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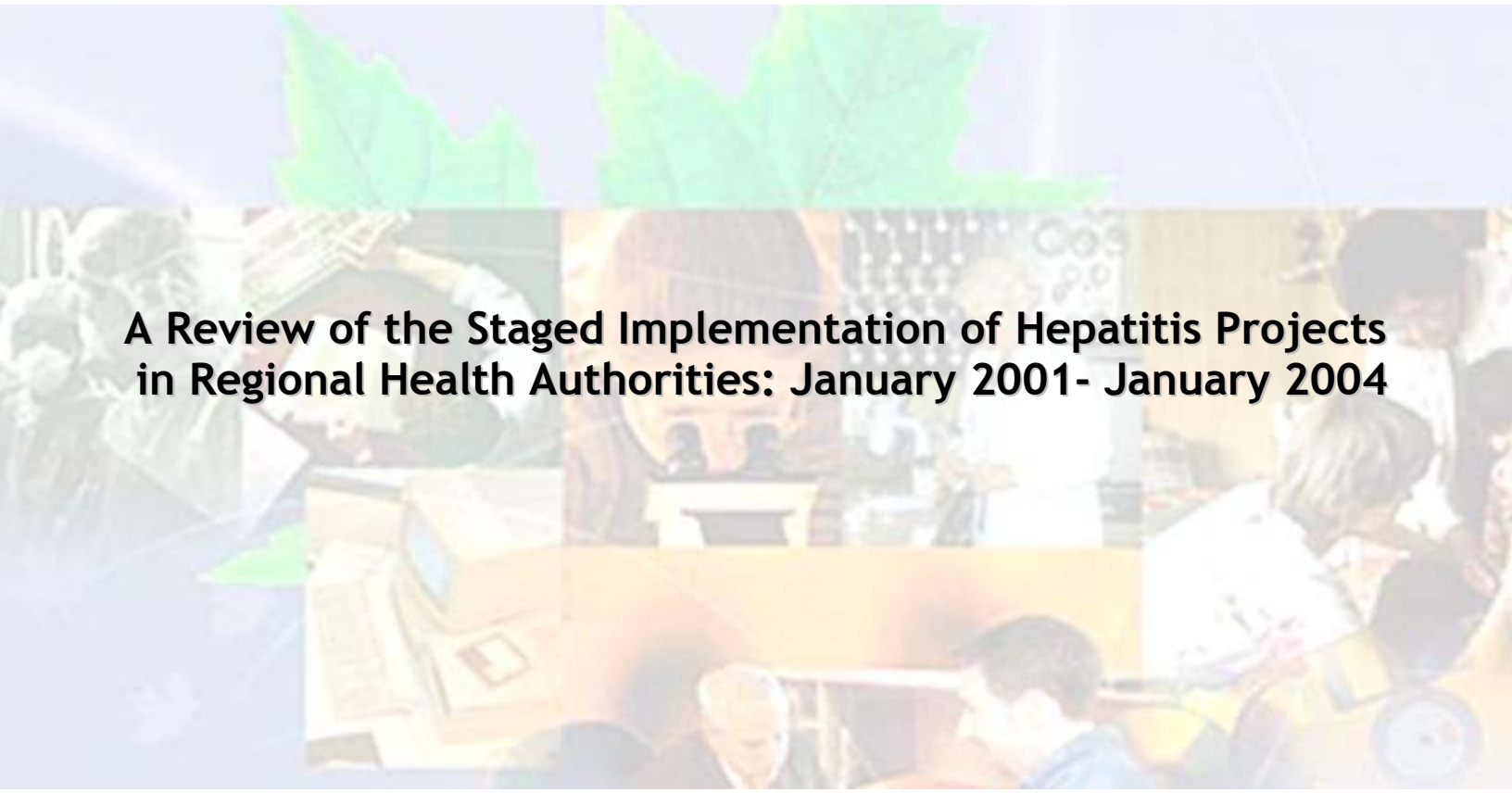

A Review of the Staged Implementation of Hepatitis Projects in Regional Health Authorities: January 2001- January 2004

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TABLE OF CONTENTS

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PURPOSE

The purpose of this report is to describe the experiences and lessons learned from January 2001 through May 2004 in the five demonstration projects that were collaboratively planned and implemented in each of the regional health authorities. Each demonstration project is described as follows: summary of implementation, results, challenges and future directions. A composite of client and partner perspectives on the integrated projects is also provided. The summary and recommendations for future programs and partnerships conclude the report.

INTRODUCTION

Approximately 40,000 persons with chronic hepatitis C (HCV) were identified in BC between 1992 and 2002 and a similar number are infected with chronic hepatitis B (HBV). Since the provincial treatment capacity is extremely limited, at least 98% of these individuals may live with chronic hepatitis and consequent liver disease for decades, a significant issue for both individuals and for BC's health care resources. In 2001, the BC Ministry of Health funded the formation of BC Hepatitis Services at the BC Centre for Disease Control to develop a comprehensive, multifaceted provincial strategy for integrated prevention and care. The concept of integrating the needs of populations (prevention) and individuals (care) recognizes the paradox of trying to address the needs of affected individuals while being fiscally equitable and serving the needs of the population.

The following issues were identified at the outset by BC Hepatitis Services in 2001: 1) *Access to assessment and treatment* was centered primarily in one tertiary referral centre, 2) *Knowledge of the disease* was advancing rapidly; it was difficult for health care providers to keep up and misinformation to clients was common, 3) *Self care management strategies and best practices* for coping with the illness were not well understood, 4) *Effective consumer advocacy* voice was lacking, 5) *Effective prevention strategies* for hepatitis C needed to be discovered and tested.

BC Hepatitis Services set the following objectives in response to these challenges:

- Integrate prevention and care services
- Connect providers and consumers to educational materials, resources, information and care options
- Identify information required to assist decision-making and evaluate outcomes
- Develop prevention and care best practices
- Build prevention and care capacity

BC Hepatitis Services identified the components that were essential for an integrated approach and developed strategies to build capacity in each component. Throughout the process, BC Hepatitis Services provided leadership, brokered partnerships, facilitated mentorship opportunities and created collaborative networks. BC Hepatitis Services and its partners developed an infrastructure that included the development of the hepatitis demonstration projects, educational materials, workshops, consumer advocacy, and laboratory and clinical practice guidelines. The program model (Figure 1) shows the diverse nature of team activities as well as their interrelatedness.

