

## FINDINGS FROM THE

# Ending the Viral Hepatitis Epidemics Assessment

Examining Health Department Infrastructure and TA Needs

### BACKGROUND

The World Health Organization (WHO) has committed to eliminating hepatitis B and C by 2030. The National Academies of Sciences, Engineering, and Medicine (NASEM) determined elimination is feasible within the U.S. and provided recommendations and targets for accomplishing this goal. The U.S. Department of Health and Human Services (HHS) Office of Infectious Disease and HIV/AIDS Policy (ODIP) is working to update the National Viral Hepatitis Action Plan to include elimination targets. Despite the momentum underway to plan for hepatitis elimination, there are significant gaps in the current infrastructure at the national, state, and local levels that must be addressed in order to make elimination a reality.

In 2019, NASTAD developed and disseminated a comprehensive needs assessment to identify areas of need critical to jurisdiction-specific elimination and strategic planning efforts. The assessment tool explores program strengths, challenges, gaps, and other information critical to grasp and address the unique needs of health department viral hepatitis programs.

### METHODOLOGY

NASTAD disseminated the *Ending the Viral Hepatitis Epidemics: Health Department Infrastructure and TA Needs Assessment* (“Hepatitis Needs Assessment”) between February and March 2019 to better understand the current state of health department viral hepatitis programs and services. The assessment tool was distributed to health department viral hepatitis programs throughout the nation and covered eight primary topics.

#### Needs Assessment Topic Areas

- Hepatitis Program Infrastructure
- Community Engagement and Strategic Planning
- Provider Engagement
- Harm Reduction and Prevention
- Epidemiology and Surveillance
- Testing and Linkage to Care
- Care and Treatment
- Stigma

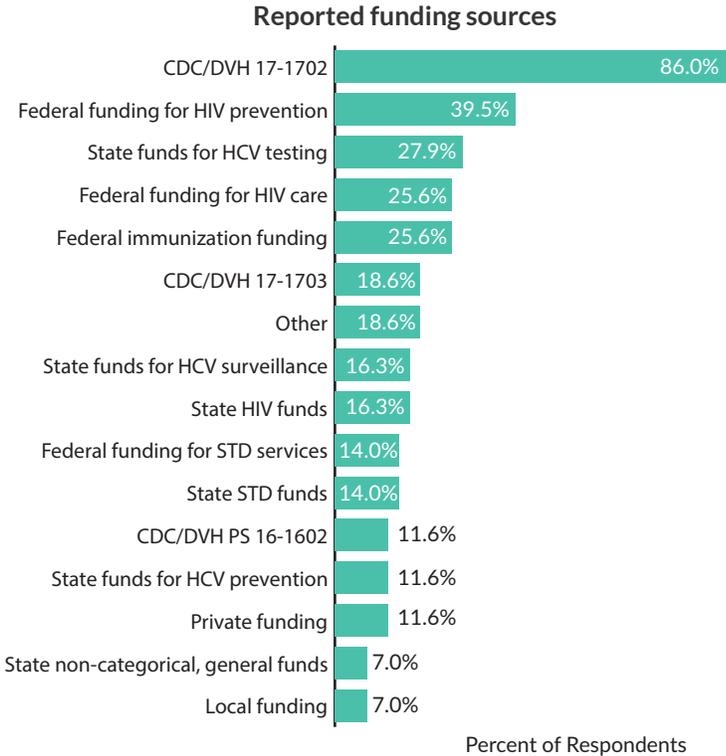
NASTAD received 43 complete assessments from states and directly funded local jurisdictions.



# HEPATITIS PROGRAM INFRASTRUCTURE

A recurring theme in this section of the assessment is the wide range of funding levels that exist for health department hepatitis programs. Nearly all respondents (n=42) report receiving funding from the Centers for Disease Control and Prevention’s (CDC) Division of Viral Hepatitis 17-1702<sup>2</sup>, though funding levels vary by jurisdiction. Close to 41% of respondents report receiving local (non-state) hepatitis funds and 45% report receiving private hepatitis funds.

