

**VANCOUVER/RICHMOND HEALTH BOARD**

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**A HEPATITIS STRATEGY FOR BRITISH COLUMBIA**

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## **A. EXECUTIVE SUMMARY AND RECOMMENDATIONS**

Emerging knowledge suggests that much of the burden of human liver disease is due to viruses that are transmissible from person to person, are potentially preventable with known public health measures, and now may be curable or treatable with appropriate drug therapy. A number of different viruses cause liver inflammation or hepatitis. The viruses differ in how they are transmitted, how long after infection they take to cause inflammation and the type of illness they produce. For example, some viruses (such as hepatitis A and E) only cause acute self-limited infections, whereas hepatitis B and C virus cause both acute and chronic liver disease. Chronic hepatitis B and C virus infections are particularly important because 20-30% of chronically infected individuals will develop liver failure over 10-30 years, be at risk for liver cancer, or require liver transplantation. Vaccines are available to prevent hepatitis A and B, but there are none currently available to prevent hepatitis C virus infection. Hepatitis C infection can only be prevented by reducing the risk factors associated with transmission. However, chronic hepatitis B and C infections can be treated and sometimes even cured (hepatitis C) with appropriate anti-viral drug therapy.

Chronic hepatitis is an important problem in British Columbia because the province has hepatitis B and C infection rates that are approximately four times the national average. This is due in part to the large number of substance abusers in the province and the recent large influx of immigrants from hepatitis-endemic regions of the world. It is estimated that British Columbia already has approximately 40,000 individuals chronically infected with hepatitis B, and another 40,000 individuals who are chronically infected with the hepatitis C virus. For these individuals, there are now new, effective, but expensive drugs that can improve outcomes and potentially cure hepatitis C. Because of the cost and potential side-effects of drug therapy, there is a critical need to provide cost-effective therapeutic care. An equally important issue is prevention of new cases of hepatitis B and C infection, which will save very significant costs in the future. To do this properly requires enhanced surveillance systems that allow targeting of prevention interventions to those at risk.

The challenge is to correctly balance the needs of individuals and the population with prevention and care management strategies. This is particularly difficult because of the current fragmentation of hepatitis care services in B.C. There are no less than fifteen different organizations in the province providing various components of surveillance, prevention, screening, diagnosis, treatment, follow-up, and support. Each organization has its own policies and databases. Fragmentation in services results in unnecessary duplication of services and, as a result, wastes resources that could be applied to improve prevention and care.

Moreover, because these organizations do not effectively exchange information with each other, the ability to collate accurate and comprehensive data is limited. Planning appropriate prevention strategies and policies is extremely difficult without being able to define the true number of acute cases, their geographic distribution, and how individuals became infected. Similarly, planning appropriate care management strategies requires assessment of the effectiveness of drug therapies and other interventions, the ability to measure outcomes directly or by using surrogate markers, and mechanisms to alter practice based on new knowledge. To improve the care of chronic hepatitis, the public, providers

and policy makers must have reliable information and education to make informed decisions.

**This document outlines the need for a coherent, province-wide strategy for British Columbia that balances both individual and population-based care. It proposes to support and streamline a continuum of care for chronic viral hepatitis, linking and building on the strengths of existing public health and partner organizations.**

## **The Compelling Case for a Hepatitis Strategy**

**This is a woman's story of her struggle with hepatitis C virus, outlining issues of gender insensitivity, lack of access, poor provider education, government unresponsiveness, personal pain and cost, and the overwhelming nature of her disease.**

“My diagnosis of chronic active Hepatitis C in April 1997 ended more than ten years of worry and uncertainty, only to be replaced by more of the same.

My physician's response to my early complaints of pain, arthritis-like symptoms, and extreme fatigue was to make comments about getting older, empty nest syndrome, and possible problems at home. I wondered if he would have made the same comments if I were a man...

Finally, in 1993, I had a full regime of testing done in the US because I felt so lousy. Even then, after making my primary physician in British Columbia aware of the test results, I received no response to my low white blood cell count and albumin and my elevated liver enzymes. My 1997 diagnosis and liver biopsy confirmed the state of liver deterioration, but it was months before the government supported my specialist's recommended treatment of Interferon.

For a year, I injected myself three times a week, endured the side effects, and struggled to cover my expenses of \$2,647 – an amount I could ill afford, and for which there seems no hope of reimbursement.

Six months later another biopsy showed some improvement in the state of my liver, but... will it last? Will I have any significant remission of my liver's damage? No one can, or has been willing to, answer these questions for me; and I am not alone.”

**Similar stories outlining the fragmentation in our healthcare system can be heard from healthcare providers, public health nurses, physicians, laboratory staff, researchers, educators, health authority CEO's, board members, and Ministry of Health representatives.**

## **What Is the Compelling Case for Setting Up an Integrated Hepatitis Program?**

**British Columbia has rates of hepatitis B and C infection that are approximately four times the national average.**

- There are 1,000-1,600 individuals in BC who may have contracted hepatitis C virus from the blood system. These individuals are part of approximately 1% (40,000) of BC residents who are hepatitis C virus-infected. In addition, 1% (40,000) of BC residents are actively infected with hepatitis B virus. Most of them have emigrated from Asia and other regions where hepatitis B is endemic.
- Without therapy, 20-30% of individuals with chronic hepatitis will die from liver failure and/or hepatocellular carcinoma over the next 10-30 years, or may require liver transplantation.

**The population of BC continues to be at increased risk of hepatitis, partly because of the province's large number of substance abusers and immigrants from hepatitis-endemic regions.**

- Over the last 5 years, approximately 400,000 individuals have emigrated from hepatitis-endemic regions.
- Approximately 5,000 people in the Downtown East Side of Vancouver have a variety of bloodborne and other communicable diseases such as HIV; hepatitis A, B, and C; tuberculosis; and syphilis.
- At least 50% or more of residents of correctional facilities are either infected with hepatitis C or have a history of injection drug use.

**The cost of chronic hepatitis care is rising.**

- It is estimated that BC currently spends \$200 million per year for diagnostic services, prevention, and treatment of individuals with chronic viral hepatitis.
- It is estimated that 100 BC residents die of hepatitis every year, with end-of-life costs of \$10 million per year.
- New, expensive, and effective therapies which can cost \$10,000 - \$20,000 per treated person per year are now a reality.
- New anti-viral therapies (Interferon/Ribavirin) are now indicated for use in approximately 20% of hepatitis C virus infected individuals. Thus, 4,000-8,000 British Columbians might benefit from therapy, of which 40% of treated individuals may be cured of their infection and require no further therapy (i.e., approximately 8% of all infected individuals). Similarly, anti-viral therapies (Lamivudine) are now indicated for use in approximately 10% of hepatitis B carriers. Approximately 4,000 British Columbians with hepatitis B might benefit from anti-viral treatment, with up to 15-30% of treated individuals responding to therapy after 1-2 years.

**Fragmentation in service delivery results in sub-optimal prevention and care; this limits our ability to assess outcomes, making cost control and appropriate resource allocation difficult.**

- More than fifteen different organizations in the province currently provide services for persons with hepatitis. Processes are inefficient, and prevention and surveillance are currently fragmented. This results in duplication of services, sub-optimal surveillance, and a limited ability to distinguish between new cases and chronic cases.
- Process improvements to permit outcome assessment and cost control are required to optimize prevention and care.

**There are many leaders, but there is a lack of coordinated authority to correct current processes; hence, costs will continue to rise.**

- There are no accepted and comprehensive guidelines to provide a standardized and consistent approach to the management of hepatitis in BC.
- There is no integrated governance structure to ensure accountability and performance management. The lack of coordination among the “silos” inhibits effective decision-making, evaluation, and change.

**The process of obtaining reliable information for prevention and care of chronic hepatitis is daunting.**

- Obtaining accurate, reliable and up-to-date information on what it means to be infected with chronic hepatitis and how to protect one’s family and friends is like traveling through a maze.
  - Accurate, multilingual, and culturally adapted information is not readily available.
  - Practitioners in remote areas may not have ready access to current treatment and teaching materials for their patients.
  - Patients find it difficult to connect with healthcare providers who understand hepatitis prevention and care, know which tests to use to find out what is wrong, can supply accurate information on treatment options, and know how to monitor therapy.
  - Administration of the current effective combination anti-viral therapy for hepatitis C virus (Interferon/Ribavirin) requires prolonged counseling and careful follow-up to increase adherence to the treatment and maximize the cure rate. These activities are currently not paid for by the Medical Services Plan, and thus additional resources (e.g., nurses and nurse practitioners) will be required to support providers in delivering these types of complex therapeutic regimens.
- Educational, social, and financial needs of individuals and their families are rarely considered. Neither are gender specific needs.
  - When the disease leads to unemployment, difficulties arise in receiving financial support. Conversely, poor and marginalized populations are at risk for substance abuse and diseases.
  - Age-related factors may be very important for therapeutic outcomes.

- The care of infected children is complicated by their growth and development. Family and social supports for children are not consistent: Who makes decisions for a child who requires expensive therapy that his or her family cannot afford?
- If an infected child goes to daycare, public health staff need to ensure that the other children are safe.
- Access to drug therapies are not universally available due to their high cost, and the introduction of new therapies needs to occur in a relevant time frame.

## **What is the vision?**

**To contribute to the improved health of British Columbians by effective and efficient management of chronic viral hepatitis through the continuum of care encompassing surveillance, prevention, screening, diagnosis, treatment, follow-up, and support.**

**Decisions and activities will be cost-effective and evidence-based, and will lead to improved outcomes for population and individual health.**

## **What is the corrective action required?**

Corrective action is required in order to achieve the vision. The strategies need to address all of the components involved in the continuum of care.

### **Surveillance/Prevention**

- Institute an expanded immunization program for hepatitis B, to include neonates and children. Aboriginals, Asian immigrants, prisoners, health care practitioners, and others at risk should also receive hepatitis B and A immunization, as appropriate.
- Support the developing Vancouver Downtown East Side Epidemic Strategy and those strategies in other health regions targeting intravenous drug users (IDUs), which include a harm reduction program – needle exchange, social support, and identifying the social determinants that lead to addiction.
- Establish a data repository of laboratory test results to minimize duplication and enable accurate assessments of acute vs. chronic cases of hepatitis.
- Enhance communicable disease reporting and follow-up.

### **Care Management**

- Implement client or patient-focused care management guidelines for hepatitis C, and develop guidelines for hepatitis B. These guidelines are meant to provide direction and information for health care professionals. They will include standardized methods to define eligibility for therapy, appropriate laboratory testing, follow-up, and outcome assessment. Supporting resources will be suggested as appropriate.
- Implement new drug therapies for hepatitis C and enhance the availability of supporting molecular laboratory tests. Streamline the process for drug approval.

- Establish a comprehensive care management database.
- Establish an interdisciplinary care management model for patients with chronic hepatitis with satellite sites throughout the province.

### **Education and Support**

- Coordinate and enhance education and support for providers, including public health nurses.
- Coordinate and enhance community group activities for patients/clients, their families, their communities, and high-risk groups in the areas of education and support.
- Coordinate the response from the Ministries of Health, Child and Family, and Human Resources, as well as the Medical Services Plan and Pharmacare, to meet the needs of infected patients.

Corrective action means ensuring effective surveillance, prevention, care management, education, and support independent of geographical location. It means ensuring that accurate, multilingual, and culturally adapted information is available. To achieve this, government ministries must work together cooperatively to promote a coordinated interministerial response to patients'/clients' needs by ensuring the availability of resources throughout the province to implement the strategies.

Corrective action also requires the development of long-term research and evaluation plans and the organization of an infrastructure that is based on coordinated information management, complementary partnerships, and systems for performance management.

### **How should the integrated hepatitis program be organized?**

An infrastructure to direct and support the partner organizations and stakeholders should be based on the ability to:

- Ensure that people who require treatment are having their needs met.
- Work with a diverse group of stakeholders – clinicians, patients/clients, the public, associations, government and health authorities, and the private sector.
- Be inclusive and respect stakeholder contribution.
- Be a decision-maker, arbitrator, advocate.
- Be able to effect and coordinate multi-organizational change while allowing independence.
- Be accountable to a regional health authority to fulfill a performance contract
- Be able to ensure data stewardship.

The infrastructure needs to be supported by human and material resources – a director, consultants, secretarial support, office supplies, meeting rooms, travel, and education.

## **What is the proposed timeline to implement the strategy?**

An urgent timeline is required to:

- Meet the care needs of individuals infected by contaminated blood products, as well as the needs of other chronically infected persons
- Curtail the communicable disease epidemic
- Promote access to services regardless of geographical location
- Decrease the costs of duplication and improve processes

## **What does this proposal recommend?**

In year one:

- Institute expanded hepatitis B and A immunization programs.
- Support the developing proposal for the Vancouver Downtown East Side Epidemic Strategy, as well as any other health authorities' plans for their high-risk populations.
- Develop and implement provincial guideline-driven care and prevention programs through an interdisciplinary care management model. Ensure that both adults' and children's needs are met through the application of best practice standards.
- Implement new drug therapies with corresponding molecular laboratory testing.
- Support information management improvements based on data integration: i.e., developing laboratory test result repository and care management databases to streamline processes, decrease duplication and collect outcome information.
- Develop and implement multilingual, culturally adapted education and support programs targeting patients/clients, the community, people at risk, and providers.
- Identify research and evaluation priorities.
- Establish a Secretariat at the B.C. Centre for Disease Control to direct and support partnerships and stakeholders.

In year two:

- Continue with information management and process improvement strategies.
- Implement enhanced communicable disease reporting.
- Continue hepatitis B immunization program.
- Evaluate education and support activities. Refine or expand them if necessary.
- Implement research and evaluation priorities.
- Review performance management processes.

## What are the resources required?

The budget development for the described Hepatitis Strategy for BC has considered existing resources in order to determine the incremental costs. The incremental costs are as follows:

### Budget Summary

	Year One	Year Two
<b>Surveillance/Prevention</b>		
Immunization of children under 12 yrs – catch-up and infant program	\$ 5,000,000	\$ 5,000,000
Enhanced immunization for hep B in persons at risk	500,000	500,000
Enhanced immunization for hep A in persons at risk	2,300,000	2,300,000
Repository of Lab Test Results	288,000	93,000
Enhanced Communicable Disease Reporting	-----	62,800
<b>Care Management</b>		
Guidelines	25,000	
Drugs and Lab Testing	20,500,000	20,500,000
Care Management Database	194,000	165,000
Interdisciplinary Care Management Model	486,000	631,000
<b>Education and Support</b>	100,000	100,000
<b>Infrastructure</b>		
Information Systems Staffing	187,000	187,000
Secretariat/Coordinating Infrastructure	340,000	340,000
<b><u>Total</u></b>	<b><u>\$ 29,920,000</u></b>	<b><u>\$ 29,878,800</u></b>

The year one activities would start on receipt of approval and funding of the strategies.

## **B. INTRODUCTION**

The high prevalence of chronic viral hepatitis, the complexity and cost of treatment, and the disease's toll on individuals and their families argue for a coordinated, province-wide approach to hepatitis management.