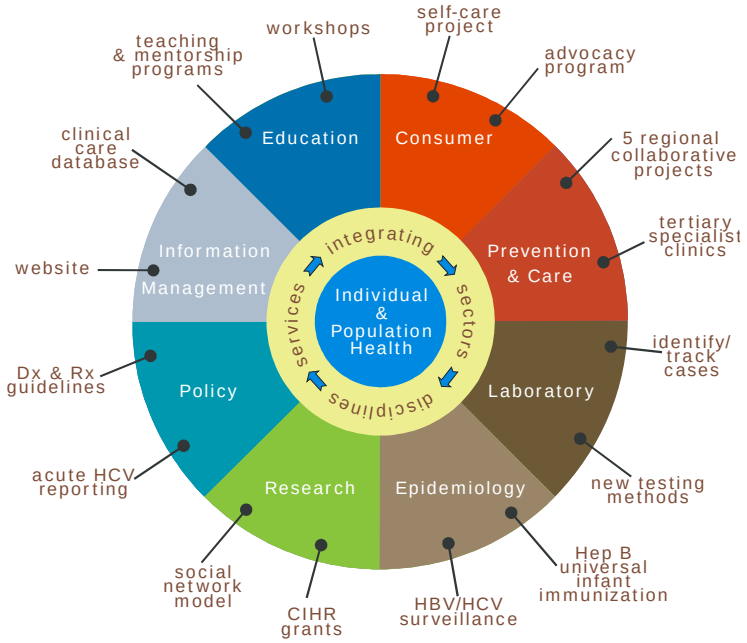

Figure 1. Hepatitis Services Interdisciplinary and Intersectoral Program Model

Initially strategies were targeted at two important areas: 1) education of health care professionals, and 2) development of locally accessible services. To respond to the need for education of health care professionals, an intensive 3-day interdisciplinary workshop on viral hepatitis was developed by BC Hepatitis Services and provided from a central site. The workshop brought together viral hepatitis experts from different disciplines and health sectors, using large-group lectures and small-group problem-solving and discussion sessions. The target audience consisted of participants in hepatitis projects, including general and specialist physicians, public health physicians and nurses, Aboriginal community health nurses and nurse clinicians, social workers, advocacy leaders, pharmaceutical industry representatives and laboratory scientists. The development of specialized hepatitis expertise was supported through an interdisciplinary education, training and mentorship program developed in partnership with the Division of Gastroenterology, Vancouver Hospital Health Sciences Centre and the UBC School of Nursing.

Recognizing that health care professionals required knowledge of the issues faced by those affected by Hepatitis, a nursing research agenda was developed which included:

- A self-care research project funded by the BC Health Services Foundation
- A partnership with Health Canada to explore community issues (e.g., advocacy, stigma) over a three-year period
- Submission of research proposals to provincial and national granting agencies
- Development of a hepatitis research library

In order to build local capacity and develop best practices for integrated prevention and care in diverse settings using nursing leadership, five demonstration projects were developed, one in each regional health authority. In June 2001, BC Hepatitis Services began collaborating with each health authority to choose sites to develop integrated models of prevention and care services outside the major urban centre of Vancouver. Funding included $25,000 in start-up and $75,000 in annual grants to each host region.

Implementation of projects was staged with Interior Health (Kamloops) starting in July 2001, Vancouver Island Health (Campbell River) and Northern Health (Prince George) in 2002, and Fraser Health (Surrey) and Vancouver Coastal in 2003. This staging method facilitated a rapid change/quality improvement approach. Vancouver Coastal Health, where care services are widely available, developed and tested a youth education curriculum and teaching package that focused on hepatitis prevention among at-risk youth.

DESCRIPTION OF THE STAGED IMPLEMENTATION OF HEPATITIS PROJECTS

By January 2004, four communities were hosting a BC Hepatitis Services-sponsored regional integration project: Kamloops, Campbell River, Prince George and Surrey. A fifth project, located in Vancouver, focused on hepatitis prevention with youth. Each project site was visited by consultant Arlene Trustham and Faye Barichello from BC Hepatitis Services in January 2004 to interview team members, clients and other hepatitis service providers. The review included information compiled from program descriptions, annual reports and information provided during yearly group meetings in which the project teams shared and compared their progress and experiences.

The process of integrating prevention and care services began with the collection of information on the status, current management and scope of hepatitis services, as well as community consultation. Steering committees of diverse hepatitis stakeholders guided planning and shared information while local public health provided project management and leadership. This initial process of integration resulted in the following immediate benefits:

- Integration of nursing teams to provide prevention counselling, community development, education, support and clinical services
- Realized efficiencies in related programs because of coordinated efforts
- Access to comprehensive services such as addictions, mental health and nutrition services through referral
- Immediate improvement in local capacity to assess and care for hepatitis clients
- Increased education for health care professionals and allied service providers
- Development of local expertise in the health care community
- Wait times for clinical assessment reduced to less than one month from greater than three months
- For clients undergoing therapy, response rates similar to published literature
- Immunization for Hepatitis A and B for 90% of high-risk clients
- Increased reach and coordinated services to hepatitis-affected communities

Each project offered a unique element to hepatitis integration such as:

- A community development person focusing on health promotion in Kamloops
- Hospital, public health and mental health/addictions partnership in Campbell River
- In Prince George, where a specialist physicians are limited, specialized hepatitis care and addictions services were provided by a family physician
- Surrey included education and support for clients receiving treatment elsewhere
- Funding was augmented by industry partners for additional nursing time and educational workshops

As the projects developed, two major program areas emerged: 1) Education and community development, and 2) Client/family education, clinical assessment, support

and monitoring. These areas are reported in detail within the results section of each project description.

This report describes the following elements for each project: (1) goals, (2) summary of implementation, (3) results, (4) challenges and future directions. This is followed by a synthesis of the projects. Interviews took place with a variety of health and social service partners who work with the projects to gain their perspective regarding program functions and service delivery impacts on their communities. Client perspectives derived from interviews are also included with reference to each project. Common themes, lessons learned, summary and recommendations are provided. To begin, the Vancouver Coastal Health Authority project with its focus on at-risk youth is considered individually. This is followed by the four integrated prevention and care projects that are reviewed separately but summarized collectively.

