

Massachusetts Department of Public Health**Hepatitis C: 2001 – 2005
Recommendations of the Hepatitis C Advisory Committee
2001****Executive Summary**

Hepatitis C is a major emerging public health issue, both because of its direct impact and because of increasing public perception of its importance. Over 100,000 people in Massachusetts may be infected with hepatitis C virus and transmission continues to occur. Hepatitis C becomes a chronic infection in approximately 85% of persons infected, and, in many, the infection is slowly progressive, with clinical symptoms and signs that develop over decades.

Hepatitis C presents complex epidemiologic, social and medical challenges. Studies carried out over the past two years in Massachusetts have revealed low levels of knowledge about hepatitis C among the public, specifically a poor understanding of the routes of transmission of the virus, the consequences of infection, and the relationship of hepatitis C to other forms of hepatitis, liver disease and other conditions. Health care provider knowledge is variable; information on hepatitis C is being constantly revised and updated.

In many ways, the health care delivery system has not yet developed the capacity to address hepatitis C fully using an array of prevention, education and medical services. Compounding these challenges is the fact that hepatitis C disproportionately affects the medically underserved and individuals eligible for public services.

The Hepatitis C Advisory Committee, first convened in April 1999, advises the department on programs, policy and planning. It is made up of consumers, providers, agency representatives, organizations with interest and involvement in hepatitis C, representatives of funded programs, experts in liver disease and infectious diseases, legislators, representatives from local health departments and state agencies, and Department of Public Health staff from all bureaus. The committee's recommendations, "Hepatitis C: 2001-2005", apply specifically to the Department of Public Health and are focused on Department programming over the next five years. However, the recommendations provide a basis for development of a broader strategic plan to address hepatitis C that goes beyond the programs of the Department of Public Health.

The recommendations deal with issues of information and communication, service integration, prevention, stigma, testing, case management, surveillance, data needs and development, and policy and interagency cooperation.

Recommendations

The Massachusetts Department of Public Health should:

1. Continue to play a central role in disseminating information about hepatitis C and educating the public, healthcare and social service providers, and persons with (or at risk of) infection;
2. Address hepatitis C within the context of the full spectrum of liver health and disease, and promote integration with existing and future public health, social and health programs and services, especially those reaching underserved populations and individuals in the care and custody of public agencies;
3. Have a primary focus on prevention of hepatitis C, its complications and chronic disease consequences;
4. Work to reduce stigma and discrimination associated with hepatitis C;
5. Take measures to ensure access to high quality hepatitis C testing and sensitive, effective and factual counseling;
6. Assume a leadership role in the development of consensus case management objectives for hepatitis C across a variety of settings and client situations;
7. Develop a surveillance system that will provide epidemiologic information necessary for program planning and policy development;
8. Work collaboratively with other agencies and organizations to identify data needs, develop data collection methods, and define approaches to research projects relevant to hepatitis C.
9. Maintain a leadership role in the development of public health policy related to hepatitis C, and, in collaboration with other state agencies, work closely with agencies of the federal government to maximize services for those living with, or at risk of, hepatitis C infection.

Introduction

It is estimated that 110,000 people in Massachusetts may be infected with hepatitis C virus. While the incidence of new infections has been reduced by the screening of blood and blood products, safer use of injection equipment, and increased awareness of hepatitis C, transmission continues to occur. Many infected individuals will not suffer the consequences of progressive liver disease, but a significant proportion of those infected will develop symptomatic chronic hepatitis, cirrhosis, liver failure and hepatocellular carcinoma.

Hepatitis C virus is transmitted primarily through blood-to-blood contact, through shared injection equipment, injuries involving blood containing virus and other exposures, including occupational incidents. Although apparently not an efficient mode of transmission, hepatitis C virus can be transmitted sexually. Prior to the introduction of sensitive screening methods for donors in 1992, blood transfusion was an important route of infection, and the virus was transmitted on occasion through organ and tissue transplantation. Hepatitis C can also be transmitted from mother to child during the perinatal period, although the transmission rate is much lower than for hepatitis B (without immunization) or HIV (without antiretrovirals). Coinfection with hepatitis C virus and HIV appears to increase the likelihood of perinatal transmission. Casual contact, kissing or sharing eating utensils does not transmit hepatitis C virus.