- **BC has the highest reported rates of hepatitis B and C in Canada** – four times the national average.
- **An estimated 80,000 British Columbians are infected** with hepatitis B and C, based on a conservative estimate of 1% prevalence. Over half of hepatitis C cases report a history of injection drug use, while an estimated 1,000 to 1,600 individuals were infected through blood transfusion.
- **Spread of the disease is preventable, yet escalating** because many individuals are unknowingly infected. For example, about 400,000 residents have immigrated from countries where hepatitis B is endemic, and preventable hepatitis transmission and serious illness is likely occurring among these new Canadians.
- **There are inadequate public health resources to investigate and follow up new cases and to prevent further spread** amongst family members and high-risk populations. Individuals infected with hepatitis C are eligible for funded hepatitis A and B vaccination (current expenditures are about \$1.8 million), but high-risk populations such as correctional facilities (with infection or injection drug history rates as high as 50%) have no resources to provide such preventive services.
- **Current surveillance mechanisms are inadequate** to forecast and plan services for prevention and care. Data are not available to determine prevalence vs. incidence, acute vs. chronic infection, or even what portion of the population has been tested (negative or positive).
- **Hepatitis care is fragmented, inconsistent, and not equitably available.** Stakeholders have described problems with accessing appropriate and consistent assessment, education, and treatment.
- **There are few specialists trained in hepatitis care**, and a lack of up-to-date guidelines and information about hepatitis management for providers, infected individuals, and the public.
- **The long-term health, human, and economic costs are high and growing.** About 25% of hepatitis C patients will develop cirrhosis and/or liver cancer. Hepatitis C is the most common indication for liver transplantation, which costs about \$100,000 per patient in the first year. The estimated medical cost of death from liver failure is at least \$50,000. The medical cost from the time of diagnosis to death, including the economic loss for that individual, is estimated at \$1 million per patient.

- BC already spends approximately \$6,000,000 per year just for hepatitis diagnostic tests (\$1,950,000 at the Provincial Laboratory at the BCCDC, \$2,300,000 for private laboratory billings to the Medical Services Plan, and approximately \$500,000 for hepatitis testing of pregnant females performed by the Vancouver Centre of the Canadian Blood Services and another \$500,000 through hospital based hepatitis testing).
- **Demand for expensive pharmacotherapy is growing, yet the cost-benefits of existing and upcoming therapies are unknown.** While currently only about 20% of hepatitis C patients are eligible for Interferon/Ribavirin treatment, there will likely be new treatments for the other 80% of patients, and these new treatments will likely be expensive.
- **Resources are being wasted through redundant, inefficient processes.** Disparate, incompatible information systems result in a need for duplicate laboratory testing, expensive reporting mechanisms, and redundant data entry that contributes to errors and data loss. Fragmented care management wastes resources and thwarts efforts to provide quality care.
- **There is no integrated infrastructure to ensure accountability and performance management.** The lack of coordination among the “silos” inhibits effective decision-making, evaluation, and change.
- **There are no accepted, comprehensive guidelines** to provide a standardized and consistent approach to the management of hepatitis in BC.
- **There are no information systems** to link, integrate, and provide the knowledge to evaluate the effectiveness of tests and treatment.

## **C. VISION, GUIDING PRINCIPLES, GOALS & OBJECTIVES**

### **Vision**

**To contribute to the improved health of British Columbians by effective and efficient management of chronic viral hepatitis through the continuum of care encompassing surveillance, prevention, screening, diagnosis, treatment, follow-up, and support.**

**Decisions and activities will be cost-effective and evidence-based, and will lead to improved outcomes for population and individual health.**

## Guiding Principles

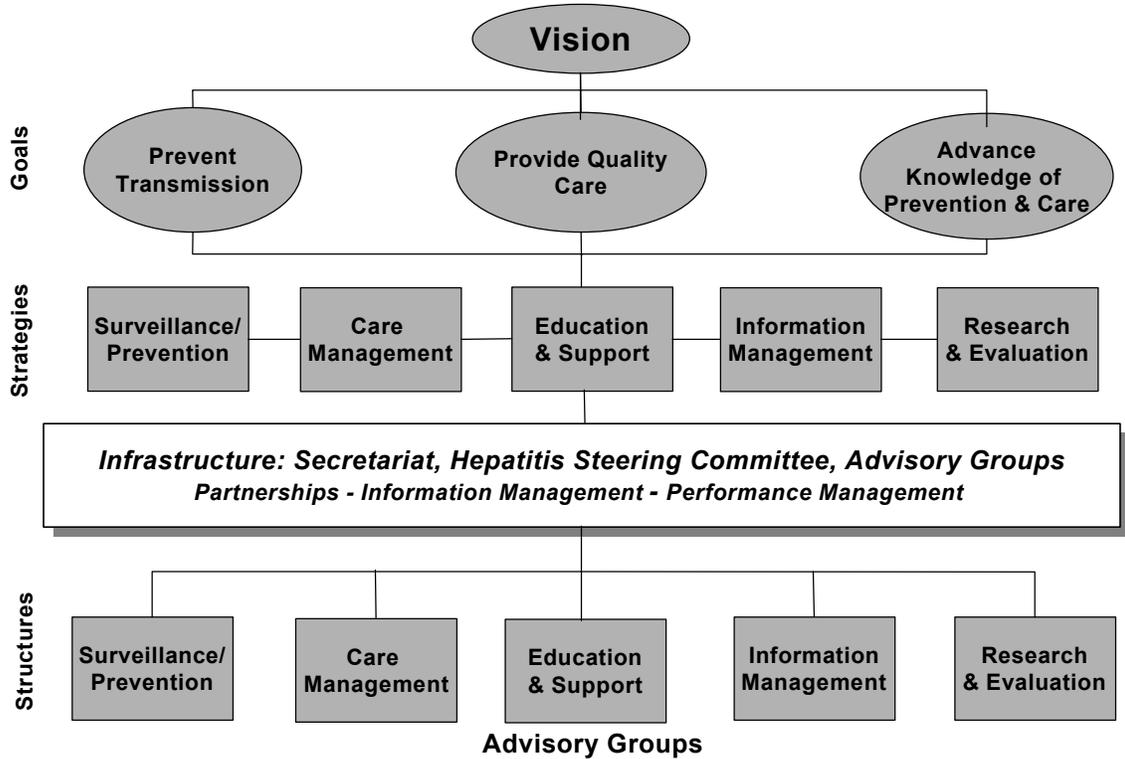
The Hepatitis Strategy will facilitate and be consistent with:

- A patient/client focus
  - A continuum of care from prevention to follow-up and support
  - Accessibility and respect for diversity
  - Continuous improvement
  - Maximizing existing resources and expertise
  - Evidence-based decision-making
  - Education and research
- Accountability and performance management

## Goals and Objectives

Goal	Objectives
A. Reduce the transmission of hepatitis through:	<ul style="list-style-type: none"> <li>• Universal vaccination for hepatitis A and B of eligible individuals and high-risk populations</li> <li>• Support of initiatives to target high-risk populations (e.g., Vancouver’s Downtown East Side and other regional health authorities’ initiatives)</li> <li>• Support of information management improvements based on data integration: i.e., developing laboratory test repository and care management databases to streamline processes, decrease duplication, and collect outcome information.</li> <li>• Developing and implementing multilingual, culturally adapted education and support programs that target patients/clients, the community, people at risk, and providers.</li> <li>• Implementing enhanced communicable disease reporting.</li> </ul>
B. Develop and implement provincial guideline-driven care and prevention programs through an interdisciplinary care management model that is inclusive of providers in the province. Ensure that both adults’ and children’s needs are met through the application of best practice standards.	<ul style="list-style-type: none"> <li>• Implement new drug therapies with corresponding molecular laboratory testing.</li> <li>• Establish an infrastructure to direct and support partnerships and stakeholders.</li> <li>• Review performance management processes.</li> <li>• Gain support for the use of guideline-driven care and prevention programs.</li> <li>• Identify a mechanism for the development of education and support programs.</li> </ul>
C. Develop a consortium of partners interested in basic, translational, epidemiological, and clinical research.	<ul style="list-style-type: none"> <li>• Identify research and evaluation priorities, identifying process improvement strategies.</li> </ul>

## A Hepatitis Strategy for BC



The goals will be achieved through five interrelated strategies:

- **Surveillance/Prevention** – to reduce the transmission of hepatitis and to provide data to support forecasting and planning services for both prevention and care.
- **Care Management** – standardized and evidence-based development of guidelines for prevention and management of chronic viral hepatitis.
- **Education and Support** – a variety of educational approaches for providers, individuals, and high-risk populations, through coordination and enhanced funding to support and build upon the existing expertise and activities of participating organizations and community groups.
- **Information Management** – There must be a commitment to shared data and systems development to improve coordination, access to information for decision-making and accountability, and resource utilization.
- **Research and Evaluation** – collaborative research and evaluation activities to support and advance the knowledge of hepatitis prevention and care.

An infrastructure of a Secretariat, Steering Committee, and Advisory Groups will provide the foundation for achieving the strategies. Performance management, including partnerships and information management, will be the bond that supports the infrastructure.

## E. INFRASTRUCTURE

### General Roles and Responsibilities

Role	Ministry of Health	Vancouver/Richmond Health Board	BC Centre for Disease Control	Regional Health Authorities
Program Planning	<ul style="list-style-type: none"> <li>• Defines hepatitis strategy and its strategic direction within its mandate for the management of communicable disease in the province.</li> <li>• Establishes expectations and standards to be met.</li> <li>• Defines the organizational model.</li> </ul>	<ul style="list-style-type: none"> <li>• Provides proposal on hepatitis strategy, identifying priority services.</li> <li>• Consults with and includes input from stakeholders.</li> </ul>	<ul style="list-style-type: none"> <li>• Provides input into proposal, recognizing provincial role for surveillance and prevention.</li> </ul>	<ul style="list-style-type: none"> <li>• Provides provincial perspective for hepatitis strategy.</li> <li>• Provides feedback to V/RHB.</li> </ul>
Evaluation	<ul style="list-style-type: none"> <li>• Develops accountability framework.</li> <li>• Monitors strategy based on performance indicators established in performance contracts.</li> </ul>	<ul style="list-style-type: none"> <li>• Monitors and evaluates performance of strategy.</li> <li>• Reports to Ministry of Health.</li> </ul>	<ul style="list-style-type: none"> <li>• Monitors and evaluates performance of strategy based on performance management program.</li> <li>• Reports to V/RHB.</li> </ul>	<ul style="list-style-type: none"> <li>• Monitors and evaluates performance of strategy.</li> </ul>
Funding	<ul style="list-style-type: none"> <li>• Identifies performance indicators and associated targets related to established funding levels.</li> <li>• Provides funding levels.</li> <li>• Reviews outstanding funding issues related to inter-regional or inter-ministerial services.</li> </ul>	<ul style="list-style-type: none"> <li>• Allocates funding.</li> </ul>	<ul style="list-style-type: none"> <li>• Monitors budget allocation.</li> <li>• Reviews costs associated with hepatitis strategy and makes recommendations to V/RHB.                             <ul style="list-style-type: none"> <li>– Reviews outstanding funding issues with providers.</li> <li>– Ensures funding is in place to support programs.</li> </ul> </li> <li>• Reports to V/RHB.</li> </ul>	<ul style="list-style-type: none"> <li>• Ensures funding is in place to support hepatitis strategy.</li> <li>• Reports issues to BCCDC.</li> </ul>
Performance	<ul style="list-style-type: none"> <li>• Ensures services provided are consistent with M of H strategic directions.</li> <li>• Ensures issues addressed and resolved in inter-regional or inter-ministerial disputes.</li> <li>• Where required, facilitates resolution of disputes.</li> <li>• Establishes performance contracts with provider health authorities.</li> </ul>	<ul style="list-style-type: none"> <li>• Establishes performance contracts with service providers within V/RHB.</li> </ul>	<ul style="list-style-type: none"> <li>• Monitors service delivery through performance management program and through steering and advisory committees, and reports to V/RHB.</li> </ul>	<ul style="list-style-type: none"> <li>• Meets health needs of the local population regarding chronic viral hepatitis.</li> <li>• Provides reports to BCCDC on the outcome of the hepatitis strategy.</li> <li>• Participates in steering and advisory committees of BCCDC.</li> </ul>

## **Secretariat**

The Secretariat overseeing the Hepatitis Strategy will be established at the BC Centre for Disease Control.

### **Key Secretariat roles and responsibilities will involve:**

- Ensuring that people who require treatment have their needs met.
- Working with a diverse group of stakeholders and clinicians, patients/clients, the public, associations, government and health authorities and the private sector – ensuring inclusiveness while being respectful of stakeholder contribution. Advisory groups in the areas of surveillance and prevention, care management, education and support, information management, and research and evaluation will be established.
- Being able to effect and coordinate multi-organizational change while allowing independence. It will build service capacity through enhancing the role of existing organizations, independent of physical location.
- Acting as a decision-maker, arbitrator and advocate.
- Being accountable to a regional health authority to fulfill a performance contract.
- Being able to ensure data stewardship.
- Initiating performance management processes to ensure that appropriate services are being provided and continuously improved.

The BC Centre for Disease Control, in consultation with the partners, will appoint the Director of the Hepatitis Strategy, who will oversee the activities of the Secretariat for an initial period of three years.

The Secretariat will be guided by a Hepatitis Steering Committee of broad-based stakeholders with community representatives from the province. The Hepatitis Steering Committee members will be appointed for a three-year term, with staggered appointments to ensure continuity. Membership will balance expertise and stakeholder representation and will include the chairs or designate representatives from each of the five Advisory Groups. The BCCDC Board of Directors, in consultation with the partners, will make the initial appointments.

Key Steering Committee responsibilities include the monitoring of the performance management of the Hepatitis Strategy implementation.

The chairs or designates of the Advisory Groups will be selected by partnership organizations for a three-year term, with staggered appointments to ensure continuity. Membership will balance expertise and stakeholder representation from the province.

Key advisory responsibilities include designing, planning, and evaluating strategies, based on state-of-the-art information.

## Partnerships

The following table lists the many key partnership organizations and their potential contributions to the success of the strategy.

