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# Addressing Health Disparities in HIV: Introduction to the Special Issue

Marguerita Lightfoot, PhD,<sup>a</sup> Norweeta Milburn, PhD,<sup>b</sup> and Lisa Loeb Stanga, DrPH, MPH<sup>c</sup>

**Abstract** Racial and ethnic minority, sexual and gender minority, and low-income people have historically experienced poorer health outcomes and poorer social conditions that lead to poorer health outcomes (social determinants of health) than nonminority people in the United States. To eliminate these health disparities, intentional and targeted interventions that address the needs and preferences of diverse populations are needed. To address disparities, the California HIV/AIDS Research Program focused their funding resources tightly on communities facing elevated HIV incidence or prevalence. This special issue describes interventions that aimed to increase linkage to and engagement in HIV-specific prevention or medical care, each uniquely tailored to the needs of an identified California population with disparate HIV-related health outcomes and each for implementation at a specific stage of the HIV prevention and care continuum.

**Key Words:** HIV, prevention, treatment, health disparities

(*J Acquir Immune Defic Syndr* 2021;88:S1–S5)

## IMPORTANCE OF HEALTH DISPARITIES RESEARCH IN HIV

Racial and ethnic minority, sexual and gender minority, and low-income people have historically experienced poorer health outcomes and poorer social conditions that lead to poorer health outcomes (social determinants of health) than nonminority people in the United States.<sup>1</sup> To eliminate these health disparities, intentional and targeted interventions that address the different needs and preferences of diverse populations are needed. To do this well, it is critical to engage and support those communities

From the <sup>a</sup>UCSF Center for AIDS Research, Center for AIDS Prevention Studies, UCSF Prevention Research Center, University of California, San Francisco, CA; <sup>b</sup>UCLA Center for AIDS Research, Center for HIV, Identification, Prevention, and Treatment Services, University of California, Los Angeles, CA; and <sup>c</sup>California HIV/AIDS Research Program, University of California, Office of the President, Oakland, CA.

Supported by the California HIV/AIDS Research Program, University of California, Office of the President, Awards HD15-LA-061 and HD15-SF-060. The content is solely the responsibility of the authors and does not necessarily represent the official views of the California HIV/AIDS Research Program or the University of California.

The authors have no conflicts of interest to disclose.

Correspondence to: Lisa Loeb Stanga, DrPH, MPH, HIV/AIDS Research Program, University of CA, Office of the President, 1111 Franklin Street, Oakland, CA 94607 (e-mail: lisa.loeb.stanga@ucop.edu).

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most affected by health disparities at all stages of intervention planning and implementation.

Although significant scientific advances have been made in HIV treatment and prevention interventions, leading to decreased HIV incidence and improved health outcomes in some populations, HIV continues to disproportionately affect marginalized communities. In the United States, most incident HIV infections are in young African American and Latinx men who have sex with men (MSM) and transgender women.<sup>2</sup> In 2018, African Americans accounted for an estimated 42% of new infections in the United States, but only 13% of the US population.<sup>2</sup> Of particular concern is the high prevalence of HIV infections among transgender women: CDC's National HIV Behavioral Surveillance survey in 7 major US cities found that 42% of all transgender female respondents and 62%<sup>3</sup> of all African American transgender female respondents tested positive for HIV. Owing to incomplete testing, these numbers may underestimate the actual prevalence of HIV infection in these groups.

