# The Meaningful Involvement of People with HIV/AIDS (MIPA): The Participatory Praxis Approach to Community Engagement on HIV Surveillance

Andrew Spieldenner, Martin French, Venita Ray,
Brian Minalga, Cristine Sardina, Robert Suttle,
Marco Castro-Bojorquez, Octavia Lewis,
and Laurel Sprague

**Abstract**

The Meaningful Involvement of People with HIV/AIDS (MIPA) has been at the core of the HIV response since the beginning of the HIV epidemic. In this study, we compare two community engagement activities concerned with molecular HIV surveillance (MHS) in the United States: one governmental and one community-led. We examine the consultative aspects of each one, especially as they relate to people living with HIV. We point to the community-based effort—which used a participatory praxis approach—as an example of MIPA. We derive two best practice principles from this research from the field.

The Meaningful Involvement of People with HIV/AIDS (MIPA) movement has long been a cornerstone of the HIV response. Since the beginning of the HIV[1] epidemic, activists and community members have worked to combat stigma, discrimination, and criminalization and to secure adequate support for those suffering and dying (Brier, 2009). They have brought attention to the discriminatory and exclusionary policies and practices of health care organizations and professionals. As a reflection of this communal experience, a number of activists living with HIV developed a manifesto—now known as the Denver Principles—at the Fifth Annual Gay and Lesbian Health Conference in 1983 that asserted "their right to a political voice in the decision-making that would so profoundly affect their lives" (U.S. People Living with HIV Caucus, n.d.). As the epidemic continued, these principles would be reiterated in multiple forms, all concerned with the importance of centering people living with HIV (Morolake et al., 2009).

In the 1994 Paris Declaration, for example, heads of government and representatives of 42 countries made a commitment to "support a greater involvement of people living with HIV/AIDS [GIPA] through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations" (Paris Declaration, 1994). By ensuring the full involvement of people living with HIV in responses at all levels—national, regional, and global—the Paris Declaration aimed not only to strengthen HIV prevention, care, and support strategies but also to "mobilize all of society" by creating "supportive political, legal and social environments" (Paris Declaration, 1994). To push from principle into practice (e.g., UNAIDS, 2007; Van Roey, 1999), people living with and affected by HIV also began using the phrase "meaningful involvement of people with HIV/AIDS," or "MIPA," to articulate modes of self-determination. This important discursive resignification—shifting from "GIPA" to "MIPA"—stemmed from community members' experiences

> of being involved as tokens by organizations that were demonstrating their practice of GIPA, rather than involving [people living with HIV/AIDS] in meaningful ways where they have a real voice in decision making and leadership and where their expertise and lived experience are both sought and

---

[1] The terms "AIDS" and "HIV" have been used to describe different conditions within the same epidemic. Whereas "AIDS" refers to a syndrome of symptoms and opportunistic infections, "HIV" refers specifically to the virus. Today, most public health organizations and community groups use the term "HIV" alone. Since this article is meant to describe community engagement methods, we will adhere to the more current parlance of "HIV" unless we refer to a specific event or group that uses "AIDS".

valued. (Ontario AIDS Network, 2011, p. 13; see also, for example, Cain et al., 2014; Carter et al., 2015; Dlamini-Simelane, 2017; Paxton & Stephens, 2007)

The movement to center and uplift the experiences of people living with HIV in the decision-making processes that affect their lives has been foundational to the development of just policies and practices in the HIV epidemic. Nevertheless, there is a pressing need to continue developing and refining processes of participation and engagement in HIV policy development and service provision (Switzer et al., 2020). This need has become especially apparent as HIV organizations and policy groups in the United States have increasingly categorized people living with HIV as "consumers," suggesting that the only place for their participation is in the passive use of services (Spieldenner et al., 2019). In this context, current innovations in MIPA offer an important foundation for the development of best practice principles for community engagement.

Among these current innovations is an intersectional ethos and set of research methods known as "participatory praxis," which challenges HIV/AIDS researchers, policy-makers, and service providers to "document, acknowledge, and respect local knowledge" (Sprague et al., 2019, p. 1). Participatory praxis provides "an approach to negotiating differences" in research, policy, and service development that is designed to prevent organizational interests from "supersed[ing] community perspectives" or subordinating them in intent or outcomes (Sprague et al., 2019, p. 1).

The field of community engagement encompasses a broad range of activities and models that include and promote relationships with communities—sometimes in a consultative way and sometimes via some form of partnership. In a systematic review of the literature, Cyril and colleagues (2015) found that a high level of community engagement—such as community control and empowerment—led to more positive outcomes, including sustainable, tailored, and nuanced policy and other interventions. On the other hand, most studies considered in the review did not have the resources to fully invest in their partner communities, and those that involved less robust forms of engagement led to frustration and even failure. The more "top-down" approaches common in public health and research were often less successful than more "bottom-up" forms (O'Mara-Eves et al., 2013).