Hepatitis C becomes a chronic infection in approximately 85% of persons infected. Infection may result in persistent inflammation of the liver, leading to chronic hepatitis and scarring that may progress to cirrhosis and liver failure. The infection is slowly progressive, with clinical symptoms and signs that develop over decades. Many individuals with hepatitis C have a benign course, without significant clinical problems in their lifetime. Persons with hepatitis C who are coinfecting with HIV appear to have a more rapid course of liver disease.

Alcohol accelerates liver damage due to hepatitis C. Individuals with hepatitis C should avoid alcohol and all other potentially hepatotoxic agents. Likewise, hepatitis A or B superimposed on hepatitis C can exacerbate liver damage, making immunization against hepatitis A and B an important component of clinical management. Specific treatment of hepatitis C with alpha-interferon and ribavirin (6-12 months) results in clearance of virus in 30-40% of selected patients in the United States. Approximately 70% of U.S. residents are infected with hepatitis C of genotype 1 which responds less well to treatment. Treatment with interferon and ribavirin is associated with significant side effects and adverse events, is difficult to administer, and is expensive. Neuropsychiatric side effects of treatment (including depression) may be significant. New, longer acting interferon preparations require once weekly administration, and appear to be more effective than shorter acting preparations.

Hepatitis C is a complex epidemiologic, social and medical problem. Individuals affected by hepatitis C typically require a variety of services. Critical are services that provide an awareness of the infection and education about the disease: the way it is

transmitted, the natural history of infection, the consequences of infection and effective clinical management and treatment. Those at risk for hepatitis C infection require counseling about risk and testing for infection. Those found to be infected must be informed about ways to prevent transmission and assess activity of disease. Active infection should prompt medical evaluation and consideration of treatment, including discussion about the benefits and risks of treatment. Persons at risk, but uninfected, should receive education and counseling about how to remain uninfected.

The Massachusetts Department of Public Health has been very active in dealing with hepatitis C and in hepatitis C-related programming over the past three years.

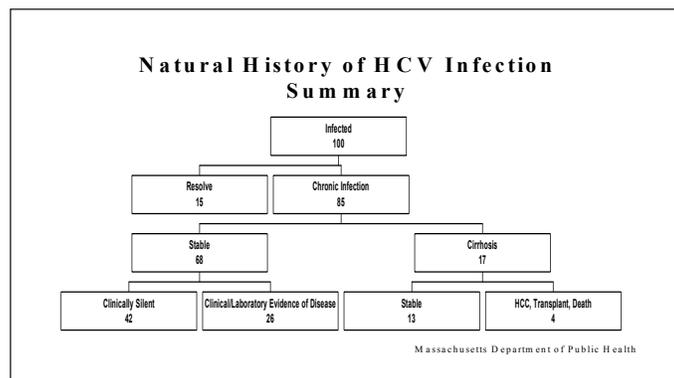
- There is now a designated Hepatitis C Program within the Division of Epidemiology and Immunization.
- The program has received state funds and federal funding from the U.S. Centers for Disease Control and Prevention.
- MDPH participated with the Tufts University School of Medicine in formative research and development of educational media.
- The MDPH program funded 15 case management, education and support referral sites across the state, seven research projects directed at questions of particular relevance to people at-risk of or living with hepatitis C, and an ongoing program of evaluation.
- A dedicated web site (www.masshepc.org) has been established and a hepatitis C hotline (888-443-HEPC) has been founded.
- Educational materials in English, Spanish and Portuguese have been produced for patients and the public, including an educational video for people recently diagnosed with hepatitis C.
- Radio and television informational spots on hepatitis C have been produced and aired.
- Posters and transit advertising have been developed and deployed in various regions of the state.
- Training materials and programs directed at nurses and physicians have been developed.
- Educational materials have been sent to over 150,000 practitioners and distributed through programs across the state.
- Instruments and procedures for surveillance are in development.
- Immunization programs have been directed toward immunizing people with hepatitis C against hepatitis A and B.
- A pilot program for integrating hepatitis C counseling and testing with HIV counseling and testing is underway.
- MDPH is working closely with the Departments of Correction and Mental Health on needs assessment and case management for those in the care and custody of those agencies.
- The Lemuel Shattuck Hospital and the bureaus of Laboratory Sciences and Communicable Disease Control have been working with the Department of Correction for several years on the assessment of hepatitis C in their population and the development of clinical practice guidelines.

