United States government initiatives to engage community stakeholders in developing Molecular HIV Surveillance/Cluster Detection and Response Interventions: A scoping literature review.

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Abstract

Background: In the US, the Center for Disease Control (CDC) has mandated that health departments receiving Ending the HIV Epidemic (EHE) funds use genetic sequences collected through Molecular HIV Surveillance (MHS) to monitor for and respond to HIV molecular clusters, also referred to as Cluster Detection Response (CDR). Public health agencies use MHS/CDR for drug resistance monitoring, detection of outbreaks, and enhanced understanding of transmission networks. However, several ethical and human rights concerns with MHS/CDR have been raised, such as insufficient individual consent to participate, failure to respect autonomy, lack of community consultation, stigmatization of highly marginalized communities, HIV criminalization, privacy, and data protection. Meaningful engagement of communities impacted by the HIV epidemic and policies designed to facilitate access to treatment may help inform effective MHS/CDR implementation and address stigma and other well-documented deterrents to HIV prevention and intervention.

Objective: This scoping literature review summarizes community-based efforts in the development and implementation of MHS as a tool for CDR interventions to enhance access to HIV-related services (e.g., HIV testing, PrEP, Treatment as Prevention) for underserved populations in the US.

Methods: Using PRISMA guidelines, we searched several databases (Google Scholar, Scopus, PubMed, and PsycInfo) to identify both peer-reviewed and grey literature English language publications that focused on MHS/CDR, and community engagement related to MHS/CDR, in the U.S.

Results: In general, there is a paucity of research focusing on the engagement of local stakeholders in the development and implementation of MHS/CDR activities. Among the 24 articles identified through the scoping review process, approximately one-half were published in peer-reviewed journals and others were grey literature (e.g., reports and conference presentations). Literature to date generally highlighted several areas of community concern. First, questions have been raised about the evidence of its efficacy in reducing HIV transmission, implementation issues such as inconsistency in administering drug resistance tests in medical practice, barriers to uptake of partner services, and its cost-effectiveness. Second, several articles noted concerns about a lack of transparency and informed consent in how HIV genetic data are used for MHS/CDR and research activities outside of its intended purpose to monitor HIV drug resistance. Third, articles highlighted concerns about MHS/CDR investigation among highly marginalized populations. Fourth, articles emphasized that inadequate representation and meaningful engagement of community stakeholders undermine efforts to address key concerns about privacy, informed consent, HIV

criminalization, and immigration issues.

Conclusions: Findings underscore the importance of initiating and evaluating strategies for meaningful community engagement in all phases of MHS/CDR activities. Future research should explore implications of structural racism and meaningful engagement of diverse members from the community to develop culturally and linguistically appropriate MHS/CDR interventions for diverse populations.

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Conclusion: Findings underscore the importance of initiating and evaluating strategies for meaningful community engagement in all phases of MHS/CDR activities. Future research should explore implications of structural racism and meaningful engagement of diverse members from the community to develop culturally and linguistically appropriate MHS/CDR interventions for diverse populations.

Keywords: HIV; Molecular HIV Surveillance; Cluster Detection and Response; Public Health; Scoping Literature Review

