



*Urgent Response Needed to  
Nation's Hepatitis C Epidemic*



# NASTAD'S Call to Action



# CHAIR'S CHALLENGE

UNITE TO END THE EPIDEMICS 2017-2018



## Foreword

I come from a family of public servants - policemen, firemen, nurses, military servicemen and women, and even activists - who worked towards achieving social justice. In fact, my fun loving, charismatic, and athletic Uncle worked towards integration as the first African American life guard at a public pool in our hometown. An excellent swimmer, he later enlisted in the United States Navy, served on the USS Hornet, and assisted in the recovery of the Apollo in the Pacific Ocean. Just last year my family said goodbye to my Uncle Barry who passed away from hepatitis C related complications. It is for Uncle Barry and all those living with hepatitis C that I Unite to End the Epidemics. I am excited to announce NASTAD's Call to Action for an Urgent Response to the Nation's Hepatitis C Epidemic.

Elimination of HCV is not possible without urgently focusing efforts toward the right people, in the right places, right now. This means implementing a strategy to prevent transmission within, and identification and treatment of hepatitis among, people who inject drugs (PWID). NASTAD's Call to Action proposes recommendations to prevent new infections; reduce deaths and adverse health outcomes; address disparities; coordinate action among federal, state, and local agencies and health systems; and ultimately reduce health care costs.

Our nation has a unique opportunity to not only eliminate a serious public health threat domestically, but to also become a leader globally. We owe the elimination of hepatitis C to people across our country, people like my Uncle Barry who honorably served our country. Although he is no longer with us, there are many others who are near and dear to us who can live if we adequately address hepatitis C. Let us respond more urgently to hepatitis C and unite to end these epidemics.

**Shanell McGoy, Tennessee, NASTAD Chair**



## Reducing HCV Infections is a Public Health Imperative

The Centers for Disease Control and Prevention (CDC) has stated that “our nation is losing ground in the battle against hepatitis – infections of which kill more Americans than all other reportable diseases combined.”<sup>1</sup> For over a decade, NASTAD and health department infectious disease programs have been calling on policymakers for a more urgent response to the hepatitis C virus (HCV) epidemic. This has included sounding the alarm about the opioid epidemic and resulting HCV infections among people who inject drugs (PWID). NASTAD believes that our public health system needs to focus greater attention and resources on preventing and controlling HCV infections, especially among people who inject drugs. This *Hepatitis C Call to Action* is intended to focus federal, state and local officials, legislators, and policymakers on the need to prioritize the populations who are most vulnerable for acquiring and transmitting HCV in order to drive down the incidence of HCV infections and the prevalence of HCV disease.

In 2015, an estimated 33,900 new HCV infections occurred in the U.S, a threefold increase in cases since 2010.<sup>2</sup> According to CDC, the most recent surveys of people who are actively injecting drugs indicate that approximately one third of those between 18–30 years are HCV-infected.<sup>3</sup> The health outcomes related to HCV infections are deadly for many individuals affected. Approximately 75%–85% of people who become infected with HCV develop chronic infection and an estimated 2.7 – 3.9 million people in the United States have chronic HCV. Chronic infection can progress to end-stage liver disease, including liver cancer; in the United States, HCV is the leading cause of end-stage liver disease requiring liver transplantation. HCV can also cause other serious and life-threatening problems including blood vessel disorders, bone disease, kidney disease, cardiovascular disease, and blood cancers. It is estimated that without changes to our current testing and treatment paradigm, in the next twenty years, annual medical costs for patients with HCV are expected to more than double, from \$30 billion to over \$85 billion.<sup>4</sup>

NASTAD is a leading non-partisan non-profit association that represents public health officials who administer HIV and hepatitis programs in the U.S. and around the world. NASTAD's mission is to end the intersecting epidemics of HIV, viral hepatitis, and related conditions. This is accomplished by strengthening domestic and global governmental public health through advocacy, capacity building, and social justice. These public health program officials serve pivotal roles in our nation's response to these epidemics by managing federal, state, and local infectious disease programs designed to prevent, care and treat HIV and HCV infections.

## A Critical Moment for Reducing Infections and Saving Lives

Three recent developments signal that we are at a critical turning point in determining whether HCV will be controlled and virtually eliminated in the United States.

