



PROMPT STUDY

Revitalizing Community Engagement in the Public Health Use of Molecular HIV Epidemiology



Executive Summary

Despite a number of remarkable advances in HIV prevention and care, tens of thousands of people in the United States are diagnosed with HIV each year, and persons living with HIV (PLHIV) may have inadequate access to services or discontinue engagement in care, particularly in marginalized communities marked by inequity and HIV-related stigma. This situation stimulated the development of innovative approaches to prevent HIV and connect PLHIV with appropriate care. Molecular HIV epidemiology (MHE) is an approach to understand how HIV is spread in communities by comparing the similarities between HIV viruses sampled from individuals. Cluster detection and response (CDR) is the public health practice that employs MHE to identify where recent and rapid HIV transmissions are taking place so as to identify where expanded services and resources are needed.

MHE and CDR are components of the National HIV Strategy to reduce and eliminate HIV throughout the US. MHE and CDR have been integrated into standard public health practice in all US jurisdictions that receive CDC funding, including North Carolina. However, these new practices have raised a number of concerns among diverse stakeholder groups, including PLHIV and community-based service organizations, that highlight the need for and importance of ongoing community engagement on MHE and CDR.

This white paper proposes a framework for renewed community engagement in public health strategies that use HIV-related data collected during clinical care. The positions presented here stem from stakeholder consultations in the form of qualitative interviews and townhall meetings conducted between 2021 and 2022 with community and public health stakeholders in North Carolina. We provide context for this framework by presenting an overview of the National HIV Surveillance System and MHE and summarizing concerns expressed by some advocacy groups and other stakeholders. Based on our stakeholder consultation process, we propose four guidance points to strengthen community engagement strategies and potentially inform future public health policy: (1) Raise community awareness; (2) Identify and expand opportunities for community involvement; (3) Amplify advocacy involvement in practice and policy; (4) Enhance accountability of institutions to the public.

These recommendations should help inform future public health policy and guide efforts to ensure that stakeholders are purposefully engaged in priority areas related to community engagement in MHE and CDR. Importantly, many of these guidance points on community engagement will require political commitment and sufficient allocation of funds to support the work of CBOs, advocates, and other front-line sources of community engagement to fully realize these strategies.

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List of Abbreviations:

CBO: Community Based Organization
CDC: Centers for Disease Control and Prevention
CDR: Cluster Detection and Response
EHE: Ending the HIV Epidemic

MHE: Molecular HIV Epidemiology
MHS: Molecular HIV Surveillance
PLHIV: People living with HIV
PrEP: Pre-exposure prophylaxis

Introduction

Forty years into the HIV epidemic, people living with HIV (PLHIV) who receive antiretroviral therapy and achieve viral suppression can expect near normal lifespans and be assured of zero risk of transmission to sexual partners. In addition, people who are HIV negative can effectively protect themselves from getting HIV by taking pre-exposure prophylaxis (PrEP). In 2019, the United States (US) launched the Ending the HIV Epidemic (EHE) initiative based on this remarkable progress, to reduce the number of new HIV diagnoses by 90% by 2030.¹

Despite these advances, social, economic, and racial disparities and deeply rooted HIV stigma have impeded vulnerable groups from fully realizing these benefits. Roughly 35,000 people are diagnosed with HIV in the United States every year, and significant gaps in the cascade of care persist, disproportionately affecting marginalized communities.² The pressing need for an improved response to the epidemic continues to fuel the search for new public health tools to detect HIV transmission in communities, and inform treatment and prevention service delivery. However, such tools also present potential risks to the autonomy and privacy of individuals and communities which are heightened in the context of a stigmatized and criminalized disease. Meaningful community engagement can help navigate these challenges and inform approaches that are responsive and acceptable to affected groups.

While partner notification has been a mainstay of public health efforts in HIV prevention for decades, molecular HIV epidemiology (MHE) now offers the potential of a more timely and nuanced understanding of the presence of the virus in communities, through the analysis of genetic relationships between HIV sequences. MHE is a key component of the Ending the HIV Epidemic in the United States (EHE) initiative,¹ and is being implemented by public health departments nationwide. To successfully mitigate potential risks and optimize communication, MHE requires robust community engagement. This white paper proposes a framework for fostering meaningful community engagement around MHE.