- MDPH is collaborating with the American Liver Foundation, the AIDS Action Committee, the Massachusetts Public Health Association and the Hepatitis C Coalition to raise awareness of hepatitis C and its impact, and learn more about the needs of people living with and at risk of hepatitis C.

An important component of the hepatitis C activities of the MDPH has been the establishment and functioning of the Hepatitis C Advisory Committee. First convened in April 1999, the committee is made up of consumers, providers, representatives of agencies and organizations with interest and involvement in hepatitis C, representatives of funded programs, experts in liver disease and infectious diseases, legislators, representatives from local health departments and state agencies, and Department of Public Health staff from all bureaus. The members of the committee have generously contributed time, expertise, and enthusiasm to the development and maintenance of hepatitis C initiatives.

It is important for the Commonwealth of Massachusetts, in particular the Department of Public Health, to map out a plan for addressing the public health impact of hepatitis C into the future. These recommendations apply specifically to the Department of Public Health, and are intended to provide guidance to the Department for programming over the next five years. Some recommendations will relate to ongoing activities, some can be implemented over a short time course, and some require phasing in over a period of years, if adopted. These recommendations also provide a basis for the development of a broader strategic plan to address hepatitis C beyond the programs of the Department of Public Health.

The following is a list of recommendations developed as a consultation process involving the members of the Massachusetts Hepatitis C Advisory Committee and Massachusetts Department of Public Health staff from many bureaus and programs. It consists of major recommendations, followed by narrative background and a list of subsidiary recommendations. The Commissioner and staff of the MDPH, as well as the Department's many partners concerned about hepatitis C will review these recommendations. Recommendations will be adopted on the bases of feasibility, compatibility with overall priorities and how effectively they can be coordinated across programs and agencies. They will be implemented to the extent possible, depending on what is achievable with resources available over the next five years.



Recommendations

1. The Massachusetts Department of Public Health should continue to play a central role in disseminating information about hepatitis C and educating the public, healthcare and social service providers, and persons with (or at risk of) infection.

Evaluation of initial health information and education efforts revealed a high degree of confidence among the public and providers in information provided by the Massachusetts Department of Public Health. While other sources of information are available, the Department of Public Health specializes in providing consistently accurate, objective information as part of a comprehensive hepatitis C program. It works closely with other organizations and agencies (e.g. the American Liver Foundation, the Hepatitis C Coalition, grassroots consumer groups, local health departments, the Centers for Disease Control and Prevention, substance abuse treatment and prevention service providers, AIDS service organizations, professional organizations, public agencies, etc.) to promote wide dissemination of information. The MDPH plays a special role in getting effective health messages to hard-to-reach populations and individuals, and helps service providers provide consistent, objective and informative messages.