VANCOUVER COASTAL HEALTH: YOUTH EDUCATION PROJECT

Goal: *To develop and test an educational curriculum and resource manual for youth educators and service providers to assist them with hepatitis C presentations*

Since Vancouver Coastal had significant hepatitis assessment and treatment resources, their project focused on primary prevention education for youth (a high-risk population). Initial consultations were held with local youth groups at community drop-in centres to identify what they wanted in a learning resource and how they preferred to have it presented. With the support of the Vancouver School Board, a package was developed and tested that included curriculum binders with a video, CD and postcard inserts. The curriculum included 2 classes: Hep 101, a basic course suitable for low-literacy, and an advanced course, Hep 202 (prerequisite Hep 101). The course materials include overhead slides and/or a blackboard method, speaker's notes, prescribed learning outcomes, activities, postcards, and games. A video created by YouthCo with Health Canada funding was included in a binder, along with a CD, which contained all course materials. The binder cover and the postcards were created by youth following a call for artwork advertised provincially in *Opus* magazine.

Results

Education and Community Development

Education sessions were provided for 300 students in 20 school and community locations. Materials were evaluated and refined based on feedback from the participants. Binders were produced and delivered to all secondary schools in Vancouver and to the four regional pilot project sites. The material was also made available electronically on the Hepatitis Services website and on a CD, which was distributed at the 2nd Canadian Conference on Hepatitis C.

Challenges and Future Directions

The package was well-received by the Vancouver School Board. However, extending the reach and use of the materials into other jurisdictions remains a challenge. The curriculum was developed to provincial education standards and is therefore amenable to use in any school district. This will require additional resources to teach and support the curriculum and its further refinement.

Future directions for Vancouver Coastal Health Authority are to focus on other gaps in hepatitis prevention. Presently, they are focusing on strategies for hepatitis B prevention since the majority of cases are in the Vancouver area.

INTERIOR HEALTH AUTHORITY: LIVER INFORMATION AND TREATMENT CLINIC

Goal: *To improve local access and reduce inequities in health care delivery in a cost efficient manner by the enhancement of existing services through the addition of nursing resources, integration with other health care providers (primary, secondary, tertiary) and the use of a standardized approach*

The first collaborative project began in August 2001 with the Interior Health Authority. A steering committee of community agencies and Health Authority leaders assisted during the start-up period. The project team initially focused on developing education, clinical and support components and called their project the *Liver Information and Treatment Clinic* (LITC). The clinic is located in the Kamloops Health Unit as a specialty project (the LITC nurses also work as generalist public health nurses). They developed a clinical protocol with five pathways: Watch & Wait, Waiting to Start Treatment, Receiving Treatment, Co-Infected on Treatment, and Complicated Liver Disease. The project team developed education and assessment modules based on samples from other liver clinics. Dedicated staffing resources included 3 public health nurses (PHNs), each at .3 FTE. Two PHNs focused on providing client/family education, clinical assessment, support and monitoring, while the other PHN focused on community education and development. Clerical support was provided with the other .1 FTE. Funding for the LITC was augmented for additional nursing time by a pharmaceutical firm, Schering Canada. The team also included two gastroenterologists who both saw patients in the clinic one half-day/month and a general practitioner experienced in addictions medicine who would see referred patients; initially all referrals were from physician to physician, but within 6 months, a physician to nurse and self-referral pathway was established.

Results

Client/Family Education, Clinical Assessment, Support and Monitoring

The clinic has been running for 2 years with Fall 2003 statistics showing 375 total referrals. In January 2004, 20 clients were being treated and 14 awaiting treatment. In addition, 1 person with HBV was being treated. Wait times for assessment were approximately 1 month. The LITC nurses report, “Most of what we do does not involve treatment but rather education and counselling and support. We’ve made working links with mental health, nutrition and drug/alcohol services. Our successes are attributable to co-location of physician and public health nursing services, the collaborative nature of the team and acceptance by the community.”

Community Education and Development

The LITC used a community development model and partnered with business, community, law enforcement, and municipal government (e.g. Business Association, City of Kamloops, AIDS Society of Kamloops) to develop a harm reduction program. These partnerships resulted in a successful initiative to clean up needles in parks and downtown areas and raise community awareness. The community education and development was part of a broader blood-borne pathogen approach to prevention and health promotion. According to the community development educator, “Our work is to

help stakeholders realize their role in supporting people with HCV through a healthy population model and through self-advocacy. There's a lot of trial and error involved. A shift was made after we discovered that the participants did not understand population health and their role in community health. Ironically, the self-advocacy element was not well received by professional advocates who have trouble even accepting peer advocacy. It will take some time for this to be accepted and this is a challenge."

Involving the municipal government and local business partners as collaborators in a health issue was a critical factor for project success. The City of Kamloops funded the development of a pamphlet and posters for children to improve safety in parks, changed policies regarding needles in the process and developed a needle deposit box program. Media and fact sheets were effective educational and support generating tools. Public Health stimulated the project but, most importantly, the community owns it.

Challenges and Future Directions

A major challenge was related to treatment and assessment capacity in the region. An immediate problem was that there were too many referrals for the time allotted to LITC project and many referrals came from outside the Kamloops area (which created an issue of equity for those living outside Kamloops). Limited capacity at the hepatitis program in nearby Kelowna was noted as a potential issue. With a 4-year wait list in Kelowna, clients were willing to travel to Kamloops for treatment.

Nurses and administrators experienced challenges with their new roles and responsibilities. Since nurses in the LITC also work as generalist public health nurses, they had difficulties with role separation. "It's hard to juggle the public health role with the liver clinic role – where does one stop and the other start?" Their LITC role has led other nurses to defer to their hepatitis expertise. For example, surveillance and follow-up of hepatitis C laboratory results--previously shared by all PHNs in the communicable disease program--now falls to the LITC nurses. Local health administrators expressed concern about providing in-kind public health resources to a clinic that includes a strong treatment component. While providing treatment for communicable diseases (i.e. tuberculosis, sexually transmissible diseases) by public health nurses has been the norm, expanding this to include hepatitis raises many issues. Future directions include exploring links with primary health services delivery projects and complementing blood-borne pathogens initiatives.