## HIV-RELATED HEALTH DISPARITIES IN CALIFORNIA

Of the 157,000 estimated persons living with HIV (PLWH) in California in 2019, most were Black or Indigenous People of Color (BIPOC): 37% were Latinx, 17% were African American, and 4% were American Indian, Alaska Native, Native Hawaiian, Pacific Islander, or multiple races). [add new source for citation here: California Department of Public Health, Office of AIDS, HIV/AIDS Health Disparities in California, May 2021.<sup>4</sup> Across the state, HIV/AIDS epidemic continues to grow in communities of color, with 50% of all new HIV diagnoses in California in 2019 occurring among Latinx people. [California Department of Public Health, Office of AIDS, HIV/AIDS Health Disparities in California, May 2021.] especially among Latinx MSM, African American MSM, African American women, and African American young MSM, ages 13–24 years [California Department of Public Health, Office of AIDS, HIV/AIDS Health Disparities in California, May 2021.] Although the number of Latino MSM with HIV in LAC is larger than the number of African American MSM with HIV, African American MSM are disproportionately [California Department of Public Health, Office of AIDS, HIV/AIDS Health Disparities in California, May 2021.] affected by HIV: In 2018, the rate of new HIV diagnoses among African American men in Los Angeles County (LAC) (91 cases per 100,000) was 2.5 times higher than that among Latino men (37 cases per 100,000) and 4 times higher than that among White men (23 per 100,000).<sup>4</sup>

Other populations at high risk of HIV transmission and infection in California include homeless young people and

transgender women. For example, in LAC, homeless young people, aged 13–24 years, are most often Latinx, African American, or multiethnic.<sup>5</sup> Many homeless young people also identify as lesbian, gay, bisexual, or transgender youth.<sup>5</sup> Homelessness further exacerbates their risk of infection and transmission of the virus.<sup>4</sup> Both African American young MSM and homeless young people have high disease burdens and unmet needs.<sup>4</sup>

## A VISION FOR HIV RESEARCH TO END THE EPIDEMIC IN CALIFORNIA

Building and maintaining research and community collaborations are essential to reduce health disparities in HIV testing and treatment. This work must center key underserved populations at high risk of HIV infection and transmission including MSM of color, homeless youth, sexually minority youth, and transgender people by increasing access to HIV prevention and treatment. To do this well, social determinants of health (such as economic stability, education access, and social and community context) that affect health outcomes in underserved populations should be addressed in the research, and community-facing research approaches that will enhance prevention and treatment should also be considered. The California HIV/AIDS Research Program (CHRP) embraces all these elements in our vision to end the HIV epidemic for all Californians, focusing our funding resources tightly on communities facing elevated HIV incidence or prevalence.

CHRP began this work in 2010 when we funded a collaborative of investigators and community representatives to create an HIV research agenda toward ending the HIV epidemic in California with a singular focus on disparities. This agenda called for examining the epidemiologic data in depth to understand the many microepidemics across the state and the highly specific populations living in them; developing a suite of community-based interventions that would be targeted toward specific populations experiencing HIV-related disparities; and providing funding to support clinical trials to establish the efficacy of these interventions. To do this, CHRP engaged academic researchers, epidemiologists, clinicians, public health departments at local health jurisdictions, the Office of AIDS at the California Department of Public Health, and community-based organizations into a collaborative tasked with designing the funding initiative. Key leadership in the newly formed collaborative came from the heads of 3 National Institutes of Health (NIH)-funded Centers for AIDS Research who were opinion leaders among their peers and had existing direct lines of communication to all other sectors in the collaborative, and at NIH. The group defined 7 populations in California for targeted efforts and intervention development: African Americans living with HIV; African American MSM; youth; cisgender women; transgender persons; people experiencing homelessness; and people with substance use disorders. By 2014, with CHRP funding, grantees in the group had developed and piloted multiple interventions to increase linkage to and engagement in HIV-specific prevention or medical care, each uniquely tailored to the needs of an identified subset of California's population with disparate HIV-related health outcomes and each for implementation at a specific stage of the HIV prevention and

care continuum (a conceptual framework of stages progressing from HIV prevention needs through HIV-specific medical care needs for persons who acquire HIV, addressing individual health outcomes and population-level risk reduction).<sup>6</sup>

To leverage this momentum, in 2015, CHRP launched 2 funding initiatives, totaling more than \$18,000,000: the first to fund the development of HIV-Related Health Disparities Centers within CA-based Centers for AIDS Research, and the second to fund demonstration projects (both behavioral interventions and biomedical clinical trials) of “pre-exposure prophylaxis (PrEP) for HIV Prevention By and For the Transgender Community” in CA. These funding opportunities were designed according to key principles of community-based participatory research. For example, each study team was required to form a partnership with at least 1 community-based organization that had an existing service relationship with the target population, and establish that partnership either before or during the planning stage of the research project, to ensure inclusion of their views in intervention design and outcome assessments.

