

The Hepatitis C Strategic Plan

A collaborative approach to the
emerging epidemic in California

**Recommendations from the
Steering Committee and Working
Group for the Prevention and
Control of Hepatitis C in California.**

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Executive Summary

The hepatitis C virus is one of the six viruses (A, B, C, D, E, and G) that together account for the majority of cases of viral hepatitis. Based on the National Health and Nutrition Examination Survey of 1988-94 and other population-based surveys, it is estimated that nearly 4 million Americans are infected with hepatitis C. The incidence of hepatitis C appears to be declining since its peak in 1989. However, because of the time lapse between hepatitis C infection and the resulting liver damage, an increasing number of people may be diagnosed or begin to experience symptoms. In 1999, it was estimated that there were approximately 30,000 new acute infections each year, but only 25-30% of these will be diagnosed. Hepatitis C accounts for 20% of all cases of acute hepatitis and is currently responsible for an estimated 8,000-10,000 deaths annually. Without effective interventions, the number is likely to triple within the next 10-20 years. Hepatitis C is now the leading reason for liver transplantation in the United States.

Based upon national data, an estimated 600,000 Californians have the infection and there are about 5,000 new cases every year. The disease adds more than \$50 million in costs every year to California's health care bill. There is no cure for hepatitis C and no vaccine is likely to be developed for at least ten years.

Because hepatitis C infection may cause few or no symptoms, many people are unaware that they have the virus. Hepatitis C is especially common among people who may have had contact with contaminated blood. Those most at risk include:

- persons who ever injected drugs, even once or a few times many years ago and who do not consider themselves drug users;
- injecting drug users who share needles;

- persons who received clotting factor produced before 1987 or who have ever received long-term hemodialysis;
- recipients of transfusions or organ transplants before July 1992;
- health care or emergency workers after possible exposure to hepatitis C-positive blood; and
- children born to hepatitis C-positive women.

The Hepatitis C Strategic Plan grew out of the need for a comprehensive, collaborative and organized approach by partners across California to address the public health problems associated with hepatitis C. It calls for the public health provider community to identify people with hepatitis C, provide counseling and case management, prevent further transmission of the virus, and educate health care and other providers, as well as the public, about this emerging problem.

The California Department of Health Services, in collaboration with local health officials, took the lead by convening a Strategic Plan Working Group, comprised of its many partners and hepatitis C stakeholders and advocates from across the state. The Steering Committee met twice to outline the problem, identify where hepatitis C activities are in place around the State, and where there are major gaps. They reviewed published studies and documents from the Centers for Disease Control and Prevention, the National Institutes of Health and other research findings. The Steering Committee identified theme or goal areas, drafted problem statements for each, drafted the ideas for a vision and mission, and recommended other groups for membership on the Working Group. The two Steering Committee Meetings were followed by two, two-day sessions of the Working Group. These

sessions served to develop and refine the problem statements, vision, and mission and the guiding principles. The Working Group divided into five smaller task groups, with each having the responsibility for developing the goal statement, objectives, and action items for one of the five goal areas. During each meeting, the entire group reconvened to discuss the recommendations and actions of each of the task groups and arrived at consensus on the key points for each area.

Since the final list of recommendations was beyond the capacity of all the partners to address within three years' time (the timeframe of the strategic plan), the Working Group recommended high priority/key issues to be addressed in the three year plan. Through this structured planning process, a strategic plan emerged comprising the mission, vision, guiding principles and five goals.

The mission of *The Strategic Plan* is to outline a coordinated, comprehensive, culturally appropriate and systematic approach that will prevent the spread of hepatitis C infection in California, limit the progression and complications of hepatitis C-related liver disease, and advocate for hepatitis C policies and resources. The five goals and their objectives of *The Plan* are stated below.

The goals, objectives and action steps outlined in *The Plan* are recommendations from the Statewide Working Group to the Department of Health Services.

Primary prevention goal:

Significantly decrease the number of people newly infected with hepatitis C using the most effective primary prevention strategies.

Objectives:

1. Develop and implement a targeted statewide media campaign to increase awareness and provide risk reduction information about hepatitis C. The campaign will be aimed at the

general public, identified high-risk populations, and other populations that may be underserved because of language, culture or other barriers.

2. Use the best epidemiological information available to develop and implement specific education and prevention strategies directed at high-risk populations.
3. Integrate hepatitis C education, counseling, testing, and referral into existing relevant programs that serve at-risk and other vulnerable populations.
4. Develop alternative sources for the delivery of hepatitis C primary prevention services for at-risk populations not served by HIV/AIDS, STD, and substance abuse treatment programs.
5. Evaluate the effectiveness of hepatitis C prevention programs.

Secondary prevention goal:

Establish a statewide system to identify as many hepatitis C-infected persons as possible and offer effective, accessible and affordable case management and treatment services to prevent or limit the progression and complications of hepatitis C infection.

Objectives:

1. Establish policies in state agencies that ensure the availability of hepatitis C counseling, testing, education, and case management or referrals for infected persons, and for all individuals in local methadone and other drug treatment as well as HIV/AIDS and sexually-transmitted disease (STD) programs, jails, local health departments and county clinics.
2. Establish policies in state agencies that ensure the availability of hepatitis C counseling, testing, education and case management of at-risk incarcerated populations served in state and community-based programs and facilities.

3. Establish a comprehensive care structure that provides hepatitis C screening, treatment, case management, patient education, substance abuse treatment and other related services to appropriate persons regardless of financial status.

Professional and public education and training goal:

Provide education and training in hepatitis C for health care professionals, policymakers, at-risk populations, hepatitis C-infected people and the general public.

Objectives:

1. Provide statewide education and training in Hepatitis C for individuals working with hepatitis C-infected persons and at-risk populations.
2. Implement a comprehensive public awareness and education campaign.

Surveillance and research goal:

Compile accurate, comprehensive and useful data on hepatitis C that will direct and support primary and secondary prevention, education and training, and long-term medical management and rehabilitation.

Objectives:

1. Make the California epidemiological profile for hepatitis C current and complete by identifying and prioritizing data gaps in order to show where interventions are needed.
2. Create an Internet-based directory linked to published and unpublished surveillance and research data on hepatitis C in California.
3. Support and participate in the national research agenda on basic, clinical, behavioral and

prevention effectiveness sciences related to hepatitis C.

Medical management and rehabilitation goal:

Slow the progression of hepatitis C, engage the patient and his or her family in disease management and rehabilitation, improve effective long-term management of hepatitis C, and improve the affected individual's quality of life.

Objectives:

1. Offer inclusive education and training opportunities on long-term clinical management of hepatitis C to physicians, nurse practitioners, physician assistants, registered nurses, social workers, drug and alcohol counselors, and allied health professionals.
2. Ensure that all health systems and facilities managing patients with liver disease offer patients and their families education about living with hepatitis C. System policies will be in place to assure, to the extent possible, that patients are provided assistance with and treatment for co-morbidity.
3. Assure continuity of care for hepatitis C patients who are transitioning to the community from incarceration.
4. Ensure that services, such as housing, employment, and social support that are currently available to HIV/AIDS patients (e.g., through the Ryan White Care Act) and that help to maintain patient functioning, are available to those with hepatitis C.

The Hepatitis C Strategic Plan Working Group envisions a coordinated local and statewide effort that will be supported by public and private partnerships providing comprehensive science-based hepatitis C virus services. *The Plan* is a dynamic document that

outlines only the beginning steps in the long process to prevent and control the spread of hepatitis C in California.

In the course of the planning process, many cross-cutting issues were identified that will need to be addressed if efforts are to be truly effective. Some of the issues identified include:

- funding for screening, testing, referral and treatment;
- public policies that support the prevention of transmission;
- case management for persons who are found to be infected;
- elimination of the stigma/discrimination that many hepatitis C-positive persons experience because of their infection; and
- the need to educate school-aged children about the disease and its transmission mode so they can make informed decisions to reduce or eliminate behaviors that put them at risk.

Subsequent to the Working Group's final meeting, Senate Bill 1256 (Polanco) passed the Legislature and was signed into law by the Governor (Health and Safety Code Section 122400-122420). It mandates several activities and responsibilities to the Department of Health Services. These include:

- making available the most recent information on detection, transmission, diagnosis, treatment and therapeutic decision-making for hepatitis C, including protocols and guidelines developed by the National Institutes of Health, the University of California at San Francisco and the California legislative advisory committees on hepatitis C, for use in educating physicians and health professionals, and in training community service providers;
- developing and implementing a public education and outreach program to raise awareness about hepatitis C among the public, health care providers and high-risk populations.