**A cure for HCV has arrived.** New direct-acting antiviral treatments for HCV can cure infection in more than 95% of patients. This is a stunning breakthrough for the treatment of HCV as an infectious disease and as a chronic infection.

**HCV control is within our reach.** The National Academies of Sciences, Engineering and Medicine released *A National Strategy for the Elimination of Hepatitis B and C* which provides recommendations on how the nation can eliminate hepatitis as a public health threat. In addition to specific recommendations for the prevention, control and elimination of hepatitis C, the report identifies one of the major barriers as viral hepatitis is not a public priority in the U.S. The National Academies highlights that reaching this goal will require more funding for prevention and treatment.

**A national strategy is in place.** The U.S. Department of Health and Human Services (HHS) *Viral Hepatitis Action Plan*, updated in January 2017, provides a framework for key stakeholders to strengthen the nation's response to hepatitis and leverage opportunities to improve the coordination of hepatitis activities across public and private sectors.

Taken together, these developments bring sharper clarity to the urgency for focusing attention on the prevention and care needs of priority populations at risk for or living with HCV. Although effective, curative treatments for HCV are now available that will reduce infections and prevent diseases and death among those living with HCV, the impact of these treatments will be severely blunted unless there is increased attention and resources for public health programs focused on PWID, including screening, disease surveillance, enrolling and retaining patients in care, and disease management.

Preventing HCV infections from occurring and providing quality care to those who are infected should be a top public health priority.

## NASTAD'S VISION FOR ELIMINATING HCV

The United States will become a place where new HCV infections are rare, and when they do occur, every person, regardless of substance use status, age, gender, race/ethnicity, sexual orientation, gender identity, disability, socio-economic status, incarceration status or geographic location, will have access to quality, affordable health care including comprehensive screening, care and treatment leading to cure, without stigma and discrimination.

## Hepatitis C: Chronic Infections and Acute Infections—Two Major Populations

There are two major yet distinct populations that require unique focus and action steps in preventing and treating the often silent, hidden epidemic of HCV. There are people who have chronic HCV infection who have had the infection for many years, sometimes decades. Then there are those who have acute HCV infection, acquiring the infection more recently, usually by sharing needles and other equipment used to inject drugs.

The first major population consists of people born between 1945 and 1965 who account for the majority of chronic HCV in the U.S.<sup>5</sup> Many of these people are unaware that they are chronically infected, and have been infected for decades, until developing cirrhosis, end-stage liver disease, or liver cancer. Most of the people with chronic HCV infection acquired it through blood transfusions and organ transplants prior to 1992, before there was widespread screening of the nation's blood supply. These individuals are not typically transmitting the virus to others, unless they are actively sharing needles or other equipment to inject drugs. CDC recommends that people born between 1945 and 1965 get screened for HCV.

The second major population is those who are more recently infected. This group largely consists of people who inject drugs, primarily people who are young, people who are homeless, and people who have been incarcerated. The opioid epidemic is the major force driving new HCV infections currently and over the last decade. CDC estimates that HCV infections tied to the opioid epidemic are widespread, though the Appalachian region, Native populations and other rural areas that have recently experienced significant increases in cases. As a result of a younger generation experiencing increases in HCV infection, there have been alarming numbers of babies born to women living with HCV, causing concern about the likelihood of increased perinatal transmission of HCV. While there is widespread agreement that our health systems must increase the number of Americans living with chronic HCV who know their status and receive curative treatments, **NASTAD believes that we must intensify attention to the ongoing and emerging epidemic of new HCV infections among PWID resulting from the epidemic of opiate use.** Preventing and controlling the transmission of HCV infections by focusing on PWID is the essential, priority role of public health.

**NASTAD believes that to achieve our goal of ending the HCV epidemic, we must focus efforts towards the right people, in the right places, and this must occur right now.**

### Recommended Action

NASTAD is the national organization that bridges and supports the work of HIV prevention and treatment managers and hepatitis prevention coordinators in health departments to improve their capacity to provide comprehensive screening, care, and treatment for HIV and HCV, including the priority populations of PWID, disproportionately affected racial and ethnic minority communities, and those who are co-infected with HIV and HCV. To focus our nation's public health strategies to face the urgency of the increasing number of HCV infections, NASTAD proposes a set of recommended actions to prevent new infections, reduce deaths and adverse health outcomes, address disparities, coordinate action among federal, state and local agencies and health systems, and ultimately reduce health care costs.