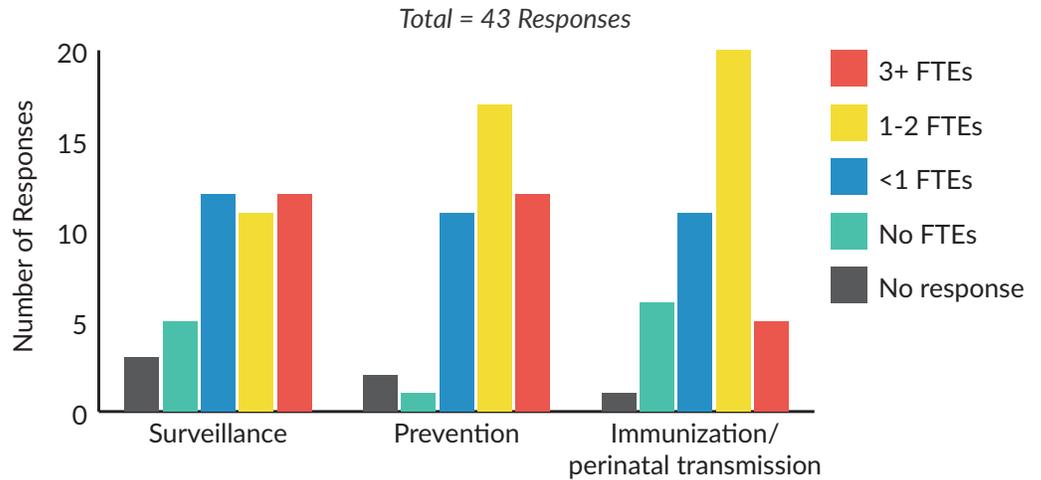
**FIGURE 2. Funding for Health Department Viral Hepatitis Programs by Source**



Health Departments overwhelmingly noted the need to increase staffing in order to provide broader hepatitis capacity (*surveillance, prevention, access to treatment, and linkage to care*). Most jurisdictions have on average one to two full time equivalent (FTE) staff per program area, with many not having a staff person designated for surveillance. Ideally, according to respondents, each program would have at least three full time staff or more to do the work of their program (*see figures 3 and 4 below*). This demonstrates that in order to make a meaningful impact on the road towards elimination, increased investment needs to be made in health department hepatitis programs to facilitate hiring more staff. Not only is there great need for additional staff, but several respondents emphasized that activities are distributed across different departments, making it difficult to coordinate hepatitis initiatives in an efficient and effective manner.

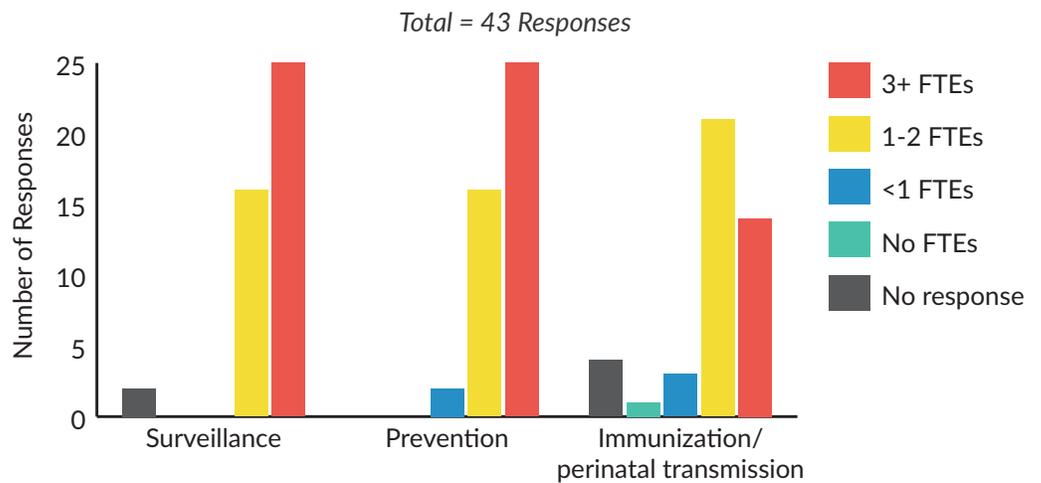
<sup>2</sup> CDC’s Improving Hepatitis B and C Care Cascades, Focus on Increased Testing and Diagnosis (17-1702) is a cooperative agreement with states and larger jurisdictions that was developed to improve hepatitis B and C care cascades and in increase testing and diagnosis through partnerships with Federally Qualified Health Centers (FQHCs).