VANCOUVER ISLAND HEALTH AUTHORITY: NORTH ISLAND LIVER SERVICE

Goal: *North Island Liver Service will build system capacity through the use of effective partnerships to enhance the capacity of individuals, communities, health and social service agencies to prevent and treat viral hepatitis*

North Island Liver Service (NILS) is based in Campbell River with a mandate to provide service to all North Island residents. The project held a series of community consultations throughout the North Island to determine program placement and priority elements. The consultation included a review of a survey funded by Health Canada in 2001 and carried out by Public Health in cooperation with the North Island AIDS Society (NIAS). Results showed a need for increased public awareness, advocacy,

education and support for people with HCV and their families as well as education for health care professionals. NILS opened October 31, 2002 with a team that included two nurses (.4 FTE from the hospital sector and .4 FTE recruited from the public health sector) who provided client/family education, clinical assessment, support and monitoring, as well as community development and education. Physician support was initially provided by a Campbell River internist and later expanded to include a Comox internist. The plan was to complement hepatitis existing services rather than duplicate them. The NILS team was expanded to include a Mental Health and Addictions counsellor (.2 FTE) and in-kind clerical support from the Campbell River Hospital diabetes outpatient program. Strong in-kind resources were provided by the hospital as well as other sectors. As with the Kamloops project, nursing time was partially funded by an industry partner. Partnerships with a number of community agencies were developed through an active advisory group from across the region. The program depends on family physicians, public health staff, acute care professionals and other support service providers such as North Island AIDS Society, mental health and addictions and nutrition services working together. The NILS nurses operate as consultants to other health care professionals and provide peer supervision related to hepatitis care. The clinic is located in Campbell River hospital while the management/leadership comes from the public health Communicable Disease Nursing Manager. This inter-jurisdictional management creates integration across three sectors of VIHA: public health, hospital and mental health/addictions.

Results

Client/Family Education, Clinical Assessment, Support and Monitoring

NILS has received 257 referrals since opening (they track referrals according to location and source of referral). Examples of additional data tracking elements include: number of clients on treatment, completed treatment, waiting, and drug/alcohol and mental health referrals. Clinic access to the internist for hepatitis assessment has reduced the wait time from 14 months to 1 month. Services are augmented by referrals to other support providers such as mental health/addictions and HIV co-infection specialists in Vancouver. In addition to assessing and treating for hepatitis C, the NILS team also provides some support and counselling for clients with decompensated liver disease.

The nurses credit the program's success to the following: beginning with a vision based on the needs assessment, strong support and active participation by the Medical Health Officer, process facilitation and the willingness of hospital and public health managers to give the team autonomy (trust built early allowed the team to thrive – it was also reflected in management support for a new job classification), support from the medical specialists for evolving nursing leadership roles and shared responsibilities, acceptance from the medical community and finally, balanced team dynamics.

Education and Community Development

Capacity building was enhanced through providing a large education workshop in Campbell River for 120 health care professionals from across the region. Sixteen physicians attended as well as nurses, social services staff, recovery workers and a variety of others. Project nurses traveled the region in 2003, giving employee education sessions and meeting with individuals. Locations visited included Campbell River's pulp-mill, a resource fair for unemployed and underemployed (in partnership

with disability groups). They also gave presentations in several First Nations communities, at a youth forum, a recovery house in Alert Bay, and to Home Care staff. A support group is in the planning stages in response to client interest.

Challenges and Future Directions
The location of NILS in the hospital strengthened the partnership between public health and tertiary services. However, as in other health authorities with a large catchment area, communication remains a challenge. While periodic meetings are held with PHNs from other areas, the ability to interact to plan and implement surveillance and prevention activities of the overall communicable diseases team could be improved. Future directions include enhancement of relationships with aboriginal communities and other vulnerable populations. As a result of the NILS demonstration project and related synergies, a similar project for the Central Island Health Service delivery area was started in Nanaimo with existing resources (i.e., without demonstration project funding).

NORTHERN HEALTH AUTHORITY: VIRAL HEPATITIS CLINIC

Goal: *To take a primary health care approach to the prevention and care of individuals infected with and affected by viral hepatitis and provide access to specialized care for individuals and families in an atmosphere of respect, dignity, and non-judgment of clients*

Northern Health's *Viral Hepatitis Clinic (VHC)* developed out of 13 years' experience in hepatitis community education and, more recently, a 3-year Health Canada funded project to develop educational resource modules. The VHC offers integrated prevention and care management and treatment support from the Prince George Health Unit. Nursing roles are carried out by 2 PHN positions (.4 FTE each) with in-kind clerical support. Due to ethical concerns, Northern Health did not have industry sponsorship of additional nursing time. A lack of internal medicine specialists able to staff the clinic in Prince George was a unique challenge to the formation of the VHC. Physician support was accomplished through recruitment of a family/methadone physician to provide the clinical assessment and follow-up. Unlike the specialist fee-for-service model used in the other projects, family physicians require sessional funding in order to participate in the program. Project funding was therefore allocated for physician sessions.

Prior to the formation of the VHC, community consultations were held with local stakeholder groups, interested physicians, and health authority administrators including the Medical Health Officer. VHC staff built on the learning and experiences of other sites and shared resources in the development of their program. VHC staff report that their program was "put together by borrowing from everyone." There is no formal advisory committee at this time in Prince George, although there are groups working together on HIV and primary care issues.

The pharmacist, dietician, social worker and nurses from home care held one interdisciplinary team meeting to streamline operational processes. Based on these discussions, client services were expanded to include referrals to pharmacists, the hospital dietician and to the Community Response Unit for acute mental health issues. For clients on treatment unable to self-inject, home care was arranged to assist.

Results

Client/Family Education, Clinical Assessment, Support and Monitoring

The clinic has been open just over a year and has received over 200 referrals simply through notification of local physicians. There is a 4-6 week wait time to be seen at the clinic. There are 26 individuals on treatment. Group teaching has not been attempted due to confidentiality concerns on the part of clients. There are several physicians who provide treatment from their offices who are not associated with VHC; the hepatitis nurses do not provide education/support to those clients at this time.

