

Ending the HIV Epidemic in the U.S. Initiative 2021 Community Engagement Listening Sessions

Executive Summary

In 2021, the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB) hosted 16 virtual *Ending the HIV Epidemic in the U.S.* (EHE) initiative community engagement listening sessions in the [10 U.S. Department of Health and Human Services regions](#). For each region, HRSA HAB offered two sessions: (1) a public health leader roundtable and (2) a community member listening session.

These sessions provided a direct line of communication among HRSA, public health leaders, and community members in EHE jurisdictions. Participants included people with lived experience; healthcare providers; community leaders; and organizations involved in HIV prevention, care, and treatment. In total, more than 1,900 participants attended at least one of the sessions.*

Participants in HRSA HAB's EHE Listening Sessions

Listening session participants included—

- community-based organizations, including organizations focused on housing, mental and behavioral health, youth, and LGBTQ+ support
- state and local health departments
- federal agencies
- Federally Qualified Health Centers and look-alikes
- faith-based organizations
- people with HIV and clients served by the Ryan White HIV/AIDS Program (RWHAP) and by HAB EHE recipients
- RWHAP AIDS Education and Training Centers
- other RWHAP organizations
- other individuals who are not captured in the categories above

Leaders from the HRSA Bureau of Primary Health Care, the HRSA Office of Intergovernmental and External Affairs, and the Centers for Disease Control and Prevention Division of HIV Prevention also were in attendance.

Listening Session Topics

The listening sessions were guided by questions on the following topics: (1) barriers to and opportunities for effective HIV prevention and treatment; (2) innovative approaches to enhance HIV prevention and treatment; and (3) current and future partners for collaboration outside of the medical and public health communities.

* Please note, this document is a high-level summary of the feedback and suggestions offered during the 16 listening sessions and does not include all the comments and ideas shared during the sessions.



Background

The Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB) oversees the Ryan White HIV/AIDS Program (RWHAP) and has a leading role in the *Ending the HIV Epidemic in the U.S.* (EHE) initiative. Community engagement has been fundamental to HRSA's success since the beginning of the RWHAP. HRSA HAB believes our collective success in meeting the goals of the RWHAP and EHE initiative depends on how well we engage people with HIV and their communities in the planning, development, and implementation of HIV care and treatment strategies.



Key Themes

Several key cross-jurisdictional themes emerged during the listening sessions:

- Building peer navigators' and community health workers' capacity:** Participants discussed the importance of empowering and increasing the number of peer navigators and community health workers (CHWs) and the number of organizations that use them to help engage people with HIV. Many believe that peer navigators instill clients with a greater sense of trust and confidence than medical professionals do because they have invaluable connections and ties to people with HIV and the HIV community. Participants also emphasized the need for competitive pay and standard certification for CHWs and peer navigators, as well as the creation of programs that enable people to pursue full-time careers as peer navigators and CHWs.

"[Being a peer navigator] is a full-time career track—not a part-time pit stop on the way to something else."

- Breaking down federal funding stream silos and improving collaboration:** Many participants noted that the disparate, insular nature of federal funding streams leads to silos in HIV funding and the treatment of people with HIV. Discussions focused on the need for improved collaboration across the RWHAP Parts and initiatives and with other federal agencies, including the U.S. Department of Housing and Urban Development (HUD) and the Substance Abuse and Mental Health Services Administration.

- Feedback on the EHE initiative:** Overall, participants found the EHE initiative to be too narrow in terms of metrics, regions, and key populations. Some also considered the EHE initiative to be too biomedically focused. Participants suggested adding a Quality Performance Measure or Quality of Life/Health indicator to the EHE initiative to assess the patient's general wellness in addition to their viral suppression.

"What's missing is heart ... How do we engage communities? Make sure people see themselves in these approaches."