**FIGURE 3. Actual Reported FTE Support by Work Area**



- ▶ Responses range from 0-16 assigned staff with FTE ranging from <25% - 100% devoted time to hepatitis programs.
- ▶ FTE positions include viral hepatitis coordinators, program managers, epidemiologists, nurses, and social workers.

**FIGURE 4. Needed FTE Support by Work Area**



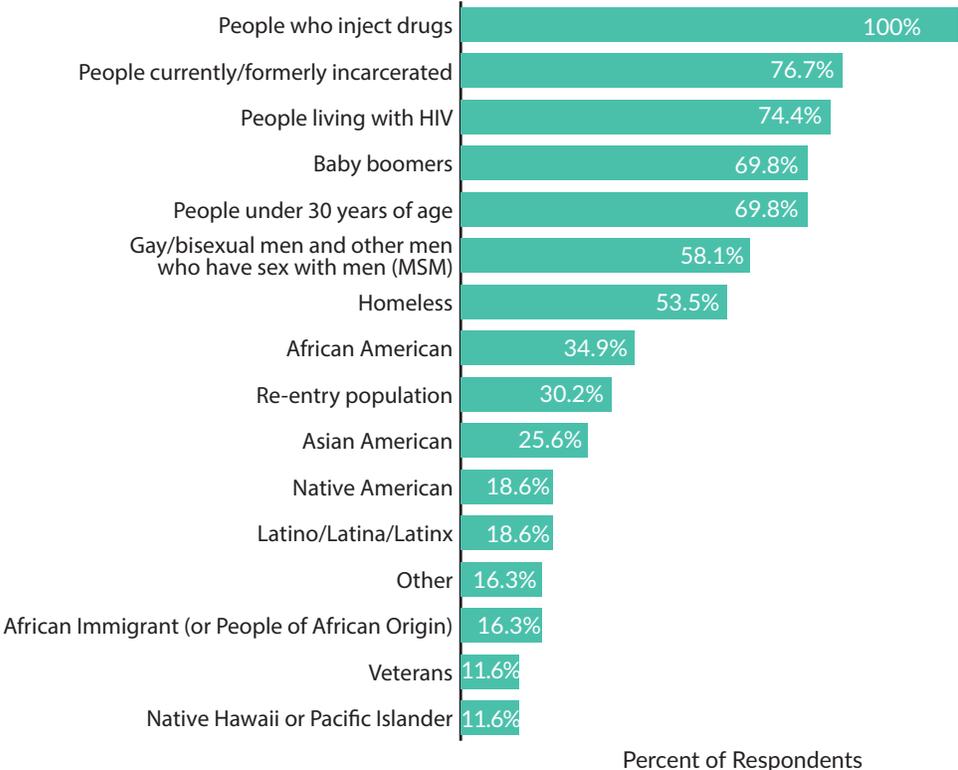
- ▶ All respondents indicated a need to increase FTEs with a desire for 100% of their time devoted to hepatitis programs.
- ▶ One jurisdiction requested up to 15 FTEs to establish regional patient navigators and others specified an increase in FTEs pending time of year and hepatitis outbreak response needs.