Partner	Component
BC Centre for Disease Control	<ul style="list-style-type: none"> <li>• House the Secretariat, which will lead the implementation of the strategy through the stakeholders</li> <li>- Support health authorities to implement the hepatitis strategy</li> <li>- Coordinate interministerial response to meet the needs of infected patients</li> <li>- Oversee surveillance and provincial public health prevention</li> <li>- Transition the Care Management guidelines to VHHSC</li> <li>- Coordinate with UBC Diagnostic Virology Lab to provide primary molecular diagnostic services</li> </ul>
Centre for Excellence in HIV/AIDS	<ul style="list-style-type: none"> <li>• Oversee care of HIV co-infected individuals</li> <li>• Play a lead role in the Care Management database design and support</li> <li>• Participate in research activities</li> <li>• Provide molecular epidemiology support</li> </ul>
Children's & Women's Health Centre of BC	<ul style="list-style-type: none"> <li>• Contribute to the development of hepatitis care management involving children and women</li> <li>• Participate in research activities</li> <li>• Provide care for women and children with hepatitis</li> </ul>
Canadian Blood Services	<ul style="list-style-type: none"> <li>• Coordinate epidemiological activities with regard to the detection of new infections in blood donors and provincial bloodborne pathogen surveillance programs</li> <li>• Collaborate in the detection of emerging pathogens and risk assessment</li> <li>• Integrate data collection and reporting of hepatitis testing from pregnant mothers in BC and coordinate the initiation of the prophylaxis program for babies of HBV-positive mothers</li> <li>• Provide blood screening</li> <li>• Participate in research initiatives</li> </ul>
Community Groups	<ul style="list-style-type: none"> <li>• Coordinate and enhance community group activities through the Canadian Liver Foundation, Hepatitis C Society, and representatives of the Aboriginal, Asian, and former prisoner groups.</li> <li>• Provide education and support initiatives</li> <li>• Provide consumer advocacy</li> </ul>
Health Authorities	<ul style="list-style-type: none"> <li>• Public health investigation, follow-up, and support</li> <li>• Provide prevention and promotion services and care management</li> </ul>
Health Canada – Health Promotions and Programs Branch	<ul style="list-style-type: none"> <li>• Enhance the capacity of regional and local community-based organizations to provide support to those infected with and affected by hepatitis C</li> </ul>
Health Canada and the Laboratory Centre for Disease Control (LCDC), Winnipeg	<ul style="list-style-type: none"> <li>• Contribute to and benefit from coordinated surveillance programs to assist in policy planning and setting national standards of hepatitis care management</li> <li>• Participate in complementary surveillance programs</li> <li>• Participate in research activities</li> </ul>
Ministry of Health	<ul style="list-style-type: none"> <li>• Set provincial policy</li> <li>• Allocate resources</li> <li>• Facilitate integration across Ministry sectors and health authorities</li> </ul>
University of British Columbia	<ul style="list-style-type: none"> <li>• Work with other partners in the planning, development, implementation, and evaluation of research initiatives</li> </ul>

Partner	Component
Vancouver Hospital and Health Sciences Centre	<ul style="list-style-type: none"> <li>• Lead development and monitoring of hepatitis care management, including clinical guidelines and provider education</li> <li>• Coordinate provincial care management program for adults with hepatitis – link with Children’s &amp; Women’s Health Centre of BC</li> <li>• Participate in research activities</li> </ul>
Vancouver/Richmond Health Board	<ul style="list-style-type: none"> <li>• Be accountable to the Ministry of Health through performance contracts and support the activities of the Hepatitis Strategy and partner organizations</li> </ul>
Viridae	<ul style="list-style-type: none"> <li>• Private sector Clinical Research Organization with experience in trial design and outcome assessment of phase I-III trials</li> <li>• Hepatitis care and specialized laboratory service provider</li> <li>• Participate in research activities</li> </ul>

## Information Management

Information Management will provide the driver that will integrate data and allow for communication, monitoring, evaluation, and cost-effectiveness.

The information provided will be accessible and available for use by all partners.

This will be extensively reviewed in Appendix 3.

## Performance Management

The proposed chronic viral hepatitis strategy implies a performance management approach which is outlined in the following **six key elements of a performance effectiveness system**.

### 1. Community and Client/Patient Needs

This strategy is focused on the needs and expectations of the hepatitis client and on the needs of the providers in order to better manage and provide state of the art care to the client.

### 2. A Vision and Values for the Management of Hepatitis

In order to provide a direction to the management strategy, a clear vision or future goal is enunciated. This allows for the formulation of strategies and processes to most effectively plan for the achievement of desired outcomes.

### 3. Balanced Strategic Goals

Five strategies to address and to achieve the vision are described, covering the complete continuum of care for the BC client:

- Prevention and Surveillance
- Care Management
- Education and Support
- Information Management
- Research and Evaluation

### 4. Care Delivery and Service Delivery Processes

The Guidelines will provide a useful and standardized tool to inform health care providers of the state of the art tests, therapy options, and support to the hepatitis patient. They will allow for evidence-based outcomes based on performance indicators identified for tests, drug therapies, and support mechanisms.

The intent to more efficiently utilize current resources and to reinforce core competencies into an integrated and efficient system reflects a process improvement approach to the management of hepatitis.

### 5. Infrastructure and Resources to Provide Enabling Support

Key to the enablement of an effective management system for hepatitis will be well-developed and linked information systems. Current systems, gaps, requirements, and a proposed solution are discussed in Appendix 3. These are essential to the effective management of hepatitis.

Human resources are also required, and this is set out in the proposal.

### 6. Information (Knowledge) Management

The success of the hepatitis strategy will depend on good and credible data, its input, the analysis of the data, and the use to which that analysis is put. Data collection and analysis will allow for pharmacoeconomics to be linked to tests and treatment outcomes.

This information or knowledge will be available to all stakeholders. It will provide for guidelines development and updating, reduction in test redundancy, choice of therapies, and ongoing monitoring of the hepatitis client.

Cost-effectiveness analysis will depend upon credible knowledge.

## Performance Indicators

Effective management of a hepatitis care/service delivery system requires:

### 1. Design

Each of the key strategies described in the strategy will be designed and improved for more efficient delivery, utilizing the competencies and resources that currently exist in the healthcare system.

### 2. Management or Monitoring

Supported and enabled by well-integrated, linked, and accessible information systems, the following indicators, where appropriate, will provide the data necessary for evidence-based outcomes management. (This applies to the care/service delivery processes, tests, therapies, follow-up, and all elements in the continuum of care.)

Appropriateness	Was the treatment necessary and was it the right treatment? Was the test necessary and was it the right test?
Acceptability	Did the result or output meet the client's requirements/needs?
Effectiveness	Did the test/treatment/process affect the client's health status?
Accessibility	How easily can clients obtain the service, the test, the treatment, the support, the information?
Safety	Are there potential risks to clients? Are they assessed?
Efficiency	Could fewer resources have been used? Were the resources used necessary and appropriate?
Competence	Are the provider's skills and knowledge appropriate and are they regularly evaluated?

### 3. Improvement

Based upon the information derived by monitoring prevention strategies, care management strategies, education and support, and research and evaluation strategies, changes and improvements to testing, treatment, guidelines, education, etc. can be achieved.

## **F. CRITICAL SUCCESS FACTORS**

*Authority and Mandate* – The Hepatitis Strategy must receive approval and a mandate from the Ministry of Health confirming the scope, structures, and funding.

*Leadership* – The Secretariat Director must build trust, foster a shared vision, and have strong technical knowledge and credibility with all stakeholders.

*Collaboration and Partnership* – Stakeholders must work together as a network to plan, implement and evaluate the Hepatitis Strategy.

*Performance Management* – Accountability mechanisms such as regular monitoring, reporting, communications, and inclusive decision-making processes must be evident. There must be an ongoing process and strategy for the administration, development, communication and implementation of provincial management guidelines for hepatitis.

*Resources* – The Strategy must have funding to secure ongoing commitment to and participation of the partners. The Secretariat must have influence on resource allocation across participating organizations.

*Information Management* - A key element is the coordination of information management and data stewardship based on a commitment to transparency, shared data and systems development, access to information for decision-making, accountability, and resource utilization, while holding confidentiality as paramount.



<b>Strategy/Responsibility</b>	<b>Year One</b>	<b>Year Two</b>	<b>Existing Resources</b>	<b>New Resources</b>	<b>Year One</b>	<b>Year Two</b>
<b>Surveillance/Prevention – per Surveillance and Prevention Advisory Group</b>						
<b>Establish a data repository of laboratory test results to minimize duplication and enable accurate assessments of acute vs. chronic cases of hepatitis</b>  <i>Responsible Partner:</i> Secretariat	<ul style="list-style-type: none"> <li>– Link data from BCCDC, Canadian Blood Services and UBC Diagnostic Virology Lab at St. Paul’s Hospital</li> <li>– Analyze and report on hepatitis lab utilization and epidemiology</li> </ul>	<ul style="list-style-type: none"> <li>– Link private and other hospital laboratories to the hepatitis test result repository</li> <li>– Further analysis and reporting</li> </ul>	Major laboratories are at St. Paul’s Hospital, BCCDC, Canadian Blood Services, Metro McNair, and BC Bio.	See IM Overview	\$ 288,000	\$ 93,000
<b>Enhance communicable disease reporting and follow-up</b>  <i>Responsible Partner:</i> BCCDC (epidemiology)	<ul style="list-style-type: none"> <li>– Complete plan for enhancement to BCCDC’s Public Health Information System (PHIS)</li> <li>– Review public health resources for case reporting, follow-up</li> </ul>	<ul style="list-style-type: none"> <li>– Develop PHIS V4 and complete pilot in 2-3 health authorities</li> <li>– Review impact of enhanced system on public health resources and recommend on resource allocation/reallocation</li> </ul>	BCCDC	See IM Overview, adjusted to begin in year 2 instead of year 1		\$62,800

Strategy/Responsibility	Year One	Year Two	Existing Resources	New Resources	Year One	Year Two
<b>Care Management – per Care Management Advisory Group</b>						
<p><b>Implement client/patient-focused care management guidelines for hepatitis C, and develop guidelines for hepatitis B. These guidelines are meant to provide direction and information for health care professionals. They will include standardized methods to define eligibility for therapy, appropriate laboratory testing, follow-up, and outcome assessment. Supporting resources will be suggested as appropriate.</b></p> <p><i>Responsible Partners:</i> Broad partner organization representation, clinicians, community. Clinical guidelines dissemination and maintenance to become the responsibility of the VHHSC.</p>	<ul style="list-style-type: none"> <li>– VHHSC to become responsible for the development, dissemination and updating of Care Management guidelines (see Appendix 2).</li> <li>– Incorporate pharmacoeconomic analysis into guideline process.</li> </ul>	<ul style="list-style-type: none"> <li>– Evaluate guidelines and measure preliminary outcomes</li> </ul>	<ul style="list-style-type: none"> <li>– Funded as part of the hepatitis strategy development</li> </ul>	<ul style="list-style-type: none"> <li>– To complete and publish current guidelines</li> </ul>	\$25,000	

Strategy/Responsibility	Year One	Year Two	Existing Resources	New Resources	Year One	Year Two
<b>Care Management – per Care Management Advisory Group</b>						
<p><b>Implement new drug therapies for hepatitis C, develop guidelines for drug therapies for hepatitis B</b></p> <p><i>Responsible Partner:</i> Secretariat and partner organizations</p>	<ul style="list-style-type: none"> <li>– Anti-viral therapies (Interferon/Ribavirin) are now indicated for use in approximately 20% of hepatitis C virus infected individuals (It is estimated that 1% or 40,000 individuals are currently infected with hepatitis c). Thus, 4,000-8,000 British Columbians might benefit from therapy, of which 40% of treated individuals may be cured of their infection and require no further therapy (i.e., approximately 8% of all infected individuals).</li> <li>– Similarly, anti-viral therapies (Interferon or Lamivudine) may be indicated for use in approximately 10% of hepatitis B carriers. Approximately 4,000 British Columbians with hepatitis B might benefit from anti-viral treatment, with up to 15-30% of treated individuals responding to Lamivudine therapy after 1-3 years and 35% to a 16 wk course of Interferon.</li> </ul>	<ul style="list-style-type: none"> <li>– See year one</li> <li>– See year one</li> </ul>	<p>Approximately \$1,500,000 is spent on Interferon per year in BC through Pharmacare mostly for hepatitis B or C but interferon is not exclusively used for these indications. Given the new data for the enhanced efficacy of the Interferon/Ribavirin combinations individuals are now awaiting combination therapy</p>	<p>Given the current estimated cost of Interferon/Ribavirin (\$10,000-20,000) for a 24 wk and 48 wk course respectively, the percent of individuals who might require short vs. long courses of therapy which is based on genotype and/or viral load (see below). The potential for discontinuation of therapy due to adverse side effects and the fact that only 1,000-1,500 individuals per year might receive therapy the net incremental cost could be \$20,000,000/year. Cost management will be critical as new therapeutic options which are currently under evaluation become available.</p> <p>Therapeutic guidelines for hepatitis B virus are under development and will impact cost estimates.</p>	20,000,000	20,000,000
<p><b>Streamline the process for drug approval</b></p> <p><i>Responsible Partner:</i> Secretariat</p>	<ul style="list-style-type: none"> <li>– Work with Pharmacare to define process for drug approval for hepatitis</li> </ul>	<ul style="list-style-type: none"> <li>– Initiate streamlining of drug approval process</li> <li>– Identify requirements of linking Care Management Database to PharmaNet claims adjudication engine</li> </ul>	Pharmacare	See IM Overview		

Strategy/Responsibility	Year One	Year Two	Existing Resources	New Resources	Year One	Year Two
<b>Care Management – per Care Management Advisory Group</b>						
<p><b>Enhance availability of supporting molecular laboratory tests</b></p> <p><i>Responsible Partners:</i>            BCCDC (Provincial Laboratory) –            UBC Diagnostic Virology Laboratory at St. Paul’s Hospital – VHHSC</p>	<ul style="list-style-type: none"> <li>– Implement guidelines-based molecular laboratory testing for diagnosis and monitoring therapy</li> <li>– Improve laboratory test utilization</li> </ul>	<ul style="list-style-type: none"> <li>– Monitor and project lab test utilization</li> <li>– Monitor test utilization and report</li> </ul>	<p>Some molecular testing supported by pharma industry and MSP at UBC Diagnostic Virology laboratory at St. Paul’s hospital. Approximately 2,000 qualitative hepatitis C virus PCR tests are funded at Provincial laboratory (global budget) but these resources are already being used for providing diagnosis confirmations.</p>	<p>Molecular diagnostic tests are <u>critical</u> for ensuring eligibility and monitoring therapy in order to offset drugs cost! Quantitative hepatitis C PCR detection is approx. \$110/test Qualitative hepatitis C PCR is approx. \$60/test Hepatitis C genotyping is approx. \$180/test. The current proposed guideline suggests 3 qualitative and 1 quantitative hepatitis C PCR tests and one genotype test (for eligibility assessment, monitoring duration of therapy, follow-up, and outcome analysis). The cost will be approx. \$300-500 per enrolled client/patient. Therefore for 1,000 persons treated per year the expected cost will be approximately \$500,000. Enhanced diagnostic hepatitis C PCR testing at the provincial laboratory due to increased screening may be offset by streamlining all hepatitis diagnostic test algorithms. The recommended testing for individuals undergoing hepatitis B therapy may be between \$60 - \$200/enrolled person, but this awaits therapeutic guideline development.</p>	500,000	500,000

