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ROLL-UP REPORT

OF

PREVENTION & COMMUNITY-BASED SUPPORT REGIONAL PROJECTS FUNDED/IN-PROGRESS

1999-2000

Prepared for:

Hepatitis C Prevention, Support and Research Program
Hepatitis C Division
Population and Public Health Branch

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This report on regional projects funded for the fiscal year 1999-2000 is provided in keeping with the Hepatitis C Division's commitment to transparency and public accountability for the effective use of the resources dedicated to the Hepatitis C Prevention, Support and Research Program.

The report is based on documents received on or before August 31 2001. Reports received after that date are recorded in the statistics but their contents do not form part of the analysis.

The Hepatitis C Prevention, Support and Research Program

In September 1998, the federal Minister of Health announced a wide-ranging strategy to address hepatitis C. The basic aims are to improve blood safety, build knowledge about hepatitis C, and ensure that people infected with hepatitis C through the blood system do not incur out-of-pocket expenses for their medical treatment.

Coordinating the federal response to hepatitis C is the Hepatitis C Division, an important part of which is the ***Hepatitis C Prevention, Support and Research Program***. This program, which was established in 1999 following wide stakeholder consultations, has four major goals – namely, to:

- contribute to the *prevention* of hepatitis C infection;
- *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; and
- strengthen the public's potential to respond effectively to hepatitis C, by raising *awareness* and building the required *capacity.*

At the community level, the Hepatitis C Prevention, Support and Research Program works primarily through two components – *Prevention,* and *Community-Based Support*. Together, these components receive almost half of the program's five-year budget, or $21 million out of a total of $50 million. (Three other program components – *Care and Treatment Support*; *Research*; and *Management, Policy, Evaluation and Public Involvement* – account for the remainder.)

For its part, the **Prevention** component seeks to:

- contribute to measures aimed at preventing the spread of the hepatitis C virus, especially among those at greatest risk;
- build the necessary commitment and capacity in key societal sectors and institutions to collaboratively pursue and support integrated prevention measures.

The **Community-based Support** component focuses on awareness and capacity-building activities that strengthen local support. Specifically, its objectives are to:

- contribute to increased public understanding of the nature and effects of hepatitis C, thereby creating a more sensitive and supportive climate for persons infected with, affected by, or at

risk of hepatitis C infection;
- increase the capacity of regional/local community-based organizations to support such persons.

Regional Project Funding

In October 1999, the Hepatitis C Prevention, Support and Research Program began making project funding available to local, regional and national organizations committed to addressing hepatitis C collaboratively at the community level. First-year funding priority was accorded to care and support initiatives for persons infected with/affected by hepatitis C, and encompassed:

- *funding* and *capacity-building support* for organizations undertaking initiatives on behalf of persons infected/affected, or at risk of hepatitis C infection;
- funding support for the development and evaluation of community-based programming in response to the needs of such persons.

Prevention initiatives, while not entirely excluded, were permitted to utilize no more than ten percent of the allotted funds in the initial year of funding. The rationale was that experience gained in the first year would expand the evidence base on community-based prevention, thus helping to guide and inform prevention initiatives in subsequent years.

Guiding principles

Regional project funding seeks to support a strong community-based response to the needs of persons infected with/affected by/at risk of hepatitis C, increase collaboration among community organizations, and secure a voice for such organizations in the national Hepatitis C Program.

Project applicants are encouraged to work from a community development perspective – i.e., to meaningfully involve the intended populations at every stage possible – and to follow the same principles which guide and inform the Hepatitis C Prevention, Support and Research program.

These principles underline the need to:

- base decisions on the best evidence obtainable;
- use a population health approach (i.e., work from a “determinants of health perspective”);
- meet the needs and priorities of people who have hepatitis C, those at risk of getting it, and others closely affected (such as family, sexual partners and caregivers);
- find practical, immediate ways of making people’s lives better;
- contribute to initiatives that will last;
- treat everyone with hepatitis C equitably, regardless of how or when they contracted the disease;
- keep overhead costs down;
- work closely with community partners, other (i.e., non-health) sectors, and the institutions of society;
- make sure that community efforts are coordinated and complementary;
- track results and performance, in order to continue learning and improving.

Application requirements

Against this background, applicant organizations were invited to submit their proposed *work plans* (spelling out goals, objectives, specific activities and expected results), and *evaluation plans* which would show how well they had met their goals/objectives, as well as pinpointing any factors or conditions that may have helped or hindered the process. Organizations were also asked to identify all project partners, and the roles and responsibilities expected of each. Where appropriate, *sustainability plans* were also requested.

Overview of projects funded

Forty-one projects from all regions of the country received funding in the first year, with a total of $795,000 disbursed. They encompassed a wide assortment of initiatives focussing on community and organizational aspects of responding to hepatitis C, and addressing the needs of a variety of special populations. In terms of size and time frame, the projects ranged from a $2,500 three-month initiative to a $116,000 endeavour extending over a 36-month period.

By the end of the fiscal year, 22 of the 41 funded projects had been completed, while 19 were still ongoing. To date, 18 organizations have provided written interim or final reports and/or evaluations[1], and a further five have submitted products (outputs) but no reports.

Geographic breakdown

Of the 41 projects funded during fiscal year1999-2000, the breakdown by Region was as follows:

Region	1999-2000
Atlantic	7
Quebec	5
Ontario	9
Manitoba/Saskatchewan	4
Alberta/NWT/Nunavut	12
BC/Yukon	4
Total	**41**

Issues and themes

The 41 projects encompassed a diversity of activities and approaches. In determining their "entry point" it appears that organizations were guided by their own (or their community's) prior experience with hepatitis C issues; resource availability (human and other); the pre-existence of partnerships (e.g., addressing other health or social issues in the community); and a (formal or informal) assessment of local attitudes, needs and concerns. In short, project content and scope,

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[1] Reports received after completion of the first draft are included in the statistics, but not in the analysis.

however ambitious or limited, depended on (a) the sponsors' assessment of their own capacity to carry out the projected activities (in partnership with others), and (b) the community's "readiness" – i.e., the potential within the intended population(s) to benefit and to become involved alongside other stakeholders.

An analysis of the projects funded reveals four main themes, or activity clusters:

- ***information collection*** (where more baseline data is needed before meaningful initiatives can be planned) ;
- ***capacity-building*** (where the priority is on developing/strengthening structures, partnerships, skills, etc. before undertaking some types of project);
- ***outreach/support*** to persons infected/affected/at risk (where the emphasis is on meeting people's immediate day-to-day needs);
- ***awareness-raising/education*** (where the issue is lack of knowledge about basic facts – such as risk factors, treatment options/management – and about sources of assistance and support).

Information collection

The collection of baseline information featured prominently among the activities of organizations, particularly in communities where hepatitis C was a newly emerging concern. As a prerequisite to launching any substantive initiatives, some project sponsors felt they first needed to clarify and document the problem locally – including needs, awareness and perspectives – and to assess the availability of resources. Activities in this category included identifying hepatitis-C-infected persons (Atlantic), determining the prevalence of the virus among HIV/AIDS clients (Atlantic), assessing needs through surveys and consultations with service providers and/or infected/affected groups (Atlantic, Quebec, Ontario, Alberta/NWT/Nunavut, BC/Yukon), identifying potential partners (Atlantic, Alberta/NWT/Nunavut). as part of an overall effort to gauge local awareness and capacities. Information-gathering covered many activities, including a literature review on liver transplants that encompassed an examination of HCV/HIV co-infection and hemophilia (Ontario).

Capacity-building

In the second broad area of focus – the *development of organizational and community structures and capacities* – projects were concerned with laying the foundation, as it were, for future initiatives (the underlying assumption being that they already had some idea of existing capabilities). Activities included promoting the profile of key organizations (Quebec), holding focus groups, sharing information (Atlantic, Ontario, Alberta/NWT/Nunavut), establishing steering committees, planning and strategizing (Ontario), strengthening fundraising (Quebec), developing leadership, strengthening the volunteer base, training service providers (Quebec, Ontario, Manitoba/Saskatchewan, Alberta/NWT/Nunavut), and organizing a solution-oriented/networking conference at the provincial level (Alberta/NWT/Nunavut, Quebec).