- a) MDPH should continue to collaborate with public and private partners to determine how to craft messages that are effective for the general public. Special messages should be developed for special populations (such as current and past substance users, people living with HIV infection, the incarcerated, those with mental illness, the homeless, etc.) using the expertise and assistance of collaborating agencies and organizations.
- b) Along with development of effective messages, the best medium for transmitting such messages should be identified and utilized.
- c) MDPH should maintain and promote its hepatitis C web site as a source of up-to-date information for providers, patients and the public.
- d) MDPH should maintain a hotline staffed by trained and multilingual personnel available to answer questions and address concerns of callers.
- e) The MDPH should increase the level of awareness and knowledge about hepatitis C among the public, providers and those at risk of infection with simple, clear messages about risk, infection and testing.
- f) Public messages should stress the manageability of hepatitis C and encourage people to get tested so something can be done about their infection (prevent transmission, get immunized, get into care, get treated, etc.).
- g) MDPH should partner with provider agencies and programs to reach individuals at risk of hepatitis C who are no longer actively using drugs, not part of the drug culture, and not participating in drug treatment programs.
- h) Over the next five years, MDPH should shift the emphasis of educational messages to focus primarily on those at risk, those living with infection and the public.

- i) MDPH should encourage individuals to assess their risk (with or without assistance of counselors and case managers) and assure availability of complete and accurate information.
- j) MDPH should employ train-the-trainer approaches.
- k) MDPH should increase accessibility to provider education by promoting local programs, self-study approaches, web-based learning and clear, specific “social detailing”.

2. The Massachusetts Department of Public Health should address hepatitis C within the context of the full spectrum of liver health and disease, and promote integration with existing and future public health, social and health programs and services, especially those reaching underserved populations and individuals in the care and custody of public agencies.

Studies carried out in Massachusetts over the past two years have revealed low levels of knowledge about hepatitis C among the public, specifically a poor understanding of the routes of transmission of the virus, the consequences of infection and its relationship to other forms of hepatitis, liver disease and other conditions. Focus group activities and surveys have also revealed significant knowledge gaps among health care providers. Hepatitis C is best addressed in the context of other viral hepatitis, liver function, alcohol and other substance use; HIV/AIDS, other sexually transmitted diseases; and health and wellness in general. These issues must be addressed, if comprehensive approaches to the management of hepatitis C are to evolve further.

Public health departments have become service providers to a wide variety of special populations and payers of last resort for a number of services to groups without adequate resources for or access to care. Hepatitis C disproportionately impacts populations served by the Department of Public Health and other state agencies. The MDPH works closely with the Division of Medical Assistance, the Department of Correction, the Department of Mental Health, and other state and local agencies. The Hepatitis C Program will be most successful when it addresses problems of access, the need for culturally and linguistically appropriate services, the limited resources available to public and publicly-funded agencies, the context of special needs and the impact of social isolation.

- a) Hepatitis C messages and programs should be promoted within the broader context of overall liver function, health and disease, the role of alcohol in disease progression, other types of hepatitis, and related infections and conditions.
- b) Bureaus and programs of the Department of Public Health should coordinate program content dealing with hepatitis C and related issues across client populations.
- c) Hepatitis C information and programming should be integrated into all appropriate MDPH programs and contracts.
- d) MDPH should require documentation of referral networks in all hepatitis C-related contracts.

