Call to Action

New York State (NYS) faces a growing hepatitis C epidemic with a rising death toll. Given the availability of new highly effective, well-tolerated curative treatments, we can no longer settle for a low cure rate that perpetuates the high fiscal and human costs of inaction. The committee that organized the NYS Hepatitis C Elimination Summit, along with the other providers, community-based organizations and individuals living with and affected by hepatitis C that sign this consensus statement, call on Governor Andrew Cuomo, the NYS Legislature, and industry partners to make a joint commitment to hepatitis C elimination, and for appointment of a formal NYS Hepatitis C Elimination Task Force.

With a new generation of all-oral, highly effective and easy to tolerate curative treatments for hepatitis C virus (HCV) infection, and proven harm reduction strategies to prevent transmission, NYS’s HCV epidemic can finally be controlled – and eventually eliminated – with the tools we have available.

For NYS and the rest of the nation, efforts to control HCV are more urgent than ever. An estimated 3.5 million to 5.3 million Americans, including more than 200,000 New Yorkers, are living with chronic hepatitis C infection, and a shocking 75% of Americans and 50% of New Yorkers are unaware of their status. Even among people with diagnosed HCV infection, many lack consistent care or access to treatment, a fact that drives increasing HCV-related mortality. Left untreated, chronic HCV infection can lead to cirrhosis, liver cancer and the need for liver transplantation. Hepatitis C now kills more people in the United States each year than AIDS, and both in NY and the rest of the country, HCV-related mortality has risen steadily during the past decade. Hepatitis C is the leading cause of serious liver disease in the United States (U.S.).

Even though NY faces concerning gaps in its HCV continuum of care that present ongoing barriers to HCV prevention and treatment, the State has built a strong foundation for an HCV elimination plan. NYS has many of the most skilled medical providers, prevention specialists, researchers, and public health officials in the nation. The NYS Department of Health (DOH) Hepatitis C Care and Treatment Initiative and the New York City (NYC) Department of Health and Mental Hygiene (DOHMH) Project Inspire have started to build HCV clinical capacity and expand access to HCV treatment. NY’s more than twenty-year history of support for syringe exchange and harm reduction services, and its role in originating and expanding medication assisted treatment for opioid dependence, have informed HIV, hepatitis, and substance use services worldwide. And NYS’s successful ongoing Medicaid Redesign provides further support for a new effort to fill the gaps in the HCV care continuum.
NYS’s trailblazing plan to end its HIV/AIDS epidemic by the end of the year 2020, and the recommendations made by Governor Andrew Cuomo’s Ending the Epidemic (ETE) Task Force, demonstrate how state, city, county and community experts can set and work toward joint disease control goals and targets. ETE initiatives have already improved health outcomes across the HIV continuum of care and NYS is on-track to achieve its ETE goals.

Every NY state and local government agency, industry leader and provider that serves people with HCV has a role to play in this work to scale-up prevention, testing and linkage to care, treatment capacity, and supportive services statewide to eliminate HCV. The Governor can lead by appointing an NYS Hepatitis C Elimination Task Force that is charged with working with the NYS DOH to establish targets and priority recommendations for HCV elimination. The State Legislature can actively participate through a campaign to combat HCV stigma and through legislative and budget action. Failure to make the necessary investments now to control and eventually eliminate HCV will lead to further transmission of HCV, higher rates of liver cancer, transplantations, hospitalizations and mortality, and far higher long-term financial costs. Now that HCV is a highly curable condition we can and must reverse these negative trends; it is time for NYS to commit to HCV elimination.

HCV in NYS

Since 2001, more than 254,200 chronic HCV cases have been reported in NYS. In 2014, there were 16,169 chronic HCV cases and 127 acute cases reported. The statewide HCV case rate in 2014 was 83.4 per 100,000. The rate was higher in NYC (94.1 per 100,000) than outside of NYC (75.7 per 100,000). Yet although NYC has historically been the epicenter of the State’s HCV epidemic, in 2014 more than half (51.2%) of new chronic hepatitis C cases were diagnosed outside of NYC.¹

Since 2004, in NYS there has been a shift in the age distribution of reported HCV cases from being primarily among persons aged 40-60 years to being reported among a growing second cohort of persons aged 20-40 years. This shift is especially striking outside of NYC. Recent increases of HCV are occurring outside of NYC among young people who inject drugs, which parallels the growing epidemic of prescription opioid abuse seen in suburban and rural areas. There has also been a shift in the distribution of cases by sex. In 2004, females accounted for 31.9% of HCV cases reported outside of NYC. This proportion increased to 38.2% in 2014.² HCV is of special concern for women of childbearing age because of the risk of perinatal transmission and the fact that HCV treatments are contraindicated for pregnant women due to the medications’ teratogenic impact on the fetus.

We Can Eliminate HCV in NYS

In the spring of 2016, VOCAL-NY and other community organizations active in the HCV response partnered with the NYS DOH and NYC DOHMH to consider and build consensus on the opportunity for statewide HCV elimination. This effort was informed by the achievements of the statewide ending the HIV/AIDS epidemic initiative, a National Academies of Medicine report on eliminating hepatitis B and C in the U.S., and HCV elimination targets set by the World Health Organization (WHO). A broad
committee of 94 stakeholders—state and local government representatives; epidemiologists; physicians; harm reduction and social service providers; and community advocates—came together to develop recommendations to inform a statewide plan to eliminate HCV infection. Between September and mid-December, work groups met to draft and prioritize recommendations in five areas of focus: prevention; testing and linkage; care and treatment access; data, surveillance and metrics; and social determinants of health. These work group recommendations, which should be considered and advanced during a more formal Task Force process, support the following five pillars for a statewide HCV elimination plan:

1. Enhance HCV prevention, testing and linkage to care services for people who inject drugs, people who are incarcerated, men who have sex with men, and other populations disproportionately impacted by HCV infection.

2. Expand HCV screening and testing to identify people living with HCV who are unaware of their status and link them to care.

3. Provide access to clinically appropriate medical care and affordable HCV treatment without restrictions, and ensure the availability of necessary supportive services for all New Yorkers living with HCV infection.

4. Enhance NYS HCV surveillance, set and track HCV elimination targets and make this information available to the public.

5. Commit NYS government and elected officials, public health professionals, HCV experts, and industry partners to leadership and ownership of the NYS Plan to Eliminate HCV alongside community members living with and affected by HCV.

Community led activism and service provision have defined NYS’s HCV, HIV and opioid epidemic responses, but these efforts have been most successful when done in collaboration with state and local government, public health professionals, service providers, researchers, and the private and nonprofit sectors. People living with, cured of, and affected by HCV must have meaningful involvement in decision making at all stages of the planning and implementation process.

The five community pillars along with priority work group recommendations will be publicly presented at the NYS Hepatitis C Elimination Summit on February 7, 2017. State and local officials, elected representatives, HCV primary care and social service providers, and community stakeholders will have the opportunity to respond to and endorse this community consensus statement.

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ii https://www.nastad.org/domestic/viral-hepatitis


v NYS Department of Health. NYS Epidemiological Profile, 2014. (September 2016)

vi NYS Department of Health. NYS Epidemiological Profile, 2014. (September 2016)