Introduction

In 2011, the Center for Disease Control and Prevention (CDC) presented the first nationwide epidemiological surveillance of Human Immunodeficiency Virus (HIV) in the United States (US) referred to as Data to Care utilizing data to identify People Living with HIV (PLWH) who have fallen out of and reestablish care [1]. In 2018, epidemiological surveillance became more advanced and the CDC required public health departments receiving Ending the HIV Epidemic (EHE) funds to integrate Molecular HIV Surveillance (MHS) for identifying and responding to HIV molecular cluster outbreaks, also referred to as Cluster Detection Response (CDR) [2]. MHS/CDR gained precedence due to its effectiveness in mitigating HIV outbreaks among male sexual minorities in Texas [3] and People Who Inject Drugs (PWID) in Indiana [4], which revealed that PLWH were not engaged in medical care and people associated with an HIV cluster were at a disproportionally significant risk of HIV exposure. In 2019, MHS/CDR was designated as a core component of EHE [5]. MHS/CDR activities require public health departments to collect HIV drug resistance test results from PLWH, which provides unique HIV genetic sequences of a person to identify HIV molecular clusters of transmission - PLWH who have highly similar HIV genetic sequences [2]. CDC protocols using MHS are data-driven to prioritize CDR investigations based on the number of cases (e.g., high priority $\geq$ 5 cases, medium priority 3-4 cases, and low priority 2 cases) and additional characteristics (e.g., genetic distance threshold, time of diagnosis, HIV viral load) that involves complex data analyses from multiple databases (e.g., eHARS, Partner Services, STD Surveillance, Hepatitis Surveillance) [2].

The utilization of surveillance data is nothing new in public health, but MHS/CDR repurposes the use of HIV drug resistance test results of PLWH [2]. Community stakeholders have raised concerns that they have been excluded from the development and implementation stages of MHS/CDR activities. They point to insufficient consent for these activities, failure to respect individual autonomy, stigmatization of highly marginalized communities, invasion of privacy, lack of data protection, and the potential for HIV criminalization [6, 7]. This is particularly salient in light of health disparities and government mistrust among historically oppressed and highly marginalized communities [8]. Concerns also have been raised about “function creep,” when a technology (e.g., HIV drug resistance tests) that was designed for one purpose (e.g., effective medical treatment for PLWH) is used for others (e.g., MHS/CDR) without informing people [9, 10]. PLWH give medical providers consent for an HIV drug resistance test to determine effective medications. However, the US government allows public health departments to use HIV genetic sequences from drug resistance testing for MHS/CDR activities without the expressed consent of PLWH [11-14]. Repurposing of HIV drug resistance test results has caused a global review of ethical concerns surrounding the use of MHS/CDR activities [11], especially among historically oppressed and highly marginalized populations.

MHS/CDR activities may enhance the understanding and mitigation of HIV outbreaks by providing detailed insights into transmission networks, drug resistance, and access to HIV services. However, it also poses challenges related to privacy, ethics, resource requirements, and data interpretation. Balancing these strengths and limitations require careful consideration of ethical guidelines, robust data protection measures, and equitable resource allocation to ensure that the benefits of MHS/CDR activities are realized while minimizing potential risks and disparities. This scoping literature review aims to summarize initiatives by the US government to integrate community-based efforts in the development and implementation of MHS as a tool for CDR interventions to enhance access to HIV-related services (e.g., HIV testing, PrEP, Treatment as Prevention) for underserved populations in the

US.

Methods

Study Design

A scoping literature review was performed to identify literature that explores US government initiatives at the national, state, and local level to engage community stakeholders in developing MHS/CDR interventions. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) was used to structure the scoping literature review for this manuscript [15]. A scoping review methodology was applied because MHS/CDR activities are fairly new and the overall research question is broad: What initiatives has the government taken to engage community stakeholders to further develop and implement local MHS/CDR activities?

Identifying Relevant Studies

On January 2, 2025, MG conducted a search of the literature in the following databases: Google Scholar, Scopus, PubMed, and PsycInfo. MG met with a librarian to strengthen efforts for identifying literature based on the following terms used across all data bases: "Molecular HIV surveillance" OR "HIV Contact Tracing" OR "HIV cluster detection and response"; Textbox 1 provides full criteria for screening using Google Scholar. The search was restricted to literature in English and focused on community engagement related to MHS/CDR activities in the US; inclusive of peer-reviewed research studies, grey literature reports (e.g., government, non-profit organizations, conference proceedings, dissertations/theses). Commentaries, perspectives, and letters to the editor were also considered if they raised MHS/CDR issues for the community. Additional references familiar to the authors were included as “other sources” that were not identified through the databases used for this scoping review.

