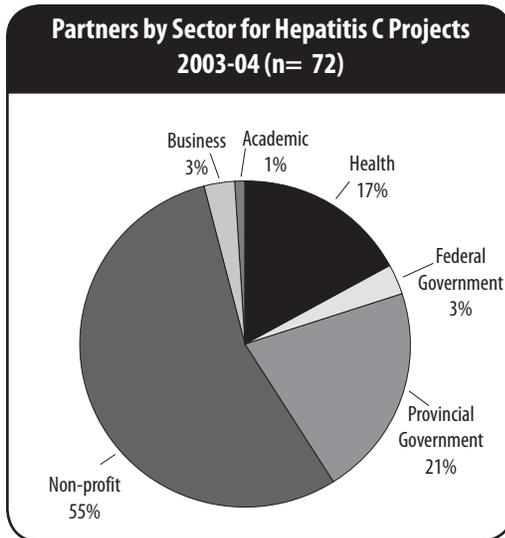
Most projects addressed the personal health practices and coping skills, social support networks, and health services that influence the health of people affected by hepatitis C or at-risk of hepatitis C infection.

Determinants of Health Addressed by Hepatitis C Projects in 2003-04 and 2004-05



Total number of project partners involved by sector

In both fiscal years, over half of the partners were from the non-profit sector. Projects were completed on behalf of a NPNU Initiative task group or committee, therefore many of the project partners shown here are NPNU Initiative task group or committee members.



EXAMINING PROJECT RESULTS THROUGH THE LENS OF THE FUND OBJECTIVES

Preventing the spread of hepatitis C

Developed by at-risk-youth, *Life on Meth* raises awareness among at-risk-youth about crystal methamphetamine and its health affects on the user. This 30-second public service announcement was distributed to several local broadcasters and to Alberta Alcohol and Drug Abuse Commission (AADAC). The same youth also created *Be Smart About It*, a two-minute documentary that can be used as a teaching tool for youth. Drug-involved youth were empowered by participating in the process from education sessions to brainstorming to film-making. In post-production interviews, the youth reported increased self-esteem, gained trust to ask for help, and a feeling of accomplishment as result of the project. Six of the ten participating youth attempted treatment at sometime during the project and two completed a treatment program.

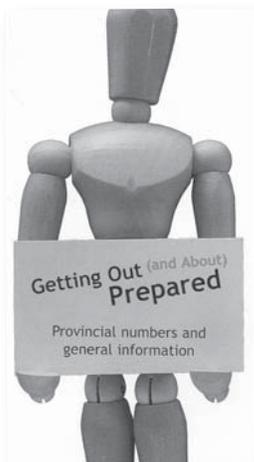
The Stop and Start Project (2003-04, 2004-05) involved Aboriginal youth and community member Fox Morin to design, develop, and distribute a DVD and peer user guide entitled, *That's It... For Now*. This 17-minute DVD focuses on hepatitis C awareness and prevention and confronts popular myths about contracting HCV. Participating youth gained insight into HCV prevention and what it is like to live with hepatitis C. Over 180 youth attended the video's premiere, featured by Global Television (Edmonton) and the Aboriginal Youth Network. Since the premiere, *That's It... For Now* has been distributed by 19 trained youth facilitators in their communities, correctional facilities, several partnering organizations, and was presented at the Canadian National Hepatitis C Conference (2004). Presentation evaluations indicate that more youth would like to be trained to deliver this video.

To prevent the spread of HCV among people recently discharged from prison, the Alberta Corrections' Harm Reduction Program project worked with 67 inmates to develop a brochure of Alberta harm reduction resources and community services entitled, *Getting Out Prepared*. These brochures are given to Alberta inmates upon release.

Increasing awareness and capacity to respond to hepatitis C

Several projects improved access to harm reduction services among people who inject illicit drugs by training and supporting the professionals that work with them on a regular basis: harm reduction programmers, healthcare professionals, corrections staff, social workers, and addictions workers. One project also developed products to raise awareness about harm reduction initiatives among the general public.

