# Presidential Advisory Council on HIV/AIDS (PACHA) 70<sup>th</sup> Meeting (Virtual) March 8–9, 2021

#### **Council Members—Present**

- Carl Schmid, M.B.A., PACHA Co-Chair, Executive Director, HIV + Hepatitis Policy Institute, Washington, DC
- John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chair, Adjunct Assistant Professor, Gillings School of Global Public Health, Health Policy and Management, The University of North Carolina at Chapel Hill, Chapel Hill, NC
- Gregg H. Alton, J.D., San Francisco, CA
- Alicia Diggs, M.P.H., Strategic Community Engagement Education, Dissemination Office Manager, Center for AIDS Research, The University of North Carolina at Chapel Hill, Chapel Hill, NC (*Day 1 only*)
- Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, ACRN, ANP-BC, AAHIVS, Professor and Associate Vice Provost of Mentoring and Outreach Programs; Director/Founder, Center for Latino Adolescent and Family Health; Pilot and Mentoring Core Director, Center for Drug Use and HIV Research (CDUHR), NYU College of Public Health
- Marc Meachem, M.B.A., Head, External Affairs, ViiV Healthcare North America, Washington, DC
- Rafaelé Narváez, Co-Founder and Director of Health Programs, Latinos Salud, Wilton Manors, FL
- Laura Platero, J.D., Executive Director, Northwest Portland Area Indian Health Board, Portland, OR
- Michael Saag, M.D., Associate Dean, Global Health, School of Medicine, and Professor of Medicine, Division of Infectious Disease, The University of Alabama at Birmingham (UAB); Director, UAB Center for AIDS Research, Birmingham, AL
- John Sapero, Director, Ending the HIV Epidemic, Collaborative Research LLC, Phoenix, AZ Robert A. Schwartz, M.D., M.P.H., D.Sc. (Hon.), Professor and Head, Dermatology, Rutgers New Jersey Medical School, Rutgers, The State University of New Jersey, Newark, NJ
- Justin C. Smith, M.S., M.P.H., Director, Campaign to End AIDS, Positive Impact Health Centers; Behavioral Scientist, Rollins School of Public Health, Emory University, Atlanta, GA
- Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC, Lead Provider and HIV Specialist, Eau Claire Cooperative Health Centers (Now Cooperative Health), Columbia, SC

#### **Council Members—Absent**

Wendy Holman, CEO and Cofounder, Ridgeback Biotherapeutics, Miami, FL

## Liaison: Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee on HIV, Viral Hepatitis, and Sexually Transmitted Disease (STD) Prevention and Treatment (CHAC)

Wendy Armstrong, M.D., FIDSA, Professor of Medicine, Emory University; Executive Medical Director, Ponce de Leon Center, Grady Health System, Atlanta, GA (*Day 1 only*)

#### **Staff**

B. Kaye Hayes, M.P.A., PACHA Executive Director, Designated Federal Officer; Acting Director, Office of Infectious Disease and HIV/AIDS Policy (OIDP), Office of the Assistant Secretary for Health (OASH), U.S. Department of Health and Human Services (HHS)

Caroline Talev, M.P.A., Alternate Designated Federal Officer, Management Analyst, OIDP, OASH, HHS

#### **Federal Partners**

Laura Cheever, M.D., Sc.M., Associate Administrator, HIV/AIDS Bureau, HRSA (*Day 1 only*)
 Demetre C. Daskalakis, M.D., M.P.H., Director, Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and Tuberculosis Prevention (NCHHSTP), CDC Antigone Dempsey, M.Ed., Director, Division of Policy and Data, HIV/AIDS Bureau, HRSA
 Neeraj Gandotra, M.D., Chief Medical Officer, Substance Abuse and Mental Health Services Administration

Maureen M. Goodenow, Ph.D., Associate Director for AIDS Research, Director, Office of AIDS Research, National Institutes of Health (NIH)

Rita Harcrow, Director, Office of HIV/AIDS Housing, U.S. Department of Housing and Urban Development (*Day 1 only*)

Heather Hauck, M.S.W., LICSW, Deputy Associate Administrator, HIV/AIDS Bureau, HRSA, (for Laura Cheever, M.D., Sc.M., *Day 2 only*)

Rick Haverkate, M.P.H., National HIV/AIDS & Hepatitis C Program Coordinator, Indian Health Service (IHS)

Douglas Olson, M.D., Chief Medical Officer, Medicaid/Children's Health Insurance Program, Centers for Medicare & Medicaid Services (CMS)

Harold J. Phillips, Senior HIV Advisor and Chief Operating Officer, *Ending the HIV Epidemic: A Plan for America* (EHE), OASH, HHS

Crystal Simpson, M.D., Medical Officer, Office of Medicare, CMS

CAPT Samuel Wu, Pharm.D., Public Health Advisor, Office of Minority Health, HHS

Sara Ziegler, Associate Director for Planning and Policy, NCHHSTP, CDC

## Day 1

## **Opening Remarks from the PACHA Co-Chairs**

Carl Schmid, M.B.A., PACHA Co-Chair, called the meeting to order at 2:01 p.m. (This meeting was broadcast live online; the recorded broadcast is available online, https://www.youtube.com/watch?v=sWkyisSPvhk&feature=youtu.be.

He acknowledged some promising scientific advances on long-acting methods for prevention and treatment of HIV. Mr. Schmid indicated that Congress appropriated nearly \$400 million for the EHE initiative, and for the first time, IHS received funding for its role in the program.

Mr. Schmid noted that on the first day of his term, President Biden signed Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, and Executive Order 13988, Preventing and Combating Discrimination on the Basis of Gender Identity or Sexual Orientation, followed shortly thereafter by an Executive Order to open enrollment for the Patient Protection and Affordable Care Act (ACA) marketplace, all as part of an effort to reverse some of the harmful policies of the previous administration. The Senate passed the American Rescue Plan, which includes funding to strengthen safety net programs, make ACA insurance plans more affordable, and incentivize more States to expand Medicaid. In addition, the White House will resurrect its Office of National AIDS Policy.