Outreach/support

High on the agenda in most regions were *outreach* activities, perhaps in response to Health Canada's directive that care and support initiatives for persons infected with/affected by hepatitis C should be accorded priority. Initiatives in this third area were geared towards increasing the availability and accessibility of immediate practical assistance, and included mobile needle-exchange services (Alberta/NWT/Nunavut), counselling and referrals (Alberta/NWT/Nunavut) and the strengthening of support in various forms, at the group and individual levels (Ontario, Alberta/NWT/Nunavut).

Awareness-raising/education

The fourth category of activities concerned *awareness-raising and education* – broadly defined to include the development and dissemination of resources and other forms of information for both service providers (especially, but not exclusively, front-line staff and volunteers) and infected/affected/at-risk populations. Initiatives in this group included holding forums and conferences; creating, testing and distributing information packages; launching public education/promotional campaigns; and producing communication tools such as newsletters, brochures, booklets, kits, a directory of community services and videos (all regions: Quebec, Ontario, Manitoba/Saskatchewan, Alberta/NWT/Nunavut, BC/Yukon).

A popular activity (Atlantic, Ontario, British Columbia/Yukon, Alberta/NWT/Nunavut) was to update, adapt or augment and disseminate existing programs, such as “Living with Liver Disease” and “Living with Hepatitis C”. In one case, *Safe Body Art*, a pamphlet aimed at young people who might seek tattoos or body piercing, was updated and reprinted, and in another, an existing English-language resource was translated into French (Moncton, NB).

Project approaches

There were marked differences among projects, both in the number of elements they contained and in the way these were linked together. Most projects were multifaceted. Sometimes the elements unfolded sequentially – i.e., as a *series* of activities that were designed to build upon and reinforce each other over time. Two examples: a Quebec organization was funded to evaluate the needs of persons infected/affected by hepatitis C, hold provincial meetings for such persons, and produce a bilingual newsletter to keep them informed; and in Edmonton, a partnership of local organizations received funding to identify issues facing high-risk inner city residents – especially women – through a needs assessment, and then develop a network of agencies and strategies designed to help service providers meet the challenges.

In other projects the various elements – although related – were less dependent on each other, and thus carried out either concurrently, or overlapping in time. For example: the Hepatitis C Society’s York Region Chapter (Ontario) received funding towards promoting itself and its work within the local media, supporting forums on HCV, conducting monthly support group meetings and creating a directory of community services; and the Saskatchewan Chapter of the Canadian Liver Foundation was funded to build organizational capacity, run skills development workshops for volunteers and staff, and develop tools and mechanisms to support infected/affected persons.

A minority of initiatives focussed on a single endeavour – for example, identifying potential members (organizations and individuals) for a proposed provincial hepatitis C interest group (Canadian Hemophilia Society – Newfoundland and Labrador Chapter); and preparing and distributing a user-friendly booklet to help infected persons make decisions on treatment, housing, employment and related issues (Hepatitis C Society of Canada – Manitoba Chapter).

Organizations

In the first year of funding, the Hepatitis C Program provided the Regions with suggestions on the organizations that might potentially be interested in receiving funding. These included the regional chapters of national organizations with an interest in hepatitis C, HIV/AIDS-related organizations, and Aboriginal organizations such as Native Friendship Centres. This is clearly reflected in the following analysis.

The large majority of projects funded in 1999-2000 involved participation at some level by high-profile non-governmental organizations with a national focus, many with chapters across the country. More than half of the projects (25) were sponsored by NGOs either directly concerned with liver disease (Hepatitis C Society of Canada, Canadian Liver Foundation), with related *health* issues (e.g., Canadian Hemophilia Society) or with related *social* issues (e.g., the Elizabeth Fry and John Howard Societies, Planned Parenthood of Canada).

In Ontario, NGOs participated in 9 projects – seven through their provincial chapters, and two through their national offices – most often in the capacity of project sponsors. In Atlantic Canada, NGOs played a role in all but one of the six projects funded (as sponsors in two, and partners in four). In Alberta/NWT/Nunavut, NGOs sponsored four projects and were involved as partners in at least four others (possibly more, given that in some cases the project sponsors and partners in this region were themselves coalitions/consortia whose members were not always identified).

A total of nine projects were sponsored by organizations (including task forces, coalitions, etc.) whose primary concern was with HIV/AIDS. In Alberta/NWT/Nunavut, such organizations sponsored six projects and were involved as partners in at least three others. Of four projects funded in BC/Yukon, they sponsored one and collaborated in three. In Atlantic Canada, three projects – or half of all those funded – were sponsored by AIDS-related organizations, and in Ontario they collaborated in two (possibly three) projects. No HIV/AIDS organizations were explicitly identified as sponsoring or collaborating in projects funded in the Manitoba/Saskatchewan or Quebec Regions.

Organizations concerned with Aboriginal issues were identified as playing a role in 10 projects. Five of these were in Alberta/NWT/Nunavut (as partners in each case), two in BC/Yukon, and one each in the Ontario, Manitoba/Saskatchewan and Atlantic Regions. Two projects sponsored by Aboriginal organizations sponsored projects: the Meyoyawin Circle Corporation (Manitoba/Saskatchewan) coordinated/implemented a community consultation aimed at education, networking and partnership development, and the Vancouver Native Health Society (BC/Yukon) sponsored an outreach and education project (in collaboration with an AIDS-related organization) which included creating materials for persons with low literacy.

Particular kinds of activity were sometimes identifiable with particular kinds of organizations – for example, projects concerned with capacity-building and larger-scale multifaceted initiatives tended to involve one or more well-established NGO's, possibly on the basis of their corporate experience, credibility and repertoire of resources. Further, pre-existing networks/partnerships/coalitions/task groups sometimes seemed more ambitious and comprehensive in their objectives than smaller community organizations who were just beginning to get their feet wet. This was evident in Alberta/NWT/Nunavut, for example, where the harm reduction approach evidently has considerable institutional support and where several complex initiatives – including the planning of a provincial harm-reduction conference – were collaboratively undertaken by well-established organizations, usually working alongside community coalitions/partnerships with a track record of their own.

Partnerships

Virtually all of the initiatives undertaken in 1999-2000 were collaborative. Many partnerships were multi-disciplinary and cross-jurisdictional. In at least five projects the sponsoring bodies were themselves coalitions and networks. For example, the AIDS Coalition of Cape Breton partnered with Sharp Advice Needle Exchange, Planned Parenthood and the Elizabeth Fry Society to develop a hepatitis C steering committee and train volunteers.

Nation-wide, approximately 145 organizations were identified as partners in the 41 projects funded, with an average of about 3.5 partners collaborating on each project. Some initiatives were conducted by a single organization, while others involved up to eight (for example, a Medicine Hat, Alberta project was led by the HIV/AIDS Network of Southeastern Alberta Association in partnership with the John Howard Society, the Palliser Health Authority, the Canadian Red Cross, Planned Parenthood, the Canadian Liver Foundation, Miywasin Centre, and Positive Culture Company).

Projects undertaken in Alberta/NWT/Nunavut involved more partners on average (five) than those in any other region. Atlantic Canada was next (four), and Ontario registered the lowest average, at 2.2. The other regions – Quebec, Manitoba/Saskatchewan and BC/Yukon – each had approximately three partners per project.

On the whole, projects sponsored by national NGOs or their Chapters involved fewer partners than those sponsored by other organizations. (Several NGO-sponsored projects – e.g., in Ontario, Manitoba/Saskatchewan and BC/Yukon – identified no additional partners.) However, there were instances in which NGO-sponsored projects involved *more* partners than average – for example, the Street Population Hepatitis C Education and Awareness Program, sponsored by the Canadian Liver Foundation – Alberta/NWT Region, with seven partners, and the Foundation's South-Western Ontario Region project to produce information materials and adapt an existing program, in which five organizations collaborated.

Some projects involved collaboration with groups/individuals not specifically identified with an organization – e.g., community health nurses, communities and schools.

Six projects explicitly included the strengthening of networks/partnerships among their objectives. In other instances, there appeared to be an unstated assumption that working together would, in and of itself, contribute to stronger ties between participating organizations.

