



MASSACHUSETTS

State HCV Report



An Analysis of the Successes,
Challenges, and Opportunities for
Improving Healthcare Access
With a Focus on People Living With
Hepatitis C

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foreword



Access to high-quality healthcare is critical for people living with hepatitis C virus (HCV), and yet there is little state or federal funding dedicated to promote outreach, screening and access to early and comprehensive care or treatment for people living with this disease. Utilizing the successful model developed under the State Healthcare Access Research Project (SHARP), the goals of this project were to identify (1) challenges to access to care and treatment faced by people living with or at risk for HCV in Massachusetts (a post-healthcare reform state in a pre-reform country); (2) successful policies that facilitate access to care; and (3) opportunities for improving access to care for persons living with HCV.

SHARP was originally developed as a model to examine state capacity to meet the healthcare needs of people living with HIV/AIDS. Since its inception in 2008, SHARP has been successful in identifying and addressing healthcare access successes, challenges, and opportunities for people living with HIV/AIDS in 10 states. In each state, SHARP has worked closely with in-state partners and produced a comprehensive report outlining successes in meeting access to care, treatment, and essential support service needs as well as challenges and potential opportunities for improvement. These reports have been used by in-state partners, including people living with HIV/AIDS, their health and social service providers, and government officials to launch new initiatives—based upon SHARP recommendations—aimed at improving access to care, treatment, and services. As part of the Massachusetts HCV report, the model developed through SHARP was used to examine access to care and treatment for persons living with HCV in Massachusetts.

Collaboration with community partners is integral to the SHARP process. We have met or spoken with people living with hepatitis C, healthcare providers (including substance use disorder treatment providers), support services providers, state and federal government officials, and other stakeholders as we conducted our in-state research for this report. These community partners have shared their opinions and insights about the successes and challenges faced by people living with hepatitis C as they seek testing and care.

Our goal is for each SHARP report to be informative and useful. It is our hope and intention that the reports will become a framework for future efforts to expand healthcare access—tools that can be used as part of a broader strategy to bring healthcare to more people living with hepatitis C and other chronic conditions. It is important to note that the reports reflect a snapshot of a state at a moment in time—with implementation of national health reform moving forward and states responding to ongoing economic difficulties, the landscape of healthcare access is changing almost every day. Some of the opportunities discussed in this report may need to be revised accordingly.

foreword



The State Healthcare Access Research Project (SHARP) is conducted by the Center for Health Law and Policy Innovation of Harvard Law School and the Treatment Access Expansion Project (TAEP), in collaboration with Bristol-Myers Squibb, with no editorial review or discretion. The content of SHARP does not necessarily reflect the views or opinions of Bristol-Myers Squibb. The Center for Health Law and Policy Innovation (CHLPI) has provided legal services to low- and moderate-income people living with chronic illnesses for 20 years. The Center is also an active participant in healthcare access advocacy efforts for low-income people, particularly individuals living with chronic medical conditions. TAEP is a national organization focused on healthcare access advocacy for low-income people living with HIV/AIDS, hepatitis, mental illness, and other chronic diseases.

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part I: introduction



WHY HEPATITIS C?

The Centers for Disease Control and Prevention conservatively estimates that more than 3 million people in the United States have chronic hepatitis C virus (HCV) and that 75% are unaware that they are infected.¹ In recent years, the number of deaths from hepatitis C in the United States has surpassed the number of deaths from HIV.² Yet unlike HIV and many other chronic illnesses, there is essentially a cure for many individuals living with HCV, with new medications on the horizon that promise even greater success.

Despite the gravity of the epidemic and the capacity to cure the illness, there has been relatively little federal or state investment in HCV education, prevention, testing, medical care, treatment, and support services. Over the next 10 years, incidence of cirrhosis and other serious liver complications is expected to rapidly increase in HCV-infected baby boomers, highlighting the need for urgent action.³ Unless the increasing incidence of this disease is addressed, healthcare costs related to HCV are expected to rise from \$30 billion to \$80 billion per year in 2020.⁴ Moreover, HCV increasingly impacts youth and young adults in the United States, as well as older Americans. It is crucial to implement a more active approach to addressing HCV if we do not want HCV to persist at epidemic proportions for generations.

WHY MASSACHUSETTS?

Massachusetts has taken incredible steps toward increasing access to healthcare for all its residents, including individuals with HCV. In many ways, Massachusetts is a post-healthcare reform state in a pre-healthcare reform country. Access to health coverage is a major barrier nationally to HCV care and treatment. By contrast, in Massachusetts 98% of the population has access to health insurance, and lack of coverage is rarely cited as a barrier to HCV treatment. Massachusetts has a comparatively robust HCV surveillance system, an integrated prevention, care and testing infrastructure for individuals at risk, and supports medical case-management sites at locations across the state. Recent legislation in Massachusetts also establishes the beginnings of a plan to reform payment and care delivery, reduce rising healthcare costs, and improve quality of care. Yet even where most people have access to coverage, barriers to prevention, testing, care, and treatment remain.

Like many states, Massachusetts has experienced severe cuts to public services over the past few years, including decreases to public health funding at both the state and federal levels. In Massachusetts, some feel that hepatitis C (and other forms of viral

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hepatitis) has been on the back burner despite evidence of the growing epidemic. Challenges include the need for: greater prevention and screening efforts targeted to youth and adults at risk for HCV, to increase knowledge, decrease stigma, and promote testing and linkage to care; stronger care coordination to support treatment and retention in care for individuals with mental illness and/or active substance use; development of training models to support primary care providers in screening patients and/or providing treatment; and increased funding to support education and treatment in correctional institutions.

The HCV landscape in Massachusetts illustrates successful policies that facilitate treatment access and persistent challenges that remain problematic to those with HCV even with access to health coverage, offering models and lessons for other states. There are many opportunities to increase access to care both in Massachusetts and nationally. Particularly as the United States implements national health reform, the lessons of Massachusetts' experience can assist in designing implementation systems and concurrent policies that will ensure greater access to testing, care, and successful treatment for individuals living with HCV.

part II: background



BACKGROUND

National Overview of Hepatitis C Virus (HCV)

Hepatitis C virus (HCV) infection is a blood-borne illness affecting the lives of millions of Americans. Estimates of the number of people infected in the United States range from 3.2 million⁵ to over 5 million.⁶ In the past few years, HCV has surpassed HIV in the number of related deaths in the United States, resulting in 15,106 deaths in 2007, compared to 12,734 deaths due to HIV.⁷ Persons with HCV can be asymptomatic for years, and as a result 75% of people living with the disease do not even know they are infected.⁸ For these reasons, HCV is often referred to as the “silent epidemic.”

Acute and Chronic HCV Infection

HCV is a blood-borne viral infection that attacks the liver.⁹ It is spread primarily through blood contact with an infected person, and may result in acute and/or chronic illness.¹⁰ Acute HCV is a short-term illness that occurs within the first 6 months of infection.¹¹ For approximately 75-85% of infected people, acute HCV infection will lead to chronic HCV infection.¹² Many people with either acute or chronic HCV infection do not experience symptoms, and when symptoms of chronic HCV occur it is often many years later when liver damage has already developed.¹³

Mortality

HCV is the top cause of cirrhosis and liver cancer in the United States, and the most common cause of liver transplant.¹⁴ Among those with chronic infection, 60-70% of transplants will develop chronic liver disease, 5-20% will develop cirrhosis (over 20 to 30 years), and 1-5% will die from cirrhosis or liver cancer.¹⁵ Heavy alcohol consumption intensifies HCV disease progression and increases the rate at which patients suffer from cirrhosis and liver cancer.¹⁶ There are also greater risks for liver disease and HCV-related death for persons who are coinfecting with both HIV and HCV.¹⁷ In fact, liver disease, much of which is attributed to hepatitis C or B infection, is now the leading cause of non-AIDS-related death among people living with HIV.¹⁸ Overall, between 1999 and 2007, mortality rates from HCV infection have been increasing at an average annual age-adjusted mortality rate of .18 deaths per 100,000 persons per year.¹⁹ Deaths attributed at least in part to HCV have been at a relatively young age, with the majority occurring between 45 and 64 years.²⁰ Currently, HCV accounts for approximately 15,000 deaths each year in the United States.²¹

Transmission/Persons at Risk

HCV is transmitted primarily through blood contact with an infected person, and can be spread through injection drug use, needle-stick incidents in healthcare settings, or being born to a mother who is HCV-infected.²² It is also possible (though less likely) to contract

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HCV through personal care items (eg, toothbrushes or razors) that have come into contact with infected blood, or through tattooing or piercing.²³ Some studies have also shown that HCV can be spread through sexual contact, though this is less common.²⁴ Persons considered to be at increased risk include:

- current injection drug users or persons with history of injection drug use (even if only once)
- those who received donated blood, organs, or other blood products (particularly prior to 1992)
- people who received a blood product for clotting problems before 1987
- hemodialysis patients or people who spent many years on dialysis for kidney failure
- people who received body piercing or tattoos performed with nonsterile tools
- people living with HIV
- people working in healthcare settings where needle-stick injury may be possible
- children born to mothers who have HCV²⁵
- veterans, particularly Vietnam War veterans²⁶
- incarcerated people²⁷

The primary mode of transmission today is through injection drug use.²⁸ However, HCV is more infectious and can survive for longer periods of time outside the body than HIV. Because of this, HCV can be transmitted not only via shared needles and syringes, but also through other injection drug equipment such as cotton and cookers, or even through water shared to rinse syringes that contains infected blood.²⁹ Further, because it is often asymptomatic, persons who many years ago may have engaged in limited injection drug use may have been infected at that time and never know it. Still others may have no idea that they were put at risk. For example, veterans, particularly those who served during the Vietnam War era, are considered to be at much higher risk for HCV, and although this risk is thought to be primarily due to injection drug use histories,³⁰ it is also possible that some of these infections may be associated with past group vaccination practices during military service.³¹ In addition, because the illness is so prevalent among the baby boomer generation, the Centers for Disease Control and Prevention (CDC) recently released recommendations that all persons born between 1945 and 1965 receive a one-time screening test for the virus, regardless of the presence of any known risk factors.³²

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Incidence (Rate of New Infections)

In general, HCV surveillance is limited, in large part due to insufficient guidance and resources at both the federal and state levels.³³ Further, the clinical and surveillance definitions for acute HCV infection are not consistent with each other,³⁴ and there is no lab test to measure whether a person has an acute HCV infection or has been recently infected.³⁵ Because acute HCV is usually asymptomatic, many individuals do not seek care until much later, meaning that a person recently infected with HCV may never present as “acute” because they did not experience symptoms during the early phase of the infection.³⁶ For these reasons, it is difficult to determine an accurate rate of new infections (incidence), but there are some estimates.³⁷ According to the CDC, overall incidence has been declining, from 262,000 new infections in 1986 down to 17,000 new infections in 2010.³⁸ However, recent data from Massachusetts and elsewhere indicate rising incidence among youth, concentrated among young injection drug users (IDUs).³⁹ In general, incidence is much higher among IDUs than the general population, estimated to be between 15 and 30 per 100 person-years at risk, and even higher among persons who recently began injecting.⁴⁰ Given that many IDUs may lack access to testing and care and thus remain undiagnosed, this rate may be even greater.

Prevalence (Persons Living With HCV)

The majority of persons living with HCV are in the baby boomer generation (persons born between 1945 and 1965); the CDC estimates that 75% of individuals living with HCV are in this age group (with a prevalence rate of 3.25%), though this age group comprises only 27% of the population.⁴¹ Within this cohort, males have twice the prevalence rate of females, with highest rates among black males: 8.12% among non-Hispanic black males compared to 4.05% among non-Hispanic white males, and 3.41% among Mexican-American males.⁴² One study suggests that the highest prevalence rate (13.8%) is among non-Hispanic black men ages 40-49.⁴³

Injection Drug Users (IDUs)

Estimated prevalence among IDUs is much higher than the general population, and varies with age group and number of injecting years.⁴⁴ Among older IDUs (over 50 years of age), prevalence may be greater than 80%, while for younger IDUs (under 40 years of age), prevalence is estimated between 25-35%.⁴⁵

Veterans

Other populations with high prevalence rates include veterans, with prevalence estimated between 5.4-41.7%.⁴⁶ The US Department of Veterans Affairs (VA) reports that among those receiving care at VA healthcare facilities, prevalence is as high as 1 in 20.⁴⁷ Prevalence among veterans is particularly high among those who served during the Vietnam War era⁴⁸ and among homeless veterans.⁴⁹

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Correctional Facilities

HCV is also highly prevalent among inmates in correctional facilities. The CDC estimates that 16-41% have ever been infected with HCV and 12-35% are chronically infected, compared to 1-1.5% in the general population (non-incarcerated).⁵⁰

Individuals Living With HIV

Persons living with HIV also have a high prevalence, with 25-33% of HIV-infected Americans coinfecting with HCV.⁵¹ The coinfection rate is even higher among HIV-positive IDUs (80-90%).⁵² Additionally, HIV-infected men who have sex with men who engage in risky sexual behaviors have higher incidences of HCV coinfection.⁵³

Outbreaks in Healthcare Facilities

Although less frequent, HCV outbreaks can also result from unsafe practices at healthcare facilities, with 16 outbreaks known by the CDC to have occurred in nonhospital settings between 1998 and 2008, and 7 in hospital settings.⁵⁴ Many of the outbreaks in nonhospital settings occurred due to unsafe injection practices.⁵⁵ From 2008 to 2011, there were an additional 13 healthcare-related outbreaks of HCV.⁵⁶ In early summer 2012 there was another outbreak in a New Hampshire hospital believed to have been caused by a healthcare worker who reused syringes on patients after injecting himself with a controlled substance, leading to at least 31 new infections.⁵⁷

Testing⁵⁸

Testing for HCV infection usually involves several different tests. Commonly, individuals are given an initial screening test that detects the presence of HCV antibody. The results of this test will indicate whether a person has been exposed to HCV, but not whether the person is currently infected. A confirmatory test that assesses the presence of virus is required to tell whether an individual remains infected.

Treatment

A person diagnosed with HCV may have several options for addressing the illness, including but not limited to antiviral treatment, deferment of treatment, or a liver transplant (in some cases). As will be discussed below, unfortunately some individuals may not be eligible for antiviral regimens due to medical contraindications, while others may not realize they are infected until it is too late to pursue either treatment or a liver transplant. All persons living with HCV (who are negative for hepatitis A and B antibodies) are recommended to receive vaccinations for hepatitis A and B, and to refrain from certain behaviors, such as consumption of alcohol, that can increase the risk of disease progression.⁵⁹

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Current recommended antiviral treatment involves weekly injections of pegylated interferon accompanied by ribavirin. However, treatment regimens and success rates can vary based on the kind of HCV, or genotype, a person is infected with, among other factors. For many years, persons with genotype 1 had lower rates of treatment success than persons with genotypes 2 or 3.⁶⁰ In June 2011, however, the Food and Drug Administration (FDA) approved two new drugs known as direct-acting antivirals, boceprevir (Victrelis) and telaprevir (Incivek) that can increase rates of treatment success when taken in combination with interferon and ribavirin. These new drugs have been shown to increase rates of successful treatment for genotype 1 patients.⁶¹

However, disparities also exist concerning the efficacy and availability of treatment among certain populations. African Americans and Hispanics are less likely to respond successfully to treatment,⁶² and rates of HCV-related deaths for both these groups, as well as for Native Americans/Alaska Natives, are higher than among whites.⁶³

For many people, treatment can be an incredibly difficult ordeal, and may involve serious physical and mental side effects. Unlike treatments for many illnesses, current antiviral treatment for HCV may not be appropriate for everyone. Many factors can influence whether treatment should be undertaken, including genotype, the presence of comorbidities, the presence or absence of existing liver damage, the presence of severe mental illness, and other factors. As of the time of this report, many experts predict that there will be new, more effective treatments developed over the next few years, which could even negate the need for interferon-based therapy.⁶⁴ Some individuals may choose to initiate treatment at a later date in anticipation of these new developments, while others may not have time to wait. Researchers also continue to work on the development of a preventive vaccine.

Insurance Status

One study estimates that in 2008, approximately 56% of chronically infected patients were commercially insured, 17% were uninsured, 13% were covered by Medicare, 10% were covered by the VA, and 4% were covered by Medicaid.⁶⁵ Other studies have found higher proportions of individuals who are uninsured,⁶⁶ and that individuals with HCV are more likely than uninfected persons to have public insurance.⁶⁷ While not everyone may be an appropriate candidate for treatment, one study estimated that eliminating insurance status as a barrier to treatment could double the number of individuals who have access to drug therapy.⁶⁸ This has important implications as the country moves toward implementation of the Patient Protection and Affordable Care Act (ACA).

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Costs

HCV has substantial economic costs. Liver transplants and other treatments for the end-stage consequences of hepatitis are expensive.⁶⁹ Lifetime healthcare costs for someone living with viral HCV can be hundreds of thousands of dollars.⁷⁰ Total HCV-associated medical care costs in the United States are estimated to be \$30 billion per year.⁷¹ Managed-care enrollees who were HCV-infected have been shown to have higher rates of hospitalization as well as higher annual healthcare expenses.⁷² HCV also has substantial health and societal costs. If left untreated, HCV can lead to severe liver damage and in some cases, death. A study of nearly 340,000 workers also demonstrated that employees with HCV had more lost work days than other employees.⁷³

HCV-related costs are projected to rise substantially over the next 2 decades, as people now infected continue to age, and people with asymptomatic infections develop progressive liver disease. Under the current trajectory, HCV-associated medical costs are predicted to more than double over the next 20 years—going from \$30 billion to \$80 billion per year.⁷⁴ Many of these costs will be borne by public programs like Medicaid, the VA, and Medicare, and these cost estimates do not include persons who are incarcerated.⁷⁵ As the baby boomer generation ages, HCV-related Medicare costs in particular are estimated to increase from \$5 billion to \$30 billion over the next 20 years.⁷⁶ However, some researchers have estimated cost savings of \$120,000 per quality-adjusted life year (QALY) gained through the use of HCV treatment.⁷⁷

Federal Funding

Despite the relatively high disease burden of HCV in the United States, there is little federal funding dedicated to combating the epidemic. The CDC receives the only viral hepatitis-specific appropriation from the federal government:⁷⁸ 29.7 million in FY2012. This allotment included a \$10 million award from the new Prevention and Public Health Fund for viral hepatitis testing.⁷⁹ The Division of Viral Hepatitis (DVH), within the CDC, is in charge of using these funds to administer viral hepatitis programs. DVH provides grant funding for viral hepatitis education and training projects.⁸⁰ Additionally, DVH funds 55 Adult Viral Hepatitis Prevention Coordinators (AVHPCs) in the states and large cities, with grant awards of approximately \$90,000 per state.⁸¹ The AVHPCs are responsible for coordinating viral hepatitis prevention efforts and integrating viral hepatitis into healthcare settings and public health programs, but there are no programmatic dollars included in the budgets provided to AVHPCs.⁸² Outside of viral hepatitis-specific programs, the CDC has also funded limited viral hepatitis surveillance sites in ten states—Colorado, Connecticut, New York, Oregon, Minnesota, California, Maryland, New Mexico, Tennessee, and Georgia—as part of the Emerging Infections Program (EIP).⁸³ No other states or local jurisdictions receive funding for routine surveillance activities. For FY2013, President Obama requested \$29.7 million for DVH, while advocates requested a total of \$59.8 million.⁸⁴

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National Viral Hepatitis Action Plan

In 2010, the Institute of Medicine released a comprehensive report detailing the challenges and opportunities regarding viral hepatitis surveillance, prevention, care and treatment, and making numerous recommendations for improvements in federal policy.⁸⁵ In response, in June 2011, the Department of Health and Human Services (HHS) released a national action plan, “Combating the Silent Epidemic of Viral Hepatitis: Action Plan for the Prevention, Care and Treatment of Viral Hepatitis” (the Action Plan).⁸⁶ The plan calls for actions to be taken in six areas: (1) educating providers and communities; (2) improving testing, care, and treatment; (3) strengthening surveillance; (4) eliminating transmission of vaccine-preventable hepatitis; (5) reducing viral hepatitis caused by drug-use behaviors; and (6) protecting patients and workers from healthcare-associated viral hepatitis. The plan calls for interagency collaboration on a number of levels, while primary responsibility for the plan rests largely with the Assistant Secretary for Health (ASH), who convenes the HHS Interagency Work Group on Viral Hepatitis, and the Viral Hepatitis Action Plan Implementation Group (VHIG).⁸⁷

Since enactment of the plan, there has been some progress on its objectives. For example, in the fall of 2011 the CDC announced several new initiatives, including:

1. improving viral hepatitis surveillance through electronic laboratory reporting in states without this capacity;
2. implementing a national educational campaign, called “Know More Hepatitis,” including both policymakers, providers, and persons at risk;
3. developing education and training for healthcare providers;
4. consulting subject matter experts about the development of new HCV guidelines;
5. developing and field testing an HCV counseling and testing manual;
6. developing a strategic framework for implementing HCV screening in a reformed health system; and
7. supplementing the national HIV behavioral surveillance system (NHBS) to survey risk populations for HBV and HCV.⁸⁸

On May 19, 2012, the first ever National Hepatitis Testing Day was held, at which time the CDC announced additional viral hepatitis funding opportunities for testing and linkage to care, as well as efforts focusing on disproportionately affected groups such as baby boomers and injection drug users.⁸⁹ Further, as discussed, the CDC also recently released new guidelines recommending a one-time screening for all individuals in the baby boomer generation,

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regardless of risk factors.⁹⁰ In September 2012, HHS published a comprehensive progress report that details its work over the past year in each of the six areas under the Action Plan.⁹¹

Additional Federal Agencies Doing Viral Hepatitis Work

There are other agencies and divisions within HHS that also provide some programming around hepatitis.⁹² For example, the Health Resources and Services Administration (HRSA) administers the Ryan White Program, which provides discretionary federal funding for HIV/AIDS services. HRSA allows Ryan White funds to be used for HBV and HAV vaccines, viral hepatitis screening for people living with HIV infection, and treatment of coinfecting individuals.⁹³ As of March 2012, 28 state AIDS Drug Assistance Programs (ADAPs) covered at least one medication for HCV, 26 states covered HBV/HAV vaccines, 27 covered at least one medication for HBV, and at least 9 states covered some form of viral hepatitis diagnostic service.⁹⁴ Many clinics receiving Ryan White Program funding have also integrated HIV and HCV testing, resulting in high rates of testing (91%) for HIV/HCV coinfection.⁹⁵ The Agency for Healthcare Research and Quality (AHRQ) also provides funding for the ECHO project, an effort to assist community-based providers in administering hepatitis treatment through the use of tele-health technological connections with academic medical centers, which will be discussed in more detail later in the report.⁹⁶ The Substance Abuse and Mental Health Services Administration (SAMHSA) also does some work through its HIV/AIDS programs, and recently released a Treatment Improvement Protocol (TIP), “Addressing Viral Hepatitis in People with Substance Use Disorders,” designed to provide technical assistance to substance use disorder providers on counseling and supporting clients with viral hepatitis.⁹⁷

In addition, the VA provides extensive HCV services through the Veterans Health Administration (VHA). Its national HCV programs are considered models of HCV prevention and care, though not all veterans are eligible for VHA services.⁹⁸

Important Federal Laws and Policies

Recent legislation has opened up new opportunities for HCV prevention, care, and treatment. The ACA will expand Medicaid to much of the low-income, at-risk population for HCV, provide tax subsidies for low-income people who do not qualify for Medicaid to purchase private coverage in new health insurance exchanges, and prohibit discrimination on the basis of pre-existing conditions in the private insurance market.⁹⁹ However, the US Supreme Court recently held that participation in the expansion of Medicaid will essentially be optional for states, and therefore the degree to which the ACA will expand Medicaid coverage to low-income individuals with HCV will largely depend on the action of individual states in determining whether to implement the Medicaid expansion.¹⁰⁰ The ACA also established the Prevention and Public Health Fund, which can be utilized for HCV screening and testing. As noted, in 2012, \$10 million was allotted to viral hepatitis testing programs.

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There is not yet legislation dedicated specifically to viral hepatitis. A number of bills have been proposed, however, including in the current Congress. Most recently, the Viral Hepatitis Testing Act of 2011 (the Act) was introduced in the House and Senate.¹⁰¹ The Act would authorize HHS to establish grants to public health agencies and private nonprofit groups for viral hepatitis screening and testing, accompanied by education and referral to medical care.¹⁰² The Act sets a target of having 75% of people with hepatitis B and HCV be diagnosed by 2016.¹⁰³ The Act has been referred to committees in both the House and the Senate.¹⁰⁴ Also introduced in the 112th Congress, Title VII of the Health Equity and Accountability Act includes a subtitle called the Viral Hepatitis and Liver Cancer Control and Prevention Act.¹⁰⁵ This act directs HHS to establish and implement comprehensive prevention, education, surveillance, and research programs for viral hepatitis.¹⁰⁶ The bill is still in committee in the House.¹⁰⁷

In FY2012, Congress reinstated a ban on federal funding for syringe exchange programs, despite the fact that such programs were recommended as part of the HHS Viral Hepatitis Action Plan.¹⁰⁸ On March 29, 2012, HHS issued a letter to states on the parameters of the ban, specifying that federal funds may not be used for:

- “human resources used specifically to distribute needles or syringes;
- delivery modes, e.g. vehicles or rent for fixed sites used specifically for distributing needles or syringes;
- purchase of needles or syringes.”¹⁰⁹

However, states may still implement and operate syringe exchange programs without federal dollars. To this end, in August 2012, the National Association for State and Territorial AIDS Directors (NASTAD) released guidance for states on how to establish and maintain syringe services programs (SSPs) while remaining in compliance with federal laws and regulations.¹¹⁰

Overview of the HCV Epidemic in Massachusetts

Number of People Living With HCV

Since 1992, approximately 110,000 individuals have been identified in Massachusetts as having evidence of past exposure to HCV.¹¹¹ As nationally, adults in the baby boomer generation comprise the largest cohort of infected individuals. However, Massachusetts was one of the first states to report the growth of HCV in a second group: adolescents and young adults aged 15-25 years.¹¹² According to the Massachusetts Department of Public Health (MDPH), since 2002 there have been 7,000 to 10,000 newly reported HCV cases annually. In recent years, 1,000 of these have occurred among adolescents and young adults. From 2002-2008, the rate of new cases (incidence) among those aged

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30 years and older decreased from 199 to 150 per 100,000 population, but rose among youth from 65 to 135 per 100,000 population.¹¹³

All healthcare providers in Massachusetts are required to report cases of HCV to local boards of health, or directly to MDPH, as are all laboratories. Because reported cases reflect only those persons who have accessed care and been tested, it is likely that even these numbers are underestimated. Nationally it is estimated that 75% of people do not realize they are infected.* There are also some gaps in the existing surveillance data. For example, while MDPH attempts to collect race/ethnicity and risk history data on each case of HCV infection, these data are largely incomplete due to the limited capacity of MDPH to follow up with providers to obtain this information.¹¹⁴

Mortality

Although mortality rates are not readily available, MDPH recently undertook a project matching the names of persons in Massachusetts reported as having an HCV diagnosis with the names of people in Massachusetts who had died (vital records), from 1992-2009.¹¹⁵ Massachusetts' data indicate that the mean age of death among those infected with HCV was 53 years (including both HCV and other causes), while the mean age of death among non-HCV-infected people was 75 years.¹¹⁶ Among individuals reported with HCV infection who died during this time period, 73% died within the first 5 years after diagnosis (from all causes). These data suggest that many people with HCV may be getting diagnosed and entering care late in their illness.¹¹⁷

Risk Factors

In Massachusetts, as nationally, injection drug use (IDU) is the most commonly reported risk factor. In 2011, among people with confirmed chronic HCV infection, nearly 68% of the people who answered questions about risk factors for hepatitis reported having injected drugs at least once.¹¹⁸ The second most commonly identified risk factor was sex, with 29% reporting sexual contact with someone with HCV.¹¹⁹ Other reported risk factors included household contact with HCV (approximately 20%); blood transfusion before 1992 (about 9%); and employment in the medical and/or dental field (nearly 2%). The risk factors of hemodialysis, receiving clotting factors before 1987, and blood transplants before 1992 each accounted for less than 1% of cases; a little over 2% of cases reported no known risks. For about 20% of cases, risk factors were unknown and/or not reported.¹²⁰

* Because Massachusetts has a more robust surveillance system than many other states, the number of persons who do not know they are infected may be lower than the national estimate. However, there is no method to accurately gauge how many people in Massachusetts are currently living with HCV but are unaware of their infections.