A Note on Terminology

A variety of terms are used to describe the analysis of HIV genetic sequences data including:

- HIV phylogenetics or phylodynamics
- Molecular HIV Surveillance (MHS)
- Molecular HIV Epidemiology (MHE)
- Cluster Detection and Response (CDR)

Epidemiology is the branch of science that deals with the incidence, distribution, and control of a disease.

Surveillance is frequently used to describe public health monitoring of epidemiological activities. However, this term often perceived negatively as surveillance is also associated with monitoring of criminal activity. In this document, we use MHE to avoid the negative connotations sometimes associated with “surveillance”, and refer sparingly to surveillance throughout.

Background

Overview of HIV Surveillance in the US and North Carolina

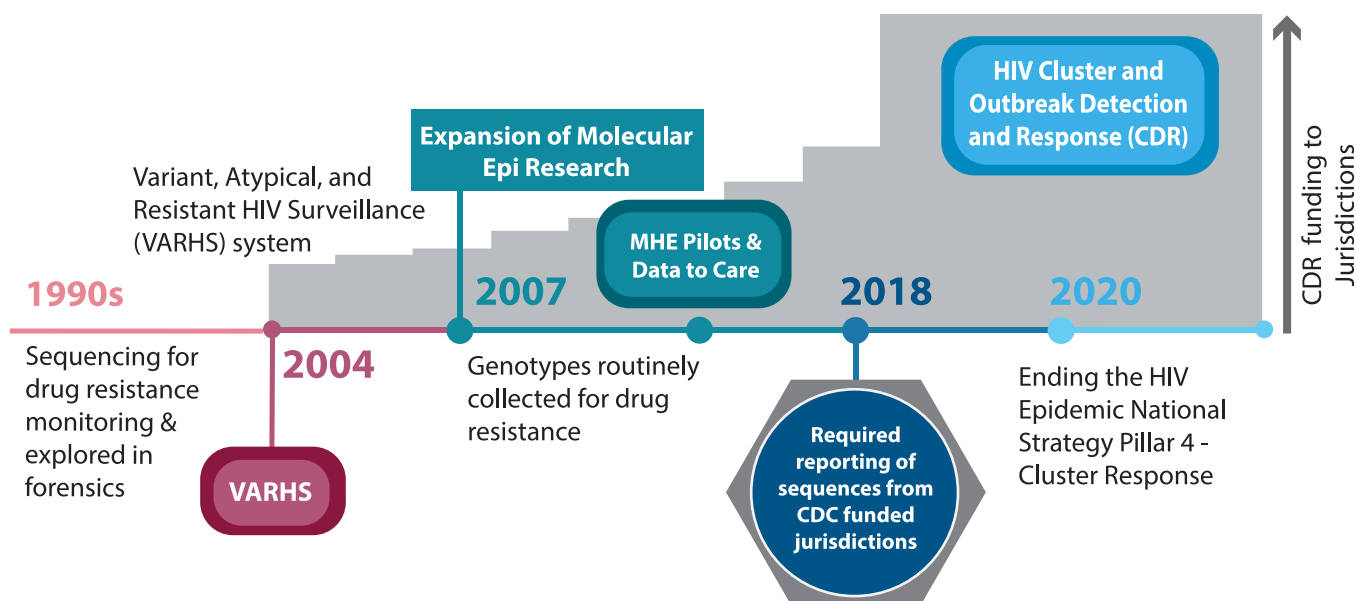
Public health surveillance is the systematic collection, analysis, interpretation, and dissemination of health data for the planning, implementation, and evaluation of public health action. In the US, the Centers for Disease Control and Prevention (CDC) has developed a comprehensive national surveillance system that guides data collection and reporting. States are responsible for gathering information on different diseases and conditions, including HIV, in accordance with state laws.