In this article, we discuss our participatory praxis approach to community engagement and suggest that it embodies a MIPA model that is lacking in other forms of engagement. First, we describe the context of our work. Our engagement activities are focused on the use and reuse of the health information and biomaterial of people living with HIV for surveillance purposes, particularly a form of surveillance—molecular HIV surveillance (MHS)—that has become more mainstream in recent years. Second, we present an example of what we take to be a rather minimal approach to community engagement in MHS. We next contrast this approach with our MIPA-informed participatory praxis approach, which we detail in a third section. In the fourth and final section of this article, we distill two best practice principles to guide community engagement related to MHS going forward.

**Context: HIV Surveillance in the United States as a Public Health Tool**

Myriad forms of HIV surveillance currently operate in the United States. The term "HIV surveillance" is perhaps most commonly associated with the public health–based epidemiological tracking of HIV in populations. For instance, the U.S. Centers for Disease Control and Prevention (CDC) assembles HIV surveillance reports that detail rates of HIV diagnosis according to variables such as place, age, race, sex, and transmission category. In this form of HIV surveillance, data are de-identified, meaning that people's personal information is removed and information about individual diagnoses is aggregated for the purpose of depicting the state of the HIV epidemic in a given population. This information is generally used by health departments, health service organizations, and other government bodies.

*Molecular HIV Surveillance (MHS)*

MHS is a form of public health, population-level surveillance that repurposes clinic-based surveillance of HIV in individuals, especially drug resistance surveillance. As operationalized by the CDC, MHS is meant to detect *transmission clusters* and *risk networks*. A transmission cluster is defined by the CDC as "a group of HIV-infected persons (with diagnosed or undiagnosed HIV) who are connected by HIV transmission," which "can represent recent and ongoing HIV transmission in a population, where prevention efforts could prevent new infections" (CDC, 2018 p. 6). Transmission clusters are supposed to "represent

an underlying risk network," which "includes persons who are not HIV-infected but may be at risk for infection, as well as HIV-infected persons in the transmission cluster" (CDC, 2018, p. 6).[2]

Federally, the development of MHS as a mode of population-level HIV surveillance is part of a broader policy and funding shift that (a) emphasizes data-driven approaches and interoperability and (b) seeks to more closely integrate HIV surveillance with HIV prevention (Molldrem & Smith, 2020). In 2017, for example, the CDC announced a cooperative funding opportunity that incentivized state health departments to develop local MHS operations (CDC, 2017). This shift toward HIV surveillance as a "cornerstone of HIV prevention" (Azar, 2019) has had the effect of displacing long-standing, thoroughly evaluated community-led and community-based prevention solutions that have relied on establishing relations of trust with persons and communities affected by HIV. From this perspective, it is disappointing to observe the rather minimal community engagement that has accompanied the rollout of MHS in the United States.

*Minimal Community Engagement With MHS*

One year after the national rollout of MHS began, the CDC conducted a series of virtual consultations with health departments and HIV community advocates. The CDC also hosted informational presentations on MHS at U.S. HIV conferences, but these presentations did not include time for dialogue (that is, there were no question and answer periods). Two of the authors took part in virtual consultations and found them lacking in their reach and in the kinds of conversations they spurred. Below, we reflect on the publicly accessible materials that were produced in relation to these virtual consultations. This sets up a contrast with our participatory praxis approach, which we will discuss in the following section.

One of the first documents highlighted on the CDC's MHS website is a two-page fact sheet entitled *Advancing HIV Prevention Through Cluster Detection and Response*. Perhaps in an effort to allay concerns about misuse of personal health information, this document stresses that MHS is not about tracking "the person" or "who infected whom" (CDC, 2019a, p. 1). Instead, the document attests, MHS is about examining "the genetics of the virus" (CDC, 2019a, p. 1). These intentional distinctions define MHS from a health department perspective but not necessarily from the perspective of people and communities living with or affected by HIV (McClelland et al., 2020). How would they define, describe, or otherwise relate to MHS? To find out, the second page of the fact sheet proposes engaging communities in HIV prevention. It states, "As health departments conduct HIV cluster detection and response activities, including molecular analysis, insights and support from community members—including people with HIV, providers and community-based organizations—will be critical" (CDC, 2019a, p. 2). In this framing, it is not a question of whether or even how cluster detection and analysis should proceed. Rather, it is a matter of improving or augmenting such detection with "insights" from the community. Stakeholders, the fact sheet recommends, will be "well informed," will have the chance to "share input and concerns," and "can assist as needed with detecting and responding to increases in HIV transmission" (CDC, 2019a, p. 2).

The fact sheet outlines different avenues for community engagement, including initiating community discussions with HIV planning bodies, providers, and local organizations; holding discussion forums, focus groups, interviews, and surveys; creating educational materials; and working with community partners on cluster response. These modes of engagement as described in this fact sheet do not contemplate the possibility that that MHS or other forms of cluster detection will be opposed by community members. They take for granted that MHS should proceed (McClelland et al., 2020).