The hepatitis infrastructure needs identified by health departments are very diverse, as each jurisdiction has varying staff capacity, infrastructure, and a variety of priority areas and populations which require a range of support. The top five technical assistance priorities identified by health departments are surveillance, data and analytics, funding, planning support, and capacity building.

# COMMUNITY ENGAGEMENT AND STRATEGIC PLANNING

Health departments cannot work towards eliminating viral hepatitis in their jurisdictions without meaningfully engaging communities that are most impacted. The Community Engagement and Strategic Planning section of the needs assessment explores jurisdiction-specific approaches to addressing hepatitis among key populations and meaningful engagement of community stakeholders, including people living with or whose lives are affected by viral hepatitis, in programming and strategic planning. The populations identified by respondents as priority or a primary focus of health department-led hepatitis efforts are people who inject drugs (100%), people experiencing incarceration (76.7%), and people living with HIV (74.4%). Additional populations prioritized for hepatitis programming include people under 30 years of age (69.8%), baby boomers (69.8%), and gay, bisexual, and other men who have sex with men (58.1%), respectively.

**FIGURE 5. Reported Priority Populations for Hepatitis Engagement**



Both the WHO and NASEM point to the importance of strategizing to identify resources and deliver core services in order to eliminate viral hepatitis. Nationally, health department viral hepatitis programs are engaged in significant efforts to coordinate jurisdiction-wide programs and services through strategic and elimination planning. More than half of respondents (53%) report having a final or draft strategic or elimination plan in place. Most (60.5%) of those respondents who do not currently have a draft or final plan, report that a plan is currently being drafted or will be completed within one year.

*“HIV-specific strategic planning could be expanded to include hepatitis, at local and national levels.”*

As noted above, establishing and strengthening relationships with people living with or affected by viral hepatitis is critical to planning and integrating their voices and expertise is

essential. In response to the question of how people living with viral hepatitis are engaged in the respondents' hepatitis response and planning efforts, over a third of respondents convene advisory committees with participants who are living with or cured of hepatitis and/or currently invite people living with hepatitis or cured of HCV to participate in elimination planning (32.6%). Additionally, health departments provide the broader advocacy community with viral hepatitis data to inform their efforts (79.1%) and meet with advocates on a regular basis (65.1%). However, under half (41.9%) report that they plan to invite individuals living with or cured of hepatitis to participate in planning in the future, but do not currently engage them in planning. These results underpin the importance of delivering technical assistance aimed at improving the capacity of health departments to meaningfully engage the communities they serve in viral hepatitis planning and decision-making.

Finally, this section of the needs assessment looks at policy levers used to advance jurisdictional hepatitis efforts. A majority of health departments (88.4%) track and/or support policy changes related to HCV prevention and treatment. Policy efforts occur primarily at the state-level (46.5%) and primarily focus on HCV treatment coverage in Medicaid programs (72.1%), naloxone access or distribution (51.2%), and syringe access (46.5%). In order to establish more comprehensive policies to support viral hepatitis activities, respondents note a need for technical assistance in the areas of policies that support population-specific outreach to those with greatest need (53.5%), substance use treatment including medication assisted treatment (37.2%), syringe decriminalization (34.9%), and data sharing (34.9%).

*“We work with community advocates to secure funding for community organizations to support hepatitis B and C navigation, and clinical and non-clinical provider training programs.”*

## HARM REDUCTION AND PREVENTION

People who use drugs (PWUDs) must be prioritized in health department efforts to address viral hepatitis and have to be included in meaningful ways. Supporting opportunities for leadership by people who use drugs and ongoing participation from planning to implementation and evaluation is critical.