Since the 1980s, physicians and other medical providers in North Carolina have been required by law to report names of persons with newly confirmed HIV diagnoses to local health departments, and this data is collected by the North Carolina Department of Health and Human Services (NC DHHS). Data collected on these individuals and reported to the health department also includes information from their laboratory results – such as HIV diagnosis date, first and ongoing CD4 tests, and viral load counts. In addition, some of this data is reported by state public health authorities to the CDC without personal identifying information, including information about new HIV diagnoses. CDC staff use the data about viral sequences and the location and timing of new infections to track the course of the epidemic, using methods called Molecular HIV Epidemiology (MHE). These methods are used to detect outbreaks of HIV within communities, called clusters. CDC staff use a process called Cluster Detection and Response (CDR) to try to stop the spread of HIV within communities and to help connect people to needed health care.

MHE What is Molecular HIV Epidemiology?

As part of routine HIV care in many countries, including the United States, testing is conducted on the HIV virus from each individual to determine its genetic sequence. This information informs the treating clinician about whether the virus is resistant to specific antiretroviral medications. In addition, the genetic analysis of the virus can also be used for public health purposes. Because the HIV virus mutates very quickly, patterns in the genes of the HIV virus are studied to look at how it is spreading throughout a community or region. Groups of people may have HIV virus with similar viral genes, telling us that HIV has likely spread quickly through this group. The public health practice of studying the patterns of HIV infection and spread in a community is called molecular HIV epidemiology (MHE), as it seeks to detect transmission patterns using genetic technology.

A Brief Timeline of MHE in the United States



CDR What is Cluster Detection and Response?

When an HIV outbreak is detected, it is referred to as a cluster of cases. The CDC, along with state and local health departments, use HIV diagnosis data and HIV sequence data that are reported in the national HIV surveillance system to systematically identify clusters through MHE and/or time-space analysis.³ Identifying the timing and location of clusters helps prioritize HIV prevention and treatment services for communities experiencing recent and rapid HIV transmission; this process is called cluster detection and response (CDR). One aspect of CDR may involve public health agencies contacting individuals that have been identified as being at heightened risk of HIV acquisition or PLHIV who no longer appear to be regularly using HIV care services. The partners of PLHIV are offered

expanded services, including access to testing and pre-exposure prophylaxis (PrEP). MHE and CDR are response components of the National HIV Strategy, which is a nationwide approach to try to reduce and eliminate HIV transmission throughout the US. MHE and CDR have been integrated into standard public health practice in all US jurisdictions that receive CDC funding, including North Carolina. This aspect of response is similar to 'Data to Care', which is a public health strategy that uses HIV surveillance data, pharmacy fill data, clinic appointment data, and other treatment and care data sources to strategically inform and direct resources and services for HIV prevention and treatment.

Concerns about MHE and CDR

Community advocates, HIV organizations, academics, and other stakeholders have raised a diverse range of concerns about the implementation of MHE and CDR in the US. These concerns include: the absence of informed consent in MHE practice; potential negative impact of MHE and CDR implementation on HIV prevention activities; privacy and data security issues; potential exacerbation of racial inequities; costs of resources allocated to MHE and CDR; uncertainties surrounding the effectiveness of MHE and CDR relative to traditional surveillance and outreach activities; and risks of MHE data being used in criminal proceedings in some states.⁴

Another area of discussion has been community engagement around MHE practice, policy & research. The national rollout of MHE and CDR has been regarded by some groups as having taken place with limited community engagement.⁵ In North Carolina, MHE practice was initiated with engagement of local and state community advisory boards. Nationally, while the CDC held a series of virtual community consultations,^{6,7} the engagement has been perceived by some groups as essentially passive, with community organizations largely being informed of a program of action that was already decided in advance. The effects of implementing MHE and CDR and lingering issues surrounding community engagement continue to reverberate, with opposition regularly manifesting at HIV and AIDS events, in statements by HIV organizations, and in academic literature.^{8,9} **The framework presented in this white paper aims to promote meaningful community involvement by providing stakeholder-identified guidance points for enhancing community engagement.**

Role of Community Based Organizations

Community based organizations (CBOs) have historically been an integral component to HIV response strategies. Such CBOs have demonstrated cultural competence and trust among community members to help highly vulnerable populations access HIV care and prevention services. Many CBOs have adapted a wide range of services to fill unmet needs by traditional health care or public health services. Embracing CBOs' local community knowledge and trust is critical to achieve the Ending of HIV Epidemic (EHE) goals. In particular, CBOs must be included as decision-making partners in MHE and cluster response planning and evaluation strategies. These strategies should include data sharing and privacy agreements between public health agencies and CBOs where permissible by law. Additionally, it is of utmost importance that sufficient funding be allocated for CBOs to have the capacity to join decision-making efforts to effectively serve their communities.