In another document, the first in a series of documents assembled under the heading "Communication Toolkit," a PowerPoint presentation gives an overview of "HIV Data in Action." The second slide in this talk is entitled "Community Engagement," and the three-fold purpose of this engagement is described as: (a)

---

[2] In addition to providing a description of how MHS works, this quotation also shows how normative views are cemented into supposedly value-neutral public health initiatives. Consider the source's use of the phrase "a group of HIV-infected persons." This type of language "carries the stigma of being contagious, a threat, unclean. HIV advocates frequently highlight the damaging consequences of this word choice" and prefer to use person-first language "emphasizing humanity" (National Institute of Allergy and Infectious Diseases, 2020, p. 5).

"increasing understanding about uses of data for HIV prevention," (b) "increasing understanding of community concerns," and (c) "working together to address concerns and minimize risks" (CDC, n.d.). This is promising. However, fast-forward to the slide entitled "Community Engagement is Critical." This slide states that community engagement aims to "inform [the] community of [the] program" (CDC, n.d.), exemplifying an approach that makes program determinations prior to consultation and then aims to get the community on board afterward. The notion of *informing* the community is notably different from engagement models that emphasize shared leadership—it is comparatively passive.

In the CDC's virtual consultations on MHS, community engagement appeared as an afterthought for a program of action whose objectives had been worked out in advance. A less charitable view would be that community engagement activities were instrumentalized to justify programming that was already in place. No organizations led by people living with HIV were involved in the planning, and few were involved in implementation or evaluation of any efforts to educate the community at a national level. In fact, these activities took place after the rollout of MHS, which affects each of the more than one million people living with HIV in the United States. This minimal consultation catalyzed community education activism around MHS from organizations led by people living with HIV (Bernard et al., 2020).

**A Participatory Praxis Approach to Community Engagement With MHS**

The concept of praxis is well established in scholarship on community engagement (Iverson & James, 2014, p. 21). It is, briefly, "action and reflection upon the world in order to change it" (hooks, 1994, p. 14). "[V]erifying in praxis what we know in consciousness" (hooks, 1994, p. 47) can be a critical strategy for reducing "stigma, unintended disenfranchisement and culturally bound bias" in approaches to community engagement (Mocarski et al., 2020, p. 29).

In order to contribute to this scholarship, we highlight the participatory praxis approach. This approach builds on the tradition of participatory action research, especially insofar as this tradition is grounded in and reflects "the struggle of those made invisible or subordinated by more powerful elements in their society to take control of their life trajectories and social and economic destinies"

(e.g., Glassman & Erdem, 2014, p. 207). The participatory praxis approach derives its name from the characteristic attempt to fundamentally embed community voices into everyday practices of decision- and policy-making. In their work on health-related stigma research, Sprague and colleagues (2019) located the participatory praxis approach on a broader continuum of participation. This continuum ranges from research embodying minimal community engagement to forms of shared leadership embodied by the participatory praxis approach. Community leadership is the hallmark of the participatory praxis model.

The goal of participatory praxis is to create conditions of "enhanced agency, dignity and wellbeing" (Sprague et al., 2019, p. 2). Sprague and colleagues identified and defined several foundational values for the praxis approach: equity, justice, dignity, participation, non-othering, accountability, reflexivity, transparency, and flipping the power dynamics. Furthermore, they outlined three essential features of the approach:

> First, everyone exists at a particular intersection of privilege and oppression; acknowledging this fact is a first step in putting the values of accountability, non-othering, and dignity into practice. Second, a reflexive understanding of one's own situatedness vis á vis different statuses of power and privilege is critical for effecting participatory praxis. Membership in a particular community is not a precursor to participatory praxis . . . [Third,] participatory praxis must be viewed as a long-term mission. Un-learning practices that instill hierarchy and distance requires constant engagement and commitment to the values. (Sprague et al., 2019, p. 3)

This strategy is driven by the community or communities affected by a given policy or program.

Below, we describe how the participatory praxis approach was developed to support our MHS-related community engagement activities. Our approach contrasts with the minimal forms of community engagement developed by institutional actors. Moreover, what we present reflects an important extension of community engagement and praxis concepts. Our articulation of participatory praxis has developed in the field; in the context of the global movement to end HIV stigma, discrimination, and criminalization;

and in light of our ongoing efforts to highlight problematic interconnections between surveillance and criminalization. Mediated by MIPA, the frontline work unfolding in this movement can enrich our understanding of community strengths, needs, and priorities (Sprague et al., 2019). By attending to these developments, scholars working on and through community engagement and praxis concepts can learn, as we shall describe, the importance of *valorizing* and *adequately resourcing* expertise that stems from experience.