The Working Group recommendations provided as part of this plan, although completed before the passage of the bill, reflect the activities and prevention intent outlined in the new law.

Using This Document — Working The Plan

The Hepatitis C Strategic Plan is written for use by all groups and organizations in California which provide services to hepatitis C-infected persons or at-risk populations. This document provides practical guidelines for activities that state and local organizations can undertake now to improve the lives of those already affected by hepatitis C and to prevent future infections. *The Plan*, described in this document, is intended to:

- develop an understanding of hepatitis C;
- give leaders and organizations ideas about needed programs and services and the action steps required to implement them;
- support discussions of service and funding priorities with policy and decision makers in the public and private sectors; and
- provide guidance or a “game plan” to ongoing or new community-based hepatitis C task forces.

The Plan begins by outlining the problem. An overview of hepatitis C is presented, including discussions regarding screening, prevalence, and treatment for

this disease. The mission, vision, and guiding principles developed and recommended by the Steering Committee and Working Group follow.

The subsequent five sections, entitled Primary Prevention, Secondary Prevention, Professional and Public Education and Training, Surveillance and Research, and Long-term Medical Management and Rehabilitation, are the heart of *The Plan* and outline the goals, complete with objectives, action steps, and timelines specific to each goal. These sections are followed by a glossary of terms, sources for the information presented in the Overview of Hepatitis C section, and a brief list of publicly available resources.

The goals, objectives and action steps outlined in *The Plan* are recommendations from the Statewide Working Group to the Department of Health Services.

The Steering Committee and Working Group hope that *The Plan* will be useful in your work to combat hepatitis C in your community.

Overview of Hepatitis C

What is hepatitis C?

Hepatitis C is not new. It was first identified as a virus distinct from hepatitis A and B in 1987.¹ Prior to that time it was classified with the non-specific hepatitis viruses. Over the past few years, hepatitis C has come to be recognized as a major cause of hepatitis and the most common blood-borne

Most people with hepatitis C are chronically infected; they carry the virus, but may have no or only mild symptoms (loss of appetite, malaise, or abdominal pain). For this reason, many have not sought diagnosis and treatment, and may be unaware that they carry the virus. Nonetheless, the disease may be progressively harming the liver and infected persons may transmit the disease to others unknowingly.

The early period after exposure (until seroconversion or the production of detectable antibodies) is referred to as “acute” hepatitis C infection. After acute infection, the immune system in about 15-25% of infected people appears to clear the virus and resolve their infection. However, most people develop chronic hepatitis C infection. At present, it can be difficult to distinguish between acute, chronic or resolved infection, based on laboratory testing.

As the hepatitis C infection progresses slowly over the years, about 20% of infected people will develop advanced liver disease, and between 1% and 5% will die from liver cancer. The remaining hepatitis C-positive people appear to function without major health problems.

Already, hepatitis C is the leading cause of chronic liver disease and of liver transplants in the United States.³ It is estimated that the number of cases needing liver transplants will grow and thereby strain an already limited supply of donated livers. Hepatitis C is responsible for 8,000 to 10,000 deaths per year nationwide; the annual costs of acute and chronic hepatitis C exceed \$600 million.¹ Using these federal figures, estimates for hepatitis C in California would add more than \$50 million to health care costs per year. Persons with hepatitis C-induced chronic liver disease are also at greater risk for severe disease due to hepatitis A and B.

Who is most at risk for Hepatitis C?

- Persons who ever injected drugs, even once or a few times many years ago and who do not consider themselves drug users;
- Injecting drug users who share needles;
- Persons who received clotting factor produced before 1987, or who have ever received long-term hemodialysis;
- Recipients of transfusions or organ transplants (before July 1992);
- Health care or emergency workers after possible exposure to hepatitis C-positive blood.

infection in the United States. The hepatitis C virus enters the body through direct blood exposure. After entering cells in the liver, it begins the process that results in liver damage. An estimated 4 million people, 1.8% of all Americans, have been infected with the virus.² Based upon national data, an estimated 600,000 Californians are currently infected with hepatitis C. Additionally, it is estimated that in California, 5,000 people are newly infected each year.¹

About 1,000–1,200 Californians per year die from hepatitis C infection; this number is expected to triple over the next 20 years.¹

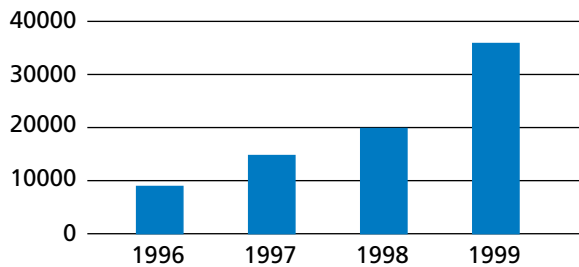
Reporting of hepatitis C

Although health care providers in California are required to report all cases of hepatitis C to the local health department, it is vastly under-reported, which makes it difficult to estimate how widespread the disease really is. Reasons for under-reporting include differences in definitions for acute and chronic infections, lack of testing, interpretation of laboratory tests, and confusion over reporting requirements. These problems are limiting factors in having accurate and current surveillance data with which to identify the number of infected persons, the number at risk of becoming infected, and the extent of the problem in California.

Who gets hepatitis C?

Hepatitis C infection occurs at all ages. Nationally, it is found most frequently among persons aged 30-49 years, and is slightly more common among males than females and among African Americans than whites.¹

Number of Reported Hepatitis C Cases in California 1996 - 1999



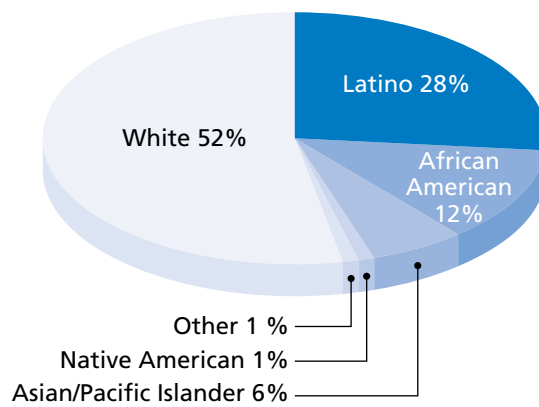
N = 76,430

Source: California Department of Health Services

Since 1996, when hepatitis C first became reportable in California, through 1999, approximately 76,430 cases have been reported.

The bar chart above depicts the number of hepatitis C cases reported in California for the four-year period for which data are available. The apparently increasing trend is most likely a function of increased testing and reporting rather than an indication of increasing numbers of new hepatitis C cases. Of the 76,430 cases reported, 64% were male and 35% female. All age groups were represented, but 91% were between 20 and 64 years old with a median age of 43. Excluding 37% for whom race/ethnicity was “unknown,” the race/ethnicity distribution is as shown in the following pie chart.

Race/Ethnicity of Hepatitis C Cases Reported in California 1996 - 1999



N = 48,151

Source: California Department of Health Services

What are risk factors for hepatitis C?

Factors which are associated with increased risk for hepatitis C include injecting drugs, even once or a few times many years ago; sharing needles; receiving long-term hemodialysis or clotting factor produced before 1987; and possible exposure to hepatitis C-positive blood.

The risk of hepatitis C transmission from mothers to infants and among non-sexual household members exposure is low. The evidence regarding the risk of hepatitis C transmission through sexual behavior is somewhat mixed. The risk from blood transfusions

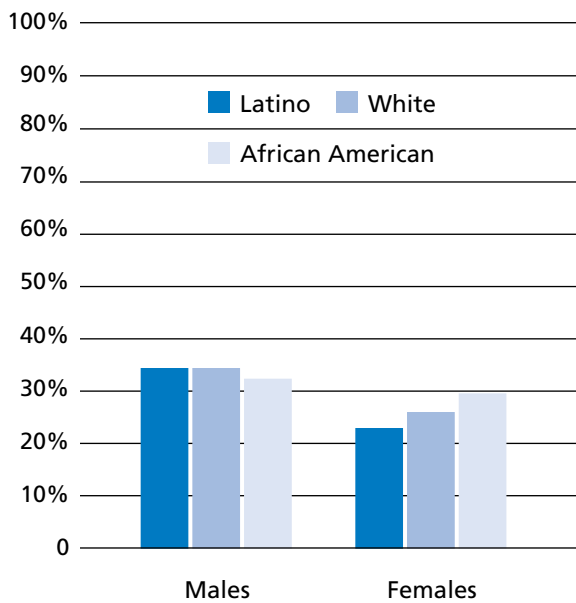
was essentially eliminated in 1992, when screening tests for hepatitis C became widely available. However, many persons infected before the tests were developed may not know they have hepatitis C. Currently, injecting drug users (primarily those who share needles), account for more than half of hepatitis C transmission in the United States. Many persons with chronic hepatitis C infection may have acquired their infection 20 to 30 years ago as a result of occasional drug injection. Surgical procedures by infected surgeons and tattooing have been associated with infection outside the United States but are not documented in this country.