Strategy/Responsibility	Year One	Year Two	Existing Resources	New Resources	Year One	Year Two
<b>Care Management – per Care Management Advisory Group</b>						
<b>Establish Care Management Database</b>  <i>Responsible Partners:</i> <i>Centre for Excellence in HIV/AIDS</i> <i>– VHHSC – Secretariat</i>	<ul style="list-style-type: none"> <li>– VHHSC to assist Centre for Excellence in HIV/AIDS to develop a hepatitis Care Management database which is synchronized to guideline driven care and capable of generating outcome assessments</li> <li>– Pilot care management database at VHHSC, C &amp; WHC and Centre for Excellence in HIV/AIDS</li> </ul>	<ul style="list-style-type: none"> <li>– Evaluate Care Management Database</li> <li>– Extend Care Management Database to regional centres</li> </ul>	Centre for Excellence in HIV/AIDS	See IM Overview	194,000	165,000
<b>Establish an interdisciplinary care management model for patients with chronic hepatitis with satellite sites throughout the province</b>  <i>Responsible Partners: VHHSC with a link to C&amp;W – Centre for Excellence in HIV/AIDS and HIV co-infected individuals</i>	<ul style="list-style-type: none"> <li>– Establish the lead care management component at VHHSC (adults)</li> <li>– Link to Children’s &amp; Women’s Health Centre of BC (children)</li> <li>– Coordinate provincial interdisciplinary care management team (physicians, pharmacists, other providers)</li> <li>– Oversee the establishment of regional expertise in 2-3 locations throughout the province</li> <li>– Support provider consultation</li> <li>– Collaborate in education programs</li> </ul>	<ul style="list-style-type: none"> <li>– Evaluate and refine clinical services and interdisciplinary model.</li> <li>– Monitor and plan services based on current and projected referral levels and patterns</li> </ul>	MSP billings for physician services. One nurse educator at VHHSC funded through drug company.	Medical director (0.5 FTE) Admin Assistant (1.0 FTE) Telecommunications Office/clinic supplies Nurse educators throughout the province (Yr 1 – 2.0 FTE. Add 2.0 FTE in Yr 2 inc. 0.5 FTE for children) Pharmacist (0.5 FTE)  Clerical (1.0 FTE)  Travel	\$ 120,000 60,000 15,000 40,000 140,000  41,000  40,000  <u>30,000</u> <u>486,000</u>	\$ 120,000 60,000 20,000 40,000 280,000  41,000  40,000  <u>30,000</u> <u>631,000</u>

Strategy/Responsibility	Year One	Year Two	Existing Resources	New Resources	Year One	Year Two
<b>Education and Support – per Education and Support Advisory Group</b>						
<p><b>Coordinate and enhance education and support for providers including public health nurses</b></p> <p><i>Responsible Partners: VHHSC – BCCDC (epidemiology) – Centre for Excellence in HIV/AIDS – V/RHB, other Health Authorities - Community groups – Canadian Liver Foundation – Health Canada’s health promotion programs</i></p>	<ul style="list-style-type: none"> <li>– Develop and implement plan for provider and public health education and support</li> <li>– Ensure that providers in remote areas have ready access to guidelines and teaching materials</li> <li>– Implement provider education activities</li> <li>– Introduce 1-800 number for provider consultation</li> </ul>	<ul style="list-style-type: none"> <li>– Evaluate and expand Year 1 education and support activities</li> </ul>	Fragmented among partners – VHHSC, BCCDC, Centre for Excellence in HIV/AIDS	Joint funding with community groups (see below)		
<p><b>Coordinate and enhance community group activities for clients/patients, their families, their communities, and high-risk groups in the areas of education and support.</b></p> <p><i>Responsible Partners: Community groups - VHHSC – BCCDC (epidemiology) – Centre for Excellence in HIV/AIDS – V/RHB, other Health Authorities - Canadian Liver Foundation – Health Canada’s health promotion programs</i></p>	<ul style="list-style-type: none"> <li>– Fund community groups for client/patient counseling and support</li> <li>– Coordinate educational content development and ongoing link to guidelines as appropriate</li> <li>– Ensure that accurate, multilingual, and culturally adapted information is readily available</li> <li>– Introduce public website</li> <li>– Contribute guidelines and educational content to existing public communications vehicles (e.g., newsletters, websites, and Canadian Liver Foundation Helpline)</li> <li>– Use CFL 1-800 number for public access to information</li> <li>– Contribute to strategies by working with interministerial groups e.g., Ministry of Human Resources</li> </ul>	<ul style="list-style-type: none"> <li>– Evaluate and expand Year 1 education and support activities</li> </ul>	Primarily self-funded by community groups	Funding of community groups Telecommunications to support prevention and care: e.g., hotline, website	\$ 100,000	\$ 100,000

Strategy/Responsibility	Year One	Year Two	Existing Resources	New Resources	Year One	Year Two
<b>Information Management – per Information Management Advisory Group (See Appendix 3)</b>						
<p>Effective health information management strives to improve decision making at all levels of the health system: at the level of <i>governors</i> (for strategic planning, policy setting and system evaluation), <i>managers</i> (for resource allocation, utilization management and operational planning), and <i>providers</i> and <i>consumers</i> (for individual and population-based prevention and care).</p> <p><b>Develop data sharing principles and agreements</b></p> <p><i>Responsible Partner:</i> Secretariat with Information Management Group</p>	<ul style="list-style-type: none"> <li>– Facilitate partnership development of data sharing principles</li> <li>– Formalize data sharing agreements among key partners</li> </ul>	<ul style="list-style-type: none"> <li>– Monitor and evaluate data sharing</li> </ul>	Federal funding to link PHIS to BCCDC	IM Project Leader (0.5 FTE) and Administration Expenses (See Information Management Appendix 3)	\$ 187,000	\$ 187,000
<p><b>Develop Information Management plan</b></p> <p><i>Responsible Partner:</i> Secretariat with Information Management Group</p>	<ul style="list-style-type: none"> <li>– Complete long term Information Management plan</li> </ul>	<ul style="list-style-type: none"> <li>– Assess impact of initiatives</li> </ul>				
<b>Research and Evaluation – per Research and Evaluation Group</b>						
<p><b>Develop long term research and evaluation plans</b></p> <p><i>Consortium of Responsible Partners:</i> VHHSC – BCCDC (epidemiology &amp; provincial laboratory) –Centre for Excellence in HIV/AIDS, UBC departments/divisions (e.g., CHEOS) - private sector collaborations (e.g., Viridae) – Secretariat - Community</p>	<ul style="list-style-type: none"> <li>– A chairperson will be elected or appointed to oversee the Research and Evaluation Advisory group whose role it will be to nurture a consortium of responsible partners.</li> <li>– This consortium of responsible partners should be inclusive and multi-disciplinary (e.g., have a broad interest in basic, translational, epidemiological, clinical hepatitis and healthcare outcomes-related research.</li> <li>– The consortium will identify research and evaluation priorities and seek external grants and/or corporate funding; e.g., Canadian Institute for Health Care Research, Canadian Institute for Health Information, etc.</li> </ul>	<ul style="list-style-type: none"> <li>– Initiate and report on priority research and evaluation projects</li> <li>– Expand research and evaluation activities</li> </ul>	Existing funding at Centre for Excellence in HIV/AIDS	Through grants		

Strategy/Responsibility	Existing Resources	New Resources	Year One	Year Two
<b>Secretariat</b>				
<b>Establish Secretariat</b> - Performance Management System	BCCDC space and equipment	Network director (0.5 FTE) Admin Assistant (1.0 FTE)	\$ 120,000 60,000	\$ 120,000 60,000
<b>Establish Steering Committee</b>		Office supplies Committees and travel	30,000 30,000	30,000 30,000
<b>Establish Advisory Groups</b>		Education Communications resources Consultants	30,000 20,000 <u>50,000</u>	30,000 20,000 <u>50,000</u>
			<u>340,000</u>	<u>340,000</u>

## Budget Summary

	<b>Year One</b>	<b>Year Two</b>
<b>Surveillance/Prevention</b>		
Immunization of children under 12 yrs – catch-up and infant program	\$ 5,000,000	\$ 5,000,000
Enhanced immunization for hep B in persons at risk: e.g, IDUs and persons with hep C	500,000	500,000
Enhanced immunization for hep A in persons at risk: e.g., IDUs and persons with hep C	2,300,000	2,300,000
Repository of Lab Test Results	288,000	93,000
Enhanced Communicable Disease Reporting	-----	62,800
<b>Care Management</b>		
Guidelines	25,000	
Drugs for hepatitis C and hepatitis B	20,000,000	20,000,000
Supportive Molecular Laboratory Testing	500,000	500,000
Care Management Database	194,000	165,000
Interdisciplinary Care Management Model	486,000	631,000
<b>Education and Support</b>	100,000	100,000
<b>Infrastructure</b>		
Information Systems Staffing	187,000	187,000
Secretariat/ Coordinating Infrastructure	340,000	340,000
<b><u>Total</u></b>	<b><u>\$ 29,920,000</u></b>	<b><u>\$ 29,878,800</u></b>

## **H. NEXT STEPS**

- Circulate final document to those listed in Appendices 5 and 6.
- Forward to Vancouver/Richmond Health Board on July 22, 1999.
- Forward to the Ministry of Health for approval in August 1999.
- Continue development of the guidelines.
- Provide feedback to those listed in Appendices 5 and 6 following Ministry of Health response.

## **I. SUMMARY**

This proposal has attempted to identify a hepatitis strategy for British Columbia. It is our best attempt at describing a coordinated, integrated, and comprehensive approach to the management of hepatitis. While a nucleus of expertise is concentrated in the Lower Mainland, others are working in offices, clinics, institutions, and communities throughout the province. It is anticipated that the strategy will link providers in the province to assist them in caring for their clients in a state-of-the-art manner.

As with any proposal, this proposal has deficiencies:

- Based on the information that was obtained, the best estimates for a budget are presented. Unfortunately, the pharmacoeconomic information is not available.
- The proposal suggests a network of providers. However, interconnectedness, consultation, and consensus building is more difficult to implement than when the resources are under the control of one organization. Most of the services for hepatitis management are community-based, but the majority of resources have been placed in institutions because of the expertise base and the academic leadership required to innovate and advance knowledge.
- In spite of the significant costs that appear in the budget, requirements may need to be adjusted based on new information.
- Results of the investment in the strategy, and particularly in information management, will be slow to appear and will accrue to various stakeholders.

In spite of the proposal's deficiencies, a number of strengths can be highlighted:

- The willingness of the participants to share information and to work on the strategy following two previous attempts to forward a proposal to the Ministry of Health
- The increased awareness by the participants of what currently is in place to manage hepatitis

- The increased awareness by the participants of the continuum of care that is required to manage the disease – surveillance, prevention, diagnosis, treatment, follow-up, and support
- The development of a model for the management of any chronic disease that is based on the establishment of a performance management approach, including partnerships and information management

Appreciation is felt for the dedication of those involved in the development of this proposal – the community representatives, the service providers, and the consultants, all of whom are listed in Appendix 5. Without the help of these people, this proposal would not have been written.

## **J. APPENDICES**

1. Participating Organizations
2. Project Status Report: *Development of Guidelines for the Management of Chronic Viral Hepatitis in British Columbia*
3. Information Management Overview
4. BCCDC Immunization Program Proposal
5. List of individuals/organizations who developed the proposal
6. List of individuals/organizations to whom the proposal was circulated

## APPENDIX 1

### Participating Organizations

Organization	Core Competencies
BC Centre for Disease Control <ul style="list-style-type: none"> <li>Epidemiology</li> <li>Provincial Laboratory</li> </ul>	Epidemiology and surveillance. Prevention, education and public health laboratory testing.
Canadian Blood Services	Donor blood and prenatal screening and reporting.
Centre for Excellence in HIV/AIDS	Model for HIV/AIDS – e.g. clinical guidelines, care management registry, cohort design, molecular epidemiology, outcomes research.
Children’s and Women’s Health Centre of BC	Care for children with hepatitis and their families
Community Groups: e.g., Hep C Society, Canadian Liver Foundation	Multilingual and culturally adapted education (e.g. website, newsletter and meetings), client/patient counselling and support.
Health Authorities	Public Health – Vaccination, limited case and contact follow-up, and public education. Hospital services - acute and ambulatory care.
Ministry of Health, Acute & Continuing Care, Public and Preventive Health	Through a broad range of programs, services and public funding, the Ministry is responsible for maintaining high quality, accessible, affordable health care for people in BC.
Ministry of Health - Pharmacare	Provincial drug insurance program. Provides reimbursement for drugs & maintains the PharmaNet database.
Private laboratories	Laboratory services relating to hepatitis
Provincial Blood Coordinating Office	Centralized transfusion registry for recipients of blood and blood products.
UBC Diagnostic Virology Laboratory (UBCDVL) at Providence Health Care	Routine and molecular diagnostic services.
University of BC	Academic/research
Vancouver Hospital & Health Sciences Centre (VHHSC)	Management of chronic viral hepatitis Transplant program.
Vancouver/Richmond Health Board	As per health authorities. In addition, provides community health services to the Downtown East Side.
Viridae	Contract research specializing in the diagnosis, management and therapeutics of chronic viral disease.

## APPENDIX 2

# Development of Guidelines for the Management of Chronic Viral Hepatitis in British Columbia

## Project Status Report

<i>Organization:</i>	Vancouver/Richmond Health Board	<i>Date:</i> July 13, 1999		
<i>Period Covered:</i>	March-July, 1999	<i>Change of Scope:</i>		No
<i>Reporting to:</i>	Mel Krajden, Marleen Wong	<i>On Budget:</i>	Yes	
<i>Prepared by:</i>	Jan Fletcher, Consultant	<i>On Schedule:</i>	Yes	
<u><i>Background</i></u>				
<p>Guidelines for the management of hepatitis in BC are necessary to provide direction and information for health care professionals. They will provide a consistent and standardized tool to monitor and evaluate the appropriateness and effectiveness of prevention strategies, laboratory tests, treatment options, follow-up practices, and support resources.</p> <p>Ongoing review of current and new information, updating of the guidelines, communication, adherence to guidelines, evaluation of their effectiveness, and cost/benefit analysis will require an infrastructure to ensure that their usefulness is optimized.</p> <p>The focus of the Guidelines is the patient, the “client” - those either at high risk, those tested and undergoing treatment, those tested and with no present indication for treatment, and patients post-treatment.</p>				
<u><i>Activities Completed:</i></u>				
<ol style="list-style-type: none"> <li>1. A Guidelines Committee has been organized with representatives from the Aboriginal Community, BCCDC, Children’s and Women’s Health Centre, the Chinese Medical Association, the Hep C Society, Pharmacare, Providence, VHHSC, and Viridae.</li> <li>2. The Roles and Responsibilities for the Committee have been outlined by the Working Committee.</li> <li>3. The Guidelines Committee has met regularly, biweekly, since May 6.</li> <li>4. A template or format for the drafting of Guidelines for Hep C and for Hep B was approved by the Committee.</li> <li>5. The Committee chose to form sub-groups to research and present recommendations to the Committee for the Assessment/Diagnosis/Monitoring and for the Treatment of both Hep C and Hep B.</li> <li>6. Comprehensive algorithms for both are also under development. They have been presented but not formally agreed to as yet.</li> <li>7. Recommendations have been received and approved for the Assessment/Diagnosis/Monitoring of both Hep C and Hep B and for the Treatment of Hep C. Recommendations for the Treatment of Hep B have been presented, but there is no clear consensus.</li> <li>8. Extensive information has been received from the Canadian Association for the Study of the Liver (CASL), the Canadian Liver Foundation, and the Hep C Society for inclusion in the Guidelines.</li> <li>9. An electronic “Chat List” has been set up for the Committee to allow for feedback and comments.</li> <li>10. A Conflict of Interest declaration has been completed by the members of the Committee.</li> <li>11. A sub-group met to address the issue of Cost-Effectiveness of the available drugs used in the treatment of hepatitis. It was unable to resolve the issue due to a lack of credible data in a very tight timeframe, but did propose a structure and process to enable the collection of appropriate outcome data to link pharmacoconomics with testing and treatment.</li> </ol>				

Activities Planned:

1. Further meetings will be held to complete the treatment recommendations for Hep B and the algorithms for both B and C.
2. A final, complete "Draft" will be compiled in accordance with the template and presented to the Guidelines Committee for approval and consensus.
3. Following approval in the Guidelines Committee, the Hepatitis Guidelines will be presented to the Working Committee for their awareness, approval, and support.
4. A Cost/Benefit analysis will be performed based on the recommendations in the Guidelines.
5. Appropriate and necessary approving agencies and organizations will be identified and their support and acceptance solicited for provincial use of the Hepatitis Guidelines. Pharmacare is an important partner.
6. Once approved, the Guidelines will be published, both in hard copy and electronic.
7. A process for provincial distribution, awareness, communication, and education will be conducted.
8. The ongoing process for the updating, revising, distribution, communication, and education of state-of-the-art provincial hepatitis guidelines will be transferred to VHHSC.