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Risk Factors Among Adolescents and Young Adults

Data indicate that the increase in incidence among youth is correlated with adolescents' opioid and injection drug use, primarily use of heroin.¹²¹ Of the reported cases among people aged 15-25 years between 2007 and 2010, 62% reported some history of IDU and 34% reported intranasal drug use (with 91% of those also reporting IDU). Among youth injecting drugs, an overwhelming majority (84%) reported using heroin in the past 12 months. Another exposure risk was history of incarceration (11%).¹²²

In March 2011, an Epi-Aid was conducted by the CDC (an epidemiologic investigation conducted at the request of state and local health departments when additional expertise and staff are required). CDC staff were deployed to investigate 394 of the reported cases among youth (aged 18-24 years) who had been reported between July 1 through December 31, 2010.¹²³ For a variety of reasons (incomplete information on surveillance forms, individuals who were in a drug treatment program, refusal to participate, among other issues), only 28 individuals were interviewed. Of these participants, 93% reported using drugs. Of those:

	Percent Reporting Use	Median Age of Initiation
Marijuana	93%	13 years (range: 9-17)
Opioid-abuse (oxycodone and/or OxyContin)	92%	17 years (range: 12-23)
Heroin (note that nearly all of those using heroin started with opioids before going to heroin)	89%	18 years (range: 14-21)

In addition, 70% of participants indicated they had shared syringes or other drug-use equipment among groups of IDUs that included people who had HCV. MDPH also received a 1-year grant from the CDC (approximately \$30,000) to continue more detailed investigations of reports among young adults aged 18-24 years through July 2012.¹²⁴

Demographics and Geographic Distribution

From 2002-2010, the average age at diagnosis in Massachusetts was 43 years, and the majority of infections (63%) were among males, while 37% were among females.¹²⁵ Unlike the overall epidemic in Massachusetts, among youth (confirmed cases) there has been a more even split among genders: from 1992-2011, 48% of cases were reported among males and 52% were among females.¹²⁶ In general, information on race and ethnicity is often not included in case reports, with 69% of cases listed as unknown, 21% of cases reported as white non-Hispanic, 7% as Hispanic, and 3% as black non-Hispanic.¹²⁷

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HCV cases occur across Massachusetts, but there is significant geographic variation and differences in geographic distribution between adult and youth HCV cases. Among adults, in 2011 the five counties with the highest incidence rates for confirmed chronic HCV infections were Hampden, combined Cape Cod counties (Barnstable, Dukes, and Nantucket), Suffolk, Essex, and Berkshire.¹²⁸ For youth, the highest incidence rates (for confirmed chronic HCV) occurred in Barnstable, Plymouth, Berkshire, Norfolk, and Essex counties.¹²⁹ More detailed demographic information about HCV case numbers and incidence rates can be found in Appendix A.

Coinfection With HIV

There were a total of 4,396 reports of HIV/HCV coinfection in Massachusetts through 2010 (out of a total 32,380 adult HIV/AIDS cases) (14%).¹³⁰ This percentage of coinfection has remained relatively constant between 10-14% in the past 5 years, much lower than the estimated national average of 25-33%.¹³¹ Coinfection was observed most frequently among males (70%, n = 3,076) and individuals aged 35-39 years (22%, n = 969).¹³² The primary risk factor for HIV/HCV coinfecting individuals is also IDU, with 73% of coinfecting HIV/HCV individuals exposed through IDU, 8% through male-to-male sex, 7% through MSM/IDU, 6% through heterosexual sex, and the rest through undetermined exposures.¹³³ Among HIV infected youth and young adults (15-29 years of age), the number of coinfecting individuals is smaller, although incidence of coinfection may be greater in urban areas.¹³⁴

Other Health Indicators in Massachusetts

Access to Health Insurance

Because of its health reform efforts, Massachusetts has an extremely high rate of insured individuals: as of 2010, 98% of people in Massachusetts had healthcare coverage.¹³⁵ However, some gaps still exist: in 2010, 15% of adults aged 19-64 years living below the federal poverty level (FPL) were uninsured; among those living below 139% of FPL, 14% were uninsured; among those living between 139-250%, 11% were uninsured.¹³⁶ Of the nonelderly uninsured, 83% were adults (266,700 individuals) and 17% (53,300) were children.¹³⁷

Hepatitis A and B

The number of chronic hepatitis A infections has been declining since 2006, with less than 100 reported cases per year since that time.¹³⁸ There has also been a decrease in the number of chronic hepatitis B infections since 2005 (with a 30% decrease from 2002-2010).¹³⁹ In 2011, there were approximately 1,932 reported cases (both probable and confirmed) of hepatitis B in Massachusetts.¹⁴⁰ As with hepatitis C, these represent those individuals who have been screened, tested, and reported to MDPH.

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HIV and AIDS

From 2000-2010, the number of people living with HIV/AIDS in Massachusetts increased by 42% while the number of annual HIV infection diagnoses decreased by 45% and the number of deaths among people diagnosed with HIV/AIDS decreased by 34%.¹⁴¹ As of December, 31, 2011, a cumulative total of 30,790 people had been diagnosed with HIV infection, 12,620 (41%) had died, and 18,170 (59%) were living with HIV/AIDS. There are an additional 2,116 individuals living with HIV/AIDS in Massachusetts who were first diagnosed in another state.¹⁴² Approximately 21% of people living with HIV infection do not know their status. Thus, including those who do not know their status, an estimated 26,000-28,000 individuals are currently living with HIV/AIDS in Massachusetts.¹⁴³

Mortality Rates¹⁴⁴

Overall mortality rates have decreased in Massachusetts, as with the rest of the nation, since 1994. The leading causes of death in Massachusetts continue to be cancer (24.6%) and heart disease (24.2%). Other causes of death include injuries (5.6%), stroke (5.1%), and chronic lower respiratory disease (4.4%).

Substance Use

Among both adults and youth, Massachusetts has some of the highest rates of substance use in the United States. Based on data from the National Survey on Drug Use and Health (NSDUH), Massachusetts has consistently ranked among the top ten states with the highest rates of past-month illicit drug use among youth aged 12-17 years (since 2002)¹⁴⁵ and is among the top ten states for past-year illicit drug dependence or abuse, as well as illicit drug dependence in the past year for this age group.¹⁴⁶ Among young adults aged 18 to 25 years, Massachusetts is also among the top ten states in past month use of an illicit drug other than marijuana, and past-month illicit drug use (since 2002),¹⁴⁷ as well as past-year illicit drug dependence or abuse, illicit drug dependence in the past year, and alcohol dependence or abuse in the past year.¹⁴⁸

Among persons aged 26 years and older, Massachusetts has some of the highest rates in the country for illicit drug use in the past month, illicit drug use in the past month other than marijuana, dependence on or abuse of illicit drugs in the past year, and dependence on illicit drugs in the past year.¹⁴⁹

Young adults between ages 18 and 25 years had the highest percentages in the state of past-month illicit drug use other than marijuana, 11.2%, compared to 4.25% among youth ages 12-17 years and 3% among adults over age 26 years.¹⁵⁰ They also had the highest past-year illicit drug dependence or abuse, with 9.24% dependent on or abusing drugs compared to 5.27% of those aged 12-17 years and 2.04% of those aged 26 years and older.¹⁵¹ Use of illicit drugs over the past month (aged 12 years and over) also varied by region, with higher rates in Boston (12.24%), the Southeast (11.83%), and Western Massachusetts (13.22%).¹⁵²

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*Youth–Use of Illicit Drugs (High School and Middle School)*¹⁵³

According to the “2011 Health and Risk Behaviors of Massachusetts Youth,” approximately 2% of high school students reported having used a needle to inject illegal drugs, 5% used inhalants in the month before the survey, and 15% reported ever taking a prescription drug that was not their own, with 6% having taken a prescription drug not prescribed to them in the previous 30 days. Among high school students, 5% reported using cocaine in their lifetime, 6% used ecstasy, 3% used methamphetamines, 2% used heroin, and 3% used steroids. Overall however, reported use of ecstasy, methamphetamines, and steroids declined since 2003. Male students were more likely to report use of cocaine (7%) as well as needles to inject drugs (3%). In addition, 8% of high school students reported taking over-the-counter medication to get high during their lifetime.

Among middle school students, 4% of students indicated using prescription drugs that were not their own during their lifetime, while 1% were currently using. In 2011, 7% of middle school students indicated using at least one of the following drugs in their lifetime: inhalants, amphetamines, methamphetamines, and ecstasy, while 3% had done so within the past 30 days. In addition, 2% of middle school students reported taking over-the-counter medication to get high during their lifetime.

*Youth–Alcohol (High School and Middle School)*¹⁵⁴

According to the 2011 survey, the number of high school students who have ever had a drink (68%) or who had their first drink before age 13 years (15%), as well as the number of middle school students who have ever had a drink (20%), has been decreasing since 2003. Among middle school students, 8% indicated current alcohol use and 3% reported binge drinking. Among high school students, 40% indicated they currently used alcohol, while 22% reported current binge drinking.¹⁵⁵

Opioid Use–Overall

Between 2002-2007, 3,265 Massachusetts residents died from opiate-related overdoses.¹⁵⁶ Such deaths increased 63.5% between 1999-2005, with 544 deaths in 2005, 637 in 2006, and 645 opioid-related overdose deaths in 2007.¹⁵⁷ Across the state, in 2007 there were 30,000 nonfatal opioid-related inpatient admissions and emergency room visits.¹⁵⁸ Boston has been hard hit by the opioid epidemic, having 18,000 hospital stays and emergency department hospitalizations attributed to opioid use in 2005, and in 2002 had the highest rate of OxyContin-related emergency department visits in the country.¹⁵⁹

In FY2011, 43,265 admissions to licensed substance use disorder treatment programs in Massachusetts involved heroin use in the year before admission, 266 of which involved individuals under age 18 years. In addition, 84% of admissions for heroin also reported injection drug use in the past year.¹⁶⁰ There were 38,517 admissions involving injection

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drug users, 189 of whom were under age 18 years. The majority of admissions involving injection drug use identified heroin as the primary substance for which they needed assistance.¹⁶¹ (Note that these data involve overlapping admissions.)

Mental Health

According to the National Survey of Drug Use and Health (NSDUH), rates of major depressive episodes in the past year, serious mental illness in the past year, any mental illness in the past year, and serious thoughts of suicide in the past year in Massachusetts were generally close to the national average for all age groups.¹⁶² However, among those aged 18-25 years who had any mental illness in the past year, Massachusetts was above the national average (33.25% compared to 30.19%).¹⁶³

State and Federal Funding and Support for HCV Programs in Massachusetts

History of HCV Funding in Massachusetts

Massachusetts first established a viral hepatitis program within MDPH in the late 1990s. Beginning in 2001, state funding for HCV was included as a separate line item in the Massachusetts budget for \$1.7 million. That amount was both increased (up to \$2.75 million) and reduced (to a low of \$563,000 for 1 fiscal year) periodically over the next 7 years. Beginning in 2008, the HCV line item was eliminated. Since then, funding for viral hepatitis services has been integrated into the HIV/AIDS line item, with explicit language to this effect included in the line item beginning in 2010.

Since 2000, MDPH has integrated its hepatitis programming through contracts with existing HIV and STD prevention and care entities.¹⁶⁴ MDPH itself has also undergone reorganization and integration. In 2008, the HIV/AIDS Bureau merged with the Bureau of Communicable Diseases to create the Bureau of Infectious Disease, which now encompasses the Office of HIV/AIDS (OHA) as well as viral hepatitis programming.¹⁶⁵ Because of this integrated approach, it is difficult to ascertain exactly how much of the line item is used exclusively for hepatitis.¹⁶⁶

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Current HCV Funding and Programs

Like all states, Massachusetts receives some limited federal funding from the CDC for an Adult Viral Hepatitis Prevention Coordinator (AVHPC), at approximately \$90,000 per year. The responsibilities of AVHPC vary by state, but in Massachusetts, AVHC has focused on surveillance, education, screening and medical management services, and policy.

Prevention, Testing, and Referral

In FY2011, \$14 million was provided through OHA for integrated HIV, STI, and viral hepatitis prevention, screening, testing, and vaccination services, with 25% provided by the CDC. With this funding, the state provides grants through OHA to 14 integrated prevention and screening sites (Prevention, Intervention, Counseling, Screening and Referral [PICSR] sites), and an additional 8 sites that also include treatment for STIs (PICSR Treatment sites, or PICSR-Ts). Funding for PICSR sites ranges from about \$80,000-\$1 million per site, and \$160,000-\$930,000 for PICSR-T sites.¹⁶⁷ For a list of PICSR and PICSR-T sites and locations, see Appendix B.¹⁶⁸

In addition to the PICSR and PICSR-T programs, MDPH also provides funding for vaccinations for hepatitis A and B. While there is no federal funding available for these programs, in FY2012 the state was able to purchase 4,000 doses of hepatitis A vaccine and 8,000 doses of hepatitis B vaccines.¹⁶⁹ For children aged 12-36 months, MDPH provides routine hepatitis A vaccinations of the first and second dose (out of three), with some “catch-up” vaccinations available for high-risk children aged 2-18 years who never received the vaccine and who are underinsured.¹⁷⁰ MDPH also provides hepatitis B vaccinations for all children under age 18 years.¹⁷¹ For adults, both hepatitis A and B vaccines are targeted to those who are at highest risk and who have no access to insurance coverage.¹⁷²

*Medical Case Management*¹⁷³

Beyond testing and prevention, Massachusetts also provides \$13 million in state and federal funding for medical case management. This allocation represents a combination of both state money and federal funding from the Ryan White AIDS Program. Funding from the Ryan White Program may only be used to provide medical case management for individuals who are infected with HIV/AIDS, some of whom may be coinfecting with HCV. Because Ryan White Program case management dollars are limited to persons living with HIV, the state provides funding for case management for persons who are monoinfected with HCV. Case management through this program is offered at five different sites, encompassing seven different locations.

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Medical Case Management Sites for HCV Monoinfected Individuals

- Baystate Medical Center (Springfield)
- Boston Medical Center
- Cape Cod Hospital (two sites: Hyannis and Falmouth)
- Stanley Street Treatment and Recovery (Fall River)
- UMass Medical Center (two sites: Worcester and Fitchburg)

The funding awards to each of these particular sites range from \$77,000-\$120,000, for a total of about \$500,000. Case management for HCV clients can include a range of services, such as phone check-in (periodic checks on individuals to see how they are faring, as well as confirmation calls for appointments), social services coordination, adherence support, meals, and coordination of other services if needed, including transportation, peer support, and housing. According to MDPH, “access to these services is based on acuity of need, with clients currently on interferon-based treatment getting highest priority, clients newly diagnosed and/or considering treatment getting second-highest priority, and all other clients with HCV, including those with end-stage liver disease getting third-highest priority.”¹⁷⁴

Breakdown of Combined State and Federal Funding for Each Program

Program	State and Federal Funding
Medical Case Management for Individuals Living With HIV (includes Ryan White Program funding) (also includes individuals coinfectd with HCV, though most HIV-infected individuals are not coinfectd)	\$12,500,000
Medical Case Management for Persons With HCV Only	\$500,000 (\$77,000-\$120,000/site)
PICSR	\$80,000-\$1,000,000/site
PICSR-T	\$160,000-\$930,000/site

Funding For HCV in the Department of Corrections

In Massachusetts, there are two concurrent systems of incarceration for adults: county jails and houses of correction (HOC) run individually by each county, and state prisons, run by the Massachusetts Department of Corrections (DOC). Currently, Massachusetts operates 17 state prisons, as well as additional medical and substance use disorder facilities, and there are 13 HOCs (with additional local jails).¹⁷⁵ In general, inmates awaiting trial or who are serving terms that are less than 2.5 years are housed in HOC facilities, while inmates serving longer sentences are sent to state prison. While each county is

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responsible for procuring its own health services to serve inmates at HOC facilities and jails, the DOC contracts with the Correctional Health Program of UMass Medical School for inmate health services.¹⁷⁶ As of December 17, 2012, there were 11,648 inmates in jails and HOC facilities, and 11,148 individuals housed in DOC facilities.¹⁷⁷ While the number of individuals living with HCV in HOC facilities is unknown, there were approximately 1,983 inmates living with HCV infection in Massachusetts DOC facilities as of November 2012.¹⁷⁸ The FY2013 budget for the Massachusetts Department of Corrections is \$559,378,000.¹⁷⁹

OHA also provides funding to the state DOC for medical case management (limited to those with HIV, including coinfecting individuals), HIV counseling and testing, and group- and individual-level prevention services in its 17 facilities. Counseling and testing services are available to all inmates throughout the period of incarceration.¹⁸⁰ In the past, OHA funded similar services at the 12 county HOC sites, but in FY2013, funding to OHA from the CDC decreased by about \$1.2 million, resulting in cuts to these HOC programs.¹⁸¹ Many counties are working to maintain HIV services, however, and OHA is working to facilitate connections with local community-based organizations to try to continue these services in facilities where essential infrastructure was lost.¹⁸² All DOC and certain HOC facilities do continue to offer HCV risk-based screening, including Barnstable HOC, which has been providing this service since 2009.¹⁸³

For inmates who are infected with HIV and/or coinfecting with HCV and HIV, OHA also funds five programs for Corrections to Community reintegration services (CTC), which offer transitional case management that begins while inmates are incarcerated and supports their transition back to the community. Services focus on prerelease readiness planning, linkage to medical care, and continued engagement in medical care and treatment post-release.¹⁸⁴

Other Programs Serving People With HCV in Massachusetts

Healthcare Reform in Massachusetts

In many respects, Massachusetts is a post-healthcare reform state in a pre-healthcare reform country. In 2006, Massachusetts adopted universal healthcare legislation that later became the model for much of the Patient Protection and Affordable Care Act (ACA), the federal healthcare reform legislation that will take full effect in 2014.¹⁸⁵ Chapter 58, as the state healthcare reform law was called, includes an expanded Medicaid program (MassHealth), a subsidized insurance program (Commonwealth Care), a health insurance exchange (run by the Health Insurance Connector Authority – “the Connector”), an

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individual and employer mandate, and standards of acceptable insurance policies.¹⁸⁶ There is a single application form for all healthcare programs, which can be filed online, in person, or via fax or mail.¹⁸⁷

As a result of Chapter 58, every adult resident in Massachusetts is now required to purchase minimum creditable health insurance, as long as there is an affordable plan available to them.¹⁸⁸ The Connector defines affordability each year using an income-based sliding scale and other relevant measures.* Failure to purchase insurance results in a fine, which individuals can appeal on the basis that purchasing available insurance would cause an unacceptable financial hardship. Collected penalties are deposited into the Commonwealth Care Trust Fund, which is used to pay for subsidized and uncompensated care.

As a result of these new laws, 98% of Massachusetts residents now have insurance.¹⁸⁹

MassHealth

MassHealth encompasses a number of different healthcare programs for low-income individuals, including Medicaid and the State Children's Health Insurance Program (CHIP), as well as state-only funded programs. The Massachusetts Executive Office of Health & Human Services (EOHHS), Office of Medicaid administers MassHealth programs.¹⁹⁰ Medicaid is a state and federal partnership program of health coverage for certain groups of low-income individuals, funded by both federal and state government.¹⁹¹ Massachusetts utilizes federal Medicaid waivers to provide broader coverage than is otherwise required under federal law (allowing the state to "waive" certain federal requirements).¹⁹² The MassHealth waivers also encompass Commonwealth Care, a subsidized insurance program for low-income persons who do not qualify for MassHealth or various other insurance programs, and do not have access to affordable employer sponsored insurance (ESI).¹⁹³ The federal medical assistance percentage (FMAP) is used to calculate the federal contribution to state Medicaid programs. In general, Massachusetts' FMAP is 50%, meaning that for every dollar Massachusetts spends on its Medicaid program, the federal government also contributes a dollar.¹⁹⁴

To be eligible for MassHealth, an individual must be a resident of Massachusetts, meet immigration documentation requirements, fit a particular eligibility category (eg, children, pregnant women, disabled individuals, long-term unemployed, persons living with HIV), and meet certain income guidelines based on that category. For some beneficiaries,

*Individuals and couples below 150% of the federal poverty level (FPL) are not required to pay premiums. For FY2012, for an individual living at 150% FPL, health insurance costing up to 2.9% of one's income is deemed affordable. Affordability is assessed by increments of 50 percentage points of FPL (eg, 151-200% FPL, 201-250% FPL), up to 504% FPL where approximately 7.7% of a person's income is considered affordable. Beyond 504% FPL, insurance is considered affordable, regardless of cost. See Audrey Gasteier, Memorandum, Re: Affordability Schedule and Premium Tables, at 4, (July 20, 2012), available at <https://www.mahealthconnector.org/portal/binary/com.epicentric.contentmanagement.servlet.ContentDeliveryServlet/Health%2520Care%2520Reform/What%2520Insurance%2520Covers/Affordability%2520Background/2012/AffordabilityandPremiumScheduleFinal.pdf>.

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MassHealth acts as the primary insurer, but for others, MassHealth offers premium assistance for individuals to purchase employer-sponsored insurance if it is available.¹⁹⁵ MassHealth requires cost-sharing and/or premium charges for some categories and/or income levels. As of November 2011, there were 1,311,868 people enrolled in MassHealth (excluding individuals in Commonwealth Care).¹⁹⁶

MassHealth benefits vary by category of eligibility, but generally include, among others, physician services, behavioral health services, inpatient and outpatient services, and prescription drugs.¹⁹⁷ As of July 25, 2011, the MassHealth prescription drug list includes teleprevir (Incivek) and boceprevir (Victrelis), as well as peginterferon alfa and ribavirin, though prior authorization requirements apply.¹⁹⁸ While the newer drugs (Incivek and Victrelis) are technically not covered for individuals who are coinfecting with HIV, as they have not yet been approved by the FDA for treatment of this population, these drugs are covered for coinfecting individuals by the Massachusetts HIV/AIDS Drug Assistance Program (HDAP), as will be discussed later in this report.

Subsidized Insurance through the Exchange: Commonwealth Care

Commonwealth Care, also known as CommCare, is a heavily subsidized insurance plan for low-income individuals. In order to be eligible, individuals must be Massachusetts residents, have household incomes below 300% FPL (\$33,510 for an individual), must be ineligible for MassHealth or other public coverage programs, and must not have access to employer-sponsored insurance where the employer pays at least 33% of the cost (for an individual).¹⁹⁹ Unlike MassHealth, documented immigrants are eligible during their first 5 years of residency.²⁰⁰ Individuals enrolled in CommCare with incomes below 150% FPL pay small copayments but no premiums or deductibles. Those with incomes between 150-300% FPL pay no deductibles but pay premiums and copayments on an income-based sliding-scale.²⁰¹ As of fall 2012, there were approximately 192,000 members in the CommCare program, about 72,000 of whom pay a monthly premium.²⁰² In general, benefits under CommCare are similar to those offered through MassHealth although benefits are more limited and all members must enroll in a Managed Care Organization (MCO).²⁰³ All of the MCOs offered on CommCare include coverage of the relevant HCV drugs, with the exception of CeltiCare, which does not appear to list the new protease inhibitors (boceprevir and telaprevir) in its formulary.²⁰⁴ Like MassHealth, prior authorization requirements apply.²⁰⁵

Medicare

Medicare is a federally funded program that provides health insurance to those who are over age 65 years and who are eligible for Social Security benefits, and to younger disabled individuals who have worked long enough to be eligible for Social Security Disability Insurance (SSDI). Low-income individuals may also receive both Medicaid and Medicare.

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Approximately 17% of the Massachusetts population received Medicare as of March 2012, compared to 16% of the US population.²⁰⁶ Approximately 83% of Massachusetts Medicare beneficiaries are age 65 years or older.²⁰⁷ As of March 2012, the total number of Medicare beneficiaries in Massachusetts was 1,104,483.²⁰⁸

Medicare Part D and Prescription Drugs²⁰⁹

Medicaid Part D covers payments for prescription drugs offered through private plans and requires an additional premium that varies depending on the prescription drug plan. While plans may determine their own drug formularies, they must offer a “standard benefit” or its actuarial equivalent. The standard benefit for 2012 had a \$320 deductible, then coinsurance of 25% up to \$2,930 in total drug costs, followed by a gap in coverage between \$2,930 and \$4,700, known as the “donut hole,” during which enrollees must pay 100% of the costs of their drugs. After reaching a total of \$4,700 in spending, the beneficiary enters the “catastrophic coverage period” and pays 5% of drug costs for the rest of the calendar year, or \$2.60 for generic and \$6.50 for brand name drugs, whichever is greater.

The donut hole affects Medicare beneficiaries with incomes over 150% FPL (\$16,755 for an individual). Those with incomes below 150% FPL who meet the asset requirements for the low-income subsidy (LIS) program do not have a donut hole, nor do those who are full dual eligibles (people on Medicare and full Medicaid), although they may have higher cost sharing within the cost parameters of what would otherwise be the donut hole. Under the ACA, the donut hole started to phase out in 2010 and will continue to gradually phase out until it is eliminated in 2020.²¹⁰ In addition, individuals in the donut hole now pay only 50% of the cost for name-brand drugs, while the full cost of the drug is included in their “true out-of-pocket expenditures” (TrOOP). TrOOP is the amount of money individuals must pay out-of-pocket while in the donut hole in order to reach the catastrophic coverage period.

Patient Assistance Payment (PAP) and Copay Programs

Certain private pharmaceutical companies also have PAP programs, which offer free HCV drugs (and other prescription drugs) to low-income people who do not qualify for any other insurance or assistance programs, such as Medicaid or Medicare.²¹¹ These programs may have limits based on total household income compared to established federal poverty levels, but may accept appeals for special circumstances if a person does not immediately qualify. Some pharmaceutical companies also offer copayment assistance for individuals who are privately insured, although this practice is prohibited by federal law for patients on Medicaid (MassHealth) and Medicare.²¹² Until recently, Massachusetts was the only state to ban this practice for individuals with private insurance, but in the FY2013 budget, the existing state law was amended to permit companies to offer copay cards to Massachusetts residents.²¹³

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Health Safety Net (HSN)

The HSN in Massachusetts provides limited coverage for Massachusetts residents who are not eligible for health insurance, do not have coverage for all medically necessary services, or cannot afford to buy insurance. In order to be eligible, individuals must be uninsured or underinsured or be unable to pay large medical bills. Generally, individuals must have income below 200% FPL (\$22,340) to qualify for full HSN, while individuals with incomes between 200-400% (\$44,680) FPL may be eligible for partial HSN. There are no citizenship or immigration status requirements. Benefits include total or partial coverage of medically necessary services at Massachusetts community health centers (CHCs) and hospitals. These services must be on the MassHealth Standard list of covered services.²¹⁴

The Ryan White Program for Persons Coinfected With HIV²¹⁵

The Ryan White Program is a \$2.1 billion federal and state partnership program, providing medical care, including prescription drugs, and supportive services to people living with HIV/AIDS who are without other sources of coverage or an ability to pay. Funding goes to state and local health departments, as well as community-based providers. Part A provides emergency assistance to metropolitan areas most severely affected by the HIV/AIDS epidemic. Part B includes a base grant for a state, and funding for the AIDS Drug Assistance Program (ADAP). Part C provides outpatient primary care, including case management services. Part D covers family-centered outpatient and ambulatory care for women, infants, children, and youth with HIV. Part F funds a variety of other programs, including dental programs and AIDS education and training.