29% of African Americans were infected. The number of Asian/Pacific Islanders in the survey population was too few to be statistically significant. The higher prevalence of hepatitis C among incarcerated populations may be due to illegal injection drug use among the population.

Screening for hepatitis C

Most people with hepatitis C have not been screened and do not know that they are infected. Screening tests currently approved by the United States Food and Drug Administration measure antibodies to the virus in the blood. The tests are successful in detecting the disease in almost all infected patients. However, this screening test does not indicate the stage to which the disease has progressed. Only a liver biopsy (biological sample of liver tissue that is used to measure the severity of inflammation and health of the liver) can show the extent to which the liver has been affected. Other tests are available for measuring the type of hepatitis C virus (which gives an indication of how best to treat) and for measuring the extent of virus (“viral load”) in the bloodstream and body tissues.

Percentage of Inmates Entering California Correctional System Infected with Hepatitis C



Source: California Department of Health Services

Hepatitis C is particularly common in certain settings, including jails and prisons. Survey research concerned with hepatitis C among inmates entering the California correctional system indicated that 34% of men and 25% of women were infected.

Among men, 36% of Latinos, 36% of whites, and 34% of African Americans were infected, while among women, 24% of Latinos, 26% of whites, and

Treatment and management for hepatitis C

California scientists are participating in efforts to develop a hepatitis C vaccine, but an effective immunization is at least a decade away. At present, diagnosis, treatment, and case management are the only choices.

Although scientists are reluctant to call it a “cure,” treatment is available which can lead to hepatitis C virus being undetectable over the long term. Further, treatment success is associated with improvement in liver biopsies for years after being discontinued. However, on assessment by the physician, not all persons who test positive for hepatitis C are considered good candidates for the current treatment, and some hepatitis C-positive persons elect not to undergo the

treatment due to serious side effects or other problems. Case management for patients with chronic hepatitis C becomes a critical factor in delaying or ameliorating the effects of the disease. Case management may include:

- counseling to reduce the risk of transmitting the disease to others;
- encouraging abstinence from alcohol consumption;
- referral for substance abuse treatment;
- vaccination against hepatitis A and B;
- evaluation for treatment options; and
- screening for liver cancer.

A biopsy is recommended for evaluating and staging the severity of liver damage before treatment begins. Testing for genetic variation (genotype) of the virus is required as various genotypes respond differently to current treatments. Genotype 1 accounts for about 75% of hepatitis C infections in the United States, but is less responsive to standard interferon-based treatments. Currently, the goal of treatment is to induce a state where the virus is not detectable in the blood during, at the conclusion of, and for six months after treatment is discontinued. Long-term follow-up studies of patients with such a response to treatment have demonstrated continued undetectability of virus in over 95% of patients, and marked improvement in liver biopsies over time. In recent trials of ribavirin combined with alpha interferon, a sustained virological response has been demonstrated in about 30% of patients infected with genotype 1, and 66% of patients infected with genotypes 2 or 3.²

Behavioral interventions

There are several things that patients with hepatitis C can do to protect their health and the health of people around them. These include: abstaining

from alcohol; getting vaccinated against hepatitis A and B; stopping injecting drug use; having a healthful diet; consulting a nutritionist or dietician; obtaining support for stress management; and if possible, avoiding sharing razors, toothbrushes, nail clippers, needles, or other items that might be contaminated by blood.

Although patients must be carefully selected for treatment with the current drug therapies due to potential side effects, treatment may prolong life and reduce costs of care. Screening, testing, counseling, and management of hepatitis C patients may, in the long run, improve their quality of life, reduce morbidity and mortality, and prevent the spread of the disease to others.

Legislation

Subsequent to the Working Group's final meeting, Senate Bill 1256 (Polanco) passed the Legislature and was signed into law by the Governor (Health and Safety Code Section 122400-122420). It mandates several activities and responsibilities to the Department of Health Services. These include:

- Making available the most recent information on detection, transmission, diagnosis, treatment and therapeutic decision-making for hepatitis C, including protocols and guidelines developed by the National Institutes of Health, the University of California at San Francisco and the California legislative advisory committees on hepatitis C, for use in educating physicians and health professionals, and in training community service providers;
- developing and implementing a public education and outreach program to raise awareness about hepatitis C among the public, health care providers and high-risk populations.

With the passage of Senate Bill 1256 (Polanco), allocating funding for hepatitis C education, outreach, and screening, the opportunity to increase

awareness among populations most seriously affected becomes a more realistic goal. The law requires cooperation among a broad group of partners across the state, e.g., existing programs

within the Department of Health Services, Department of Corrections, Department of Veterans Affairs, local health officials, and community-based non-profit organizations.

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The Working Group Process

Who was included in the process?

In recognition of the growing medical, human, and financial burden associated with hepatitis C, the California Department of Health Services convened key stakeholders from the public and private sectors to make recommendations for a three-year strategic plan. Altogether more than 70 people participated in discussions and made recommendations at meetings held during winter and spring, 2000. Members of the group gave hundreds of hours of their time to developing *The Plan* (see list of members on pages iii - v).

How did the process work?

The Department of Health Services identified the need for a strategic plan as a first step in responding to hepatitis C in California. Department staff, working with local health officials, identified key stakeholders from across the state, and enlisted their support and participation in the planning process.

Throughout the process, the group worked for consensus among the partners. Since the group primarily focussed on addressing the goals and objectives for the three-year plan, many issues remain to be addressed in future discussions and plans.

The Steering Committee met twice to outline the problem, identify hepatitis C activities in place around the state, and determine major challenges or gaps. At the start of the process, four themes were proposed: primary prevention, secondary prevention, professional and public education and training, and surveillance and research.

To address the emerging needs of the population chronically affected by hepatitis C, a fifth theme was added: long-term care and rehabilitation.

Key Stakeholders

- State agencies
- Local health jurisdictions
- Health-related groups
- Managed care organizations
- Professional societies
- Community-based organizations
- Physicians and medical educators
- Policymakers
- Persons infected with hepatitis C
- Universities and research centers
- Centers for Disease Control and Prevention

The Steering Committee reviewed published studies and documents from the Centers for Disease Control and Prevention and the National Institutes of Health, as well as other research findings. National experts and speakers provided current information about the extent of the hepatitis C problem in California and the nation. The committee drafted the problem statements, ideas for a vision and mission, and suggested other groups to include in the planning process. The expanded number of participants would join with the Steering Committee to become the Working Group.

The two Steering Committee meetings were followed by two, two-day sessions of the Working Group. Again, the national and state experts provided current information on hepatitis C. The problem statements, vision and mission were redefined and

refined, and the guiding principles developed. To address discrete issues, the Working Group divided into five small task groups with each having the responsibility for developing the goal statement, objectives, and action items for one of the five goal areas. Visualizing the intended impact of each objective helped the group to determine which objectives and action steps were necessary. After each small group meeting, the entire group reconvened to discuss the recommendations and actions of each task group and arrived at consensus on the key points for each area.

The final list of objectives, recommendations and action steps were greater than the capacity of all the partners to address within a three-year plan. To ensure that a realistic and workable plan was developed, the Working Group assigned priorities to the objectives thought to be most urgent to the goals of preventing transmission of hepatitis C and reducing disease progression for those already infected.

The Working Group then recommended high priority, key issues to be included in the three-year plan. Through this structured planning process, a strategic plan emerged comprised of the mission, vision, guiding principles and five goals, with objectives

and action plans for each. The committee process ensured that all groups working with or having program responsibilities for hepatitis C prevention and control contributed to identifying concerns and planning strategic actions.