Textbox 1. Google Scholar eligibility criteria for screening.

1	Find articles with the exact phrase: "Molecular HIV surveillance" OR "HIV Contact Tracing" OR "HIV cluster detection and response"
2	Where my words occur: anywhere in the article.
3	Return articles published in: any type.
4	Return articles dated in: any time.
5	Remove articles from: -China, -Africa, -Mexico, -Europe, -Canada, -Cuba, -Brazil, -UK, -Asia, -Singapore

Screening and Selection

MG administered the literature screening as illustrated in Figure 1, the PRISMA 2020 Flow Diagram [16]. All the references were reviewed using EndNote to remove duplicates. Titles and abstracts were further screened to remove references not meeting eligibility criteria. The remaining references were retrieved for full-text review and determine final outcome of eligibility. MG drafted Supplement 1 to summarize findings and hosted online sessions with community partners based in Texas (SV) and California (JZ) to review findings and include their contributions for the methods and results sections.

Results

Study Characteristics

Overall, limited research has focused on the engagement of local stakeholders in the development and implementation of MHS/CDR activities for their local communities. Among the 24 articles (Supplement 1) identified for this scoping literature review, approximately half of the articles were published in peer-reviewed scientific journals as a literature review [17], evaluation [18], qualitative [5, 19-22], quantitative [23], and implementation [24-27] research methods. Some articles published in scientific peer-reviewed journals were commentaries [6, 7, 13, 28, 29], or ethical papers [12].

There also were conference presentations [30], reports [8, 11, 31, 32], and one petition published by a collective [33]. Community feedback on MHS/CDR activities was garnered by most studies through forums [25, 31], presentations [27], surveys [23], and focus groups or interviews [5, 8, 18-22, 24, 30]. Only a few studies reported engagement of local stakeholders to enhance implementation of MHS/CDR in the community [17, 19, 22, 27]. All the articles focused on how MHS/CDR activities will affect PLWH, but about half of the articles explicitly discussed racial implications for Black and/or Latino populations [6, 7, 11, 13, 17, 20, 21, 27, 32, 33].

Summary of Pertinent Articles

Implementation and Structural Factors Associated with MHS/CDR

The effectiveness of MHS/CDR activities to mitigate HIV outbreaks has been questioned [5, 20, 30] and community stakeholders have raised concerns about exploiting PLWH [31]. Some articles indicated that MHS/CDR have been proven effective to mitigate HIV outbreaks in real-time [8, 18], but others emphasized a lack of a randomized control trial to establish its efficacy in reducing HIV transmission [12, 24, 29, 30]. Authors of one article raised concerns that the CDC has not provided standard guidelines to support local health departments [32]. MHS/CDR requires information from multiple databases that are not readily available to understand important characteristics for developing a real-time tailored response to an HIV outbreak [20, 24, 25], which has caused some stakeholders to question the cost effectiveness in comparison to routine public health interventions [8]. For example, CDR requires further investigation of PLWH associated with a cluster, which includes a partner service interview regardless of whether or not a PLWH has completed one at the time of a diagnosis [18, 24, 33]. PLWH have shared their support for CDR investigations to engage people into HIV services [23, 30], but clarified that they would be unwilling to participate in HIV partner service activities that requires a PLWH to meet with a health provider and provide contact information of partners that may have been exposed to HIV for testing and services [30]. MHS/CDR also depends on medical providers to administer HIV drug resistance tests to collect HIV sequences, but MHS data is typically incomplete because medical providers may not administer HIV drug resistance tests or may not report results to the local health department [20]. However, academic partners play a critical role in circumventing issues related to data management and assisting local health departments with using MHS data to expedite tailored CDR interventions based on characteristics of the cluster outbreak [18].