**1 Focus on Prevention, Care, and Treatment for Priority Populations.** The opioid epidemic is driving a national focus on injection drug use in America. Front page and evening news stories are now routinely describing the impact of opioid use on individuals, families and communities. Stories are constant about drug overdoses and deaths, multiple generations of family members using drugs, newer, synthetic and more lethal varieties of opiates, substance use treatment systems strained and underfunded to meet the demand, and law enforcement personnel stretched to the limit or challenged to address the problem. The opioid epidemic is real and it is pervasive. It is a problem that is not only happening in rural America, but in urban and suburban areas as well. HCV infections among PWID compound the opioid problem, but must be considered an important component of the solutions for addressing prevention, care, and treatment for people who use drugs to reduce HCV transmission and to improve health outcomes. PWID should have the opportunity to prevent HCV infection, know their status, rapidly connect to care on diagnosis, and receive quality treatment leading to a cure.

The National Academies of Sciences, Engineering and Medicine elimination strategy determined that meeting the target of a two-thirds reduction in HCV related deaths by 2030 will require special attention to testing and treatment among people who inject drugs. Similarly, a reduction in the number of new HCV infections will require programs to reduce the number of people starting injection drug use, expanding harm reduction programs for those already injecting, and providing HCV treatment to PWID. Finally, the strategy recommends that the only way to achieve elimination goals is to remove treatment restrictions and provide access to all, expand screening to diagnose 80% of infected persons by 2030, and continue to treat at least 260,000 patients per year. This strategy will reduce infections by 90% and avert nearly a quarter million deaths in the next 14 years.<sup>7</sup>



**Step 1: Recognize that we need a heightened national focus on primary HCV prevention for people who inject drugs (PWID) as a priority for public health infectious disease programs.**

With an intensified focus on addressing HCV infections among PWID, emphasis must also be placed on strategies for effectively reaching and serving populations disproportionately affected by HCV, including people of color, Native Americans, homeless individuals, incarcerated populations, and people co-infected with HIV and HCV. Nearly every community in the United States is dealing with injection drug use, but it is fair to say that there are many rural counties that are especially vulnerable to outbreaks of HCV and HIV infections due to injection drug use because of limited systematic resources for individuals to access testing and treatment services, and a lack of infrastructure to address drug user health. CDC has identified 220 such rural counties in America in a vulnerability assessment conducted in 2016 to prevent HCV and HIV infection outbreaks similar to the one in Scott County, IN in 2015.

**2 Addressing Opioid Epidemic and Drug User Health.** Among the highest priority strategies and the most cost effective approaches for communities to prevent HCV infections are to focus energy and resources on drug user health service infrastructure. These measures include syringe services programs, access to clean drug injection equipment, overdose prevention, substance use counseling and treatment, and opioid treatment medications, collectively known as harm reduction services. There is strong scientific evidence to support the approach that harm reduction services and related strategies can reduce HCV transmission, especially among young people and those who have recently started injecting drugs. Researchers have demonstrated that cities with strong syringe service programs (SSPs), such as New York and San Francisco, have shown significant reductions in HCV prevalence.<sup>8</sup>

Health department infectious disease programs have a long history of commitment to the HCV and HIV prevention needs of PWID. Hepatitis prevention coordinators, who NASTAD represents, are at the hub of state and local public health responses to the needs of PWID, working in partnership with substance use prevention and treatment agencies and communities. Increasing the number of health care, substance use, and mental health professionals knowledgeable about HCV is central to maximizing the benefits afforded by new treatment options. Targeted outreach to and engagement with health care, substance use and mental health professionals, and systems that provide care to PWID on the importance of testing is critical to identifying those vulnerable for and living with HCV.

The priority population of PWID also need to be aware of the epidemic and what actions they can take to protect their health. By increasing knowledge and awareness of HCV, increasing rates of testing, and most importantly, getting people who are infected into care and treatment, morbidity and mortality can be decreased. Substance use treatment and SSPs are often the most effective and appropriate venues for reaching persons at the highest risk for transmitting HCV to others. With leadership from health department infectious disease programs, all stakeholders must join together and mount a comprehensive response to turn the tide of the opioid and HCV epidemics.