Taken together, these funding initiatives aimed to (1) jump-start a statewide effort to close the gap of HIV-related health disparities; (2) set the HIV research agenda on course to directly address health disparities; (3) establish the efficacy of multiple interventions to improve HIV-related outcomes for the identified target populations, including the first large-scale trials of PrEP for transgender persons; and (4) facilitate collaboration between academia, government, community, and industry and among 3 University of California campuses.

The 3 HIV-Related Health Disparities Centers received up to \$2,400,000 each in direct costs over 4 years to fund at each site:

- Newly developed disparities “cores” within each CFAR to engage academic researchers, community-based organizations, community members, and local public health jurisdictions in collaborative work toward reducing HIV-related health disparities in their region; the cores would serve as an identified single point of responsibility for the multiple activities of the center and would provide visibility for the focus on disparities at higher levels of the CFARs and at NIH;
- Two clinical trials of social/behavioral/structural interventions designed to address the specific needs of an identified HIV disparities population in their region, developed with members of the community, and implemented at a specific stage of the HIV prevention and care continuum;
- Formal collaboration with at least 2 community-based organizations and at least 1 local health jurisdiction by each center;
- Convening community advisory boards to provide input and guidance on the cores' development and to review study plans, protocols, outcomes, and dissemination.

The “PrEP By and For Transgender Persons” initiative funded 3 collaborative research teams, including 6 community-based organizations with expertise and community acceptance in providing transgender health care and social services, 3 academic centers, and 1 public health department. Each team received approximately \$3,000,000 in direct costs over 4 years to fund for the following:

- Three clinical trials to determine the safety and effectiveness of HIV PrEP medication [(tenofovir and emtricitabine, supplied as Truvada (Gilead Sciences, Inc., Foster City, CA)] for use by transgender persons at risk of HIV, stratified by use/nonuse of gender-affirming hormonal therapy;
- Qualitative studies of the acceptability of PrEP among trial participants;
- Evaluation of interventions to support PrEP uptake and adherence; and
- Pharmacokinetic assessment of potential interactions of Truvada with gender-affirming hormonal therapy; this research question was raised by community members at the formative stage of the research agenda as a key aspect of potential acceptability of PrEP for transgender persons.

Most of the clinical trials included a year or more of funding for intervention development or modification (including focus groups, qualitative interviews, and pilot testing) and at least 2 years from onset of enrollment for study completion. All projects incorporated community-based participatory research principles, including relationship building, community-driven needs assessment, and significant investment, in community advisory board development and engagement. In this special issue, the researchers funded under these initiatives highlight selected outcomes from those funded studies.

## SIX RESEARCH CENTERS TO ADDRESS DISPARITY RATE HIV OUTCOMES

The UCLA HIV Disparities Center focused on 3 populations experiencing health disparities: transgender persons, young African American MSM, and homeless youth. The UCLA core implemented a multilevel structural intervention targeting current clinicians at UCLA Medical Center, trainee clinicians at UCLA School of Medicine (SOM), and the standing curriculum at UCLA SOM to improve capacity and skills in providing culturally competent care for transgender persons. A second team of investigators designed and implemented a social work and legal case management intervention with a mobile application for young African American MSM living with HIV infection but who were not in care. Each arm in this randomized, controlled trial received a weekly text-based ecological momentary assessment to assess medication adherence. A third team designed a popular opinion leader intervention for homeless young people at risk of HIV acquisition that leveraged artificial intelligence that was implemented at drop-in centers in central Los Angeles.