Harm Reduction Programmers: Research articles, technical reports, guides, and other relevant resources were gathered and collated into the electronic *Alberta Harm Reduction Programmers Resource Library* (CD-ROM) and distributed among Alberta's six harm



reduction programs. In 2003-04, mentoring visits between Safeworks and Streetworks allowed staff to better understand each other's programming, methods, perspectives, and challenges. The programmers were also able to reconnect with clients with whom they had lost contact. In 2004-05, rural harm reduction programmers visited the urban (i.e., Calgary and Edmonton) harm reduction programs to discuss similar concerns and validate the progress being made with the smaller sites.

Health professionals: A legacy of the 2003-04 *Essentials of Harm Reduction* project is the continuing pharmacy distance education course entitled, *Harm Reduction: Opportunities for Pharmacists to Prevent the Spread of Blood-borne Pathogens*, that will be offered to community pharmacists until September 2006. Course evaluations indicated that that the course has raised awareness among community pharmacists and has increased their comfort-level for working with clients that use non-prescription drugs. Twenty *Essentials of Harm Reduction* presentations were also made to 800 interdisciplinary health students. Another project provided Methadone Maintenance Treatment (MMT) training for 128 physicians, pharmacists, and allied health professionals in 2003. Participants reported in workshop evaluations that the MMT training was a valuable learning experience, felt that MMT training would enhance their professional effectiveness, and would recommend MMT training to their colleagues. One success factor of this project was the continuing education credits given to participating physicians, nurses, and pharmacists. All project partners recognized that this training was an important step for advocating for MMT.

Corrections staff: While providing support and information to male and female inmates, three projects also provided educational workshops to corrections officers and caseworkers from Alberta prisons about hepatitis C, harm reduction, and community resources. As a result of one workshop with 24 Alberta Correctional Services employees, most participants reported in workshop evaluations that they have an increased understanding of blood-borne pathogens and how to protect themselves from occupational exposure. Two-thirds of participants felt that it was important to implement harm reduction strategies in their workplaces. Another project trained 16 Alberta Corrections caseworkers about blood-borne pathogens, harm reduction principles, and relevant community resources so that they could share this information with their clients. This project has been adopted by Alberta Correctional Services, and caseworkers in the major correctional centres are providing the pre-discharge workshop to inmates at least once a month.

Social Workers: *The Essentials of Harm Reduction* presentation (CD-ROM) was adapted for social workers and distributed to all of the harm reduction programs in Alberta. In addition, 39 social workers were given professional development accreditation from the Alberta College of Social Workers for their participation in the *6th Alberta Harm Reduction Conference*.

The *Essentials of Harm Reduction* reached pharmacists, health students, physicians, and allied health professionals.

Addictions Workers: The *Essentials of Harm Reduction* presentation was also adapted for addictions workers and nine workshops were presented by Alberta's harm reduction programmers to 148 AADAC staff and addictions students at Alberta colleges. Although most addiction workers in the community know about harm reduction, workshop evaluations revealed that awareness of harm reduction principles and local programs increased. The workshops also gave the addictions workers an opportunity to share their harm reduction experiences and to talk about the ongoing challenges. Almost all participants reported in the workshop evaluations that they felt better prepared to share information with others about harm reduction.

To generate awareness and public support for harm reduction programs and services among the general public in Alberta, one project developed brochures and presentation materials entitled, *Harm Reduction Saves Lives*, which are available to NPNU Initiative members for their ongoing use.



Alberta Harm Reduction Conference

www.albertaharmreduction.ca

The event that brings together harm reduction programmers, health professionals, corrections staff, social workers, and addictions workers every year to learn more about harm reduction is the *Alberta Harm Reduction Conference* (2004, 2005). The goal of the *Alberta Harm Reduction Conference* is to raise awareness about the application of harm reduction principles among service providers from Alberta and beyond who work with populations vulnerable to contracting HCV and HIV/AIDS and to build capacity among those populations. This 2-day conference offers at least 4 plenary sessions and 24 presentation workshops. The 2004 Conference, *A Serious Fix*, was held in Edmonton where over 204 professionals and people who use drugs attended. An advisory committee of community members who have used drugs were involved in the conference planning. Dr. David March, project leader for the North American Opiate Medication Initiative (NAOMI) Study, gave the keynote presentation. Grande Prairie hosted 239 professionals and people who use drugs at the 2005 Conference, *Exposing the Elements*. Canadian social marketing consultant, François Legarde provided the keynote address about how to deliver strong harm reduction messages within the community. Local television, radio, and print media covered both events.