MHS/CDR Transparency and Informed Consent

Many articles in the review emphasized ethical practices to support PLWH in making informed decisions to determine how their genetic data is being used outside of its intended purpose for MHS/CDR and research activities [5-8, 11, 12, 17]. MHS/CDR activities have been justified as a public good to protect society through public health investigation to prevent the spread of infectious communicable diseases. Many argue that data used for this purpose should not require explicit consent from PLWH [34-36]. However, others have criticized this approach, suggesting it dehumanizes and stigmatizes PLWH as a public threat in spreading HIV [5, 7]. Furthermore, local health departments collaborate with scholars at academic institutions to utilize MHS/CDR data for research purposes [18, 20, 24, 30], which some have argued increases the need for PLWH to make informed decisions to consent or opt-out of research activities not related to treatment based on HIV drug resistance test results [6, 12, 21, 22, 28, 32]. Despite MHS/CDR being a core pillar of EHE, information to the public on how HIV genetic sequences are collected from PLWH for MHS has been limited and a greater focus has been placed on the benefits of CDR to enhance access to HIV services [30]. Community stakeholders have expressed support for MHS/CDR activities to enhance access to HIV services [19, 23], but emphasized a need for greater transparency and supporting PLWH to make informed decisions to consent or opt-out of MHS/CDR activities [5, 7, 8, 12, 13, 21,

28]. Medical providers are also encouraged to inform PLWH about MHS/CDR activities when they collect the blood specimen for the HIV drug resistance test [21, 32]. Some scholars indicated that informing the community about MHS/CDR activities is paramount because not being completely transparent increases government and medical mistrust among racially underserved and highly marginalized populations [6, 17, 21, 22, 27, 33]. For example, research findings for a large quantitative study (N=2,524) indicated that participants with higher levels of awareness were more likely to support MHS/CDR activities, but participants still had concerns after reviewing an informational video (38.7%) or handout (16.9%) [23].

Investigation of Highly Marginalized Populations

MHS/CDR was characterized in some articles as a deficit-based approach for EHE, which is highly stigmatizing and disproportionately affecting Black and Latino populations [7]. Specifically, several articled emphasized how MHS/CDR activities reinforce structural inequities that oppress and control highly marginalized populations such as PLWH, SGMs, people of color, and immigrants [6, 7, 13, 29]. Although none of the articles explored the implications of structural racism, some did mention that MHS/CDR activities echo historical public health initiatives that exploited Black and Latino populations without their consent to be included in medical investigations [7, 27, 33]. Structural racism garners greater attention because it places an emphasis on how social structures (e.g., government organization, institutions, agencies) reinforce policies, laws, and practices systemically to subjugate populations based on race/ethnicity [37], which have contributed to Black and Latino health inequities. MHS/CDR activities reinforce policing of Black, Latino, and trans populations that have historically been targeted by law enforcement and are disproportionately impacted by HIV [13]. Local health departments are responsible for maintaining an MHS/CDR database with identifiable information of PLWH, but some have argued that CDR investigations do not protect anonymity [7]. Historically, the court has used HIV genetic sequencing to prosecute PLWH [11, 13]. People fear that maintaining a central MHS/CDR database with their identifiable information will make them susceptible to HIV criminalization [5, 8, 12, 17, 19, 22, 27] and anti-immigration [11, 32, 33] legal statutes, which will discourage people from getting tested. CDR investigations become more complicated in protecting identifiable information when investigating people associated with a cluster from different jurisdictions that involve multiple health departments and different HIV and immigration statutes [24, 33]. Recommendations have been made to train legal counsel at local health departments to be well informed of local HIV criminalization laws and immigration enforcement to contest legal demands for using HIV genetic data to prosecute PLWH [32].