The UCSF HIV Disparities Center worked with members of the faith community, HIV-positive women experiencing syndemic exposures (ie, histories of substance use, mental health disorder, trauma, intimate partner violence, and others), and African American persons living with HIV who were out of care. The team held public faith-based HIV educational events with DJs and gospel choirs and offered free HIV testing; held community HIV research summits; and hosted the 2020 National CFAR meeting. This center also developed a two-way Community Partner Registry in which community-based organizations (CBOs) could request assis-

tance with technical skills usually limited to academia, including grant application writing and data collection methods, and UCSF researchers could contact CBOs to identify potential study sites and/or study participants. To aid in recruitment and retention across multiple studies, the team established a social media management system through Hootsuite and a transportation system to bring volunteers to the clinic with direct billing through Lyft Concierge.

The UCSF HIV Disparities Center engaged scientific leaders to host multiple symposia on HIV-related health disparities (with a particular focus on homelessness), form a coordinated regional response to HIV, and host the 2020 IAS International Conference on HIV/AIDS. Locally, the UCSF clinical trials addressed the needs of young people (aged 18–29 years) living with HIV and who had histories of substance use in 1 trial and members of the House Ball community in Oakland and the wider Bay Area in another. The youth-focused project, known as Y2TEC, established a Youth Advisory Panel at the start of funding, which proved to be critical to its success: an initial face-to-face clinical encounter was added to the study design before onset of the mobile application-based intervention on the suggestion of the Youth Advisory Panel, and research participants reported this session to be important to them. Moreover, at UCSF, the *We Are Family* project, built on long-standing relationships between academic investigators and members of the local House Ball community (generally young sexual minority people of color who form families of choice and provide social support and/or housing), held group educational sessions hosted by the community partner (CAL-PEP), cohosted balls (glamorous events with participant competitions), established a mobile application-based support system that strengthened community cohesion, and hosted mobile HIV testing events.

The San Francisco Department of Public Health (SFPDH) PrEP By and For Transgender Persons Center, in partnership with 5 local clinics, developed and implemented the STAY Study, an innovative demonstration project that evaluated PrEP uptake, adherence, safety, impact on sexual risk behaviors, and potential interactions between the PrEP medication (tenofovir disoproxil fumarate/emtricitabine, or TDF/FTC) and gender-affirming hormonal therapy among transgender persons in the San Francisco Bay Area transgender community. This team piloted the use of PrEPmate, a mobile health intervention using MSM text messaging to promote adherence to PrEP medication and retention in PrEP care. As a result of working at multiple local clinics, they demonstrated that offering a decentralized PrEP-only clinic that was independent of primary care led to a rapid PrEP enrollment, including among those at greater sexual risk of acquiring HIV. Testing multiple social marketing campaigns, they found that campaigns that showed PrEP in the context of the beauty, vibrancy, and resilience of transgender and nonbinary communities were more acceptable than messages that sensationalized HIV and the promise of prevention. Continuity of care and medication provision are provided as part of peer navigation services at postintervention follow-up visits.

The UC San Diego PrEP By and For Transgender Persons Center conducted studies to address knowledge gaps of PrEP in transgender individuals for: (1) linkage and engagement of transgender persons to PrEP, (2) measuring and testing methods to improve adherence to PrEP, and (3)

determining whether there are differences in TDF/FTC pharmacology for HIV-uninfected transgender persons who are taking gender-affirming hormonal therapy. The team conducted 2 primary studies: a randomized controlled clinical trial to evaluate the ability of a transgender PrEP outreach worker (T-POWr) to link HIV-uninfected transgender persons to PrEP providers; and a randomized controlled clinical demonstration project to determine whether the use of a text message-based adherence intervention (iTAB) plus a telephone-based, brief, motivational interviewing (MI-b) intervention improve retention in and adherence to PrEP compared with iTAB alone in transgender/GNC persons. Multiple substudies examined the interaction of gender-affirming hormonal therapy and PrEP and their effect on biomarkers of each; the role of resilience, social support, and coping skills in PrEP adherence; and (c) the impact of STIs, inflammation, and the vaginal microbiome on genital tenofovir (TFV) levels. Three new studies have arisen from the parent CHRP grant, further examining the interaction of gender-affirming hormones and PrEP when used by transgender persons.