✓ **Step 2: Prioritize access to harm reduction services as a key strategy for reducing HCV transmission among PWID by removing policy restrictions and funding access to syringe service programs (SSPs), substance use counseling and treatment, and opioid replacement therapy.**

Among the most important elements of a comprehensive harm reduction strategy to prevent HCV transmission include:

**Substance Use Prevention and Treatment** — Individuals at risk for substance use or who are living with substance use disorders must have increased access to prevention and treatment services on demand. This includes increased access to inpatient and outpatient treatment facilities and fully scaling up the use of opioid treatment medications such as buprenorphine and methadone. Services that are tailored to address substance use among young people are critical. Increased resources should be dedicated to ensuring longer term support is available for individuals (and the support networks of those individuals) in recovery. Additionally, services that effectively address the intersection between substance use and mental health issues among young people remain critical to mounting an effective response among this population.



**Access to Sterile Syringes** — The Congressional ban on the use of federal funds for syringe services programs must be fully lifted and additional resources specifically for SSPs should be allocated. These programs have decades of research that support their efficacy. SSPs provide lifesaving strategies to protect individuals from blood borne infections, in addition they provide access to other medical services and linkage to substance use and mental health treatment. Efforts to support broader access to sterile syringes on the state and local level through legislation, local approval, policies and/or funding for syringe services programs and pharmacy sales are essential in bringing sterile syringe access to people in need. Rural areas of America are especially vulnerable to outbreaks due to the

combined assault of the opioid epidemic and restrictive policies on harm reduction services.

**Overdose Prevention** — Individuals with substance use disorders, as well as their families and other support networks, should receive information about the risks of overdose, the use of naloxone, a medication used to block the effects of opioids, especially in overdose, and the importance of seeking emergency assistance should an overdose occur. Naloxone should be available without restriction through syringe services programs, pharmacies, health departments, health care providers and community based organizations. In addition, emergency responders including law enforcement officers who are often the first on the scene when there is an overdose should be supplied with and trained to use naloxone.

**Meaningful Engagement of People with Substance Use Disorders** — Policy and program decisions related to opioid use prevention and treatment, HCV and HIV prevention, care and treatment as well as overdose prevention should include the meaningful engagement of people with substance use disorders.

**Screening, Diagnosis and Linkage to Care.** A key initial step to preventing and controlling HCV infections is making people at risk for or living with HCV aware of their condition by testing, diagnosis, linking and retaining them in care. Most often HCV screenings are being done in clinical settings where referral to care, treatment, and follow-up can be more effectively assured. By focusing the spotlight on reaching those most vulnerable for HCV, including marginalized populations of PWID, homeless individuals, and people experiencing incarceration, public health infectious disease programs recognize that these populations are often outside the reach of many clinical care settings. That means we need to focus greater attention and resources on screening people where they live—in community settings.



There are multiple lessons to be learned from the history of HIV prevention, care, and treatment and harm-reduction programs that can be translated for HCV programs, especially for PWID, homeless individuals and incarcerated individuals. Among the major insights are the many examples of the effective use of non-traditional testing sites, including testing conducted through mobile outreach units, in jails and prisons, in homeless service programs, and through substance use and mental health treatment and harm reduction programs. Community-based HCV screening (as well as screening in jails and prisons) should be employed as strategy to reach more patients, provided there are strong referral and linkage to care measures in place for those diagnosed with HCV infection.

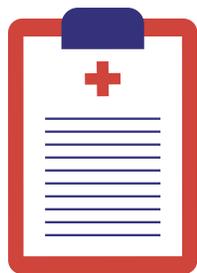
✓ **Step 3: Integrate and expand HCV testing into community settings where priority populations live and are served, and improve the quality and timeliness of hepatitis surveillance for new HCV cases.**

## Improving and Supporting Surveillance for HCV

Surveillance for HCV in the United States is limited and underfunded. Surveillance and reporting for HCV requires a strong public health infrastructure that is similarly available for other infectious diseases. The high volume of testing must move through the system promptly to allow for real-time follow-up on potential outbreaks. Identifying new cases is essential to identifying an outbreak and instituting control measures. An effective surveillance system can promptly identify seroconversion in population groups and avert new community-wide outbreaks. Public health surveillance programs require greater attention and resources to improve the quality, efficiency, effectiveness, and timeliness of hepatitis surveillance for new HCV cases at the national, state, and local levels.