*Approaches to Community Engagement Led by People Living with HIV*

Three U.S.-based organizations led by people living with HIV—the U.S. People Living with HIV Caucus (HIV Caucus), the Sero Project, and Positive Women's Network–USA (PWN-USA)— partnered with the Legacy Project to develop a MIPA-informed MHS community education series built on participatory praxis principles. Rather than focusing on a fixed list of items to cover, participatory praxis actively encourages open spaces for dialogue. It also examines on-the-ground concerns in terms of implementation of the proposed initiatives. Organizations like the Legacy Project have been actively engaged with participatory praxis through their work on HIV research collaborations. The Legacy Project is a program of the Office of HIV/AIDS Network Coordination, which is funded by the Division of AIDS at the National Institute of Allergy and Infectious Diseases. It focuses in part on community engagement among populations underrepresented in HIV research in the United States. The HIV Caucus, Sero Project, and PWN-USA represent networks of people living with HIV. Networks like these were once an entrenched part of the HIV response in the United States, and these three organizations have developed multiple materials and trainings on the importance of MIPA.

The four partnering organizations developed four interactive webinars that examined MHS from the point of view of people living with HIV. In particular, the organizations wanted to center the discussion outside of the public health framework that governs CDC presentations and to concentrate instead on the issues facing people living with HIV—people who are largely from communities of color and may be marginalized due to their sexuality, gender identity, mental health status, substance use, sex work, or immigration status. These webinars covered a range of topics from a community perspective, including the relationship that people living with HIV have to policing, genotype sequencing and HIV research, and MHS and the CDC. The series of webinars concluded with a town hall session to verify key findings. The majority of the panelists involved were people of color who were openly living with HIV. One representative from the National Institutes of Health and one from the CDC each presented. The webinars ran over the course of six weeks. Nearly 300 individuals attended the four live webinars, and the recordings have been viewed over 650 times. There was no external funding to support these efforts.

We present the first webinar as a case study to illustrate our participatory praxis approach. Titled "Without Our Consent: Centering People Living With HIV in HIV Genetic Sequencing," the webinar was specific to communities and policing in the MHS context. The title refers specifically to the fact that HIV genetic sequences are used for surveillance purposes without the consent of the people from whom the sequences are acquired. Individuals are not informed that their biological samples will be sequenced and compared with other local samples for possible connection as a "transmission cluster." When this identification occurs, public health institutions enter individuals' lives through disease intervention specialists, whose powers in most states include deploying law enforcement to support their investigation.

Unfortunately, public health discourse on HIV surveillance rarely addresses the fact that some aspects of public health organizations share with law enforcement the capacity to exercise coercive power. Discussions of HIV surveillance also rarely acknowledge that data gathered for public health reasons can be repurposed in criminal justice proceedings (e.g., criminal investigations and trials). For example, in circumstances that criminalize people living with HIV for allegedly not disclosing their HIV status to sex and drug-sharing partners, criminal investigators, prosecutors, judges, and juries routinely use public health data to make determinations of guilt (Hoppe, 2018). This is especially true among communities that have been disproportionately affected by coercive power in the United States, including African Americans, immigrants, people of trans experience, sex workers, and people who use drugs. We know that these communities are more heavily policed than others and thus more vulnerable to coercion by government agencies and the use of law enforcement (Hoppe, 2018).

These same communities are marginalized in the United States, often excluded from social protections and institutions such as education, health care, and employment. Over 30 states have laws that punish people living with HIV for alleged nondisclosure in a range of activities, including but not limited to sex and drug-sharing (Hoppe, 2018); therefore, increased and targeted surveillance carries serious concerns, particularly for groups more likely to be policed. In order to recenter the discussion of MHS on the implications of the practice for people living with HIV, advocates from four communities—African American, Latinx, people of trans experience, and sex workers—led the webinar. These leaders were selected because they could speak to the concerns of communities that are perhaps put at the greatest risk by MHS due to overpolicing.

After briefly summarizing MHS processes, the moderator introduced the presenters. This discussion moved MHS outside of public health "ideal type" frameworks and into how MHS implementation would work in practice. It pointed out that public health surveillance in the United States can and does use law enforcement in order to obtain its goals. For tuberculosis, for instance, public health agencies has used law enforcement to enforce directly observed therapy (CDC, 2019b). Surveillance officials from health departments have also been called to testify for district attorneys in HIV criminalization cases (Hoppe, 2018).

The webinar presenters spoke about their particular community histories and issues related to law enforcement. Experiences with police differ dramatically in the United States depending on one's socioeconomic class, occupation, race, gender, sexuality, and region. African Americans and Latinx people are more likely to be stopped by law enforcement and to receive harsher punishments than their White counterparts. In addition, as the backlash against immigrants and migrants has extended from border protection rhetoric to the active exclusion of migrants and immigrants from work, health care, and social services, immigration status further complicates relationships to law enforcement and government organizations. Sex workers and people of trans experience have been particularly hard-hit by policing and by the criminalization of their identities, which has increased with the passage of "bathroom bills" in several states as well as the federal Stop Enabling Sex Traffickers Act and Allow States and Victims to Fight Online Sex Trafficking Act (more commonly referred to as SESTA/FOSTA). The presenters connected these narratives to HIV criminalization laws.