John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chair, outlined the agenda, which centers on implementing the HIV National Strategic Plan and addressing health inequities in HIV and the syndemics of sexually transmitted infections (STIs), viral hepatitis, and COVID-19. He observed that although concerns about new variants of COVID-19 continue, there is also cause for hope, given the remarkable achievement of producing multiple effective vaccines within a year of the emergence of the novel coronavirus. Dr. Wiesman hoped that PACHA would eventually resume in-person meetings, including those outside of Washington, DC, where the Council had the opportunity to meet directly with stakeholders in their communities.

## Welcome

RADM Felicia Collins, M.D., M.P.H., FAAP, U.S. Public Health Service (USPHS), Acting Assistant Secretary for Health (ASH), HHS

RADM Collins welcomed the participants. She described herself as a pediatrician by training and a public health practitioner by heart who has focused throughout her career on vulnerable and underserved populations in the pursuit of optimal health for all. RADM Collins said she was humbled to be the acting ASH amidst a worldwide pandemic that has resulted in so much illness and loss of life, unprecedented strain on the health system, and clear worsening of health disparities among racial and ethnic minorities and other vulnerable populations. She offered gratitude for the health care professionals who support families across the Nation.

RADM Collins observed the parallels between HIV and COVID-19, noting that the pandemic shined a light on what people with HIV (PWH) have long known: health disparities persist for far too many people. COVID-19 presented an opportunity to spotlight infectious disease, health inequities, and public health in ways that have not been appreciated for the past decade. The data and tools exist to end the HIV epidemic, but collaboration with communities is needed to design and implement strategies that can address social determinants of health (SDH) effectively and eliminate the unequal impact of HIV on people of color and sexual and gender minority populations. RADM Collins noted the wide range of subject-matter experts (SMEs) and stakeholders scheduled to speak at this meeting, and she looked forward to the resulting insights and advice from PACHA.

In the past few months, OIDP finalized strategic plans for 2021 to 2025 on four topics, all of which interrelate and complement EHE: HIV, viral hepatitis, STIs, and vaccines. RADM Collins encouraged all stakeholders to review the strategies, particularly the *HIV National Strategic Plan: A Roadmap to End the Epidemic for the United States, 2021–2025*, and consider how their organizations and communities can play a role. Prevention is key to ending HIV, so HHS launched the Ready, Set, PrEP campaign to provide free preexposure prophylaxis (PrEP) to people who do not have prescription drug insurance. Ready, Set, PrEP recently expanded mailorder options, enabling program participants at federally funded health centers and IHS, Tribal, and Urban Indian Health Centers to receive primary care and PrEP counseling in one visit and obtain medication by mail. HHS PrEP outreach campaigns are expanding to better represent the key populations identified by the HIV Plan, including cisgender and transgender women and American Indians and Alaska Natives (AI/ANs).

In addition, HHS is leveraging Prevention through Active Community Engagement (PACE) officers to implement EHE on the ground and enhancing America's HIV Epidemic Analysis Dashboard (AHEAD) to include more demographic data and enable comparisons by jurisdiction, as requested by stakeholders. RADM Collins noted that EHE faced hurdles because of COVID-19. She thanked all those who continued to push for innovation in HIV diagnosis, prevention, and care through such mechanisms as telehealth and home delivery of condoms. In closing, RADM Collins pointed to B. Kaye Hayes, M.P.A., PACHA executive director and acting director of OIDP, as "the embodiment of a great leader" and thanked Ms. Hayes, PACHA, its Federal partners, and all the participants for their dedication and commitment to end HIV.

## Roll Call

Ms. Hayes called the roll.

## **CHAC Liaison Update**

Wendy Armstrong, M.D., FIDSA, outlined the major topics of discussion at the November 2020 CHAC meeting:

- Effects of COVID-19 on preventive care and treatment
- Recommendations for standardizing perinatal infection screening and care
- Standardized assessments for aging PWH to improve outcomes
- Recommendations for a broader, more streamlined strategy for testing, including point-of-care testing, and for revising regulations as needed to facilitate testing
- Increasing community partnerships in support of the EHE initiative
- Drawing attention to trauma-informed care, especially for women with HIV

## **PACHA Subcommittee Reports**

## EHE and the Updated National HIV/AIDS Strategy

Carl Schmid, M.B.A., and John Sapero, Co-Chairs

Mr. Sapero reported that the Subcommittee is assessing how the new HIV Plan builds on the previous National HIV/AIDS Strategy and links with EHE. The Subcommittee is pleased that the

HIV Plan has new, detailed indicators to assess progress. The group also reviewed the development of AHEAD. Mr. Sapero commented that the Subcommittee looked forward to learning more about HHS plans around ending HIV and how EHE will be refined after the COVID-19 pandemic subsides.

### Stigma and Disparities

Rafaelé Narváez and Justin C. Smith, M.S., M.P.H., Co-Chairs

Mr. Smith pointed out that the past year has included an uprising against racial injustice, and those in the HIV community are aware of long-standing racial disparities. The Stigma and Disparities Subcommittee has prepared a resolution on equity and justice in the context of EHE for consideration by PACHA later during this meeting.

#### Global

Robert A. Schwartz, M.D., M.P.H., D.Sc. (Hon.), and Gregg H. Alton, J.D., Co-Chairs Dr. Schwartz was pleased that Angeli Achrekar, Dr.P.H., M.P.H., of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), will address PACHA for the second time, offering insights from international work that might be applicable to domestic initiatives. Mr. Alton added that the Subcommittee contributed to organizing the PACHA panel discussion on meeting the needs of women, recognizing that PEPFAR has a lot to offer. The Subcommittee has offered to advise the new administration on global HIV work.

## Federal Panel on EHE and the HIV National Strategic Plan

Facilitators: Carl Schmid, M.B.A., and John Wiesman, Dr.P.H., M.P.H.

PACHA asked its Federal partners for an update on implementation of EHE and the HIV Plan in light of the Executive Order on advancing racial equity and support for underserved communities. Mr. Schmid noted that EHE and the HIV Plan are among the best examples of initiatives that address these communities, but more can be done.