A component of both *Alberta Harm Reduction Conferences* was the involvement of people who use drugs in conference planning and the event itself. Scholarships were offered so 60 people who use drugs could attend the conferences to enhance their own capacity to respond to their health needs and have a voice in harm reduction programs and services. Their involvement kept the content, design, and discussion of both conferences relevant.



Supporting persons infected with, affected by, or at risk of developing hepatitis C

The *Reaching Across Alberta Communities* projects (2003-04, 2004-05) increased access to hepatitis C and mental health supports for people living in Edmonton, central Alberta, and Lethbridge. Both one-on-one peer support and group meetings were offered that included educational videos, discussions about hepatitis C, and social activities. Feedback from participants indicates that the peer support group is a popular resource. The *Reaching Across Communities: Alberta Hepatitis C and Peer Support Group Toolkit* was developed in 2003 to aid the start-up of peer support groups in Alberta. In 2004-05, this document was revised and expanded to create the *HCV Support Group Toolkit Phase II: for the Peer Supporter*. The toolkits contain information about living with hepatitis C such

as local resources, nutritional needs, when to disclose hepatitis C status, and treatment options.

People infected or affected by hepatitis C also helped raise awareness of the disease within their communities to create more supportive environments. Volunteers presented hepatitis C information on several occasions to community organizations, treatment centres, businesses, schools, and corrections facilities in Edmonton, central Alberta, and Lethbridge. Presentations about hepatitis C support in Alberta were made at the *Aboriginal Hepatitis C Conference* (2003), the *Canadian Liver Foundation Regional Conference* (2003), the *Third Aboriginal Partnership Conference* (2004), and the *National Hepatitis C Conference* (2004).

One project helped reduce the risk of hepatitis C among women about to be released from prison by increasing their awareness of HIV, hepatitis C, and social supports available in the community. Eight information sessions were presented to 56 women at all three Edmonton area women's correctional institutions. Participants reported in the session evaluation forms that they had an increased knowledge of the risk factors associated with contracting and spreading hepatitis C. This project also prepared and distributed 300 "release kits" containing personal hygiene products, bus passes, up-to-date information on hepatitis C/HIV, and related community resources to women recently released from prison. Follow-up interviews with women who re-initiated contact with the Elizabeth Fry Society after release reported that the kits eased the transition from prison into the community.

Providing evidence for hepatitis C policy and programming decisions

Three projects provided evidence that may impact policy and programming decisions in Alberta: the *Inmate Health Study*, the *Hepatitis C and Mental Health Issues – Alberta Needs Assessment*, and the *User's Network Development Project Needs Assessment*.

The *Inmate Health Study* explored injection drug use and other risk behaviours inside Alberta's adult correctional centres. The study surveyed 232 people at twelve different community agencies after they had been released from provincial prisons. The study found that the risk behaviours for hepatitis C infection exist in Alberta's prisons: 77% of respondents reported using drugs in prison, 46% reported sharing drug injection equipment in prison, and 30% have been tattooed in prison. The study also surveyed respondents' perceptions of the living conditions inside Alberta's correctional centres. The resulting report provides the information and understanding necessary to work towards developing harm reduction strategies and policies for the corrections system in Alberta. Several recommendations were made that encourage healthy and safer practices in Alberta's correctional centres, for example, the introduction of methadone maintenance and condoms. It was also recommended that HIV and HCV testing should be made universally available at inmates' request. Two reports resulted from this study: the *Inmate Health Study* and the *Alberta Inmate Non-Prescription Needle Use Study*.

The *Hepatitis C and Mental Health Issues Alberta Needs Assessment* determined the professional and peer supports needed by people living with hepatitis C. Over 60 people affected by hepatitis C participated in six focus group interviews and 34 health professionals completed surveys. Several recommendations were made for enhancing services and policies including: reducing stigma and discrimination about hepatitis C; improving access to professional and peer support; employing more health professionals that are aware of hepatitis C issues; providing transportation to treatment centres; enhancing access to treatment and support for people living in rural and remote communities; and improving access to safe housing, employment and nutrition for people living with hepatitis C. The resulting report is a potential tool for hepatitis C advocacy and program planning in Alberta.