Issues/Risks/Concerns:

1. *Funding* for the recommended testing, treatment and monitoring options.
2. *Acceptance* by the participating stakeholders and practicing physicians in BC for the approved Guidelines as the appropriate and sole guidelines for the management of hepatitis in BC.
3. Mechanisms for the *monitoring* of adherence to the Guidelines.
4. *Information systems* for the input and analysis of use, cost, and clinical outcomes.
5. *An infrastructure and resources* to ensure ongoing coordination, integration, data analysis, process improvements, performance management, and cost-effective analysis for the global strategy.

Action Required:

1. V/RHB and Ministry of Health acceptance and support for the Strategic Proposal.
2. Commitment from Pharmacare for funding of the necessary and appropriate drugs.
3. Resources to conduct a Cost/Benefit analysis of the recommended Guidelines.
4. Resources to publish the provincial Hepatitis Guidelines and conduct a process of education and understanding of the approved Guidelines.
5. Information systems for the collection and sharing of data and for knowledge management.

Attached Documents:

1. Guidelines Template.

jmmf llb/july99

## **TEMPLATE FOR THE DEVELOPMENT OF GUIDELINES**

At the initial meeting of the Committee, the following format or template for the development of guidelines was approved:

1. Introduction
  - Preferred Management Personnel
  - High-Risk Groups
2. Baseline Medical Assessment:(Family doctor/Specialist)
  - History and Review of Systems
  - Physical Examination
  - Investigations
  - Maintenance – Psychosocial Assessment
  - Etc.
  - Clinical Manifestations:
    - Diagnosis
    - Indications
3. Recommended Treatment/Therapy:
  - Eligibility: Decision to/not to Treat
  - Preferred Regimen
  - Alternate Regimen
  - Maintenance
  - Alternative Treatment
  - Drug Dosages per Indications
  - Contraindications
  - Adverse Effects
  - Special Considerations
4. Assessment and Treatment Algorithm
5. Referral: essential information (pathology, operative, lab, imaging, etc.)
6. Monitoring
  - During Treatment
  - Following Treatment
7. Follow-up: (Patients Treated/Not Treated)
  - History and Physical
  - Investigations
  - Monitoring
  - Prognostic Clues
  - Illness Work-up
8. Ambulatory Management
9. Public Health Support
  - Social Services
  - Nutrition/Nursing/Social Work
10. Education (multilingual): Individual and Population
  - Patient Information – drugs, alternatives, support
11. Maintenance and Disability Support
  - Aging Women/Children
  - Psychosocial Support
  - Counselling Guidelines
12. End Stage Disease
  - Transplant
13. Palliative Care
  - Grief Management

## APPENDIX 3

### Information Management Overview

#### A. EXECUTIVE SUMMARY

A key component of the Hepatitis Strategy will be improved information management to support planning and evaluation, resource allocation and management, and activities for individual and population-based prevention and care.

Unfortunately, hepatitis information management in this province is currently ineffective because data are stored in multiple disparate systems, requiring duplicative processes to exchange data within the key functions of surveillance, prevention and care management. Moreover, data are not linked across these key functions to evaluate outcomes of activities for prevention and care.

However, some groundwork for improved hepatitis information management has been laid in the form of existing infrastructure and systems, technical expertise, and information sharing initiatives already underway or planned. The Hepatitis Strategy strives to build on this existing investment in information management by the partners.

#### Proposed Action Plan

1. Establish an Information Management (IM) Advisory Group to advise the Secretariat at a high level on information management planning, priorities, and data sharing issues.
2. Establish an IM Project Team to develop an annual project plan and to oversee design and implementation of key information management projects.
3. Adopt a Project Management Approach to implement the following IS initiatives: .

⇒ Interim Repository of Laboratory Test Data - Upload data from the UBC Diagnostic Virology Lab and Canadian Blood Services systems to a single data repository, to be managed by the BCCDC under contract from the Secretariat.

Year 1 – Develop repository \$ 288,097

Year 2 – Establish link to private labs 93,008

⇒ Enhanced Surveillance System – Building on the interim repository, initiate a PHIS pilot to streamline hepatitis reporting and case follow-up.

Year 1 – Design PHIS enhancement and linkages to repository \$ 62,803

Year 2 – Pilot in 2-3 regions 197,979

- ⇒ Care Management Database – Adopt the Centres for Excellence in HIV/AIDS database model or develop a PHIS enhancement to establish a care management database for hepatitis patients.

Year 1 – Pilot with VHHSC, CWBC physicians \$ 194,391

Year 2 – Extend to other regional centres 164,983

## **B. INTRODUCTION**

This report, an appendix of the document entitled “*A Hepatitis Strategy for British Columbia*”, provides:

- ⇒ a summary of the current situation in BC of information management and systems for chronic viral hepatitis;
- ⇒ a high level needs assessment of the information management requirements of a provincial hepatitis strategy;
- ⇒ a discussion of opportunities and challenges for improving hepatitis information management in BC; and
- ⇒ recommendations for specific information management initiatives including:
  - establishment of an interim repository of laboratory results;
  - enhancements to the provincial communicable disease reporting system; and
  - development of a care management database.

## **C. SCOPE AND METHODOLOGY**

This report focuses on the information management requirements of managing chronic viral hepatitis (Hepatitis B and C) in British Columbia. There are many organizations involved and this report attempts to reflect the current situation and potential contributions of each. In addition, similar information management initiatives were reviewed in order to identify technical opportunities and critical success factors.

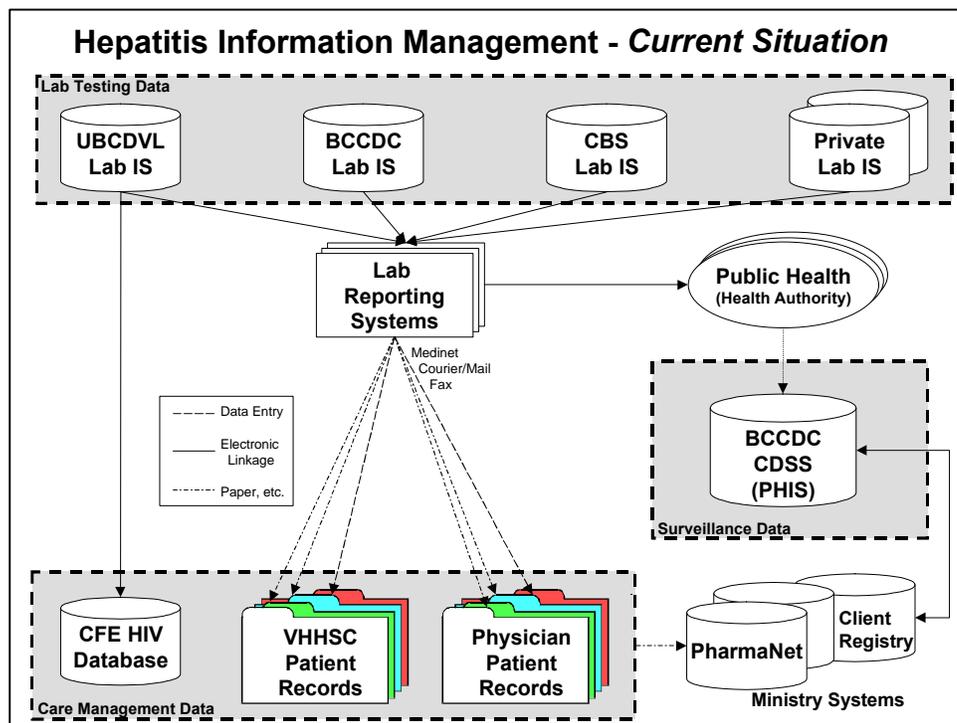
Information was gathered through interviews with one or more key representatives of each organization. Documentation review included process flow diagrams and data models of existing systems. Where available, a demonstration of existing systems was observed.

## D. CURRENT SITUATION

### 1. General Findings

Effective health information management strives to improve decision making at all levels of the health system: at the level of *governors* (for strategic planning, policy setting and system evaluation), *managers* (for resource allocation, utilization management and operational planning), and *providers* and *consumers* (for individual and population-based prevention and care).

Currently, information management for hepatitis in this province is not supporting optimal decision making and, in fact, is undermining efforts to improve hepatitis management and resource utilization. The following diagram shows how existing multiple data sources are not linked or integrated, and how multiple duplicative processes are required to exchange data between the key functions of laboratory testing, surveillance, and care management.



Current information management problems include:

- ⇒ Data are fragmented, non-standardized and technically isolated, and therefore difficult to integrate for analysis and comparison.
- ⇒ It is impossible to accurately estimate hepatitis incidence and prevalence, or to track outcomes of identified cases, due to fragmented laboratory test data and limitations of the province's Communicable Disease Surveillance System (CDSS).
- ⇒ Care management for hepatitis patients is currently documented in various manual charting systems and standalone databases, which track patient demographics, health history, clinical status, treatment and outcomes. There are currently no data standards that would facilitate the integration and analysis of this data to support development and application of care guidelines and outcome evaluation.
- ⇒ There is no ability to link surveillance and care management data in support of longitudinal outcome evaluation (including evaluation of outcomes for untreated individuals).

However, some groundwork for improved information management for hepatitis has been laid in the form of existing infrastructure and systems, technical expertise, and informal information sharing initiatives already underway or planned. Examples include:

- ⇒ The BC Centre for Disease Control (BCCDC) is already downloading hepatitis test order data from the MDS Metro and BC Biomedical private laboratories, including information on Hepatitis B tests performed prior to redirection to the provincial lab.
- ⇒ The UBC Diagnostic Virology and Reference Laboratory at St. Paul's Hospital (UBCDVL) and BCCDC have completed initial investigations on linking Hepatitis C data from their laboratory databases. Discussion of a similar initiative is underway between BCCDC and CBS. A draft Memorandum of Understanding that addresses information access and sharing issues is under consideration by both CBS and the UBCDVL.
- ⇒ The Centre for Excellence in HIV/AIDS (CFE HIV) has developed a comprehensive set of integrated databases that track enrolled patients, treatments and clinical trials, clinical staging, drug approvals and dispensing, alternative therapies, and evaluation of a wide range of outcomes. The databases accept downloaded lab data from the UBCDVL and are linked to Ministry of Health databases for hospital separations, MSP billing and Vital Statistics.
- ⇒ MDS Metro and BC Biomedical labs have announced a joint venture to develop a real-time repository of laboratory test orders and results, with a pilot involving up to 50 physicians scheduled for August. The joint venture partners have indicated a willingness to include BCCDC results in their repository.

⇒ The CDSS module of PHIS will be implemented in 17 of 18 health authorities by the end of 1999. In addition, the BCCDC has recently received federal funding to develop linkages between the CDSS and key laboratory information systems (BCCDC, the private labs) to enable download of positive results directly to the communicable disease reporting system.

## **2. Ministry of Health Systems and Related Initiatives**

a) Client Registry / Health Registry – In 1998, the Ministry published compliance standards for applications developers wishing to establish an electronic linkage to the Client Registry's database of client demographics. The Ministry recently launched an enhanced client registry, the Health Registry, which offers a web interface and will include an expanded data set including providers and facilities.

b) PharmaNet – This province-wide application provides on-line drug interaction checking and claims adjudication for all of the province's community pharmacies. Introduction of PharmaNet access in hospital-based pharmacies is underway.

The BC Cancer Agency and HealthNet/BC team initiated a project last year to link the Agency's system to the Client Registry and PharmaNet claims adjudication engine. In addition to automating claims adjudication, the proposed link would automate the upload of BCCA-dispensed medication data into the PharmaNet databases. While much of the project's technical work has been completed, administrative issues have delayed the linkages from being implemented.

c) Lab Test Standards – A provincial Lab Test Standards Task Group, comprised of representatives from BCCDC, the private labs, and health authorities, published this comprehensive standard in January, 1999. The standard guides the exchange of lab test orders and results, and addresses multiple complex issues of privacy, security and data standardization.