Massachusetts HIV/AIDS Drug Assistance Program (HDAP)

HDAP is Massachusetts' ADAP program, funded through the Ryan White Program (under Part B), and offers assistance with prescription drugs to people who are HIV-positive with incomes below 500% FPL (\$55,850 for an individual). Low-income individuals who are not eligible for Medicaid and Medicare or other programs may be eligible for HDAP. HDAP can also provide assistance with copays, as well as premium assistance through the Comprehensive Health Insurance Initiative (CHII).²¹⁶ HDAP also provides coverage for both telaprevir and boceprevir.²¹⁷ During FY2010, more than 7,000 clients were enrolled in HDAP.²¹⁸ As a result of federal health reform, HDAP payments made on behalf of an individual now count toward that individual's TrOOP for those who are also on Medicare Part D, helping them to progress more quickly through the donut hole.

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Healthcare Providers in Massachusetts

Hospitals and Community Health Centers

There are 81 hospital sites in Massachusetts, 10 of which are in Boston.²¹⁹ Massachusetts also has 49 community health centers operating at 281 sites.²²⁰ In general, in 2012, 9% of the state's residents reported difficulty accessing care with variations based on income: 21% of individuals with incomes below \$50,000 per year reported extreme difficulty in accessing care, compared to only 2% of those earning over \$100,000 per year.²²¹

As more people are seeking care with the expanded insurance coverage, fewer primary care physicians are accepting new patients, particularly for patients with MassHealth or other public coverage.²²² While the average primary care provider-to-population ratio is high, physicians are not proportionately distributed geographically, with more clustered in Suffolk County.²²³ According to the Health Resource and Services Administration (HRSA), as of February 2012, Massachusetts had 74 Health Professional Shortage Areas (HPSAs) for primary medical care.²²⁴ However, in July 2012, Massachusetts also passed expansive payment reform legislation, which includes some provisions related to increasing the primary care workforce.²²⁵

Hospitals and Healthcare Organizations That Provide Treatment for HCV

In 2009, the Massachusetts Department of Public Health (MDPH) maintained a list of the community-based providers, including hospitals and health centers, that provide testing and treatment for HCV. While this list is likely not all-inclusive, according to this publication, in 2009 there were 99 community-based providers who offered testing for HCV, and 29 providers who offered treatment.²²⁶ Note that those numbers did not necessarily include specialty clinics and hospitals that may also provide comprehensive care and treatment for people with HCV-related liver disease.²²⁷ A recent resource guide compiled by Massachusetts Viral Hepatitis Coalition (MVHC) identified (in total) approximately 57 facilities (including some independent practitioners) with HCV specialists and/or doctors.²²⁸ However, it is likely that neither of these compilations is all-inclusive, and the exact number of treatment providers is unknown. There may also be some facilities with multiple providers able to administer treatment. Massachusetts also funds an HCV Hotline at 1-888-443-HEPC, which can help locate medical providers in Massachusetts specializing in HCV management and the diagnosis and treatment of liver disease.²²⁹

Substance Use Disorder and Addiction Services Providers

There are approximately 165 substance use disorder treatment facilities across the state, which provide services that include but are not limited to detoxification, methadone maintenance, methadone detoxification, and halfway housing. Some also provide mental health services. Types of care range from residential short-term treatment (less than 30

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days) to long-term treatment (more than 30 days), and can also include hospital inpatient care and/or outpatient care.²³⁰ Although the path for every person in need of services is different, the continuum of care for individuals with substance use disorder includes, but is not limited to²³¹:

- Acute Treatment Services (ATS): medically necessary detox services (length of stay is about 3-5 days);
- Clinical Stabilization/Step Down Services (CSS): clinical stabilization services for individuals leaving detox who need additional services or people who need acute treatment but do not qualify for ATS;
- Transitional Support Services (TSS): short-term residential programs for individuals leaving detox who need additional stabilization (length of stay is about 14-21 days);
- Residential Rehabilitation Programs: therapeutic communities (TC), recovery homes (RH), and social model recovery homes (SM)—residential programs are also available for specialty populations such as women and children; and
- Ambulatory Programs: including outpatient counseling, narcotic treatment (including suboxone and methadone treatment for opioid dependence), day treatment, and driver alcohol education.

There are also programs specifically for youth. These include seven residential programs (youth aged 13-17 years), three youth intervention programs, two detox/acute treatment centers for youth, and four recovery high schools. Massachusetts also has a substance use disorder information and education helpline and website.²³²

According to the National Survey on Drug Use and Health (NSDUH), a large number of adolescents and young adults in Massachusetts had unmet needs for treatment for illicit drug use in the past year. Massachusetts ranked among the highest states (top ten) for individuals needing but not receiving treatment for illicit drug use in the past year among youth aged 12-17 years and young adults aged 18-25 years.²³³

The Opioid Overdose Prevention and Reversal Project

To combat the rising number of deaths related to opioid overdose (one of the leading causes of death in the state), MDPH has been piloting a new initiative involving the distribution of nasal naloxone (also known as Narcan).²³⁴ When a person is overdosing, opioids can slow breathing, potentially resulting in death. Naloxone is a substance that can prevent the potentially fatal effects of an overdose by acting to block the opioid and restoring normal breathing function. Naloxone itself is safe with no possibility for abuse. Programs that participate in the project train opioid users, family members, and friends

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on how to prevent and identify an opioid overdose. Trainings provide information on how to respond to an overdose, and include instructions on how to administer naloxone. Massachusetts also recently passed a “Good Samaritan” law, limiting potential liability of individuals who call 911, and/or administer naloxone in cases of overdose.²³⁵

Since 2007, the program has resulted in over 1,500 overdoses being reversed.²³⁶ A recent report by the Centers for Disease Control and Prevention (CDC) documented similarly successful outcomes, finding that since 1996, among 188 local programs, naloxone had been distributed to over 53,000 people (who also received training) and over 10,000 overdoses were reversed.²³⁷

Relevant Massachusetts Laws and Regulations

HCV Surveillance and Reporting

In Massachusetts, every healthcare provider and laboratory must report any evidence of HCV infection to the local or state health department.²³⁸

Syringe Access

Despite the national ban on using federal money for syringe programs, Massachusetts has two laws that provide for access to clean syringes. First, Massachusetts state law allows the Massachusetts Department of Public Health (MDPH) to establish up to ten pilot syringe exchange programs in cities and towns, with each site subject to local approval.²³⁹ Second, a Massachusetts law from 2006 authorizes the sale of syringes without a prescription to anyone who is age 18 years or older.²⁴⁰

MDPH is also required to develop and distribute an educational insert that includes information about HIV and HCV that must be given to all purchasers of syringes at the point of sale.²⁴¹

Prescription Assistance

In 2012, the Massachusetts state legislature repealed a law forbidding prescription drug companies from providing certain forms of copay assistance. Pursuant to the new laws, prescription drug companies may now provide assistance in the form of copay cards and coupons for any drugs that do not have generic equivalents,²⁴² which would include telaprevir and boceprevir (the new HCV direct-acting antiviral drugs do not have generic equivalents). However, federal law still prohibits this practice in regards to Medicaid and Medicare patients.

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Off-Label Drug Access for Individuals Living With HIV

In Massachusetts, individual insurance policies, group insurance policies, contracts between subscribers and corporations under individual or group hospital service plans, subscription certificates under individual or group medical service agreements, and individual or group health insurance maintenance contracts cannot exclude coverage of any prescription drug for HIV/AIDS treatment on the grounds that the off-label use of the drug has not been approved by the FDA for HIV/AIDS. To qualify under this law, however, the drug must be recognized for treatment of HIV/AIDS in standard reference compendia, in the medical literature, or by the commissioner of an advisory panel that provides information about off-label uses of drugs for HIV/AIDS treatment.²⁴³

Hepatitis in Relation to Substance Use Disorder Programs

In Massachusetts, all substance use disorder programs must meet certain requirements in order to become licensed, and several of the requirements are relevant to HCV. First, all licensed substance use disorder treatment programs are required to have a written policy for staff growth and development that outlines monthly in-service training sessions over the course of year, and these sessions must include HIV/AIDS, STI, and viral hepatitis education.²⁴⁴ Each licensed organization must have an HIV/AIDS coordinator who is also responsible for overseeing hepatitis education for both staff and clients, and who must provide access to education (either individually or in a group setting) and testing for clients.²⁴⁵ Second, every licensed substance use disorder treatment program must also maintain records for each client, which document that the client received viral hepatitis, STI, TB, and HIV education as well as a risk assessment for viral hepatitis, STI, TB, and HIV.²⁴⁶

Further, all licensed inpatient and outpatient detoxification facilities are required to ensure that every patient receives a physical examination within 24 hours of admission that includes an assessment of viral hepatitis,²⁴⁷ and all licensed opioid treatment maintenance providers must ensure the patient receives an annual physical examination that includes assessment for the possibility of viral hepatitis.²⁴⁸ However, due to restrictions on confidentiality, reporting of test results for surveillance purposes can be hindered.²⁴⁹

Hepatitis Education

Massachusetts has one law pertaining specifically to HCV education, requiring that

[t]he department of public health shall make available to all veterans, physicians, other health care providers, and other persons at high risk for HCV, educational materials, in written and electronic forms, on the diagnosis, treatment, and prevention of HCV. The materials shall include the recommendations of the Centers for Disease Control, and any other person or entity having knowledge of HCV, including the American Liver Foundation, and shall be written in terms which are understandable by members of the general public.²⁵⁰

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Health Education in Schools

In Massachusetts, local districts have control over what to teach in health class. Districts' authority to teach health classes comes from the schools statute, chapter 71 of the Massachusetts General Laws: in general, schools must "give instruction and training in ... health education, physical education and good behavior ... In connection with physiology and hygiene, instruction as to the effects of alcoholic drinks and of stimulants, including tobacco, and narcotics on the human system ... shall be given to all pupils in all schools under public control."²⁵¹ Most Massachusetts secondary schools have health courses, and a large percentage of these have a written curriculum adopted by the district or school. In 2010, 59.7% of secondary schools had two or more required courses in health and an additional 25.5% had one required course in health.²⁵² It should be noted that "secondary schools" include both junior and senior high schools.

Massachusetts Economic Profile

In 2011, Massachusetts had a gross state product (GSP) of \$391.8 billion, and had the 7th largest state economy.²⁵³ In 2010, the largest industry in Massachusetts was financial activities, followed by professional and business services.²⁵⁴ Massachusetts is one of the wealthiest states in the country, with a per capita income of \$51,302, and is well above the national per capita income of \$39,945.²⁵⁵ Massachusetts also has a lower unemployment rate (6.5%) compared to the national average (7.8%).²⁵⁶

About 15% of Massachusetts residents (1,017,200 people) live below the federal poverty level (FPL), compared with 21% nationally.²⁵⁷ In 2010, Massachusetts had the 9th lowest poverty rate in the country (10.6% of households live in poverty in Massachusetts versus a national rate of 15.1%).²⁵⁸ Another 7% of residents (461,400 people) had incomes between 100-138% FPL, which was closer to the national average of 8%.²⁵⁹

Revenues (Taxation) and Expenditures

In 2011, Massachusetts was the 11th highest tax revenue-collecting state, collecting \$22.1 billion in revenue.²⁶⁰ The majority of this revenue was derived from income taxes (about \$13.5 billion), sales and gross receipts (about \$7.1 billion), and licenses (about \$854 million).²⁶¹

Massachusetts' expenditures for its FY2010 totaled approximately \$50.4 billion.²⁶² Of this total, 34.3% was spent on Medicaid, 15.6% on elementary and secondary education, 4.4% on corrections, and 3.1% on higher education.²⁶³ Massachusetts' Medicaid spending as a percentage of its total budget in FY2010 was almost twice as much as the US average.²⁶⁴

Despite its relatively strong economy, Massachusetts faces an increasing shortage of funding for state programs. There have been significant recent cuts to education, health,

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and other important public programs.²⁶⁵ From FY2009-2012, funding for MDPH was reduced by 13.5% (\$82.9 million), hitting prevention, education, and screening programs particularly hard. HIV/AIDS prevention and treatment services for instance, were cut by \$7 million (17.9%). The Department of Mental Health has also faced cuts, with a reduction of \$52.7 million (7.4%). Many other departments and programs have faced similar funding decreases.²⁶⁶

TESTING AND PREVENTION

Testing and prevention are crucial components of combating the spread of HCV. Individuals who are living with HCV and are unaware of their status will not know to seek care and treatment, and may unknowingly pass the virus on to others. Those who are at risk for HCV infection may not know how to prevent being exposed to HCV and therefore may not take measures to prevent infection. From a prevention standpoint, stopping the spread of HCV saves lives and allows for conservation of both personal and public resources that might otherwise have to be spent on treatment.

Successes

Integrated Hepatitis, HIV, and Sexually Transmitted Infections (STI) Prevention and Testing Sites

As recommended by the Institute of Medicine (IOM), Massachusetts has fully integrated HCV prevention and screening programs into its existing infrastructure for HIV and STI prevention, testing and counseling, funded through the Massachusetts Department of Public Health (MDPH). Research has demonstrated that integrating viral hepatitis prevention and testing into HIV and STI prevention and testing sites is an effective way to reach individuals living with or at risk for HCV, as these sites often serve overlapping at-risk populations.²⁶⁷ Similarly, the National Association of State and Territorial AIDS Directors (NASTAD) has also recommended using existing HIV and STI infrastructures to provide viral hepatitis services, and in 2004 released a resource guide aimed at helping existing HIV/AIDS and STI programs integrate hepatitis into their work.²⁶⁸

In Massachusetts, there are 14 sites that are funded to provide prevention, intervention, counseling, screening, and referral services (PICSR sites), and another 8 sites that additionally provide treatment for identified STIs (known as PICSR-T sites). Some of the grantees, such as those in some community health centers and hospitals, are also able to offer internal referrals for HCV treatment assessment. In FY2011, PICSR and PICSR-T sites screened 3,052 people, of whom 6.5% (99) were seropositive for HCV.²⁶⁹ Massachusetts also operates an HCV hotline that individuals can call to obtain information about HCV, as well as referrals for providers.

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The PICSR and PICSR-T sites are involved in various community-based outreach and education efforts. Outreach occurs through mobile health vans, partnerships with local homeless shelters and halfway houses, and collaborations with other community-based settings.²⁷⁰ For example, nurses from Boston Healthcare for the Homeless Program (BHCHP) offer testing and counseling at various homeless shelters throughout the city. In 2011, BHCHP counseled 1,244 people and screened 1,327 individuals for HCV, with 238 people testing positive for antibodies (of those, 106 received a follow-up test for RNA/viral load, with 75 individuals having a detectable viral load).²⁷¹ Health Innovations operates a mobile health van that visits sites across Boston and other areas of the state to provide HCV counseling and testing, as well as other health services.²⁷² Others provide hepatitis and HIV education sessions to clients at local suboxone clinics or county corrections facilities.²⁷³ There are also non-PICSR sites, such as Charlestown and Revere Community Health Centers, that provide HCV testing and care to individuals.²⁷⁴

Culturally and linguistically appropriate services that are tailored to the communities they serve are also important. Hampden County, for example, has a large Latino population along with one of the highest HCV incidence rates in the state.²⁷⁵ At least one study of a city in Hampden County found that HCV may be even more prevalent among the Latino community compared to the general population, consistent with national data.²⁷⁶ La Voz, a program associated with the Tapestry Health PICSR, provides neighborhood-based community education and intervention services specifically targeting the Latino population, mostly in nonclinical settings ranging from “soup kitchens to street corners to shooting galleries.”²⁷⁷ La Voz also operates a drop-in center where people can come to do laundry, take showers, and receive other services in addition to those related to HCV. La Voz staff can provide culturally competent information about HCV in English and Spanish, allowing individuals to access health information in a nonmedical setting.²⁷⁸

Availability of Clean Syringe Services

Injection drug use is the largest HCV risk factor both nationally and in Massachusetts. Safe access to syringe exchange programs (SEPs) has been recognized by IOM as an important strategy for reducing the spread of viral hepatitis.²⁷⁹ For example, in New York, implementation of a large-scale syringe access program resulted in a significant drop in rates of HCV infection, from 91% of IDUs to 56%.²⁸⁰ At least one study has also demonstrated that 76% of the participants in a syringe exchange program obtained their medical and preventive care only through the exchange programs.²⁸¹ Increased access to safe injection equipment is also a key prevention component of the US Department of Health & Human Services National Viral Hepatitis Action Plan.²⁸² Despite the proven effectiveness of SEPs, in FY2011 Congress passed legislation reinstating a ban on the use of federal funds for these programs.²⁸³

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Massachusetts state law, however, authorizes MDPH to utilize state funds for SEPs with local consent. MDPH funds five different “harm reduction” programs where individuals can go to obtain clean syringes, cotton, and other safe injection equipment, as well as health information.²⁸⁴ Because these sites use only state or local funds, they are not affected by the recent federal ban.²⁸⁵ At these sites, staff are available to educate clients about HCV and other illnesses, including prevention and harm reduction practices, and to make referrals to medical care. Some sites also provide HCV testing and vaccination against HAV/HBV. One site estimated that 80% of their clients were HCV-positive.²⁸⁶ The goal of these programs is to meet people “where they are at,” meaning that staff do not pass judgment on clients’ actions and help people practice safer behaviors no matter what their stage of addiction.²⁸⁷ These programs also offer training in overdose prevention, including use of naloxone. As noted, MDPH also supports a naloxone distribution and training program, which has resulted in the reversal of over 1,500 overdoses since the program’s creation in 2007.²⁸⁸

In addition to the designated access sites, Massachusetts law allows all persons over age 18 years to purchase clean syringes in pharmacies without a prescription.²⁸⁹ When these syringes are purchased, each packet of syringes comes with information (created by MDPH) about HCV and other transmittable infections, and includes the number for the state’s HCV hotline.²⁹⁰

Surveillance²⁹¹

Compared to many other states, Massachusetts has a robust surveillance program for viral hepatitis. In Massachusetts, all providers and clinical laboratories must report any laboratory evidence of HCV infection to the local board of health or directly to MDPH. Many clinical laboratories utilize electronic laboratory reporting (ELR), which provides this information directly to the Massachusetts surveillance system, MAVEN. Positive laboratory evidence of HCV infection triggers the distribution of one of two case-reporting forms (one is a one-page scannable form for HCV infection past or present and one is for suspected acute HCV infection). These are sent to the ordering physician for completion. Once MDPH receives the information requested on this form, additional follow-up with the physician or patient may be initiated if it appears the patient has an acute infection or if risk-history data indicate the patient may have acquired the infection through contact within the healthcare system.

Massachusetts was also among the first states to identify the rising HCV epidemic among youth, and has been active in pursuing additional surveillance data related to this population. As previously discussed, in March 2011, MDPH participated in an Epi-Aid with the Centers for Disease Control and Prevention (CDC) to follow up with young people who had been recently reported with evidence of HCV infection. In FY2012, MDPH received additional funding from the CDC (\$30,000) to do more follow up with a

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subset of cases in this age group. MDPH Epidemiology Program staff members continue to perform analysis on available data. During summer 2012, MDPH began analyzing data related to children born to HCV-positive mothers, and has also been working on a project to match HCV surveillance and MDPH cancer registry data.

Finally, MDPH has recently developed an HCV point-of-care case reporting form. This form enables reporting from PICSR and PICSR-T sites that currently do not report directly to MDPH surveillance due to the use of de-identified specimens (tests that do not include the name of the individual being tested), as currently case reports can only be collected from tests that include a name. These new forms will also be used to allow reporting from rapid HCV tests. The new forms will help provide a more accurate assessment of the number of individuals living with HCV in Massachusetts by capturing data from individuals who may test positive in the community but never make it to a treatment or follow-up provider. In addition, these forms can potentially be used to track linkage to care from community-based sites to providers.

Requirements for Hepatitis Education of Staff and Clients at Licensed Substance Use Disorder Treatment Programs

Substance use disorder and HCV are intricately connected in terms of causality, at-risk populations, and support services needed for treatment and recovery. Effective strategies for combating HCV must involve coordination with substance use disorder treatment programs.²⁹² Massachusetts has several requirements relating to substance use disorder treatment programs that aim to ensure individuals in these programs have opportunities for HCV education and testing. In particular, Massachusetts regulations require that licensed substance use disorder treatment programs keep client files that include documentation of hepatitis risk assessment and education.²⁹³ Programs must also have a written policy for staff growth and development that outlines monthly in-service training sessions over the course of year, and these sessions must include HIV/AIDS, STI, and viral hepatitis education.²⁹⁴ Each licensed organization must also have a Program HIV/AIDS Coordinator (PAC) who is responsible for overseeing hepatitis education for both staff and clients, and who must provide access to education and testing for clients.²⁹⁵

The Bureau of Substance Abuse Services (BSAS) also contracts with the Statewide Partnership for HIV Education in Recovery Environments (SPHERE), a nonprofit organization that provides HIV and hepatitis education and support to all programs that receive funding from BSAS to provide substance use disorder treatment. SPHERE works with these substance use disorder organizations through each organization's PAC, with the aim of helping to integrate HIV/AIDS, viral hepatitis, and overdose prevention into substance use disorder treatment programs.²⁹⁶

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The Massachusetts Viral Hepatitis Coalition²⁹⁷

In February 2012, the Massachusetts Viral Hepatitis Coalition (MVHC) was created to “increase awareness of viral hepatitis and build support for programs addressing the needs of those living with or at risk for viral hepatitis.” A coalition had also been in existence in the past, but for various reasons had ceased to be active for several years. Over the past year, the reinvigorated MVHC held a viral hepatitis lobby day and educational session with 50 people in attendance, including many people living with hepatitis, to educate legislators about HCV and advocate for increased state funding. Representatives from several legislative offices attended the educational session and participants met with at least 20 different legislative offices. MVHC also held a second viral hepatitis educational briefing at the state legislature that was attended by five legislators and many other staff members. Working in conjunction with other groups, MVHC was able to maintain level funding for the state budget line item that includes HCV programs during a fiscally challenging time and after the line item had been repeatedly cut over the past few years. The coalition now has over 100 individual and organizational members.

The Massachusetts Viral Hepatitis Advisory Committee

As part of its work on viral hepatitis, MDPH convenes a quarterly Viral Hepatitis Advisory Committee. This committee was formed in 1999, and originally included providers, consumers, representatives from state agencies (including agencies other than MDPH), legislators, and other stakeholders. The goal of the committee is to provide feedback and advice on viral hepatitis policy, planning, and programs. In 2001, the committee created a strategic plan, “Hepatitis C: 2001-2005,” identifying major areas of focus for viral hepatitis work (see Appendix C). At the quarterly meetings, committee members share and receive updated information on various factors related to the epidemic, including best practices and the latest information on treatment. For example, at one recent meeting, the committee hosted a presentation by an infectious disease physician on use of the new protease inhibitors (telaprevir and boceprevir) to treat individuals coinfecting with HCV and HIV in response to questions from members.

Challenges

Education and Awareness

In Massachusetts, as across the country, one of the biggest challenges to addressing HCV is that most people do not know they are infected. Nationwide, it is estimated that 75% of people are unaware of their infected status.²⁹⁸ This may be attributed partly to the fact that people living with HCV can outwardly be asymptomatic for many years, even while the disease is quietly attacking the liver. For these reasons, HCV is also known as the “silent epidemic.” Across Massachusetts, community partners interviewed for this report consistently identified the need for widespread HCV education as a priority.

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Many people (including providers) are simply unaware of, or misinformed about what HCV is, who is at risk, how it can be treated, and how to reduce transmission. For example, in talking with groups of people in recovery, many people knew of HCV but had varying knowledge levels about the disease and were eager for more information.²⁹⁹ As will be discussed in the following section, there are different educational challenges that pertain to adults as compared to youth.

Adults

Nationally, the CDC estimates that the largest cohort of infected individuals (75%) are within the baby boomer generation (those born between 1945 and 1965), and education among this age group is urgently needed as deaths related to cirrhosis and other liver disease are anticipated to greatly increase among this cohort over the next ten years.³⁰⁰ An analysis of Massachusetts death records between 1992 and 2009 similarly shows that the mean age of death among those infected with HCV was 53 years (including both HCV and other causes), while the mean age of death among non-HCV-infected people was 75 years.³⁰¹ Among individuals reported with HCV infection who died (from all causes) in Massachusetts during this time period, 73% died within the first 5 years after diagnosis.³⁰² These data emphasize the critical need for education and linkage to care among this age group in Massachusetts.

However, the CDC notes that only 55% of individuals ever infected reported a risk factor, and therefore offering testing only to those who report a risky behavior has not been effective at identifying the majority of those infected.³⁰³ Many individuals may have injected drugs years ago and now have no current risk factors, and therefore have no idea they put themselves at risk for HCV and are now infected. These individuals may not be presenting at PICS and PICS-T sites, which are not targeted at baby boomers generally, but rather toward currently at-risk groups such as intravenous drug users (IDUs). A concurrent, broader education strategy is needed to reach those who no longer engage in active IDU or other HCV-risk behaviors, both at existing testing sites as well as through additional initiatives. This strategy must also include provider education.³⁰⁴

At the same time, there are some groups of currently at-risk adults (for example, active IDUs) who are aware of HCV, but have a fatalistic attitude that “everyone has it.” Many of these individuals have also heard about the challenging side effects of treatment, and so may choose not even to get tested. This cohort may still be at risk and continues to need additional information about HCV prevention, testing and treatment, as well as harm reduction and substance use disorder recovery resources.

Youth

In addition to adults, Massachusetts data show an increasing epidemic of HCV among young injection drug users, ages 15-25 years, correlated with increased heroin injection.

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Despite this increase, people who work closely with youth and young adults noted that although at-risk youth seem now to know about HIV, they are unaware of specific risk factors for HCV, or that it can be spread through other drug practices besides sharing needles.³⁰⁵ Substance use disorder treatment providers also cited a prevailing attitude of invincibility among at-risk youth, a feeling that they will never be really ill, and a general lack of emotional maturity.³⁰⁶ Like adults, young people do not go to the doctor until they start to feel sick. One doctor noted that some at-risk youth even think of HCV as a badge of experience.³⁰⁷ As with adults, some youth just assume they already have HCV infection, and therefore do not take steps to protect themselves.