Education and Community Development

A VHC nurse participates in a support group for those with Hepatitis C (held at the hospital) with 4-6 people attending each session. A volunteer phones support group participants and advertises the next session in the local paper. Concerns about anonymity and stigma are frequently discussed issues, which obviates the need for one-on-one counselling. Over 300 community education presentations were given throughout the region, with a lot of travel involved. There is a demand from northwest and east for HCV education but capacity is an issue. The clinic nurses conduct outreach and education sessions weekly at a local detox centre and in provincial jails. These sessions focus on harm reduction and preventing the spread of blood borne pathogens. The Prince George Health Unit has a strong history of hepatitis C follow-up by its communicable disease nursing team and street nurses. In addition to the hepatitis clinic nurses, all communicable disease nurses carried out hepatitis follow-up.

Challenges and Future Directions

As in other projects, there has been some confusion about the roles of VHC nurses versus the communicable disease team duties. As the project developed, roles and responsibilities were negotiated to minimize overlap and confusion. Overlap with the Needle Exchange Program (NEP) enabled them to focus on gaps in services, since the NEP provided outreach education, blood testing and counselling.

Capacity quickly became an issue. Discussions were held to consider how referrals would be prioritized with respect to considerations of geography and need. Advertising for VHC was limited to local physicians.

There is a need to expand communication and partnerships with physicians and agencies to build capacity. Staff stressed a need to develop linkages with specialist physicians (i.e., the infectious disease specialist) in Prince George and in other areas such as Terrace and Dawson Creek where hepatitis C consultation is provided. Collaboration with Native Health Services hepatitis initiatives should be expanded. Staff noted that Northern Health Authority would like to develop a standard of care for hepatitis follow-up for the whole region. Finally, a mechanism for evaluating client satisfaction is required as well as a referral mechanism to social work.

FRASER HEALTH AUTHORITY: FRASER HEPATITIS SERVICE

Goal: *To build capacity among individuals, the community and health and social service agencies to prevent and treat viral hepatitis*

Fraser Health Region has a high number of newly reported HCV cases, reflecting the presence of both federal and provincial corrections facilities in the region. *Fraser Hepatitis Service (FHS)*, as the final project implemented, benefited from the lessons learned in the other projects. During the planning process, FHS created a steering committee and an advisory group that helped to develop the program and tailor services to the local clientele. An initial step was to develop support for treatment and build linkages and partnerships with mental health, social workers, existing practitioners and specialists.

Results

Client/Family Education, Clinical Assessment, Support and Monitoring

FHS accepts referrals from physicians, agencies or individual clients. Unique to FHS is the ability for clients to self-refer for education and support only, while treatment continues to be monitored by their personal physician. On intake, all clients receive a comprehensive nursing assessment and depending on their needs are referred to the appropriate services. Two internists provide client consultations once a month. FHS is staffed by two PHNs (.4 FTE and .5 FTE). Other team members include a mental health/addictions counsellor (.2 FTE) and clerical support (.2 FTE). An industry partnership was negotiated to assist with funding of nurse time and is reviewed annually. FHS operates from North Surrey Health Unit, which already provides anonymous public health services. This ensures client confidentiality. FHS opened in January 2004 and received 25 referrals in its first month, one from as far away as Hope.

A needs assessment completed in 2001 identified gaps in prevention and follow-up of hepatitis C positive lab reports. The assessment noted that clients requested personal contact with a public health nurse for information and education about transmission and self-care. A training module for enhanced PHN follow-up was developed in Fraser South and could in future be adapted for implementation throughout the region.

Education and Community Development

An educational workshop for health and social service professionals is planned for Fall 2004 in partnership with Fraser South Community Services/Street Health Outreach Program (SHOP). Partnerships have been developed with physicians, SHOP, Mental Health/ Addictions, Corrections Services, nutrition, hospitals, and community. There is a commitment to provide services to any HCV+ person in the region. As there are a number of treating specialists in Fraser Health who have developed hepatitis programs from their offices, FHS may focus on filling gaps in services to vulnerable populations.

Challenges and Future Directions

Transportation was seen as an access barrier to a centralized program in Surrey. Differences in communicable disease program delivery between the three health service areas presented challenges to regional service integration. Building sustainable partnerships is critical to continued success. North Surrey Health Unit already has a working partnership with the Street Health Outreach Program (SHOP) located several blocks away, with public health nurses as part of the team that provides medical care for people living with HIV and/or HCV as well as addictions, mental illness and homelessness. With SHOP considered a primary care demonstration site, there is an opportunity for collaboration on hepatitis issues, especially as one of the FHS nurses also works with SHOP. In Abbotsford, several physicians and health

authority staff are now meeting (facilitated by an industry partner's representative) to form an alliance of local providers to integrate hepatitis support in Fraser East.

OUTCOMES OF THE INTEGRATED PREVENTION AND CARE PROJECTS

Client/Family Education, Clinical Assessment, Support and Monitoring
From a provincial perspective, an under-utilized opportunity for reaching affected populations was identified. It became evident that there was no consistent public health approach for follow-up of hepatitis-positive laboratory results. The integrated projects addressed this issue in several ways. In some projects, follow-up on positive lab reports is now provided where previously it was not. Other projects have identified gaps in the surveillance and prevention system and have worked with their partners to coordinate follow-up. An additional benefit of follow-up is the option for physician or self-referral to a hepatitis program.

The comprehensive assessment of client/family needs and referral to appropriate services has emerged as an important advocacy role of the hepatitis program nurses. Comprehensive assessment and care planning initiates important lifestyle changes and prepares clients to manage the psychological and physical side effects of drug therapy.

While only a relatively small number of persons with chronic hepatitis C (~30/program/year) are ready to receive treatment (about 50% of those completing therapy will clear the virus), increasing treatment capacity has been a goal of the hepatitis program teams. Clients receive nursing assessment, hepatitis education and preparation for specialist assessment as required, then physician assessment and treatment planning when appropriate. Nurses offer training in self-injection, medication and side effects management and ongoing compliance support by phone and in person throughout the 6-12 months of treatment. In some programs, education, counselling and support is provided to individuals who receive treatment through a physician or specialist not directly associated with the program. This group may expand as more people seek access to treatment. The care pathways are summarized in the Integrated Hepatitis Services Flow Chart (Figure 2).