- e) MDPH should standardize guidance for how patients with hepatitis C are counseled and managed in clinical settings. Educational programs should address quality of services, accuracy of information and appropriateness of counseling and treatment across clinical service providers.
- f) MDPH should investigate what is needed to expand the capacity of the health care delivery system to provide consistent and effective hepatitis C services.
- g) MDPH should note and address (within the limits of its role and capacity) housing issues that arise in regard to persons with hepatitis C (in addition to those issues faced by people with HIV/AIDS and past or current substance use).
- h) Hepatitis programming directed to at-risk youth should be based on behavioral risk data and age/culturally-appropriate approaches.
- i) The development of culturally and linguistically appropriate materials, at appropriate literacy levels should be a priority for hepatitis C programs, and MDPH should take the lead in their development and promotion.
- j) MDPH should continue to assess prevalence of infection and impact of hepatitis C in a variety of potentially higher risk groups and populations, including the incarcerated, the homeless, substance abusers, the foreign born, and others.
- k) Special consideration should be given to the difficulties faced by injection drug users in recovery with regard to the use of injection equipment for long term therapy with injectable interferon preparations.
- l) MDPH should encourage the criminal justice system to develop the capacity to deal with hepatitis C as a health and public health issue.
- m) MDPH should support efforts to develop and promulgate guidelines for the prevention and control of hepatitis in correctional settings.
- n) MDPH should continue to work with the Department of Correction and its health care provider on clinical management guidelines for hepatitis C and provision of continuity of care following release.
- o) MDPH should pursue development of hepatitis C support group models that are integrated into correctional programs.
- p) MDPH should assist state and county correctional systems in developing and updating policies, procedures and record-keeping systems for better tracking of health care and provision of case management.
- q) MDPH should continue to work with the Department of Mental Health on assessing the impact of hepatitis C on the health of its patients and on patient management.
- r) MDPH should assist the Department of Mental Health in the development of guidelines for the assessment of individuals for treatment and support services that address neuropsychiatric side effects of treatment.
- s) MDPH should assist the Department of Youth Services and the Department of Social Services in assessing the impact of hepatitis C on their clients and in the development of prevention programs.
- t) MDPH should serve as a primary resource for hepatitis C education for public agencies through technical assistance, multi-media programming and train-the-trainer approaches.
- u) MDPH should facilitate effective inter-agency communication regarding developments in hepatitis C prevention, education and treatment.

- v) MDPH should be a resource for public employees on hepatitis C prevention.

3. The Massachusetts Department of Public Health should have a primary focus on prevention of hepatitis C, its complications and chronic disease consequences.

Prevention of infection, morbidity and disability is central to public health practice in regard to hepatitis C. All three levels of prevention - primary, secondary and tertiary are all important in the public health response to hepatitis C and are interrelated. Efforts directed at one level will affect other stages of chronic infection, with known routes of transmission and progressive pathologic consequences. Accessible and effective hepatitis C counseling and testing services (with referral to informational and clinical services) are not only crucial elements of secondary prevention, but are also among the most important ways of preventing infection; if infected individuals are aware of their infection, they can learn about ways to prevent transmission and apply that knowledge to ways of preventing new infection. Routine screening of populations without attention to risk context is not a cost-effective approach, and it has negative aspects related to false positive results in test performance. Targeted testing is desirable, since hepatitis C virus transmission occurring today is most likely related to sharing of injection equipment.

- a) MDPH should investigate a variety of mechanisms to assure access to hepatitis C counseling and testing services, including integration of hepatitis C issues with HIV counseling and testing services, substance abuse prevention and treatment programs, clinical services, and at other sites where those at higher risk are seen and served.
- b) MDPH should develop effective mechanisms to assist infected individuals with notifying their needle-sharing and sexual partners about potential risk of exposure to hepatitis C.
- c) MDPH should encourage the routine incorporation of hepatitis C risk assessment, counseling and testing into primary care and HIV counseling and testing, and work with other agencies and professional societies to accomplish this objective.
- d) Case management services for the effective delivery of primary, secondary and tertiary prevention support should be encouraged.
- e) Counseling and testing programs should maximize capacity for referral to further clinical and support services.
- f) Harm reduction (such as safer injection practices, needle/syringe exchange and legal access to clean needles and syringes through prescription, deregulation and decriminalization) should be encouraged in order to prevent the transmission of hepatitis C.
- g) Immunization of susceptible hepatitis C-infected individuals against hepatitis A and B should be encouraged to prevent serious and even life-threatening superinfection.
- h) Integration of hepatitis education and referral into programs that provide services to past or current substance users and people living with HIV/AIDS should be a high priority for prevention efforts at all levels.

- i) A full spectrum of preventive measures for people with hepatitis C, including immunization, sexual health education, alcohol avoidance counseling, reduction of other potentially toxic exposures, nutritional consultation, etc., should be promoted.
- j) The capacity of community health centers (and other primary care sites that are likely to serve those at higher risk of hepatitis C) to deal with hepatitis C should be enhanced through provider training and establishment of referral networks.
- k) MDPH should explore creative approaches to removing barriers to prevention outside of traditional social and medical services (such as providing Voicemail services for the homeless, innovative testing strategies, peer support groups, etc.).