Interventions that focus on personal social networks have proven useful in reducing drug-associated harms.^{10, 11} The *User's Network Development Project (UNDP) Needs Assessment* explored Alberta's readiness for, and the design of, a drug user network. Over 100 people who use drugs were surveyed in six Alberta cities, and results were verified by three focus groups that were conducted in Edmonton, Red Deer, and Calgary. This needs assessment found that people who use drugs have an interest in their health and want more peer support and information about harm reduction and hepatitis C. The needs assessment recommends that two monthly user groups in Calgary and Edmonton and one annual provincial user group be initiated. The UNDP report will guide the development of user groups as it recommends topics the groups should address, meeting format, and who should be involved.

LESSONS LEARNED

1. ABOUT THE TARGET POPULATION

A participatory approach is integral to successful community programs.^{12,13} The Canadian HIV/AIDS Legal Network states: "Nothing about us without us".¹⁴ The target populations gladly participated in several hepatitis C projects. Some people travelled several hours to attend a focus group. Many projects found that their target population have information to share about their health concerns and want a voice in the programs and services they receive. In their own words, here are some lessons projects learned about their target populations:

"Working with youth involved in the drug scene requires considerable support to sustain their participation in the project, as they are difficult to contact and have transient, chaotic lives. Staff that works with drug-involved youth must be flexible, non-judgmental, and sensitive. Food, support, and payment for the youth were significant incentives for their participation. Treatment facilities for youth with crystal meth are very limited".

“Prison populations near Edmonton continue to hide their hepatitis C infection”.

“[For the drug user groups] it is easier to recruit participants in larger cities where harm reduction programs are more established and have a larger population of users accessing their services. Drug users have a genuine interest in having a user group they can attend. Planning meetings on dates and at times when drug users are already at the location will help maintain group attendance”.

“Having the youth peer educators present the That’s It... for Now video at conferences allowed them to express how they perceived the development of the video”.

“The support needs of people taking treatment [for hepatitis C] and people not on treatment vary greatly. We may have to split the support groups to provide relevant information to both groups”.

“Reaching and involving rural people continues to be a struggle financially”.

“Many workers use harm reduction approaches with clients, but have few outlets to discuss challenges and frustrations, or even successes-especially if harm reduction is not a policy endorsed by their workplace”.

2. ABOUT THE DETERMINANTS OF HEALTH

Working with people that are affected by or at-risk for hepatitis C has also raised awareness of the factors that determine health among project staff. For example, one hepatitis C support project found that workshops on the Freedom of Information and Protection of Privacy Act and tenant rights were valued the most among people living with hepatitis C because they learned when it is okay to disclose their health status and how to protect their jobs and homes. Results from the *Hepatitis C and Mental Health Issues – Alberta Needs Assessment* also touched on many of the determinants of health, including employment and housing. Another project heard that offenders upon release need government-issued identification so that they can secure employment and access other services. Here are some of the projects’ insights about other determinants of health:

“There is a need to develop skills in setting boundaries and understanding what “healthy” relationships are with friends. Peer pressure and experimentation were seen as key factors in exposure to risk activities”.

“The development of social support networks has positively influenced the personal health practices and coping skills of many of the people receiving service”.

“Access to information is affected by poverty”.

3. ABOUT PARTNERSHIPS

Partnerships are key to building community capacity.^{15,16} One project found that an unintended outcome was their partners' increased awareness and action related to harm reduction. For another project, working on a common project allowed partners to share ideas, resources, and a vision in a very practical manner. In their own words, here are some other lessons learned about partnerships:

“Partnering with medical professional organizations presented benefits (e.g., legitimacy) and also challenges”.

“Teleconferences are an important tool to keep project partners across the province up-to-date”.

“Non-Aboriginal organizations were receptive to working with an Aboriginal organization”.

Projects also learned that working in partnership requires time and role clarity:

“While the collaborative model which the NPNU [Initiative] represents has many positive features, it also created difficulties for project completion [for example, timelines, roles] as [the project sponsor] did not actually have full control of the work which was guided by the [task group]”.