Some young adults in recovery discussed that in school, they remembered receiving education about sexually transmitted diseases, but nothing about viral hepatitis.³⁰⁸ Advocates also identified the lack of education in schools related to substance use, hepatitis, and/or harm reduction, and reported that even when offered free educational programs, many schools are not receptive or are unwilling to offer this kind of education.³⁰⁹ At the same time, advocates identified a lack of safe, alternative spaces where youth can go to access information on topics such as safe injection practices and/or viral hepatitis.³¹⁰ In Massachusetts, while adults over age 18 years can access clean equipment and syringes, pharmacies and harm reduction programs are prohibited from providing these materials to persons under 18 years of age, and therefore younger IDUs have less incentive to visit these programs where they might at least obtain information.³¹¹

Primary Care Providers

Stakeholders consistently identified a strong need for increased education of primary care providers. Recently, doctors at a prominent Boston hospital took part in an informal survey of HCV screening practices among primary care physicians, and the results indicated that most were doing very limited testing, and some were misinformed about treatment options.³¹² A provider expert at another area hospital similarly indicated that he receives phone calls from providers across the state with varying levels of knowledge about HCV risk, testing, and treatment.³¹³ This lack of knowledge is consistent with national studies, and the CDC notes that provider knowledge of HCV is generally low.³¹⁴ Even among providers who offer testing, many may not be aware of current treatment options, where to make referrals, or how to provide information on risk reduction. For example, some callers on Massachusetts' statewide viral hepatitis hotline have already been diagnosed with HCV infection by their primary care provider, but need help understanding their test results and report they received no information on next steps.³¹⁵ Further, providers who feel uncertain about how to counsel patients with a positive HCV diagnosis may also then be hesitant to offer testing.³¹⁶ Because so many of those living with HCV are not aware of their infection and may not present with risk factors, it will be especially important to educate primary care providers about HCV. Education efforts should also target pediatricians who may be unaware of the increase in HCV infections among youth.

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Stigma

HCV is a highly stigmatized disease, largely because the predominant mode of transmission is through injection drug use, and many people have negative feelings toward addiction and substance use disorder, particularly injection drug use. Fear of being stigmatized can play a significant role in a person's decision (for both youth and adults) about whether to ask a provider for an HCV test or even to admit to risk factors such as prior injection drug use. Youth may be afraid to admit to family pediatricians that they have started using drugs. For older adults who may not currently be engaging in any risky behavior but have done so in the past, concern about stigma creates a hesitancy or refusal to talk with their providers about their past activities. Even those who already know they have HCV may be scared to disclose this condition to current health providers for fear of being identified as an injection drug user or addict.³¹⁷ For providers, it can be difficult to initiate more personal discussions with patients about their potential risk factors, as patients may feel that providers are making assumptions about them, and there may be a general lack of trust in the relationship.³¹⁸ At the same time, providers may have stereotypes about what "at-risk" individuals look or act like, and may not realize some of their patients are former injection drug users or otherwise at risk.

For people actively engaged in injection drug use or other substance use, fear of stigma may discourage them from seeking any kind of medical care or other support services, including HCV testing or treatment.³¹⁹ Some clients report to advocates that they are treated poorly by providers because they are addicts (for example, being berated for bringing health problems upon themselves), while others who may not have experienced negative reactions from a provider express concern that this will be the case.³²⁰ Distrust of medical providers can lead to avoidance of primary care and higher use of the emergency room (ER). Recent data show that the number of nonfatal ER visits involving heroin (a major risk factor for HCV) or other opiates rose over 18% from FY2002 to 2007.³²¹ Yet when people seek care at ERs for drug-related issues, some report that ER doctors do not always reach out to them to offer counseling or testing related to HCV, and/or substance use disorder treatment.³²² In some cases, ERs are openly hostile to substance users and their families who are seeking treatment for overdoses or other related health conditions.³²³ This is a missed opportunity to provide both substance use disorder and HCV interventions.

"We are missing a huge opportunity and doing a disservice to our youth by constantly cycling them through ER services and not addressing the root problem."

—Diane Marino, Infectious Disease Clinical Services (IDCS), Cape Cod Healthcare

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Stigma also plays a role in access to safe injection equipment. While Massachusetts state law allows MDPH to establish syringe exchange programs, these programs can only be created with “local approval.”³²⁴ This means that the location of syringe programs can be highly politicized, and result in lack of access in areas where services are most needed. For example, Tapestry Health Services was recently able to establish a syringe exchange program in Holyoke, MA, but only after much controversy. Despite initial approval by the Board of Health, opponents forced the issue to a second vote through procedural mechanisms. When the new site was again approved, opponents vowed to continue to fight the measure.³²⁵

Other communities have not been as successful. There is no syringe exchange program in Springfield, despite high need. This has forced some advocates in Springfield to come up with creative ways to assist their clients. For example, while needles are available at pharmacies for purchase, this option is not always affordable. To address this issue, one program works with a local pharmacy to provide vouchers for their clients to obtain clean syringes. However, stigma against injection drug use also exists at the pharmacy level. Several advocates relayed stories of clients who would go to pharmacies to try to purchase syringes, only to be met with judgment and hostility from some pharmacists.

Finally, stigma can cause infected individuals to hide their HCV diagnosis from their friends or family. This in turn makes treatment more difficult, as family and social support networks can be essential components of successful treatment.³²⁶

Lack of Funding for Prevention and Testing

In Massachusetts, as in many states, budget allocations for public health initiatives have decreased. Since FY2009, state funding for MDPH has decreased from \$588,655,000 to \$499,715,000 in FY2012. The line item that funds MDPH’s HIV and viral hepatitis work has also declined from \$37,667,000 to \$31,598,000.³²⁷ In FY2013, advocates were able to maintain level funding. Unfortunately, there is little direct federal funding for HCV prevention and testing outside of HIV funding, and federal funding for HIV has also decreased. In FY2012 for example, the CDC reduced Massachusetts’ HIV prevention funding: over the next 5 years, the total reduction will be \$4.5 million, which may affect the existing HIV and STI prevention and testing infrastructures now used for HCV testing and prevention.³²⁸ While Massachusetts currently receives CDC funding (about \$90,000) for an Adult Viral Hepatitis Coordinator (AVHC), there is some concern that the CDC may eventually move away from funding coordinators in all 50 states and instead begin consolidating and shifting funds to particular areas it considers to be most at risk.

Additional money for surveillance will also be critical. For example, while national data indicate high prevalence rates among black males, Massachusetts surveillance data on race and ethnicity has been much more limited due to funding constraints. While

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MDPH tries to collect reports on race/ethnicity and risk history data on each case of HCV infection, these data are largely incomplete due to the limited capacity of MDPH to follow up with providers to acquire this information. However, Massachusetts' efforts in this area are improving.³²⁹

Additional Barriers to Testing

While staff at harm reduction programs and PICSR and PICSR-T sites are able to provide HCV education and testing, many of the clients they work with may be transient or dealing with poverty or homelessness. Clients may also not be in the community consistently, not have telephones, and otherwise not be accessible. This can be a barrier to communicating test results, as test results from PICSR programs for example can take up to 2 weeks, and clients may not be reachable when results are in. As will be discussed later in the report, this also creates a problem in linkage to care and treatment.³³⁰

At least one detox treatment provider identified an additional concern that some longer-term residential facilities for persons in recovery may be less inclined to accept individuals with complex medical conditions such as HCV or severe mental health diagnoses because of the level of care involved in helping these individuals.³³¹ This may create a perverse disincentive for individuals entering detox programs to get tested and/or initiate treatment for HCV and other conditions. While there is no outright policy against admitting such individuals, there is a shortage of available beds in many facilities, which allows programs to enroll only individuals whom they think are most likely to be successful in the program. In addition, there simply may not be adequate numbers of clinical or medical staff in these programs to provide appropriate care for persons with more complex needs. While it is not clear whether this is a widespread issue, it is important to ensure that substance use disorder providers receive the support they need to engage individuals with co-occurring substance use disorders and HCV infection so that clients receive care and treatment for both illnesses.

Public Health and Cost Consequences

Persons who are unaware that they are infected can unknowingly pass the virus on to others. This is particularly true for active injection drug users. Conversely, uninfected individuals who think they have HCV but never actually get tested may be exposing themselves through continued risk behaviors, like sharing needles. To the extent that HCV continues to spread, particularly among people with limited resources, a large portion of the costs of treatment may be borne by the state through MassHealth, the state's Medicaid program. For example, MassHealth spent \$22.3 million on HCV drugs in FY2012.³³² Late diagnoses can also lead to increased costs when patients with HCV

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need expensive care due to cirrhosis and other complications that might have been avoided with early access to education and/or treatment.³³³ The cost of the first year of a liver transplant, for example, is estimated at \$267,000.³³⁴

Opportunities

New CDC Age-based Screening Guidelines

In August 2012, the CDC released updated, age-based screening guidelines recommending that all persons born between 1945 and 1965 receive a one-time HCV test regardless of reported risk factors.³³⁵ The guidelines also recommend that each person diagnosed with HCV be screened for alcohol use and that alcohol interventions be implemented. These guidelines are an important first step toward federal recognition of the increased severity of this issue, as the last time they were updated was 1989.

Screening of all persons in the baby boomer generation is a crucial opportunity to identify those who are HCV-positive and link them to care and treatment. Because screening is recommended regardless of risk factors, these guidelines are a mechanism to test people who may have no idea they are (or were) at risk, and people who know they are at risk (eg, from past or current injection drug use) but are too embarrassed or concerned about stigma to ask to be tested. Providers who feel uncomfortable asking patients for personal information to ascertain risk factors can point to the CDC guidelines in recommending the test, rather than concerns or assumptions about past behaviors of the patient.

The new guidelines also provide a stepping stone for engaging primary care providers. Advocates should reach out to organizations such as the Massachusetts Medical Society (MMS), the Massachusetts League of Community Health Centers (MLCHC), and the Massachusetts Nursing Association (MNA) to offer education and training for primary care providers and/or nurses on testing and resources in light of the new recommendations, and build relationships for referral. These efforts should be made in conjunction with broader provider education initiatives by MDPH, enlisting organizations like the MMS, MLCHC, and MNA as partners. However, the new guidelines also raise potential challenges. Assuming the guidelines are successful at identifying a large number of people who are infected, it will be important for the state to prepare for the influx of infected persons by ensuring an adequate number of competent providers who will be able to give appropriate follow-up care and treatment.

Educating providers about the new CDC guidelines may be of particular importance because as of the time of this report, the current US Preventive Services Task Force (USPSTF) draft recommendation gives only a “C” rating to this baby boomer testing strategy.³³⁶ Unfortunately, most providers and medical institutions rely more heavily on “A” and “B” rated recommendations of the USPSTF than the CDC in guiding their behavior.³³⁷ Similarly, insurers are less likely to cover preventive services unless they

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are given an “A” or a “B” rating, a practice reinforced by the Patient Protection and Affordable Care Act, which requires insurers to cover such services without cost sharing but does not similarly mandate coverage with respect to “C” services.³³⁸ As of the time of this report, both national and state advocates were urging the USPSTF to change their draft recommendations. If these efforts are unsuccessful, advocates should consider Health & Human Services to include coverage of this one-time screening without cost sharing as part of the essential health benefits package (which will be discussed later in the report), and/or consider passing legislation in Massachusetts that would similarly require all insurers to cover this service.

Increase Hepatitis Educational Initiatives for Youth

While the new age-based screening guidelines may be an effective way to target older adults, they will not address the growing HCV epidemic among youth. Youth have different means of accessing information than older generations, including through social media and schools.³³⁹ Many community members identified the need for greater health education for youth around both substance use and viral hepatitis, but reported they had met with resistance when trying to engage with schools. In addition, according to the 2011 Health and Risk Behaviors of Massachusetts Youth, the number of youth reporting that they have ever been taught about HIV/AIDS, for example, has been decreasing since 2003.³⁴⁰

In Massachusetts, local districts have control over what is taught in health class.³⁴¹ Most Massachusetts secondary schools have health courses, and a large percentage of these have a written curriculum adopted by the district or school. In 2010, 59.7% of secondary schools (including both junior and senior high schools) had two or more required courses in health and an additional 25.5% had one required course in health.³⁴² The state Department of Elementary and Secondary Education has also issued a guidance document called the “Massachusetts Comprehensive Health Curriculum Framework,” which specifies content that could be included in a health curriculum, but does not include content on hepatitis.³⁴³ The Health Curriculum Framework is not revised often, with the last revision occurring in 1999.

HCV and substance use disorder advocates should work together to make revisions to Massachusetts law to create a statewide requirement for education around substance use and viral hepatitis. The Massachusetts OxyContin and Heroin Commission of the state legislature made a similar recommendation in its 2009 report, suggesting that school education programs be updated to include illicit drugs and prescription drug abuse, and that a statewide program should be required throughout the continuum of education, including in elementary schools.³⁴⁴ (Of note, the report itself failed to mention the overlap between illicit drug use and HCV.) In addition or in the alternative, advocates should work toward updating the existing health curriculum framework to specifically integrate

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viral hepatitis education. Advocates should also generally engage school-based health education teachers and nurses, as well as state officials in the Department of Education to increase awareness of the rising incidence of HCV among youth.

Advocates should also assess the extent to which viral hepatitis education is provided or could be integrated into youth substance use disorder prevention programs (such as recovery schools and youth intervention programs), regional centers for healthy communities, and town-based community partnerships on youth substance use disorder prevention.³⁴⁵ The Hepatitis Education Project in Washington state has developed viral hepatitis curricula geared specifically toward youth that could serve as a helpful tool for Massachusetts advocates in this work.³⁴⁶ Peer-based advocacy and other youth intermediary strategies have also been identified as effective means of promoting viral hepatitis prevention and education among youth, particularly when youth are involved in their development.³⁴⁷

Collaborate With the American Liver Foundation to Identify and Fill in Educational Gaps

Staff members at the American Liver Foundation (ALF) New England Chapter offer free educational classes on HCV, including youth programming. Recently, members of MDPH met with the lead educator from the ALF to discuss potential opportunities for increasing education through partnerships between the ALF and MDPH. Partnering with the ALF would be an effective way to provide additional education initiatives at no cost increase to the state.

Promote and Join the ‘Know More Hepatitis’ National Campaign as a Statewide Initiative

While prevention and testing efforts must target IDUs, there is also a broad community of older adults in the baby boomer generation who are no longer engaging in risky behaviors and may not realize they contracted HCV infection many years ago. As a means of reinforcing messages across all groups of individuals, advocates should consider building on the national “Know More Hepatitis” campaign that is currently underway through the CDC.³⁴⁸ While there are no funding opportunities currently associated with this campaign, there is an active website with educational and counseling resources that could be adapted to reflect local efforts. A statewide campaign could include signs on subways and buses, public service announcements, and social media efforts that build upon the consistent messaging strategies used by “Know More Hepatitis.” This campaign could both educate the public around the dangers of viral hepatitis and help to reduce stigma associated with testing and treatment.

This education campaign must also include creation and promotion of culturally sensitive materials. For example, one advocate noted that the current materials produced by MDPH

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have photos that are not reflective of most of his Latino and/or younger clients, so it is harder for them to relate to the materials. Creating their own materials is complicated because of lack of funding and because MDPH's approval process can be onerous. For example, to reach the Latino population, Holyoke Health Center recently began a new education campaign around the word "CEPA," short for Center for Education, Prevention and Action in Holyoke, and a play on the Spanish words "to know" (as in *pa' que lo sepas*—just so you know). The goal is to promote awareness of both HIV and HCV in the Latino community with the theme to get tested "just so you know."³⁴⁹ Advocates hope that this campaign will help the community to make connections between empowerment and knowing one's HIV/HCV status, but additional funding for testing incentives and/or other materials will be needed for this and other community-based strategies to be most successful.

Finally, members of the newly formed Massachusetts Viral Hepatitis Coalition (MVHC) should consider creating a more publicized, coordinated statewide testing and awareness day, and advocating for a statewide viral hepatitis week. Advocates could approach pharmaceutical companies and the American Liver Foundation for funding and sponsorship to support these initiatives.

Increase Peer-based Outreach on Harm Reduction Strategies for Active IDUs

As IDU is the greatest risk factor for HCV, many prevention and testing efforts should target individuals who are currently injecting. Advocates at harm reduction programs stress that effective interventions for the IDU community must involve knowledge of IDU culture, including the social groups and power dynamics within IDU communities, as access to clean equipment or use of safe injection practices may be controlled by certain members of the community.³⁵⁰ Women may be less likely to have access to safe equipment, as they may be in relationships controlled by an abusive partner who dictates the terms of their substance use.³⁵¹

One way to promote safe practices and share health information within IDU communities is through peer education, and many advocates cited the importance of peer-to-peer services.³⁵² Peer education programs conducted by those who have been or remain a part of the IDU culture can have an enormous impact on increasing safer injection practices among active users, as well as provide resources and referrals for individuals in recovery.³⁵³ For example, Addicts Health Opportunity Prevention Education (AHOPE) of the Boston Public Health Commission has a Consumer Advisory Board (CAB) that has put together peer trainings such as "Direct and Indirect Sharing: Viral Risks" that have been successful at reaching at-risk individuals.³⁵⁴ As will be discussed in the next section, peer groups can also play an important role in linkage to care and treatment. Efforts like AHOPE's should be supported and expanded to other communities.

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Increase Use of Electronic Medical Records (EMR)

Implementation and use of EMR for patients could significantly increase testing rates and promote linkage to care. For example, Boston Health Care for the Homeless Program (BHCHP) uses an EMR system so that its medical providers in the network can keep track of who has been screened and who might need follow-up services such as confirmatory testing, harm reduction counseling, and/or referral to treatment.³⁵⁵ When different clinicians and care providers from BHCHP visit shelters and other community-based sites, they all have access to the same EMR system as the providers in their Boston-based medical center. This allows clinicians to check immediately whether someone at a shelter or other site has been screened, and/or whether they may have already had an HCV test and have either not been notified of a result, or have not been connected to treatment.³⁵⁶ At Beth Israel Deaconess Medical Center, providers are working to create an electronic prompt in their EMR system that would remind the clinician to screen any patient within the baby boomer age group who has not already been tested.³⁵⁷ Because testing for HCV among this age group is generally a one-time test, such a system could quickly identify who still needs testing and/or who needs referral to treatment, without relying on the clinician to know whether an individual may be otherwise at risk. Advocates should identify existing efforts around creation and/or implementation of EMR (particularly those created through Massachusetts' new payment reform legislation), and work to create a similar electronic prompt at medical offices across the state.

Increase Funding for Hepatitis Programs and Include Funding to Implement Rapid Testing

Advocates should continue lobbying for increased funding for HCV programs, including surveillance, and with additional funding, MDPH should require a greater number of HCV tests from program sites. For example, one PICSR site is currently funded to do at least 25 HIV tests per month, but only five HCV tests.³⁵⁸

In November 2011, the US Food and Drug Administration (FDA) approved a rapid HCV test.³⁵⁹ Like the rapid HIV test, results can be obtained within approximately 20 minutes. The test detects the presence of HCV antibodies, which indicate past exposure to HCV. Harm reduction advocates at Tapestry Health Services indicate that the rapid HCV tests have made a big difference in their ability to provide follow-up counseling for their clients who get tested but then might otherwise fall through the cracks before the results were available. However, advocates at Tapestry note that reimbursement for the rapid test by MassHealth is far below the actual cost of administration.³⁶⁰ Though rapid testing would not eliminate the need for additional confirmatory testing, widespread availability of rapid testing including increased MDPH funding will allow providers to offer more effective interventions to transient populations, increasing the opportunity to educate and refer people who may not have otherwise been reachable for results. When implementing

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the use of rapid tests, it will be important for MDPH to align its standards with those of the FDA to ensure the least amount of administrative work for community-based organizations and other already overburdened test settings.³⁶¹

While the hepatitis community is in agreement that more funding is needed, the issue of whether hepatitis funding should be integrated into the existing HIV line item in the state budget rather than listed separately is still debated among some members. Some advocates argue that this integration has resulted in the unique needs of individuals living with or at risk for hepatitis being subsumed by a focus on HIV, particularly for monoinfected individuals. Others, including MDPH, suggest that having an integrated line item rather than siloed funding promotes greater flexibility for the state to be responsive to community need with regard to each illness. Still others worry that having an independent line item may make hepatitis funding more vulnerable to cuts. Advocates will need to make a decision about which strategy will be most effective.

Integrate HCV into the Screening, Brief Intervention, and Referral to Treatment (SBIRT) Project

The Screening, Brief Intervention, and Referral to Treatment program, or SBIRT, is a project in Massachusetts that is administered by the Bureau of Substance Abuse Services (BSAS), funded by a \$14 million, 5-year grant from the federal Substance Abuse and Mental Health Services Administration (SAMHSA).³⁶²

This program uses the following model to identify people who need substance use disorder services:

Screening – short, proven-effective questionnaire

Brief **I**ntervention – brief, structured conversations

Referral – for more in-depth evaluation and/or counseling and

Treatment – when necessary, refer for treatment

SBIRT is an effort to take advantage of the opportunities provided by visits to primary care providers and/or emergency rooms (ERs) to give information about substance use disorder to struggling individuals. By teaching pediatricians and primary care providers to perform a short questionnaire accompanied by a brief intervention, providers can identify and refer more individuals in need of substance use disorder support. In ER settings, a health promotion advocate is trained to screen individuals who come in for what appear to be substance use-related problems, and then to apply SBIRT.³⁶³ This model has been shown to be successful and is already being implemented in some community health centers and ER settings across Massachusetts.

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Increasing efforts to expand SBIRT interventions is part of the FY2011 Massachusetts Substance Abuse Strategic Plan Update, and could also be an important opportunity to provide HCV information and/or referrals for testing.³⁶⁴ Advocates should work with state officials from BSAS and the Office of HIV/AIDS (OHA) to incorporate HCV information into training for health educators in ERs, and to incorporate HCV information into the resource materials currently being offered through SBIRT. For example, on the BSAS SBIRT website, there is a provider manual designed to educate primary care providers who treat adolescents on how to implement behavioral health screening and referrals for possible alcohol and/or drug use through a similar screening tool known as CRAFFT.³⁶⁵ Providers who detect possible substance use disorders through this tool (a mnemonic acronym of the first letters of key words in the six screening questions) are advised by the manual to make referrals for substance use disorders and mental health counseling, but are not informed of the concurrent risks for HCV.³⁶⁶ This tool could be updated to include information about the related HCV epidemic among youth and incorporate HCV counseling and referrals for youth thought to be at risk. Moreover, reimbursement from MassHealth is available for this screening in youth under age 21, and may be available on a wider scale for SBIRT interventions for adults from both MassHealth and Medicare.

Increase Coordination and Collaboration Between Hepatitis Initiatives and Substance Use Disorder Treatment and Prevention Services

Substance use disorder and HCV are intricately connected in terms of causality, at-risk populations served, and support services needed for treatment and recovery; however, primary responsibility for viral hepatitis work in Massachusetts falls under the Bureau of Infectious Disease (BID), as well as with the Adult Viral Hepatitis Prevention Coordinator (AVHPC), while substance use disorder services are provided through BSAS. The extent of BID's coordination with BSAS on HCV issues is not always clear.³⁶⁷ Although BSAS requires all licensed substance use disorder programs to provide training and education to staff and clients on viral hepatitis, some providers in these programs felt their knowledge of viral hepatitis was outdated and incomplete.³⁶⁸ An educator at the American Liver Foundation also reported varying degrees of knowledge around viral hepatitis among providers and their clients.³⁶⁹ SPHERE (Statewide Partnership for HIV Education in Recovery Environments) is working to fill this educational gap for substance use disorder providers who receive funding from BSAS, and was identified as a great resource.³⁷⁰ However, SPHERE is only contracted to work with BSAS-funded programs, and other substance use disorder programs may not have access to these services.

State officials at BID/OHA and BSAS should collaborate with the Massachusetts Organization for Addiction Recovery (MOAR) (an organization that advocates on behalf of individuals in recovery), the Association of Behavioral Healthcare (ABH) (an organization representing community-based addiction services and mental health providers), and other substance use disorder providers to undertake a more in-depth analysis of the existing efforts on the part

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of substance use disorder programs in regards to HCV testing, referral, and/or treatment for their clients. This analysis should also encompass an evaluation of substance use disorder treatment providers' needs for financial and educational support around HCV.

Appropriate BSAS staff, as well as representatives from MOAR, ABH, and other substance use disorder providers, should regularly attend the meetings of the Viral Hepatitis Advisory Committee and participate in updating the draft HCV statewide strategic plan (to be discussed later in the report), which contains numerous goals related to working with substance use disorder programs. Substance use disorder providers and individuals in recovery are in the best position to advise about where in the recovery continuum and in what transitional programs HCV interventions might be most appropriate/effective (ie, during detox versus outpatient long-term recovery).

Conversely, the Massachusetts "Substance Abuse Strategic Plan Update FY2011-FY2016" includes a goal to use integrated data to help identify individuals with co-occurring disorders such as mental health, HIV/AIDS, and HCV infection, and evaluate whether they are receiving "appropriate access to services."³⁷¹ To achieve this goal, substance use disorder providers and advocates could benefit from a better understanding of existing HCV programs within local communities, and how best to support their clients in accessing care and treatment. There may also be other goals within the strategic plan update where HCV efforts could be integrated (such as the expansion of the SBIRT program discussed above). Overall, both strategies should be aligned around specific goals and objectives related to supporting individuals with co-occurring substance use disorder and HCV.

Similarly, work is also needed to assess the efforts and needs of mental health providers around HCV, and to identify means of coordination with mental health providers and programs to support individuals with co-occurring mental illness and HCV.

As will be discussed in the next section, more research is needed to identify how best to coordinate and fund models of care and treatment that incorporate both medical and community-based supports for individuals with co-occurring disorders. These efforts may be complicated by the limited availability of state funding. For example, decisions by MDPH in the past few years to focus funding for case management services on the "medical" model and away from more community-based organizations has been controversial, with limited transparency around the decision-making process. One treatment provider indicated that while the funding disappeared, there is still a continued need to support clients dealing with hepatitis C. This can feel like an unfunded mandate for some substance use disorder programs, particularly in trying to keep up with all the latest information around HCV treatment. More research is needed to identify how best to coordinate and fund models of care and treatment that incorporate both medical and community-based support for individuals with co-occurring disorders.

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ACCESS TO CARE AND TREATMENT

While testing and prevention are important components of combating the HCV epidemic, individuals who know their status must be connected to care and treatment in order for testing to be meaningful. In many ways, Massachusetts is far ahead of the rest of the country in its provision of health insurance for almost all of its residents. At the same time, even for insured individuals in Massachusetts, there are still barriers to care and treatment as well as opportunities for improvement.

HEALTH COVERAGE

Successes

High Rates of Insurance

In many ways, Massachusetts is a post-healthcare reform state in a pre-healthcare reform country; as a result of its own health reform law (Chapter 58) which went into effect in 2006, about 98% percent of Massachusetts residents have access to health insurance.³⁷²

Chapter 58 became the model for much of the 2010 Patient Protection and Affordable Care Act (ACA), the federal healthcare reform bill. Like the ACA, Chapter 58 included an expansion of Medicaid (MassHealth), subsidized coverage options offered through an exchange (Commonwealth Care), and a mandate that everyone purchase health coverage. As a result of healthcare reform, most people with incomes below 300% of the federal poverty level (FPL) who do not otherwise have access to health insurance are eligible for subsidized coverage through the state. For persons living with HCV, both the MassHealth and Commonwealth Care drug formularies cover antiviral treatment, including ribavirin, interferon, and the newer HCV drugs, boceprevir (Victrelis) and telaprevir (Incivek), although prior authorization is required.³⁷³ The Massachusetts HIV/AIDS Drug Assistance Program (HDAP) also covers these drugs for individuals who are coinfecting with HIV.