Populations

Well over one-third (about 40 percent) of the projects identified their priority populations simply as people infected/affected by hepatitis C. Across all regions, 17 initiatives directed activities to this "catch-all" category. Projects were wide-ranging, and included: identification of infected persons; needs assessments in both urban and rural areas; strategic planning (re: awareness-raising); developing action plans for individuals; developing and disseminating information (e.g., on services, HCV management, harm reduction, prevention/health promotion); strengthening services and support; and adapting existing programs.

Many projects clearly identified which infected groups they were addressing (persons co-infected with HIV/AIDS, newly diagnosed persons, expectant mothers with HCV). At-risk populations included persons living with addictions (1), persons with HIV/AIDS (5), persons with hemophilia (2), persons who inject drugs (5) and, variously, inner-city populations, youth, sex trade workers, homeless people, persons in prison (often expressly including Aboriginal people). "Affected" populations were addressed in a number of instances. Sometimes they were included in a general grouping that included those infected, and sometimes addressed as a group in their own right (e.g., family members of infected persons, and sexual partners of persons injecting drugs).

The needs of Northern and rural communities (including Aboriginal) were also expressly targeted, generally with early-stage activities such as needs assessments, public education campaigns and focus-testing of resources in use in other communities.

In keeping with the objective of capacity-building, many projects were directed to the needs of community organizations/agencies and their personnel – executive board members, policy-makers, management, staff, frontline workers (community/street, youth, correctional, addictions, health, social justice), and volunteers/peer helpers. Initiatives were mainly in the areas of skills/training (e.g., in support, education and prevention), information-sharing, and network development, most often directed to frontline workers and volunteers.

Determinants of health

A determinants-of-health perspective recognizes that the options and opportunities open to people at different stages and in various spheres of their lives can profoundly affect their health[2]. For example, poverty and lack of education can increase risk behaviours, such as needle-sharing. To encourage organizations to bear in mind the bigger picture when developing and delivering their interventions, the application form required them to specify which health determinants they planned to address.

One Nova Scotia project revealed the importance of identifying the broader factors influencing health. A survey of its partners for their views on service gaps and barriers showed that several of those identified – such as racism, sexism, homophobia and "elitism" – were strongly connected to the determinants of health. This information will be invaluable in guiding future interventions.

Several approaches to the determinants of health were evident. One group of projects attempted to overcome or offset their negative effects in people's lives – seeking, for example, to: improve *personal health practices* (e.g., through use of clean needles and harm reduction approaches, as for example, in Alberta/NWT/Nunavut); remedy *educational deficits* (e.g., by developing low literacy resources and evaluation formats/approaches, in Manitoba/Saskatchewan and Alberta/NWT/Nunavut respectively); reduce the impact of *cultural differences* (e.g., by adapting services/resources to Aboriginal communities, youth, street-involved people, as for example in Alberta/NWT/Nunavut, and Manitoba/Saskatchewan); reduce the impacts of *social isolation, homelessness and disadvantage* (e.g., through peer/support group development, and provision of mobile and other outreach services – several Regions).

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[2] Factors known to influence health – acting separately and in concert – include gender, culture, income, social status, education, employment and working conditions, the physical and social environments, personal health practices and coping skills, and the availability of social support networks.

Another set of initiatives addressed the determinants of health by strengthening awareness, capacity and skills in organizations/workers serving communities affected by homelessness, poverty, isolation, social stigma, and so forth. One example was a project in which AIDS Vancouver collaborated with Correctional Service of Canada and the BC Centre for Excellence in HIV/AIDS to organize a workshop for health/community-care, social-service and correctional workers, management and policy makers. The workshop, which included people living with addictions, focussed on health and social justice issues related to HIV, hepatitis C and addictions.

A third group of projects provided specific resources and/or information geared to helping persons affected/infected (e.g., inner-city populations) overcome various barriers related to health determinants (such as employment and housing). Thus, the topics discussed in one HIV/hepatitis C peer support group included discrimination, social isolation, homelessness, family rejection, and daily coping.

A further indication that the social determinants of health were recognized, even prominent, in the development and implementation of many project activities was the presence, in various projects across the country, of national, provincial and local organizations/agencies with a focus on social and economic inequalities and/or their consequences. Included in this group were: the Elizabeth Fry Society, the John Howard Society, such organizations as the Common Front for Social Justice (Saint-John, NB), the Kamloops Community Advocacy Council, various Native Friendship Centres, and provincial departments of Corrections and Social Services.

Involvement of priority populations

It is clear from the composition of the project partnerships that infected/affected/at risk populations played a key role in many initiatives. Reports received to date suggest that although the exact nature of their involvement may not always have been explicit from the outset these groups and their organizations made considerable contributions to *project development* (providing input/advice – as partners, in focus groups, on committees, etc.), *project delivery* (volunteering/peer support), and *evaluation* activities (via feedback on workshops, etc.).

The following examples will illustrate this.

- In one Alberta/NWT/Nunavut project which produced a harm reduction policy kit, persons who inject drugs attended and presented at a conference, and were consulted through the Streetworks Natural Helpers Program.
- In another Alberta/NWT/Nunavut project which led to the creation of an HIV/hepatitis peer support group, the need for the group was identified by the clients themselves, who also determined the weekly discussion topics and evaluated each session.
- In a *Helpline* hepatitis C project run by the Canadian Mental Health Association – NWT Division, volunteers were consulted regarding needs; prison inmates provided ideas for the public service announcements and reviewed materials; people with hepatitis C provided feedback on the workshop agenda and pamphlet; volunteers evaluated the workshop; and Inuit and Aboriginal men and women recorded the public service announcements (PSAs).
- In a project led by the Canadian Liver Foundation – Alberta/NWT/Nunavut Region, funding was used to identify and involve interested individuals in planning, writing and producing a video to increase awareness of hepatitis C among Aboriginal youth. Plans called for the docu-drama to feature culturally appropriate characters, played by Aboriginal youth themselves.

Project results

Definitions

In the first year, most projects were designed to be "doable" in a relatively short space of time – i.e., to produce specific outputs, rather than longer-term outcomes. "Outputs" include:

- *one-time or time-limited events*, such as meetings (for consultation, educational, planning and/or training purposes) campaigns (public education, fundraising) and displays.
- *products,* such as resources (pamphlets, newsletters, directories, videos), planning/strategy tools (action plans/strategies, needs assessments, literature reviews, surveys, evaluations) and models/approaches (e.g., life skills, peer education, needle exchange programs).

"Outcomes", on the other hand, describe *changes* (e.g., in behaviours, transmission or prevalence rates)*,* and/or *mechanisms* (e.g., a steering committee, a strategy) resulting from an intervention[3].

Project outputs

As the Table shows, project outputs ran the gamut, but with heavier concentrations in two areas: *meetings* of various types (planning/consultation, education and training), and *resources* (development and/or modification). This suggests that many organizations concerned about hepatitis C wanted to "start from the ground up" by getting together to share, strategize, network, educate and inform both themselves and, in some cases, the infected/affected/at risk populations. The information and education activities would logically include adaptation and development of resources.

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[3] In hepatitis C community-based projects, outcomes could (conceivably) be organized under the following headings: *health and quality of life* (improved health status/living conditions/quality of life, decreased risk of transmission, reduced incidence of hepatitis C); *populations* (increased knowledge of treatment/support options; increased awareness of risks; better informed families, caregivers; etc.); *behaviours* (increased adoption of harm-reduction behaviours; increased participation/ utilization rates – in programs, support groups, needle exchanges, etc.); *organizations* (enhanced response capacity, improved skills, strengthened volunteer base); *systems/ structures* (increased accessibility/availability of community programs/services/supports; strengthened networks, partnerships; more culturally sensitive services); *mechanisms* to facilitate action and collaboration (working groups, steering committees, advisory committees, etc.)