Outcome of the process

The Working Group agreed that health, medical, and community services in California must be better equipped to respond to the needs of those who are infected, or at risk for hepatitis C. *The Hepatitis C Strategic Plan* provides a road map for the actions that California partners and stakeholders can take to reduce the growing burden that hepatitis C imposes. Many of these actions can be undertaken now, using existing resources, facilities, and infrastructure. Recognizing hepatitis C as an emerging public health problem, distinct from other communicable diseases, will give focus to the delivery of services.

The goals, objectives and action steps outlined in *The Plan* are recommendations from the Statewide Working Group to the Department of Health Services. Activities or services recommended in the plan for Health and Human Services and other state agencies are contingent on resources being available.

Timeline of Strategic Plan Development

- November – December 1999: Formation of Steering Committee and survey of priorities
- January 21, 2000: Steering Committee agrees on key goal areas; discusses mission and vision
- March 24, 2000: Steering Committee develops mission and vision statements; identifies target groups, stakeholders; identifies goals, outcomes
- April 17-18, 2000: Working Group hears background presentations; generates/revises vision, mission, guiding principles; develops and reports back on goals, objectives; develops implementation strategy
- May 30-31, 2000: Working Group finalizes mission, vision, guiding principles, goals; identifies action steps, timelines, responsible parties, priorities
- June – December 2000: Plan writing, development and review
- August 2000: Governor signs SB1256

What are the next steps?

A key feature of *The Plan* is that stakeholders need not wait for the State to provide further guidance. They can begin to improve hepatitis C-related services now by identifying opportunities for moving forward, drawing upon the action steps outlined by *The Plan*.

The Working Group recognized that several areas of concern relate to all goals of the strategic plan for hepatitis C. Recommendations include, first and foremost, the need to continue a broad-based, collaborative, and inclusive advisory process in which the voices of all representative parties are heard.

The effort to reduce hepatitis C in California will be undertaken through the continuing partnership of key stakeholders. These stakeholders and others will

work with the Department of Health Services to implement *The Hepatitis C Strategic Plan*.

As with the planning process, the statewide group may convene small task groups to track progress on the five major goals of *The Plan*. This includes providing input on primary and secondary prevention, professional and public education and training, surveillance and research, long-term medical management and rehabilitation, and program evaluation. Task groups may include members whose special experiences will assist in moving the objectives and action steps forward, although they may not participate in the larger statewide group. As part of its process, the group will also address other crosscutting issues such as advocacy, policy change, and funding.

Mission, Vision, and Guiding Principles

Mission Statement

The purpose of *The Hepatitis C Strategic Plan* is to outline a coordinated, comprehensive, culturally appropriate, and systematic approach that will prevent the spread of hepatitis C infection in California, limit the progression and complications of hepatitis C-related liver disease, and advocate for hepatitis C policies and resources.

Vision Statement

The vision for hepatitis C prevention and control is a coordinated local and statewide effort supported by public and private partnerships providing comprehensive, science-based hepatitis C services that assures:

- affordable and accessible hepatitis C counseling, screening, education, treatment, harm reduction and prevention efforts are available to all persons in need;
- education of patients, providers, policymakers and the public about hepatitis C;
- collection and analysis of hepatitis C data and dissemination of findings to stake holders;
- support for hepatitis C-related research; and
- reduction in the number of new hepatitis C infections and hepatitis C-related deaths.

Guiding Principles

As part of its process, the Working Group identified several guiding principles as critically important. According to these principles, *The Hepatitis C Strategic Plan*:

- represents a comprehensive approach to hepatitis C that recognizes the inherent value of all individuals regardless of route of infection;
- builds hepatitis C services on the existing infrastructure for HIV/STD, methadone, alcohol and other drug treatment systems for common target populations and, where appropriate, provides hepatitis C-specific services to those individuals outside of, and not served by the existing infrastructure;
- recognizes that there are groups that are disproportionately affected by hepatitis C and makes funding allocations to decrease disparities;
- advocates for hepatitis C services that are culturally and linguistically appropriate, accessible and non-discriminatory;

- recognizes the social and economic impact of hepatitis C infections on families, communities, and the health care system;
- recognizes that hepatitis C prevention is a shared responsibility between the public and private sector;
- supports action steps and policies that are evidence-based;
- ensures confidentiality; and
- improves quality of life for those with hepatitis C infections.

Primary Prevention

Goal

Significantly decrease the number of people newly infected with hepatitis C using the most effective primary prevention strategies.

Overview

Primary prevention is the process of providing information and education services to healthy populations to allow them to make decisions that will reduce their risk and protect them from contracting illness or disease. As it relates to hepatitis C, primary prevention involves those strategies used to reduce the risk of contracting hepatitis C. It can also include counseling hepatitis C-infected persons on methods to prevent the transmission of their infection to other people.

Primary prevention includes the steps that can be taken to reduce the spread of the hepatitis C virus in the population through:

- screening and testing of blood, plasma, organ, tissue and semen donations;
- screening, testing and counseling of those who have engaged in high-risk activities such as injecting drug use;
- screening, testing, and counseling of individuals who have had percutaneous (through the skin) exposures to blood in health care or emergency situations;
- risk-reduction counseling and services; and
- implementation and maintenance of infection control practices.

An important goal of primary prevention is to encourage high-risk individuals to participate in

screening, testing, and counseling. This can be accomplished through prevention interventions that include:

- public education using strategies such as targeted media campaigns;
- efforts aimed at high-risk populations, hepatitis C-infected persons, and members of their family and social networks; and
- messages integrated into harm reduction, STD and HIV/AIDS counseling, testing, and treatment services, as well as substance abuse and mental health programs.

To be effective, a prevention strategy for hepatitis C must reach:

- individuals who have injected drugs, including those who injected once or more times many years ago and do not consider themselves to be drug users;
- injecting drug users who share needles;
- persons who are or have been on long-term hemodialysis;
- recipients of transfusions or organ transplants prior to July 1992, or anyone who received clotting factor produced prior to 1987;
- children born to hepatitis C-positive mothers;
- health care, emergency medical and public safety workers who were exposed to hepatitis C-positive blood;
- persons incarcerated in California correctional institutions; and
- the public, including those who may be infected with hepatitis C.

Challenges to prevention

A lack of available epidemiological data about the extent of the hepatitis C problem is a major challenge to effective prevention planning. Without data, it is difficult to raise public and provider awareness and garner support for disease interventions. Lack of public interest in, and support for, programs serving substance users, the mentally ill, and individuals infected with infectious disease, along with categorical and programmatic restrictions which make it difficult to integrate hepatitis C into existing STD and HIV/AIDS programs, pose additional challenges. Added to the above challenges is the need to address the many different cultural and language groups in California with relevant prevention messages.

Current prevention efforts

California scientists are participating in efforts to develop a hepatitis C vaccine, but effective immunization is at least a decade away, highlighting the need for other prevention interventions. Since 1992, blood banks have screened blood donors, tested blood and blood products, and taken steps to inactivate the virus. These steps have sharply reduced the rate of new infections due to blood transfusions and blood products.

Some local health agencies have taken the initiative to form community task forces on hepatitis C. These task forces are providing local services that include education, screening and counseling. Additionally, they are promoting the integration of hepatitis C prevention into existing risk reduction services such as STD/HIV/AIDS testing and counseling programs and other community-based programs that serve at-risk populations. Several county health officials have introduced primary prevention measures and counseling through their clean needle and syringe exchange interventions. These interventions are made possible by the implementation of Health and Safety Code Section 11364.7 that allows for the clean needle and syringe exchange activities to be

authorized “pursuant to a declaration of a local emergency due to the existence of a critical local public health crisis.”

There is no comprehensive statewide program to address all of the problems and challenges associated with hepatitis C prevention and control, however.

Public health surveys are currently being used to guide prevention efforts. These surveys help to identify who is infected with hepatitis C, their geographic distribution, and modes of transmission. Hepatitis C is also being addressed in the training of health workers and infection control personnel.

The need for a comprehensive approach to prevention

Despite this promising beginning, California needs a comprehensive strategic approach to hepatitis C prevention. With improved knowledge about the risk factors for hepatitis C, health care providers can more effectively promote risk reduction and prevent behaviors that put individuals at risk. Health care providers can help by educating their patients, clients, and communities.

The Hepatitis C Strategic Plan Working Group has recommended educational interventions for hepatitis C-positive and high-risk negative individuals with the goal of preventing future transmissions or re-infections. Under the leadership of public officials and policymakers, programs will seek to increase knowledge and decrease fear and stigma directed at individuals infected with hepatitis C.