#### **Update on the EHE and HIV National Strategic Plan**

Harold J. Phillips, M.R.P., Senior HIV Advisor and Chief Operating Officer, EHE, OASH, HHS Although the COVID-19 pandemic upended many plans for EHE implementation, it also paved the way for innovations that accelerated the EHE response, such as use of telemedicine, home testing, and multi-month prescriptions. Enrollment in Ready, Set, PrEP is up to 1,800 participants and on track to meet the goal of 2,500 people by July 2021. AHEAD launched several interactive features in February 2021 and now includes data from all States. Efforts are underway to incorporate data on SDH so that users can explore questions around equity. PACE program officers in three regions are identifying service providers within communities that can help advance the goals of EHE, especially those addressing SDH, such as housing and food insecurity. EHE's goals are based on modeling that assumes adequate financial resources. Mr. Phillips commented that the initiative has made impressive gains despite underfunding and the COVID-19 pandemic, but it could do more—and do it more quickly—with more funding.

The HIV Plan complements EHE but engages agencies across the U.S. government and calls on all stakeholders to play a part. Its goals reflect the need to look differently at ending HIV and to

capitalize on the opportunity presented by COVID-19 to reimagine public health. OIDP is developing implementation plans for its four new strategies that recognize the interplay of HIV, STIs, viral hepatitis, and vaccines and therefore will have similar instructions and pave the way for novel collaborations among agencies. OIDP also is working with OASH to incorporate the priorities of the new administration.

Mr. Phillips described OIDP's role in advancing racial equity using the analogy of a river. Downstream, OIDP supports provision of clinical care to individuals. Midstream, it is focused on advancing individual social needs through comprehensive services and mechanisms to achieve good individual health outcomes. Upstream, the administration has challenged OIDP to think more boldly about working toward racial equity to achieve health and wellness for all by looking at legal, regulatory, and policy barriers. Upstream efforts might include addressing HIV criminalization, scaling up syringe services, and advancing health education in areas with a heavy burden of STIs and HIV, such as the South.

### **HRSA Progress**

Laura Cheever, M.D., Sc.M., Associate Administrator, HIV/AIDS Bureau, HRSA Dr. Cheever presented early data from HRSA Ryan White HIV/AIDS Program grantees who received EHE funding in 2020. Ryan White programs engaged 6,000 new patients as part of EHE, most commonly providing rapid initiation of antiretroviral treatment. Despite the COVID-19 pandemic, such programs re-engaged nearly 3,600 patients in care, primarily through case management approaches. With limited ability to provide direct services during the pandemic, grantees focused on bolstering community engagement, administrative infrastructure, data collection, and new partnerships.

HRSA health centers received funding in early 2020 to foster PrEP uptake, resulting in impressive growth in patient testing and diagnosis, with nearly 50,000 PrEP prescriptions. Throughout 2020, in support of EHE, HRSA funding expanded interventions, developed capacity among Ryan White providers, and increased data use. The community listening sessions that began in 2019 continued virtually in 2020 and will inform 2021 engagement. For example, in response to public input, the HIV/AIDS Bureau is developing tools and providing leadership training for PWH and supporting organizations in hiring more PWH.

Viral suppression among Ryan White clients has increased dramatically in the past decade, from 69.5 percent in 2010 to 88.1 percent in 2019, yet disparities persist and might be increasing in the Southeast. Although they have lower overall suppression rates, African American people, transgender people, people who are unstably housed, and those ages 24 years and younger have seen double-digit increases in viral suppression since 2010. African American women have slightly lower suppression rates than the overall population, and certain subpopulations of African American women have even lower rates. To mitigate these disparities, HRSA initiated a quality improvement collaboration from 2018 to 2019 that focused on specific populations. It reached 130,000 Ryan White clients and reduced the number of people not virally suppressed by 25 percent. Dr. Cheever announced that HRSA had just launched a similar quality improvement collaboration to address disparities further.

## CDC's Efforts to End the HIV Epidemic and Reduce Disparities

Demetre C. Daskalakis, M.D., M.P.H., Director, Division of HIV/AIDS Prevention, NCHHSTP, CDC

Dr. Daskalakis explained that progress in reducing HIV infections has slowed in the past decade. White gay and bisexual men have experienced significant decreases in new infections, but other people at risk have not seen such drops. African American and Hispanic communities are disproportionately affected by HIV. Despite reductions in new HIV diagnoses among women, substantial disparities persist for Black and transgender women. Only 18 percent of those eligible are on PrEP, but PrEP use is far higher among white people than those of other races and ethnicities. In addition, HIV outbreaks are increasing among people who use injection drugs.

Although Ryan White clients and others have achieved high viral suppression rates, African American PWH consistently have lower rates of HIV care, retention in care, and viral suppression. African American and Latino people again are overrepresented among those with STIs. Having an STI is associated with double the risk of HIV infection, so routine screening and treatment for STIs will reduce HIV infections, said Dr. Daskalakis. Furthermore, stigma, housing insecurity, and systemic racism influence how people access and use HIV services. Although some public health departments had to scale back on EHE efforts because of COVID-19, CDC recognizes that those departments continue to exhibit resilience and innovation.

CDC aims to reduce disparities through several steps. In January 2021, CDC called on States to align their HIV criminalization laws with science and ensure that those laws serve public health goals. With \$2 million from the HHS Secretary's Minority HIV/AIDS Fund for HIV self-testing, CDC has made 100,000 HIV self-test kits available to order online at no cost. It awarded \$42 million to 90 community-based organizations (CBOs) serving populations disproportionately affected by HIV and another \$54 million over 5 years to 30 CBOs serving young men of color who have sex with men and transgender people of color. NCHHSTP aims to become an anti-racist organization through internal and external steps to improve equity across the workplace. Among its priorities for 2021, CDC seeks to ensure health equity is central in all forms of care and to intensify efforts to address systemic causes of disparities.