Over 46% of respondents directly support legal syringe service programs (SSP) using hepatitis program funds, while 41.5% are in the process of implementing SSPs. Some SSPs have been approved but not implemented, whereas others are in the developing stages and will be implemented pending legislation. For legal SSPs, several venues were identified as top settings in which they operate:

- ▶ Community Based Organizations (CBOS), 74.4%
- ▶ Mobile Vans, 62.8%
- ▶ Local Health Departments, 44.2%
- ▶ Peer Based Exchange, 39.5%

Respondents indicate that HCV testing is the number one service supported through hepatitis programs at SSPs (58.1%) while 44.2% support linkage to HCV related medical care. Other services offered include, syringe disposal (48.8%), wound abscess care (32.6%), condom distribution (55.8%), linkage to housing, education and job training (34.9%) and overdose prevention (44.2%), including naloxone training and distribution. Fourteen percent offer medical assisted therapy (MAT) and 9.3% offer mental health services. Hepatitis A and

hepatitis B vaccinations are offered, specifically twelve jurisdictions (27.9%) provide adult HAV and HBV vaccinations at their legally operating SSPs. Five jurisdictions limit HAV and HBV vaccination services to periods of reported outbreaks.

Several respondents indicate a need for technical assistance on how to best advocate for harm reduction models and obtain buy-in from stakeholders, state staff, and community members who do not agree with proposed harm reduction initiatives. Another barrier identified is a lack of provider education and willingness to treat HCV among PWUD, which perpetuates the cycle of stigma as a barrier to care.

*“There are very little harm reduction efforts given the climate of stigma and limited leadership support.”*

Some health department staff noted that harm reduction should be more integrated into HIV and HCV prevention and care in order to leverage funding and coordination for drug user health and SSPs as health departments can directly contribute to effective operationalization.

## DETERMINATION OF NEED (DON) FOR SYRINGE SERVICES PROGRAMS

CDC has [developed guidance](#) and consults with state, local, tribal, and territorial health departments to determine if a jurisdiction is experiencing or at risk for significant increases in hepatitis infections or an HIV outbreak due to injection drug use. In this needs assessment, there were 25 respondents (58.1%) who indicated that they submitted DON requests to CDC to use federal funds for SSPs, and 24 of the 25 were accepted—the remaining one had a request pending as of March 2019.

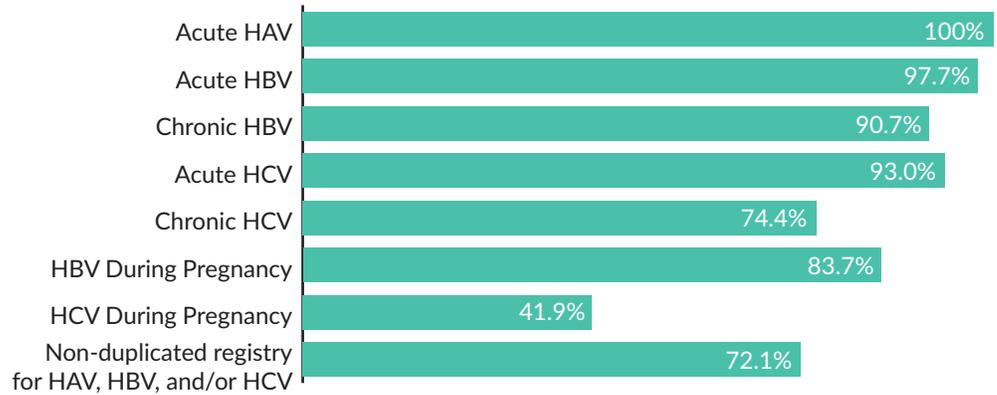
Eighteen jurisdictions (41.9%) noted difficulty obtaining funding for harm reduction and syringe exchange services. NASTAD will utilize HepTAC and the expertise of its consultants to provide needed support to jurisdictions with a DON submission to CDC on how to most effectively apply federal funding to evidence-based harm reduction strategies.