While having health insurance does not guarantee access to care and treatment or that needed services will be covered, lack of insurance was rarely identified by Massachusetts providers interviewed for this report as a barrier to care and treatment for persons with HCV in Massachusetts.³⁷⁴ By contrast, nationally it is estimated that 16.3% of Americans are uninsured,³⁷⁵ and some studies estimate that persons living with HCV are even more likely to be uninsured than persons without the disease.³⁷⁶ Unlike in Massachusetts, across the country, lack of insurance has been cited as a major barrier to accessing HCV treatment.³⁷⁷ In fact, in one focus group, an individual indicated that she had moved from another state to Massachusetts in part so that she could afford health insurance to help treat her HCV infection.³⁷⁸

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Challenges

High Copays/Cost Sharing for Consumers

Despite the significant advancement made by Massachusetts in implementing access to health coverage for most people, several barriers still exist within the system. In particular, many people reported that the cost of copays for individuals with private insurance can act as a major barrier, with some copays for those undergoing treatment in the thousands of dollars.³⁷⁹ One consumer stated that his copays for one of the new protease inhibitors were \$2,600/month.³⁸⁰ While some individuals may be eligible for patient assistance programs offered through pharmaceutical companies, some of these programs limit assistance to those who do not have any insurance.³⁸¹ Even individuals who have subsidized insurance plans through MassHealth or Commonwealth Care can have difficulty affording copays and cost-sharing requirements.³⁸² For example, individuals with Commonwealth Care Type 2 (individuals with incomes between 101-200% of FPL), can have copays of up to \$40 for some prescriptions, with up to a \$500 out-of-pocket maximum.³⁸³

Churning

Many callers on the HCV hotline identified a need for more supportive services to help people navigate the health coverage system, particularly as income fluctuated and eligibility for various subsidized insurance programs changed, also known as “churning.”³⁸⁴ In Massachusetts, churning may be even more of an issue in regions of the state that depend on seasonal tourism. For example, in Provincetown as with many summer tourist communities, residents’ income can vary widely from the summer (when tourists are in town) to the winter months when they may be largely unemployed.³⁸⁵ Churning can be a barrier to continuity of HCV treatment, as income may change and make prescribed medication unaffordable or unavailable, resulting in disruptions in care. Further, individuals with mental health and substance use disorders may be disproportionately impacted by complicated and burdensome administrative procedures and other barriers to enrollment that can lead to lack of coverage.³⁸⁶

Increasing MassHealth Expenditures on Treatment Drugs³⁸⁷

Lack of coverage of antiviral medications was rarely mentioned as a barrier to treatment, and some people spoke positively about MassHealth coverage in relation to prescription drugs. However, from FY2011 to FY2012, overall expenditures on HCV prescriptions more than tripled, from \$7.3 million in 2011 to \$22.3 million in 2012, and it is noteworthy that 2011 was the first year with claims for the new protease inhibitors (boceprevir [Victrelis] and telaprevir [Incivek]), with 17 claims for the new drugs in 2011, and 1,213 claims in 2012. During that same period, the average cost of HCV drugs per utilizing member also increased from \$9,520 to \$22,874, with the number of unique members utilizing HCV drugs growing from 765 to 978. However, Massachusetts’ new payment reform legislation, passed in 2012, creates a new pharmaceutical cost-containment commission, which may help to bring down the cost of HCV drugs.³⁸⁸

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Opportunities

New Laws Allowing Pharmaceutical Companies to Help With Copays

In FY2013, the Massachusetts state legislature repealed a law forbidding prescription drug companies from providing certain forms of copay assistance. Pursuant to the new laws, prescription drug companies may now provide assistance in the form of copay cards and coupons for any drugs that do not have generic equivalents,³⁸⁹ which could include the new protease inhibitors. Through this law, more individuals in Massachusetts with private insurance may be able to receive direct copay assistance with their HCV medications. However, federal law still prohibits this practice in regards to Medicaid and Medicare patients.

Implementation of Federal Healthcare Reform: Challenges and Opportunities³⁹⁰

Under the new federal healthcare reform law, the Patient Protection and Affordable Care Act (ACA), significant changes will be taking place across the country that will increase access to health coverage for millions of individuals. While in many ways Massachusetts was the model for federal reform, under the new laws there will also be changes to the Massachusetts system. In particular, the subsidized Commonwealth Care Plan (CommCare) will likely be replaced by an even more expansive MassHealth program (that will include individuals with incomes below 133% FPL), a Basic Health Plan (for individuals with incomes between 133-200% FPL), and tax subsidies for individuals (with incomes between 200-400% of FPL) to purchase Qualified Health Plans (QHPs) that will be offered through the Connector.

Opportunity: Increased Access to Health Coverage Through Expansion of MassHealth and a New Basic Health Plan

In many ways, differences in the federal law could result in greater opportunities for coverage for individuals in Massachusetts. For example, beginning in 2014, all individuals in Massachusetts with incomes below 133% FPL (\$14,656/year for an individual) will now be eligible for MassHealth. This could reduce churning for some individuals who move back and forth between CommCare and MassHealth (for example, long-term unemployed individuals). Benefits for these newly eligible individuals are expected to be similar to those currently offered in CommCare Type 1 plans (through which many of these individuals may currently be receiving insurance).

Massachusetts is also considering implementation of a new public health plan to cover people with incomes between 133-200% FPL (\$14,656-\$22,340/year for an individual) called a Basic Health Plan, another option for states created by the ACA. The Basic Health Plan will likely have a benefit package similar to CommCare Type 2 coverage, and include coverage for documented immigrants with incomes below 133% FPL (as these individuals would have to be residents for 5 years prior to becoming MassHealth eligible).

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There would also be some challenges to implementation of the Basic Health Plan. In particular, for certain populations currently on MassHealth (for example, individuals living with HIV with incomes between 133-200% FPL), this could mean a shift in coverage from MassHealth to a Basic Health Plan. To the extent that benefits in the new Basic Health Plan may differ from those currently offered in various MassHealth plans, this could potentially lead to lesser benefits and slightly increased cost sharing for some consumers. At the same time, advocates are currently working with the Office of Medicaid to explore ways to create safeguards that would ensure that these populations continue to maintain access to the same levels of benefits and cost sharing.

By implementing the Basic Health Plan, state officials hope to reduce the number of persons who experience gaps in coverage by creating greater continuity between plans offered on MassHealth and those offered through Basic. Unlike CommCare for example, the new Basic Health Plan will be administered by the Office of Medicaid (which also administers MassHealth). Further, the alternative would likely be that individuals in this income bracket (between 133-200% of FPL) would be moved off of CommCare and instead receive federal tax credits to purchase QHPs on the Connector. Because people would receive these new tax credits prospectively, they could be subject to a reconciliation process where they would have to return a portion of their tax credit should their expected income change. By contrast, under the Basic Health Plan option, Massachusetts would receive the tax credits rather than the subsidies going directly to the individual, eliminating the problem of potential reconciliation for people in this income bracket. Finally, the Basic Health Plan option might also allow Massachusetts to provide greater subsidization for this population, as the subsidies offered through federal tax credits will be lower than the current level of subsidization for individuals in this income bracket on CommCare. Unfortunately, the state has recently indicated that it may no longer be able to utilize the Basic Health Plan option due to a lack of federal guidance, as no federal regulations concerning state implementation of this option have been released. Advocates should push for federal guidance and state implementation of the Basic Health Plan.

Challenge: Maintaining the Same Levels of Affordability for Individuals on CommCare

Individuals with incomes between 200-300% FPL will likely be moving off of CommCare and given tax subsidies to purchase QHPs on the Connector. Although the state has indicated that it will work to cover the gaps in cost to some degree, it is not clear yet whether these individuals will receive the same level of subsidization as is currently available through CommCare.

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Opportunity: Expanded Access to Subsidies for Health Coverage Among Individuals With Incomes up to 400% FPL

Another positive change under federal reform will be that many individuals with incomes up to 400% FPL (\$44,680 for an individual) will receive tax subsidies for the purchase of private insurance. In Massachusetts, access to subsidized coverage (CommCare) is currently only available to individuals with incomes below 300% FPL (\$33,510/year for an individual).

Challenges and Opportunities Relative to the Essential Health Benefits Package

Pursuant to the ACA, most private health plans will have to offer an essential health benefits (EHB) package. The EHB consists of ten different categories of required health services, including mental health and substance use disorder services, as well as prescription drug coverage, and each state will be responsible for selecting its own “benchmark plan” to fill in the details of each covered service. The Massachusetts Division of Insurance (DOI) has chosen the BlueCross BlueShield of Massachusetts HMO Blue \$2,000 Deductible Plan as the state’s benchmark.³⁹¹ This benchmark plan will be used to define the floor of required services in each category, but will not dictate the terms of utilization management (for example, prior authorization requirements under the benchmark plan are not considered part of the EHB package).

Upon initial examination, the plan appears to cover the relevant drugs for HCV treatment, including the newer protease inhibitors. However, advocates should closely examine the details of this plan to ensure that it will meet the care and treatment needs of individuals living with HCV, including chronic disease case management, and access to comprehensive substance use disorder (including methadone and suboxone treatments) and mental health services. In addition, advocates will need to monitor all new QHPs for utilization management techniques and attempts at substitution of benefits that could decrease the ability of individuals living with HCV to access needed care and treatment.

Opportunity: Increased Federal Revenue

Finally, among other improvements, federal health reform will bring significant federal dollars to Massachusetts, as well as cost savings. For instance, beginning in 2014, the matching amount Massachusetts receives from the federal government for state expenditures on MassHealth, called the federal matching rate, will increase for certain individuals who have been receiving MassHealth but who will now be considered as “newly eligible” pursuant to the ACA. This is expected to bring \$1.8 billion to Massachusetts between 2014-2019, and \$347 million per year thereafter.³⁹²

The above changes represent just some of the ways in which the state will be transitioning under federal healthcare reform. As Massachusetts begins to implement federal reforms, there will be opportunities for increased access to healthcare services

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important for individuals living with HCV, but advocates must also be diligent in ensuring the gains made by Massachusetts are preserved. Such changes will also require expansive outreach and enrollment efforts to help explain the evolving system, as many individuals may be transitioning from one program to another (for example, CommCare to the Basic Health Plan). It will be important for HCV advocates to join in the process as Massachusetts moves forward with implementation to help ensure that individuals with HCV have access to the care and treatment they need.

LINKAGES TO CARE

Challenges

Linkages Between Testing at Community-based Sites and Access to Care

Even though many individuals may be eligible for health insurance, there are several ways in which people living with HCV may fall through the cracks in the steps between testing and access to treatment and care. First, as mentioned in the previous section, the current HCV screening tests funded through MDPH and offered through PICS and PICS-T sites, as well as other community-based organizations, can take up to 2 weeks for results. Many of the individuals served through these programs may be homeless, battling addiction, and/or low income, and some people never make it back to the test sites to receive and discuss their results. If clients cannot afford phones, counselors may receive test results but be unable to reach the affected individuals for follow-up.³⁹³ Second, many insurers require approval from a primary care provider (PCP) before clients can be referred directly to a specialist for treatment. This requires additional administrative steps that extend the time between testing and access to treatment (eg, calling MassHealth to identify a PCP, calling the PCP, and/or sending the client to the PCP for a referral) and can create additional lapses where an individual may become discouraged and decide not to follow through.³⁹⁴

Finally, there can be wait times to meet with either a primary care provider or a specialist. A recent report by the Massachusetts Medical Society found the average wait time to see a physician in internal medicine or family medicine to be 44 and 45 days, respectively, with a similar wait time (44 days) for gastroenterologists (liver specialists who may treat HCV).³⁹⁵ Other HCV treatment providers may have waits of weeks to months for patients to make an appointment and/or begin treatment due to the high volume of existing patients.³⁹⁶ Wait times can also vary by county. For example, the average wait time in Hampden County for internal medicine was 99 days, and for gastroenterologists it was 67 days.³⁹⁷ Further, after making an appointment for initiation of treatment, it may be necessary to make additional appointments for substance use disorder and/or mental health evaluations (as will be discussed later in this report) prior to beginning drug therapy. All of these factors can lead to instances where an individual may be lost to follow-up.

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Even when an individual is committed to seeing a provider, in many parts of the state transportation to care can be a barrier.³⁹⁸ On Cape Cod, for example, the lack of hepatologists can be a huge barrier for people who are coinfecting with HIV, and/or who may be at later stages of liver failure.³⁹⁹ These patients often have to travel to Boston to receive specialty services, and for low-income people or more symptomatic individuals, travel can be a significant problem. In other areas such as Fall River and Fitchburg, public transportation is available only during working hours.⁴⁰⁰ While Medicaid does provide some funding for transportation, this service is only available for individuals with MassHealth Standard (a program that primarily covers children and families), and even these services are sometimes inadequate to meet the needs of patients.

Still other individuals may simply not feel comfortable in a medical setting (due to stigma or other factors) or may not be ready or able to prioritize their HCV diagnoses. These individuals may be frequenting the same community-based sites for harm reduction but never actually see a medical provider.⁴⁰¹ Finally, even individuals who do initially connect to a medical setting may be lost to follow-up. For example, in a study done at Charlestown Community Health Center, loss to follow-up was the most common barrier to treatment among adults ages 40 and older (23%), and even more common among younger adults, ages 20 to 39 (40%), who had received a positive test result but not treatment.⁴⁰²

Individuals With Existing Positive Tests Who Do Not Understand the Results

Some community partners indicated that they come across patients who request tests or counseling, having already known of their chronic HCV infection diagnoses, or having received a positive antibody test in the past, but never having had a confirmatory test.⁴⁰³ Some individuals, particularly youth, do not understand the severity of the disease, as the illness can be asymptomatic, and they may not realize the importance of treatment or harm reduction (such as abstaining from alcohol).⁴⁰⁴ Multiple substance use disorder providers talked about a feeling of invincibility among youth.⁴⁰⁵

On the opposite end of the spectrum, others have received a positive test result from a provider and have an intense fear that their HCV diagnoses means they are immediately going to die.⁴⁰⁶ In other cases, individuals simply do not understand what their results mean and have indicated to advocates that their medical provider never spoke with them about next steps, harm reduction strategies, and/or where to go for any needed specialty care or treatment. This was a common concern reported on Massachusetts' statewide HCV hotline.⁴⁰⁷

These reports are indicative of the need for increased provider education. For example, one HCV antiviral treatment provider raised concerns about whether primary care physicians adequately follow up and track some of their HCV patients who may not be

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undergoing interferon-based treatment but who should be monitored for viremia, liver damage, and other impacts of the disease.⁴⁰⁸

Several advocates also mentioned that many of their clients have a low level of health literacy, and that some providers do not have the time, or take the time, to sit with a patient and explain (in simple terms) what an HCV diagnosis really means. Particularly for the Latino community in western Massachusetts, advocates identified a lack of providers with linguistic and cultural competence, which may also affect a patient's understanding of a test result.⁴⁰⁹

At the same time, some patients may just not be ready to hear or think about a positive test result when they receive it. Therefore, educational and counseling interventions must be available at multiple levels in the community—for example, at both a clinical setting and a community-based organization—so that when an individual is ready, information on HCV is available.

Fear of Treatment/Difficulty of Treatment

Fear of the side effects of interferon-based treatment was another challenge identified by community advocates. Particularly among adults in the baby boomer generation, people may recall friends or acquaintances who went through the treatment and had a terrible experience, with side effects of medication so bad for some people that they may have even gone back to using substances or become suicidal.⁴¹⁰ These fears are not necessarily without merit.

The current recommended antiviral treatment for HCV can lead to severe mental and physical side effects for some individuals, including nausea, depression, fatigue, and rash, among others. More than one individual who had been through treatment said it was one of the hardest things they have ever done, and described constant fatigue, anorexia, and generally feeling horrible. As a result, there is a pervasive feeling among some people that treatment is too difficult and they choose not to pursue it.⁴¹¹ While earlier HCV treatments of just ribavirin and interferon were far less effective for patients with certain genotypes (different strains of HCV), older adults may be unaware that new drugs (telaprevir and boceprevir) can shorten the time of treatment, and have higher success rates in genotype 1 individuals. Further, each individual responds differently to treatment, and for some, the process may not be nearly as onerous. For both these reasons, it is important for individuals to have all the most recent information prior to making an informed decision with their doctor about whether to pursue treatment.

“Undergoing [HCV] treatment was the most difficult thing that I have ever done, and that includes basic training in the army.”

—*Raphael DuBard Jr.*

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Not Everyone Is an Appropriate Candidate for Treatment

Even when an individual may wish to undergo HCV treatment, not everyone is an appropriate candidate for drug therapy utilizing the available antiviral drugs. A minority of people (10-25%) clear the virus spontaneously and never develop chronic illness. For people who do develop chronic HCV infection (about 75%), whether treatment is appropriate, the type of treatment, and the likelihood of success depends on a number of factors, including but not limited to genotype, presence of scarring and other liver damage, age, pregnancy, whether they have previously tried treatment, as well as major psychiatric disorders and current substance use.⁴¹²

Some people, particularly young adults, may not have symptoms or other immediate medical concerns and make an informed decision with their provider to avoid the current treatment side effects, monitor the illness, and wait until more advanced treatments are developed.⁴¹³ Others may be too far advanced in liver deterioration for antiviral treatment to be possible, and may either need a liver transplant or end-of-life care.

Treatment in Relation to Substance Use Disorder and Mental Health

Substance use disorder (past or current) and mental health issues were identified as frequent barriers to treatment by many community members. Similarly, one study of primary care providers who were experienced in working with homeless and marginally housed individuals coinfecting with HCV and HIV found that of 133 patients, only 29 were deemed eligible for treatment, largely due to depression, drug and alcohol use, and medication-adherence issues.⁴¹⁴

In the past, certain behaviors, such as active injection drug use (IDU), were considered to be contraindications to treatment, and generally accepted guidelines recommended that treatment not be administered to active substance users until the individual had demonstrated at least 6 months of sobriety.⁴¹⁵ Since that time, the guidelines have been changed and do not specify whether people with substance use disorders should or should not be treated, but rather recommend evaluating each individual patient for substance use and mental illness prior to initiating treatment, and making a decision based on the individual.⁴¹⁶ Because side effects of treatment may involve mental health (such as depression or hallucination), there are some forms of untreated mental illness that may be considered a contraindication, again depending on the individual.⁴¹⁷

As a result, there are different levels of discretion that may be exercised by either a patient, a referring social or medical provider, or by a treatment specialist in determining whether treatment is appropriate. This means that even when individuals have access to medical care, there can be additional medical or structural barriers to actually receiving treatment.⁴¹⁸ For example, treatment providers in Massachusetts have varying standards in relation to initiating HCV treatment with current drug users: some will treat active IDUs

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and have done so successfully,⁴¹⁹ while others may generally require a certain period of sobriety (such as 4 to 6 months).⁴²⁰ As one provider explains to his younger patients who are still struggling with addiction or only more recently sober, “you are more likely to die from an overdose than your hepatitis,” and he recommends getting the rest of their lives in order first.⁴²¹ Other doctors may discontinue treatment or decide not to initiate treatment because a patient has relapsed or missed a certain number of appointments.⁴²²

Some community members express frustration that some providers are not more willing to work with individuals where they are at, and there are concerns that these requirements are sometimes related to assumptions and stigma associated with substance use.⁴²³ In general, some individuals living with past or current substance use disorders have reported negative past experiences with health providers (of all kinds) who they feel have treated them badly simply because of their substance use history and/or generally did not understand the nature of addiction or how to work with individuals living with addiction disorders.⁴²⁴ Further, treatment providers may also have limited time and support staff, and therefore may feel unable to assist patients like IDUs who they perceive as potentially having more difficulties with adherence and requiring more resources.⁴²⁵

At the same time, there can be legitimate medical concerns with respect to substance use and HCV treatment. For example, patients who are actively injecting drugs may develop fungal and/or bacterial infections, and antiviral medications can decrease their body’s ability to respond to the infection.⁴²⁶ The potentially severe medical side effects of treatment, such as anemia, can also cause depression, or other mental health issues, and prompt patients to self-medicate, which could lead to continued IDU or relapse.⁴²⁷ Excessive alcohol use has been associated with increased risk of HCV disease progression and it is generally recommended that alcohol use be suspended or severely restricted while in treatment.

Patients also make choices about whether to engage in treatment, regardless of a provider’s recommendation. Those who are in the midst of addiction may not be mentally or emotionally prepared to deal with their HCV infection.⁴²⁸ Substance use disorder and addiction are deeply personal and difficult struggles. Individuals affected by these diseases may feel they need to effectively address their addictions before they can initiate HCV treatment.⁴²⁹

Severe mental health issues were also identified by community members as a barrier to treatment.⁴³⁰ Nationally, persons with mental or psychiatric diseases are estimated to be 4-20 times more likely to have HCV than persons without these issues, but there are some psychiatric conditions, such as active suicidal ideation or uncontrolled depression, that may be considered contraindications to treatment.⁴³¹ Part of the reason is that side effects of antiviral treatment can have an impact on mental health (such as depression, suicidal ideation, and mania) that may exacerbate existing conditions. One provider had

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a patient who experienced severe psychological symptoms to the point of heightened aggression while on treatment.⁴³² Yet for many persons with mental health conditions, treatment may still be possible with the right support.⁴³³

Insufficient Substance Use Disorder and Mental Health Treatment Resources

Because of the complex interconnection between substance use disorder, mental health, and HCV, in many cases the ability of individuals to access HCV treatment will be linked to their ability to receive comprehensive substance use disorder and mental health services. However, several community members expressed concern that there are not enough substance use disorder treatment programs in Massachusetts, particularly for youth.⁴³⁴ In addition to having some of the highest rates of drug and alcohol abuse in the United States, Massachusetts' rates of unmet drug treatment need for all age groups have also generally been above national levels. For example, Massachusetts ranked among the highest states (top ten) for individuals needing but not receiving treatment for illicit drug use in the past year among youth aged 12-17 years and young adults aged 18-25 years.⁴³⁵

There is also a concern about a lack of mental health providers, again with youth particularly impacted.⁴³⁶ For instance, Massachusetts has 59 designated Health Professional Shortage Areas* (HPSAs) for mental health.⁴³⁷ Without access to adequate mental health and substance use disorder support, persons struggling with these issues will not be able to treat their HCV infection.

Finally, some community members further identified the fragmentation of primary care, mental health, and substance use disorder treatment providers as a barrier to HCV care and treatment.⁴³⁸ As one person stated, people tend to enter the system through health services, through mental health, or through substance use disorder, and that's where they tend to stay.⁴³⁹

Opportunities

Create Regional and Local Strategic Plans to Address Viral Hepatitis

State officials and advocates, particularly those participating in the Massachusetts Viral Hepatitis Coalition (MVHC), should partner with local boards of public health to develop localized, integrated strategic plans to address the compound problems of substance use disorder and HCV in their communities. The plans should aim to create a network within the community so that individuals who are dealing with viral hepatitis will know where to go, and support providers will know where to refer them. It will be important to

* In general, an HPSA designation can refer to (1) a geographic area with high ratios of population compared to the number of mental health core providers and/or psychiatrists, and providers within the area are overutilized and excessively distant or inaccessible to residents within that area; (2) a population group with a high ratio of people compared to the number of mental health core providers and/or psychiatrists, and the population faces barriers to providers; and (3) a designated facility that also fulfills similar requirements.

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build relationships between medical and community-based support providers to promote a no-wrong-door approach. Some community members (both HCV medical providers and community-based support organizations) did not always seem to be aware of each other. As one community member recounted, in the earlier days of HIV, “we had [those networks] ... but people are so siloed now and have stopped talking to each other.”⁴⁴⁰

Smaller, more regional, or locally based plans may be more likely to garner buy-in from the community as well as create better structures for accountability. At the same time, the process of creating these local plans will help MVHC to develop a viral hepatitis advocacy infrastructure. Further, as previously discussed, communities may have coalitions and even strategic plans to address substance use disorder, and these plans should be revisited to incorporate viral hepatitis education and prevention.

Also essential to increasing linkage to care at the community level will be use of the rapid HCV test. Tapestry Health has already begun administering the rapid HCV test through a grant from the pharmaceutical industry. Using rapid tests significantly alleviates the problem of clients not returning to receive test results, and allows immediate referral to other resources when necessary. As a result, counselors report an increase in the number of people they are able to effectively counsel and refer.⁴⁴¹ As use of rapid testing increases, it will also be important for MDPH to use the newly developed point of care case reporting forms to determine the effectiveness of both new rapid tests and existing test programs in linking clients to follow-up care.

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Spotlight on Massachusetts General Hospital/Charlestown Community Health Center: A Community-Based Approach to Prevention, Testing, and Treatment*

The community of Charlestown has extremely high rates of opioid abuse, and one of the highest rates of drug-related deaths in the Boston area. Increasingly, young adults are presenting at clinics suffering from overdoses and other substance use problems. Over the past year, providers at Charlestown Community Health Center (CCHC) have developed a three-pronged, community-based approach to addressing HCV. First, Charlestown operates an HCV clinic once a week using a primary care clinician, with support from specialists in gastroenterology and infectious disease at Massachusetts General Hospital. Second, providers and health educators work with the local substance use disorder coalition to educate the community about the prevalence of HCV and its connection with substance use disorder. They are also building relationships with other primary care providers (including pediatricians), who may not be aware of the risk factors for substance use disorder and/or hepatitis. Third, Charlestown has begun offering hepatitis testing to all patients in its suboxone clinic.

In addition, in collaboration with the Harvard School of Public Health, Charlestown has developed a database of its suboxone patients who may be at risk for HCV but have not yet been tested. With the help of a staff member, every week providers at the center are alerted if a suboxone patient is coming in who should be referred for hepatitis testing. At the health center, 95 out of 110 suboxone patients have been tested for hepatitis, with 47 testing positive for hepatitis antibodies. Of those tested, 95% were provided with basic education on hepatitis, including alcohol interventions where appropriate, and referrals to additional care. Charlestown is currently working to expand these database efforts to include all patients of the center who may be at risk (and not just those in the suboxone program).

* Interview with Dr. James Morrill, primary care, Charlestown Community Health Center, (January 24, 2012, and follow-up on November 20, 2012); Dr. James Morrill, primary care, Charlestown Community Health Center, "The MGH Community Hep C Program: A Distant Echo?" presentation to the Massachusetts Viral Hepatitis Coalition, June 5, 2012.

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Increase the Availability of Peer Support Groups for People Living With HCV

Many community partners also discussed the importance of having peer supports in place so that individuals who had been diagnosed with HCV could talk to others who have been through treatment, and this was consistently stressed by individuals living with HCV (including those who had been cured through treatment). One counselor talked about how one of her clients was terrified of going through treatment, but that participating in a peer support group and hearing first-hand about the experience from someone who had been through it helped change her mind.⁴⁴² Peer support groups may increase treatment adherence and also help to reduce feelings of stigma. For example, one individual recounted how a member of his peer support group told the group he did not feel worthy of treatment because of his injection drug use. When this individual approached him to tell him that everyone deserved treatment, he said it made a world of difference.⁴⁴³ While there seems to be some peer support groups available in Massachusetts, advocates identified the need for more groups, a need which will likely intensify as more people are diagnosed. At the same time, peer support groups may be more effective if they are tailored for individuals struggling with different facets of the illness.⁴⁴⁴ For instance, there may be individuals for whom treatment has failed or who, due to later-stage liver disease, may not be appropriate treatment candidates. More targeted support groups for these individuals will be needed.