“When working with a diverse group of partners, it is important to make sure the role of the community organizations is also highlighted”.

“An explicit description of each partner role is critical to ensure that the workload is distributed fairly, and not [only] to the host agency”.

4. ABOUT RESOURCE DEVELOPMENT

Most funded projects developed a workshop, presentation or a product to raise awareness about hepatitis C and harm reduction. Many lessons were learned about developing workshops and products including the importance of: identifying the specific target population of any product; tailoring harm reduction information to the target group and context; providing local content; having a key contact or liaison with the target population to provide insight and feedback; and coupling information with a personal story to maximize its impact. One project learned that they would focus test content and hire a speechwriter if they had to develop a product again. Hiring a conference coordinator and a local coordinator for the *Alberta Harm Reduction Conference* was reported to be extremely helpful. Projects also gained insight into the marketing of the workshops and presentations: using key contacts and an early, comprehensive marketing campaign at various levels may boost attendance. They also learned about the importance of

considering the needs of the target population. While email and a website are critical tools to spread the word about an activity or product, posters reach people who have less access to computers and the internet. Community members appreciated a room to relax in at the *Alberta Harm Reduction Conference*. A certificate of attendance and continuing education credits at conferences and workshops were appreciated by professional groups.

5. ABOUT FUTURE PROJECTS

Based on the lessons learned from their project activities and evaluations, some projects had ideas about possible future projects. Here are some of their project ideas, in their own words:

“Feedback [on the Harm Reduction Essentials for Addictions Workers project] has lead to an idea for an ‘advanced’ harm reduction curriculum that could be helpful for those already using harm reduction strategies on a consistent basis. Examples of content include a more in-depth look at things like safer injection facilities, prescription heroin, injection drug use culture, etc.”.

“With the recognition that HCV is an issue with long standing implications for Aboriginal people and communities, the depth of information that has to be shared must go beyond what we have outlined in the That’s It...for Now video and training”.

“We have learned that in order for caseworkers to implement this workshop they will need the support of management and other related staff. If we were to do things differently we would include corrections staff and other additional harm reduction programmers from across Alberta in our Getting Out, Staying Safe [project]. The development of a video for caseworkers to use would be an important addition to this Train the Trainer - it would make delivering this workshop less difficult for the caseworkers”.

PRODUCTS PRODUCED

Reports

Inmate Health Study^f

Alberta Inmate Non-Prescription Needle Use Study^f

Hepatitis C and Mental Health Issues – Alberta Needs Assessment^h

User's Network Development Project (UNDP) Needs Assessment^a

Course Curriculum

Harm Reduction: Opportunities for Pharmacists to Prevent the Spread of Blood-borne Pathogens (for the University of Alberta)^e

Presentations

Essentials of Harm Reduction for Pharmacists^e

Essentials of Harm Reduction for Social Workers^e

Essentials of Harm Reduction for Addiction Workers^c

Harm Reduction Saves Lives (for the general public)^d

Videos

Life on Meth (30 second public service announcement for youth-at-risk)^d

Be Smart About It (2 minute video about crystal meth and harm reduction)^d

That's It...For Now (17 minute DVD about hepatitis C and prevention for Aboriginal youth)^g

Brochures

Harm Reduction Saves Lives (for the general public)^d

Getting Out Prepared (for prisoners upon release from prison)^d

Toolkits

Reaching Across Communities: Alberta Hepatitis C and Peer Support Group Toolkit^b

*HCV Support Group Toolkit Phase II: For the Peer Supporter*ⁱ

Reference for Products Produced

a. AIDS Calgary Awareness Association

b. Bissell Centre

c. Central Alberta AIDS Network Society

d. HIV Network Society of Edmonton

e. HIV North Society

f. John Howard Society of Alberta

g. Kimamow Atoskanow Foundation

h. Lethbridge HIV Connection

i. Life with Hepatitis Society of Central Alberta

Feedback on the Hepatitis C Prevention and Community-based Support Fund

The projects provided useful feedback that will be used to improve the delivery of the Hepatitis C Prevention and Community-based Support Fund.