Representation and Meaningful Engagement of Community Stakeholders

Articles documented significant community concerns related to privacy, informed consent, HIV criminalization and immigration issues [6, 8, 11, 20, 27]. Many of the concerns could have been addressed if there was Meaningful Involvement of People with HIV/AIDS (MIPA) in government initiatives to integrate MHS/CDR as a core initiative for EHE [5-7, 12, 21, 32, 33]. Government representatives have made efforts to engage the community, but they have been criticized for controlling the narrative to highlight strengths of MHS/CDR as an effective intervention without acknowledging potential harms [5, 6]. Efforts by local health departments to engage communities about MHS/CDR have been limited [5, 6, 11-13]. Lack of transparency in developing and implementing MHS/CDR activities locally has resulted in community mistrust of government [5, 6, 21, 32]. Advocates have called for educational materials on MHS/CDR activities to inform the community and improve transparency about detecting and investigating people associated with an HIV cluster [6, 8, 17, 19, 22, 27, 32, 33]. Some local health departments engaged the community to develop videos and handouts to increase awareness of MHS/CDR activities, which enhanced support from the community [19, 22, 27, 30]. However, community advocates have emphasized that

structural inequities are reinforced by not hiring PLWH to promote MIPA and strengthen efforts for EHE [6, 31]. Special considerations need to be made when conceptualizing and identifying representatives of the community to ensure that their best interests are considered [6, 17]. Some have advocated for local health departments to establish community advisory boards (CAB) to strengthen efforts in developing local MHS/CDR activities [26, 32]. A limited number of reports have evaluated peer-based interventions that integrate people from an HIV cluster to recruit people from their network to access HIV-related services as a way to overcome issues related to government mistrust [20, 26]. Multiple stakeholders have requested a moratorium on MHS/CDR activities until it has been proven to be effective in mitigating HIV outbreaks and ethical considerations have been taken into consideration for engaging as well as protecting the rights of PLWH [7, 11, 27, 32, 33].

Discussion

Our scoping review found that meaningful engagement of community stakeholders by government health entities has been limited, which has raised community concerns at the local, state, and national level. Government health agencies initially did not engage community stakeholders in the process of developing and implementing MHS/CDR as a core component of EHE. Government health agencies slowly began to engage community stakeholders through formal consultations [8], community forums [31], and CABs [38]. Local health departments have also taken initiatives to administer qualitative interviews to deepen their understanding about concerns in the community and identify best approaches for utilizing MHS/CDR to enhance access of HIV services for highly vulnerable populations. Important findings indicate that the community would support MHS/CDR activities if they were more informed about the process. MHS/CDR related videos and handouts may be useful tools to increase awareness and support from the community [23, 30]. Although CDC required protocols to administer secondary partner service interviews as part of CDR, it provided limited information to enhance CDR interventions (e.g., identifying additional partners that may have been exposed or benefit from receiving HIV services) and PLWH associated with the cluster were less likely to support initiatives to complete a secondary partner service interview [18, 30]. The implications of structural racism and cissexism for MHS/CDR activities has been overlooked in the EHE plan, which raises significant concerns among highly marginalized populations (e.g., trans, immigrants). This scoping review suggests that, despite multiple attempts made from national and local government health agencies, community stakeholders continue to raise concerns regarding informed consent and transparency about MHS/CDR as an effective intervention for EHE.

Principal Results

Government health agencies have been criticized for not being transparent about MHS/CDR and have not routinely engaged the community in planning for the implementation and development of MHS/CDR as a core component of EHE. In 2018, the CDC placed an emphasis on MHS and