## EPIDEMIOLOGY AND SURVEILLANCE

Responding to viral hepatitis epidemics requires a better understanding of the burden of disease to both fully recognize the scope of the problem and to be able to target prevention, screening, treatment, and other interventions. Surveillance for viral hepatitis is woefully underfunded, fragmented, and needs to be strengthened to achieve elimination in the U.S. Currently, only 14 states receive funding to support hepatitis surveillance through CDC’s Division of Viral Hepatitis Strengthening Surveillance in Jurisdictions with High Incidence of Hepatitis C Virus and Hepatitis B Virus Infections (17-1703) cooperative agreement.

Surveillance plays a critical role in elimination planning and strengthening this infrastructure is essential. Having a formal viral hepatitis surveillance infrastructure is critical to accurately estimate prevalence and understand how many people within a jurisdiction are living with hepatitis at any given time. It is also important to have a registry to be able to identify who is living with HCV and track those individuals as they move through the continuum to cure. Further, core surveillance is needed to establish realistic elimination targets and goals, and to track progress and success along the way.

**FIGURE 6.** Percentage of Health Departments that Report Receiving or Collecting Surveillance Data



Health departments receive large amounts of data related to hepatitis such as acute HAV, acute HBV, chronic HBV, acute HCV, chronic HCV, HBV during pregnancy and HCV during pregnancy through electronic lab reports and passive surveillance. The majority, 72.1%, also maintain non-duplicated registries for HAV, HBV, and/or HCV but most respondents note that they do not have the infrastructure or staff capacity to analyze or use these data in their programs.

Less than a quarter of respondents (20.9%) receive enzyme negative immunoassays (EIA)/antibody tests and less than half (39.5%) receive negative RNA results. This poses a barrier to jurisdictional understanding of treatment and cure rates. In work external to this assessment, health departments have expressed difficulty or complete inability to access pharmacy data and as a result often rely on negative results reported through laboratories to assess treatment.

One theme that emerged is limited data sharing with stakeholders, even in jurisdictions where viral hepatitis surveillance currently exists. While 64.7% of respondents have jurisdictional epidemiological profiles that are updated regularly, less than half (41.9%) present these results to providers in the state or put the information together in a more accessible way such as through infographics (46.5%). Even fewer (25.6%) host meetings to share the results with community partners. Strengthening surveillance infrastructure and creating bi-directional engagement with key stakeholders in data collection, such as having community partners inform the information that is collected and sharing out reports such as state epidemiology profiles in accessible and easy to understand ways, is a key piece in engaging the community and raising awareness of the need to better respond to hepatitis, all of which build a strong foundation for elimination planning.

**FIGURE 7. Jurisdictions that Report Having a Viral Hepatitis Epidemiologic Profile or Report**

Has your state and/or city created an epidemiologic report or profile?



Regularly updated?  
N=29



How is profile disseminated? N=29

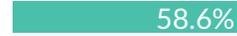
Posted report or profile on the health department website



Used the information in the report to create infographic or other resources



Presented the epi profile to providers in the state



Sent out the epi profile to providers in the state



Hosted a community meeting to share profile or report



Other



Micro-elimination has emerged as an opportunity to initiate work towards elimination and curing people who are co-infected with HIV and HCV is a good place to start. Although health departments conduct regular matches between their HIV and HCV registries (64.7%), only 25.6% of respondents are able to track the number of people living with HIV who have been screened on a regular basis (annual) and only 44.2% are able to track the number of people treated for HCV in ADAP.

The greatest need identified by health departments is increased staffing capacity. Other common themes are access to non-surveillance data sources such as all payer claims and Medicaid databases, receiving and using negative results (antibody and RNA), using data to inform prevention efforts, hepatitis B surveillance, developing care cascades, best practices for a hepatitis surveillance program, tracking indicators for HCV re-infection, estimating prevalence, and case investigation.