Hepatitis C prevention interventions and services will be integrated into existing primary care, HIV/AIDS, STD, substance abuse, mental health, and family planning services, as well as corrections. They will reach out to people at high risk of contracting hepatitis C or those who may not know that they have been exposed. In order to reach as many people as possible, hepatitis C prevention messages must be relevant to affected individuals of all cultures and backgrounds across the state.

Steps to develop a comprehensive hepatitis C prevention strategy

The following five objectives are the identified priorities for development of an effective primary prevention strategy.

Objective 1: Develop and implement a targeted statewide media campaign to increase awareness and provide risk reduction information about hepatitis C. The campaign will be aimed at the general public, identified high-risk populations, and other populations that may be underserved because of language, culture or other barriers.

Action Steps

During year one, the Department of Health Services (DHS) should:*

1. Convene a group to advise the Department on the planning and implementation of a targeted statewide media campaign.
2. Develop targeted social marketing, public relations and advertising strategies using the best epidemiological information available, and issue requests for proposals to implement them.

During year one, advocacy groups will:

3. Take the lead in the development of appropriate policy and legislation to support a hepatitis C media campaign.
-

Objective 2: Use the best epidemiological information available to develop and implement specific education and prevention strategies directed at high-risk populations.

Action Steps

During years one, two and three, DHS should:*

1. Prepare a summary of California epidemiological data on hepatitis C from all sources in order to target primary prevention services.
2. Identify appropriate science-based prevention and risk reduction strategies for California populations and assess and prioritize interventions.
3. Provide guidance and technical assistance to local health jurisdictions on hepatitis C prevention interventions.
4. Use existing public agencies to reach out to target populations with hepatitis C prevention interventions.
5. Work with relevant community-based organizations to provide prevention services to target populations.
6. Identify gaps and advocate for the development of hepatitis C-specific programs and policies.

* Contingent on resources being available.

Objective 3: Integrate hepatitis C education, counseling, testing, and referral into existing relevant programs that serve at-risk and other vulnerable populations.

Action Steps

During year one, DHS should:*

1. Promote the incorporation of hepatitis C prevention messages and interventions into existing HIV/AIDS, STD, harm reduction, substance abuse and mental health treatment programs whenever possible.
2. Develop hepatitis C-specific procedures and protocols (i.e., guidelines) for program screening and counseling personnel.

During years two and three, DHS should:*

3. Develop or adapt existing hepatitis C prevention training curricula for program staff.
4. Design and produce or adapt existing hepatitis C prevention training materials for program staff.
5. Encourage identified programs for high-risk populations to integrate newly developed hepatitis C risk reduction messages into existing procedures and protocols for the delivery of prevention services.
6. Coordinate staff training in hepatitis C prevention procedures.

Objective 4: Develop alternative sources for the delivery of hepatitis C primary prevention services for at-risk populations not served by HIV/AIDS, STD, and substance abuse treatment programs.

Action Steps

During year one, DHS, working with local health jurisdictions and community-based service providers, should:*

1. Conduct a needs assessment to determine what prevention services are available, what services are needed for an effective intervention and what areas/regions may have a higher priority for services.

During years two and three, DHS, in collaboration with existing training providers, should:*

2. Provide training to those community-based service providers (identified in Objective 3) that reach the high-risk and at-risk populations to assure that their counseling and referral services provide current and accurate information.

* Contingent on resources being available.

Objective 5: Evaluate the effectiveness of hepatitis C prevention programs.

Action Steps

During year one, DHS, working with local service providers, should:*

1. Identify key evaluation questions and standard measures of program effectiveness.

During years one and two, DHS should:*

2. Provide guidance on how to evaluate primary prevention programs for hepatitis C.

During years two and three, DHS, in collaboration with relevant groups, should:*

3. Provide technical support and training for contractors and health program staff so that they can evaluate hepatitis C primary prevention activities.
4. Evaluate the effectiveness of prevention strategies, using appropriate process and outcome measures.
5. Prepare and distribute reports resulting from the evaluation of hepatitis C primary prevention activities to local health departments, community-based organizations, and other relevant agencies providing hepatitis C prevention services.

* Contingent on resources being available.

Secondary Prevention

Goal

Establish a statewide system to identify as many hepatitis C-infected persons as possible and offer effective, accessible, and affordable case management and treatment services to prevent or limit the progression and complications of hepatitis C infection.

Overview

Secondary prevention is the process of developing strategies to identify, counsel and test individuals most likely to be infected with hepatitis C (or other infectious diseases) and to provide them with appropriate medical and case management.

Secondary prevention activities can reduce the risks for chronic liver disease by identifying hepatitis C-infected persons as early as possible through diagnostic testing and by providing appropriate medical treatment.

A comprehensive approach to hepatitis C screening and management will enable health care providers to best identify and serve hepatitis C-infected people. Appropriate care and case management will minimize liver damage, encourage patients to engage in actions to improve their health and well being, and reduce the risk of transmitting hepatitis C to others.

Who should be tested?

The Centers for Disease Control and Prevention recommends that hepatitis C testing should be routinely offered to people most likely to be infected and that testing should be accompanied by appropriate counseling and medical follow-up. Testing should also be available for persons wishing

to know their hepatitis C status. Routine testing for hepatitis C virus should be available to:

- Persons who ever injected drugs, even once or a few times many years ago and who do not consider themselves drug users;
- Injecting drug users who share needles;
- Persons who received clotting factor produced before 1987 or who have ever received long-term hemodialysis;
- Recipients of transfusions or organ transplants (before July 1992);
- Health care or emergency workers after possible exposure to hepatitis C-positive blood;
- Persons incarcerated in California correctional institutions; and
- Children born to hepatitis C-positive women.

Secondary prevention activities

The Hepatitis C Strategic Plan outlines a framework that will enable infected individuals to receive immunizations for related diseases such as hepatitis A (HAV) and B (HBV), and case management for the coordination of services. It outlines activities needed to develop and set standards for screening, treatment, and case management for public and private services in locations ranging from physicians' offices to health department clinics to HIV, STD and other screening and testing sites.

In order to be economical and efficient, secondary prevention activities build upon existing services, standards of care for hepatitis patients, and assurance that staff is appropriately trained to implement them.

The time from infection to the appearance of the symptoms of hepatitis C can be many years. Currently, effective treatments are limited, but science is progressing with new studies underway. Available treatments are expensive and carry serious side effects.

For this reason, it is important to ensure that health care providers are fully aware of:

- Treatment options and consequences;
- The importance of immunization against other infectious diseases such as hepatitis A, hepatitis B, and influenza; and
- Counseling on alcohol and other drug abuse, and risk reduction to prevent disease transmission and progression.

Providers can also counsel hepatitis C-positive persons against donating blood, organs, or other tissue, sharing toothbrushes, razors, or other personal articles that might have blood on them.

Comprehensive services decrease morbidity and mortality

People infected with hepatitis C often experience a number of medical, social and psychosocial challenges, such as depression and pain, nutrition and eating problems, and mental health and substance abuse problems. Helping hepatitis C-infected persons to deal with these problems, in addition to their medical problems, requires a wide variety of support and expertise from health and social services.

Advocacy groups and community-based organizations have taken the lead in providing support services, but their efforts are insufficient without increased counseling, testing, treatment and case management services in the public sector. Hepatitis C services can be integrated with STD, HIV/AIDS, and drug and alcohol programs. Public agencies, local health departments, and private medical providers need to join community-based organizations in a comprehensive approach to hepatitis C.

Steps toward developing comprehensive services

The following three objectives were identified as priorities in developing comprehensive services to counsel, test, support, and treat people with hepatitis C.

Objective 1: Establish policies in state agencies that ensure the availability of hepatitis C counseling, testing, education and case management or referrals for infected persons, and for all individuals in local methadone and other drug treatment as well as HIV/AIDS and STD programs, jails, local health departments and county clinics.

Action Steps

During year one, DHS should:*

1. Review the most recent Centers for Disease Control and Prevention screening and testing guidelines.

During year one, DHS, the Department of Alcohol and Drug Programs (DADP)*, the California Conference of Local Health Officers (CCLHO), and the Board of Corrections (BOC)* should:*

2. Draft and develop California-specific screening/testing and education guidelines that are consistent with *The Hepatitis C Strategic Plan*.

* Contingent on resources being available.