Some clients referred to the hepatitis programs had advanced liver disease and were unable to undergo therapy. These individuals required close monitoring and support as they lived with the complications of their chronic illness. In some cases, the lifestyle management support significantly improved their quality of life. In rural and remote areas, this kind of support was critical for clients awaiting transplantation or other tertiary care services.

Education and Community Development
Community and agency consultations were used to identify and plan education initiatives for each project. Advisory committees and community consultations helped to shape the activities that were undertaken in the community. In Fraser Hepatitis Service, the advisory group meets regularly to assess the program and further refine the services provided.

All projects employed a population health approach to prevention, education and community development with a focus on vulnerable or at-risk populations. This required knowledge of the needs of vulnerable populations, risk behaviours, and locally available

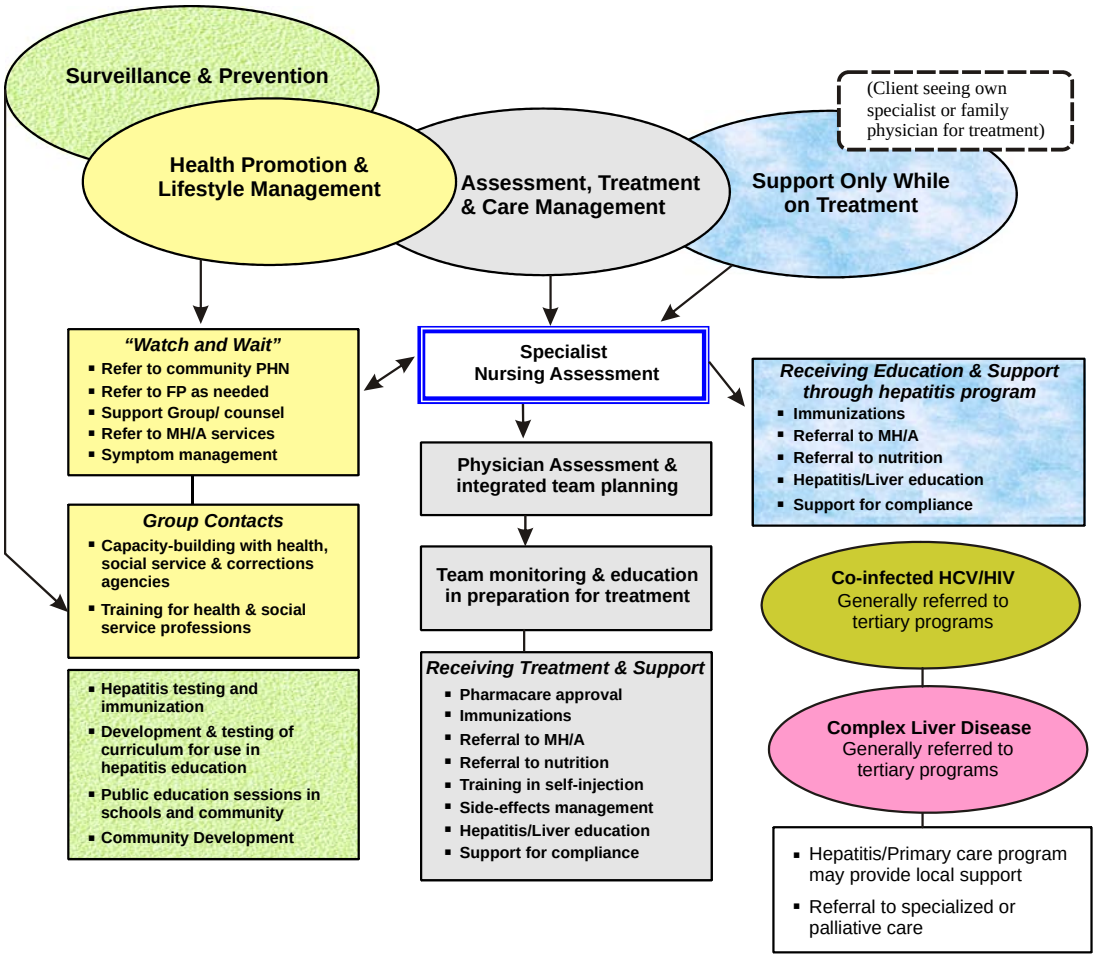

Figure 2: Integrated Hepatitis Services Flow Chart

resources. For example, a Geographic Information Systems (GIS) mapping project in Kamloops, mapped the locations of vulnerable populations based upon a number of socio-economic parameters that were dependent on where an individual lived. This information was subsequently used to plan interventions and determine the optimal location of service provision.

The development of hepatitis services has provided an opportunity to explore the specific needs, and the level of support required for the diverse populations infected with hepatitis C. For example, those with established health and social supports can be their own advocates. However, vulnerable populations require a wide array of community services and supports.

CLIENT PERSPECTIVES ON PROGRAM SERVICES

The experiences of people living with hepatitis provide insight into the challenges of providing integrated health services. The client portraits are composites of information collected from program nurses and from client interviews. They help

illustrate the significant role of the pilot programs in the lives of those infected with or affected by hepatitis. To protect confidentiality, client names have been changed.

Client Portrait 1: Vera

Vera contracted Hepatitis C through a blood transfusion in the early 80's. She learned of her diagnosis through a failed insurance application. When she disclosed her Hepatitis C status to family members and colleagues, she encountered stigmatizing attitudes and behaviours. As a result, Vera stopped disclosing and withdrew from her social networks. The program clinic was the only place where she felt comfortable discussing her illness. To gain additional support, Vera drove to a nearby town to attend a chronic illness support group "anonymously." With support, Vera began treatment and continued to work despite treatment side effects. The program staff supported her self-care efforts and she completed therapy; She is now cured (Hepatitis C negative). Vera talks openly about her life with HCV and travels to conferences and public events to share her experiences as a way of helping others living with Hepatitis C.