**Treatment and Follow-Up.** Public and private health insurance payers, whether Medicaid, Medicare, the Veterans Administration (VA), AIDS Drug Assistance Programs (ADAP) or private health plans, are all challenged to absorb the high cost of treatments to adequately treat people living with HCV. Newer treatments approved for the market that increase competition among products and manufacturers have usually led to overall HCV drug price reductions and improved affordability.

Competition and market forces typically bring the prices down, but negotiation with payers is another important, proactive factor that leads to price reductions, discounts, rebates and increased affordability for patients and health systems. The first order of business for public payers, such as state Medicaid programs and ADAPs, should be to call for further discounts and purchasing arrangements that have proven to be successful in driving down drug prices or achieving equivalent discounts and rebates. The priority is to get as many individuals onto effective treatments, and that outcome can only be achieved when payers have the wherewithal within finite budgets to stretch dollars to provide necessary coverage to as many eligible people as possible.



The greatest single barrier to widespread uptake of curative HCV treatments is the high price of therapies and the resulting eligibility restrictions instituted by insurers.



**Step 4: Achieving acceptably lower prices on curative HCV treatments through further discounts is a key initial step to bringing the promise of breakthrough therapies to more people in order to reduce infections, illnesses and deaths.**

Additional public health system measures are needed to expand treatment access for people living with HCV infection.

**Removing Restrictions on HCV Treatment** — For individuals with substance use disorders who are living with HCV, treatment should be available without restriction. Before approving a prescription, some payers require prior authorization, including evidence of advanced liver fibrosis, or consultation with a specialist. Many payers also require that patients abstain from alcohol and drugs for an arbitrary period before beginning treatment or require drug screening to confirm sobriety. In many cases restrictions on access in public and private insurance programs are due to the high price of drugs and expected high demand for treatments. However, public and private insurance program requirements on eligibility for HCV treatment based on length of sobriety are discriminatory and at odds with clinical guidelines and evidence. Payers should maximize access to HCV treatments to accomplish health promotion and disease prevention objectives and increase cure rates without increasing stigma. Withholding HCV treatment also increases the likelihood of continued transmission. Medical providers should offer medication-assisted therapies for substance use disorders while simultaneously treating HCV. HCV treatment should be available to all those who are infected, with price and other access restrictions removed as barriers.

**Provider Education, Capacity, and Expertise** — Education and ongoing training for health care providers must include diverse approaches to chronic pain management in order to reduce incidence of opiate dependence. Health care providers working in rural and underserved areas can leverage emerging technologies and practices such as telemedicine to better serve people with substance use disorders. AIDS Education and Training Centers (AETCs) and Addiction Technology Transfer Centers (ATTCs) offer excellent options for public health programs to leverage and provide HCV and substance use educational support to prevention, care, and treatment providers. All providers interacting with people with substance use disorders should provide high quality, culturally competent, and client centered services to address the complex needs of their patients.

**Strong Public and Private Insurance Protections** — As millions of people continue to gain access to Medicaid and private insurance coverage, it is imperative to ensure that access to insurance translates into meaningful access to mental health and substance use disorder services. Benefit mandates, non-discrimination provisions, and parity requirements must be enforced to ensure access to the range of prevention, treatment, and overall drug user health services.

NASTAD believes that controlling and eventually eliminating HCV in the U.S. is possible. To achieve this goal, policymakers, public health professionals, pharmaceutical and diagnostics companies and public and private payers must work together to ensure that adequate resources are allocated to prevent HCV infections from occurring and providing quality care to all who are infected. We believe that eliminating HCV should be a top public health priority. Unless we act boldly and urgently, we will continue losing ground in the battle against hepatitis and more generations of Americans will be infected. This does not have to be the case. We are hopeful that stakeholders at the national, state, and local levels will join our efforts to make the elimination of HCV in the U.S. a reality.