Several projects noted that the late confirmation of funding for 2004-2005 fiscal year created short timelines for the application process and less than six months to complete the work plan. They report that the short funding period was a barrier to collaboration and employing project staff. Projects recommended that the call for proposals should be done with enough time to allow for proposal planning and writing, and prefer funding periods that are longer than 12 months.

Feedback about the Fund: The projects appreciated that hepatitis C funding was available to increase awareness about hepatitis C and harm reduction, address needs in the community, and to bring partners together to work on the project. One project stated that the Fund “acknowledges that HCV is an important public health issue”.

Feedback about the Program Consultants: The projects also appreciated the three program consultants that supported them over the two years by hosting teleconferences about new reporting requirements, responding quickly to emails, answering questions about re-allocating budget lines, providing statistics, and sharing information. As was described on feedback forms, the program consultant was “friendly”, “open to discussing project approaches and ideas”, and “provided reassurance when needed”.

Feedback about knowledge sharing: One project suggested that projects that received funding should be brought together at the end of the funding period to share accomplishments and lessons learned.

Special events

ACHF SKILLS BUILDING WORKSHOP AND NETWORKING SESSION

In September 2004, the Alberta Community HIV Fund (ACHF) provided a *Skills Building Workshop and Networking Session* to its funded projects and operational sites. As most of the hepatitis C project sponsors also receive ACHF dollars, the Hepatitis C Prevention and Community-based Support Fund partnered with ACHF to send the remaining hepatitis C project sponsors to participate. The workshop focused on program evaluation planning. It also provided an afternoon of information sharing and networking. Forty people attended this one-day event.

Hepatitis C Projects: 2003-04

Building Awareness of Harm Reduction: Youth at Risk

SPONSOR: HIV Network of Edmonton Society SITE: Edmonton

On behalf of: Alberta NPNU Public Awareness Task Group

PHONE: (780) 538-3388

WEBSITE: www.hivedmonton.com

This project built on previous efforts of the NPNU Public Awareness Task Group to raise harm reduction awareness among high-risk youth. With the help of a local film producer, 10 drug-involved youth created and edited a 30 second PSA entitled, *Life on Meth*, which has been distributed to local broadcasters through the Alberta Alcohol and Drug Abuse Commission (AADAC). The same youth also created and edited a two-minute documentary about crystal methamphetamine and harm reduction entitled, *Be Smart About It*. About 125 copies of the video have been made for distribution through HIV Edmonton. The youth that participated in the project received HIV, hepatitis C, crystal methamphetamine, harm reduction, and peer education training.

Using crystal methamphetamine can put people at risk of hepatitis C infection.

The Release Kit Project

SPONSOR: Elizabeth Fry Society of Edmonton SITE: Edmonton

On behalf of: Alberta NPNU Prisons Task Group

PHONE: (780) 421-1175

WEBSITE: www.elizabethfry.ab.ca

The goal of this project was to enable women released from correctional institutions in the Edmonton area to access social support and decrease risk behaviours related to hepatitis C and HIV. Elizabeth Fry Society of Edmonton and HIV Edmonton hosted eight HIV and hepatitis C educational sessions at all three Edmonton area prisons for inmates. They also held one educational session for staff. Release kits containing personal hygiene products, up-to-date information on hepatitis C/HIV, and related community resources were prepared and distributed to approximately 300 women. Follow-up surveys with women who re-initiated contact with Elizabeth Fry Society on release and close case monitoring determined the impact of the project on social support networks and risk-related behaviours.

The first 72 hours upon release from prison are critical to successful community re-integration.

Inmate Health Study

SPONSOR: John Howard Society of Alberta SITE: Province-wide
On behalf of: Alberta NPNU Consortium: Surveillance Task Group
PHONE: (780) 423-4878 WEBSITE: www.johnhoward.ab.ca

The project determined the current prevalence of hepatitis C and non-prescription needle use in Alberta's prisons and gained a better understanding of inmates' risk behaviours, harm reduction practices, and determinants of health. The project consolidated relevant data currently available collected by harm reduction programs, regional health authorities, and the Alberta Corrections system. Gaps in information were identified and a new survey instrument exploring hepatitis C and HIV prevalence, health risk behaviours, substance use, and living conditions was developed and reviewed by project partners. A sample of 232 recently released inmates was surveyed at social service agencies throughout the province. Several recommendations have been made in the resulting reports: the *Inmate Health Study* and the *Alberta Inmate Non-Prescription Needle Use Study*.