Over 120 people attended the first webinar, including participants from health departments, the CDC, AIDS Service Organizations, and HIV advocacy groups. One community-based organization in Mississippi hosted the webinar for 50 local people living with HIV in preparation for their HIV Advocacy Day.

During the webinar, one health department official expressed disagreement using the webinar's chat function. The official disagreed with the portrayal of MHS processes, saying that the presentation was "unscientific" and differed from health department terminology and guidelines. In addition, the health department official expressed concern that the community representatives were talking about "worst case scenarios" that had not happened. The moderator responded by pointing out that this was an engagement with HIV communities and that the health department was welcome to participate respectfully without trying to control the community dialogue.

This webinar demonstrates how the participatory praxis approach can advance MIPA and how MIPA, in this context, enriches participatory praxis. First, networks of people living with HIV were responsible for initiating, conceptualizing, and implementing the webinars, exemplifying the praxis values of accountability and non-othering. Second, the webinars purposefully centered particular communities and gave people space to articulate how MHS might impact their minoritized communities outside the context of the state's rhetoric, which holds that surveillance is a public good that serves everyone. Third, the organizations behind these community education efforts have continued to provide leadership and resources to advocacy and media groups about MHS for people living with HIV. Finally, unlike the CDC's conference presentations that did not include question and answer periods, participants were able to air disagreements in the webinar through the chat function, thus demonstrating a respect for dialogue as opposed to unilateral communication. The community engagement in this webinar (and in the ensuing series) allowed for discussions outside of the parameters carefully prescribed by those holding formal state and institutional power. The community dialogue in the first webinar framed how the rest of the MHS webinars would proceed. Participants were aware that their views and concerns would be carried forward and revisited at the closing town hall webinar.

**Lessons Learned**

Below, we highlight two key lessons learned during the course of our community engagement exercises. By attending to these developments, scholars working on and through community engagement and praxis concepts can learn the importance of *valorizing* and *adequately resourcing* expertise that stems from experience.

*Lesson 1: Valorizing MIPA and Contesting Its Decline in the HIV Response*

The course of the HIV epidemic in the United States and around the world has been transformed by activists and community members who, since the beginning, have demanded more humane public policy responses and decried "the failure of government at every level to provide the funding necessary" to deal with the epidemic (Crimp, 1987, p. 5). When funding did eventually start to funnel into medical research, activists and community members were there to critique the "elegant" approach to medical research and to "show defiance" for what established researchers thought of as "good science" (from an activist chant, fall 1988, Harvard University; cited in Epstein, 1996, p. 1). These protests centered first on acquiring adequate resources and then on the meaningful involvement of those with actual, lived experience with HIV and AIDS in important decision-making processes.

Since that time, HIV treatments have become effective and accessible to many in the Global North. With the knowledge that a person who is virologically suppressed can no longer transmit HIV, focus on treatment as prevention initiatives has increased in the United States (Hoppe, 2018). While this is ostensibly valuable for the public good, it also privileges interventions that occur in the clinic with a physician—interventions that do not necessarily require extensive community engagement. Clinics often operate under the presumption that people want good health—or want to solve potentially damaging or debilitating health conditions—and that people have the means and access to satisfy these health-related wants in partnership with providers at clinics. The HIV movement has thus shifted away from community building among those most impacted (such as the LGBTQ community, sex workers, people who use drugs, and people living with HIV) toward investment in the medical establishment, including clinics and pharmaceutical solutions (Spieldenner et al., 2019).

In light of these developments, it has become increasingly important to valorize MIPA and the important work of centering the expertise of experience. In the case of our webinars, the participatory praxis approach advanced MIPA, marking an important contrast with the minimal forms of institutionalized consultation that were not organized by people living with HIV. Moreover, in valorizing MIPA, we developed our participatory praxis approach, which has not yet fully articulated its relationship with MIPA. Sprague and colleagues (2019) have called for an examination of current practices, gaps, and opportunities that "could enhance understanding of the state of participatory praxis" (2019, p. 5). The ongoing elaboration and articulation of participatory praxis in relation to MIPA is one such opportunity.

MIPA offers important lessons that can be applied to all health and social conditions. Those most impacted should be at the center of the planning, implementation, and evaluation of any prospective responses and solutions. We recognize the vast differences in resources and capacity that exist between institutions like governments and universities, on the one hand, and those most impacted by a particular condition, on the other (whether a health condition, such as HIV, or a condition of social discrimination, such as homophobia, transphobia, sexism, racism, or ableism). The resourcing of community-led efforts is our second lesson.