### 3. Inventory of Existing Information Systems

Organization / System	System Description	Information Management Issues and Opportunities
<p><u>BCCDC</u> Laboratory Information System (LIS)</p>	<p><u>Platform:</u> MUMPS <u>Volume:</u> over 200,000 hepatitis tests/year <u>Source:</u> Specimens sent to BCCDC for testing <u>Key Data Elements:</u></p> <ul style="list-style-type: none"> <li>• Patient Demographics</li> <li>• Specimen Information</li> <li>• Results</li> </ul>	<ul style="list-style-type: none"> <li>- The database contains duplicate occurrences of individuals, despite periodic attempts to merge duplicate records.</li> <li>- HIV patient records are maintained in a separate table, with minimal identifiers, and cannot be correlated with non-HIV results.</li> <li>- LIS data has been mapped to an SQL structure to support integration with other databases.</li> </ul>
<p><u>UBCDVL</u> Laboratory Information System</p>	<p><u>Platform:</u> SQL Server <u>Volume:</u> over 13,000 hepatitis tests/year <u>Source:</u> Specimens sent to UBCDVL for testing <u>Key Data Elements:</u></p> <ul style="list-style-type: none"> <li>• Patient Demographics</li> <li>• Specimen Information</li> <li>• Results</li> </ul>	<ul style="list-style-type: none"> <li>- The current database is being rewritten using SQL Server, which will enhance reporting functionality and facilitate development of electronic interfaces to other databases.</li> <li>- An existing electronic interface permits download of lab test results to the CFE HIV database.</li> <li>- UBCDVL and BCCDC are investigating integration of hepatitis test results to form a repository of hepatitis tests and results.</li> </ul>

Organization / System	System Description	Information Management Issues and Opportunities
<p><u>Canadian Blood Services</u> (CBS)</p> <p>Laboratory Information System</p>	<p><u>Platform:</u> Revelation for prenatal testing</p> <p><u>Volume:</u> over 50,000 hepatitis tests/year</p> <p><u>Source:</u> Blood from pregnant women sent to CBS for screening; screening of donated blood products</p> <p><u>Key Data Elements:</u></p> <ul style="list-style-type: none"> <li>• Patient Demographics</li> <li>• Specimen Information</li> <li>• Results</li> </ul>	<ul style="list-style-type: none"> <li>- CBS and BCCDC are investigating integration of hepatitis test results to form a repository of hepatitis tests and results.</li> </ul>
<p><u>Private Labs</u></p> <p>Joint Venture Repository</p>	<p><u>Platform:</u></p> <p><u>Volume:</u> over 70% of total lab tests performed in BC</p> <p><u>Source:</u> Specimens sent to the private laboratories for testing</p> <p><u>Key Data Elements:</u></p> <ul style="list-style-type: none"> <li>• Patient Demographics</li> <li>• Specimen Information</li> <li>• Results</li> </ul>	<ul style="list-style-type: none"> <li>- A pilot involving up to 50 physicians will be launched in August, 1999.</li> <li>- BCCDC has expressed interest in having their test results made available to physicians through the joint venture repository.</li> <li>- Development of the repository will involve partial implementation of HealthNet/BC Lab Test Standards for test orders and results reporting.</li> </ul>

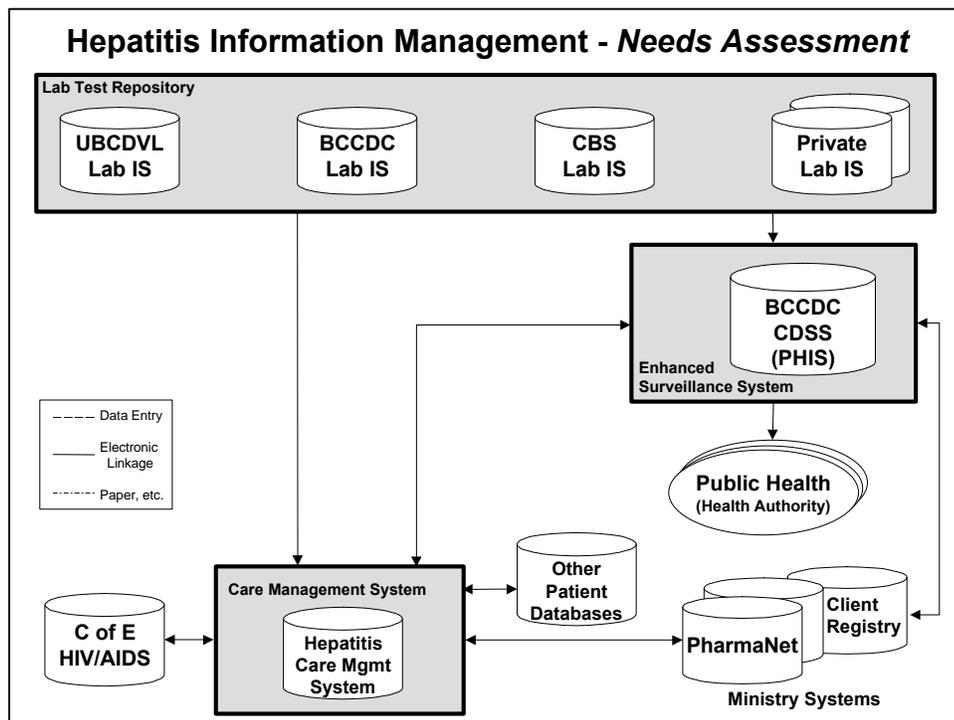
Organization / System	System Description	Information Management Issues and Opportunities
<p><u>BCCDC</u></p> <p>Communicable Disease Reporting System</p> <p>(CDSS II – a module of PHIS)</p>	<p><u>Platform:</u> Oracle</p> <p><u>Volume:</u> approximately 10,000 cases of Hepatitis B and C reported last year</p> <p><u>Source:</u> Regional standalone databases of identified cases, uploaded weekly to BCCDC</p> <p><u>Key Data Elements:</u></p> <ul style="list-style-type: none"> <li>• Client Demographics</li> <li>• Case/ Reporting Source</li> <li>• Reportable Disease</li> <li>• Case Intervention</li> </ul>	<ul style="list-style-type: none"> <li>- Duplication of case reporting within and across regions may result in duplicate occurrences of cases in the BCCDC database, and there are limited resources to identify and integrate these duplicate records.</li> <li>- There is limited availability of fields to track follow-up activities and outcomes, and virtually no regional resources for collection and data entry of this information.</li> <li>- Replacement of CDSS I with the Y2K-compliant CDSS II will provide regions with an improved user interface and enhanced access for multiple users.</li> <li>- The current upgrade to CDSS II requires regions to perform data cleaning to identify and delete duplicate client records.</li> <li>- BCCDC has recently received federal funding to link internal and external lab test reports of communicable disease to CDSS, thereby reducing the need for duplicate data entry by health authorities.</li> <li>- 17 of 18 regions are planning to implement CDSS II during 1999; VRHB will submit CD data to CDSS via an electronic interface with their proposed RISE community health IS.</li> </ul>

Organization / System	System Description	Information Management Issues and Opportunities
<p><u>Centre for Excellence in HIV/AIDS</u></p> <p>(CFE HIV)</p> <p>HIV Drug Treatment Programme Database</p>	<p><u>Platform:</u> Oracle</p> <p><u>Volume:</u> approx. 7,000 patients in database</p> <p><u>Source:</u> Data entry from forms submitted by enrolling physicians and patients; UBCDVL lab data; pharmacy data</p> <p><u>Key Data Elements:</u></p> <ul style="list-style-type: none"> <li>• Patient Demographics</li> <li>• Diagnostic Information</li> <li>• Physician Information</li> <li>• Drug Information</li> <li>• Lab Test Results</li> <li>• Clinical Staging/Patient Status</li> <li>• Mortality Data</li> <li>• Hospital Separations</li> <li>• MSP Billing Info</li> <li>• Alternative Therapies</li> <li>• Other Illnesses</li> </ul>	<ul style="list-style-type: none"> <li>- Linkages to Ministry systems provide annual upload of information on patient mortality, hospital separations and MSP billing</li> <li>- Currently, all data is entered into the database by CFE HIV staff.</li> <li>- An interface for physicians to directly enter data or even to view patient records is not currently available; firewall concerns prevent remote access at this time.</li> <li>- Comprehensive reports are produced regularly including: <ul style="list-style-type: none"> <li>- geographic distribution of patients</li> <li>- distribution of accidental exposures</li> <li>- new drug therapy participants by drug type and combinations</li> <li>- program enrolment</li> <li>- drugs dispensed and treatment costs</li> <li>- health status</li> <li>- income and employment status</li> <li>- alternative therapies</li> </ul> </li> </ul>
<p><u>VGH – Dr. F. Anderson</u></p> <p>Hep Manager</p>	<p><u>Platform:</u> MS Access</p> <p><u>Volume:</u> over 2,000 patients</p> <p><u>Source:</u> Patients referred to Dr. Anderson for treatment; data entry of lab test and other information from paper-based records</p> <p><u>Key Data Elements:</u></p> <ul style="list-style-type: none"> <li>• Patient Demographics</li> <li>• Lab Test Information</li> <li>• Drug Information</li> <li>• Other Diagnostics</li> <li>• Contact Information</li> <li>• Depression Ratings</li> <li>• Other Illnesses</li> </ul>	<ul style="list-style-type: none"> <li>- This custom-designed database assists with care management and outcome evaluation for Dr. Anderson’s patients.</li> <li>- Schering Canada Inc. plans to distribute the application (at no charge) to physicians who treat hepatitis patients; each physician would upload data on a regular basis to Dr. Anderson for analysis.</li> </ul>

## E. INFORMATION MANAGEMENT NEEDS ASSESSMENT

The statement “...information informs us, and *forms* us” is as true for a provincial hepatitis strategy as for any other health initiative. The existence of multiple partners, complex prevention and care requirements, and the highly fragmented current situation argue for a priority focus on information management as the “glue” that will hold the partnership together and enable it to achieve its goals.

The diagram below depicts the key components of effective hepatitis information management in BC:



### 1. Repository of Laboratory Testing

Surveillance begins with timely and accurate identification of hepatitis cases through laboratory testing. Timely access to comprehensive test information is also critical for effective care management and outcome evaluation.

Effective utilization of lab test information has two attributes: standardization of data to enable comparison over time and across patients, and timely access to multiple sources of lab test information. Such attributes are achieved through establishment of a lab test repository, involving either a centralized repository or network of repositories.

There is urgent need for a lab test repository to support management and analysis of laboratory testing for hepatitis. Such a repository would serve several functions:

- ⇒ to provide comprehensive data on hepatitis testing and positive/negative results, for analysis to determine levels of incidence, prevalence and acute vs. chronic disease;
- ⇒ to enable laboratory utilization management and anticipated reduction of redundant testing through enhanced access to historical results and through application of guidelines to support test ordering;
- ⇒ to provide the trigger for public health investigation, case finding, communicable disease reporting and follow-up, and contact tracing.

## **2. Surveillance System**

An enhanced communicable disease reporting system is required to improve surveillance of hepatitis (and other reportable diseases). A fundamental redesign in test result and communicable disease reporting is required to improve quality and consistency of information reported and to reduce unnecessary duplication of efforts by local health authorities.

Ideally, lab reports for reportable diseases should be electronically transmitted to BCCDC where they would be analyzed against the provincial database and identified as either new cases or as follow-up tests for previously identified cases. This would streamline the current process whereby positive results are sent to local health units who must investigate each new individual's result as a potential new case even if already identified as such by another region. Transferring responsibility for case identification to BCCDC would therefore eliminate the current problem of duplicate reporting across regions, which currently lack access to either the provincial database or to other regions' records.

Once case status is identified from the BCCDC database, positive test results would be relayed to local health authorities through the CDSS module of PHIS, not as a paper lab result. The positive result would be accompanied by case identification status plus guidelines for case follow-up and contact management. Such guidelines would assist in solving current problems of duplicate case identification within regions and inaccurate or incomplete information on follow-up and outcomes.

In the long term, surveillance data should be linked periodically to data on care management, in order to facilitate longitudinal outcome evaluation including comparison of outcomes for treated and untreated individuals.

## **3. Care Management**

A comprehensive care management database will significantly improve consistency of access to services and treatment, development and application of guidelines, and outcome evaluation.

An effective patient registry requires a stable minimum data set with tight data quality controls and the capacity for additional fields to support specific prospective research and evaluation initiatives. While privacy and confidentiality will be of paramount concern,

the database must also provide appropriate access to physicians and even to patients. Flexible reporting and access to data for research and related purposes will be critical to the success of the partnership.

Other attributes of an effective care management system for hepatitis are:

- electronic access to historical and current lab test data;
- electronic or streamlined access to PharmaNet claims adjudication processes for approval according to established guidelines;
- a web-based or “thin client” interface that meets the hardware and user-friendliness needs of participating physicians.

## **F. OPPORTUNITIES AND CHALLENGES**

### **1. IM Leadership and Resources**

The need to integrate and link data across multiple organizations and platforms will require a centralized, coordinated approach to planning for hepatitis information management. Moreover, there will be a requirement for IM leadership and for resources to fund specific projects and to build and maintain the linkages and interfaces that will be required.

The Hepatitis Strategy would provide this leadership through recruitment of an IM Project Leader, reporting to the Secretariat. The Secretariat would also manage funding for information management activities including specific systems projects as identified in Section F.

### **2. Data Standardization**

Data standardization will be a significant issue for the Hepatitis Strategy. Even the seemingly simple task of linking hepatitis lab data will require months of collaboration and negotiation to achieve. This estimate is supported by the recent experience of the Lab Test Standards Task Group (over a year) and the private laboratories’ joint venture repository project (8 months). These initiatives have done significant groundwork in data standardization, although full adoption of the Lab Test Standard would likely exceed the initial requirements of an interim lab repository for hepatitis. Additional work would be needed to refine the data standards for hepatitis testing, and the private labs and HealthNet/BC could be invited to contribute to a working group for this purpose.

A working group would also be required for the significant data definition and standardization issues of a care management database, to be discussed in Section F.

### 3. Information Stewardship, Sharing and Privacy

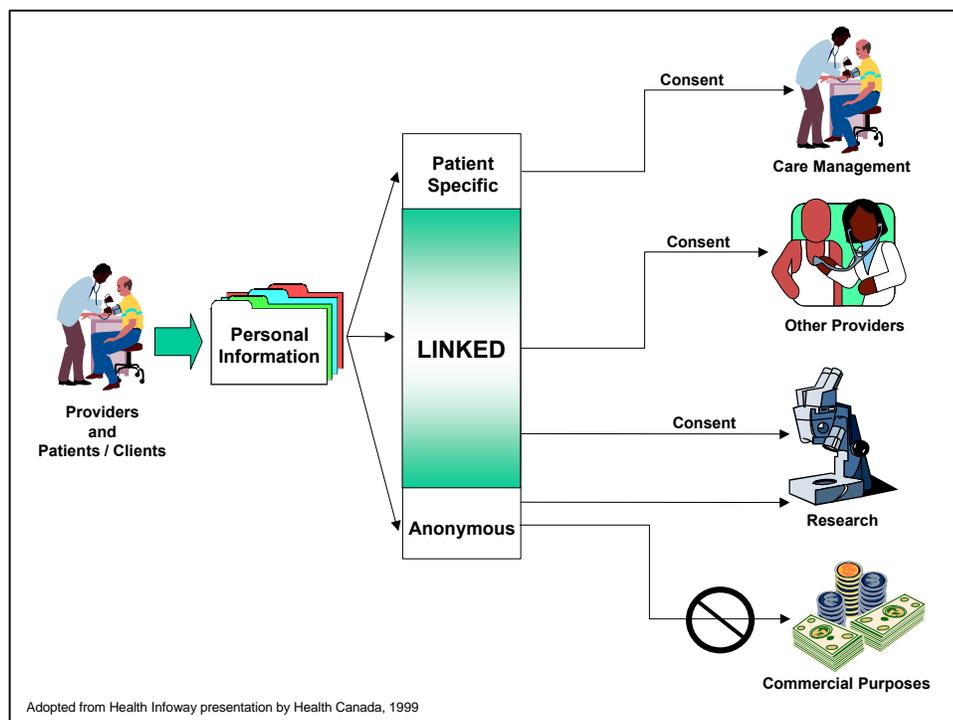
The success of the Hepatitis Strategy will depend on the willingness and resource capacity of partners to share their data with others and to support the analysis and reporting of data products. These are significant issues that will need to be addressed through a combination of Secretariat and IM leadership, and adoption of mutually acceptable principles on data sharing, utilization and publication.

Dr. Richard Schabas prepared a 1999 report entitled “*Surveillance Transition: Principles of Data Sharing*” that would assist in the development of data and information sharing principles for the Hepatitis Strategy partners. He identified four categories of issues related to creation and use of surveillance products, third party access, data quality, and data ownership or stewardship. He recommends that partnerships develop written agreements that specify:

1. Principles of data sharing
2. Processes for decision making to ensure that surveillance products:
  - ⇒ have scientific credibility
  - ⇒ are arm’s length from stakeholders
  - ⇒ have real authority
  - ⇒ reflect priorities
  - ⇒ meet the needs of stakeholders
3. Protocols for release of surveillance products
4. Procedures for data sharing with third party users.