#### **Discussion**

Mr. Schmid observed that even during the COVID-19 pandemic, Ryan White clients made gains against HIV because of the funds provided under EHE. Yet the pandemic also is causing more people to lose their health insurance, which likely will drive more people into Ryan White programs, and, at the same time, budget shortages are causing some States to underfund AIDS drug assistance programs (ADAPs). He anticipated that the Ryan White program would need more money as a result. Dr. Cheever described steps HRSA has taken to help States manage ADAPs, acknowledging that State budgets are stretched thin. She noted that funding new staff to focus on PrEP has made a significant difference in promoting PrEP.

Dr. Cheever added that the COVID-19 pandemic broke down barriers to telemedicine and home testing. Dr. Wiesman proposed that PACHA express support for addressing regulatory and other issues to ensure that such breakthroughs can be maintained when the pandemic is over.

Laura Platero, J.D., appreciated the inclusion of AI/ANs in the HIV Plan and urged HHS to work with Tribal epidemiology centers to capture more data. She asked how organizations that claim to serve AI/ANs would be held accountable. Mr. Phillips responded that IHS will conduct Tribal consultations to assess funding needs and work with Tribes to determine priorities, approaches, and timelines. Dr. Cheever and Dr. Daskalakis added that programs must meet certain requirements around representation and engagement, and local jurisdictions dictate the distribution of funding.

Mr. Sapero raised concerns that health care delivery systems for HIV rely on infrastructure and policies created in the 1980s. Dr. Cheever pointed out that half of the HRSA grant recipients sought out new partners in the past year in an effort to expand and modernize delivery. HRSA recognizes the need for new approaches to achieve better viral suppression over time. Dr. Daskalakis added that home testing is one example of a new strategy to reach more people. He also emphasized the importance of weaving together effective HIV prevention and care approaches and applying them with the aid of new technology and forward-thinking strategies.

Dr. Daskalakis commented that public health sometimes refers to "hard-to-reach" populations, but services must be available where those people are. HRSA's work to expand Federally Qualified Health Center (FQHC) services to increase PrEP outreach is a good example, as is the expansion of EHE funding to include STI clinics. The syndemic approach can work, said Dr. Daskalakis, and HIV services do not always need to be at the center, as they are in Ryan White programs. Dr. Cheever noted that providers working in the community, outside of Ryan White programs, could expand PrEP services if they had more funds to support them.

Mr. Phillips pointed to successes among community health centers that had relationships with Ryan White programs and FQHCs. The next round of EHE funding will facilitate HIV screening and PrEP prescription in health centers that do not already have HIV programs, making HIV services more accessible in those communities. Community-based and mobile PrEP services are also vital to expanding PrEP, added Mr. Phillips.

Mr. Phillips indicated that CMS was not involved in the initial EHE planning but has since been engaged. CMS could be a key partner by providing and sharing data, offering incentives to providers, expanding access to care and treatment, and modifying regulations to support telehealth, for example.

## **HIV and COVID-19: Getting to Zero Through Greater Health Equity**

Gregorio (Greg) Millett, M.P.H., Vice President, amfAR, the Foundation for AIDS Research HIV and COVID-19 disproportionately affect the same racial and ethnic groups as a result of intentional, structural factors that concentrate disease and mortality in specific U.S. communities, Mr. Millett stated. COVID-19 is part of a syndemic—along with HIV, hepatitis, and opioid abuse—that affects marginalized communities. Notably, of the SDH that contribute to health disparities, half are related to the environment, and less than 20 percent are related to health care. A 2020 study of four U.S. cities, conducted before the pandemic, indicated that ending HIV by

2030 is an achievable goal among white Americans. For Black and Hispanic Americans, ending HIV is unlikely even by 2040, and COVID-19 might delay that goal further.

Analyses consistently demonstrate that race, ethnicity, and SDH—such as poverty, unemployment, racial segregation, and homelessness—drive morbidity and mortality around COVID-19 and HIV. Intimate partner violence has increased during the pandemic, and its interrelation with poverty and joblessness makes it particularly worrisome for women and people of color who have HIV. Five of the seven States targeted by EHE did not expand their Medicaid programs, resulting in a high proportion of uninsured people in those States. One in 10 non-elderly PWH is uninsured. Immigration status also affects access to health care. Geographic location and transportation barriers disproportionately affect the health of African American and Latino people. Racism and negative racial attitudes also are associated with poor health outcomes. Mr. Millett emphasized that health inequities resulting from SDH are deeply entrenched. Gains in life expectancy among nonwhite people in the United States have been erased by COVID-19.

Despite broad and persistent health inequities, Mr. Millett pointed to some potential paths forward, expressing optimism that under the new administration, EHE could have an impact. Some of the COVID-19 response could help reduce disparities. For example, more States are considering expanding Medicaid. Some clinical settings are pairing COVID-19 and HIV testing, an approach that could identify and reduce HIV infections.

Guidelines and algorithms for care used in many fields were developed on the basis of research conducted among white patients and thus reflect systemic bias. The U.S. Preventive Services Task Force (USPSTF) is evaluating how systemic racism affects preventive health care and how to improve its approach. Others are considering how guidelines and algorithms could reduce racial disparities in health care if they better reflected patients' perspectives rather than providers' biases. Mr. Millett called for attention to the PrEP eligibility guidelines, which should be updated to better identify potential candidates.

The Ryan White program exemplifies one successful approach to reducing disparities and achieving high rates of viral suppression. The U.S. Department of Veterans Affairs has seen higher rates of COVID-19 infection in African American and Latino veterans, but not higher rates of mortality, possibly because of its focus on equity. A 2014 study proposed that a 27-percent reduction in HIV incidence among Black gay men could be achieved if they received the same treatment as white gay men. Long-acting drugs for HIV prevention and suppression could have a profound effect on people for whom taking daily medication is a barrier.

Mr. Millett observed that the new administration's focus on reducing racial inequities across all Federal agencies is a positive step forward. Federal agencies are well positioned to convene experts in HIV, health inequity, and other disciplines to discuss short- and long-term options. CDC and NIH have already moved toward declaring racism a public health threat, which should spur organizations to measure it and manage it.

