

## CONTACTS

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## BACKGROUND

A new research report, produced as part of the State Healthcare Access Research Project (SHARP), identifies: (1) challenges to access to care and treatment faced by people living with or at risk for hepatitis C virus (HCV) in Massachusetts; (2) successful policies that facilitate access to care; and (3) opportunities for improving access to prevention, testing, care, and treatment for persons living with or at risk for HCV. The full report is available at [www.taepusa.org](http://www.taepusa.org) and [www.law.harvard.edu/academics/clinical/lsc/](http://www.law.harvard.edu/academics/clinical/lsc/).

## OVERVIEW

In creating this report, the Center for Health Law and Policy Innovation (CHLPI) of Harvard Law School and the Treatment Access Expansion Project (TAEP) examined health policies in Massachusetts, met with stakeholders, and invited comments from state officials. In particular, our research included (1) meeting with state government officials to review state epidemiological data and state-run HCV testing, care, treatment and prevention initiatives; (2) facilitating community group meetings and individual interviews with people living with HCV and their health and support service providers; and (3) conducting independent research on the HCV epidemic nationally and in Massachusetts.

Through our work, we found that Massachusetts has taken important steps towards increasing access to health care for all its residents, including individuals with HCV. In many ways, Massachusetts is a post-health care reform state in a pre-health care 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 was rarely cited as a barrier to HCV care and treatment. In addition, Massachusetts has: integrated HCV testing and prevention into its existing HIV and STD testing, referral, and counseling centers, including syringe exchange programs; funded medical management sites to provide enhanced case management to those living with HCV; and increased access to care and treatment through the ECHO model and use of telehealth initiatives.

In short, the report highlights many successful policies and programs that facilitate access to HCV care and treatment in Massachusetts and offers models and lessons learned for other states. At the same time, persistent care and treatment challenges remain for individuals living with HCV. This report analyzes these challenges and makes recommendations for improvements that are relevant both in Massachusetts and nationally.

## SUMMARY OF RECOMMENDATIONS

- 1. Increase Testing and Prevention Efforts:** Over 110,000 individuals are estimated to be living with HCV in Massachusetts, with 7,000-10,000 newly reported cases in Massachusetts every year. As nationally, adults in the baby-boomer generation comprise the largest cohort of infected individuals in the state. Massachusetts was also one of the first states to report the growth of HCV in a second group: adolescents and young adults aged 15-25 years, with about 1,000 of newly reported cases each year within this age group. Because individuals living with HCV can be asymptomatic for many years, one of the most challenging facets of addressing this epidemic is that so many individuals do not realize they are infected. Education, prevention, and testing are crucial components of combating the spread of HCV.
  - a. Use the new Centers for Disease Control and Prevention (CDC) age-based screening guidelines as a tool to increase awareness among providers.** Preliminary data in Massachusetts from 1992-2009 indicate that the mean age of death among those infected with HCV was 53 years, compared to 75 years among non-infected persons. Moreover, 73% died within the first 5 years of diagnosis. These data suggest that many people with HCV may be getting diagnosed and entering care late in their illness, and more must be done to identify those who may be infected. New CDC guidelines recommending a one-time HCV test for all baby-boomers can be used as a tool to reach out to primary care providers to increase awareness, build relationships, and create infrastructure for referral and advocacy.

- b. Increase HCV educational initiatives for youth.** Data from Massachusetts indicate a growing HCV epidemic among youth and young adults (ages 15 to 25 years) who will not be reached through baby-boomer screening. To reach youth, HCV information should be integrated into school health curricula as well as youth substance use disorder treatment and prevention programs.
  - c. Collaborate with the American Liver Foundation (ALF) to increase access to education.** By partnering directly with ALF, education efforts could be increased at no additional cost to the state.
  - d. Promote and join the “Know More Hepatitis” campaign.** Promoting a national campaign with broad and consistent messaging increases the chances of reaching a larger audience and decreasing stigma.
  - e. Increase peer-based outreach among injection drug users.** The primary mode of HCV transmission is through intravenous drug use (IDU), and peer-based strategies have proven effective in increasing access to testing and harm reduction information within this community.
  - f. Increase use of electronic medical records (EMRs).** Adding a simple prompt to EMRs on HCV testing is an easy way to promote testing and linkage to care without necessitating potentially stigmatizing discussions about risk factors.
  - g. Increase funding for HCV programs, including rapid testing.** Like many public health programs, funding for HCV surveillance, prevention, and services has been declining. Additional funding is needed to promote access to prevention, testing, and care. While current HCV antibody tests can take up to 2 weeks, widespread use of the rapid test (with results available in 20 minutes) would help increase awareness and linkage to care.
  - h. Integrate HCV counseling into the Screening, Brief Intervention, and Referral to Treatment (SBIRT) project.** SBIRT is designed to identify people struggling with substance use disorders who seek care at primary care offices and emergency departments and refer them to services. Given the overlapping risk factors between substance use disorder and HCV, information on HCV testing and care should also be integrated into this tool.
  - i. Increase coordination and collaboration between hepatitis initiatives and substance use disorder treatment and prevention programs.** Coordination and collaboration with substance use disorder treatment programs around education, testing, linkage to care, and prevention should be strengthened and include increased support for substance use disorder treatment programs as needed.
- 2. Increase access to care and treatment.** Unlike many chronic illnesses such as HIV, many individuals living with HCV can actually be cured through anti-viral treatment. While treatment is expensive, delaying treatment is even more costly. Liver transplants can cost over \$267,000 in the first year alone. For others, lack of treatment can result in death from cirrhosis or other complications. Yet access to care and treatment can be limited due to stigma and lack of supportive services, particularly for individuals living with mental illness or substance use disorders. Increased support is needed for both providers and individuals during treatment.
- a. Use opportunities through federal healthcare reform to increase access to comprehensive services and reduce churning.** Massachusetts will need to ensure that the gains it has made in increasing access to health coverage are maintained, and use opportunities created through the Patient Protection and Affordable Care Act to address existing problems such as churning.
  - b. Create regional and local strategic plans to address viral hepatitis.** Combating HCV will require integrated, community-based efforts. Creating local plans to address viral hepatitis and creating infrastructures for referral will ensure a “no wrong door” approach and promote greater awareness and linkage to care.
  - c. Increase the availability of peer-support programs.** Access to peer services is a critical component of helping individuals living with HCV to deal with stigma, access services, and cope with the severe side effects of treatment.
  - d. Include HCV treatment in existing initiatives to integrate primary and behavioral healthcare.** Co-occurring mental health and substance use disorders can be barriers to HCV treatment. Access to coordinated behavioral and mental health support can decrease or eliminate these barriers; therefore, existing integration initiatives could be ideal settings to offer HCV treatment.
  - e. Increase provider education and cultural competency training at the medical school level.** Taking advantage of Massachusetts’ many medical schools to increase HCV and substance use disorder education among aspiring providers would help decrease stigma and ensure that individuals living with these disorders can access appropriate care and treatment.

