

ACCESS
engage
& **ACTIVATE**
RECENTERING
KEY POPULATIONS

SUCCESS STORY

Leading with Lived Experience: Informing Health Department Viral Hepatitis Elimination Programs



**TARGET
POPULATION**

People who inject drugs (PWID) and priority populations



LOCATION

Nationwide



**FUNDING
SOURCE**

This is a five-year CDC cooperative agreement, award #: PS21-2105.

| SUMMARY

The Hepatitis Network for Education and Testing (HepNET) is a partnership between NASTAD, National Viral Hepatitis Roundtable (NVHR) and the National Association of County and City Health Officials (NACCHO), supporting state and local health departments (HDs), community-based organizations (CBOs), clinical providers, people with lived experience, syringe services programs (SSPs) and harm reduction programs, and other key partners to identify and address the unmet needs of people who inject drugs (PWID) and improve their access to viral hepatitis education, prevention, testing, linkage to care, and treatment.

NASTAD and its partners provide technical assistance and training to a network of over 200 members with a focus on hepatitis B and hepatitis C testing and linkage to care. Network members are the individuals and organizations who make up HepNET, with the shared aim of reducing inequities in viral hepatitis care among PWID.

| CORE ACTIVITIES

Who are HepNET Leading with Lived Experience (LLE) Consultants?

HepNET onboarded three consultants with lived hepatitis and/or substance use experience in October 2022. They underwent a three-month training series, led by two experts with lived experience, who provided coaching on leadership development, built knowledge and skills on viral hepatitis, and harm reduction, and how to use their lived experience as an advocacy tool. Upon completion of the training, the LLE Consultants now provide TA to the three jurisdictional

learning community cohorts. Learning Communities are select cohorts of network members who receive intensive TA from NASTAD, partners, and LLE consultants.

Learning Communities – Strengthening Partnerships

In February 2023, HepNET launched the first Learning Community (LC), welcoming three jurisdictions who expressed interest in strengthening partnerships between health departments, community-based and tribal organizations, people with lived and living experience, healthcare providers, and other entities to improve health equity for people who inject drugs (PWID) and priority populations.

There are active participants from Houston, Idaho, and New Hampshire who receive direct technical assistance (TA) from HepNET consultants with lived expertise in viral hepatitis care for people who inject drugs.

The LC Members work collaboratively with HepNET partners and consultants to engage in peer-to-peer learning, providing examples of how to strengthen health department and community partnerships in their respective jurisdictions. Activities include *case-based presentations, asset-mapping guidance, equity grounding, and populating goals, activities, and action steps to strengthen partnerships with viral hepatitis and harm reduction programs.*

Strengths & Data: Impact and Awareness

Impact: Increase knowledge and awareness for Learning Community members

“...the effect of multiple forms of discrimination that intersect and further marginalize PWID, including racial and ethnic communities, people born outside of the US, women of color, LGBTQIA people, people engaged with the criminal justice system, people experiencing homelessness, and other groups, with resulting disparities in hepatitis outcomes.”

“...to address inequities in hepatitis morbidity and mortality for priority populations and promote or provide hepatitis services through partnerships in a variety of settings to effectively reach PWID.”

Qualitative data from Learning Community Members:

“...love the inclusivity and representatives of the leadership and the opportunity to learn from and collaborate with two other jurisdictions at different point in their harm reduction evolution.”

“The ability to collaborate and coordinate with key players in the field”

“The HepNET structure is proving super helpful for making nodes and strands of our local web visible to make connections and build partnerships.”

Impact: Increase knowledge and awareness for LLE Consultants

...how to teach providers about stigma and the deficits in patient/provider relations

...how to share their story as an advocacy tool

...knowledge of race, equity, and health disparities in communities of color as it relates to viral hepatitis

Qualitative data from LLE Consultants:

“The trainers created an environment of relatedness, dignity, and respect. Everyone’s honest and vulnerable engagement in a professional setting is a radical act that challenges our traditional, often oppressive systems and structures.”

“Participating in the training was an invaluable experience. It deepened my understanding of the project itself and allowed me to see firsthand the transformative impact of professional development designed for leaders with lived experience

“I am so proud to work with NASTAD on the HepNET project as an LLE consultant. It is my hope that sharing my experience navigating my own diagnosis, treatment, and cure will help health care agencies and providers design care mechanisms that work for patients and set them up for success.”

Limitations

- Between Idaho, Houston, and New Hampshire there are similar opportunities and challenges faced to strengthen partnerships, but there are also systemic barriers between jurisdictions that don’t allow for models to be adapted, i.e., state policy/advocacy initiatives
- The 2023 LC cohort was a five-month pilot. NASTAD recognizes that more time is needed to devote to group sessions and additional time for office hours for jurisdictions and the LLE Consultants.
- Working with systems that have internal limitations to equitably compensate people with lived experience. NASTAD is developing an incentives guide resource for how health departments can advocate for equitable pay i.e., cash, transportation, etc.

Stakeholders

HepNET Partner Team: NASTAD, NVHR, NACCHO

HepNET LLE Consultants: Donte Smith, Dziko Singleton, Jennifer Sharp

HepNET Training Consultants: Nick Voyles, Tina Reynolds

LC Members: Idaho, Houston, New Hampshire
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