throughout the years has transitioned the focus to CDR as an intervention [30]. The transition is important because MHS places an emphasis on collecting HIV genetic sequences from PLWH without their expressed consent to use this data to help identify and monitor HIV clusters [2]. CDR relies on MHS data to identify HIV outbreaks to investigate people associated with the cluster [2]. Transparency requires consistent nomenclature to increase awareness and understanding of an intervention that benefits the community. However, MHS/CDR terms have been evolving throughout its implementation and local health departments interpretations based on the CDCs guide for HIV transmission clusters [2]. Community advocates have emphasized that the guide's reference to populations as a "transmission cluster" and "risk network" further stigmatizes and marginalizes populations. Some health departments have also decided not to disclose MHS/CDR activities to the public or refer to CDR as "HIV contact tracing", which raises issues when investigating clusters of people residing in different jurisdictions. The CDC also has been criticized for controlling the narrative and not being transparent about MHS/CDR activities during community forums, which undermines dialogue about controversial issues regarding autonomy, privacy, informed consent, and protection of PLWH [6]. In 2023, the CDC and the National Alliance of State & Territorial AIDS Directors (NASTAD) established a partnership to implement a CDR learning collaborative panel with about eight community representatives [38]. However, NASTAD required community representatives in 2024 to sign a nondisclosure agreement to remain on the CDR panel. Full transparency requires government agencies at the national, state, and local level to inform people disproportionately impacted by HIV that EHE-funded public health departments are required to support MHS/CDR activities. Government organizations have and continue to miss opportunities to promote MIPA and contextualize MHS/CDR activities for highly marginalized populations. CABs and consultants enhance MHS/CDR activities, but it still maintains the power imbalance in favor of government agencies in controlling the narrative and making final decisions for EHE. Health equity requires change from within social structures to hire people from the Black and Latino SGM community in leadership positions and increased funding for government agencies to partner with community-based organizations (CBO) towards developing culturally and linguistically appropriate HIV interventions for diverse populations by region.

Findings for this scoping literature review emphasize social structural impediments for the implementation and development of MHS/CDR activities as an effective approach for mitigating HIV outbreaks in local communities, especially among highly marginalized Black and Latino SGMs. Several studies stressed the effectiveness of MHS/CDR to identify and mitigate HIV outbreaks in real-time [25, 39-43]. However, an emphasis has been placed on HIV molecular cluster case studies based on a local health department focused on PLWH as the mode of transmission and not structural determinants. For example, MHS/CDR has been proven to identify Latino PLWH not engaged in care, but the local health departments in Texas and Georgia also did not provide culturally and linguistically informed HIV services to mitigatethe Latino community [3, 39]. MHS/CDR as a data driven intervention reinforces a deficit-based approach focused on HIV incidence and response to an outbreak as opposed to a strengths-based approach of closely monitoring and evaluating government agencies in providing effective services for diverse populations, especially in heavily HIV-burdened counties. Some important limitations to consider about MHS/CDR as an intervention is its reliance on multiple databases and lack of addressing the implications of structural racism. Health department staff have indicated that gathering existing data from multiple databases is complex, data is not easily accessible, and time-consuming [20, 25]. The CDC is still in the process of developing standardized approaches to support local health departments with MHS/CDR activities and they have provided capacity-building to address cluster outbreaks among PWID [40], but some health departments also rely on academics to further analyze and understand the data [18]. Collaborations between the CDC and local health departments falls within the purview of investigating highly communicable diseases. However, involvement of academics as a third party to assist local health departments in analyzing

MHS/CDR data raises concerns related to the feasibility of MHS/CDR activities as well as other ethical issues raised by the community regarding data security, confidentiality, and informed consent of PLWH. Transparency on how MHS data is being collected and utilized for CDR is imperative for PLWH to make an informed decision to opt-out from the government using test results for MHS/CDR activities [21, 22, 32] outside of its intended purpose to determine if PLWH have HIV drug resistance and are engaged in treatment. The data only provides limited information that needs to be further contextualized based on the intersections of race/ethnicity, gender, sexuality, and region among other factors.