Client Portrait 2: Joe

Joe, a middle-aged husband and father, contracted Hepatitis C during a brief period of drug use in his early twenties. He consumed alcohol on a regular basis and his family relationships were troubled. The program nurses and other service providers supported him while he eliminated alcohol use in order to qualify for treatment. Once on treatment, the side effects were extremely challenging, forcing him to quit work. This financial stress combined with extreme fatigue and mood swings contributed to the collapse of his marriage. During this period, the couple sought counselling, information and referral from the program nurses. A mental health provider encouraged him to examine his priorities and life goals. With the support of the program, he completed the treatment and reunited with his family. Joe credits Hepatitis C and the program as life altering for the better, "In my whole life I have never felt this good. I would never, ever have got here without this clinic."

Client Portrait 3: Martin

Martin lived in Vancouver's downtown eastside for a few years and contracted Hepatitis C through injection drug use. At the time of diagnosis, he quit drinking alcohol because of symptoms such as pain in his abdomen, skin rashes and digestive problems. After his diagnosis, Martin joined a recovery program and stopped using drugs. His symptoms decreased and within two years, he was able to begin treatment. During this time, program nurses helped facilitate access to treatment and provided support through regular contact. Martin completed treatment and feels better but is still Hepatitis C positive. He is hopeful that as new therapies emerge he can attempt treatment again. Now he works to help others overcome their addictions. He wonders how Hepatitis C will impact him over time, for example, how he will incorporate it into future relationships, and appreciates the ongoing support of the program.

Client Portrait 4: Irene

Irene was diagnosed in the 1980s and received little information about Hepatitis C (it was then called "non A/non B" hepatitis) except to avoid blood-to-blood contact. She continued a lifestyle that included heavy drinking and also developed physical disabilities. When she was referred to the program, Irene was diagnosed with decompensated liver disease and placed on the transplant list. Soon afterward, she attempted suicide. She reflected on how the program nurses provided ongoing care management to ease the overwhelming effects of this stage of the disease as well as counselling to maintain quality of life and to assist her family to provide her with support.

Clients articulated their need for a combination of knowledge, competency and caring from their providers--people who acknowledge them as individuals. They noted the "exemplary" team expertise of program clinic staff. One person commented that to make this [treatment] work required "a plan, support and personal perseverance." Accurate, up-to-date information provided by program staff was helpful to clients struggling to make self-care decisions. "They answer any questions, even the littlest thing." Other components of information delivery identified were sensitivity and timing. Information translation was crucial to help them understand and make better self-care decisions. "This was the first time anyone spent the time to explain my test results. Had it not been for the nurses coming with me to the internist and answering my questions and explaining everything, I don't know what I would have done."

The team approach was a significant part of the program service, for example one person said, "If the clinic was just doctor-based—here's your drugs, come back for blood work—I'd have never done it." The care and support of the whole team was responsible for his completion of treatment. Clients said the team approach helped keep their family doctors well-informed. Many clients contrasted the care that they received at the program clinics to their experiences with care elsewhere.

Clinic nurses provided additional support by calling clients to check on how they were doing. A participant liked it that, "they know who I am, what I'm on" and that nurses would make a phone call to report on blood test results. Sometimes, nurses would call in the evening outside of clinic hours. One client emphasized that support from clinic nurses was most crucial in the initial stages of treatment. Clients also appreciated that support extended to families and caregivers helped them deal with symptoms and side-effects. The wife of one client stated that the support and information she received about her husband's mood swings was a critical component of her ability to cope.

Clients valued clinic staff facilitating access to other service providers. The program staff also provided information to the clients on related services. Services included Alcoholics Anonymous and Narcotics Anonymous, as well as Hep C support groups. Support groups were a source of strength for some while others felt that there was a need for more peer support. Some clients wanted a train-the-trainer advocacy program that would build local capacity. Other supportive services included pharmacists, the library and the internet.

Clients used complementary and alternative medicine as an integral part of their self-care. Therapies included Tai Chi, Reiki and meditation, as well as Traditional Chinese medicine to deal with symptoms. Many clients used nutritional supplements, altered their diet, and incorporated exercise into their daily routine.

PARTNER PERSPECTIVES ON RESULTS AND FUTURE DIRECTIONS

Collaborative planning has produced a network of partners and diverse stakeholders who have realized synergies related to their common focus. Examples of emerging partnerships include physicians associated with the program clinics, specialized clinic staff and generalist public health nurses, public health managers who support the program, support services and educators such as social workers, community volunteers and AIDS service organizations. BC Hepatitis Services has supported this collaborative process and built infrastructure according to the input received.

Interdisciplinary workshops that integrate education across all sectors of health and social services encouraged collaborative teamwork and supported the development of integrated services. Access to education was an issue for some health and social service professionals because of travel constraints. In response, BC Hepatitis Services videotaped a 3-day hepatitis prevention and care workshop and distributed a set of videos to each project.

These projects demonstrate the value of integrating prevention and care services within a public health framework. Champions in public health field, specifically managers and medical health officers, navigated organization barriers to form integrated prevention and care projects. However, HCV prevention remains a challenge because there is no vaccine, the populations affected are diverse, often stigmatized, and hard to reach. *The clinical assessment, support and monitoring components of the projects serve as an important gateway to reaching these populations*. Clients wanted to receive services in a setting that preserved confidentiality and precluded stigmatizing them. The name and location of clinics within a public health or hospital setting allowed clients to access services and remain anonymous. Project teams demonstrated that hepatitis C clinics provide 'positive prevention' of an important communicable disease. Providing clinical services is an accepted part of public health practice for other communicable diseases but sometimes controversial for hepatitis as evidenced by the requests in some sites for clarification of the fit within the public health mandate.

An important lesson from the projects is that relatively few of the clients who were assessed were eligible or were ready to initiate treatment; the majority of clients were educated about hepatitis and its mode of transmission, counselled for lifestyle and chronic illness issues, and referred to alternate services. In addition, much of the teaching focused on families—it was common to observe partners and other family members participating in educational sessions. *By concentrating efforts on positive prevention, clients and their families took on expanded roles as peer educators in the community*. Peer educators were critical for capacity building, for example, every educated client and family member was important locally for harm reduction and accurate information dissemination. These prevention efforts ultimately increased the reach of public health.