As will be discussed later in this report, advocates should explore the possibility of Medicaid or other third-party reimbursement for coordinated care models that include peer support. The Medicaid Health Home, for example, is an option for states to provide enhanced Medicaid reimbursement to providers who offer health home services, including peer support.

Increase Integration Among Primary Care Providers, HCV Treatment Providers, and Mental Health and Substance Use Disorder Providers

Ideally, new treatments will someday reduce or eliminate the severity of side effects currently associated with antiviral therapy, including new drugs that do not require the use of interferon. Such developments could go a long way in increasing accessibility of treatment for individuals with mental health and substance use disorders. Until that time (and even when such drugs may become available), advocates should aim to increase coordination and collaboration between viral hepatitis treatment programs, mental health services, and substance use disorder treatment programs. First, primary care, substance use disorder, and mental health providers should all be educated about the treatment options for their patients. Some mental health and substance use disorder providers may not refer their HCV-infected patients for treatment evaluation because they don't realize that despite their co-occurring illnesses, their clients may still be eligible for treatment with appropriate support. For example, successful treatment of HCV patients has been demonstrated in conjunction with methadone treatment.⁴⁴⁵ More research should also be

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done to examine the extent to which some HCV treatment providers in Massachusetts have already developed successful partnerships and collaborations with methadone and/or suboxone programs, and explore opportunities to integrate provision of HCV treatment into other existing programs. In general, methadone and suboxone programs offer medication assistance to help individuals dealing with opioid addiction (a major risk factor for HCV), and may offer a structured regimen through which to coordinate HCV antiviral treatment.

Second, it will also be important to identify and invest in existing models of care in Massachusetts (for example, among current medical management sites and other models) that optimize communication and coordination between primary care and/or HCV antiviral treatment providers as well as substance use disorder and mental health providers. One strategy is to invest in models that provide one central location for many of these services. Stanley Street Treatment and Resources (located in Fall River) gives patients on-site access to substance use disorder and mental health services, and case managers can even walk with people to their additional providers.⁴⁴⁶

Massachusetts has been making progress toward replicating similar integrated care models. For example, in July 2012, the Massachusetts League of Community Health Centers, MDPH, and the Association for Behavioral Healthcare, among others, participated in the Massachusetts Health Integration Summit, where several opportunities for integrated healthcare were discussed, including the Medicaid Health Home model as well as the new Department of Public Health Integration Initiative. This new initiative aims to encourage coordinated care models by streamlining licensing requirements for providers who wish to offer both primary care and behavioral health services, including mental-health care and substance use disorder treatment.⁴⁴⁷ HCV advocates should explore new models as they are developed under these initiatives and look for ways to incentivize participating providers to integrate HCV care and treatment.

Finally, advocates should also look at the additional integration opportunities created by Massachusetts' recent payment reform legislation. Among other behavioral health integration initiatives, the payment reform legislation creates a task force specifically charged with making recommendations for integrating behavioral healthcare into new alternative payment models,⁴⁴⁸ and HCV advocates should meet with this taskforce to explore possibilities for broadening these integration initiatives to include HCV care and treatment.

Increase Provider Education and Cultural Competency Training at the Medical School Level

While increased coordination and collaboration between behavioral health and viral hepatitis providers will be important, some barriers related to HCV care for individuals with mental health and substance use disorder issues may be related to stigma on

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the part of some primary care and treatment providers. To help address this issue, advocates should investigate further what efforts are already being undertaken by the state's multiple medical schools and teaching hospitals to provide education around viral hepatitis, as well as cultural competency, including holistic approaches to helping persons dealing with past or current substance use disorder. For example, staff members from AIDS Project Worcester (APW) meet yearly with medical students from the University of Massachusetts to provide education around HIV and cultural competency, and students spend time at APW to get to know the community and the providers there. Next year, the project will also include HCV as part of this work.⁴⁴⁹ Reaching providers at the medical school level could help address potential stigma and help future providers learn how to create environments of trust where former or current substance users feel safe in seeking testing or medical treatment for conditions like HCV infection.⁴⁵⁰

Advocates should also build and expand upon efforts to promote cultural competency among existing providers. One place where this is already happening is at the Addicts Health Opportunities Prevention Education (AHOPE) program. Members of AHOPE's consumer advisory board reach out to local physicians to educate them about harm reduction practices and working with former and current injection drug users, including risk factors and recovery.⁴⁵¹ These efforts should be expanded.

PROVISION OF CARE AND TREATMENT

Successes

Funding Medical Management Programs for Persons with HCV

Largely because so many people have health insurance, rather than funding treatment directly, MDPH Bureau of Infectious Disease Prevention, Response and Services (BID) funds five medical management programs to provide enhanced medical case management for persons who are monoinfected with HCV at seven sites throughout Massachusetts.⁴⁵² (Note that for many persons coinfecting with HIV, case management services are available through Ryan White-funded programs.) These sites include: Infectious Disease Clinical Services (IDCS) on Cape Cod (in Falmouth and Hyannis), Stanley Street Treatment and Resource Center in Fall River, Baystate Medical Center in Springfield, and UMass Memorial Health Care (in Worcester and Fitchburg). The program in Fitchburg is located at a community health center, which allows access to specialist care for individuals who may otherwise lack such access due to transportation problems and other concerns. While it is still getting off the ground, another site at Boston Medical Center was recently added. Though treatment for HCV is often considered a specialty of gastroenterologists, these medical management sites are all located within existing MDPH-funded HIV case management programs, and are built on the existing infrastructure developed at these sites for persons living with HIV. All of the sites use a coordinated, team-based approach to care.

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Over the past 20 years, the model of coordinated, holistic care and supportive services developed through the Ryan White Program has helped transform HIV from a terminal illness to a chronic medical condition. As a result, these programs may be more experienced at treating complex medical conditions and providing case management services and therefore may be ideal settings to provide similar services for persons who are either coinfecting with HIV and HCV, or monoinfected with HCV.⁴⁵³ While the needs faced by those undergoing HCV antiviral treatment differ from those on HIV treatment, particularly in regards to the time-limited duration of treatment, many of the same issues apply. For example, providers who have worked with HIV patients may have more experience dealing with clients who face stigma and other barriers, and may be more comfortable discussing risk factors such as sexual health and drug use.⁴⁵⁴ Yet, frequently money is not available to provide the same level of supportive services for individuals living with HCV who are not also infected with HIV. MDPH helps to fill the gaps at these funded sites.

Utilizing the ECHO Model to Expand Access to Treatment

To address the growing number of HCV patients and lack of treatment providers, one major academic teaching hospital in Massachusetts, Beth Israel Deaconess Medical Center, has begun using the Extension for Community Healthcare Outcomes Project (ECHO) model to provide guidance and assistance on treating HCV patients to providers in local community health centers.

ECHO was initially developed by the University of New Mexico Health Sciences Center (UNMHSC) as a way to address the healthcare needs of the large numbers of people living with HCV in rural and underserved areas of New Mexico. These patients were waiting months to initiate treatment due to the lack of local specialty providers and problems with transportation. Primary care physicians (PCPs) caring for patients in these communities also had limited access to HCV specialists for consultation. The ECHO project uses a telehealth model to provide consultations on HCV treatment to PCPs through the use of internet and video. ECHO participants attend a 3-day orientation session and then assume responsibility for treatment of their patients, while continuing to participate in weekly, 2-hour telehealth sessions. These sessions bring together participating PCPs from across the state to consult with a team of experts in the fields of gastroenterology, psychiatry, addiction medicine, and/or pharmacology, among others. In this way, participating PCPs are able to learn from one another as well as from specialists in the field, creating a “knowledge network” across the state and gradually developing their own expertise. Recent data demonstrate that ECHO providers had rates of successful treatment that were comparable to treatment provided in other specialty settings.⁴⁵⁵

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In the winter of 2012, Boston's Beth Israel Deaconess Medical Center began an HCV ECHO project with Outer Cape Health Services in the outer Cape Cod area of Massachusetts, an area that is traditionally underserved with respect to specialty care.⁴⁵⁶ The project participants are located at three different sites: Provincetown, Wellfleet, and Harwich, and they have access to a specialty team that includes a pharmacologist, psychiatrist, and hepatologist from Beth Israel. Participation in ECHO does require a commitment on the part of providers, both to provide the necessary treatment to their patients, and to participate in weekly 2-hour sessions for about 18 months, or until they feel able to administer treatment independently.⁴⁵⁷ However, beyond the time and treatment commitment, the only elements required for participation are a camera and an internet connection, with no other fees or costs for participation (though additional administrative support may be needed).⁴⁵⁸ To incentivize participation, ECHO also offers continuing medical education credits.⁴⁵⁹

The basic model has also been adapted to fit different participants' needs. For instance, the Beth Israel ECHO project has now expanded to include more experienced HCV treatment providers at Lawrence Community Health Center, who need occasional consultations for more complex cases, and/or for patients who are coinfecting with HIV.⁴⁶⁰ Similarly, a primary care provider at Charlestown Community Health Center has also recently begun providing HCV treatment using a more informal ECHO model to connect with specialists at Massachusetts General Hospital (MGH) as needed and as a means of creating a "knowledge network," although this connection does not take place through telehealth technology.⁴⁶¹ While the Beth Israel ECHO project is still in its early stages, the Charlestown/MGH project has provided successful treatment to patients at rates comparable to treatment at other settings.⁴⁶²

The overarching goals of the ECHO program are to help create niches of expertise in complex conditions such as HCV in more localized, community-based settings, and to help community-based care providers feel more connected to academic institutions.⁴⁶³ Beyond increasing community-based access to care and treatment, ECHO may also generate time and cost savings for patients. For example, getting from Provincetown to Boston requires a 2-hour drive. In addition, the field of HCV is rapidly changing, and these "knowledge networks" created through ECHO provide a good mechanism to disseminate the most up-to-date information about HCV.

Challenges

High Level of Administration and Coordination Required for Treatment and Care

A barrier for both medical providers and community-based organizations in offering treatment is the lack of funding or adequate reimbursement for all the services that are often involved in providing successful HCV care and treatment, particularly for monoinfected persons.⁴⁶⁴

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Care Coordination

HCV antiviral drug treatment is a complex process that can require additional medical and administrative support beyond just giving medications, usually necessitating a team-based approach involving both doctors and supportive service providers.⁴⁶⁵ On the medical side, patients will need to visit their treatment provider an average of 18 times, both to receive medication and to obtain follow-up lab work.⁴⁶⁶ Patients will also need continued monitoring of lab results to check the response to treatment and for any adverse effects. Some individuals may be on additional drugs for co-occurring disorders such as HIV and other chronic illnesses. For these individuals, treatment providers need to be in communication with pharmacologists as well as any involved substance use disorder and mental health counselors to ensure that they receive appropriate support and are being monitored. Finally, patients often have questions about side effects and need continuous access to a point person whom they can call or speak with on a regular basis as they progress through treatment.⁴⁶⁷

Administrative Work

Providing treatment can also create a significant administrative burden. Many of the drugs needed for treatment require prior authorization, and obtaining initial authorization from insurers for the newer medications can sometimes be a challenge.⁴⁶⁸ Insurers also require continued renewal of prior authorizations with updated lab results in order to continue covering the drugs. Medicare Part D programs can be particularly administratively challenging to work with.⁴⁶⁹ All of these requirements often necessitate both continued lab testing of the patient as well as administrative work to ensure the appropriate paperwork reaches the insurers. If the proper forms are not received in time, patients may experience disruptions in treatment, which may jeopardize efficacy and/or lead to resistance to antiviral medications.⁴⁷⁰

Adherence Support

Because of the intense nature of the illness and treatment, some patients need additional adherence support, such as help with social services like housing and nutrition, and phone calls to remind them about appointments. Often, for treatment to be successful and to help deal with the side effects, a network of support among family or friends is needed that some people may simply not have,⁴⁷¹ while others may be too ashamed of their status to reach out to their support networks.⁴⁷²

Funding/Reimbursement

MDPH is able to assist with funding for these additional services at the seven HCV medical management sites, but no funding is available beyond those sites. Further, as funding from MDPH is potentially subject to cuts from the state legislature, it may not be sustainable. Some other providers obtain grants or other monies to fund an additional nurse practitioner or case manager to help coordinate HCV treatment, but funding for

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these positions may also not be guaranteed. While insurance may cover the cost of medications, there can be an incongruence between the multitude of services that are often provided to patients with chronic health needs, and what insurers consider to be “case management.”⁴⁷³ In order to ensure continued access to care and encourage additional providers to take on HCV treatment, there must be adequate funding mechanisms available for care coordination, case management and other support services, and for innovative models such as ECHO.⁴⁷⁴

Lack of Providers Able to Administer Care and Treatment

With over 100,000 people in Massachusetts with evidence of HCV infection, and only a limited number of community health and other providers offering treatment (the recent resource guide for example, identified only 57 different facilities), it is likely that additional providers will be needed to treat this population.⁴⁷⁵ The new CDC age-based screening guidelines will likely generate many more patients who will be newly aware of their infection, while some treating providers already have waits of several weeks to months to begin treatment.⁴⁷⁶ In some parts of the state, access to treatment providers is already limited by geography or accessibility of providers who speak other languages, which can be particularly challenging for low-income people.⁴⁷⁷ In the Springfield area, there is also a lack of culturally competent and Spanish-speaking HCV providers, despite a large Latino community.⁴⁷⁸

Part of the solution will involve relying on more community health centers and primary care providers to offer care and/or treatment. Some primary care providers may be interested in providing treatment but think it’s too difficult or don’t have the necessary knowledge base and support. At the same time, primary care providers are becoming increasingly burdened with more and more responsibility for care coordination and holistic care, particularly with the shift toward the medical home model. While in many ways this may be a good development for patients, providers may become overwhelmed and concerned that they simply do not have the time or the staff to provide HCV treatment.⁴⁷⁹ By one estimate, if primary care providers implemented every recommendation from the US Preventive Services Task Force (USPSTF) for example, they would spend at least 7.4 hours each day just providing preventive services to their patients.⁴⁸⁰ HCV, in particular, is a field where there are many new developments emerging that can be difficult to keep track of,⁴⁸¹ and offering HCV treatment can be administratively burdensome with comparatively low reimbursement for services.⁴⁸² Despite these challenges, projects like ECHO may make treatment provision manageable, particularly for providers in community health settings.

However, some people also reported that even nontreating PCPs have waitlists, and that the state is generally in need of primary care providers.⁴⁸³ For example, in 2012 Barnstable, Berkshire, and Hampden counties had average wait times of approximately

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90 days for an appointment in internal medicine, compared to 35 days in Plymouth County and 64 days in Suffolk County.⁴⁸⁴ As more people are seeking care with the expanded insurance coverage provided in Massachusetts, fewer PCPs are accepting new patients.⁴⁸⁵ In addition, the percentage of PCPs who accept MassHealth has also been declining.⁴⁸⁶ As with the number of providers and average wait time, the number of providers accepting MassHealth also differs by region, with far fewer providers accepting MassHealth in Hampden County for instance. Recent payment reform legislation passed in July 2012 may help to address some of the issues related to primary care, as it includes provisions related to increasing the primary care workforce, but this will be difficult to discern until after implementation.⁴⁸⁷

Lack of Additional Supportive and Social Services for Low-income Persons Living With HCV

Many community partners reported that more case management and supportive services are needed for people living with HCV infection, particularly low-income individuals. Nationally, some research has shown that people with incomes below the federal poverty level (FPL) are nine times more likely to be HCV-infected than their counterparts with incomes at 200% FPL.⁴⁸⁸ In Massachusetts in general, 15% of residents (1,017,200 individuals) have incomes below the FPL (\$11,170/year for a single person), a rate which varies by race and ethnicity: 11% for whites, 30% for blacks, and 38% for Hispanics.⁴⁸⁹ For people living in poverty, accessing essentials like food and housing can take priority over seeking care for HCV infection.⁴⁹⁰ In addition, for persons with HCV, lack of access to adequate food and shelter can itself be a barrier to treatment.⁴⁹¹ For example, one HCV medication must be taken in conjunction with a “fatty meal” in order to ensure that the drug is properly metabolized by the body. This can present a barrier for low-income people in Massachusetts who may have insurance, but lack access to appropriate nutrition services.⁴⁹² (The Food Research and Action Center estimates that, on average, 11.9% of Massachusetts households are food insecure.⁴⁹³)

In addition, the newly available medications for HCV must be taken three times a day, and an injection must be administered once per week; some of these medications must also be refrigerated. For homeless individuals, this can be another barrier, as homeless shelters often do not have storage capacity for medications, and persons may not otherwise have access to a refrigerator.⁴⁹⁴ For these reasons, providers may also require persons to have some stability (including housing) before initiating treatment, which can be frustrating for some people who are otherwise capable of successfully completing treatment even while living in a shelter.⁴⁹⁵

As mentioned, some consumers identified that going through treatment was one of the most difficult experiences of their lives, requiring constant support and the ability to lie down and rest during the day due to side effects. Because shelters may be closed during

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the day, this can again present a barrier for individuals who are homeless and have nowhere to go to recover. In Gloucester, the North Shore Health Project has been able to use grants and other funding to provide short-term housing to some people for the duration of HCV treatment. However, for many other individuals in other communities, these services are just not available. One individual living with HCV indicated that one reason he had not gone on treatment was because he was sleeping on the streets at night, so he would have nowhere to keep and protect his medications, nor a place to go when needing rest.⁴⁹⁶

Because of the side effects of treatment, some patients need to take time from work, which can result in lost wages or termination of employment, and may either decide not to initiate treatment or end treatment prematurely to avoid loss of income.⁴⁹⁷ At the same time, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) applications typically take a long time before a final determination is reached, and these benefits are often not available to persons just because they have HCV infection and are initiating what could be physically difficult treatment.⁴⁹⁸

For individuals who are coinfecting with HIV, there are separate funding streams available to provide greater access to case management, food, housing, and other support services as part of the Ryan White HIV/AIDS Program and the Housing Opportunities for Persons with AIDS program. The importance of these programs for people living with HIV (and by extension, those who are coinfecting) cannot be overstated. In Massachusetts, there has been an enormous decline in HIV/AIDS infections and deaths, likely in part as the result of the interaction between Massachusetts health reform, and the Ryan White Program.⁴⁹⁹ Continued funding of these programs is essential to maintaining these individual and public health successes.

Opportunities

Medicaid Health Homes⁵⁰⁰

As discussed, HCV care and treatment often involves coordination among multiple service providers as well as administrative and patient support throughout treatment. It will be important to identify models of successful, coordinated care for HCV treatment and adequate funding mechanisms. One potential model for the state to consider for its MassHealth patients is the Medicaid Health Home option. Medicaid Health Home is an option under the ACA whereby a provider, a team of providers, or a health team may be designated as a health home and receive increased reimbursement for providing holistic care for their patients. Holistic care includes care coordination and follow-up, as well as peer-based educational support—services that are frequently required for successful care and treatment of HCV. To be eligible for a health home, a patient must have at least two chronic health conditions, or one chronic condition and be at risk for another, or a serious and persistent mental health condition.

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The Medicaid Health Home is one way in which states are encouraged to provide more integrated services for persons with mental health and substance use disorder illnesses, and states must consult with the Substance Abuse and Mental Health Services Administration (SAMHSA) prior to receiving approval for implementation. Moreover, the Medicaid Health Home option provides enhanced FMAP reimbursement for coordination and support services. States that implement the health home model receive increased FMAP rates of up to 90% for the first 2 years of implementation, and states may spend up to \$500,000 for planning efforts and receive federal matching dollars at their existing FMAP rates. Oregon recently received approval from the Centers for Medicare & Medicaid Services to begin providing health home services to individuals with HCV infection,⁵⁰¹ and Massachusetts should consider doing the same.

Opportunities Through Payment Reform: HCV-specific Considerations for Medicaid and Other Medical Health Home and/or Coordinated Care Models

In addition to the federal Medicaid Health Home option, there are also several existing initiatives in Massachusetts that involve the use of the medical home model for chronic illness such as diabetes, including projects through MDPH, although none thus far are focused specifically on HCV.⁵⁰² In fact, the Executive Office of Health & Human Services has set a goal of having all PCPs become medical health homes by 2015 (potentially including all their patients, not just individuals with chronic illnesses).⁵⁰³ In July 2012, Massachusetts passed expansive payment-reform legislation, establishing a new Health Policy Commission (the Commission) charged with, among other tasks, working with MassHealth to develop general standards for certification of patient-centered medical homes and Accountable Care Organizations (ACOs)—new provider systems that focus on cost-reduction and quality improvement—in addition to other alternative payment methods and delivery models.⁵⁰⁴ In developing standards for medical homes as well as ACOs, the Commission is specifically directed to consider the goals of providing more patient-centered care, with a particular focus on individuals with chronic diseases, and the Commission must develop these standards utilizing input from providers and consumers.⁵⁰⁵ As Massachusetts begins to explore further development of the health home and other models for coordinated care, HCV advocates, state officials, providers, and persons with HCV infection must be involved in creating a medical health home and coordinated care model that truly works for people living with HCV infection.

While there may be tension between community-based organizations and the focus on a “medical home” that is more clinically based, ideal support systems for individuals with HCV may involve both. For example, in one focus group, members with HCV identified the general importance of having support from a community-based organization like La Voz while dealing with their HCV, but also mentioned that they were receiving good care from their medical providers.⁵⁰⁶ Another community-based counselor described how for HIV, there is a program that allows him and other staff from his community-based

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organization to be present at the time when a client receives a positive HIV test result at the local community health center, accompany their patients to medical follow-ups, and be kept informed about treatment progression. He discussed how these community-based services would be similarly helpful for his HCV clients who may be falling through the cracks of the medical system in the meantime.⁵⁰⁷ Further, some providers expressed the importance of individuals having access to both community support and someone with more medical technical ability, such as a nurse case manager, who can provide the medical expertise to help individuals understand and monitor their HCV care needs, disease progression, and side effects for treatment.

Yet, a medical health home model need not exclude community-based organizations, and opportunities for collaborative models should be explored. For example, in New York, Medicaid Health Home entities can contract with community-based supports.⁵⁰⁸ Massachusetts payment reform legislation also seems to envision collaboration between community-based supports and medical providers. The newly formed Commission is tasked with creating standards that enable the “utilization of a range of qualified healthcare professionals ... which may include but not be limited to, nurse practitioners, physician assistants, and social workers.”⁵⁰⁹ The Commission must also create a directory of “key existing referral systems and resources that can assist patients in obtaining housing, food, transportation ... peer services and other community-based supports” to be utilized by patient-centered medical homes to help connect their patients to their communities.⁵¹⁰

There could also be models where clinical providers are funded to go directly to community-based organizations to provide care and treatment.⁵¹¹ For example, the Northeastern School of Nursing places six nursing students, working under an experienced supervisor, at the Cambridge Cares About AIDS syringe exchange site, where they can offer care and services.⁵¹² Having medical providers in community-based settings (such as a youth drop-in center or mobile health van) allows clients to meet these providers in a potentially less-intimidating environment, and may increase the likelihood that clients will subsequently follow up with the providers in a medical setting. MDPH should explore having HCV specialists visit these existing initiatives to offer HCV treatment.⁵¹³ In addition, the Boston Health Care for the Homeless Program (BHCHP) is currently participating in a Special Project of National Significance, or SPNS, through the Ryan White AIDS Program to provide HCV treatment to HIV+ individuals in their community-based primary care facility, and may also provide a future model for care delivery for coinfecting patients.⁵¹⁴

Another consideration for health home development is that specialty providers may offer HCV treatment but not act as the PCP for patients, and therefore sometimes non-primary care providers may be the nexus of holistic care coordination and monitoring

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during patients' treatment. For example, treatment providers at IDCS (Infectious Disease Clinical Services) are often doing much of the coordination and monitoring for their HCV patients, but do not serve as PCPs for persons who are monoinfected. Massachusetts' payment reform specifically allows for specialists to be medical health homes and this possibility should be considered for individuals with HCV.⁵¹⁵ In addition, payment reform legislation also permits behavioral health providers to serve as health homes, which may be appropriate for HCV patients struggling with concurrent substance use and/or mental health issues.⁵¹⁶

Within all of these potential models, an additional issue to be considered is that some HCV patients who go through treatment successfully may only require coordinated services for a limited period of time, so more flexible models, such as temporary health homes, may be appropriate. Further, while patient-centered medical homes and other coordinated care models provide new opportunities to improve care and treatment services for individuals who have been diagnosed with HCV infection, medical homes that generally focus on treating individuals with other chronic illnesses, particularly mental health and substance use, could also be important opportunities to encourage HCV screening and testing.

Finally, payment reform also includes some initiatives that may help to reduce the burden of administration, such as standardizing prior authorization forms.⁵¹⁷ In addition, the new payment reform legislation establishes a commission to examine the fairness of public payment reimbursement rates and their effect on providers and services.⁵¹⁸ Through all these efforts, advocates and treatment providers must work with MassHealth and other insurers to ensure that reimbursement for all of the required health home services is truly adequate to cover the services involved for treating individuals with HCV.⁵¹⁹ This will also be true for chronic disease case management services that may be included in private healthcare plans through the Essential Health Benefits (EHB) package.

Advocate for State Funding for the ECHO Model

The ECHO model provides an important opportunity to offer integrated HCV treatment services through primary care clinicians and/or community health centers, and advocates should push for the development of sustainable funding mechanisms, as insurers do not currently reimburse this model. Initially, the ECHO project in New Mexico was funded by grants from the Agency for Healthcare Research and Quality (AHRQ) and grants from the Robert Wood Johnson Foundation. In New Mexico, the project also receives more than \$1 million from the state legislature to help support its HCV work statewide. Currently, the Beth Israel project receives funding from the Robert Wood Johnson Foundation, in addition to federal money from the Health Resources and Services Administration (HRSA).⁵²⁰ In order to ensure that ECHO becomes sustainable, it will be important for providers and insurers, particularly MassHealth, to work together to find appropriate ways

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to provide reimbursement for this project, potentially in conjunction with the health home model described earlier. This should be an appealing prospect for insurers, as it has the potential to save money on patients who would otherwise require individual specialty care appointments. As with medical homes, advocates should also explore new opportunities created by the payment reform legislation that focus on the development and use of innovative healthcare technology and telemedicine.

Advocate for a Supportive Services Program for People with HCV

Even comprehensive health services and adequate reimbursement may not be enough to address issues that low-income persons living with HCV infection face as far as access to case management, food, and housing. To address these issues, advocates should create a program of supportive services for people with HCV infection that includes case management, food and housing support, as well as other services, using the Ryan White Program as a model. There is a significant overlap in need between people living with HIV and people living with HCV. Indeed, MDPH has recognized this overlap and utilized the existing HIV care and support services infrastructure for its HCV programs. Many of these programs serve clients who are HIV-infected, coinfecting, and monoinfected with HCV.

At the same time, while the Ryan White Program is an excellent model in many respects, the needs of persons monoinfected with HCV are not necessarily the same as those of persons living with HIV, and therefore the model will need to be adapted to fit the unique needs of the HCV community. For example, unlike HIV, people with HCV may be asymptomatic for many years, and may never actually need treatment. For those who do initiate treatment, more short-term intensive services may be appropriate; for example, short-term housing, transportation, and income support programs for the duration of treatment. Similarly, other individuals may not be viable candidates for treatment or may be treatment resistant, and therefore may need support systems in place as they live with the illness, as well as social support in coping with the realization that treatment was not effective.