Black and Latino sexual minority males are overrepresented in rapidly growing HIV clusters [44]. Syndemics theory elucidates deleterious effects of racism and susceptibility to HIV among Black and Latino SGMs despite the availability of efficacious HIV biomedical treatment and prevention services [45-47]. Although syndemic theory has enhanced our understanding of the biological interactions of HIV with other infectious diseases, implications of social factors such as structural racism on diseases is less understood to develop efficacious HIV interventions for Black and Latino SGMs [45-47]. Structural racism has also been identified as a significant deterrent for EHE [37, 48-53], but there is a dearth of literature exploring the implications of structural racism and MHS/CDR as an intervention for Black and Latino SGMs who are disproportionately impacted by the epidemic. Exclusion of Black and Latino SGMs or PLWH from meaningfully being engaged throughout the development and implementation of MHS/CDR activities at the national, state, and local government levels have hindered efforts to eradicate HIV among highly vulnerable populations [6, 50, 54, 55]. Consequently, MHS/CDR is data driven and a response to HIV cluster outbreaks is determined predominantly from outsiders, not represented by communities disproportionately impacted by the epidemic (e.g., Black and Latino SGMs, PLWH), who have neglected addressing social structural factors hindering efforts for EHE. Hence, the significance of advocates emphasizing “We are people, not clusters!” [7]. MHS/CDR interventions rationalize HIV transmission due to behaviors of highly vulnerable populations, but disregard structural racism as an influence on health inequities and subjugating Black and Latino SGMs. Greater research is needed to explore the implications of structural racism and marginalization of Black and Latino SGMs within as well as outside of government agencies at the national, state, and local level.

Intersectionality theory bolsters syndemics rationale for addressing social structural factors that reinforce inequities based on complex multiple identities experienced by Black SGMs [56, 57], which also pertains to Latino SGMs. Government reliance on HIV surveillance to inform interventions has undermined MIPA and perpetuates oppressive structures to subjugate historically oppressed and highly marginalized populations [6]. Over half of new HIV diagnoses have been concentrated in the South, which includes 20 out of 48 counties and 6 out of 7 states receiving EHE funds [31, 58, 59]. The US political climate in the South is generally not conducive to MHS/CDR activities for SGM, PLWH, and immigrant populations. Black and Latino populations are less likely to have health insurance and encounter greater health disparities among SGMs that have limited access to HIV services (e.g., testing, PrEP, treatment) [59]. Most states in the South have not expanded Medicaid, which has impeded efforts to address HIV among low-income populations [59]. HIV services (e.g., testing, treatment, PrEP) may be available in the South, but not highly accessible for Black and Latino SGMs [60-62]. Community-centered approaches are important to consider the risks versus benefits for addressing health outbreaks among historically oppressed populations. For example, HIV criminalization laws still persist throughout the US that include exposure to communicable infectious diseases such as sexually transmitted infections [63], which involves public health authorities right to further investigate infectious diseases. MHS/CDR activities that monitor and investigate PLWH and their partners who may have been exposed to HIV have raised concerns about policing and criminalization of the community [7, 13]. Onus of exposure is placed on the first

person diagnosed with a sexually transmitted infection and HIV genetic sequencing may be used to prosecute PLWH [63], regardless of HIV transmission directionality. This raises the issue of social structural factors impeding efforts to mitigate HIV outbreaks among historically oppressed populations and concerns of being included in an MHS/CDR database that has identifiable information with a date of HIV diagnosis and potential partners that may have been exposed. Plans to use MHS/CDR as a standardized approach to EHE may not be conducive to improving community engagement in states where PLWH lack legal protections from prosecution. Governors have the power and authority to enact laws that may subjugate SGMs. For example, Tennessee is an HIV burdened area and the governor has rejected HIV funding. Conservatives have organized an "army" to dismantle the Administrative State in 2025, which has specifically focused on repealing policies promoting equity of SGMs to prioritize the needs of "stable, married, nuclear families" [64]. Project 2025 has also emphasized a mass deportation of immigrants who are undocumented [64], which raises concerns of protecting highly sensitive information of vulnerable populations in a government administered MHS/CDR database. This warrants community stakeholders concerns on the role of local health departments in protecting the privacy of PLWH and preventing authorities from enforcing local HIV criminalization or anti-immigrant laws, especially in the South.