#### Discussion

Opening up the ACA exchanges will help more PWH and people at risk, Mr. Millett noted, and incentivizing more States to expand Medicaid would also be beneficial. Proposed infrastructure legislation could include mechanisms to strengthen the public health workforce and address transportation barriers. It also could address digital infrastructure, which would, in turn, broaden access to telehealth for those who lack sufficient internet access. The American Rescue Plan for COVID-19 relief could potentially reduce poverty in the United States by one third, and poverty is strongly associated with morbidity and mortality. Efforts like these that tackle issues larger than HIV can have a significant benefit on PWH and improve equity overall.

Mr. Millett pointed out the abundance of research on SDH and inequity; CDC and NIH have recently turned attention to funding more implementation science to understand how to move interventions out of trials and into communities. Such research should consider how interventions differ depending on the community. Mr. Millett hoped that CDC and others would consider identifying a single community to model how to end HIV, perhaps within 3 to 5 years, to draw attention and reignite enthusiasm for ending HIV across the country.

## **Closing Remarks and Recess**

Dr. Wiesman appreciated the many practical ideas put forth by presenters. Mr. Schmid recessed the meeting for the day at 5:02 p.m.

## Day 2

## **Opening Remarks from the PACHA Co-Chairs**

Mr. Schmid and Dr. Wiesman welcomed the participants at 2:01 p.m. They reviewed the proceedings of Day 1 and the agenda for Day 2.

#### Roll Call

Ms. Hayes called the roll.

## **Meeting the Needs of Women**

Facilitator: Laura Platero, J.D., PACHA Member

Panelists: Angeli Achrekar, Dr.P.H., M.P.H., Acting U.S. Global AIDS Coordinator and

Special Representative for Global Health Diplomacy, Department of State—

U.S. President's Emergency Plan for AIDS Relief (PEPFAR)

Tori Cooper, M.P.H., Director of Community Engagement, Transgender Justice

Initiative, Human Rights Campaign

Niasha A. Fray, M.A., M.S.P.H., Program Director, Duke University Office of

Durham and Community Affairs, Research and Advancement Unit

As an introduction, Ms. Platero pointed out that women account for 25 percent of HIV infections in the United States but often do not receive the attention and resources they need, as highlighted by recent literature. Panelists discussed the following questions.

### What does health equity mean to you?

Ms. Cooper noted that Black transgender women face even more inequity than Black cisgender women. All PWH must navigate a system of HIV services that was created by and for white gay men. Those services have changed little since they were established and have left out everyone else. People of color, and Black transgender women in particular, are not represented in research, in funded programs, or among the funders. Black transgender women face systemic racism and misogyny from a system that does not recognize their unique needs. Achieving health equity requires systemic change.

Ms. Fray stated that the field has been "data rich and resource poor" for a long time, emphasizing that many have known for years what needs to be done to address health equity challenges, especially for PWH, and now is the time to do it. One step is to challenge blanket statements about economic health, because it is clear that only a small group of people is doing as well as or better than before the COVID-19 pandemic. Until all people benefit from economic prosperity, the country is not maximizing its potential for growth, innovation, prosperity, and health. In terms of equity, there should not be a sense of "us versus them." Ms. Fray stated that justice "just is." Although it is true that all lives matter, all lives cannot matter unless Black, transgender, Latinx, and other lives matter. Health equity means providing for the physical, mental, emotional, spiritual, economic, and biologic health needs of all people regardless of their diverse demographic identities.

To work toward equity, Dr. Achrekar said, PEPFAR relies on data to identify gaps and tailor programs to address the needs of people where they are. To help with the challenges of navigating systems and overcoming structural barriers, PEPFAR has focused on the structural drivers of inequity.

## What are the most meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of EHE at the national level and in the community for women to meet the goal of ending HIV?

Dr. Achrekar summarized PEPFAR's global investments in ending HIV in ways that align with the sustainable development goals agreed to by the countries that PEPFAR supports. Countries are making great strides, and some are even making progress during COVID-19. Critical to success has been full involvement and meaningful engagement of communities in all aspects of the programs, including community-led monitoring.

Ms. Fray described four areas to target: social marketing and media, economic justice, universal health care, and transparency. Social marketing and media should seek to put forward positive images and messages of people living healthy lives, but also should emphasize that HIV remains a real threat to public health. Discussions of HIV and AIDS should be normalized in every sector, such as the sex industry, dating apps, the fashion industry, alcohol producers, faith organizations, and Hollywood, to name a few. Educators and community leaders should partner to teach about sexual health and safer sex. Efforts should be made to increase PrEP use among

women. Routine HIV testing should be promoted, with more reliance on home testing and lay health advisors, which offer privacy. PrEP should be more readily available for those unexpectedly exposed to HIV.

To improve economic justice, Ms. Fray continued, more attention is needed to the root causes of sex trafficking and forced sex work. Sex work for those who choose it should be safer and less criminalized. People who are most vulnerable to HIV should be well paid for planning, implementing, disseminating, and translating HIV programs and outreach. Funding opportunities should consider whether the budget for salaries is adequate to ensure that workers feel economically secure. Community-rooted organizations, led by PWH, should be engaged in developing the terms of the funding opportunities.

Embracing universal health care is an opportunity to minimize the challenge of access to care, particularly under a plan that focuses on medication adherence to reach the goal of ending HIV. Taking on all of these challenges in a transparent way is essential for building trust and ensuring effectiveness. As steps are taken, it is also important to avoid protecting the status quo and not be rigid in the expectations for success. Once the SDH are addressed, work can better focus on disease-specific interventions, Ms. Fray concluded.

Ms. Cooper commented that the most meaningful action to implement plans would be to prioritize health equity. All the systems that people navigate—banking, hospitals, health insurance, and others—were created by white, cisgender, heterosexual men of economic means. Prioritizing SDH means addressing the inequity that affects people who do not look like those who created the systems. For people at high risk of HIV, housing equals health. Education is needed to ensure that PWH, people at risk, and providers all speak the same language and can communicate effectively.