*Lesson 2: Adequately Resourcing the Power of the People*

Over the past 10 years, networks of people living with HIV have been organizing across such issues as race, gender, aging, and HIV criminalization at national and regional levels. Often, networks organize around a particular affinity, such as a region, identity, or specific concern. Since the dissolution of the National Association of People with AIDS (NAPWA), the HIV Caucus has represented the voices of people living with HIV at the national level alongside member networks PWN-USA, the International Community of Women Living with HIV–North America, the Sero Project, Positively Trans, the Global Network of People living with HIV/AIDS–North America, and THRIVE SS. These networks have worked to develop advocacy events, such as the AIDSWatch lobbying day in Washington, D.C., as well as multiple community convenings and training academies. These activities are rooted

in the long history of organizing among networks of people living with HIV.

The protest and advocacy group AIDS Coalition to Unleash Power (ACT UP) and the art collective Gran Fury are highly visible examples of these kinds of networks. ACT UP led many historic protests in the 1980s and 1990s, when government and health care responses to the disease were slow, inadequate, and often discriminatory (Brier, 2009). Gran Fury produced and disseminated several art pieces, including the "Kissing Doesn't Kill" advertisement that ran on buses in New York City (Spieldenner, 2017). Besides ACT UP and Gran Fury, organized groups of people living with HIV existed in almost every city and state (Brier, 2009). These groups gathered to share support, medical advice, and sometimes advocacy strategies. The now-defunct NAPWA grew out of these efforts in the United States.

Since the emergence of effective HIV treatment, the activism that spurred these networks has dimmed. With the focus now on HIV clinical services, resources for networks of people living with HIV have been subsumed under other community engagement strategies, such as community advisory boards. These other strategies are often restrictive in terms of their mission (e.g., they are limited to offering approval and advice to a specific organization or about a specific program or policy) and scope (e.g., they do not have the power to initiate programs or policies; Spieldenner et al., 2019). Many HIV organizations in the United States have removed "HIV" from their name and/or mission in an explicit strategy to address other health concerns and other communities. Whatever benefits they may have, these shifts in the HIV movement have also effectively limited the voices of people living with HIV.

The legacy of the early HIV movement—perhaps best embodied by the social demand "nothing about us without us"—is more relevant than ever. While some in public health may imagine MHS as a necessary next step in understanding and identifying new HIV transmissions within a community, this initiative has been developed and implemented with very little meaningful community engagement at the national and regional levels. The lack of funding to resource community engagement across public health is one key part of the challenge. Without equipping organizations and individuals with the resources (in terms of time, expertise, access and funding), the community will be left behind. The dearth in resources has direct impact on the participation of people living with HIV, especially those who are most marginalized in education, employment and other government systems (e.g. people of color, people in poverty, people of trans experience, people who have been in prison, sex workers).

In light of structural inequities in the resourcing of the HIV response, the vision of shared leadership embodied by the participatory praxis approach may be difficult to realize. A second key lesson from our community engagement activities, therefore, is that it will be critical going forward to work in an intersectional frame that fosters racial, language, economic, and social justice. If some of the funding currently devoted to surveillance and policing were diverted to support community organizing and the uplifting of experiential expertise, the participatory praxis vision of shared leadership could be more widely realized.

**Conclusion**

We present the participatory praxis approach to demonstrate how MIPA can be implemented in community engagement in questions related to MHS. Although MIPA is considered in the HIV response, program and implementation models are lacking. Our participatory praxis approach centers MIPA and presents viable methods for community engagement and education about the evolving HIV response. In the case of MHS, people living with HIV are particularly affected because their information and biomaterial are being reused for surveillance, making some people living with HIV vulnerable to coercive and punitive interventions (McClelland et al., 2020).

Funding for community engagement efforts remains inconsistent and erratic. We have discussed two different community education efforts on MHS: one from the government and one from community groups. While the government engagement was well resourced, the community group effort was conducted primarily by volunteers and activists from groups centered around people living with HIV. This, perhaps, could have affected how the implementers chose their engagement strategies. The participatory praxis approach requires more setup, more time, (under ideal circumstances) more funding, and more connections to the community, but it can eventually encourage community investment in the process.

The praxis of MIPA is integral to an effective HIV response. Within the public heath mechanisms of epidemiology, intervention, and policy, MIPA ensures that those most directly affected are able

to assert their needs, concerns, and rights. Beyond public health, MIPA is also important when considering other community concerns. People living with HIV have driven political change in the United States in multiple health, housing, and labor agencies (Brier, 2009).

By presenting this case study of the participatory praxis approach, we hope to expand community engagement scholarship by introducing a practice that centers those most affected by the social condition being addressed. To be successful, participatory praxis requires an ongoing engagement with community groups. It also allows for divergent opinions and discussions across constituents. In our case, health department officials were able to express their disagreement with the presentations and community dialogue. In other, more superficial examples of community engagement, divergent views were easily restricted due to the invitation-only nature of the meeting or the control of the chat function in the virtual engagement. We understand that this may be intentional due to the goals of the different community education sessions. We also recognize that community members who are meant to receive the information may resent their positioning as passive consumers, particularly when the information affects them directly (Spieldenner et al., 2019). Participatory praxis requires time and investment but also makes the community the center of the engagement.