The UCSF PrEP By and For Transgender Persons Center launched the TRIUMPH Project or Trans Research-Informed communities United in Mobilization for the Prevention of HIV. The team developed a PrEP delivery system and implemented a PrEP uptake and adherence intervention within a network of clinics and community-based organizations designed specifically to serve transgender communities and determined the feasibility, acceptability, and effectiveness of both. Their i-BrEATHe substudy assessed (1) the pharmacokinetics of daily oral tenofovir disoproxil fumarate/emtricitabine (TDF/FTC) in transgender women and transgender men, using directly observed therapy; (2) determined whether TDF/FTC drug concentrations were lower among transgender women who were using feminizing hormonal therapy and among transgender men who were using masculinizing hormonal therapy compared with historical controls in non-trans men who have sex with men without hormonal therapy; and (3) determined whether daily oral TDF/FTC was associated with comparable rates of adverse events (AEs) in transgender women and transgender men compared with historical controls in nontransgender MSM. A follow-on study of the implementation of the TRIUMPH intervention has been funded by NIH.

### LESSONS LEARNED: “WE ARE NOW OUR OWN COMMUNITY”

In anonymous process evaluation questionnaires completed at semiannual consortia meetings, multiple participant leaders of the collaborative centers (representing academia, community, industry, and government) reported that the “newly formed critical mass of health inequalities experts in HIV” was a key and unanticipated outcome of these funding initiatives. This cross-sector group went on to influence leaders at NIH and at multiple NIH-funded CFARs to shift focus to HIV-related health disparities, as evidenced by new disparities-specific funding opportunities and programming changes at NIH and NIH-funded centers.

The emergence of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and its halting effect on academic research endeavors were also unanticipated. Many of the investigators and community partners adapted to clinic closures by pivoting to telehealth, which coincidentally was the primary intervention mode of multiple clinical trials within these projects.) The continued engagement of trial participants during that pivot would not have been as successful had each of the research teams not invested significant resources and time in building trust with the communities experiencing health disparities before launching research activities. This pillar of good participatory research practice was embraced by each of the research teams, without exception, and proved to be a key to their success—because research and change both move at the speed of trust.

Some participants in the clinical trials noted stigma, isolation, and research fatigue as barriers to participating in research studies such as these; future collaboratives could consider addressing these challenges in the early stages of study planning. Staff reported that the iterative process of reapplying for IRB approval at the academic institution to accommodate needs of community partner CBOs added unplanned delays; building in extra time to secure and revise institutional assurances was suggested for future collaboratives. The unfavorable fiscal climate for CBOs at the time became worse during the study period (2016–2021) and contributed to instability at or closure of multiple partner agencies, necessitating new partnership building and revisiting community-informed outcome measures.

We recognize that the true focus of this work is the individuals who may benefit from better HIV prevention and care services as provided by the public and academic entities dedicated to serving their needs; the new cases of HIV that may be averted, the people now living with HIV who may enjoy longer and healthier lives, and the communities that deserve to be free from stigma and discrimination. We are grateful to the community members who volunteered to join these research projects, served on advisory boards, recruited their friends, and trusted us to serve them, all while holding memories of past systemic injustices and hopes for a different future.

### DISCUSSION: COMMUNITY ENGAGEMENT WAS CRITICAL

The voices of those who are most affected by HIV/AIDS must be heard and valued in the development of HIV/AIDS prevention, care, and treatment strategies. Community engagement is necessary to gain a better understanding of how HIV/AIDS prevention, care, and treatment may better serve communities of color in California and to determine how to build sustained research and service capacity in communities of color.