*“Our greatest technical need is staff time. We have lots of data sources, but we do not have the staff time to routinely complete the data analyses needed for viral hepatitis.”*

## TESTING AND LINKAGE TO CARE

Currently, 75% of the estimated 5.3 million Americans living with viral hepatitis are undiagnosed. Efforts to diagnose and link individuals to care need to significantly increase to have an overall impact on the care continuum and move towards elimination.

In 2018, health departments and/or health department supported programs (51.2% of responses included these data) conducted 22,847 HBV (HBsAG) tests. The range for health departments was 30 to 13,144 tests. Health departments and/or health department supported programs (64.7% of responses included these data) conducted 431,721 HCV screening and confirmatory tests. The range for health departments was between 100 and 160,115 tests. The top three sites where health departments support testing are federally qualified health centers (FQHC), community-based organizations (CBOs), and HIV sites (routine testing, targeted testing, expanded testing initiatives, outreach, testing and linkage).

**FIGURE 8. Reported Settings Where Health Departments Conduct or Fund Viral Hepatitis Testing**



The top two strategies health departments or health department-supported providers use to facilitate linkage to confirmatory testing and care include providing clients with contact information alone (74.4%) or following up with a phone call to check-in with the client (58.1%). Over half (58.1%) have also instituted reflex testing to ensure that the confirmatory testing process is automated. Only half (53.5%) of health departments support clients in setting up appointments and/or escorting them to a visit (30.2%) both of which are known to improve linkage to care outcomes.

The biggest facilitators to linkage to care, according to respondents, are having a provider champion (48.8%), dedicated funding and staff focused on linkage (41.9%), and co-located services (37.2%). These results highlight the need to invest further into this part of the continuum so programs can support their clients to overcome the barriers that stand in the way of them getting into care.

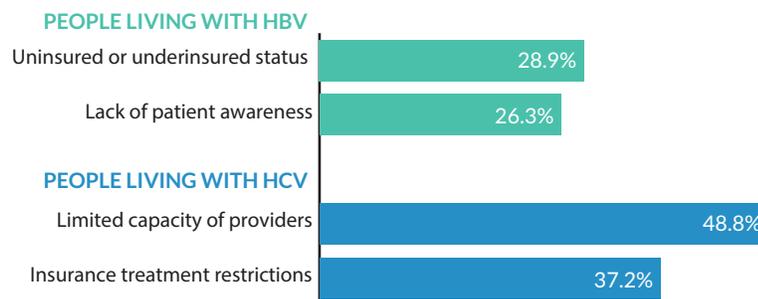
The technical assistance needs identified in the assessment related to testing and linkage to care focus on identifying funding to pay for testing and linkage, such as billing, ensuring reflex and confirmatory tests are done, targeting testing and other interventions without surveillance data, and strategies/best practices for linkage to care, particularly for people that experience more barriers to navigation to care, such as people who use drugs.

*“We are increasingly trying to move toward co-located treatment as opposed to traditional linkage/navigation services (i.e. low threshold HCV treatment access at syringe access programs, etc.)”*

## CARE AND TREATMENT

Direct acting antivirals with efficacy over 95% have created the opportunity to cure HCV, making elimination feasible. For HBV, current antiviral medications are effective at slowing down the virus and preventing liver damage and can help prevent HBV transmission to others. To achieve elimination, treatment as a form of prevention should be prioritized among people most at risk of spreading the virus. Whether providing treatment through health department-based clinical services, syringe services, and drug treatment programs or coordinating access, health departments have an important role to play to ensure quality viral hepatitis care and treatment. When asked about the two most significant barriers to treatment access for people living with HBV and people living with HCV in their jurisdictions, respondents were asked to “select all that apply”. The most common barrier to treatment cited for people living with HBV was uninsured or underinsured status (28.9%) and lack of patient awareness (26.3%); for people living with HCV it was limited capacity of providers to treat HCV and related conditions (e.g. substance use) (50.0%) and lack of provider awareness (21.1%), followed by Medicaid treatment restrictions based on fibrosis stage, substance use, and provider type.