4. The Massachusetts Department of Public Health should work to reduce stigma and discrimination associated with hepatitis C.

Stigma, associated with perceived and actual discrimination, has a significant negative impact on reception to hepatitis C-related messages, determination of infection status and utilization of services. Compounding stigma that may be attached to hepatitis C are the difficulty and discrimination that people with substance use problems and HIV/AIDS face. It is critical to reduce stigma that society attaches to hepatitis C as a result of societal views of the behaviors associated with transmission of infection and ignorance about how the infection is transmitted. Concern about loss of medical insurance coverage can be a barrier to testing or to raising the issue of hepatitis C with a provider. Stigma is a considerable barrier to engaging public support of hepatitis C prevention efforts through advocacy. The Department of Public Health has a long experience in confronting stigma that impacts public health and public health practice, most recently in dealing with HIV infection and AIDS. The MDPH can apply the lessons learned in the past to the issue of hepatitis C.

- a) MDPH should investigate the sources and characteristics of stigma attached to hepatitis C and hepatitis C infection in order to address this problem more effectively among communities at higher risk of hepatitis C.
- b) MDPH should encourage discussion of hepatitis C and the full spectrum of possible transmission modes and behaviors in all public and provider education and service initiatives.
- c) MDPH should study the need for anonymous hepatitis C testing in targeted settings and for particular populations (while taking care to not normalize the need for anonymity).
- d) MDPH should support and encourage community-based organizations to educate communities about hepatitis C and to counter stigma and discrimination.
- e) MDPH should ensure that information produced by the Department and administrative materials do not carry any inference of stigma or acceptance of such inference.

5. The Massachusetts Department of Public Health should take measures to ensure access to high quality hepatitis C testing and sensitive, effective and factual counseling.

The State Laboratory Institute of the Massachusetts Department of Public Health has been a leader in virologic research, laboratory test development and testing supportive of public health programs. The State Laboratory is also a major reference laboratory for the state and region. This expertise has been (and should continue to be) brought to bear on hepatitis C. MDPH, through its Clinical Laboratory Program of the Bureau of Health Quality Management has oversight of clinical laboratories and MDPH is developing guidelines and algorithms for hepatitis C counseling and testing that will be available for general use.

- a) The Infectious Diseases Laboratory of the State Laboratory Institute should continue to provide research, testing and reference services supportive of hepatitis C initiatives.
- b) All testing should be done with the knowledge of the person being tested and with implied or explicit consent.
- c) MDPH should continue to support blinded and consensual serologic surveys of populations at risk of hepatitis C virus infection to assess burden of infection.
- d) The State Laboratory Institute should investigate and pilot new methods and technologies for hepatitis C diagnosis and identification of early infection.
- e) MDPH should assess the resources that may be necessary to provide diagnostic laboratory services for state-sponsored counseling and testing and clinical services.
- f) MDPH should explore the regulatory authority and mechanisms available to address identified deficiencies in testing methodologies.
- g) MDPH should develop model protocols for hepatitis C counseling associated with diagnostic testing.
- h) MDPH should assess needs related to hepatitis C counseling and testing services, and do everything possible to assist with content and quality of services.

6. The Massachusetts Department of Public Health should assume a leadership role in the development of consensus case management objectives for hepatitis C across a variety of settings and client situations.

Hepatitis C case management (individualized assistance provided to persons with hepatitis C infection designed to meet needs for education, support and referral) has been identified as an element of service required by many persons living with hepatitis C in order to navigate the currently fragmented service delivery system and interpret a large volume of often contradictory information. Currently, services in many areas are limited and potential consumers are unaware of what services are available.

The Department of Public Health has a role working with its partners to define the scope of what is needed and what works with regard to case management services and funding such services. MDPH can build on the experience and success of HIV/AIDS programs in developing standards across the spectrum of department-funded programs.