Start and Stop

SPONSOR: Kimamow Atoskanow Foundation (KAF)
On behalf of: Alberta NPNU Aboriginal Youth Task Group
SITE: Province-wide PHONE: (780) 967-2997

The project raised awareness and knowledge of hepatitis C among Aboriginal youth in Alberta by creating an educational video tool and training Aboriginal youth peer facilitators to effectively use this tool. Project activities included: recruiting a project advisory committee; brainstorming a series of Start (taking control) and Stop (taking unnecessary risks) scenarios; editing and finalizing video content and scripts; filming and editing scenario footage; recruiting and training Aboriginal youth on how to use the video; and developing a supplemental training manual. Mirroring everyday life of Aboriginal youth, *That's It... For Now* (in DVD format), confronts popular myths about contracting HCV and discusses prevention strategies. Over 180 youth attended the video's premiere, featured by Global Television (Edmonton) and the Aboriginal Youth Network. The video has been presented at the Canadian National Hepatitis C Conference, Lethbridge Correctional Centre, and the NPNU Consortium Meeting among others.

Hepatitis C Projects: 2004-05

Building Awareness of Harm Reduction, Hepatitis C and Other Blood Borne Pathogens

SPONSOR: HIV Network of Edmonton Society SITE: Province-wide

On behalf of: Alberta NPNU Public Awareness Task Group

PHONE: (780) 538-3388

WEBSITE: www.hivedmonton.com

This project built on the previous efforts of the NPNU Public Awareness Task Group by compiling, refining and marketing NPNU Initiative materials that explain the philosophy and practice of harm reduction to various audiences. A list of recently produced harm reduction materials was compiled. This project developed a pamphlet for the general public entitled, *Harm Reduction Saves*, and an accompanying presentation. It also developed a Harm Reduction 101 pamphlet and conducted a seminar about blood borne pathogens and harm reduction to 24 prison guards. Lastly, the *Harm Reduction Information Kit for Professionals Working with At-risk Populations (2000)* was focus tested for revisions and updates.

Stop and Start: Continuing the Process

SPONSOR: Kimamow Atoskanow Foundation (KAF)

On behalf of: Alberta NPNU Aboriginal Task Group

SITE: Province-wide

PHONE: (780) 967-2997

This project built on the previous efforts of the NPNU Aboriginal Task Group by further developing, promoting, and using the *That's It ... For Now* video, which describes risk behaviours for HCV infection using Aboriginal youth and role models. This project trained 17 Aboriginal youth facilitators to deliver hepatitis C prevention and awareness presentations using the *That's It ... For Now* video and accompanying manual to youth within their own communities. Fox Morin, a respected hepatitis C advocate in the community, presented the project at the *Lethbridge Youth Conference*, in a correctional institution, at the *6th Alberta Harm Reduction Conference*, and three other out-of-province events.

Only 8% of adult Albertans have heard about the concept or principles of harm reduction, but when they were told that it could control the spread of blood-borne pathogens, 82% reported that it is a useful approach to take with people who inject drugs.¹⁷

Hepatitis C and Mental Health Issues – Alberta Needs Assessment

SPONSOR: Lethbridge HIV Connection SITE: Province-wide
 On behalf of: Alberta NPNU Mental Health Task Group
 PHONE: (403)-328-8186 WEBSITE: www.lethbridgeHIV.com

This needs assessment was conducted to increase understanding of needed professional and peer support for Albertans living with hepatitis C and provide information for the enhancement of such supports. The research consultant hired for this project conducted six focus groups with people infected with or affected by hepatitis C. In addition, medical professionals (mostly nurses) and mental health caseworkers from all of Alberta's health regions completed a survey. The resulting report, *Hepatitis C and Mental Health Issues - Alberta Needs Assessment*, includes several recommendations were for enhancing services and policies in Alberta and has been disseminated among the NPNU Initiative membership, Alberta's regional health authorities, and participating service organizations. Preliminary findings were presented at the *6th Alberta Harm Reduction Conference*.