We believe that eliminating HCV should be a top public health priority. Unless we act boldly and urgently, we will continue losing ground in the battle against hepatitis and more generations of Americans will be infected.

## NOTES

- 1 CDC, Pathway to Eliminating Hepatitis B and Hepatitis C and Professional Judgement Budget, Fiscal Year 2018-2027
- 2 CDC, Hepatitis C FAQs for Health Professionals Fact Sheet, Division of Viral Hepatitis, 2016, <http://www.cdc.gov/hepatitis/hcv/hcvfaq.htm>
- 3 Ibid
- 4 Milliman, Consequences of Hepatitis C Virus (HCV): Costs of a Baby Boomer Epidemic of Liver Disease, May 2009
- 5 CDC, Hepatitis C FAQs for Health Professionals Fact Sheet, Division of Viral Hepatitis, 2016, <http://www.cdc.gov/hepatitis/hcv/index.htm>
- 6 Durier, N., C. Nguyen, and L. J. White. 2012. Treatment of hepatitis C as prevention: A modeling casestudy in Vietnam. *PloS One* 7(4):e34548. Hellard, M. E., R. Jenkinson, P. Higgs, M. A. Stooove, R. Sacks-Davis, J. Gold, M. Hickman, P. Vickerman, and N. K. Martin. 2012. Modeling antiviral treatment to prevent hepatitis C infection among people who inject drugs in Victoria, Australia. *Medical Journal of Australia* 196(10):638-641. Martin, N. K., P. Vickerman, and M. Hickman. 2011. Mathematical modeling of hepatitis C treatment for injecting drug users. *Journal of Theoretical Biology* 274(1):58-66.
- 7 National Academies of Sciences, Engineering, and Medicine. 2017. A National Strategy for the Elimination of Hepatitis B and C: Phase Two Report. Washington, DC: The National Academies Press. Doi: 10.17226/24731.
- 8 Des Jarlais, D. C., T. Perlis, K. Arasteh, L. V. Torian, H. Hagan, S. Beatrice, L. Smith, J. Wethers, J. Milliken, D. Mildvan, S. Yancovitz, and S. R. Friedman. 2005. Reductions in hepatitis C virus and HIV infections among injecting drug users in New York City, 1990-2001. *AIDS* 19 Suppl 3:S20-S25. Tseng, F.-C., T. R. O'Brien, M. Zhang, A. H. Kral, B. A. Ortiz-Conde, J. Lorvick, M. P. Busch, and B. R. Edlin. 2007. Seroprevalence of hepatitis C virus and hepatitis B virus among San Francisco injection drug users, 1998 to 2000. *Hepatology* 46(3):666-671.

## Additional NASTAD Resources

[Statement of Urgency: Addressing the Opioid Epidemic in the United States](https://www.nastad.org/sites/default/files/NASTAD-Statement-of-Urgency-Opioid-Epidemic-July-2015.pdf)

(<https://www.nastad.org/sites/default/files/NASTAD-Statement-of-Urgency-Opioid-Epidemic-July-2015.pdf>)

[Maximizing Health, Minimizing Harm: The Role of Public Health Programs in Drug User Health](https://www.nastad.org/blog/maximizing-health-minimizing-harm-role-public-health-programs-drug-user-health)

(<https://www.nastad.org/blog/maximizing-health-minimizing-harm-role-public-health-programs-drug-user-health>)

[Modernizing Public Health to Meet the Needs of People Who Use Drugs](https://www.nastad.org/sites/default/files/ModernizingPublicHealth-NASTAD.pdf)

(<https://www.nastad.org/sites/default/files/ModernizingPublicHealth-NASTAD.pdf>)

This document was developed by NASTAD, which represents the chief health agency staff who have programmatic responsibility for administering HIV and hepatitis health care, prevention, education and support service programs funded by state and federal governments.

NASTAD's mission is to end the intersecting epidemics of HIV, viral hepatitis, and related conditions by strengthening domestic and global governmental public health through advocacy, capacity building, and social justice.

NASTAD's vision is a world free of HIV and viral hepatitis.

Joe Kelly, Mariah Johnson, and Chris Taylor are the chief authors of this document. Special thanks to the contributing authors and editors, including Murray Penner, Terrance Moore, Magalie Lerman, and Alyssa Kitlas.

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