Our Stakeholder Engagement Process

The framework to revitalize community-engagement in molecular HIV epidemiology that follows was informed by a multi-phase engagement process with diverse stakeholders in North Carolina, including community members living with HIV, providers (medical professionals providing HIV care), public health professionals working in HIV field services (epidemiologists, disease intervention specialists, health directors), community advocates (HIV activists, community-based organization leaders), and bioethicists.

From 2020 to 2021 we conducted semi-structured stakeholder interviews with 41 participants. These interviews explored participants' views on and ethical considerations surrounding MHE and community engagement practices. Our qualitative analysis of these interviews identified thematically and conceptually related categories and overarching themes in the data. These findings were then shared and discussed at two sequential virtual townhall meetings with stakeholders. The first, held

on June 28, 2022, was a three-hour meeting where findings from the interviews were presented and discussed, and implications for the community engagement framework considered. The second was a two-hour virtual townhall on October 7, 2022, which focused on the development of guidance points for enhancing community engagement around MHE public health practice and research.

Each townhall meeting was discussed and summarized by the research team, and considered in the context of the stakeholder interview data. The research team then drafted guidance points to inform community engagement strategies, and solicited feedback from townhall participants. The guidance was revised, integrating feedback from participants in an iterative process. The resulting 4 guidance points outlined below provide a pathway forward to revitalize community engagement around MHE in North Carolina, with potential broader applicability to other states.

Guidance Points to Strengthen Community Engagement



Guidance Points to Strengthen Community Engagement



1. Raise Community Awareness

Public awareness of MHE is extremely limited, even among HIV advocates and health care providers. Access to information, tailored to the needs of the intended audience, is a critical element of meaningful community engagement. Increasing community awareness of MHE – situated in the broader context of public health HIV surveillance – should be a primary focus of efforts to enhance engagement among stakeholders including people living with and at-risk of HIV, advocates, community-based organizations, and health care providers. We identified two approaches to raise community awareness of MHE:

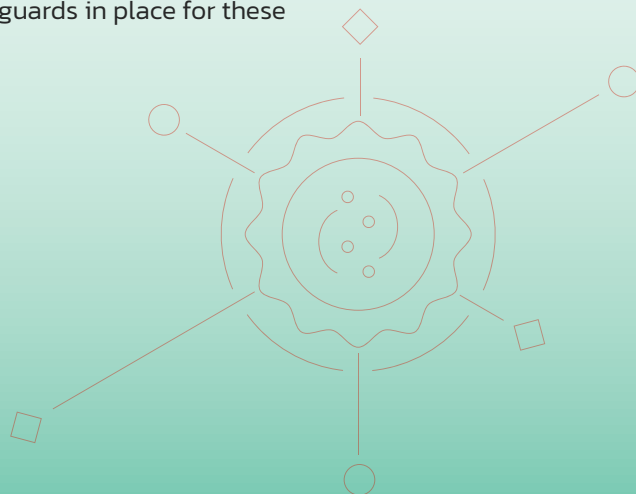
* Build capacity among key stakeholders who are well-positioned to raise awareness of MHE in their communities

The capacity of NC DHHS to raise awareness of MHE across the state is hampered by limited resources and structural constraints. There is a pronounced need to identify and engage a larger team to build community awareness of MHE. Stakeholders on the ‘front-lines’ of community engagement, including health care providers, community based organizations, and community advisory boards are potentially well positioned and trusted sources to actively build awareness of MHE in communities. Adequate resources and support from federal, state and local governments in coordination with advocacy groups and provider education organizations are needed to develop the knowledge and skills of key stakeholders and support their ability and commitment to disseminate accurate and accessible information.