During year one, DHS and DADP* should:*

3. Incorporate hepatitis C screening and testing guidelines/directives into state contracts where appropriate (e.g., Medi-Cal managed care).

During year one, DHS should:*

4. Assess the need for regulatory change necessary to implement Objective 1.

During years two and three, local health departments, blood centers and transplant centers should:*

5. Maintain community-based activities to locate, screen, and test people who may be hepatitis C-positive.

Objective 2: Establish policies in state agencies that ensure the availability of hepatitis C counseling, testing, education and case management of at-risk incarcerated populations served in state and community-based programs and facilities.

Action Steps

During year one, the Department of Corrections (DOC) and California Youth Authority (CYA)* should:*

1. Review the most recent Centers for Disease Control and Prevention and national prison guidelines for hepatitis C screening/testing.
2. Draft/develop California-specific screening/testing/education guidelines that are consistent with *The Hepatitis C Strategic Plan*.
3. Implement guidelines widely, where possible.

During year one, DHS should:*

4. Assess the need for regulatory change necessary to implement Objective 2.

Objective 3: Establish a comprehensive care structure that provides hepatitis C screening, treatment, case management, patient education, substance abuse treatment and other related services to appropriate persons regardless of financial status.

Action Steps

During years one and two, DHS, other state and local agencies*, medical associations and health care providers should:*

1. Incorporate hepatitis C screening and counseling services, and referral for persons found to be infected into existing STD, HIV/AIDS, drug abuse, mental health and primary care programs that reach both at-risk and low-risk populations.

* Contingent on resources being available.

During year two, DHS*, CCLHO, California Medical Association (CMA), and physicians should form a task force to:

2. Develop and/or adapt and distribute medical standards for hepatitis C treatment and case management.

During year two, state agencies*, CCLHO, physicians, and health maintenance organizations will:

3. Develop case management standards for hepatitis C.

During year two, DHS*, CCLHO, CMA, the Medical Board of California, and academic medical centers should:

4. Educate physicians and other providers regarding the new hepatitis C medical and case management standards.

During year three, DHS*, CYA*, DOC*, Board of Corrections*, local health agencies*, medical societies, and health maintenance organizations should:

5. Encourage the incorporation of a comprehensive care model for hepatitis C, including case management, into public and private sector medical practice.
6. Determine where hepatitis C services are not provided and develop a plan to offer services in these settings.

* Contingent on resources being available.

Professional and Public Education and Training

Goal

Provide education and training in hepatitis C for health care professionals, policymakers, at-risk populations, hepatitis C-infected people and the general public.

Overview

Despite the large number of people in California infected with hepatitis C and the costs of treatment for liver disease, the virus is unfamiliar to the public and policymakers. Awareness of hepatitis C has increased within the health and medical community, and grassroots and advocacy organizations have formed in support of affected populations. Knowledge about hepatitis C is evolving, but many clinicians do not have easy access to current information. There is a significant need for information, education, and communication about the disease.

There are many reasons why this is an important time to undertake training and educational activities around hepatitis C:

- Many members of the public do not understand the differences between hepatitis C and hepatitis A and B;
- Some Californians may be unaware that they are hepatitis C-infected; others with chronic hepatitis C may not know what steps they can take to improve their long-term health and functioning;
- The absence of readily available information about the disease makes it difficult to motivate people to seek services;
- Many clinicians are not current on hepatitis C screening, counseling and treatment information

and need additional education and training about the natural history and medical management of hepatitis C and liver disease;

- Health and social service professionals lack information about when and where to refer hepatitis C patients for support services, patient education, and financial assistance.

Given these needs, a goal of *The Hepatitis C Strategic Plan* is to increase public and provider awareness of the disease in order to prevent hepatitis C transmission. Another goal is to enhance provider ability to help people with hepatitis C to manage their illness.

Educating professionals

A major goal of *The Plan* is to increase professional knowledge and awareness of hepatitis C and to educate all health and community service personnel working with hepatitis C-infected and at-risk populations. This requires education for staff at many levels, from students to supervisors, and across settings. Curricula and training methods must be adapted to staff working in community primary care and specialized services, correctional agencies, teaching hospitals and elsewhere.

Educating the public

In addition to professional training and education, a statewide comprehensive public education campaign will reach out to a more general audience. The campaign will raise awareness about hepatitis C and outline steps that can be taken to reduce the risk of acquiring or transmitting the disease. It will include messages with broad appeal as well as those that are culturally and linguistically relevant

to California's diverse populations. Messages for reaching the public will be identified during a formative phase. They can be broadcast via radio or television and made available at schools and colleges, libraries, video stores, and other commercial sites. The Internet offers a powerful tool for reaching out to broad and special audiences. The statewide campaign will take place in coordination with Primary Prevention activities (see Goal 1).

Evaluations to assess progress

Evaluations will monitor the implementation and the accomplishments of professional training and education and of the public awareness campaign. These evaluations will assess the extent to which strategic actions have been successful and highlight where changes in approach should be made.

Steps to develop a comprehensive educational strategy

The following two objectives are priorities in developing a comprehensive education and training strategy.

Objective 1: Provide statewide education and training in hepatitis C for individuals working with hepatitis C-infected persons and at-risk populations.

Action Steps

During year one, DHS and its partners (who may include community-based organizations, health educators, and state and local educational organizations) should:*

1. Conduct a statewide assessment of the need for hepatitis C education among health and community services professionals and students.

During year two, DHS and its partners should:*

2. Design and develop or adapt existing educational and training materials that are culturally and linguistically relevant to California's diverse populations based upon the needs assessment and drawing from existing educational and training resources.

During years two and three, DHS and local health agencies* should coordinate statewide professional hepatitis C education and training to:*

3. Develop or adapt existing curricula appropriate to different audiences.
4. Develop training programs or adapt existing training programs.
5. Ensure that program staff has access to hepatitis C education and training.

During years two and three, DHS and its partners should:*

6. Ensure that hepatitis C training programs offer continuing education credit.

During year three, DHS and its partners should:*

7. Promote evaluation of hepatitis C professional training and education.

* Contingent on resources being available.

8. Make hepatitis C education and training available, but not limited, to the following groups:

- Health care professionals, including students and trainees,
- Health care and other program volunteers,
- Staff of alcohol and drug treatment programs,
- Outreach workers, especially those at needle exchange and other community-based programs,
- Staff of local health agencies such as STD and substance abuse services,
- Management and frontline workers in correctional facilities, and
- Staff of organizations that work with the homeless.

Objective 2: Implement a comprehensive public awareness and education campaign.

Action Steps

During year one, DHS and its partners should:*

1. Assess print and video materials on hepatitis C that are currently available in public places such as libraries, video stores, universities.
2. Encourage the production and distribution of up-to-date information on the disease as needed.

During years one and two, DHS and its partners should:*

3. Maintain and publicize a website for up-to-date hepatitis C educational and informational resources, including an events calendar.
4. Solicit support for the development of web-based education and information.

During year two, DHS and its partners should:*

5. Collaborate with private and public schools to identify and update HIV/AIDS and STD health education curricula to include a component on hepatitis C.

During years two and three, DHS and its partners should:*

6. Conduct a statewide media hepatitis C education campaign that is culturally and linguistically appropriate for California's population (see Primary Prevention, Objective 1).

During year three, DHS and its partners should:*

7. Promote evaluation of the hepatitis C public awareness and education campaign consistent with assessment of other activities (see Primary Prevention, Objective 1).

During years one, two, and three, community-based organizations will:

8. Use state-supported surveillance and reports to educate policymakers about hepatitis C.

* Contingent on resources being available.

Surveillance and Research

Goal

Compile accurate, comprehensive and useful data on hepatitis C that will direct and support primary and secondary prevention, education and training, and long-term medical management and rehabilitation.

Overview

The purpose of hepatitis C surveillance is to:

- Identify new cases and monitor trends in the disease;
- Determine risk factors for infection and hepatitis C transmission;
- Assess how widely and among whom the disease is found; and,
- Identify infected persons for counseling and medical follow-up.

Surveillance helps to understand where prevention efforts are successful and where more or different interventions are needed by collecting information on new infections and their possible transmission methods, geographic locations of newly identified cases, and rates of increase or decrease in new infections.

In order to have effective surveillance and reporting of hepatitis C, policies and procedures must be in place to support timely collection, analysis, and reporting of data from laboratories, hospitals, and physicians' offices.