A broad base of supports is required from communities, government, and professionals to overcome the physical, emotional, social, and financial impacts of hepatitis C.

Addiction Worker Training in Harm Reduction

SPONSOR: Central Alberta AIDS Network Society (CAANS)
 On behalf of: Alberta NPNU Community and Professional Development Task Group
 SITE: Province-wide PHONE: (403) 346-8858

This project built upon the previous *Essentials of Harm Reduction* workshops and presentations to increase awareness of hepatitis C, HIV, and harm reduction among addictions workers and addictions counselling students in Alberta so that they can understand and integrate the principles of harm reduction into the treatment process for their clients. This project hired a harm reduction educator, modified existing workshop material towards the needs of addictions workers, and provided nine workshops for 148 Alberta Alcohol and Drug Abuse Commission (AADAC) staff and addictions students at Alberta colleges as well as one presentation to the general public. In addition, addictions students were given tours of local harm reduction agencies.

Shared Resources and Mentorship at a Provincial Level, Phase 2

SPONSOR: Streetworks SITE: Province-wide
 On behalf of: Alberta NPNU Harm Reduction Programmers Task Group
 PHONE: (780) 423-3122 ext 210 WEBSITE: www.streetworks.org

This project built upon the previous efforts of the NPNU Harm Reduction Programmers Task Group to provide harm reduction agencies with current harm reduction information and increase support and opportunities for inter-agency knowledge sharing and mentorship for harm reduction agency staff in Alberta. Project activities included

updating and distributing an electronic library of resources (CD-ROM) for use by harm reduction agencies, and facilitating harm reduction agency exchanges in Alberta.

Alberta Corrections' Harm Reduction Program

SPONSOR: HIV Network of Edmonton Society SITE: Province-wide
 On behalf of: Alberta NPNU Prisons Task Group
 PHONE: (780) 538-3388 WEBSITE: www.hivedmonton.com

This project aimed to build awareness of hepatitis C transmission and harm reduction approaches among inmates preparing to be discharged from correctional facilities across the province. The project conducted focus groups with 67 inmates to determine the multiple barriers they face upon release and what resources they need during the transition into the community. These focus groups informed the creation of a brochure entitled, *Getting Out, Staying Safe*, that lists the Alberta harm reduction resources and community services that are available. A “Train the Trainer” Workshop that addressed blood-borne pathogens, harm reduction principles, and relevant community resources was also developed and delivered to 16 Alberta Corrections staff. The project resources were presented and distributed at the *6th Alberta Harm Reduction Conference*.

User Network Development Program (UNDP)

SPONSOR: AIDS Calgary Awareness Association
 On behalf of: Alberta NPNU Harm Reduction Programmers
 SITE: Calgary, Red Deer and Edmonton
 PHONE: (403) 508-2500 WEBSITE: www.aidscalgary.org

This project aims to determine the needs of people who use drugs across the province in terms of support, networking, education, and prevention order to create a plan of action for the development of a provincial network of people who use drugs. A survey among 109 people who use drugs from six Alberta cities identified what the purpose of the groups should be, who should attend, who should start it up, where to meet, frequency of meetings, and interest in meetings. The survey results were verified by three focus groups (one each in Edmonton, Red Deer, and Calgary) that involved a total of 24 participants and further determined the need for users groups in Alberta. Preliminary findings and recommendations were presented at the *6th Alberta Harm Reduction Conference*.

Involving people who use drugs in policy, programming changes, initiatives, and other strategies for harm reduction and health promotion will likely lead to positive outcomes.

Next steps

In March 2005, the government announced that the Hepatitis C Prevention, Support and Research Program would be extended for one more fiscal year. In April 2005, Alberta region conducted an anticipatory call for proposals to the committees and task groups of the NPNU Initiative and the Life with Hepatitis Society of Central Alberta for seven-month projects focused on hepatitis C prevention, harm reduction, and support to people infected or affected by hepatitis C. The Hepatitis C Advisory Committee determined that projects funded in 2005-2006 should enhance or expand on initiatives that have been previously funded through the NPNU Initiative or support new projects that support the NPNU Initiative and will reach completion in March 2006.

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