

Meeting summary

Responsible Use of HIV Cluster Data for Public Health Action: Amplifying Benefits, Minimizing Harms

Background

Advances in HIV treatment and prevention have made it possible to envision the end of the HIV epidemic. To realize this vision, gaps in service delivery must be addressed so that persons who most need HIV services such as testing, HIV antiretroviral treatment (ART), and pre-exposure prophylaxis (PrEP) have access to them. At HIV diagnosis and during treatment, providers order laboratory tests which generate viral sequence data to identify drug resistance mutations. These sequence data are reported to state and local health departments, along with other HIV-related diagnostic and clinical testing results. Analysis of HIV sequence data, combined with targeted epidemiologic investigation and public health action, can identify groups of people who may not be receiving services and uncover gaps where additional clinical and public health services are most needed.

CDC Virtual Webinar Series: Summary of Meeting

Some, including people with HIV, advocates, and others, have raised concerns that the collection and use of HIV sequence data could cause harm to individuals; for example, if used in legal settings as evidence, or if future technologies have the capacity to determine direction of transmission. To consider these and other implications of this work, in 2019 the HIV Incidence and Case Surveillance Branch (HICSB), Division of HIV/AIDS Prevention (DHAP), National Center for HIV/AIDS Prevention, Viral Hepatitis, and STD Prevention, Centers for Disease Control and Prevention sponsored a series of three virtual meetings, ***Responsible use of HIV cluster data for public health action: Amplifying benefits, minimizing harms***. Invitees included state and local health departments, representatives of community-based organizations including people with HIV, national organizations representing state and local health departments, academics, and experts in public health ethics and law.

Meeting Objectives

1. To discuss and review an ethical framework for cluster detection and response
2. To discuss best practices to minimize potential harms and strengthen data protections against release of surveillance data for non-public health purposes
3. To discuss ways to amplify the benefits of molecular cluster detection and response through collaboration with other stakeholders, and through sharing of surveillance data with partners when appropriate for public health purposes.

Discussion Themes

Engaging communities to ensure that implementation is responsive to the local cultural context

Community engagement is crucial to successful implementation. Public health agencies have a duty to initiate and expand efforts to engage key communities, to increase public awareness of HIV surveillance

generally, and specifically HIV cluster detection and response. Many participants identified a need to go beyond HIV planning groups, and to make information and engagement accessible to broader communities. Public health agencies can work with communities and organizations to minimize distributive justice issues. Agencies can be aware that communities of color are at increased risk of HIV transmission, as well as often being targeted by policing and immigration enforcement, and consider these perspectives.

Monitoring to measure benefits and risks of cluster detection and response

The potential for HIV sequences to be used as evidence in criminal cases was a concern for many participants. Many states criminalize HIV exposure. Often, these prosecutions do not align with current science (for instance, criminalizing behaviors that would not lead to HIV transmission such as spitting or engaging in sex while virally suppressed). Participants discussed the need for policy analysis to better understand the impact of laws, policies and procedures on people with HIV in the context of cluster detection and response activities. In addition, non-governmental partners may have important roles to play in addressing HIV criminal laws.

Participants discussed the need for public health agencies to monitor cluster detection and response activities and outcomes, to better understand real-life impact and to establish program effectiveness. This could include collecting information on harms or unanticipated outcomes of cluster detection and response (e.g., requests for or release of data for the purpose of evidence in a court of law) or monitoring relevant legislation in jurisdictions and assessing population impacts. Participants noted a need for implementation and evaluation science, especially to understand the effect of cluster detection and response efforts on stigma and disparities.

Communication and education

Participants discussed the need to increase awareness and knowledge about cluster detection and response efforts. Agencies implementing this work could develop tools to assist in communicating clearly about HIV cluster detection and response. Participants identified a need to more clearly articulate the public health justification for cluster detection and response; to educate health departments' general counsels about molecular HIV detection and response, including limitations and potential harms; and, to proactively inform communities, clinicians, service providers, and provider groups about cluster detection and response efforts. Some health departments have provided information to legislators for decision-making to improve patient privacy and to align state HIV criminal laws with current science. These efforts may serve as examples for other health departments. Participants noted that tools and communication products must be culturally competent and transparent.

Data sharing and data protections

When responding to a cluster or outbreak, health departments may need to share data with other agencies for public health purposes. Some health departments expressed concerns about sharing with other jurisdictions when other states' laws did not provide the same client protection. Others discussed best practices, such as those outlined in the 2011 [NCHHSTP Data Security and Confidentiality Guidelines](#) (e.g. only share the minimum amount of data necessary to achieve the desired goal). Participants stressed the need to update these guidelines to incorporate advances in technology and public health practice.

Health departments generally operate under a principle of limited data release but have sometimes been required to release data for legal purposes (usually in the context of criminal cases). Agencies have limited influence over legislation and must comply with local laws, and may use rules, regulations and administrative procedures to strengthen data protections. In addition, to ensure reporting of important public health data while limiting information that could potentially determine direction of transmission, guidelines could limit the scope of data that labs report to states, and states to CDC (i.e., reporting of only consensus sequences when next generation sequencing is conducted rather than more detailed sequencing data). Finally, participants mentioned the need for more guidance regarding how to respond to data requests from researchers or others.

Ongoing Conversations

This meeting raised important considerations for HIV cluster detection and response activities and highlighted the need for continued communication and education efforts, continued monitoring and evaluation, and additional guidance on data sharing and data protections. CDC is working with state and local health departments and other partners to address these and other issues raised in these discussions, to maximize the benefit and minimize potential harms of this work.

Content Source

Detection and Response Branch (DRB), Division of HIV Prevention (DHP), National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC)

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