

# Cluster Response Community Engagement Resources



Incorporating community input is part of a health department's foundational work to build a successful and ethical cluster response program and a CDC funding requirement. Building meaningful community relationships and coming to mutual understanding of the role of cluster response in preventing HIV and linking people to care will support a smoother more effective cluster response program. Community engagement for cluster response is essential for communicating the benefits of responding proactively to emerging clusters and potential outbreaks, for identifying key roles for community partners and stakeholders, and for hearing and addressing any concerns that community members may share. Before beginning community engagement activities, it is advisable to review existing resources discussing some of these concerns. This resource list contains several resources that health departments can reference to help plan or enhance their community engagement work related to cluster response.

## General Community Engagement

- The [Community Engagement](#) section of the [Community Planning Toolkit](#) provides an array of information on community engagement and planning, including: issues that need to be considered when designing community engagement activities, proposed possible standards of quality for community engagement, and descriptions of a range of possible engagement events.

## Community Engagement for HIV

- NASTAD's [A Path to Policy: A Blueprint for Community Engagement and Advocacy](#) contains advantages to enlisting the support and perspective of the community, principles to use when trying to increase community engagement as well as an example of an innovative way of keeping community partners engaged through online communication. Of additional benefit, this document describes the distinctions between advocacy and lobbying, which is especially important in cluster response given potential concerns about use of public health data and HIV criminalization laws in many jurisdictions.
- The NMAC document: [Expanding Your Reach to End the HIV Epidemic: Community Engagement Toolkit](#) is based on the community engagement requirements as described in CDC's 2012 [HIV Planning Guidance](#).
- The Sero Project's [Network Empowerment Project](#) includes a list of networks in the U.S. that health departments may consider for engaging people who were selected by the community. The Sero Project also has a presentation: "[10 Things to Think about when Starting your Coalition](#)" about building a coalition and thinking beyond natural allies by considering, for example, including faith-based communities
- The [Denver Principles](#) and the concept of Meaningful Involvement of People with AIDS ([MIPA](#)) are important to understand when engaging with community to build on the history of community involvement in HIV prevention. The key concepts include recognition that PLWH are uniquely qualified to advise on effective ways to reach and provide services to PLWH.

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- The Sero Project's [HIV Communication: Using Preferred Language to Reduce Stigma](#). Staff conducting community engagement processes should use mutually respectful, clear language. The Sero Project has posted an example of common terms. Avoiding jargon may also be helpful, especially for complex topics like cluster response. Health departments should keep in mind that language evolves and that different terms may be favored in different locations. HPG members or other community members can provide insight on which terms are most appropriate for local settings.
- The Sero Project has also developed a short list of [suggestions for ground rules and facilitation techniques](#) to help run an effective meeting. Follow meeting 'best practices' such as setting ground rules and utilizing good facilitation skills will help health departments to create meeting environments conducive to full group participation.

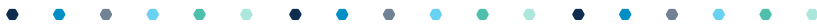
### Sample Cluster Response Presentations for Community Engagement

- The Urban Coalition for HIV/AIDS Prevention Services (UCHAPS) webpage devoted to [molecular HIV surveillance](#) presents resources in a variety of formats such as a frequently asked question guide, flyer, presentation slides, video clip, webinar, and social media toolkit.
- This [cluster response presentation by the District of Columbia Department of Health](#) includes HIV surveillance facts and the role of partner services, terms used in cluster response, the security and confidentiality principles that govern the health department's responsible custody of sensitive data and local laws, and the District's community engagement process.
- Cluster response-related tools and presentations on [CDC's HIV Cluster and Outbreak Detection and Response webpage](#). These include a Communication Toolkit and a PowerPoint presentation HIV Data in Action that can help explain to partners and stakeholders how HIV data, including molecular data, are used to prevent new HIV infections and improve health. Additional helpful cluster response tools that can be used or adapted for community engagement include:
  - [Advancing HIV Prevention through Cluster Detection and Response](#) is a two-page summary that includes five key facts about molecular analysis and has a visual on how health departments can work with the community to support cluster response.
  - [HIV Molecular Cluster Fact Sheet](#) is a two-page fact sheet answers that answers key questions. Geared towards health departments, the fact sheet describes molecular clusters and is a tool that can be used for both internal and external stakeholders
  - [Molecular HIV Surveillance Questions and Answers](#) web page has detailed information about molecular HIV surveillance and how it can be used to improve HIV prevention in the US. It can be used for both internal and external stakeholders.

### Considerations for Responsible Implementation of Cluster Response

- [Ethical Considerations for a Public Health Response Using Molecular HIV Surveillance Data: A Multi-Stakeholder Approach](#): The summary report from this May 2017 consultation discusses prosecution based on state laws and past practices. The attendees included, among others, health department, community, and CDC representatives. Participants agreed that there was potential for using molecular data for cluster response but noted further evidence is needed to determine its benefits.
- [Considerations for Modernized Criminal HIV Laws and Assessment of Legal Protections Against Release of Identified HIV Surveillance Data for Law Enforcement](#)<sup>ii</sup>: This recently released article articulates community concerns with cluster response and outlines practical ways forward to address the problem.

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- Big Ideas: Policy Action Can Increase Community Support for HIV Cluster Detection: This report, from Georgetown Law's O'Neill Institute, highlights four critical actions where community stakeholders and public health officials can work together to minimize risks associated with cluster detection and broaden support for its use. A principal recommendation is to enact a number of policy changes to ensure that HIV molecular data collected for cluster detection is not disclosed to law enforcement. Other recommendations include promoting meaningful partnerships between communities and health departments, ensuring data and security compliance, and educating stakeholders on public health practices.

### Request Technical Assistance (TA)

- CDC-funded health departments can request individualized TA from a capacity building assistance (CBA) provider through the CBA Tracking System (CTS): <https://wwwn.cdc.gov/CTS>.

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<sup>i</sup> Centers for Disease Control and Prevention. Additional Implementation Guidance for PS18-1802 Strategy 3: Cluster Detection and Response. Atlanta, GA; November 2018. Available from: <https://www.cdc.gov/hiv/pdf/funding/announcements/ps18-1802/cdc-hiv-additional-cluster-implementation-guidance.pdf>

<sup>ii</sup> Galletly CL, Benbow N, Killelea A, Lazzarini Z and Edwards R. Considerations for Modernized Criminal HIV Laws and Assessment of Legal Protections Against Release of Identified HIV Surveillance Data for Law Enforcement. *Am J Public Health*. Published online ahead of print September 19, 2019; e1–e4. doi:10.2105/AJPH.2019.305284