Based on the work of these collaboratives, we suggest that health planners could initiate dialog among service providers in, and advocates from, communities of color and policy makers to identify rigorous and culturally humble approaches to develop and sustain community-based HIV/AIDS services planning and implementation to address

HIV/AIDS disparities. This type of discussion should include the groups most at risk of HIV infection and transmission, and the areas where these individuals reside relative to the clinics and organizations where HIV testing, treatment, and care are available. In Los Angeles County, for example, this would include African American and Latinx men who have sex with men, African American women, and BIPOC youth.<sup>4</sup> Health planners can bring together (a) members of the community, (b) service providers, (c) advocates, (d) local public health officials, and (e) policy makers to collaboratively dialogue at the planning stage, to identify how best to develop and sustain community-based HIV/AIDS services to bring those most at risk into care and sustain that engagement. CHRP provided funding before the development of the CHRP Health Disparities Cores to support this strategy.

Community engagement can be fostered before health programs are implemented by including community advisory boards in the conceptualization, development, implementation, and dissemination of research projects. All the Health Disparities Cores relied on community advisory boards. For example, the UCLA Core convened an Executive Advisory Board (EAB), which ensured that all initiatives it undertook were developed, conducted, and reported with the needs of HIV-infected individuals and affected communities held paramount. The EAB was vital for 3 primary reasons. First, the Core investigators strongly believed that research in HIV/AIDS is strengthened in its equity, scientific integrity, and practicality by the integral involvement of the community. This belief is foundational to the CBPR model and informs the theme of “fostering collaboration to decrease health disparities.” Second, the central mission of the Core was to foster collaborative projects involving the community, academia, and government, which are scientifically based, rigorously evaluated, acceptable to, and sustainable by the target communities. Third, the Core relied on the professional and social relationships of members of the EAB to help plan and facilitate culturally humble community outreach and dissemination of the research, with a focus on reaching out to and engaging communities in underserved areas of Los Angeles. Similar processes occurred in both the San Francisco and San Diego community advisory boards. In short, community members were included from the inception of planning for the Cores and had access to and impact on all central decisions.

These strategies are just a few examples of how to practice community engagement in HIV/AIDS research. Although strategies may vary, what is most important is that community engagement is essential to reducing health disparities to achieve health equity in HIV prevention and treatment. Going forward, CHRP will continue to build on this successful community collaborative model. Based on feedback from the academic researchers, community advisory board members, governmental officials, and industry representatives in this collaborative, CHRP will encourage cross-sector partnerships in future funding initiatives, where applicable. Addressing HIV-related health

disparities remains a critical part of CHRP’s strategic direction going forward because so much more work needs to be done in this area.

## SUMMARY

Persistent disparities in HIV incidence, prevalence, access to care, and other HIV-related health outcomes in California and the United States indicate that remediation efforts have been insufficient. To begin to mitigate these disparities and bring more equity to health outcomes, new ways of doing public health research must be adopted. The California HIV Research Program set out to demonstrate a new model for collaborative planning and implementation of public health research to address these persistent disparities across many highly specific populations throughout CA. We fostered collaborations, jointly developed a detailed research strategy, strengthened community ties to academia, and built capacity at local community-based organizations, all of which resulted in an extraordinary set of data, capabilities, and public health innovations. The cross-sector community collaborative model that these 6 groups codesigned served as a home for multiple community-based participatory research projects, each addressing diverse and marginalized groups at risk for or living with HIV. Including those groups in the research from its very formation was necessary for its success; the overarching aim of bringing equity to health outcomes among those communities was explicit from the beginning. As researchers and health planners look to the future, adopting this cross-sector framework of community engagement with unequivocal goals of diversity, equity, and inclusion at the planning stage could help to move us all toward ending the HIV epidemic, together.

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