## References

Azar, A. (2019, February 5). *Ending the HIV epidemic: A plan for America*. U.S. Department of Health and Human Services. https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview

Bernard, E.J., McClelland, A., Cardell, B., Chung, C., Castro-Bojorquez, M., French, M., Hursey, D., Khanna, N., Minalga, M.B., Spieldenner, A., & Strub, S. (2020). We are people, not clusters! *The American Journal of Bioethics*, *20*(10), 1–4. https://doi.org/10.1080/15265161.2020.1809550

Brier, J. (2009). *Infectious ideas: U.S. political responses to the AIDS crisis*. University of North Carolina Press.

Cain, R., Collins, E., Bereket, T., George, C., Jackson, R., Li, A., Prentice, T., & Travers, R. (2014). Challenges to the involvement of people living with HIV in community-based HIV/AIDS organizations in Ontario, Canada. *AIDS Care*, *26*(2), 263–266. https://doi.org/10.1080/09540121.2013.803015

Carter, A., Greene, S., Nicholson, V., O'Brien, N., Sanchez, M., de Pokomandy, A., Loutfy, M., Kaida, A., & CHIWOS Research Team. (2015). Breaking the glass ceiling: Increasing the meaningful involvement of women living with HIV/AIDS (MIWA) in the design and delivery of HIV/AIDS services. *Health Care for Women International*, *36*(8), 936–964. https://doi.org/10.1080/07399332.2014.954703

Centers for Disease Control and Prevention. (n.d.). *HIV data in action: Using HIV data to prevent infections and improve health*. U.S. Department of Health and Human Services. https://www.cdc.gov/hiv/ppt/programresources/guidance/cluster-outbreak/hivdatainaction.pptx

Centers for Disease Control and Prevention. (2017). *Funding opportunity announcement (FOA) PS18-1802: Integrated human immunodeficiency virus (HIV) surveillance and prevention programs for health departments*. U.S. Department of Health and Human Services. https://www.cdc.gov/hiv/funding/announcements/ps18-1802/index.html

Centers for Disease Control and Prevention. (2018, June). *Detecting and responding to HIV transmission clusters: A guide for health departments, Draft version 2.0*. U.S. Department of Health and Human Services. https://www.cdc.gov/hiv/pdf/funding/announcements/ps18-1802/CDC-HIV-PS18-1802-AttachmentE-Detecting-Investigating-and-Responding-to-HIV-Transmission-Clusters.pdf

Centers for Disease Control and Prevention. (2019a, February). *Advancing HIV prevention through cluster detection and response*. U.S. Department of Health and Human Services. https://www.cdc.gov/hiv/pdf/programresources/guidance/cluster-outbreak/cdc-hiv-advancing-HIV-prevention-through-cluster-detection.pdf

Centers for Disease Control and Prevention. (2019b). *A promising HIP intervention: Electronic directly observed therapy for active TB disease*. U.S. Department of Health and Human Services. https://www.cdc.gov/nchhstp/highimpactprevention/promising-hip-intervention.html

Crimp, D. (1987). Introduction. *October*, *43*, 3–16. https://doi.org/10.2307/3397562

Cyril, S., Smith, B.J., Possamai-Inesedy, A., & Renzaho, A.M.N. (2015). Exploring the role of community engagement in improving the health of disadvantaged populations: A systematic review. *Global Health Action*, *8*(1), Article 29842. https://doi.org/10.3402/gha.v8.29842

Dlamini-Simelane, T. (2017). The GIPA concept 'Lost in Transition.' *Anthropology in Action*, *24*(3), 1–10. https://doi.org/10.3167/aia.2017.240301

Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. University of California Press.

Glassman, M., & Erdem, G. (2014). Participatory action research and its meanings: Vivencia, praxis, conscientization. *Adult Education Quarterly*, *64*(3), 206–221. https://doi.org/10.1177/0741713614523667

hooks, b. (1994). *Teaching to transgress: Education as the practice of freedom*. Routledge.

Hoppe, T. (2018). *Punishing disease: HIV and the criminalization of sickness*. University of California Press.