**FIGURE 9. Most Common Barriers to Treatment**



*“We have learned that success may take a long time, but that persistence can pay off (i.e. removal of fibrosis and sobriety restrictions for state Medicaid).”*

These responses speak to the need to enhance provider capacity and education to improve provider and patient awareness and improve policies related to treatment financing to expand access.

### Capacity to Manage and Treat Viral Hepatitis

Treating viral hepatitis will require a scaling up of the clinical workforce, provider training and education, and clinical infrastructure enhancement. A larger workforce is needed to address the nation's significant viral hepatitis burden. Scaling up the size of the clinical workforce that prescribes antiviral therapies to treat or cure viral hepatitis requires expansion from specialists (i.e. gastroenterologists, hepatologists, infectious disease) to primary care clinicians. Building the capacity of primary care providers to address viral hepatitis is a primary recommendation for achievement of the *National Strategy for the Elimination of Hepatitis B and C*. To expand primary care capacity to treat viral hepatitis, clinicians need training to embed them with the skills to effectively screen, diagnose, and treat viral hepatitis, especially among key populations such as people who use drugs (PWUD). Additionally, clinicians must also be able to effectively communicate to patients the benefits and risks of viral hepatitis treatment and describe potential barriers patients may encounter with treatment coverage. Health departments are engaged in significant efforts to provide and support comprehensive training and education for clinical providers. Currently, 48.7% of health departments provide direct in-person provider training via mechanisms such as provider detailing and 43.6% offer formal provider training through a telehealth or videoconference program (e.g. Project ECHO). When asked about barriers to implementing provider training and education programs as well as technical assistance needs in this area, respondents pointed to limited funding for program development, incentivizing clinician participation, identifying clinical trainers, and incorporating clinical principles/standards for treating people who use drugs. NASTAD will develop technical assistance resources that prioritize addressing the identified barriers in the implementation of provider training and education programs.

## STIGMA

Stigma related to HBV, HCV, and drug use are one of the biggest barriers to accessing prevention, testing, and care. Addressing stigma and discrimination is critical to ensure people can access the care they need and is essential in any efforts towards hepatitis elimination.

Health departments are working to address stigma and discrimination in several ways including harm reduction training, the use and promotion of "people first" language, and storytelling campaigns. Health departments identify this as a huge priority but have been limited in their ability to address it due to a lack of dedicated resources, limited capacity, and competing priorities. The technical assistance needs identified in this section of the assessment focus on changing the mindset of providers and the public to see drug use as a health and medical issue that should be addressed using a public health response, examples of anti-stigma media campaigns and programs established by health departments as models to address stigma that can be translated to other jurisdictions, how to engage providers in rural communities, and how to normalize routine testing for HCV to remove the stigma of risk-based testing.

*"We would love to be able to do this work, but we can barely keep our program doors open with surveillance and testing at the current time. Lack of capacity to address overarching social justice issues."*

## CONCLUSION

Health department hepatitis programs face many challenges including limited infrastructure, unreliable funding, and incredible work that needs to be done. Despite these challenges, hepatitis programs have been able to expand access to services across the continuum and many are engaged in at least preliminary discussions about elimination. NASTAD will use the data collected through this assessment to further enhance the capacity of health department hepatitis programs to respond to and eliminate viral hepatitis through its Hepatitis Technical Assistance Center—HepTAC.

NASTAD sincerely thanks all of the health department leadership and staff that responded to the *Ending the Viral Hepatitis Epidemics: Health Department Infrastructure and TA Needs Assessment*. We sincerely appreciate the time devoted and your continued commitment to addressing viral hepatitis.

For more information, email [hepatitis@nastad.org](mailto:hepatitis@nastad.org)



@NASTAD



@nastad1992



[www.nastad.org](http://www.nastad.org)