Surveillance data on hepatitis C are inadequate

At present, surveillance for hepatitis C is minimal and existing data are inadequate. Many health care providers are unaware of the need to screen for and report hepatitis C. There is confusion over disease definitions and reporting requirements. Most health departments do not have the resources to identify whether a laboratory report is for acute or chronic infection, or even whether an individual has already been tested.

Diagnostic blood tests for hepatitis C became available in 1992, but are not commonly used by physicians. Local health jurisdictions are required to report only acute cases; however, "acute" is not clearly defined, and reporting is inconsistent. There is a need for improved definitions and mandated procedures for reporting the disease. This lack of data has forced California to use national data from the Centers for Disease Control and Prevention (CDC) to estimate state hepatitis C incidence and prevalence.

Why good data are needed

In spite of the problems that make it difficult to develop precise estimates, surveillance data for California are important to key populations and stakeholders such as:

- Federal, state and local health agencies;
- Healthcare providers and health-related foundations;
- Pharmaceutical companies;
- Managed care organizations;

- Correctional agencies;
- Emergency and public safety workers; and
- Community-based organizations.

Reliable data on disease incidence, prevalence, and trends promote the efficient and economical targeting of public health resources and are the cornerstone of effective disease prevention planning. Collecting information from people who test positive for hepatitis C would assist in efforts to determine the long-term effects of various treatment and intervention modes, providing new information to increase the effectiveness of local and community-based hepatitis C prevention and control programs.

What steps can be taken now to obtain reliable and useful data?

Given the pressing need for hepatitis C surveillance, and with encouragement from the CDC, some local health jurisdictions, including San Francisco and San Mateo Counties, have moved forward with pilot efforts. Even though health experts anticipate building upon existing infrastructure, serious effort is required to improve hepatitis C surveillance. Priorities include:

- Standardizing the procedures for reporting hepatitis C cases;
- Making hepatitis C a laboratory-reportable disease;
- Making sure that reported data are analyzed;
- Ensuring that interested people have access to hepatitis C data in useful forms; and,
- Exploring the need and logistics to establish a case registry.

Research on hepatitis C

Research is complementary to surveillance. A comprehensive hepatitis C research program would include:

- Epidemiological studies of hepatitis C;
- Clinical or program-based research (for example, to monitor treatment effects);
- Basic research to understand the nature of hepatitis C and develop appropriate vaccines and treatments;
- Research on the effectiveness of alternative therapies; and
- Behavioral research on risk-taking, decision making, help-seeking and treatment adherence.

Research will improve knowledge about the role of sexual contact and other ways of contracting hepatitis C, the personal, public and economic burden of hepatitis C, and the most effective strategies for its prevention.

Training and education

Training and education in case recognition and reporting will enable health care providers and laboratory staff to distinguish between acute and chronic disease and, where appropriate, to detect hepatitis C. It will also make available critically needed information on other related liver diseases such as hepatitis A and B.

Action is needed

Surveillance and research are time consuming and costly; however, they provide invaluable insights and information to service providers and program planners. Overall, action is needed to:

- Improve existing hepatitis C surveillance systems and reporting,
- Obtain, analyze and report data to policy makers, program planners and service providers, and
- Assist public health and service providers to understand hepatitis C risk factors and modes of transmission.

Steps to develop a surveillance and research plan

The following three objectives are high priorities in developing an effective surveillance and research strategy.

Objective 1: Make the California epidemiological profile for hepatitis C current and complete by identifying and prioritizing data gaps in order to show where interventions are needed.

Action Steps

During year one, DHS, CCLHO and DOC*, in consultation with CDC, should:*

1. Analyze available surveillance and epidemiological data on hepatitis C in California in order to identify and prioritize data gaps to be addressed.
2. Develop a standard hepatitis C case history form, distribute it to all health jurisdictions, and ensure that it is used.

During years one and two, DHS, CCLHO, and the California Association of Public Health Laboratory Directors should:*

3. Amend state regulations to require reporting of hepatitis C by laboratories.
4. Establish plans for a hepatitis C case registry with the ability to track cases over time, thereby improving our understanding of disease trends.

During year three, DHS should:*

5. Compile and distribute a California-specific hepatitis C epidemiological profile.
-

Objective 2: Create an Internet-based directory linked to published and unpublished surveillance and research data on hepatitis C in California.

Action Steps

During year three, DHS and CCLHO, together with the participation of researchers, should:*

Establish plans for a web-based directory of hepatitis C data and research.

Objective 3: Support and participate in the national research agenda on basic, clinical, behavioral and prevention effectiveness sciences related to hepatitis C.

Action Steps

During years one, two, and three, DHS and CCLHO, together with researchers, should:*

Identify and collaborate with key federal and state agencies participating in hepatitis C research, including CDC, the National Institutes of Health and the DOC.

** Contingent on resources being available.*

Medical Management and Rehabilitation

Goal

Slow the progression of hepatitis C, engage the patient and his or her family in disease management and rehabilitation, improve effective long-term management of hepatitis C, and improve the affected individual's quality of life.

Overview

At the present time, most hepatitis C patients are seen in hospitals or in specialty clinics by a gastroenterologist or liver specialist. Many specialists do liver biopsies to determine staging and disease progress. They offer combination therapy to patients who follow their directions and people with drug and alcohol problems are often excluded because of their dependencies. Often, acute hepatitis C is not diagnosed and therefore not treated. In prisons and jails there is sporadic treatment. The desired goal of the current practice is to improve individual health status, where possible.

A public health approach to hepatitis C would include diagnosis and medical management by a general physician. Patients with drug and alcohol problems would receive attention and care for their dependencies along with medical care for their disease. Combination therapy could be provided, as well as co-management of drug and/or alcohol problems. As with the current approach there would be genotyping and viral load studies to determine treatment options and measure the progress and effectiveness of the treatment selected. There would be a focus on treatment in jails, prisons and juvenile facilities, and acute illness would be diagnosed and treated aggressively when possible. The outcome of this approach would be to limit the public health

impact of the disease and related conditions by treating the individual.

By improving the medical management and quality of life for persons with hepatitis C, their chances of leading a healthy, satisfying and economically productive life are increased for as long as possible. An effective medical management and rehabilitation system will reduce the likelihood that hepatitis C patients will develop complications of the disease or be vulnerable to other harmful conditions. It is especially important to set such a system in place because hepatitis C most often manifests itself as a long-term chronic condition; its symptoms, such as fibromyalgia or muscle pain and fatigue, make it difficult for patients to function effectively in the community.

Support and education are needed

Hepatitis C can put a strain on the patient's family, friends, and employers. Hepatitis C patients may have fragile support systems or striking psychosocial problems. As much as possible, existing medical and community service providers need to be educated about the needs of hepatitis C patients and the clinical and support infrastructure needs to be strengthened to deal with the disease. This is especially important in light of the expected increase in new cases likely to occur among persons screened and tested for hepatitis C (as described in Goal 2, "Secondary Prevention").

Minimizing costs of hepatitis C

Like most other chronic diseases, hepatitis C can be costly to patients and providers. One way to minimize these costs is by being proactive rather than reactive in patient management over the long-term.

Other ways to decrease the costs of hepatitis C treatment and management include: developing sound training curricula for clinicians and social service providers; improving the healthcare system capacity to respond to hepatitis C; encouraging links among system elements; and assessing the extent to which practice is changed and patients helped.

As services are developed for hepatitis C patients, planning and training for long-term management of their needs becomes critically important.

Policy changes are needed

In addition to these program or system changes, the Working Group believes that policy changes may also be necessary. Policy changes would assure continued medical insurance and care for hepatitis C-infected individuals. Services would be available and accessible from healthcare and social services providers to hepatitis C patients.

Steps towards a long-term management and rehabilitation strategy

Early and effective treatment of hepatitis C reduces the viral load, informs about risk, and may limit the possibility that the virus will be transmitted further. The following objectives are priorities in developing an effective strategy for long-term management and rehabilitation of hepatitis C patients.

Objective 1: Offer inclusive education and training opportunities on long-term clinical management of hepatitis C to physicians, nurse practitioners, physician assistants, registered nurses, social workers, drug and alcohol counselors, and allied health professionals.

Action Steps

During year one, DHS, together with the American Association for the Study of Liver Diseases (AASLD), and other professional associations should:*

1. Develop a curriculum on the long-term management of hepatitis C.

During years two and three, DHS and AASLD should:*

2. Make use of the following for training and education:
 - Teleconferencing and other distance learning methods;
 - On-site workshops, conferences and/or grand rounds;
 - A telephone hotline;
 - A mentoring program to train clinicians; and
 - Continuing education units for distance as well as on-site programs.