- Social determinants of health:** Participants discussed the need for federal funding to further address underlying and pervasive issues in economic stability, education access and quality, and healthcare access and quality. They highlighted the impact of the coronavirus disease 2019 (COVID-19) pandemic as related to the availability of affordable housing, food insecurity, and mental health care—critical challenges that already were greatly affecting people with HIV. To address gaps in mental health care, participants suggested creating mental health first aid programs and improving coordination and integration with substance use disorder programs.

- Stigma as a barrier to accessing care:** Participants discussed how stigma is a universal barrier to HIV care, prevention, and treatment. They described the public's apathy and general lack of knowledge around HIV and highlighted how closely HIV-related stigma is tied to greater health disparities. Across all listening sessions, participants called to end the "tokenization" of people with HIV as a valid form of participation. Many participants believe that hiring more people with HIV in federal, state, and local public health organizations would be a good first step toward bringing people with HIV to the table in a meaningful way.

"Listen to me—don't just use me to check off the box. End tokenization. Get rid of the ivory tower effect in agencies managing funding for HIV, and get more people with lived experience in."

Additional Noteworthy Themes

During many of the listening sessions, participants also discussed the need for **better access to data and a centralized data system for EHE, enhanced funding support for pre-exposure prophylaxis (PrEP) and non-occupational post-exposure prophylaxis (nPEP), and increased use of social media platforms** to promote prevention and treatment education messages and connect with the HIV community.



HRSA HAB Moving Forward

Community members provided substantial ideas and suggestions throughout the EHE listening sessions, many of which touch on activities already underway. HRSA HAB has implemented policies, projects, and initiatives to address many of these key themes. For example, HRSA HAB—

- Released [policy clarification notices \(PCNs\)](#) to reduce the administrative burden on RWHAP recipients. [PCN 21-01](#) reduces the documentation that must be submitted to HRSA HAB when RWHAP recipients request waivers. [PCN 21-02](#) eliminates the 6-month recertification requirement, allowing RWHAP recipients and subrecipients to conduct timely eligibility confirmation in accordance with their policies and procedures.
- Published a [program letter](#) to reaffirm the importance of providing gender-affirming healthcare and services in the RWHAP. This guidance supports HRSA's efforts to reduce health disparities and improve access to HIV care, medication, and support services for transgender and gender diverse people with HIV.
- Released several [notice of funding opportunity \(NOFO\) announcements](#) to address social determinants of health and quality of life for people with HIV. These include NOFOs to improve

health outcomes for people aging with HIV, implement and evaluate housing-related interventions and strategies for people with HIV experiencing unstable housing, and identify and maximize telehealth strategies that improve health outcomes for people with HIV.

- Partners with HUD, which runs the federal Housing Opportunities for People with AIDS Program, to address the housing needs of our RWHAP clients.
- Funds [RWHAP Part F Special Projects of National Significance \(SPNS\)](#) initiatives to develop innovative models of HIV care and treatment that address the needs of RWHAP clients, especially for Black women, transgender women, and Black men who have sex with men (e.g., [E2i](#) and [Black Women First](#)). Other SPNS-funded initiatives aim to [leverage CHWs](#) to improve linkage to and retention in care, address [HIV-related stigma](#), [increase organizational capacity](#) to hire people with HIV, and design and implement interventions that coordinate [HIV care and treatment with housing and employment services](#).

HRSA HAB staff continue to integrate the feedback garnered during these community engagement listening sessions while preparing the HRSA HAB implementation plan for the [National HIV/AIDS Strategy \(2022-2025\)](#) and planning future policy and program implementation.

Acknowledgments

HRSA HAB would like to acknowledge the important work that RWHAP recipients and subrecipients, community leaders, healthcare providers, people with lived experience, and organizations involved in HIV prevention, care, and treatment have been doing in support of ending the HIV epidemic in their jurisdictions and communities. HRSA HAB is thankful for their participation and candid contributions during the 2021 Ending the HIV Epidemic Virtual Public Health Leader and Community Engagement Listening Sessions.

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