Type of Output	Region						
	Atlantic	Quebec	Ontario	Man./ Sask.	Alberta/ NWT/Nun.	BC/ Yukon	Total
Gatherings							
consultation/planning	1	-	1	-	1	-	2
education/info (inf/aff/at risk)	1	1	-	-	1	-	3
training/info/skills (providers)	3	1	2	2	1	1	10
support groups	2	2	2	-	-	-	6
Campaigns							
education	1	-	-	-	-	-	1
fundraising	-	1	-	-	-	-	1
Resources	2	-	6	3	5	1	17
Planning/strategy tools							
action plans/strategies	-	2	-	-	2	-	4
needs assessments	1	2	2	-	2	1	8
literature reviews	-	-	1	-	-	-	1
surveys	1	-	-	-	-	-	1
evaluations	-	-	-	-	1	-	1
Models / approaches	-	-	-	-	1	-	1

Project outcomes

Intended outcomes

Intended outcomes are those occurring as originally planned or anticipated, whether over the short, intermediate or long term.

Short-term outcomes include mechanisms established during the project's life – for example, a *network* of service agencies (Alberta/NWT/Nunavut), a *Hepatitis C committee* in Prince Albert (Manitoba/Saskatchewan); a *partnership* of organizations with capacity to host workshops and facilitate support groups in the Medicine Hat area (Alberta/NWT/Nunavut). They also include changes which are observable or measurable immediately following the intervention – for example, *enhanced* access to resources/support (Atlantic), *strengthened* services for those who are infected/ affected (Ontario); *increased* organizational capacity (Alberta/NWT/Nunavut); *enhanced* volunteer knowledge/awareness re transmission in the North (Alberta/NWT/Nunavut); *increased* awareness of issues related to hepatitis C among frontline workers (Quebec); *strengthened* community partnerships in support of those living with the hepatitis C virus (Alberta/NWT/ Nunavut).

Other kinds of changes (e.g., a change in disease transmission rates), may only become apparent over time, after sustained effort and often integrated/complementary initiatives. Given the time-limited nature of these projects, many did not identify such ambitious outcomes. However, one project sponsor who received funding for a lifestyle survey (in order to develop appropriate harm reduction strategies) was sufficiently confident to predict both an intermediate outcome (improved access to services) *and* an ultimate outcome (enhanced health status) (Alberta/NWT/Nunavut). This example illustrates the important point that short-term project outputs (i.e., the survey results) and outcomes (i.e., strengthened services) are intended to pave the way to long-term positive health outcomes (i.e., improved health)[4].

Unintended outcomes

Projects may also have unintended outcomes, both positive and negative. A positive unintended outcome identified in the 1999-2000 funding period was that a booklet originally intended for urban HCV-infected/affected populations turned out to be useful to other populations as well, including service providers, rural dwellers and at-risk groups (Manitoba/Saskatchewan).

It is important to capture both positive and negative types of unintended outcomes in evaluation reports, given that best practices can be derived from failures as well as successes. Project sponsors may need encouragement in this area, as they may withhold information about unexpected negative outcomes, fearing that it will reflect badly on the project or spoil the prospects of future funding.

Lessons learned

In the first year of funding, many organizations were still feeling their way. To generalize from the experience of just a few projects would be unwise, but it seems important to draw out from the reports preliminary pointers on “what worked” and “what did not work”. At the very least, this may alert organizations applying for funding in the future to potential facilitators and barriers.

Region	Projects funded	Written reports received
Atlantic	7	3
Quebec	5	2
Ontario	9	-
Manitoba/Saskatchewan	4	2
Alberta/NWT/Nunavut	12	10
BC/Yukon	4	1
Total	**41**	**18**

Project “learnings” (drawn from the reports received to date – see Appendix A) are organized below under four broad headings: *Working in partnership*, which deals with comments concerning collaboration of various kinds; *Tapping into expertise*, which addresses the

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[4] Similarly, an effective training session (output) might lead to increased skills and awareness (outcome), a user-friendly, comprehensive resource directory (output) might result in a better informed public (outcome), and a dramatic skit (output) might lead to reduced risk-taking (outcome) and – eventually, perhaps – lower transmission rates (outcome).

importance of knowing in advance what outside help will be needed, and budgeting accordingly; *Knowing the audience*, which highlights the need for interventions and approaches that are not offensive to the population; and *Planning realistically*, which speaks to the importance of estimating time requirements and costs accurately.

Working in partnership

Tentative lesson:
Successful partnerships do not just come into bloom, but require careful planning, a common understanding of project objectives and processes, and an appreciation of each other's agendas and cultures.

One project reported considerable success with its two committees, each handling different facets of the work (conference organization, and production of a resource). Here, group decision-making ran smoothly. In contrast, sharing responsibility proved to be so challenging in another project that the committee had to be severed into three, with each partner managing one component (site). Reportedly contributing to this situation – which led to delays and budget overruns – were various project management issues (e.g., ignoring input from other partners, and lack of attention to day-to-day management).

These experiences suggest that committee members need to develop a common understanding of the project from the outset (including deadlines and reporting requirements), and a clear definition of their own and others' roles and responsibilities, and the procedures to be followed. Further, it may be useful to assign different (sub)committees to different aspects of the work, to ensure that they remain focussed.

Another type of collaboration that proved to be successful was the co-facilitation of support group meetings by peers and professionals representing two agencies – one principally concerned with HIV/AIDS issues, and the other with hepatitis C. Participants' evaluations of the sessions were overwhelmingly positive. The project report listed flexibility, communication, understanding and shared goals as benefits of the co-facilitation approach which, it was felt, broadened each partners' understanding of the other's primary population and their needs. The report also noted that the facilitators' "personal styles were conducive to working with the peer support group", suggesting that the attributes of individuals are an important ingredient of success in any partnership situation.

In one project, two provincially-based NGOs (Canadian Hemophilia Society, Hepatitis C Society of Canada) formed an effective partnership, with the former providing the latter with proposal-writing support, advice/expertise on key tasks (e.g., field testing, proofreading), and arranging for meeting space.

Having common issues does not guarantee that organizations will work well together, as it is their differences that may come between them. Thus, the fact that hepatitis C can be contracted in some of the same ways as HIV/AIDS suggests that collaboration between these two communities would be beneficial (as in the support group mentioned above). However, hepatitis C is only one kind of liver disease, and some segments of the liver community appear to be wary of the stigma associated with HIV/AIDS. They fear that going to HIV/AIDS-based organization for programming will only increase the stigma associated with hepatitis C and, further, that HIV/AIDS-based organizations – being new to hepatitis C – may lack the capabilities needed to deliver hepatitis C programming. If energies are to be harnessed effectively, these issues must be confronted.

Tapping into expertise

> ***Tentative lesson:***
> Recognizing what you don't know, and making provision for the expertise you will need (even if you have to pay for it) saves time and trouble.

One project (to create an information booklet) reported that its community advisory group worked well, and that good use was made of the committee's input. Group members had been carefully chosen according to specific criteria, and included infected/affected people, representatives from Health Canada (federal) and the Regional Health Authority (provincial), a hepatologist (knowledge of the hepatitis C virus), and individuals with resource development expertise in HIV/AIDS. Both genders were represented, as well as rural and urban dwellers.

This is an example of involving the "right" people – knowing who the experts are and where to find them. Another project which used "knowledgeable people" as resources for its workshops commented on how well this had worked.

In the booklet project mentioned earlier, the need for plain language expertise was not foreseen at the planning stage. Once they became aware of it, however, the organizers managed to trade the services of a plain-language specialist from Heritage Canada for expertise needed by that department (from Health Canada). They also succeeded in getting a local print shop to underwrite some of the printing costs, and identified volunteer proofreaders for the resource from among infected/affected members of the local Hepatitis C Society Chapter, and found a person infected with HCV who could undertake the graphic design work. Fundraising activities (by the Society), coupled with a grant from the provincial lottery corporation, helped defray the unforeseen costs. Creative solutions were found in this particular project. Nevertheless, it serves as a reminder of the importance of correctly forecasting what professional/other assistance will be needed, and building in cost and time requirements from the outset.

In another project, if there had been professional advice on questionnaire design, better use might have been made of the evaluation findings. This was a case in which the need to gather demographic data was inadvertently overlooked (e.g., respondents' culture, gender, age group), limiting the usefulness of the results. The needed expertise can often be found within the community, whether on a volunteer basis or for a modest outlay of funds. As one project report pointed out, using community people wherever possible (e.g., editing, printing, graphics) can help reduce costs. It can also help to build local capacity.