In addition to such principles, careful consideration will need to be given to privacy and confidentiality issues. Information management activities will occur in consultation with the Ministry’s resources for Freedom of Information.

The Evaluation and Research Advisory Group of the Secretariat would be responsible for development of principles on data and information sharing for the partnership. The diagram below, adapted from the Federal Health Minister’s Health Infoway project, proposes a broad framework for data sharing and access:



## G. PROPOSED ACTION PLAN FOR INFORMATION MANAGEMENT

### 1. Information Management (IM) Advisory Group

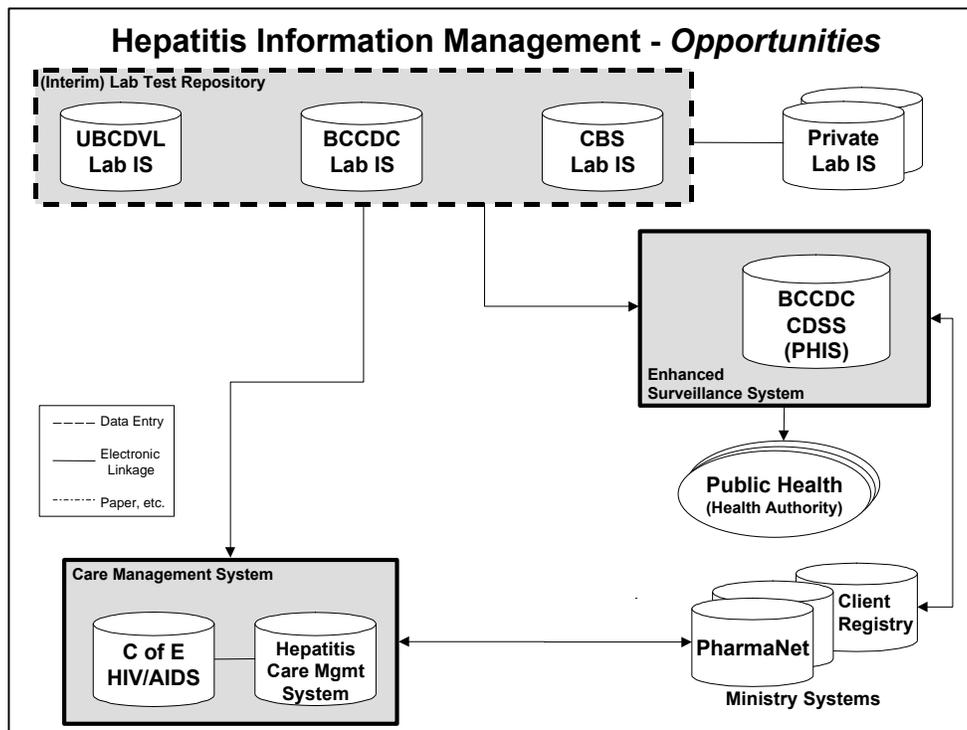
A key first step will be establishment of an IM Advisory Group to advise the Secretariat at a high level on information management planning, priorities, and data sharing issues. The Committee, comprised of senior representatives of participating organizations plus the IM Project Leader, would be responsible for collaborative development of an IM plan. Key areas of focus would include data integration and analysis to support surveillance and prevention, care management, outcome evaluation and research.

### 2. Information Management Project Team

Reporting to the Secretariat, this group would be chaired by the IM Project Leader and be comprised of IM and systems representatives of the participating organizations. This group would be responsible for development of an annual project plan and for the design and implementation of key linkage projects. A key focus of this group would be development and implementation of the necessary data and security standards.

### 3. Project Management Approach to Specific IS Initiatives

The diagram below proposes three IS initiatives which would introduce significant information management improvements while positioning the Hepatitis Strategy to meet its long-term needs and to participate in and/or contribute to provincial initiatives.



A project management approach is recommended to expedite specific systems initiatives by leveraging the available IS expertise and resources of participating organizations. This approach would require a project manager to lead participating organizations and assigned resources for each project. Project managers would report to the IM Project Leader, who would oversee projects within the context of the IM plan, report to the IM Advisory Group on progress and issues, and manage resource allocation among projects.

Once a project is completed, ongoing responsibility for management of the resulting database or interface would be transferred to one of the participating organizations or retained for ongoing management by the IM Project Leader if no suitable “steward” can be identified.

For Years 1 to 3, the following three specific systems initiatives are proposed:

a) Interim Repository of Laboratory Tests -

There are two known initiatives underway that may lead to development of a provincial repository of laboratory test results:

- ⇒ *Private Labs Joint Venture* – MDS Metro and BC Biomedical recently announced a joint venture to develop a repository of test results, initially to include only the two private labs. The joint venture repository will be piloted in August, 1999 with a group of up to 50 physicians. If their planned provincial implementation is successful, the private repository will comprise more than 70% of the province’s total lab test results even if no other labs participate. Already, discussions with the BCCDC and the BC Cancer Agency are underway to plan for future inclusion of these key data sources.
- ⇒ *Provincial Lab Repository* – Although the recently published Lab Test Standard permits sharing of lab test information among multiple decentralized repositories, there is reportedly interest by the Ministry in development of a provincial repository, modeled after the highly successful PharmaNet system.

Widespread access to these alternative provincial registries is a long-term option, at best. It is therefore recommended that an interim repository of hepatitis lab test data be created by uploading data from the UBCDVL and CBS systems to a repository to be managed by the BCCDC under contract from the Secretariat. Creation of the interim repository should involve adoption of HealthNet/BC Lab Test Standards to the greatest extent possible in order to position the repository for participation in a provincial initiative if announced.

One Time Costs:

Year 1 - Develop Repository	\$ 288,097
Year 2 - Link to Private Labs	93,008
Year 3 - Maintain and Refine	93,008
Ongoing Costs (Year 4 and beyond):	93,008

b) Enhanced Surveillance System – Pilot

The interim lab repository would then be used to initiate a pilot on streamlined hepatitis reporting and case follow-up, involving 2 or 3 regions. A pilot PHIS Version 4 module would be developed, which would relay positive results to pilot health authorities once the case status has been identified through analysis of previous reports in the provincial CDSS database at BCCDC.

The PHIS V4 data set would be reviewed and enhanced to improve tracking and outcome evaluation. Impact of the streamlined reporting process and enhanced data set would be evaluated to determine workload implications for extending the system to other health authorities.

A key component of the pilot would be development and application of on-line guidelines to support hepatitis case follow-up, contact tracking, counseling, referral and outcome evaluation.

One Time Costs:

Year 1 – Plan, design linkages to interim repository	\$ 62,803
Year 2 – Pilot in 2-3 regions	197,979
Year 3 – Extend to province	148,335
Ongoing Costs (Year 4 and beyond):	56,224

c) Care Management Database

There are two options for development of a care management database for hepatitis:

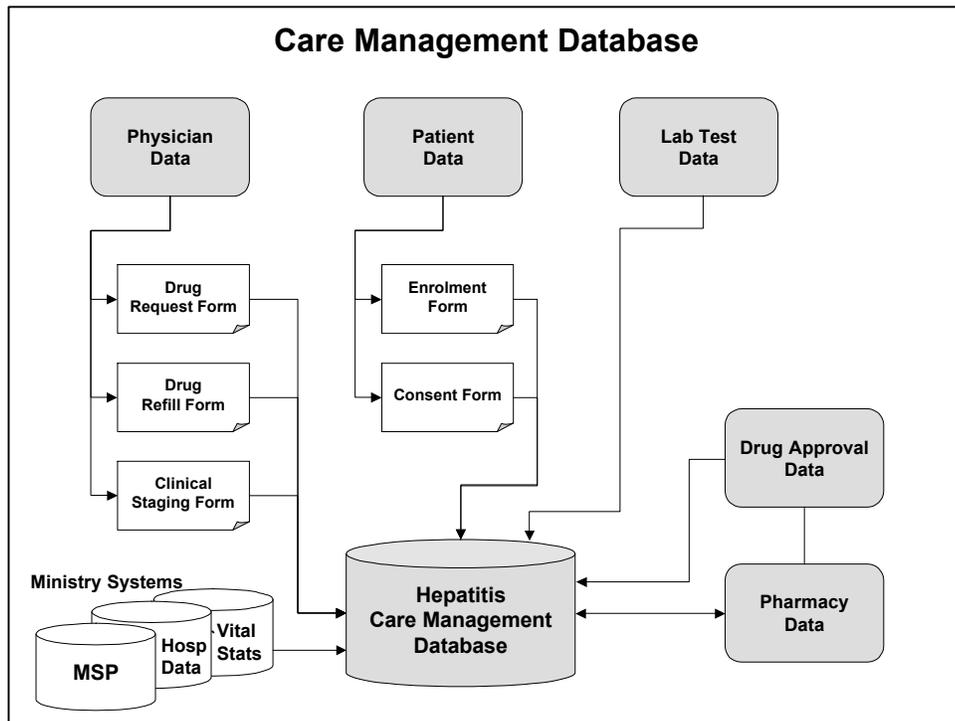
- ⇒ Adopt the Centre for Excellence in HIV/AIDS database model and resources to establish a separate but linked care management database for hepatitis patients. Identify requirements for new fields and reports and implement a web-based or other “thin client” interface to enable access and update of information by physicians.
- ⇒ Develop a hepatitis care management module for PHIS and introduce a web-based or “thin client” interface for physicians.

A key element of either solution would be real-time access to hepatitis (and eventually all) lab test data plus on-line or streamlined access to the PharmaNet claims adjudication process.

It is recommended that a pilot database and interface be developed and tested extensively by physicians at VHHSC and BC Women’s and Children’s Hospital. Upon completion of a successful pilot, this database could be extended to other

participating physicians and clinics in the province. Future enhancements could include access by hepatitis patients.

A high-level data model for the proposed database, based on the CFE HIV Drug Treatment Programme Database, is:



One Time Costs:

Year 1 – Pilot with VHHSC, CWBC physicians	\$ 194,391
Year 2 – Extend to other regional centres	164,983
Year 3 – Maintain and refine	75,962
Ongoing Costs (Year 4 and beyond):	75,962

<b>INFORMATION MANAGEMENT OVERVIEW - FUNDING</b>							<b>Ongoing</b>	
<b>Funding Component / Project</b>	<b>FTE</b>	<b>Year 1 \$</b>	<b>FTE</b>	<b>Year 2 \$</b>	<b>FTE</b>	<b>Year 3 \$</b>	<b>FTE</b>	<b>\$</b>
IM Project Leader	0.50	77,756	0.50	77,756	1.00	166,398	1.00	166,398
Administrative Assistant	1.00	54,000	1.00	54,000	1.00	54,000	1.00	54,000
Consulting (IM Plan, Data Standards)		30,000		25,000		25,000		25,000
Admin. Expenses (travel, supplies, phones)		25,000		30,000		25,000		25,000
<b>Subtotal</b>	<b>1.50</b>	<b>186,756</b>	<b>1.50</b>	<b>186,756</b>	<b>2.00</b>	<b>270,398</b>	<b>2.00</b>	<b>270,398</b>

### **Interim Lab Repository Project**

***Year 1: Develop Repository; Year 2: Link to Private Labs; Year 3: Maintain and Refine***

Project Manager	0.33	47,850						
Database Administrator	0.33	43,863	0.20	26,318	0.20	26,318	0.20	26,318
Network analyst	0.08	9,969						
Oracle Developer	0.50	71,775	0.10	14,355	0.10	14,355	0.10	14,355
Quality Assurance/Testing/Evaluation	0.42	39,875						
Report Development	0.17	14,953	0.25	22,430	0.25	22,430	0.25	22,430
Resources for participating labs*	0.50	59,813	0.25	29,906	0.25	29,906	0.25	29,906
Admin Expenses (Phones, travel)		15,000		15,000		9,000		9,000
Hardware/Software		110,000		50,000		10,000		10,000
<b>Project Subtotal</b>	<b>2.33</b>	<b>288,097</b>	<b>0.80</b>	<b>93,008</b>	<b>0.80</b>	<b>93,008</b>	<b>0.80</b>	<b>93,008</b>

### **Enhanced Surveillance System**

***Year 1: Planning and interface to lab repository; Year 2: Pilot in 2-3 health authorities; Year 3: extend to rest of province***

Project Manager	0.13	17,944	0.25	35,888	0.50	71,775		
Database Administrator	0.17	21,931	0.25	32,897	0.25	32,897	0.25	32,897
Content Development	0.08	10,966	0.25	32,897				
Oracle Developer	0.08	11,963	0.40	57,420	0.20	28,710	0.10	14,355
Quality Assurance/Testing/Evaluation			0.25	23,925				
Report Development			0.17	14,953	0.17	14,953	0.10	8,972
PHIS Help Desk Enhancement			0.25	23,925	0.25	23,925	0.10	9,570
Admin Expenses (Phones, travel)		20,000		10,000		25,000		5,000
Interface to VRHB CHIS			1.00	131,588	0.17	21,931	0.17	21,931
Hardware/Software				25,000		25,000		25,000
<b>Project Subtotal</b>	<b>0.46</b>	<b>62,803</b>	<b>1.57</b>	<b>197,979</b>	<b>1.12</b>	<b>148,335</b>	<b>0.45</b>	<b>56,224</b>

### **Care Management Database**

***Year 1: Pilot with VHHSC/CWBC physicians; Year 2: Extend to other provincial centres***

Project Manager	0.50	71,775	0.25	35,888				
Database Administrator	0.25	32,897	0.25	32,897	0.40	52,635	0.40	52,635
Content Development	0.50	65,794	0.17	21,931				
Oracle Developer	** 0.00		0.25	35,888	0.10	14,355	0.10	14,355
Quality Assurance/Testing/Evaluation	0.25	23,925	0.17	15,950				
Report Development			0.25	22,430	0.10	8,972	0.10	8,972
Help Desk			0.25	23,925	0.25	23,925	0.25	23,925
Admin Expenses (Phones, travel)				15,000		5,000		5,000
Hardware/Software				125,000		15,000		15,000
<b>Project Subtotal</b>	<b>1.50</b>	<b>194,391</b>	<b>1.33</b>	<b>164,983</b>	<b>0.60</b>	<b>75,962</b>	<b>0.60</b>	<b>75,962</b>
<b>TOTAL IM FUNDING</b>	<b>5.79</b>	<b>732,047</b>	<b>5.20</b>	<b>642,727</b>	<b>4.52</b>	<b>587,704</b>	<b>3.85</b>	<b>495,592</b>

\* - HealthNet/BC standards implementation

\*\* - to use existing CFEHIV resources in year 1

## **APPENDIX 4**

### **BCCDC Immunization Program Proposal**

#### **Universal Infant and Childhood Catch-up Hepatitis B Immunization Program for British Columbia**

##### **ISSUE:**

The goal of British Columbia's hepatitis B immunization program is to prevent transmission of hepatitis B virus and prevent chronic disease due to hepatitis B infection.

Since 1992, British Columbia has had a highly successful, universal hepatitis B immunization program for grade 6 students. The intent of the program is to immunize students before they engage in high-risk activities that place them at risk of acute hepatitis B infection.