Iverson, S.V., & James, J.H. (2014). Feminism and community engagement: An overview. In S.V. Iverson & J.H. James (Eds.), *Feminist community engagement: Achieving praxis* (pp. 9–27). Palgrave Macmillan US. https://doi.org/10.1057/9781137441102

McClelland, A., Guta, A., & Gagnon, M. (2020). The rise of molecular HIV surveillance: Implications on consent and criminalization. *Critical Public Health*, *30*(4), 487–493. https://doi.org/10.1080/09581596.2019.1582755

Mocarski, R.A., Eyer, J.C., Hope, D.A., Meyer, H.M., Holt, N.R., Butler, S., & Woodruff, N. (2020). Keeping the promise of community-based participatory research: Integrating applied critical rhetorical methods to amplify the community's voice for trial development. *Journal of Community Engagement and Scholarship*, *13*(1), Article 4. https://digitalcommons.northgeorgia.edu/jces/vol13/iss1/4

Molldrem, S., & Smith, A.K.J. (2020). Reassessing the ethics of molecular HIV surveillance in the era of cluster detection and response: Toward HIV data justice. *The American Journal of Bioethics*, *20*(10), 10–23. https://doi.org/10.1080/15265161.2020.1806373

Morolake, O., Stephens, D., & Welbourn, A. (2009). Greater involvement of people living with HIV in health care. *Journal of the International AIDS Society*, *12*(1), Article 4. https://doi.org/10.1186/1758-2652-12-4

National Institute of Allergy and Infectious Diseases. (2020, February). *NIAID HIV language guide*. U.S. Department of Health and Human Services. https://www.hptn.org/sites/default/files/inline-files/NIAID%20HIV%20Language%20Guide%20-%20March%202020.pdf

O'Mara-Eves, A., Brunton, G., McDaid, D., Oliver, S., Kavanagh, J., Jamal, F., Matosevic, T., Harden, A., & Thomas, J. (2013). Community engagement to reduce inequalities in health: A systematic review, meta-analysis and economic analysis. *Public Health Research*, *1*(4). https://doi.org/10.3310/phr01040

Ontario AIDS Network. (2011, October). *Living and serving 3: GIPA engagement guide and framework for Ontario ASOs*. http://oan.red/wp-content/uploads/2013/06/living_serving3_oct2011.pdf

Paris Declaration, December 1, 1994, http://data.unaids.org/pub/externaldocument/2007/theparisdeclaration_en.pdf

Paxton, S., & Stephens, D. (2007). Challenges to the meaningful involvement of HIV-positive people in the response to HIV/AIDS in Cambodia, India and Indonesia. *Asia Pacific Journal of Public Health*, *19*(1), 8–13. https://doi.org/10.1177/10105395070190010301

U.S. People Living with HIV Caucus. (n.d.). *The Denver principles*. https://www.hivcaucus.org/denver-principles

Spieldenner, A.R. (2017). Infectious sex? An autoethnographic exploration of HIV prevention. *QED: A Journal in GLBTQ Worldmaking*, *4*(1), 121–129. https://doi.org/10.14321/qed.4.1.0121

Spieldenner, A.R., Sprague, L., Hampton, A., Smith-Davis, M., Peavy, D., Bagchi, A., Cardell, B., Johnson, V., Brown, G., & Brewer, R. (2019). From consumer to community-based researcher: Lessons from the PLHIV Stigma Index. In P. Kellett (Ed.), *Narrating patienthood: Engaging diverse voices on health, communication, and the patient experience* (p. 151–166). Lexington Press.

Sprague, L., Afifi, R., Ayala, G., & Lumumba El-nasoor, M. (2019). Participatory praxis as an imperative for health-related stigma research. *BMC Medicine*, *17*, Article 32. https://doi.org/10.1186/s12916-019-1263-3

Switzer, S., Flicker, S., McClelland, A., Carusone, S.C., Ferguson, T.B., Herelle, N., Yee, D., Guta, A., & Strike, C. (2020). Journeying together: A visual exploration of "engagement" as a journey in HIV programming and service delivery. *Health & Place*, *61*, Article 102247. https://doi.org/10.1016/j.healthplace.2019.102247

UNAIDS. (2007). *The greater involvement of people living with HIV (GIPA)* [Policy brief]. http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf

Van Roey, J. (1999). *From principle to practice: Greater involvement of people living with or affected by HIV/AIDS (GIPA)*. UNAIDS. http://data.unaids.org/publications/irc-pub01/jc252-gipa-i_en.pdf

**About the authors**

Andrew Spieldenner is associate professor in communication at California State University-San Marcos, executive director of MPact: Global

Action for Gay Health & Rights, and visiting scholar at Concordia University. Martin French is associate professor in sociology/anthropology at Concordia University. Venita Ray is co-executive director of Positive Women's Network-USA. Brian Minalga is a project manager for the Office of HIV/AIDS Network Coordination based at the Fred Hutchinson Cancer Research Center. Robert Suttle is a student affairs practitioner, consultant, and changemaker with extensive experience in the academic and non-profit sectors in the areas of community advocacy and program management. Cristine Sardina is the director of Desiree Alliance, a national sex worker rights organization. Marco Castro-Bojorquez was a cultural worker and advocate across a range of social justice issues, including HIV, who passed away in 2021. Octavia Lewis is an activist and transgender health coordinator at Montefiore Health System. Laurel Sprague is chief, Community Engagement Division, at the Joint United Nations Programme on HIV/AIDS.