Table 1 summarizes the composite achievements and future directions from the perspectives of physicians, project nurses and PHNs, managers, agency partners, and educators and community developers.

Table 1. Summary of Lessons Learned from the Integrated Prevention and Care Projects

Achievements	Future Directions
Physicians ▪ Developed physician and nurse hepatitis expertise ▪ Capacity to manage complex illness & lifestyle issues through nursing consultation, follow-up & support. Results include: o Clients make significant positive lifestyle changes, esp. during treatment o Reduced wait times to see a specialist o Fewer specialist visits required (reduced from 5 to 2 visits due to integrated services)	▪ Expansion of program to other areas with limited number of physicians ▪ Build capacity to manage co-infected locally
Project Nurses and PHNs ▪ Project nurses as resources for other PHNs: o Streamline education process o Review and revise education/ information materials o Educate others (e.g., PHNs from STD clinic who follow newly diagnosed HCV positive clients and street nurses) ▪ Model of client partnership and delivery of integrated care increases nurse job satisfaction ▪ Client pre-treatment education done in groups which builds peer support ▪ Positive change in community and client attitudes ▪ Improved communication/synergies between sectors and divisions that facilitated when nurses have dual roles (public and clinic) or part time work in other agencies	▪ Include project nurses in blood-borne/communicable disease planning ▪ Expand capacity by training other nurses in HCV & building skills to deal with vulnerable populations ▪ Develop measures to estimate cost savings from prevention activities ▪ Expand program reach ▪ Clerical support is critical to integrated teams; where possible reporting relationship should be to the project.

Achievements	Future Directions
Managers ▪ Significant change in hepatitis management overall o Education of health professionals o Positive community response o Increased efforts to educate the community o Reduction of stigma ▪ Time spent in comprehensive nurse assessments (1-2 hours per client) results in client benefits ▪ Program nurses have become effective leaders	▪ Strategic planning for a comprehensive blood-borne disease strategy that includes hepatitis ▪ Evaluate the effects of integration with other service providers and community partners
Agency Partners ▪ Integrating support services increases advocacy: o Ancillary services such as accompanying clients to health services and appointments (e.g. ER visit) helps them communicate complex health status, obtain respectful care, manage medications o Linking them through referrals to other resources and services ▪ Screening by project staff identifies appropriate referrals ▪ One-on-one counselling is now available ▪ Clients are addressing addictions issues before initiating therapy which results in significant and immediate health benefits	▪ Designate office space within the clinic for support service partners ▪ Increased counselling resources to meet the needs of street-involved clients ▪ Alternatives to one-on-one counselling such as support groups with options for evening meetings
Educators and Community Developers ▪ Providing education in correctional facilities by promoting session as prevention of infection ▪ Integration with partners stimulated HCV education in schools ▪ Volunteers provide education in tattoo parlors and hairdressing schools ▪ Liaison with First Nation nurses increases education reach	▪ Work effectively with corrections staff to integrate prevention education efforts in facilities ▪ Funding for professional development ▪ Increase education in regular schools and parent advisory committees ▪ HCV needs to be incorporated in university level curriculum ▪ Increased education about HCV chronicity of disease and the role of treatment and self-care

SUMMARY AND RECOMMENDATIONS

The projects demonstrated the ability of public health to effectively reach out with minimal financial incentives to improve the health status of hepatitis-affected populations. Beginning with a strong history of prevention and community development, the project sites built capacity to improve the quality of life for those affected by hepatitis C. The program focus has shifted from building capacity for treatment to include chronic illness prevention and self-care management, thus integrating the strengths of both the public health and care systems.

The highlights of accomplishments include:

- A hepatitis prevention education curriculum for at-risk youth developed, approved and tested in the Vancouver School District
- Steering committees of diverse hepatitis stakeholders came together to guide planning and share information
- Sharing of resources across sectors did not require funding a separate infrastructure
- Integrated programs formed with Public Health leadership
- Hepatitis project nurses played a key role in coordinating services and fostering integration
- Integration of prevention, community development, education and support as well as clinical services; this was well-received by clients
- Referrals to each project averaged 220 clients/year; clients were assessed by nurses in specialized roles; teams worked collaboratively with clients
- Majority of clients received support for chronic illness and self care management
- 25 clients undergo treatment/year/site; 50% of clients achieve sustained viral response i.e. cure
- Wait times for assessment have been reduced to one month
- Hepatitis education sessions provided to over 1000 health and social service professionals
- Addictions, mental health and nutrition services incorporated into many projects
- Consistent team support empowered clients to make lifestyle-change and treatment decisions
- Clients connected with health and social service supports in a timely manner
- Expanded capacity for education, health promotion, treatment and support
- The complexity of living with chronic hepatitis and the compounding effects from stigma revealed
- Protocols and care pathways developed and tailored to reflect the needs of the local clientele
- An evaluative framework developed to track clinical measurements and outcomes

Site-specific contributions include:

- Education module for at-risk youth developed in Vancouver
- Dedicated resources to focus on health promotion in Kamloops
- Hospital, public health and mental health/addictions partnership in Campbell River
- Specialized hepatitis care and addictions services provided by a family physician in Prince George
- Surrey provided education and support for clients receiving treatment elsewhere

RECOMMENDATIONS

1. Continue to fund projects and expand their capacity throughout the region
2. Explore synergies with developing regional chronic and primary care programs
3. Increase the scope and capacity of client support services
4. Expand capability of hepatitis databases to evaluate clinical and prevention outcomes while protecting client privacy and confidentiality
5. Develop strategies to locate and reach populations with hepatitis including corrections, aboriginals, immigrants, and rural and remote areas, who do not access testing, education or treatment
6. Expand services and partnerships to other communities and agencies through integration
7. Develop new modalities of information-sharing and communication such as web connectivity and peer conferencing
8. Clarify the distinctions between generalist, specialist and/or advanced practice nursing roles and identify their education and support needs
9. Review the role and impact of advisory and steering committees
10. Develop outcome measures for client satisfaction
11. Evaluate the degree and effectiveness of integration and its impact
12. Focus on strategies for hepatitis B prevention in Vancouver Coastal Health Authority
13. Identify and implement strategies to reduce stigma
14. Initiate research strategies related to the hepatitis nursing role

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