There are unique aspects of hepatitis C case management related to a changing knowledge base, available therapeutic interventions, and public and provider awareness. There are also unusual aspects of hepatitis C itself, especially a long latency to appearance of clinical signs and symptoms and the sparing of many with infection from clinical progression and presentation.

Case management models should be client centered (addressing the client's concerns rather than preconceptions and provider presumptions of what those concerns might be), integrated (with HIV/AIDS programs, substance abuse prevention and treatment, STD care, etc.), and relevant to particular populations and communities. Services are best developed with the participation of the communities at risk. Multiple models, with an array of psychological support, social and clinical services, should be encouraged.

- a) MDPH should continue discussion about case management among MDPH-funded programs, other case management providers, consumers and the Advisory Committee in order to delineate effective components and strategies.
- b) Case management programs should build on the extensive MDPH experience in programming case management for people with substance abuse issues, HIV/AIDS, and other acute and chronic problems.
- c) MDPH-funded evaluation of case management programs should be used for ongoing program modification and development and administrative and client survey data from programs should be maximally utilized for information regarding behavior, health status and outcomes.
- d) The case management needs of particular populations and communities should be determined.
- e) Case management services should be linked with other service providers through referral networks.
- f) MDPH should foster case management as a key component of hepatitis C services at least until (and most likely after) more natural history and clinical information becomes available and the full development of the care and support system has taken place. (Case management will change as client understanding and perceptions change, and as services become more available.)
- g) MDPH should prioritize funding for case management services in areas of the state without access to services.
- h) MDPH should consider and encourage innovative approaches for providing case management services.
- i) Case management programs should market their services and promote participation through outreach efforts.

7. The Massachusetts Department of Public Health should develop a surveillance system that will provide epidemiologic information necessary for program planning and policy development.

The Department of Public Health (and its forerunner, the Massachusetts Board of Health) has carried out disease surveillance since 1874. Hepatitis C has been reportable to local boards of health since 1993. Primary notice of hepatitis C infection is a laboratory result (in most instances) and completion of a case report typically requires follow-up with health care providers and interviews with the individual reported as a case.

The volume of laboratory reports of positive tests has been enormous over the past 5-7 years. Most local health departments have neither the resources nor the expertise to do complete follow-up on cases. In many communities (especially the smaller ones) challenges to confidentiality and privacy have already been identified. Yet, there is important information related to each case of hepatitis C that could be of value in assessing the impact of the infection, further defining epidemiology and identifying modes of transmission - all important in the planning of prevention efforts and services.

MDPH is committed to improving surveillance of hepatitis C, and has an updated surveillance case definition, new case report forms for hepatitis A, B and C, a manual for disease reporting and surveillance that incorporates hepatitis C, collaboration with clinical and social service providers, enhanced laboratory reporting mechanisms, and educational efforts directed at local health departments and healthcare providers.

- a) MDPH should clearly enunciate the purposes of hepatitis C surveillance.
- b) MDPH should seek collaboration with others to supplement laboratory reporting with additional case information.
- c) Surveillance systems geared to the identification of early hepatitis C virus infection would be developed to provide maximal opportunity for clinical management and prevention.
- d) An enhanced passive surveillance system (with providers acquiring and reporting case information) should be explored to take into account limited resources and capacity on for case follow-up and interview at both the state and local level.
- e) MDPH should investigate making hepatitis C reportable directly to MDPH similar to the reporting of sexually transmitted diseases, HIV infection, AIDS and tuberculosis.
- f) Case reports should trigger feedback to the provider on services and referral.
- g) Surveillance should be used to promote provider education.
- h) Surveillance data should be used as an incentive to further reporting.
- i) Sentinel surveillance, carefully crafted to avoid systematic bias, should be explored and considered.

8. The Massachusetts Department of Public Health should work collaboratively with other agencies and organizations to identify data needs, develop data collection methods, and define approaches to research projects relevant to hepatitis C.