Consumers of care are the SMEs of their own health, Ms. Cooper stressed. PWH understand the demands of the health care and HIV services systems better than providers do. PWH should be empowered with the tools they need to overcome systemic barriers so they can get care, take medicines, and achieve an undetectable viral load. Until all people have all the tools they need for success, the country will continue to fail. COVID-19 has revealed innovative approaches, such as telehealth, that can be applied to HIV care and services immediately and permanently. The country must shore up its weak foundations to build a stronger system, said Ms. Cooper.

How can domestic HIV/AIDS programs better meet the needs of women and address the systemic barriers women face in order to achieve the goals of the President's Executive Order on advancing racial equity and support for underserved communities?

Ms. Cooper responded that programs should listen to the people they serve, and those in the populations being served should have opportunities to lead. It may be time for others to step down so that new faces can take the lead. PWH are the SMEs of their own lives and therefore have the expertise needed to make decisions.

Ms. Fray noted that many plans look at biologic, pharmacologic, and medical aspects of HIV and how to make care more accessible, but they neglect the social and public health conditions that exacerbate HIV, such as economic and power imbalances, violence, structural inequity, and

homelessness. To better meet the needs of women, programs should focus on the problem of homelessness among women, which is interrelated with aspects of HIV. Efforts should be made to address all the social needs that contribute to a sense of security—such as access to healthy food; affordable and clean housing; dependable transportation; culturally respectful, comprehensive health care; effective education; and social systems, policies, and laws that advance equity, prosperity, justice, compassion, accountability, environmental responsibility, and respect. Pointing to the relationship between economic justice and homelessness, Ms. Fray called for an end to immoral practices that eliminate rent control and landlord accountability and promote gentrification, which makes a few wealthy while many suffer. She urged policymakers to think more critically about the lessons from COVID-19 about who is vulnerable and the overlapping systems of oppression that lead to loss of life and income.

Dr. Achrekar emphasized the importance of putting women and girls at the center of program development by asking about their experiences and what should be done differently to serve them. PEPFAR has invested \$1 billion in 15 countries through its Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe (DREAMS) Partnership, which reaches millions of girls and women with comprehensive, youth-friendly services addressing violence, education, economic strength, and medical care. The DREAMS Partnership employs young women to implement programs and is successfully improving health. Also, PEPFAR currently is incorporating the innovations and adaptations that resulted from COVID-19 into its work.

## What specific needs of transgender women should be better addressed by EHE?

Ms. Cooper said programs and systems are only now beginning to acknowledge transgender women. Few shelters accept transgender people, and almost none will house transgender women. Almost no medical research includes people taking cross-hormonal therapies, and little is known about how PrEP affects such people. Major health centers claim they have no transgender clients and so do not provide services for them. Transgender people are everywhere, Ms. Cooper emphasized, and they need access to all the same services and programs that others have.

## What other concerns need to be addressed?

Ms. Fray said the concept of "domestic terrorism" should look beyond shootings and violent insurrection and consider the terror that individuals and communities face as a result of homelessness and joblessness or the daunting task of navigating a complex health system on behalf of a child, for example. She observed that localities are once again promoting gentrification and urban renewal without recognizing how such policies have demolished the lives of many in the past. If people lack the basic necessities to survive—such as housing, food, education, and income—they cannot contribute to their best ability, because they live in a state of terror, Ms. Fray concluded.

## How can global innovation be translated into domestic efforts, and what kind of leadership is needed to replicate the PEPFAR model domestically?

Dr. Achrekar emphasized the importance of political will at all levels, from the highest government offices down to the grassroots CBOs. The countries that PEPFAR serves have committed to a larger framework of sustainable development goals, which has helped them implement PEPFAR programs at every level. Also, using the data collected to inform decisions

on a daily basis is critical. PEPFAR collects granular data on a range of variables, monitors those data in real time, and revises programs as needed.

## How can transgender women be more empowered to act as SMEs?

Ms. Cooper stated that people should be given access and opportunity and paid for the knowledge they contribute based on their lived experience.

## **Meeting the Needs of the Community**

Facilitator: Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, ACRN, ANP-BC, AAHIVS,

PACHA Member

Panelists: Guillermo Chacón, President, Latino Commission on AIDS; Founder, Hispanic

Health Network

Carolyn Melenani Kuali'i, Executive Director, Kua'aina Associates, Inc.

Jesse Milan Jr., J.D., President and CEO, AIDS United

Jeff Taylor, Executive Director, HIV and Aging Research Project-Palm Springs

## What are the most meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of EHE in your community to meet the goals of ending HIV?

Mr. Chacón said he believed the new administration would advance the goals of the HIV Plan and EHE and emphasized that now is the time to look more deeply at community needs. It is essential that HHS lead a Federal campaign to address homophobia, transphobia, and xenophobia that informs the work of States and Territories. HHS agencies should capitalize on their capacity to convene communities and give individuals the opportunity to speak to leaders directly as a way to generate institutional will. Community consultations should highlight the voices of people most affected and recognize the challenges faced by the rising number of aging PWH. Politicians and policymakers at the State and local levels must be engaged. Federal funding opportunities should explicitly seek to invest in transgender- and minority-led CBOs, because the messengers matter.

Ms. Kuali'i expressed gratitude to the Native people who paved the way for current efforts but said little has changed for Native Americans. She praised the funding of the IHS in EHE and the explicit inclusion of Tribes and Native American men who have sex with men in the HIV Plan. Through the 1990s, Native Americans had a strong network of local HIV providers; it was defunded in 2014 and should be restored now. Money from IHS and the Minority HIV/AIDS Fund has helped support some programs, but more funding is needed to grow and sustain them.

Programs and messages must be tailored to meet the specific needs of the particular community, said Ms. Kuali'i. Native Americans come from diverse communities with different languages, cultures, and traditions. As several speakers have already pointed out, each population should determine what works for its people, and those representing priority populations should be engaged in planning and implementation. Ms. Kuali'i implied that low enrollment in Ready, Set, PrEP, especially among priority populations, reflects the absence of appropriately targeted messaging. Federal and State policymakers should consult with Tribes in rural and urban areas to gather input on policies, messaging, and implementation.