* Contingent on resources being available.

During year two, DHS* should:

3. Distribute the hepatitis C clinical management curriculum to public and private sector agencies that provide long-term services to hepatitis C patients, and to institutions (medical, professional, and vocational schools) engaged in clinical training.

During year three, DHS* and AASLD should:

4. Train trainers and offer continuing education units in medical management and long-term needs of hepatitis C patients.

During year three, DHS* and clinical care providers should:

5. Develop and distribute “model of care” guidelines on whom to screen, test, and treat, and how to identify patients who are not responding to follow-up.

Objective 2: Ensure that all health systems and facilities managing patients with liver disease offer patients and their families education about living with hepatitis C. System policies will be in place to assure, to the extent possible, that patients are provided assistance with and treatment for co-morbidity.

Action Steps

During years one and two, DHS* and clinical care providers should:

1. Conduct a survey of hepatitis C patients to determine their hepatitis C-related long-term co-morbidity.

During year two, AASLD and other professional organizations should:

2. Design a curriculum to teach clinical and program staff how to assist hepatitis C patients in living with long-term co-morbidity such as back pain, muscle pain, fatigue, depression, and nutritional needs.

During years two and three, clinical care providers will:

3. Conduct interactive, learning theory-based training for staff at all levels in how to use the long-term management curriculum to educate hepatitis C patients.

During years two and three, DHS* and DOC* should:

4. Offer education about co-morbidity to all personnel in correctional facilities serving hepatitis C patients.

* Contingent on resources being available.

Objective 3: Assure continuity of care for hepatitis C patients who are transitioning to the community from incarceration.

Action Steps

During years one and two, DHS, CCLHO, and the Youth and Adult Corrections Agency (YACA)* should:*

1. Design a system for the transition of hepatitis C patients from incarceration to the community such that physicians and clinics accept these patients, continue the treatment started in prison, and attend to their co-morbidity.

During year three, DHS, CCLHO, and YACA* should:*

2. Train correctional facilities staff and community health care providers on how to implement the hepatitis C transition system, in order to continue care and support for hepatitis C patients once in the community.

Objective 4: Ensure that services, such as housing, employment, and social support that are currently available to HIV/AIDS patients (e.g., through the Ryan White Care Act) and that help to maintain patient functioning, are available to those with hepatitis C.

Action Steps

During years one, two, and three, community-based organizations and affected populations will:

Advocate for comprehensive long-term services such as drug and medical care coverage, job counseling, and housing for hepatitis C patients.

* Contingent on resources being available.

Glossary of Terms

Acute hepatitis C Newly acquired hepatitis C virus, sometimes but not always accompanied by symptoms.

AIDS Acquired Immune Deficiency Syndrome.

Barriers Conditions that affect the hepatitis C community's ability to carry out recommended actions and reach objectives.

Case management A system in which a professional works with a client or patient to assure that they get diagnosis, treatment, support services, monitoring and referral, as needed.

Chronic hepatitis C A stage of hepatitis C that usually begins about six months after initial infection and results in liver inflammation; occurs when the disease does not clear up or resolve spontaneously, often leading to permanent liver damage.

Epidemiological profile The gathering of data in order to establish when and where diseases are occurring, who is affected, and what behaviors or exposures place individuals at risk; provides evidence from which to develop and target prevention activities and programs.

Fibromyalgia Pain in the muscles and fibrous connective tissue; a common complaint of patients with hepatitis C.

Goal Long-range preference statement of what the Working Group wants to accomplish in three years. More broadly stated than objectives, goals are impact- and outcome-oriented. The goal summarizes the overall plan to address problems as well as the anticipated results of the strategic actions.

Guiding Principles Defines stated beliefs and values guiding work on *The Hepatitis C Strategic Plan*.

Harm Reduction A set of practical strategies, including clean needle and syringe exchange, that reduce negative consequences of drug use, incorporating a spectrum of approaches from safer use, to managed use, to abstinence.

HEDIS (Health Plan and Employer Data Information Set) A system that requires reporting of certain health conditions so that services and prevalence may be monitored for compliance with regulations.

Hepatitis A virus (HAV) A virus transmitted most often through fecal-oral contact or water; there is a highly effective vaccination against hepatitis A; HAV is almost never chronic and rarely leads to permanent liver damage.

Hepatitis B virus (HBV) A virus transmitted through blood, sexual contact, and perinatally (from mothers to infants); similar to hepatitis C, it can result in chronic disease and permanent liver damage. A vaccine against hepatitis B has been available since 1982. Groups at high risk of acquiring hepatitis B include injecting drug users and men who have sex with men.

Hepatitis C virus (hepatitis C) A virus that enters the body through direct blood exposure and attacks cells in the liver, while often going undetected for many years; blood exposure can result from unsafe injecting drug practices, perinatal transmission or through occupational hazards such as needle stick injuries. Hepatitis C can result in scarring of the liver (cirrhosis), liver cancer, and death. There is no vaccine for hepatitis C.

Human Immunodeficiency Virus (HIV) A family of viruses that results in the Acquired Immune Deficiency Syndrome (AIDS).

Incidence The number of new cases of infection that occur in a given population over a period of time.

Interferon A genetically-engineered product used to treat hepatitis B and C and other viruses.

Mission The fundamental reason or purpose for the existence of *The Hepatitis C Strategic Plan*; the mission statement expresses what Californians want to achieve in the long run by creating and implementing *The Plan*.

Objective A specific statement of a measurable amount of progress toward goal attainment; objectives are specific, measurable, attainable, realistic, and time-bound. An objective states in measurable terms what will be accomplished to help meet a goal and provides the target to evaluate program results.

Prevalence The number of infected individuals in a population at a given point in time.

Primary prevention The process of providing information and education services to healthy populations to allow them to make decisions that will reduce their risk and protect them from contracting illness or disease. As it relates to hepatitis C, primary prevention involves those strategies used to reduce the risk of contracting hepatitis C. It can also include counseling hepatitis C-infected persons on methods to prevent the transmission of their infection to other people.

Ribavirin An anti-virus drug often used in combination with interferon to treat hepatitis C.

Secondary prevention Strategies used to identify, counsel, and test individuals most likely to be infected with hepatitis C (or other infectious diseases) and to provide them with appropriate medical and case management.

Sexually transmitted disease (STD) An infection transmitted through sexual contact such as chlamydia, gonorrhea, or HIV.

Solutions Ways to address, eliminate, or diminish barriers.

Stakeholders Potential partners from various groups, including public and private organizations, constituencies, funding organizations and others that in some way influence or are affected by hepatitis C prevention and management efforts. These include the partners that can help carry out recommendations.

Strategic Actions/Recommendations

The specific activities that will be carried out by hepatitis C programs and others to meet *The Plan's* goals and objectives.

Surveillance Procedures used in public health to monitor disease incidence, prevalence and trends, and the effectiveness of prevention strategies.

Target Populations Groups within the community, region, or state impacted by the issues identified in the problem statement; groups whose needs and situations are addressed through the objectives and recommendations.

Vision The collective sense of where the California hepatitis C community wants to go in three years in prevention and management, and why. A picture of the future vision makes the mission or purpose more concrete and tangible.

References

The following sources were used to provide background information for *The Strategic Plan*. They were particularly helpful in preparing the Overview.

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Rosenberg J. *Hepatitis C: epidemiology, detection, diagnosis, and treatment*. Unpublished report. Division of Communicable Disease Control, California Department of Health Services, April 1999.

Wong JB. Cost-effectiveness of treatments for chronic hepatitis C. *American Journal of Medicine* 1999; 107: 74S-78S.

Further information about hepatitis C can be obtained from the following:

California Department of Health Services:
<http://www.dhs.ca.gov/ps/dcdc/dcdcindex.htm>

United States Centers for Disease Control and Prevention (CDC): <http://www.cdc.gov/hepatitis>

CDC Hepatitis Branch:
<http://www.cdc.gov/ncidod/diseases/hepatitis/partners/>

National Institute of Diabetes and Digestive and Kidney Diseases: <http://www.niddk.nih.gov>

American Liver Foundation:
<http://liverfoundation.org>

Hepatitis Foundation International:
<http://www.hepfi.org>

Hepatitis C Support Project (a California resource):
<http://www.hepatitis Cadvocate.org>

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