* Develop and disseminate educational materials tailored to the needs of the intended audiences

Capacity-building among key stakeholders will enable their ability to develop and disseminate tailored educational materials to their audiences. Such materials need to utilize clear, accessible language, and culturally appropriate communication tools and channels. Accurate messaging, which improves understanding of public health activities broadly and MHE specifically, is needed to both dispel misconceptions and provide a balanced, transparent picture of what is known about the the potential benefits, risks, and existing safeguards in place for these approaches.





2. Identify and expand opportunities for community involvement

Community awareness of the existence, nature and implications of MHE is essential for community engagement, but in addition communities need meaningful ways to help shape how this form of public health surveillance is practiced – otherwise, engagement processes are limited to the provision of information rather than consultations or opportunities for input. Our findings suggest that MHE programs and policies are still evolving, and there is room for community organizations and leaders to have an impact on how MHE is designed and implemented. We identified three approaches to enhance community involvement:

* **Combat misinformation about MHE in communities**

Misinformation about MHE can undermine or misdirect community involvement efforts. As seen with COVID-19 and vaccination, concerns about MHE may be amplified and distorted by more general societal worries, such as about the rise of a ‘surveillance state’. While social media platforms are influential channels of misinformation, they are also appropriate venues to combat it through dissemination of accurate information. Public health communication efforts, together with community representatives or advisory boards, must ensure that relevant community information about MHE is provided in engaging, balanced and lay (non-technical) formats.



* **Consider specialized community advisory boards**

Community advisory boards (CABs) have played an important role in the history of HIV and AIDS, particularly in health research. They have acted as mediators between public health institutions and communities, aiming to represent community interests in decision-making processes. A similar model may be appropriate in the case of MHE, though unlike other CABs, it should focus specifically on the policy and practice details of this kind of surveillance, and partner with federal, state and local agencies responsible for MHE.



* **Identify and engage with MHE decision-making structures**

Who is making decisions about MHE, and how these decisions are being made, are often unclear to communities. Greater clarity is needed on MHE decision-making structures at federal, state and local levels. This requires public health and governmental agencies to be more transparent about their MHE-related policy processes, and to meaningfully include community voices in these processes; for example, by having community advocates or representatives of knowledgeable and engaged CBOs as members of key committees and decision-making panels.

3. Amplify advocacy involvement in practice and policy

Community-based advocacy groups can play a crucial role in MHE practice and policy by bringing community concerns and priorities to the table – if given the opportunity, and with sufficient resources and support to enable this work. Our findings suggest that capacity-building among advocacy groups should thus be a key concern for enhancing community engagement on MHE. We identified three promising approaches to building this capacity:

* Address misinformation among advocacy groups

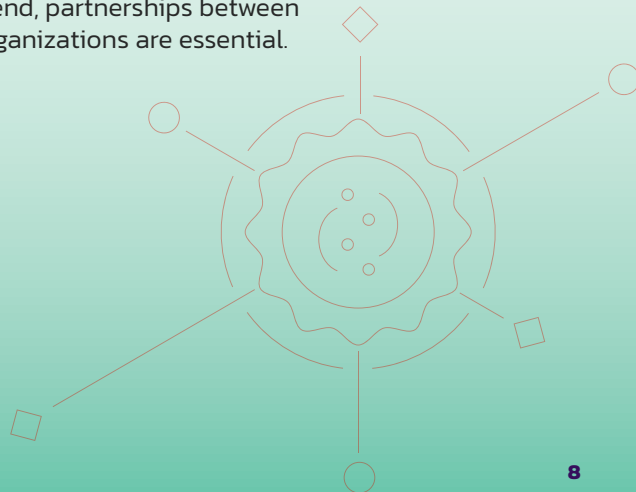
Misinformation is not only an issue at the broader community level, as noted above, but may also be an issue within community-based advocacy organizations. There is thus a need to ensure that advocates have up-to-date and accurate knowledge of MHE practice and policy to inform the communities they serve. As with raising community awareness about MHE generally, information communicated to advocacy groups by federal, state and local governments about MHE should be inclusive of concerns and unknowns, rather than attempting to ‘sell’ MHE or only use advocacy groups to foster community buy-in. Information should be provided as a resource, with bi-directional opportunities for learning.