Ms. Kuali'i emphasized that Federal agencies must honor the trust relationships established with Native Americans. Plans and programs should do more than include Native Americans in their written statements; communities need funding and culturally appropriate capacity-building assistance. Ms. Kuali'i specifically recommended removing barriers to syringe services, addressing stigma and discrimination, and including harm reduction approaches in all HIV work.

Mr. Milan said bold leadership is needed to undo the setbacks of the past 4 years and move aggressively toward ending HIV by 2025. As the COVID-19 pandemic underscores, unrestricted access to health care is essential. Mr. Milan called for universal health care, starting with Medicaid. He urged President Biden to rescind the previous administration's rules for Medicaid block grants, which diminish access to care, and to encourage States to expand Medicaid if they have not already, whether through incentives or penalties. In the short term, increasing funding for Ryan White programs will allow States to reach more people with treatment and support services. The AIDS Education and Training Centers should have more funding to train more health care providers to treat PWH, especially aging PWH. ADAP can serve as a model for PrEP access. President Biden could support a bill originally proposed by then-Senator Kamala Harris to expand access to PrEP.

Mr. Milan advocated refocusing the Minority HIV/AIDS Fund on its original purpose of bringing more resources to minority communities and minority-led organizations. He proposed bold funding to promote the message that an undetectable viral load means the virus cannot be transmitted (undetectable equals untransmittable, or U=U), which has the added benefits of reducing stigma and encouraging sexual health and wellness. Mr. Milan also supported hiring PWH for leadership roles at the White House Office of National AIDS Policy.

Mr. Taylor pointed out that the majority of PWH already are more than 50 years old; aging PWH, their partners, and others at risk for HIV cannot be ignored. Effective health and prevention efforts, such as PrEP, require health care providers to acknowledge that older people are sexually active. Cultural competency involves understanding the needs, concerns, and values of all kinds of cultures, including the specific needs of aging PWH. Psychosocial health also should be addressed. Many aging PWH have lost their social supports, first as a result of AIDS, then because of gentrification that drove them out of affordable housing, and now because of COVID-19. As a result, they face depression and isolation, and an increasing number of aging PWH have turned to drug use. All PWH would benefit from more funding for housing, transportation, peer counseling, and navigation services, but money also is needed to provide training about the unique needs of aging PWH and the effectiveness of age-appropriate peers demonstrated by earlier models.

Mr. Taylor said posttraumatic stress disorder is common among aging PWH, contributing to isolation and self-medication. To combat drug use, programs should adopt harm reduction models, expand access to treatment on demand, and ensure cultural competence, especially when it comes to the intersection of methamphetamine use and sex addiction among men who have sex with men, which is driving new infections. Syringe services are needed for people who use injection drugs, as are housing options for people with substance use disorders. The psychosocial

health issues of aging PWH have resulted in some PWH falling out of care, as well as a loss of biologic control of HIV in their communities. All these issues must be addressed to end HIV.

How can domestic HIV/AIDS programs better address the systemic barriers that underserved communities face in order to achieve the goals of the President's Executive Order on advancing racial equity and support for underserved communities?

Mr. Taylor noted that aging PWH include people from marginalized communities. FQHCs could add a geriatric model and address sexual health for older adults. At the local level, Ryan White programs should have more flexibility to address HIV among aging people, a topic that is not yet recognized in many communities.

Mr. Milan applauded President Biden's Executive Order but suggested additional bold steps are needed to break down structural barriers. AIDS United instituted the Racial Justice Index Project in an effort to align communities with the organizations that serve them. He called on the White House to assess racial justice across the Federal government and acknowledge the disconnect between those in leadership and the people they serve. To tackle SDH, first and foremost, the Housing Opportunities for Persons with AIDS program should be adequately funded. Other Federal efforts should seek to improve transportation and vocational training, expand broadband access, forgive student debt, expand access to credit, and enact a moratorium on convictions. To help drug users and sex workers, who have been heavily stigmatized, policymakers should end the ban on syringe services, because needle exchange programs work. Harm reduction policies need Federal support. Federal legislation should bring a modern lens to the safety of sex workers and addresses the stigma of HIV among lesbian, gay, bisexual, transgender, and queer (LGBTQ) people.

Ms. Kuali'i pointed out that Tribes are sovereign nations. Despite the Federal government's obligation to provide health care for Tribes, such programs have never been fully funded. Ms. Kuali'i called for analysis of how HIV funds are spent to better illuminate which communities are being served. Current data collection practices designate Native people into the demographic category of "other" or categorize all Indigenous people into one group, which results in further exclusion from funding. Ms. Kuali'i suggested working with Tribes to improve surveillance and data collection. Native communities should be given the power to design programs that address systemic barriers and local priorities. PrEP should be prescribed routinely by primary care providers in all communities. Access to PrEP, including the capacity of clinics and ease of access, should be monitored. Programs should have multiyear funding so that they can focus on meeting the 10-year goals of EHE. Congress must increase appropriations for IHS, and other Federal agencies must consider Tribal and Native-serving organizations in their funding distribution, because more can be done with more money, as others have noted.

Mr. Chacón highlighted the importance of applying an equity lens broadly and ensuring commitment to inclusion. National strategies to end HIV must involve the Department of Homeland Security and the Department of Education, for example, to achieve change. Organizations at every level need leadership that can translate verbal commitments to inclusion and equity into concrete action. Mr. Chacón urged inclusion of citizens of Puerto Rico and the U.S. Virgin Islands in research and data collection to inform strategies around engagement and retention in care. Providers are beginning to see the relationships between HIV, STIs, hepatitis,

mental health disorders, and substance use. Mr. Chacón hoped the administration would recognize the urgent need to reprioritize the public health infrastructure.

## How can organizations that already face limited capacity provide more services to aging PWH?

Mr. Taylor recognized the ongoing challenge, especially given limited time for health care appointments. He proposed focusing on small, manageable steps, such as incorporating into visits brief mental health screening questionnaires to identify depression or cognitive impairment, which can facilitate referrals to other services as needed. Mr. Taylor indicated that more research is needed to demonstrate the benefits of, for example, human papillomavirus screening for aging PWH, so that insurers will cover such services.