Since 2018, stakeholders have raised concerns that the government has not meaningfully engaged the community in the development and implementation of MHS/CDR activities [8], which is evident in this scoping literature review. An emphasis has been placed on further conceptualizing community [17] and meaningful engagement [6]. Various perspectives of the community exist from the systems, social, virtual, and individual that play a critical role for establishing collaborations on addressing health issues [65], which makes it really difficult because communities are diverse and fluid [17]. Focusing on race/ethnicity as primary characteristic of a community or population to address a health epidemic neglects complex critical factors that increase susceptibility to health disparities such as HIV. Greater initiatives are needed to support community-based participatory research approaches where government agencies and researchers meaningfully engage local community stakeholders represented by the HIV epidemic [7, 17]. The community engagement continuum clearly explains the path starting with outreach, consultation, involvement, collaboration, and shared leadership with community stakeholders [65]. Despite CDC endorsement of community engagement [65], efforts towards engaging the community in MHS/CDR activities remain in the consulting phase; the CDC engages the community by getting feedback on initiatives and decides how to proceed. Shared leadership is built on trust and requires a strong bidirectional partnership that places precedence on community-level recommendations [65]. Furthermore, it emphasizes principles raised by community stakeholders on ethics, public involvement, academic partners, research partners, CBOs, and the general public [65] on issues related to MHS/CDR activities for EHE.

Limitations

This scoping literature review had some limitations. First, the search was limited to literature based in the US and published in English. MHS/CDR activities are being administered internationally, but an emphasis on the US was important to highlight the intersection of US government agencies and legal environments affecting health inequities among historically oppressed populations at the national, state, and local levels. Secondly, we only utilized four search engines (i.e., Google Scholar, Scopus, PubMed, PsycInfo) to identify literature and Google Scholar was included to broaden the search of additional publications from community stakeholders. Finally, community stakeholders from historically oppressed populations are less likely to publish in peer-reviewed journals or administer studies exploring the implications of MHS/CDR in the community. We attempted to address this limitation by including commentaries, correspondences, perspectives and additional publications. However, a dearth of literature from community stakeholders in academic journals

underscores inequities and a need for scholars to engage community stakeholders as co-authors to ensure their perspectives are included.

Conclusions

Findings from this scoping literature review emphasize social structural impediments to the implementation and development of MHS/CDR activities as an effective approach for mitigating HIV outbreaks in local communities, especially among highly marginalized Black and Latino SGMs. Findings also underscore the importance of initiating and evaluating strategies for community engagement in all phases of MHS/CDR planning and implementation. Specifically, new and expanded initiatives are needed to support community-based participatory research approaches where government agencies and researchers meaningfully engage local community stakeholders impacted by the HIV epidemic.

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Authors Contributions

MG contributed to the conceptualization of the study, completed the methodology, selected the literature, summarized results, and completed the discussion. SS completed the introduction. JZ and SV contributed to the literature review and results section. JDF contributed to the conceptualization of the study, discussion, and edited the manuscript. LD contributed to the conceptualization of the study, abstract, conclusion, and edited the manuscript. All authors reviewed the final draft and approved the manuscript for submission.

Conflicts of Interest

The authors report no conflict of interest.

Disclosure

The views expressed herein are of the authors and do not necessarily reflect official policies of the Department of Health and Human Services nor of the City and County of San Francisco.

Abbreviations

CAB: Community Advisory Board
CBO: Community Based Organization
CDC: Centers for Disease Control and Prevention
CDR: Cluster Detection and Response
DIS: Disease Intervention Specialists
EHE: End the HIV Epidemic
MHS: Molecular HIV Surveillance
MIPA: Meaningful Involvement of People with HIV/AIDS
NASTAD: National Alliance of State & Territorial AIDS Directors
PACHA: Presidential Advisory Council on HIV/AIDS
PLWH: People Living With HIV
PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses

PWID: People Who Inject Drugs
SGM: Sexual and Gender Minorities
US: United States

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Supplementary Files

Untitled.