* Identify and close gaps in outreach to advocacy groups

While some community-based advocacy groups may be well-informed about MHE, others may not be sufficiently folded into existing communication channels. To close these gaps, it is particularly important to enhance communication between health departments and relevant community-based advocacy organizations. Consider also expanding the view of which organizations might be relevant as advocates: for example, organizations that are health-focused but not necessarily HIV-related. Other potential advocates would be groups addressing HIV criminalization and providing legal assistance to PLHIV, people lacking stable housing, and people accessing substance use and mental health services.

* Provide realistic and meaningful opportunities for input

It is important for advocacy groups to know where the opportunities and limits are for inclusion of community-based voices. Clarity is needed on what processes are open for feedback, and what processes are not (and why), to avoid a false sense of opportunity for impact. For feedback opportunities to be meaningful, the most direct pathways for providing feedback should be transparent and clearly communicated to community-based advocacy groups. To this end, partnerships between local governments and community-based organizations are essential.





4. Enhance accountability of institutions to the public



Increased use of MHE has resulted in discussions regarding the level of institutional accountability on the part of those conducting MHE activities to the public and vulnerable populations. PLHIV or those who seek HIV testing may be unaware that clinical data are shared for public health purposes, including MHE. Institutional accountability can increase individual and community understanding and foster earned trust. Participants noted an unresolved tension in the fact that patient consent is not part of MHE processes. Improved institutional accountability may be achieved through greater transparency and understanding of how MHE data is collected, managed, and reported.

* **Open discussions and dialogue about individual consent**

There are potential negative consequences to obtaining individual consent for genotype or other public health reporting. At the same time, patients also have concerns about the absence of consent in data collection for public health reporting. In light of this tension, the topic of consent should be included in open and transparent discussions as part of community engagement efforts, including reasons for and against obtaining consent, potential unintended consequences, and whether and how to change the status quo.

* **Enhance transparency in data collection, management, and reporting**

Often PLHIV are unaware their data is reported to health departments for the purpose of MHE. The lack of MHE transparency by institutions can foster mistrust and raise concerns among patients in vulnerable circumstances, particularly ethical issues related to privacy and autonomy. Patient populations affected by HIV and MHE activities should be offered accessible and reliable information about how MHE data is collected, managed, used, and reported. These efforts could benefit from coordination with broader educational initiatives on health literacy and also could be coordinated through public health programs—but will require funding to develop and sustain.



* **Strengthen accountability through community engagement**

Institutional accountability to communities is essential to the acceptability of MHE. Meaningful community engagement requires centering the voices of the community, particularly those most likely to be impacted by MHE and CDR actions. Input from community-based agencies and recommendations can positively influence MHE policies and practices. Public health institutions have both an opportunity and an obligation to partner with community experts in order to benefit from their wisdom and improve MHE practices.



Summary and Closing Remarks

Meaningful community engagement is essential to reach the goals of the Ending the HIV Epidemic (EHE) initiative in the US. Failing to address advocacy groups' concerns about the use and implementation of Molecular HIV Epidemiology (MHE) will jeopardize the success of not only the fourth EHE pillar (Cluster Response) but could have unintended effects on prevention and care services if community trust in HIV public health is weakened. Many concerns surrounding MHE underscore those raised about HIV surveillance and public health activities, such as outreach to partners and using care data to support outreach to people not in care, which necessitate privacy, confidentiality, and data sharing protections. Through a community engagement process, which included qualitative interviews with a diverse group of stakeholders and two townhall meetings in North Carolina, we have developed four guidance points as a framework for community engagement in MHE. Importantly, many of these guidance points on community engagement will require sufficient allocation of funds to support the work of CBOs, advocates, and other front-line sources of community engagement in order for these strategies to be fully realized. The recommendations made herein should guide efforts to ensure that stakeholders are purposefully engaged through: raising community awareness of MHE; identifying and expanding opportunities for active community involvement; amplifying CBO involvement in MHE practice and policy, and enhancing the accountability of institutions to the public and vulnerable populations.





Endnotes

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