Knowing the audience

Tentative lesson:
Understanding the intended population/audience – how they think, feel and are likely to react – is vital to the success of an intervention. The population must also know and trust project organizers.

In one project to conduct a survey, lack of familiarity with the population made the work more difficult, perhaps even compromising the results. Project organizers were caught by surprise when their audience, which included "marginalised communities", reacted to the researchers with distrust. Another project illustrated the importance of understanding the population's concerns and sensitivities when creating a questionnaire. It suggested that better results are achieved when questions are framed non-threateningly – e.g., ask about risk behaviours, rather than directly about respondents' HCV status.

Participant evaluations from a project that established a HIV/hepatitis C peer support group provided some useful pointers regarding their perceptions of themselves and their needs. Their least positive evaluations centred on their own ability "to talk and get support from the group", and "to say how they feel about HIV and hepatitis C". This is valuable information for future projects, suggesting the need to find more supportive ways of drawing people out.

On the other side of the coin, an organization's credibility with interviewees can engender their trust and openness. In a project to canvas the views of persons who injected drugs, the interviewees' perception that this was an established, trusted program resulted in honest responses on their part, presumably improving the usefulness of the information gathered.

Knowing the audience can also help to ensure that it will be receptive to messages. One project noted the need to "soft pedal" or downplay certain aspects of harm reduction programming – for example, the needle-exchange component – so as not to lose public support. Hearing about needle exchanges only served to reinforce the public's misconception that this is all there is to harm reduction.

The "audience" can also include the media, whose attitudes and sensibilities it is important to understand (given the need for their cooperation and support). In one instance, a radio station donating $3000 worth of air-time to public service announcements objected to the content of an announcement (about snorting cocaine), leading to project delays. At the same time an overly cautious approach can backfire. Fearing controversy, the organizers of one project were so circumspect in selecting which media to involve that they ended up getting "nearly no media coverage". They concluded that a more aggressive approach would be needed in future.

Planning realistically

Tentative lesson:
Without a good grasp of what each task entails, project organizers may misjudge the amount of time and money required to accomplish the work.

A coalition which conducted an environmental scan of its partner organizations (for skill-building purposes) found the12-week time frame inadequate to do its work in sufficient depth. No time had been allotted for the researcher to attend staff/board meetings in the respective agencies, to explain the project, or to follow up with phone calls to key individuals. Another project failed to anticipate the amount of development and preparatory work needed in advance of issuing a public service announcement. As a result the public service announcement was "poorly timed" and "poorly prepared".

If all facets of the work are not clearly spelled out in advance, with appropriate budgetary allocations, some may end up being shortchanged. For example, one project noted that its budget was "unrealistic" and "inflexible", with no funds allocated to preparing final reports (and apparently no way of shifting funds around).

Another project to prepare a hepatitis C presentation package noted that the funds were insufficient to accomplish the work. It also reported that the timelines were difficult to meet, and attributed this to the late approval of funding (hopefully, a problem that will be reduced over time).

Towards best practice . . .

It is too early to be able to identify which approaches hold out the most promise, especially as the reports received to date focus more on what was done and delivered (one aspect of best practice) than on what changed as a result (another aspect of best practice). Moreover, the evaluations received largely relate to client satisfaction (e.g., after training or support group sessions), and do not provide information about longer-term effectiveness.

Every community is unique and one size will not fit all. Nevertheless, a few fragments worth noting did surface in the project reports. The observations that follow are quite specific and noticeably lacking in mystique, suggesting that good practice may have more to do with common sense than magic formulas:

- in support groups, hold frequent meetings (weekly – versus bi-weekly – meetings were found to increase participants' regularity of attendance);
- find approaches that increase the attractiveness of programs and still save costs (one group scheduled support-group sessions to coincide with a collective kitchen that provided participants with fresh nutritious meals at lower cost than ordering food in);
- in support groups, keep information current (evaluations showed that participants were most positive about up-to-date information on HIV/HCV);
- look for ways to maximize opportunities (one project found that the distribution process for resources could also be used to increase networks);
- plan public announcements well in advance, and include information on the potential benefits to the community;
- when training frontline workers, emphasize exercises that involve interaction between participants (getting to know each other, building relationships, learning about successful strategies used by other organizations);
- also include information on biomedical aspects of the virus – e.g., symptoms, medication, etc.– in training sessions;

- provide front-line workers with practical, easily accessible information;
- seek out “second-generation” opportunities (to help carry the work forward after project funding ends) – e.g., in one case a provincial health ministry provided $5000 to reprint a resource, as well as repackaging the material into a new manual for nurses.

As they stand, these seem like no more than useful tips, some of which may be just as relevant to other health issues. In time, however, projects may be able to confirm each other’s experience with particular approaches, settings, populations and so forth, yielding a body of information that provides communities combatting hepatitis C with confidence in their methods and a head start (i.e., no time needed to reinvent the wheel).

Future plans

As the following illustrate, most organizations submitting reports conceived of their projects as building-blocks to further activities:

- The Canadian Liver Foundation (Street Population Hepatitis C Education and Awareness Program Presentation Package) saw its project as the foundation for future work, both with the original priority population and with communities in Northern Alberta.
- Streetworks Edmonton (Hepatitis C Survey of Injection Drug Users) hoped its findings would serve as a base for future work in the area of hepatitis C and injection drug use.
- The Hepatitis C Society of Canada – Southern Alberta Chapter (Harm Reduction Services Program) said it would use its evaluation findings to assess further needs, as well as sharing them with the National Office, other chapters, and the Chinook Health Region.
- The Safe Body Art project (to update, print and disseminate a pamphlet) identified the need for a lower-literacy or less dense pamphlet, and reported that it had already applied for funding to undertake this work.
- From its environmental scan (of partner organizations), the AIDS Coalition of Nova Scotia uncovered a wide range of needs that suggest future action – e.g., for: anonymous testing; more physician training; professional standards of care; annual training for non-profit boards, staff and volunteers; consistent medical information emanating from governments and non-profit organizations; more research into co-infections (HIV/HCV); incorporation of harm reduction modules into educational efforts; a resource manual reflecting all organizations that work in the field; educational materials recognizing the diversity and multicultural nature of populations living with HCV; public awareness campaigns; an accessible resource room to be established by the province and non-profit organizations; HCV genotyping; provincial safety standards for businesses in which transmission is a risk (barbers, tattoo parlours, and estheticians); better coordination among non-profit and hepatitis C organizations and different levels of government with respect to education.
- A SIDA/AIDS Moncton Hepatitis C Joint Project to train front-line service providers recommended ongoing education/training for this group, including in-house professional development and educational materials (videos, brochures, etc.).
- The Central Alberta AIDS Network: Harm Reduction Outreach Program pointed to the need

to increase data collection on the hepatitis B and C viruses, and for larger longer-term projects in which persons who inject drugs and persons infected with HCV can formally participate in project management on a continuing basis.

- The *Association des Intervenants en Toxicomanie du Québec Inc*. noted that: there were waiting lists for training in three regions of the province; many Health Departments were keen on partnerships; they had received lists of organizations potentially interested in receiving training in future, and requests for copies of the training resource. As a result the organization is considering running four more sessions (three in new locations, and a repeat session in Montreal).
- Another project report called for more resources urging that people be tested for hepatitis C.

Conclusion

The broad intent of regional project funding is to increase capacity to respond to hepatitis C at the community level. Much has been written about community capacity, its definition and its measurement. Without entering into these debates, which are ongoing, it is possible to identify empirically some indicators of community capacity (to respond to hepatitis C) – such things as the number of organizations actively involved in an issue, the degree of collaboration and coordination among them, the understanding of the issues to be addressed and the needs to be met, the skills available (trained, knowledgeable personnel), the size of the volunteer complement, their skills/knowledge level and degree of commitment, the level of participation by the populations whose health is at stake (in all phases of the project), the resources available (financial, human, other), and the supportiveness of the social environment (in terms of discrimination, fear, political will, etc.).