While there have been major advances in the understanding of hepatitis C and its public health and clinical implications, there remain many areas of uncertainty. Data are

needed to inform clinical response and guide public health programs. The Department of Public Health plays a role in identifying data needs of programs and providers. Further, it attempts to meet those needs through the identification of data sources or the implementation of studies or data gathering efforts. However, it is recognized that programs must often go forward to address need despite gaps in pertinent data. This is an important reason for ongoing program evaluation. MDPH has already added to a long history of epidemiologic and laboratory studies in the areas of hepatitis virus and HIV infection, by performing hepatitis C serosurveys among populations of critical interest.

- a) Hepatitis C Program objectives should inform data needs and guide data collection.
- b) Data should be collected not only on who is affected, but also on how they are affected and how they deal with their disease.
- c) Program evaluation should be considered essential and collection of process data measures from funded programs should be considered basic.
- d) Program and administrative data should be collected in a consistent fashion across hepatitis C programming and in a fashion as compatible as possible with other MDPH programs.
- e) MDPH should assist programs in assessing and upgrading their data system hardware and other infrastructure.
- f) MDPH should continue to support and carry out seroprevalence and other epidemiologic studies of hepatitis C virus infection, as well as studies of knowledge, attitudes, beliefs and outcomes, especially those pertaining to locally relevant questions.
- g) State efforts should be made to fund applied research that will have local impact. While the need for basic and clinical research is still large, basic and clinical research is best funded by the federal government and industry.
- h) MDPH should assist those living with hepatitis C and foster clinical research by working with partners to develop a research study directory similar to that provided for people seeking HIV-related research studies.
- i) MDPH should play a role in assessing information developed in research studies and in making results accessible to the public and those directly affected by hepatitis C.

9. The Massachusetts Department of Public Health should maintain a leadership role in the development of public health policy related to hepatitis C and, in collaboration with other state agencies, work closely with agencies of the federal government to maximize services for those living with, or at risk of, hepatitis C infection.

Hepatitis C is a major public health issue, both in its direct impact and because of increasing public perception of its importance. It must be addressed on the national, state and local levels. In the coming years, it is likely that the federal government will be playing an even larger role in the public health response to hepatitis C, as a result of increasing awareness of the extent of hepatitis C infection and its impact on the nation's health, the expense of clinical management, and the socioeconomic status of many of the persons at risk. It is critical for public health and other state and local agencies to

participate in federal efforts and maximize resources for the Commonwealth. Policy development is a core activity of public health, and, in Massachusetts, the Department of Public Health is lead agency for public health policy development. It is the role of MDPH to pose policy questions, facilitate discussion, facilitate input from all stakeholders, coordinate with the federal government and localities, and draft policy for public review and comment.

- a) Because issues related to hepatitis C involve a large number of stakeholders (including the general public, persons at risk, persons infected, service providers, local health agencies, payers for services, care and custody agencies, educators, clinicians, the pharmaceutical industry, researchers, etc.), all major stakeholders should be involved in the policy discussion.
- b) While convening and facilitating discussion among stakeholders, the MDPH should provide opportunities for input from individuals and groups not yet identified as stakeholders.
- c) MDPH should recognize that advocacy for hepatitis C issues among the public and consumers is in an early stage of development, and encourage existing programs and agencies that serve individuals at higher risk of hepatitis C to solicit consumer participation.
- d) MDPH should work with the Division of Medical Assistance to develop guidelines for the clinical management of hepatitis C.
- e) MDPH-funded hepatitis C services should assist eligible clients with application for MassHealth.
- f) MDPH should pursue appropriate federal requests for proposals for service programs and studies.
- g) MDPH should develop strategic partnerships with other agencies and industry.
- h) MDPH should learn from and share resources with other states with similar hepatitis C initiatives that are already developed or in process.
- i) Policy development should proceed in a context of program and service integration, cognizant of impacts on all components of integrated programming.