Instead of creating a separate program, advocates could also explore the possibility of including some of these services as part of public and private insurance coverage. To help make the case for coverage by insurers, advocates should investigate the cost-effectiveness of providing these services for a specific duration while an individual undergoes treatment, versus the costs of managing a lifelong chronic illness, the costs of end-stage liver disease, and/or the costs of a liver transplant. Another factor in the cost-effectiveness calculation is that individuals with HCV may essentially be cured, reducing the possibility of transmitting the virus to others and overall incidence of the disease.

For some populations, advocates should also consider using the home health aide benefits that may be available to individuals living with HCV who may be too sick to access care at a provider's office.⁵²¹ Home health aides are a service offered to individuals on certain types

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of MassHealth and CommCare. Home health aides provide care (such as administering an interferon injection) to individuals directly in their homes, including temporary housing facilities such as shelters. Unfortunately, there will also be some individuals living with HCV infection who are too sick to be eligible for antiviral treatment and/or liver transplants. For those individuals, referrals to palliative and/or hospice care should be considered.

Finally, advocates should investigate any existing housing or food programs that could be used to provide services (even temporarily) to individuals undergoing HCV treatment. For example, the North Shore Health Project applies annually for Tenant-Based Rental Assistance (TBRA) funding from its local HOME consortium (which in turn receives monies from the US Department of Housing and Urban Development [HUD]).⁵²² The TBRA funds are used by the North Shore Health Project for a specific program that provides temporary housing (up to a year) for individuals on the verge of homelessness who are living with HCV infection and preparing for, undergoing, or recovering from HCV treatment.⁵²³ Similar funding opportunities may be possible through other community-based HUD programs.

Expand and Build Upon the Existing Hepatitis C Strategic Plan

In 2001, the Massachusetts Viral Hepatitis Advisory Committee released a 2001-2005 strategic plan to address hepatitis C in Massachusetts, with recommendations similar to many of those made in this report (see Appendix C). An updated strategic plan draft is currently in development, but many community members seem unaware that this is in progress. Advocates should play a larger role in providing input for the plan and MDPH should make even greater efforts to include community-based organizations, other state bureaus and agencies (such as the Department of Mental Health, BSAS, and the Department of Corrections [DOC]), substance use disorder providers (and/or the Association for Behavioral Healthcare [ABH]), members of the Massachusetts Organization for Addiction Recovery (MOAR), and the Massachusetts League of Community Health Centers (MLCHC), among others. The strategic plan should set specific goals and time frames, and advocates should consider more broadly publicizing the strategic plan to help generate additional buy-in as well as structures for accountability. This plan could also be used as an advocacy tool to generate additional funding.

Create a Statewide HCV Consumer Advisory Board

To help address concerns around awareness and improve access to care, MDPH should consider implementing a consumer advisory board comprised of individuals living with HCV and those who have been through treatment. Currently, Massachusetts already has a statewide consumer advisory board for persons living with HIV and AIDS (SWCAB) that meets on a monthly basis to “provide advice to the staff and senior management of MDPH Office of HIV/AIDS (OHA) about policies and programmatic issues affecting the lives of consumers and individuals at risk.”⁵²⁴ An HCV consumer advisory board would have a similar function and ensure greater visibility and attention to HCV issues. The

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advisory board could also participate in creating and presenting educational seminars on viral hepatitis to bring to providers. Like SWCAB, the composition of the consumer advisory board should reflect the demographics of the epidemic in Massachusetts, and ideally include young people (ie, HCV-infected persons between ages 18 and 25 years), incarcerated persons, veterans, and members of the IDU community. The board could report to the Bureau of Infectious Disease (BID), but also meet regularly with BSAS, the Department of Mental Health, the DOC, and the US Department of Veterans Affairs.

PREVENTION, TESTING, AND TREATMENT FOR INCARCERATED INDIVIDUALS

Compared to the general population, there is a much higher prevalence of HCV infection among incarcerated individuals, largely due to the high number of inmates who have engaged in injection drug use and other high-risk behaviors. Nationally, it is estimated that 16-41% of incarcerated persons have been infected with HCV, with 12-35% chronically infected.⁵²⁵ Correctional facilities are thus an important setting to provide viral hepatitis education, testing, HAV/HBV vaccination, and treatment to high-risk populations.

In Massachusetts, there are two concurrent systems of incarceration for adults: county jails and Houses of Correction (HOCs), run individually by each county, and the state prisons, run by the Massachusetts Department of Corrections (DOC). Currently, Massachusetts operates 13 HOCs (with additional local jails) and 17 state prisons, as well as additional medical and substance use disorder treatment facilities. In general, inmates awaiting trial or who are serving terms that are less than 2.5 years are housed in HOC facilities, while inmates serving longer sentences are sent to state prison. While each county is responsible for procuring its own health services to serve inmates at HOC facilities and jails, the DOC contracts with the Correctional Health Program of the UMass Medical School for the majority of its healthcare services, with some additional services provided by Lemuel Shattuck Hospital.⁵²⁶

As of December 17, 2012, there were 11,648 inmates in jails and HOC facilities, and 11,148 individuals housed in DOC facilities.⁵²⁷ While the number of individuals living with HCV in HOC facilities is unknown, there were approximately 1,983 inmates living with HCV infection in Massachusetts DOC facilities as of November 2012.⁵²⁸ HCV may be much more prevalent among women in DOC facilities than men: a 2001 study suggests that seropositivity is 43.9% for women, compared to 27.3% for men.⁵²⁹

As with all providers, considerations for treatment include a variety of health factors, including symptoms and signs of decompensated cirrhosis, pregnancy, and other factors.

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With regards to substance abuse and mental health, criteria within the DOC include:

- No history of injection drug use or alcohol use within 12 months;
- Documented history, if applicable, of substance abuse treatment; and
- No current major depression (if current depression, must have psychiatry input).⁵³⁰

Prior to initiating treatment, inmates must complete a “one-year period of demonstrated compliance with medical and mental health treatment plans, as well as social compliance . . . to ensure that the inmate-patient has the stability and reserve to withstand the rigors of treatment,” and part of the criteria for treatment includes “within past year, evidence of social, medical treatment plan, and mental treatment plan compliance.”⁵³¹ For “social noncompliance” to have an effect on beginning and/or continuing treatment, “a documented pattern must exist to bring into question the inmate’s ability to comply with treatment expectations.” For example, tattooing in the prison setting or continued drug use is considered by DOC to put the patient at risk for coinfection with HIV, other forms of hepatitis, and/or other infections and could be considered “social noncompliance.”⁵³²

After one year, inmates are set up for an initial appointment with a gastroenterologist and assigned to an Infectious Disease (ID) case manager. The ID case managers are an important resource for the inmates and provide comprehensive education about their illness, including possible side effects from treatment. Liver panels and other tests are performed as needed, and a mental health evaluation is conducted. After their initial lab results, their ID manager will meet with them to discuss the results and the inmate will meet again with the gastroenterologist. A team-based decision is then made about whether to recommend the inmate for treatment. The DOC reports that typically inmates will begin treatment within 2 months of a recommendation.⁵³³

As of December 2012, there were 24 patients receiving anti-HCV medication, with 120 inmates awaiting treatment.⁵³⁴ Individuals who are waiting currently do not meet clinical guidelines for immediate treatment, meaning they are asymptomatic or are otherwise “safely waiting.”⁵³⁵ More follow-up research is needed to understand whether the other inmates currently living with HCV in DOC facilities are also seeking treatment, and/or whether these current treatment policies are adequate.

Successful Policies That Aim to Increase Access to Care for Inmates

County-Level Correctional Screening and Testing: Barnstable County Pilot Project

Although each county has different policies, a pilot project between Barnstable County, the Sheriff’s Department, and MDPH’s Bureau of Infectious Disease demonstrated high rates of success in testing and linkage to care for county inmates who are offered HCV testing in conjunction with HIV testing. Beginning in July 2009, OHA provided funding for

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a pilot program to integrate HCV antibody testing with HIV screening in the Barnstable County jail and HOC. Through this project, all inmates and detainees were first offered access to both HIV and HCV antibody testing during their mandated intake screening, and were periodically offered testing thereafter. The project also enabled the facility to offer HIV and hepatitis education programs for the general inmate population, as well as to provide more targeted support services for persons found to be HCV-positive.

Over the first 17 months of the pilot program, MDPH found that offering concurrent HCV and HIV screening was a highly accepted intervention (with 22% of inmates accepting the test), and was an effective way to identify HCV-positive individuals (of those tested, 20% were positive). Of those testing HCV antibody-positive, nearly half (49%) had reported injection drug use and 40% of inmates and detainees reported having injected in the past 12 months. In addition, many of the HCV-positive inmates (43%) were young injection drug users (IDUs) between ages 18-29 years. The results from this program indicate that county and jail settings can play an important role in identifying HCV in young IDUs as well as undiagnosed HCV in the general inmate/detainee population.⁵³⁶

Because of the relatively short period of incarceration, Barnstable (like most other counties) generally does not offer HCV treatment to individuals unless they are coinfecting with HIV. However, this project does enable Barnstable HOCs to facilitate linkages to community-based providers from Infectious Disease Clinical Services (IDCS) and Duffy Health Center (Duffy) for inmates during their incarceration and to continue these linkages as part of the discharge process. As a result, preliminary data indicate that about 38% of HCV-positive inmates who were released followed up with an initial appointment at Duffy after release.⁵³⁷ However, these data also highlight that 62% of these individuals did not have any evidence of follow-up care post-release, and therefore may suggest a need for additional reintegration case management support for HCV-positive inmates upon release.

In recognition of these implications, MDPH had hoped to expand the number of HOCs throughout the state offering similar HCV screening and testing programs, but unfortunately, due to funding cuts, it is unclear whether any other additional counties will be able to implement similar initiatives.⁵³⁸

Screening and Testing Through the Department of Corrections

As recommended by Centers for Disease Control and Prevention (CDC) guidelines,⁵³⁹ the DOC administers a risk-based screening process to assess incarcerated individuals entering its facilities who should be referred for HCV testing. Prior to entering the general population, all individuals serving sentences through the DOC are given an initial medical screening, followed by a physical examination within 7 days.⁵⁴⁰ During the initial screening

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process, the nurse performing the screening administers a brief (3-minute) questionnaire related to HCV risk factors, including questions about prior injection drug use. If risk factors have been identified in the screening, the nurse or the physician conducting the subsequent physical examination may recommend that the inmate receive HCV testing. Persons who test positive are referred, based on “clinical acuity, for acute or chronic follow-up care.”⁵⁴¹

The questionnaire has also been effective at identifying a large percentage of recently incarcerated inmates in Massachusetts (who are new drug users) with acute infection.⁵⁴² Further research has also demonstrated the efficacy of treatment of inmates with acute HCV infection in Massachusetts’ correctional settings, and publication of additional research is forthcoming.⁵⁴³

However, additional follow-up is needed to confirm this screening process is happening consistently for all inmates. In addition, with the recent release of the new CDC age-based screening guidelines, the DOC will need to adapt its screening procedures to ensure that all inmates within the baby boomer generation receive the recommended one-time test.

Challenges

Limited Access to Health Education

Health educational classes offered at DOC and HOC facilities vary considerably. In Suffolk County, the county partners with MDPH and provides mandatory HIV education classes. As discussed above, Barnstable also offers health education classes, but they are voluntary. DOC also offers a health awareness (HIV/AIDS education) program, but it is not offered at every facility and it is not mandatory.⁵⁴⁴ The class is taught in part by peers, who themselves have received training through a selective 12-week peer-training program, where they learn basic information about HIV/AIDS, HCV, safe sex, harm reduction, TB/MRSA, and personal care. In order to take the class, inmates must be on good behavior, and class size is limited due to funding and restrictions on the number of inmates who can be assembled in one place at a given time. At some facilities there are wait lists for individuals who wish to take health classes.

Limited Funding and Increasing Costs

As previously discussed, the new protease inhibitors are extremely expensive. Incorporating these new drugs is expected to increase costs of HCV treatment for incarcerated individuals from \$18,000 to \$35,000–\$65,000 per individual.⁵⁴⁵ In addition, as of January 1, 2012, 38.8% of the DOC jurisdiction population was between ages 40-60 years, and 6% were over age 60, indicating a large population of baby boomers.⁵⁴⁶ If the DOC follows CDC recommendations to do a one-time test of all individuals in the baby boomer generation regardless of the presence of risk factors, costs for testing will likely increase and may identify significantly larger numbers of infected individuals who need treatment.

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While healthcare expenditures and funding for the DOC have remained relatively stable over the past 2 years,⁵⁴⁷ the DOC did experience recent cuts in funding from MDPH due to a decrease in federal funds.⁵⁴⁸ This decrease may result in lower availability of hepatitis A and B vaccinations to HOC and DOC inmates, as well as fewer health education classes.⁵⁴⁹ In addition, the facilities operations budget also experienced a cut of about \$19.5 million from FY2009 to FY2012.⁵⁵⁰

Opportunities to Improve Access to Care for Inmates

Increase Treatment Access

As of December 13, 2012, the DOC had implemented updated treatment guidelines that included all currently available medication therapies (which presumably includes the new protease inhibitors), and was in the process of evaluating patients for treatment under these new guidelines.⁵⁵¹ This is an important and exciting stepping stone to ensure access to the most current treatments for inmates, and advocates should follow up and monitor implementation of these new guidelines. At the same time, because the treatments available for individuals living with HCV are expected to change rapidly over the next several years, it will be critical that the DOC has policies that can be responsive to these new treatment developments so that inmates can access them as soon as they become available. For example, while the FDA approved the new protease inhibitors in spring 2011, treatment for individuals within the DOC did not include access to these newer drugs until December 2012. In general, more research is needed to understand access to treatment (and the reasons for any lack of access) in DOC facilities and/or whether it could be improved. For example, advocates may want to consider whether a 1-year period of “demonstrated compliance with medical and mental health treatment plans, as well as social compliance” is really a necessary standard, although it should be noted that the DOC maintains that there are legitimate medical concerns related to this standard, and that its goal is always to ensure successful completion of therapy and virologic cure.⁵⁵²

Given the cost of the new drugs as well as those that may become available in the future, access to treatment may be affected by limited resources, and advocates should mobilize for increased funding for HCV treatment (including additional ID case managers as needed) and educational services offered at DOC facilities to ensure that inmates have access to treatment at the same levels as the general population. Incarceration can be a unique period of stability for some individuals and prison provides a very structured, sober environment with multiple support systems to help ensure adherence, which may lead to high rates of treatment success.⁵⁵³ Research by Barbara McGovern and others for example has demonstrated the efficacy of both identifying and administering HCV treatment to inmates with acute infection, as well as successful treatment of individuals who are coinfecting with HCV and HIV.

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Increase Access to Educational Programs

Because of the high prevalence of HCV risk factors among the prison population, advocates should push for both HOC and DOC facilities to expand access to viral hepatitis education classes for all inmates (not just those considered to be at risk). The DOC reports that “efforts are underway to increase capacity to accommodate more inmate-patients for the classes,” but it will be important for advocates to follow up to ensure accountability.⁵⁵⁴ Further, advocates should push for health education, which includes HCV and other health concerns, to be made mandatory for all inmates, not only for those considered to be at risk.

Although funding for such programs is currently limited, one option for increasing access to HCV education through both county and state facilities is to facilitate a partnership with the American Liver Foundation (ALF) New England Chapter. The ALF is able to offer HCV education classes free of charge to inmates (and other individuals) in Massachusetts, and staff from the ALF recently met with staff from MDPH to discuss this possibility. Particularly if no increased funding is available, partnering with the ALF could be an important opportunity to offer more widespread HCV prevention education to all inmates while keeping costs low.

The DOC should also consider expanding its current peer-education program. Peer-education programs for inmates have been shown to be a highly successful intervention; for example, the Peer Health Education Program (PHEP) is a successful program run in select facilities in California to educate prisoners about HCV.⁵⁵⁵ The program includes a variety of materials, presentations, and trainings (including “Hepardy,” a Jeopardy-like game that incorporates information on HCV), and its materials could enhance the curriculum currently being offered through the DOC. Moreover, while funding may not be available to fully expand educational opportunities to all inmates, by focusing on peer trainings, inmates may be able to pass along prevention and harm reduction information to other inmates in more informal settings.

Expand Access to Treatment for Inmates With Shorter Sentences Through Initiation of Programs to Link HCV-Positive Inmates to Continued Care Post-Release

For inmates whose sentences may be considered too short for initiation of antiviral treatment during their incarceration, another possibility would be to offer treatment initiation to inmates who are close to release and provide a supportive follow-up referral. A similar model is currently being piloted in New York.⁵⁵⁶ Through New York’s program, individuals who have shorter sentences are given the option to begin treatment while incarcerated, but are also directly linked with a provider in the community where they will be reintegrating. Just prior to release, HCV-infected inmates are given the opportunity to initiate antiviral therapy, and are enrolled in Medicaid as part of their pre-release services. When inmates are released, they are given a 2-week supply of ribavirin medication, and

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the community partner provider is given a 2-week supply of the individual's interferon injection. (Participating providers must have an available follow-up appointment within 2 weeks of an inmate's release.) To facilitate linkage to the partner provider and ensure continuity of care, the inmate's parole officer is also given information about the inmate's HCV treatment as well as the community partner provider. The parole officer is then able to provide assistance with adherence, along with other post-release services such as housing and social service assistance.

Like New York, Massachusetts already has a system in place for enrolling inmates in MassHealth (Medicaid) prior to release, and creating a similar hepatitis program could help link more inmates to HCV treatment without the DOC ultimately having to bear the full costs of the drugs.

Another option for Massachusetts could be to build upon existing pre- and post-release programs that are in place for individuals with HIV. MDPH currently funds five Corrections to Community programs (CTCs) that provide case management and services for individuals who are HIV+ as they are reintegrated back into communities.⁵⁵⁷ The programs are designed to promote continued engagement in care and treatment by working with inmates for both pre-release planning and post-release follow-up. With additional funding, this model could be expanded to include individuals who may be monoinfected with HCV.

Explore Options for Education and Testing Interventions Through the Department of Youth Services

Given the recent increase in HCV infection among young injection drug users, advocates and state officials should also investigate what types of viral hepatitis programming (if any) exist among Department of Youth Services (DYS) programs. Like DOC inmates, there may be a large number of youth in DYS custody who are at risk. For example, in 2009, there were 57 youths who were committed to DYS for drug-related charges.⁵⁵⁸ Currently, DYS operates 54 residential facilities and 28 programs that provide services to youth in community settings. As of January 1, 2011, there were 1,288 youths committed to DYS.⁵⁵⁹ All youths who are committed receive HIV/STD risk-reduction education,⁵⁶⁰ and all are screened for potential substance use disorder needs. Depending on the results of the screening, all youths are either referred for substance use disorder treatment or placed on a prevention track that also includes education.⁵⁶¹ MDPH officials and advocates should work with DYS to explore whether hepatitis education is (or could be) included in these initiatives.

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HEPATITIS C DEMOGRAPHICS IN MASSACHUSETTS

Massachusetts tracks both probable cases (where only an initial antibody test has been performed with a low or unclear signal to cutoff ratio), and confirmed cases (where the initial antibody test had a high signal to cutoff ratio and/or an additional confirmatory test has also been reported). More detailed demographic data are available for cases of confirmed chronic HCV, among which the following breakdowns apply:

Race and Ethnicity—Confirmed Cases⁵⁶²

In 2011, the highest number of confirmed chronic HCV infections occurred among whites:

Race	Number
White	4,132
Black African American	402
Other	504
Unknown	556

Ethnicity	Number
Non-Hispanic	2,580
Hispanic	605
Unknown	5,234

Geography—Confirmed Cases⁵⁶³

There are HCV cases in almost every county in Massachusetts, but there is significant geographic variation. The numbers of reported confirmed chronic HCV infections by county in 2011 were as follows (in descending order):

1. Middlesex (789)
2. Suffolk (607)
3. Essex (557)
4. Worcester (477)
5. Hampden (454)
6. Bristol (368)
7. Norfolk (332)
8. Plymouth (324)
9. Cape Cod (208)
10. Berkshire (96)
11. Hampshire (60)
12. Franklin (38)

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The incidence rates (per 100,000 population) also varied by county. Rates for reported confirmed chronic HCV infections by county in 2011 were as follows (in descending order)⁵⁶⁴:

1. Hampden (97.952)
2. Cape Cod Counties (85.74)
3. Suffolk (84.069)
4. Essex (74.95)
5. Berkshire (73.16)
6. Bristol (67.118)
7. Plymouth (65.465)
8. Worcester (59.733)
9. Franklin (53.242)
10. Middlesex (52.492)
11. Norfolk (49.489)
12. Hampshire (37.955)

Demographics – Adolescents and Young Adults (Aged 15-25 Years)

Race and Ethnicity—All Reported Cases⁵⁶⁵

As in the general HCV-infected population, the highest number of confirmed infections in this age group occurred among non-Hispanic whites. Among newly reported cases from 2007-2010, the following breakdowns apply (n=3,692):

Race	Number
White	2,144
Black African American	74
Asian	31
American Indian Alaskan Native	10
Hawaiian/Pacific Islander	2
Other	107
Ethnicity	Number
Hispanic	175

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Geography–Youth Confirmed Chronic Cases

As in the general population, there are HCV cases among youth in every county in Massachusetts, but there is significant geographic variation. The number of reported confirmed cases by county in 2011 were as follows (in descending order):⁵⁶⁶

1. Middlesex (140)
2. Essex (83)
3. Plymouth (71)
4. Worcester (71)
5. Norfolk (71)
6. Suffolk (62)
7. Bristol (62)
8. Barnstable (49)
9. Hampden (46)
10. Berkshire (19)
11. Hampshire (8)
12. Franklin (7)
13. Dukes (<5)
14. Nantucket (0)

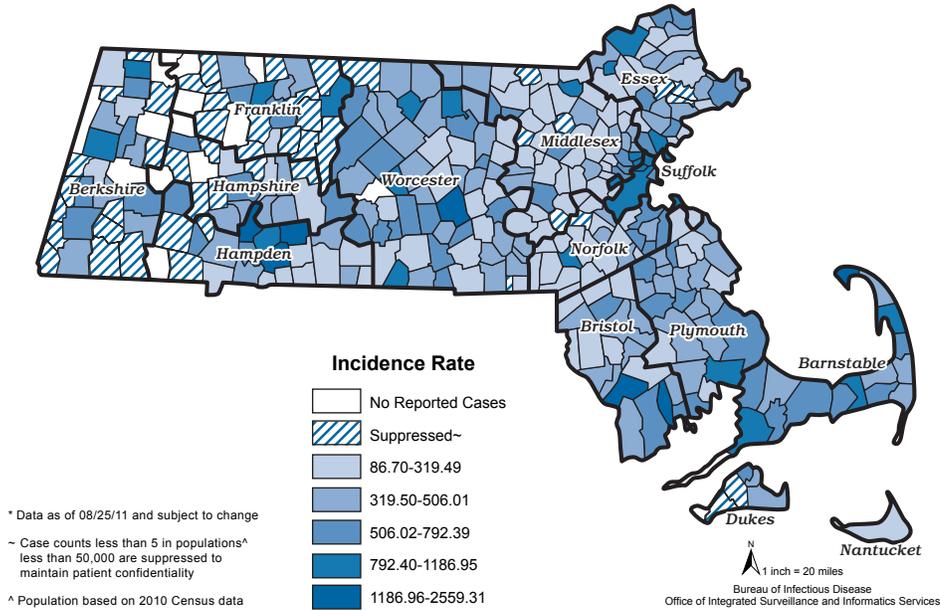
The incidence rates also vary, with higher rates in Barnstable, Plymouth, and Berkshire counties. The rates per 100,000 population per county in 2011 were as follows (in descending order):⁵⁶⁷

1. Barnstable (251.8)
2. Plymouth (130.32)
3. Berkshire (110.94)
4. Norfolk (102.75)
5. Essex (100.15)
6. Bristol (92.195)
7. Franklin (79.491)
8. Middlesex (76.944)
9. Worcester (75.908)
10. Hampden (74.088)
11. Suffolk (49.242)
12. Hampshire (22.849)
13. Nantucket (0)

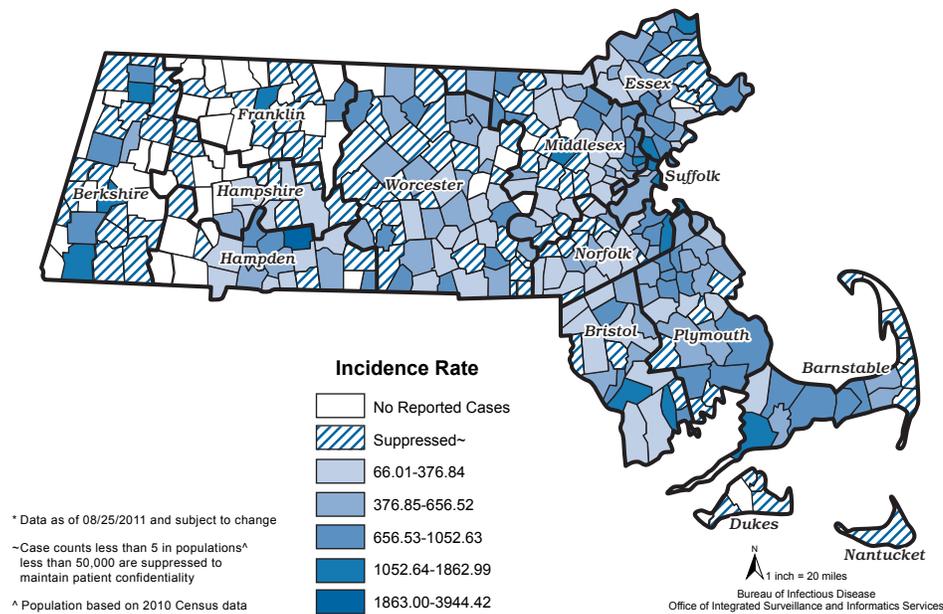
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Maps of the HCV Incidence Rate (Broken Down by Age Group) Over the Past 4 Years:

Incidence Rates (per 100,000 population[^]) for Confirmed and Probable Hepatitis C Among 30+ Year Olds in Massachusetts 2006-2010*



Incidence Rates (per 100,000 population[^]) for Confirmed and Probable Hepatitis C Among 13-29 Year Olds in Massachusetts 2006-2010*



Adapted from maps provided by the Massachusetts Department of Public Health.

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PREVENTION, INTERVENTION, COUNSELING, SCREENING, AND REFERRAL TO CARE AND/OR TREATMENT SITES

PICSR Sites

- Berkshire Medical Center
- Boston Children's Hospital
- Boston Health Care for the Homeless Program
- Cambridge Public Health
- East Boston Neighborhood Community Health Center
- Edward M. Kennedy Community Health Center
- Greater Lawrence Family Health Center
- Greater New Bedford Community Health Center
- Holyoke Health Center
- Justice Resource Institute
- Manet Community Health Center
- MAPS/Health Innovations
- Massachusetts General Hospital
- Tapestry Health Systems

PICSR-T Sites

- Baystate Medical Center
- Boston Medical Center
- Brockton Neighborhood Health Center
- Cape Cod Hospital/IDCS
- Fenway Health
- Lowell Community Health Center
- Lynn Community Health Center
- Stanley Street Treatment and Resource Center

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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.

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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.

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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

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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.
- 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.

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- 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.