This list will undoubtedly be expanded and refined as time goes on. However, even the most cursory review of the projects supported in the first year of funding indicates that positive change may already be under way in many of the “indicator” areas identified above. These community-based initiatives – their focus, their activities, the results expected (outputs and outcomes), their population involvement strategies, their attention to the determinants of health, and their collaborative approach – are set to strengthen local response capacity in the months and years to come. Lessons learned, from both successes and failures, will enrich that capacity.

Judging from the material available – project summaries and a limited number of reports – the funding is providing an important stimulus for community awareness, support and partnership-building which (if early feedback is indicative) will change Canada’s hepatitis C landscape in positive and significant ways. The challenge will lie in effectively capturing and disseminating the many types of knowledge the projects generate.

Limitations of this report

This report is based on materials and information provided by the Hepatitis C Program. As noted at the beginning, reports (interim and/or final) had been received from fewer than half of the 41 projects funded at the time of writing, while several projects submitted products but no reports.

Budgetary and other considerations precluded the review of original project applications. Therefore, information on the non-reporting projects was garnered mainly from one-paragraph project summaries prepared by the Hepatitis C Program. These sometimes lacked specificity – e.g., about approaches, partners and expected results (for example, referring to "educational tools and mechanisms" without defining what type). Even where project elements were spelled out, it is possible that they may have changed as the project unfolded. In the absence of a report it is not possible to tell. Moreover, except in a few cases no information was provided on time frames and budgets. Whether such information would have been useful is not known, but its unavailability is noted for the record.

These factors have the potential to affect both the quality and accuracy of the present report. For one thing, differences between the original plans (as set out in the summaries) and what actually took place (as set out in project reports where available) suggest that errors in the numbers are unavoidable (e.g., in the Outputs Table, and in the sections on *Organizations* and *Partners*). The report also lacks balance, in the sense that key sections (*Lessons Learned*, *Toward Best Practice...* and *Future Plans*) have had to be based only on those projects for which reports were received, rather than on the collection of projects as a whole.

These limitations underline the importance and urgency of establishing standard reporting formats and intervals (both periodic and final) for the submission of project reports. Only in this way will it be possible for projects – their experiences and results – to contribute fully to meaningful improvements in community capacities and practices.

Appendix A

Table of Contents

1. Projects submitting reports

Atlantic Region

Quebec Region

Manitoba/Saskatchewan Region

Alberta/NWT/Nunavut Region

British Columbia/Yukon Region

2. Projects submitting products only

Quebec Region

Ontario Region

1. Projects submitting reports

ATLANTIC REGION

AIDS Coalition of Nova Scotia (1999-2000)

Hepatitis C Skills Building and Environmental Scan (membership of three partner organizations)

Partners:
- Stepping Stone
- Atlantic First Nations AIDS Task Force
- Canadian Liver Foundation – Atlantic Chapter
- Hepatitis C Society of Canada

Outputs:
- survey results (22 respondents from three organizations)

Determinants of health:
- gaps and barriers defined by scan included homophobia, racism, sexism, elitism (preventing access to information and health care)

What did not work:
- 12-week time frame was not enough to carry out project with sufficient depth, or to establish numbers infected with HCV
- not enough time to prepare HCV resource manuals, medical agency contact sheets, or to participate in formal discussions with provincial/federal officials who could influence policy and funding

Lessons learned:
- need to take account of different cultures within each organization (reflecting membership)
- marginalised clients distrust of researchers
- instead of asking whether respondents ever diagnosed with HCV, concentrate on risk behaviours in questionnaire
- researcher should attend staff/board meetings of each agency to explain rationale/importance of project, and follow up with phone calls to key individuals
- provide full lists of all board members/key contacts in major centres to researcher (to reflect as many voices as possible)

Future needs:
- anonymous testing
- more physician training
- establishment of professional standards of care
- annual training for staff, board, volunteers on non-profits
- consistency of medical info between federal/provincial and non-profit organizations

- more research, hard data on co-infections (HIV/HCV)
- organizations should include Harm Reduction modules in educational efforts
- resource manual needed that reflects all organizations working in field
- educational materials should reflect diversity and multicultural nature of populations living with HCV
- public awareness campaigns
- accessible resource room should be established by province and non-profits
- HCV genotyping should be done in the province
- provincial safety standards for businesses where transmission is a risk (barbers, tattoo parlours, estheticians)
- more education coordination between non-profits, hepatitis C organizations and different levels of government that provide funding

SIDA/AIDS Moncton Inc (SAM) (New Brunswick) (1999-2000)

Hepatitis C Joint Project: Training for Front-line Service Providers

Partners (Steering Committee):
- Correctional Service of Canada
- Hepatitis C Society of Canada
- PEI Public Health
- AIDS New Brunswick
- SIDA/AIDS Moncton

Outputs:
- focus group of frontline community workers[5] to obtain input into development of conference agenda
- two-day educational conference for cross-section of community workers (40-50 attendees)
- French-language educational brochure (English version translated, printed)

Outcomes:
- enhanced capacity of regional/local community-based organizations in Prince Edward Island and New Brunswick to provide support to those infected/affected/at risk, by providing such organizations with knowledge and resource information
- enhanced networks, potential for future partnerships
- increased knowledge of hepatitis C and access points for community services

Future needs (gaps identified):
- ongoing education/training for frontline community workers, e.g.,
  - in-house professional development
  - educational materials (videos, brochure, etc.)

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[5] Corrections, public health, hospital, community agencies, First Nations, people infected with hepatitis C

QUEBEC REGION

Association des Intervenants en Toxicomanie du Québec Inc. (1999-2000)

Hepatitis C Training Days (“Hépatite sans frontières”) for 380 workers (addictions, youth centre, street, etc.) from various regions of Quebec

Outputs:
- training sessions
- participants’ training resource
- report, including evaluation results (re: knowledge levels, satisfaction)

What worked:
- evaluations showed:
    a) considerable gains in knowledge about all aspects of hepatitis C aired at the sessions
    b) overwhelmingly favourable reviews of the training sessions

Lessons learned:
- training should offer more exercises involving interaction between participants (getting to know each other, strengthening ties, learning about strategies adopted by other organizations – what works and what does not work)
- more information should be included on biomedical aspects of the virus – e.g., symptoms, medication, etc.
- practical, easily accessible information is needed on the front lines

Future:
- waiting lists for training (three regions of the province)
- many Health Departments interested in partnership, and some have provided lists of organizations potentially interested in receiving training
- considerable interest expressed since the session (about the training and the resource)
- requests received for copies of the training resource (to distribute to their colleagues)
- contemplating giving sessions in three new locations, and a repeat session in Montreal

Hepatitis C Foundation of Quebec/Fondation de l’Hépatite C du Québec (1999-2000)

Partners:
- Dawson Community Centre
- CLSC
- St-Justine Hospital
- Schering Canada

Outputs:
- bilingual promotional pamphlet and bookmark

Other components not reported on:
- development of volunteer structure
- partnership development
- consolidation of fundraising activities

MANITOBA/SASKATCHEWAN REGION

Hepatitis C Society of Canada – Manitoba Chapter (1999-2000)

Booklet to increase awareness of programs/services in Winnipeg area

Outputs:
- booklet
- evaluation report (community development process)

Outcomes:
- increased organizational knowledge
- increased knowledge/skills of target population (infected/affected)
- better health practices (hope that in long term, booklet will contribute to changing behaviour and stopping the spread of HCV)

Unintended outcomes:
- booklet proved useful to service providers, rural dwellers and those at risk (although intended for infected/affected)

Lessons learned:
- the most challenging aspect of the project was putting the booklet into plain language – the nature of the process (community driven and conducted) meant that a number of drafts were needed. As well, professional input was required to produce the final draft
- affected families provided input on some sections (coping, and the type of information they found helpful)
- the number of visits to Health Canada could have been reduced
- distribution process can be used as a means of increasing networks
- users' evaluation questionnaire led to improvements in second edition
- knowledge and experience gained were invaluable
- community advisory group worked well – infected/affected people involved, and input was used (RA., Health Canada, a haematologist, people with resource development expertise). Criteria were: hepatitis C people, female and male, rural and urban, provincial and federal health, specific abilities – designer with experience working on HIV, knowledge of hepatitis C virus, haematologist)
- community played key role throughout
- involvement of community people at every stage (editor, printing, graphics) helped reduce costs