From 1991-1997, an annual average of 3 to 10 cases of reported and an estimated 30 to 100 actual cases of vaccine-preventable hepatitis B have occurred in British Columbia infants and children below grade 6. Infected infants have a 90% risk of developing chronic hepatitis B and children between ages 1 and 5 run a 30% risk of developing chronic hepatitis B infection. Early childhood infections account for up to 35% of all cases of chronic hepatitis B. Chronically infected persons are at increased risk for developing chronic liver disease (cirrhosis or chronic hepatitis) or liver cancer later in life.

To prevent hepatitis B infections in infancy and early childhood, and subsequent chronic infection and disease, the British Columbia Centre for Disease Control Society requests Ministry of Health funding for a universal infant hepatitis B immunization program, along with a catch-up program for susceptible children below grade 6.

##### **OPTIONS & IMPLICATIONS / RECOMMENDATIONS:**

The recommended program consists of the following 5 components:

##### **1. Universal Infant Hepatitis B Immunization Program**

Implement a universal infant hepatitis B immunization program as soon as possible. This program would prevent 30-100 cases of hepatitis B infection and 7-21 cases of chronic hepatitis B disease each year in children below grade 6. Hepatitis B vaccine would be administered at 2, 4 and 6 months of age, by the same provider (either a physician or public health nurse) who would normally administer the 2, 4 and 6-month "Pentacel " immunizations (Pentacel and hepatitis B vaccines can safely be administered concurrently).

##### **2. High-Risk Infants Not Identified by Prenatal Maternal Screening**

In addition, if a newborn or infant younger than 2 months is identified to be at higher risk of infection by hepatitis B virus (e.g., families at high risk, without a known infected individual, where a parent or other household member is a prostitute or known

injection drug user; the family has immigrated to BC from an area of high hepatitis B prevalence; or at least one parent was born in a country of high hepatitis B prevalence) then the infant should be offered hepatitis B immunoprophylaxis as soon as possible, ideally at birth.

### **3. Catch-up of all Children Entering Kindergarten, Over a 5-Year Period**

A fully funded catch-up is recommended to more rapidly protect susceptible children below grade 6 from vaccine-preventable hepatitis B infection. The recommended catch-up is to immunize all children entering kindergarten, over a 5 year period. Such a catch-up will prevent an estimated 75-286 acute hepatitis infections and 10-35 cases of chronic hepatitis disease in children below grade 6. After this period, the grade 6 program and kindergarten catch-up would end.

### **4. Catch-up of High-risk Children, Including High-Risk Immigrant Children Under Age 7 Currently Residing in BC, in the First Year of a Catch-up Period**

Preschool or school-aged children who are at high risk of exposure and infection by hepatitis B virus (e.g., families at high risk, without a known infected individual, where a parent or other household member is a prostitute or known injection drug user; the family has immigrated to BC from an area of high hepatitis B prevalence [e.g. Asia or Africa]; or at least one parent was born in a country of high hepatitis B prevalence), should be immunized against hepatitis B within the first year of a catch-up period.

There are approximately 12,000 high-risk immigrant children currently living in BC who are under age 7 and have immigrated to BC from Asia and Africa - regions of high hepatitis B prevalence. These children are at high risk of chronic hepatitis B disease and the National Advisory Committee on Immunization recommends they be vaccinated. They should also be immunized during the first year of a catch-up. Approximately 7,000 are school-aged children and 5,000 preschoolers. School-aged immigrant children would be immunized by public health at the time these children first enter the school system, while preschool immigrant children could be immunized through community public health clinics.

### **5. Annual, Ongoing Catch-up of All Immigrant Children under 12 Years of Age**

Each year, approximately 7,000 immigrant children under 12 years of age, settle in BC. These new Canadian children and youth are entitled to the same protection against hepatitis B infection as native-born Canadians. The National Advisory Committee on Immunization recommends a universal program during childhood. Approximately 80% (5,500 of 7,000) of immigrant children under 12 who settle each year in BC arrive from Asia and Africa, regions of high hepatitis B prevalence. All immigrant children should be immunized against hepatitis B in the first year after arriving in BC.

### **High-Risk Infants Identified by Prenatal Maternal Screening**

The current programs of prenatal maternal screening for chronic hepatitis B infection and provision of hepatitis B immune globulin at birth and hepatitis B vaccine for newborn infants of chronically infected mothers, and follow-up testing of persons at high risk of infection, would continue.





#### 4. Catch-up of High-risk Children, Including High-Risk Immigrant Children Under 7 Years of Age, Currently Residing in BC

Based on 100% coverage of 12,000 children under 7 years of age (estimate is based on data of immigration landings in BC from Asia and Africa between 1993-97) currently residing in BC, with a complete 3 dose series of hepatitis B vaccine; 100% of doses delivered by public health:

BCCDC cost	\$0.131 million	includes vaccine cost of \$0.113 million [at \$3.00 per dose] and provincial promotion, surveillance and evaluation
MSP cost	\$0	
Health Region cost	\$0.545 million	includes public health nursing and clerical resources, immunization supplies, regional promotion, client/public/health professional awareness and education, and regional evaluation
Ministry of Health	\$0.030 million	includes MOH preventive health communications

Total Cost \$0.706 million

Cost per person immunized \$58.90

Catch-up of other children considered at high risk because of their home circumstances (e.g., household contact of a prostitute or injection drug user) could be implemented with no added funding, if funding for a catch-up program for high-risk immigrant children under age 7 is approved.

At a cost of approximately \$59 per person immunized, the most conservative cost-benefit estimate of immunization is an overall direct cost of \$6 per person, based on the \$53 per person of cost savings estimated for the grade 6 program. More likely, immunizing this group will actually provide direct cost savings, because these children are at much higher risk of hepatitis B infection and chronic disease than grade 6 students.

#### 5. Ongoing Annual Catch-up of All Immigrant Children Under 12 Years of Age

Based on 100% coverage of 7,000 immigrant children under 12 years of age (estimate is based on data of immigration landings in BC between 1993-97) who settle each year in BC, with a complete 3 dose series of hepatitis B vaccine; 100% of doses delivered by public health:

BCCDC cost	\$0.077 million	includes vaccine cost of \$0.066 million [at \$3.00 per dose] and provincial promotion, surveillance and evaluation
MSP cost	\$0	
Health Region cost	\$0.299 million	includes public health nursing and clerical resources, immunization supplies, regional promotion, client/public/health professional awareness and education, and regional evaluation
Ministry of Health	\$0.030 million	includes MOH preventive health communications

Total Cost \$ 0.406 million per year

Cost per person immunized        \$58.00

At a cost of \$58 per person immunized, the most conservative cost-benefit estimate of immunization is an overall direct cost of \$5 per person, based on the \$53 per person of cost savings estimated for the grade 6 program. More likely, immunizing this group will actually provide direct cost savings, because these children are at much higher risk of hepatitis B infection and chronic disease than grade 6 students.

**Additional Incremental Costs for Expanded Hepatitis B Vaccination for Persons at High Risk**

**In addition to the above, between 1997 and 1999, there has been an increase of approximately 110,000 doses of hepatitis B vaccine given from year to year, at a cost of \$5.50 per dose. This has been ascribed to the following increased utilization by high-risk individuals, which are listed as follows:**

1. The grade 6 cohort, which has experienced a population growth of approximately 13,000 students since 1992: a 14% increase overall
2. The following high-risk groups:
  - a) men having sex with men
  - b) people with hepatitis C/injection drug users
  - c) others identified as being at higher risk of contracting hepatitis B
3. Students in post-secondary schools, including universities
4. Inmates of correctional institutions

**Summary of Expanded Hepatitis B Vaccination Costs**

<b>Program</b>	<b>Cost per Year</b>
Universal Infant Hepatitis B Immunization Program	\$1.57 million
High-Risk Infants Not Identified by Prenatal Maternal Screening	Nil if universal infant program approved
Catch-up of Children Entering Kindergarten over a Five-Year Period	\$2.4 million
Catch-up of High-Risk Children, Including High-Risk Immigrant Children under 7 Years of Age, Currently Residing in B.C.	\$0.7 million
Ongoing Annual Catch-up of All Immigrant Children under 12 Years of Age	\$0.4 million
<b>Subtotal: Expanded Neonatal and Catch-up Hepatitis B Program</b>	<b>\$5.07 million</b>
Enhanced Immunization for Hepatitis B in Persons at High Risk	\$0.5 million
<b>Total</b>	<b>\$5.57 million</b>

**Hepatitis A Vaccination**

The B.C. Centre for Disease Control needs additional funds from the Ministry of Health for hepatitis A vaccination of injection drug users (IDUs) and people infected with

hepatitis C virus (HCV). This vaccination program is needed to reduce both hepatitis A infection among IDUs and fulminant hepatitis in those already infected with HCV. It will also not only lessen the number of people with hepatitis A in correctional facilities, but will reduce the need for tracking their potentially infected contacts and administering immune serum globulin (ISG) to these contacts.

There are high rates and frequent outbreaks of hepatitis A among IDUs, a majority of whom are infected with HCV. If people with HCV become infected with hepatitis A, their risk of fulminant hepatitis and death increases. There are approximately 23,000 admissions to provincial correctional centres each year. An estimated 50 to 80 percent of inmates admit to injection drug use. There has been continued reporting of hepatitis A cases among inmates at provincial correctional centres. A recent increase in cases in Lower Mainland correctional centres has paralleled an increase among IDUs in Vancouver. Correctional centres therefore provide an ideal setting to target IDUs and persons with hepatitis C.

On February 16, 1998, the Ministry of Health allocated \$500,000 per year over the next two fiscal years (1998/99 and 1999/2000) to purchase hepatitis A vaccine for persons infected with HCV and for IDUs. Immunization began on April 30, 1998. It was noted from the start that the available funds were inadequate to provide complete coverage to all qualifying individuals. Because of the limited funds available for vaccine purchase, and because there is no funding for program delivery, the regions have not been able to optimally target and fully implement this program for IDUs and persons with hepatitis C. Most health regions had used all of their available vaccine for 1998/1999 prior to the end of the fiscal year. Vancouver used more than its 2-year allotment within 10 months.

The program requires that 2 doses of hepatitis A vaccine be administered. The second dose of vaccine should be provided within 12 months of the first dose. This means that all individuals who were immunized in 1998/1999 should receive a second dose in 1999/2000. There are not sufficient funds to provide these people with a second dose of vaccine as well as to provide first doses to other individuals during 1999/2000.

Since the program began, hepatitis A outbreaks have occurred among IDUs in a number of health regions in B.C., including Vancouver and South Fraser (April – June 1998), Vancouver (February – March 1999), and the Okanagan (January – March 1999). Control of each outbreak has required more vaccine than is available through current funding. It has also been necessary for these regions to expend considerable public health resources identifying and following up contacts of cases.

Contacts of cases of hepatitis A must be identified and administered with ISG within 14 days. In some settings, particularly in correctional centres, large numbers of ISG doses may be needed. Immune globulin products, including ISG, have become increasingly difficult to obtain in the past year. There are nationwide shortages of these products. We are at risk of not having sufficient ISG to follow up contacts of hepatitis A cases if IDUs and inmates at correctional centres are not immunized with hepatitis A vaccine.

If people at risk are not immunized, there will be increased costs for treatment and follow-up of infected IDUs and people with hepatitis C, and their infected contacts in turn. People at high risk who should be eligible for publicly funded vaccine, and

who seek immunization, will be turned away by regional health authorities. Because hepatitis A can be fatal in people with hepatitis C, there will be deaths that could have been prevented.

<b>Program</b>	<b>Cost per Year</b>
Purchase of Hepatitis A Vaccine (\$600,000) and Administration Costs (\$300,000) for IDUs and Persons with Hepatitis C Living in the Community	\$0.9 million
Purchase of Hepatitis A Vaccine (\$900,000) and Administration Costs (\$500,000) for Inmates of Provincial Correctional Centres	\$1.4 million
<b>Total</b>	<b><u>\$2.3 million</u></b>

## APPENDIX 5

### List of Individuals and Organizations who Participated in the Development of the Hepatitis Strategy

British Columbia Centre for Disease Control (BCCDC)	D. Cook A. King L. Engwer
Canadian Blood Services	P. Doyle
Centre for Excellence in HIV/AIDS	A. Anis M. O'Shaughnessy
Children's and Women's Health Centre of British Columbia (C&W)	S. Dobson R. Schreiber
Chinese Medical Association	K. Fung K. Yang
Community	L. Barney (Aboriginal Population Health Advisory Committee) N. Butterfield (Canadian Liver Foundation) N. Caplette G. Coburn (Hepatitis C Society) C. Dawson Y. Kwok (Canadian Liver Foundation) T. Lam D. Mazoff (Hepatitis C Society) H. Moeller (Hepatitis C Society) D. Morrow (Hepatitis C Society) D. Nguyen M. Scarborough-Cruz (Canadian Liver Foundation) W. Than K. Winiski (Hepatitis C Society)
Ministry of Health (M of H)	C. Gale A. Hazlewood S. Solven
Providence Health Care	M. Schecter C. Sherlock
Vancouver Hospital and Health Sciences Centre (VHHSC)	F. Anderson S. Erb P. Jewessen P. Kwan U. Steinbrecher E. Yoshida
Vancouver/Richmond Health Board (V/RHB)	J. Altman
Viridae	S. Sacks G. Stephens
Project Leaders	M. Krajden (BCCDC) M. Wong (V/RHB)
Consultants	K. Copeman-Stewart J. Fletcher K. Marks T. Roberts

## APPENDIX 6

### List of Individuals and Organizations To Whom the Proposal is being Circulated

In addition to those listed in Appendix 5:

British Columbia Cancer Agency	D. Carlow A. Weiss
British Columbia Centre for Disease Control (BCCDC)	D. Patrick M. Rekart R. Zapp
British Columbia Medical Association	I. Courtice
British Columbia Transplant Society	B. Barrable S. Vojnovic
Canadian Hemophilia Society, BC Chapter	S. Gibson
Children's and Women's Health Centre of British Columbia (C&W)	D. Money E. Reilly
Regional Health Boards, Community Health Councils, and Community Health Services Societies	CEOs and J. Sidorov, S. Killam, G. Mateus
College of Physicians and Surgeons of BC	P. Hickey
Community	S. Bilkhu L. Gibbenhuck M. Harris J. King-Diemecke C. Makarenko B. Milner D. Nicolaas H. Wong
Health Association of BC	L. Odegard
Health Canada, Health Promotion and Programs	M. Clarke
Ministry of Health (M of H)	L. Bayne L. Hollins E. Kanigan M. Knock A. McFarlane J. Murtagh
Providence Health Care	P. Hassen
Provincial Association of Medical Health Officers	A. Larder
Provincial Association of Public Health Nurses	S. Brown
Provincial Blood Coordinating Office	D. Pi
Vancouver Hospital and Health Sciences Centre (VHHSC)	B. Bowie M. Martin M. Whyte C. Wright
Vancouver/Richmond Health Board (V/RHB)	J. Blatherwick P. Daly M. McLean B. Shorter
Viridae	J. Farley