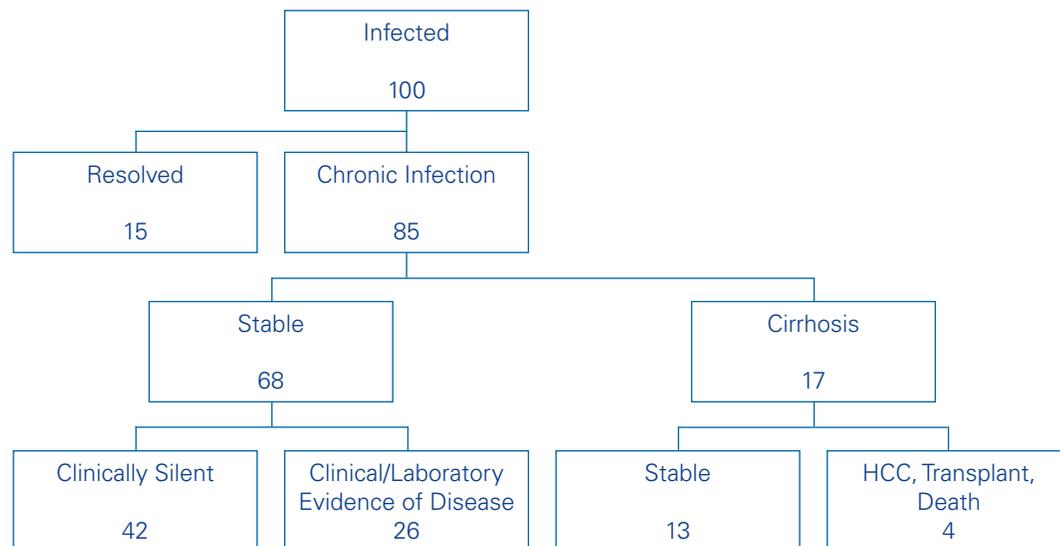
An important component of the hepatitis C activities of MDPH has been the establishment and functioning of the Hepatitis C Advisory Committee. First convened in April 1999, the committee is made up of consumers, providers, representatives of agencies and organizations with interest and involvement in 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 MTHE DEPARTMENT, 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.

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Natural History of HCV Infection Summary



Massachusetts Department of Public Health

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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. 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. 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.

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- 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

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populations served by the Department of Public Health and other state agencies. 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.

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- 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.

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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.

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- 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. 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 B and hepatitis C infection in order to address this problem more effectively among communities at higher risk of hepatitis C.

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- 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. MDPH 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. The department, through its Clinical Laboratory Program of the Bureau of Health Quality Management, oversees clinical laboratories and MDPH in 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.

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- 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

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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 MTHE DEPARTMENT-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. MTHE DEPARTMENT-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.

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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.

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- 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.

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- 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.

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- b. While convening and facilitating discussion among stakeholders, 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. MTHE DEPARTMENT-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.

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- 390 For information on Massachusetts' transition through federal health care reform, see Massachusetts Executive Office of Health and Human Services, *Masshealth: Roadmap to 2014, Affordable Care Act Transition Plan (DRAFT)*, available at <http://www.masslegalservices.org/content/masshealth-roadmap-2014-affordable-care-act-transition-plan-draft> (July 1, 2012); note that the components of federal health reform and state implementation are constantly changing – for updated information on the Massachusetts transition, *see also*: Massachusetts Executive Office of Health and Human Services, *Federal Health Care Reform website*: <http://www.mass.gov/eohhs/provider/guidelines-resources/services-planning/national-health-care-reform-plan>; materials from the public stakeholder program (with information on the process so far) can also be found at <http://www.mass.gov/eohhs/provider/guidelines-resources/services-planning/national-health-care-reform-plan/stakeholder-meetings/previous-quarterly-stakeholder-meetings.htm> (last visited December 12, 2012); Kaiser Family Foundation, *Massachusetts Health Care Reform: Six Years Later*, available at <http://www.kff.org/healthreform/upload/8311.pdf> (May 2012).
- 391 For information on Massachusetts' Essential Health Benefits benchmark selection (as well as those of other states), see: Centers for Medicare & Medicaid Services, Center for Consumer Information & Insurance Oversight, *Additional Information on Proposed State Essential Health Benefits Benchmark Plans*, available at <http://www.mass.gov/eohhs/provider/guidelines-resources/services-planning/national-health-care-reform-plan/stakeholder-meetings/previous-quarterly-stakeholder-meetings.htm> (last visited December 12, 2012).
- 392 Massachusetts Executive Office of Health and Human Services, *How Does Healthcare Reform Affect You?*, available at <http://www.mass.gov/eohhs/gov/commissions-and-initiatives/healthcare-reform/national-health-care-reform-plan/how-does-health-care-reform-affect-you.html>.
- 393 Interview with Catherine O'Connor, clinical director, Health Innovations, Faculty Member, Bouve College School of Nursing, Northeastern University, August 3, 2012; interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012.
- 394 Interview with Tracy Cheattle, Harm Reduction counselor, Tapestry Health Services, January 26, 2012; interview with Liz Whynott, Harm Reduction counselor, Tapestry Health Services, January 24, 2012.
- 395 Massachusetts Medical Society, *2012 MMS Patient Access To Care Studies*, at 5, available at http://www.massmed.org/AM/Template.cfm?Section=Research_Reports_and_Studies2&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=74671 (August 2012).
- 396 Interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012; interview with Dr. Mireya Wessolowsky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012; interview with Tracy Cheattle, Harm Reduction counselor, Tapestry Health Services (January 26, 2012); Interview with Liz Whynott, Harm Reduction counselor, Tapestry Health Services, January 24, 2012; interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012.
- 397 Massachusetts Medical Society, *2012 MMS Patient Access To Care Studies*, at 18, available at http://www.massmed.org/AM/Template.cfm?Section=Research_Reports_and_Studies2&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=74671 (August 2012).
- 398 Interview with Tracy Cheattle, Harm Reduction Counselor, Tapestry Health Services, January 26, 2012; interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012; transportation may also be a barrier even in Boston: interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012.
- 399 Interview with providers at Infectious Disease Clinical Services (IDCS), April 4, 2012.
- 400 Interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012; interview with Pauline Himlan, University of Mass Memorial Healthcare at Fitchburg Health Center, August 14, 2012.
- 401 Interview with Catherine O'Connor, clinical director, Health Innovations, Faculty Member, Bouve College School of Nursing, Northeastern University, August 3, 2012.
- 402 Dr. James Morrill, primary care, Charlestown Community Health Center, The MGH Community Hep C Program: *A Distant Echo?*, presentation to the Massachusetts Viral Hepatitis Coalition, June 5, 2012.

notes and references

- 403 The antibody tests are what PICSR and PICSRT sites are able to offer. This test indicates that an individual has been exposed to hepatitis C, but does not necessarily mean the individual has the virus. In order to confirm presence of the virus, additional testing is needed at a medical facility.
- 404 *Eg*, interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Lee Thornhill, director of prevention and education, Cambridge Cares About AIDS, AIDS Action Committee, February 10, 2012.
- 405 Association for Behavioral Healthcare, Acute Treatment Services (ATS) committee meeting on June 5, 2012.
- 406 Interview with Pauline Himlan, University of Mass Memorial Healthcare at Fitchburg Health Center, August 14, 2012; interview with Raul Matta, program director, Center for Education, Prevention and Action (CEPA) Holyoke Health Center, August 2, 2012.
- 407 Interview with Katie Boos, associate director of Health Information and Training, AIDS Action Committee, February 3, 2012.
- 408 *Eg*, interview with Catherine O'Connor, clinical director, Health Innovations, Faculty Member, Bouve College School of Nursing, Northeastern University, August 3, 2012; interview with providers at Infectious Disease Clinical Services (IDCS), April 4, 2012.
- 409 *Eg*, Interview with Marilyn Rodriguez, HIV Counseling and Testing coordinator, AIDS Project Worcester, July 27, 2012.
- 410 Interview with Dr. Mireya Wessolossky, University of Massachusetts Memorial Health Care, July 16, 2012.
- 411 Interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, February 7, 2012; interview with Larry Day, manager, HIV Health Promotion, AIDS Action Committee, January 20, 2012; conversation with Maryanne Frangules, executive director, Massachusetts Organization for Addiction Recovery (MOAR), June 21, 2012; interview with Sarah Mackin, program coordinator, Harm Reduction Services, Boston Public Health Commission, January 19, 2012; interview with Adam Butler, Addicts Health Opportunity Prevention Education (AHOPE), Boston Public Health Commission (BPHC), January 25, 2012; interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012.
- 412 *See eg*, H.S. Yee, et al., Update on the management and treatment of HCV virus Infection: recommendations from the Department of Veterans Affairs HCV Resource Center Program and the National HCV Program Office. *Am J Gastroenterol.* 2012;107(5):669-689; M.G. Ghany, et al., Diagnoses, Management and Treatment of Hepatitis C: an Update; Practice Guideline by the American Association for the Study of Liver Diseases. *Hepatology.* 2009;49(4):1335-1374; M.G. Ghany, et al., An Update on Treatment of Genotype 1 Chronic Hepatitis C Virus Infection: 2011 Practice Guideline by the American Association for the Study of Liver Diseases. *Hepatology.* 2011;54(4):1433-1444.
- 413 Many providers are aware that more advanced treatments for HCV are expected within the next few years.
- 414 V.V. Thompson, et al., Provider assessment of eligibility for HCV treatment in HIV-infected homeless and marginally housed persons. *AIDS.* 2005;19(suppl 3):S212-213.
- 415 In 1997, the National Institutes of Health (NIH) published a Consensus Development Conference Statement on the Management of Hepatitis C. In this statement, the NIH specifically recommended that treatment of persons who were drinking significant amounts of alcohol or who were actively using illicit drugs should generally not be initiated until the individual had abstained from these activities for at least 6 months, as these patients were at risk for "potential toxic effects of alcohol and other drugs and also present problems with compliance." See National Institutes of Health, *Management of Hepatitis C, Consensus Development Conference Statement*, Mar. 24-26 (1997).
- 416 In 2002, the NIH updated the 1997 statement to indicate that treatment had been successful in some individuals who had not abstained from continued alcohol or drug use. The statement therefore recommended that active injection drug users be evaluated for treatment on an individual basis, noting that active injection drug use in and of itself should not be used to exclude patients from treatment. See National Institutes of Health, *NIH Consensus Statement on Management of Hepatitis C: 2002*. The American Association for the Study of Liver Disease (AASLD) made a similar recommendation in its updated 2009 guidelines.
- 417 M.G. Ghany, et al., Diagnoses, Management and Treatment of Hepatitis C: an Update; Practice Guideline by the American Association for the Study of Liver Diseases. *Hepatology.* 2009;49(4):1362; H.S. Yee, et al., Update on the Management and Treatment of HCV Virus Infection: Recommendations From the Department of Veterans Affairs HCV Resource Center Program and the National HCV Program Office. *Am J Gastroenterol.* 2012;107(5):669-689.

notes and references

- 418 For some people with substance use disorder or mental health issues, even just going through the process of the evaluation, particularly if it requires trips to multiple different providers, can be too overwhelming; eg, interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012; interview with Dr. Mireya Wessollosky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012. As is discussed throughout the report, there can also be medical and structural barriers even for those without substance use disorders or mental health issues. See for example, Shruti H. Mehta, *Why We Fail To Treat HCV*, Presentation Slides, (April 27, 2011).
- 419 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, February 7, 2012; interview with Dr. Mireya Wessollosky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Gary Langis, hepatitis advocate, January 10, 2012; interview with Lee Thornhill, director of Prevention and Education, Cambridge Cares About AIDS, AIDS Action Committee, February 10, 2012; interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012.
- 420 Note that these practices do not necessarily employ these policies, but may have heard of other providers who do; interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, February 7, 2012; interview with Dr. Mireya Wessollosky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012; interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012; interview with Lee Thornhill, Director of Prevention and Education, Cambridge Cares About AIDS, AIDS Action Committee, February 10, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012; interview with Dr. Bill Shay, Outer Cape Health Services, August 3, 2012.
- 421 Interview with provider at Lawrence Community Health Center, June 22, 2012.
- 422 Note that these practices do not necessarily employ these policies, but may have heard of other providers who do; interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Lee Thornhill, director of Prevention and Education, Cambridge Cares About AIDS, AIDS Action Committee, (February 10, 2012); Interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012; interview with Catherine O'Connor, clinical director, Health Innovations, faculty member, Bouve College School of Nursing, Northeastern University, August 3, 2012.
- 423 Eg, interview with Catherine O'Connor, clinical director, Health Innovations, faculty member, Bouve College School of Nursing, Northeastern University, August 3, 2012.
- 424 Interview with Larry Day, manager, HIV Health Promotion, AIDS Action Committee, January 20, 2012; conversation with Maryanne Frangules, executive director, Massachusetts Organization for Addiction Recovery, (MOAR), June 21, 2012; interview with Tracy Cheatle, Harm Reduction Counselor, Tapestry Health Services, January 26, 2012; interview with Liz Whynott, Harm Reduction counselor, Tapestry Health Services, January 24, 2012; interview with Sarah Mackin, program coordinator, Harm Reduction Services, Boston Public Health Commission, January 19, 2012; various recovery action meetings of the Massachusetts Organization for Addiction Recovery (MOAR), spring 2012.
- 425 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012.
- 426 *ibid.*
- 427 *ibid.*
- 428 Interview with Liz Whynott, Harm Reduction counselor, Tapestry Health Services, January 24, 2012; interview with Sarah Mackin, program coordinator, Harm Reduction Services, Boston Public Health Commission, January 19, 2012; interview with Sandi Carlson, University of Massachusetts Memorial Health Center, June 19, 2012.
- 429 Interview with Adam Butler, Addicts Health Opportunity Prevention Education (AHOPE), Boston Public Health Commission (BPHC), January 25, 2012; various recovery action meetings of the Massachusetts Organization for Addiction Recovery (MOAR), spring 2012.

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- 430 Interview with Dr. Mireya Wessołosky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012; interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Sandi Carlson, University of Massachusetts Memorial Health Center, June 19, 2012; interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012; interview with Pauline Himlan, University of Mass Memorial Healthcare at Fitchburg Health Center, August 14, 2012.
- 431 M.G. Ghany, et al., Diagnoses, Management and Treatment of Hepatitis C: An Update, Practice Guideline by the American Association for the Study of Liver Diseases. *Hepatology*. 2009;49(4):1362; H.S. Yee et al., Update on the Management and Treatment of HCV Virus Infection: Recommendations from the Department of Veterans Affairs HCV Resource Center Program and the National HCV Program Office. *Am J Gastroenterol*. 2012;107(5):669-689.
- 432 Interview with Dr. Mireya Wessołosky, University of Massachusetts Memorial Health Care, July 16, 2012.
- 433 M.G. Ghany, et al., Diagnoses, Management and Treatment of Hepatitis C: An Update, Practice Guideline by the American Association for the Study of Liver Diseases. *Hepatology*. 2009;49(4):1362.
- 434 Interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012; interview with Pauline Himlan, University of Mass Memorial Healthcare at Fitchburg Health Center, August 14, 2012.
- 435 SAMSHA, State Estimates, at 74-75, available at <http://www.samhsa.gov/data/NSDUH/2k10State/NSDUHsae2010/NSDUHsaeCover2010.pdf> (July 2012).
- 436 Interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, February 7, 2012; interview with Ann-Marie K. Duffy-Keane, project director, Community Health Associates, Massachusetts General Hospital, April 11, 2012; interview with Lee Thornhill, Director of Prevention and Education, Cambridge Cares About AIDS, AIDS Action Committee, February 10, 2012; interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012; Interview with Susan Oleksiw, Executive Director, North Shore Health Project, July 19, 2012; interview with Pauline Himlan, University of Mass Memorial Healthcare at Fitchburg Health Center, August 14, 2012.
- 437 Health Resources and Services Administration (HRSA), Mental Health Care Health Professional Shortage Areas, at 76-78, <http://bhpr.hrsa.gov/shortage/updateddesignations/2012June29/mentalhealthpsas06292012.pdf> (as of April 2012).
- 438 Interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012; interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012.
- 439 Interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012.
- 440 Interview with Catherine O'Connor, clinical director, Health Innovations, Faculty Member, Bouve College School of Nursing, Northeastern University, August 3, 2012.
- 441 Follow-up interview with Harm Reduction Counselor at Tapestry Health Services, July 2012.
- 442 Interview with Tracy Cheatle, Harm Reduction counselor, Tapestry Health Services, January 26, 2012; interview with Pauline Himlan, University of Mass Memorial Healthcare at Fitchburg Health Center, August 14, 2012.
- 443 Conversations with Raphael DuBard Jr., March 2, 2012, and summer 2012.
- 444 Interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012; interview with providers at Infectious Disease Clinical Services, (IDCS), April 4, 2012.
- 445 Interview with Dr. James Morrill, primary care, Charlestown Community Health Center, January 24, 2012.
- 446 Interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012).
- 447 For more information, visit the Massachusetts Executive Office of Health and Human Services, Integration Initiative at: <http://www.mass.gov/eohhs/gov/departments/dph/programs/substance-abuse/providers/program-licensing/integration-initiative.html>. More information and summit materials can also be found on the website for the Association of Behavioral Healthcare, at <http://www.mhsacm.org/publications/health-integration.html>.

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- 448 2012 Mass. Senate No. 2400, enacted by House and Senate on July 31, 2012 at I. 7184.
- 449 Interview with Marilyn Rodriguez, HIV Counseling and Testing coordinator, AIDS Project Worcester, July 27, 2012.
- 450 Interview with Dr. Mireya Wessołosky, University of Massachusetts Memorial Health Care, July 16, 2012.
- 451 Interview with Sarah Mackin, Program Coordinator, Harm Reduction Services, Boston Public Health Commission (BPHC), January 19, 2012; interview with Adam Butler, Addicts Health Opportunity Prevention Education (AHOPE), Boston Public Health Commission (BPHC), January 25, 2012; see also “AHOPE Client Manual,” available at: <http://www.bphc.org/programs/aptrss/ourservices/preventionandharmreduction/harmreductionandoverdoseprevention/Forms%20%20Documents/AHOPE%20Client%20Manual.pdf>.
- 452 Interview with Daniel Church, Adult Viral Hepatitis coordinator, Massachusetts Department of Public Health, November 7, 2011.
- 453 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012.
- 454 Interview with Liz Whynott, Harm Reduction counselor, Tapestry Health Services, January 24, 2012; interview with Katie Boos, associate director of Health Information and Training, AIDS Action Committee, February 3, 2012.
- 455 S. Arora, et al., Expanding Access to Hepatitis C Virus Treatment—Extension for Community Healthcare Outcomes (ECHO) Project: Disruptive Innovation in Specialty Care. *Hepatology*. 2010;52:3; S. Arora, et al., Outcomes of Treatment for HCV Virus Infection by Primary Care Providers. *N Engl J Med*. 2011;364:23; more information about the ECHO project can also be found on the University of New Mexico School of Medicine’s website, <http://echo.unm.edu>.
- 456 Interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, February 7, 2012.
- 457 *ibid*.
- 458 *ibid*; interview with Dr. Bill Shay, Outer Cape Health Services, August 3, 2012.
- 459 Interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, February 7, 2012.
- 460 Interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center; follow-up: July 12, 2012.
- 461 Interview with Dr. James Morrill, primary care, Charlestown Community Health Center, January 24, 2012; interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012.
- 462 Interview with Dr. James Morrill, primary care, Charlestown Community Health Center, January 24, 2012; overall SVR rate of 42% (begun prior to advent of triple combination therapy), with more triple-therapy patients pending
- 463 *ibid*.
- 464 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012; interview with Monique Tula, AIDS Action Committee of Massachusetts, February 2, 2012, and interview with Ann-Marie K. Duffy-Keane, project director, Community Health Associates, Massachusetts General Hospital, April 11, 2012 (both noting that while there is funding for community-based support for coinfecting individuals, it is hard to find funding to provide the same support for individuals who are mono-infected); interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012; interview with providers at Infectious Disease Clinical Services (IDCS), April 4, 2012.
- 465 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Dr. Mireya Wessołosky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012; interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012.
- 466 Interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, February 7, 2012.
- 467 Interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012.

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- 468 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Dr. Mireya Wessolossky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012; interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012.
- 469 Interview with providers at Infectious Disease Clinical Services (IDCS), April 4, 2012.
- 470 Interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012.
- 471 Interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012.
- 472 Interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012.
- 473 Interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012; interview with Infectious Disease Clinical Services (IDCS), April 4, 2012.
- 474 *See also*, Trust for America's Health and the American Association for the Study of Liver Disease, HBV & HCV: America's Hidden Epidemics, September 2010, at 32.
- 475 Interview with Dr. Mireya Wessolossky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012.
- 476 *Eg*, interview with Dr. Mireya Wessolossky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012; interview with Tracy Cheatle, Harm Reduction counselor, Tapestry Health Services, January 26, 2012; interview with Liz Whynott, Harm Reduction counselor, Tapestry Health Services, January 24, 2012; interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012.
- 477 Interview with Tracy Cheatle, Harm Reduction counselor, Tapestry Health Services, January 26, 2012; interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012. Transportation may also be a barrier even in Boston: Interview with Sonia Burgos, patient advocate/health educator, Massachusetts General Hospital (Charlestown, Revere, and Chelsea Health Centers), February 29, 2012; interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012.
- 478 Interview with Dr. Claudia Martorell, director and principal investigator, The Research Institute, May 24, 2012; interview with Nellie F. Kuilan, program supervisor, La Voz, July 27, 2012.
- 479 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Katie Boos, associate director of Health Information and Training, AIDS Action Committee, February 3, 2012; interview with Sandi Carlson, University of Massachusetts Memorial Health Center, June 19, 2012.
- 480 K.S.H. Yarnall, et al., Primary Care: Is There Enough Time for Prevention? *Am J Public Health*. 2003;93(4):637.
- 481 *Eg*, interview with Dr. Arthur Kim, Massachusetts General Hospital, January 18, 2012.
- 482 *Eg*, interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012.
- 483 Interview with Ann-Marie K. Duffy-Keane, project director, Community Health Associates, Massachusetts General Hospital, April 11, 2012; Timothy Purington, director of Prevention Health, Tapestry Health Services, Massachusetts Viral Hepatitis Coalition (MVHC) meeting, September 28, 2012.
- 484 Massachusetts Medical Society, 2012 MMS Patient Access to Care Studies, at 24, <http://www.massmed.org/AM/Template.cfm?Section=Home6&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=74671> (August 2012).

notes and references

- 485 For example, the percentage of family medicine providers accepting new patients declined from 70% in 2007 to 50% in 2012; for internal medicine, the percentage was 66% in 2005 down to 51% in 2012 (with some fluctuations in between). Massachusetts Medical Society, 2012 MMS Patient Access to Care Studies, at 20 and 24, available at <http://www.massmed.org/AM/Template.cfm?Section=Home6&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=74671> (August 2012).
- 486 For example, in 2012, only 64% of providers in family medicine accepted MassHealth (down from 75% in 2007), and similarly the number of internal medicine providers accepting MassHealth decreased from 79% in 2005 to 54% 2012. Massachusetts Division of Health Care Finance and Policy, Primary Care in Massachusetts: An Overview of Trends and Opportunities, at 21, available at http://www.mass.gov/chia/researcher/health-care-delivery/dhcfp-publications.html#primary_care (July 2010).
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- 489 Kaiser Family Foundation, Massachusetts: Poverty Rate by Race/Ethnicity, States (2010-2011), US (2011), available at <http://www.statehealthfacts.org/profileind.jsp?cmprgn=1&cat=1&rqn=23&ind=14&sub=2> (last visited December 11, 2012).
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- 491 Interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012.
- 492 Interview with Dr. Rachel Baden, Beth Israel-Deaconess Medical Center, follow-up July 12, 2012; interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012.
- 493 Food Research and Action Center, Prevalence of Household Level Food Insecurity and Very Low Food Security, by State 2009-2011 (Average), available at <http://frac.org/wp-content/uploads/2010/07/ma.pdf> (September 2012).
- 494 Interview with Susan Oleksiw, executive director, North Shore Health Project, July 19, 2012; interview with Provider at Lawrence Community Health Center, June 22, 2012.
- 495 Interview with Marguerite Beiser and Carole Hohl, Boston Health Care for the Homeless Program, February 13, 2012 (this reluctance could generally include persons with substance use disorders such as IDU, as well as persons who are homeless or otherwise in marginalized populations). Interview with Catherine O'Connor, clinical director, Health Innovations, Faculty Member, Bouve College School of Nursing, Northeastern University, August 3, 2012.
- 496 Consumer Group Discussion, August 29, 2012
- 497 Interview with Dr. Michael Wong, Beth Israel-Deaconess Medical Center, February 2, 2012; interview with Dr. Mireya Wessolossky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Sarah Mackin, program coordinator, Harm Reduction Services, Boston Public Health Commission, January 19, 2012; interview with Lee Thornhill, director of Prevention and Education, Cambridge Cares About AIDS, AIDS Action Committee, February 10, 2012.
- 498 Interview with Dr. Mireya Wessolossky, University of Massachusetts Memorial Health Care, July 16, 2012; interview with Robert Hitt, program manager, Project Aware, Stanley Street Resource and Treatment Center, May 16, 2012; *see also*: HCV Basics- Getting Benefits Under Social Security, available at http://www.hcvadvocate.org/Hepatitis/Basics/Benefits_basics.pdf (October 2010).
- 499 *See eg*, Center for Health Law and Policy Innovation, Massachusetts HIV/AIDS Resource Allocation Project, working draft, available at <http://www.taepusa.org/Portals/0/Documents/Massachusetts%20HIV%20AIDS%20Resource%20Allocation%20Project%20Dec.%202011.pdf> (December 13, 2011).
- 500 ACA, 42 U.S.C. §2703, Centers for Medicare & Medicaid Services, State Medicaid Director Letter re: Health Homes for Enrollees with Chronic Conditions (November 16, 2010); available at <http://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/SMD10024.pdf>.

notes and references

- 501 A copy of the approved Oregon State Plan Amendment (SPA) can be found at [http://www.chcs.org/usr_doc/OR11-011_Approval_Package_\(3_13_12\).pdf](http://www.chcs.org/usr_doc/OR11-011_Approval_Package_(3_13_12).pdf).
- 502 For more information about Medical Health Home initiatives, see Massachusetts Executive Office of Health and Human Services, Patient Centered Medical Home Initiative, available at <http://www.mass.gov/eohhs/gov/commissions-and-initiatives/healthcare-reform/pcmhi>.
- 503 Massachusetts Executive Office of Health and Human Services, Mission and Goals of the Massachusetts PCMHI, available at <http://www.mass.gov/eohhs/gov/commissions-and-initiatives/healthcare-reform/pcmhi/mission-and-goals-of-the-massachusetts-pcmhi.html>.
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State Healthcare Access Research Project

About SHARP – The State Healthcare Access Research Project (SHARP) is conducted by the Center for Health Law and Policy Innovation of Harvard Law School and the Treatment Access Expansion Project (TAEP), in collaboration with Bristol-Myers Squibb, with no editorial review or discretion. The content of SHARP does not necessarily reflect the views or opinions of Bristol-Myers Squibb. The Center for Health Law and Policy Innovation (CHLPI) has provided legal services to low- and moderate-income people living with chronic illnesses for 20 years. The Center is also an active participant in healthcare access advocacy efforts for low-income people, particularly individuals living with chronic medical conditions. TAEP is a national organization focused on healthcare access advocacy for low-income people living with HIV/AIDS, hepatitis, mental illness, and other chronic diseases.



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Treatment Access Expansion Project

An Analysis of the Successes, Challenges, and Opportunities for Improving Healthcare Access



MASSACHUSETTS

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