Future needs (gaps identified)**:**
- need for more resource tools re: importance of being tested for hepatitis C virus
- another haematologist to reduce diagnosis time
- public awareness to reduce discrimination (determinants of health)

Meyoyawin Circle Corp, Prince Albert (Saskatchewan) (1999-2000)

One Day Educational/Awareness-raising Workshop for Community Workers

Outputs:
- workshop
    - 74 participants + 17 life skills students
    - provincial health speakers
    - community nurses
    - educators
    - direct service providers
    - community members infected with hepatitis C
- report on workshop

Outcomes:
- establishment of hepatitis C committee in Prince Albert (reps: Health District, Friendship Centre, AIDS Society, Meyoyawin Circle Corp, Pine Grove Correctional Centre)
- formation of a community hepatitis C working committee to address the critical needs of at-risk youth and issues related to injection drug use (with representatives from Prince Albert Health District, Youth Activity Centre, West Flat Citizens' Group Inc., Prince Albert Indian and Metis Friendship Centre, Prince Albert Grand Council, Public Health – STD, Pine Grove Correctional Centre, Prince Albert City Police)

ALBERTA/NWT/NUNAVUT REGION

AIDS Calgary Awareness Association/Safeworks Calgary (Alberta) (1999-2000)

HIV/Hepatitis C Peer Support Group

Outputs:
- guide – Hepatitis C Resources for Service Providers (disseminated to partner organizations and organizations throughout Canada and Alberta)
- peer support group facilitation guide
- evaluation form adapted for low-literacy population (using smiley faces)

Outcomes:
- development of a culturally/socially sensitive approach to a support group
- initiation of bi-weekly (now weekly) peer support group for clients with a history of substance abuse infected with HIV or hepatitis C virus (2-12 attendees per week)
- strengthened "a very effective partnership"

- increased participation (repeat clients regularly bringing new members)
- increased sense of self-empowerment and support
- increased awareness of shared needs and concerns
- increased awareness of hepatitis C, HIV and related health awareness
- development of a sense of program ownership
- increased organizational capacity to address hepatitis C issues
    - increased understanding of needs
    - improved ability to respond to questions
- increased skills in facilitation through co-leadership approach
- mutually beneficial partnership with local collective kitchen (which prepares fresh, nutritious meals for participants)

Community participation:

- need for group identified by clients
- clients determine weekly topics
- clients evaluate sessions

Determinants of health:

- culturally sensitive approach and information
- topics addressed included discrimination, social isolation, homelessness, family rejection, daily coping
- participant evaluation approach/format adapted for low-literacy population

What worked well:

- co-facilitation of meetings by peers and professionals from both agencies (broadened understanding of each other's populations and their needs)
- participants responses overwhelmingly positive
- most positive about up-to-date info on HIV/hepatitis C virus
- facilitators' ability to keep topics current
- facilitators' "personal styles conducive to working with the peer support group"
- offering sessions to coincide with collective kitchen which meets on same day and provides fresh nutritious meals at lower cost than ordering food

What worked least well:

- participants least positive evaluations were around their ability to talk and get support from the group", and the "ability to say how they feel about HIV and hepatitis C"
- benefits of co-led groups: flexibility, communication, understanding, shared goals

Lessons learned:

- weekly meeting increased regularity of attendance (vs. bi-weekly)
- lack of demographic data (future evaluation form should request info on culture, gender, age group, to allow for description of sample)
- this would enable a determination whether the findings are culture- and /or gender-sensitive, and indicate whether age is a factor in whether participants considered the group supportive

Sustainability plans:

- Project will be sustained through the partnership formed between the two organizations

Canadian Liver Foundation – Alberta/NWT/Nunavut Region (1999-2000)

Street population Hepatitis C Education and Awareness Program (Presentation Package)

Partners:

- (Canadian Liver Foundation)
- Capital Health Authority
- Sexual Health Clinics
- Streetworks
- Bissell Centre
- Boyle-McCauley Health Centre.

Outputs:

- hepatitis C educational workshop for community workers
- focus groups for frontline staff/health professionals
- effective, appropriate presentation kit for frontline staff working with street population

Outcomes:

- increased awareness and knowledge of frontline staff working with the street population
- increased sense of community and strength among workers

Community participation:

- input through focus groups

Evaluation:

(to be completed)

What worked:

- good information collected for further work and development on hepatitis C with the population, and in Northern Alberta

What did not work:

- insufficient funds to accomplish needs
- timelines difficult to meet
- late approval from Health Canada
- difficult to keep people focussed on only one objective (provision of kit)

Canadian Liver Foundation – Alberta/NWT Region (1999-2000)

Aboriginal Youth Hepatitis C Awareness Video

Outputs:

- workshops to recruit participants
- educational video

Outcomes:

- increased community pride and participation
- increased awareness of issues among participants

Community participation:

- youth participated in development of video at all stages

N.B. Information very scanty

Canadian Mental Health Association – NWT Division (1999-2000)

Helpline Hepatitis C Project

Outputs:

- workshop to educate/inform volunteers on hepatitis C and health promotion (26 participants)
- reference binder with handouts and information covered in workshop (resource for volunteers)
- six public service announcements re hepatitis C and HIV/AIDS transmission and prevention
- reproduction of hepatitis C Society pamphlet for distribution to local physicians, volunteers, AIDS Yellowknife and Folk Music Festival Information Booth)
- mail-out of info re: help line (to physicians, nursing stations, alcohol/drug workers in Western Arctic, and Hamlet, Housing and Band Offices)

Outcomes:

- addition of hepatitis C component to Western Arctic Helpline and HIV/AIDS info line, and to services provided
- increased complement of knowledgeable help line volunteers (re: basic knowledge, risk behaviours, etc.)

Community participation:

- Helpline volunteers consulted re: needs
- inmates provided ideas for public service announcements and reviewed pamphlet
- people with hepatitis C provided feedback re: workshop agenda and pamphlet
- Inuit and Aboriginal men and women recorded public service announcements
- evaluations of volunteer workshop

What worked well:

- station donated $3000 in air time

What did not work well:

- delays in implementation
- acknowledgement of Health Canada’s role
- stations objected to public service announcement content (on snorting cocaine)

Lessons learned:
- active involvement of focus groups is vital to success
- consultation with key players avoids problems
- value of using knowledgeable people as resources for workshops

Central Alberta AIDS Network (1999-2000)

Harm Reduction Outreach Program

Partners:
- David Thompson Health Authority
- Canadian Liver Foundation

Outputs:
- harm reduction resources
  - educational/training workshops
  - needle exchange services
  - condoms
  - pamphlets and other information (posters)
  - referrals
  - booths

Outcomes:
- links among members of specific target populations (NPN, high-risk teens, sex-trade workers, persons infected with hepatitis C virus/HIV, health and social service workers)
- strengthened community partnerships (including new partners)
- improved ongoing and annual evaluation processes
- participation in provincial committees (target groups, volunteers, service providers)
- identification of key areas to be strengthened in Harm Reduction program

Community participation:
- wide community input and consultation/contact
- day to day decision-making included input from staff, persons infected with hepatitis C and persons who inject drugs
- board and local planning committee included persons who were NPN or infected with hepatitis C

What did not work well:
- resistance encountered from Canadian Liver Foundation (due to primary HIV mandate)
- Health Canada funding guidelines are project-oriented (better suited to one-shot solutions, favouring new/novel approaches over tried and proven responses), making it challenging to integrate the project into a successful ongoing program
- delays in receiving funding

Future needs (gaps identified)**:**
- need to increase hepatitis C virus (HCV) data collection
- larger, longer-term projects will include formalized means for persons who inject drugs, persons infected with hepatitis C to participate in ongoing project management
- CASC funds already requested to strengthen key areas in Harm Reduction program identified through the project

Hepatitis C Society of Canada – Southern Alberta Chapter (1999-2000)

Harm Reduction Services Program

Partners:
- John Howard Society
- Lethbridge HIV Connection
- Sik-Ooh-Kotoki Friendship Centre