- f. Develop HCV-specific health homes/coordinated care models.** Providing HCV care and treatment can require coordination among multiple providers, high levels of administrative work, and provision of treatment adherence help and other support services. Building off of Massachusetts' existing medical management sites and other efforts, opportunities offered through federal healthcare reform and Massachusetts' payment reform bill to create medical health homes should be used to support and create best practices for delivery of HCV care and treatment.
- g. Increase state and/or insurance funding of telehealth models that increase the number of HCV treatment providers.** To address the potential shortage of competent specialists able to offer HCV treatment, the ECHO model uses innovative health technology to offer specialist support to medical practitioners (like primary care providers) to enable them to treat their HCV patients directly. New reimbursement structures are needed to sustain these initiatives.
- h. Create a supportive services program for individuals living with HCV.** Treatment for HCV can be a very difficult ordeal for many individuals, causing both physical and mental side effects. For treatment to be effective, individuals must have access to adequate food and housing. As with HIV and other chronic illnesses, creating a program that offers holistic care and support services, including case management, nutrition, and housing, would increase access to care and treatment for individuals living with HCV, particularly those who have lower incomes.
- i. Expand and build upon the Massachusetts viral hepatitis strategic plan.** Massachusetts is currently in the process of updating its strategic plan, however, many community members seem unaware of these efforts. For the plan to be successful and ensure greater accountability, more efforts must be made to engage community-based organizations, substance use disorder and mental health services providers, and individuals living with or at risk for HCV.
- j. Create a statewide consumer advisory board of individuals living with HCV.** Like the state-wide consumer advisory board of individuals living with HIV, a similar board of individuals living with (or recovering from) HCV would increase awareness, create greater state accountability, and ensure their unique needs are considered and addressed.
- 3. Prevention, testing, and treatment for incarcerated individuals.** The prevalence of HCV among individuals in correctional settings is significantly greater than that of the general population, and incarceration can provide a uniquely structured setting for individuals to access education, testing, care, and treatment.
- a. Increase testing and treatment access.** Current policies related to testing should be updated to incorporate the new CDC age-based screening guidelines. Policies governing access to treatment should be further examined and potentially revised to enable increased access to treatment. These policies must also be able to quickly adapt as newer treatments become available.
- b. Increase access to educational programs.** Despite the high prevalence rates of HCV and other chronic illnesses, health educational programs in correctional settings are severely limited. Advocates should push for mandatory, peer-based health education programs (that include HCV and harm reduction) for all inmates.
- c. Expand access to treatment for inmates with shorter sentences through programs that link inmates infected with HCV to continued care post-release.** Because treatment can be a lengthy process, individuals in correctional settings who have shorter sentences may be unable to access treatment while incarcerated. Advocates should build on existing infrastructures that provide post-release case management for individuals with HIV and include individuals with HCV so that those with shorter sentences may begin treatment while incarcerated and continue treatment upon release.
- d. Explore opportunities for education and testing interventions through the Massachusetts Department of Youth Services (DYS).** Given the growing HCV epidemic among youth, young people in the custody of DYS—particularly for substance-related issues—should have access to targeted HCV education, prevention, testing, and/or treatment. More research is needed to determine the degree to which these programs already incorporate HCV-related services and whether and how such services could be added or expanded.

## CONCLUSION

The HCV landscape in Massachusetts reflects effective policies that help people living with HCV access care and treatment, and can serve as an example for policy development in other states. While Massachusetts has had many successes, persistent challenges remain for individuals living with HCV even with access to health coverage, and there are additional 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 prevention, testing, care, and successful treatment for individuals living with or at risk for HCV.



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**About SHARP** – A national project of the Center for Health Law and Policy Innovation of Harvard Law School and the Treatment Access Expansion Project, the State Healthcare Access Research Project (SHARP) examines access to care for people living with either HCV or HIV. SHARP develops state-level research reports by conducting a series of focus groups and one-on-one interviews with people living with HCV or HIV/AIDS, community-based services providers, healthcare providers, faith leaders, state and federal government officials, and other researchers and advocates. The insights gained from these meetings are supplemented with independent research. SHARP is designed to examine states' capacities to meet the healthcare needs of people living with HCV or HIV/AIDS and has three main goals: (1) improve access to care and treatment, with an emphasis on addressing state-level barriers to care; (2) share information and advocacy strategies that reduce barriers in access to care within and among states; and (3) support coalition development and self-sustained, grassroots advocacy capacity in states.



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