Outputs:
- committee (Hepatitis C Society of Canada – National Task Force, Lethbridge HIV/AIDS Health consortium, HIV Connection Hiring Committee, Provincial NPN Harm Reduction Programmers Committee, Hepatitis C Harm Reduction/Health Consortium)
- series of meetings/workshops/seminars/conferences (national, regional, local)
- adapted versions of existing information (pamphlets)
- new material (in development)
- harm reduction slide presentation
- mobile unit (condoms, needles, educational materials)
- fixed in-site office (clean needles, condoms, info materials, referrals)
- fixed satellite in-site office (services as above)
- activities logs, data collection forms, surveillance evaluation surveys, contact sheets, workshop/class evaluation forms

Outcomes:
- increased awareness of hepatitis C and harm reduction initiatives at all levels (national, regional, local)
- development of organizational linkages
- harm reduction programming implemented

Community participation:
- members of target population encouraged to offer input at all stages of development, design, implementation, evaluation of project – including decision-making
- volunteers from target populations helped develop evaluation materials
- target pop members involved in setting up and renovation of fixed site
- had a say in physical development and renovations – some suggestions workable and incorporated

What worked:
- input from target population volunteers

- completion of all work despite problems
- found we had "capabilities we didn't know existed"

What did not work:
- inadequate development and prep work ahead of public service announcements
- project as written (until the three components were severed)
- project setbacks led to delays and budget overruns
- poorly timed, poorly prepared public announcement
- project management issues – partners input ignored, lack of day to day management – eventually projects were severed, with each project partner managing one component (sites), overseeing day to day management
- budget was unrealistic and inflexible (e.g., no budget for final reports)
- mix-up re: funding process

Lessons learned:
- necessity to soft pedal some aspects of harm reduction programming (downplay needle exchange aspect of program, as public believes this is all there is to harm reduction – those who need them know where to find them)
- going to HIV/AIDS-based organization for programming only increases the stigma associated with hepatitis C
- HIV/AIDS-based organizations are new to hepatitis C and may lack capabilities needed to deliver hepatitis C programming
- need to make public aware of other components
- public announcements need to be well planned in advancer with info on potential benefits to community
- scale project to fit budget
- budget actual costs before spending begins
- ensure project partners all have common understanding of project, including deadlines and reporting requirements

Future plans:
- use evaluation findings to assess further needs
- share evaluation findings with National Office of Hepatitis C Society of Canada and other chapters, and Chinook Health Region

HIV Network of Edmonton Society (HIV Edmonton) (1999-2000)

Safe Body Art Pamphlet (aimed at youth and others likely to seek body art): updating, printing, dissemination

Partners:
- Capital Health Authority
- Canadian Liver Foundation (Western Region)
- Alberta Health and Wellness

Distribution network:

- Tom Edge Resource Centre
- Canadian AIDS Society
- Alberta Community Council on HIV
- Capital Health's Blood-Borne Pathogen Committee
- Edmonton HIV Consortium
- provincial Non-Prescription Needle Use Consortium
- Canadian Liver Foundation
- other collectives related to hepatitis and HIV issues

Outputs:

- updated version of original pamphlet (70,000 copies printed)
- pamphlet distribution (ongoing, to the body art industry, interested youth)
    - already distributed to Edmonton Grade 12 students (via Liver Foundation, Alberta Health)

Outcomes:

(too early to say)

Community participation:

- consultation with various tattoo establishments and youth
- feedback from students and other distributees

Sustainability plan:

- Post-project distribution expenses absorbed into budget of HIV Edmonton

Future needs:

- ongoing evaluation indicates need for lower-literacy pamphlet or one that is less dense (funding applied for)

HIV Network of Edmonton Society (HIV Edmonton) (Alberta) (1999-2000)

Harm Reduction Policy Kit and Conference Project

Outputs:

- Harm Reduction Policy Kit (basic info re: harm reduction as related to non-prescription needle users), distributed to members of the NPN consortium at their January 2001 meeting.
- partnership committee to oversee conference
- hiring of conference organizer
- one-day province-wide harm reduction conference (139 participants – individuals including users, organizations wanting more info re: HR and how to implement HR in their organizations and communities, including out-of-province attendees)
- evaluation (verbal, from Consortium members, selected professionals including the consultant with the Canadian Harm Reduction Network, written from attendees) of kit – suggestions being incorporated in final version of kit

Community participation:

Persons who inject drugs

- attended and presented at conference (but not involved in planning)
- provided feedback on harm reduction policy kit through involvement in Streetworks Natural Helpers Program

What worked:

- conference committee
- group decision making
- committee for producing kit
- production and evaluation process went smoothly

What did not work:

- lack of media coverage, due to cautious policy in selecting media included (due to fear of controversy). Resulted in "nearly no media coverage"
- lesson: pursue more aggressive coverage for next conference

Streetworks Edmonton (Alberta) (1999-2000)

Hepatitis C Survey of persons who inject drugs (53 past and active)

Outputs:

- survey instrument
- survey results (needs, level of understanding, drug use patterns, things they believe will assist them to maintain/improve their health)

Outcomes:

- increased organizational knowledge/understanding of
    - current state of drug use
    - potential effects on liver function
- increased understanding of IDU needs

Community participation:

- Streetworks Natural Helpers tested survey questions, fine-tuned tone and language
- program advertised by word of mouth through Natural Helpers and staff

What worked well:

- Streetworks is an established, trusted program for persons who inject drugs – this allowed for honesty by interviewees

What did not work well:

- project delayed due to lack of funds (needed to borrow money to carry out survey. Time extension granted by Health Canada)

Future plans:

- use of survey results as base for future work in hepatitis C and injection drug use

BRITISH COLUMBIA/YUKON REGION

Canadian Liver Foundation – British Columbia Region (1999-2000)

Adaptation of Living with Liver Disease Program (Development and Promotion)

Outputs:

- Information booklet on Hepatitis C – Risk, Transmission, Treatment (from National Hepatitis C Education program)
- 7-week workshop series (Vancouver)
- treatment information workshops (Vancouver) – in response to calls
- 6-week workshop series including treatment issues (planned for Victoria)
- 6-week workshop series (Powell River) – once monthly
- use of modified version of Living with Liver Disease Program (developed for rural areas, to accommodate differences in culture, population, and local availability of services)
- planned workshop for physicians and the public (Prince George)
- provincial volunteer recruitment program
- workshop for health care professionals
- CME series (Courtney, Campbell River, Powell River)
- Wellness Show (Vancouver) with information booth for 26,000 attendees
- information booth for attendees of Deepak Chopra Lecture (Insight on Health Expo, Vancouver)
- promotional posters
- media materials
- workshop materials
- patient handouts
- evaluation forms

2. Projects submitting products only

QUEBEC REGION

Canadian Hemophilia Society – Quebec Chapter (1999-2000)

Partners:

- Canadian Liver Foundation

Outputs:

- bilingual newsletter on hepatitis C

Other components not reported on:

- evaluation of needs of persons infected/affected
- provincial meetings for infected/affected clients

ONTARIO REGION

Canadian Liver Foundation – Eastern Ontario Region (1999-2000)

Outputs received:

- pamphlet: Hepatitis C information for pregnant women (distributed)

Other components not reported on:

- expansion of Living with Liver disease program in Kingston
- Hepatitis C Educational Forum in Cornwall

Canadian Liver Foundation – Southwestern Ontario Region (1999-2000)

Partners:

- London Middlesex Public Health Department
- Canadian Hemophilia Society – London Chapter
- AIDS Committee of London
- Hepatitis C Society of Canada – London Chapter

Outputs:

- pamphlet – comprehensive information on hepatitis C (French version to follow)

Other components not reported on:

- adaptation and delivery of Living with Hepatitis C Program

Hemophilia Ontario (1999-2000)

Outputs received (not for public distribution)**:**

- "An Overview of Liver Biopsies, Transplants and Hemophilia"
- "An Overview of Self-Help Initiatives Within Health Care"

Other components not reported on:

- information sessions in five regional chapters
- assessment of viability of peer support networks
- development of two moderated e-mail discussion groups
- an Executive Board planning session