## **Public Comments**

PACHA specifically requested suggestions for meaningful actions to implement the HIV Plan and EHE at the national and community levels and how domestic HIV/AIDS programs can better address the systemic barriers that underserved communities face.

Vanessa Johnson, co-executive director of Ribbon, explained that governments and organizations at all levels continue to ask PWH to come to the table to help them shape funded programs and services on a volunteer basis or for nominal compensation. Ribbon believes that women with HIV who are asked to act as SMEs should be afforded the same consideration as other expert professionals in the form of fair compensation for their lived and earned experiences, knowledge, and expertise. Many women are heads of household and responsible for covering expenses related to caring for themselves and their loved ones. Thus, women must receive compensation at a rate higher than a thank-you card, gift card, or stipend. At the very least, women must be compensated at a rate that truly reflects their value so they can continue this type of work. Unfortunately, grant-funded programs that require the engagement of women often do not include them as contractors or consultants, but rather relegate them to the budget lines for stipends, gift cards, or refreshments. Budgets must reflect the time, effort, and value of all the resources needed to create successful programs. The Federal government must require all government entities and organizations to fairly compensate women for their time and effort. This recommendation is one small step toward addressing the income inequities that make it difficult for women with HIV to thrive beyond the goal of viral suppression. Ribbon would be glad to assist in the development of fair compensation policies and program guidelines.

Ronald P. Hattis, M.D., M.P.H., secretary of the Beyond AIDS Foundation (BAF), reported that a survey of State and Territorial HIV directors found that 28 percent of jurisdictions rely entirely on CDC for HIV prevention and surveillance funding. On the opposite extreme, New York State requires every county to contribute to HIV prevention, and the State contributes a significant amount of money as well. CDC grants are renewed every year mostly on the basis of demographics; renewal is not necessarily contingent on the States' and Territories' making promised changes to their programs. For example, some jurisdictions did not routinely try to reach out to newly diagnosed patients to link them to care and partner services.

Looking at other aspects of the HIV continuum of care, BAF supports syndemic screening for communities in need. Dr. Hattis referred to a simple, 1-hour presentation that prepares primary

care providers to initiate HIV treatment, available on the BAF website. Regarding retention in care, several States have taken the innovative approach of monitoring not only viral loads, but also missed viral loads by identifying patients who are not in care or have moved out of the jurisdiction. When patients miss appointments, a follow-up process should support retention in care. With regard to suppression, only a few specially funded States report genotypes. Only 38 percent of States and Territories even have mechanisms for reporting genotypes and phenotypes, and CDC does not have a comprehensive database to determine where viral resistance may be developing. BAF proposes that CDC recommend reportability and that the databases be forwarded to CDC for tabulation and analysis. Dr. Hattis pointed out that Ryan White clinics are funded only to treat people who have HIV and therefore cannot prescribe PrEP. The seronegative partners of PWH are at highest risk for HIV and represent the most cost-effective target population for PrEP, so a method should be developed to fund PrEP prescription within the HIV treatment sphere.

Mark Misrok, executive director of the National Working Positive Coalition, stated that the current HIV services infrastructure lacks the capacity to respond to the employment needs of people with or at greater vulnerability for HIV across most of the country. Few PWH understand what employment options may be possible to help them achieve optimal physical, mental, and economic health and well-being and maintain or improve their access to health care, medications, housing, and economic security. Few HIV care and prevention providers are equipped with such knowledge to share. For decades, many thousands of PWH have advanced into impoverished older age with no or minimal participation in employment and vocational development. The urgency of responding to these employment needs has only been heightened by the impact of the COVID-19 pandemic.

Mr. Misrok noted that the exclusion of employment services from the Ryan White program helps institutionalize minimal attention to the employment needs of PWH by their most trusted, well-connected providers. The AIDS Education and Training Centers offer little to no training on employment needs, either directly or through informed linkage and referral, and the few HIV-focused employment programs developed by HIV service providers with other sources of funding too frequently struggle or collapse, regardless of their success. Mr. Misrok commented that economic and employment opportunity are not valued, and connections between employment and equity are not recognized. There is a perception that no models exist to address employment needs within the service delivery infrastructure. Employment services help "level the playing field" for job seekers who lack equal opportunities. PWH and people at greater vulnerability for HIV deserve and need nonstigmatizing, nondiscriminatory, affirming, health-promoting employment services, located in the programs where they access care and prevention services, to address SDH and to achieve a more just quality of life and improved well-being.

**Tyler Barbarin, coordinator for the Health Not Prisons Collective,** a group of organizations tackling HIV decriminalization on a national scale, offered five meaningful actions around the HIV Plan and EHE:

- Elevate the focus on racial equity in the HIV response.
- End the practice of HIV criminalization.
- Declare an immediate moratorium on molecular HIV surveillance.

- Protect the rights of sex workers, who are at disproportionate risk of HIV criminalization.
- Consider decriminalization as a priority in EHE funding strategies.

High levels of health risks and poor health outcomes are inseparable from race-driven criminalization and incarceration patterns. The HIV Plan and EHE must lead the way in ending the use of incarceration to deal with poverty and public and mental health conditions, because incarceration only exacerbates the problem. The HIV Plan can rectify the lack of attention paid to underrepresented communities by addressing enacted, internalized, interpersonal, community, and institutional stigma. HIV criminalization is one form of institutionalized stigma, and the language describing the problem of HIV criminalization must be strengthened.

Molecular HIV surveillance (also called cluster detection) entails sequencing HIV genomes without consent from the individuals involved. This practice creates vulnerabilities for inadvertent disclosure; stigma; risks to physical safety, employment, and housing; and even criminal liability for PWH. Molecular HIV surveillance must be stopped immediately and has no place in a national HIV plan. The HIV Plan must uphold sex workers' rights and ensure that sex workers are meaningfully engaged in HIV prevention and care activities. The HIV Plan should ensure that competent and nonstigmatizing HIV services are provided to sex workers and that sex workers can participate in HIV services without fear of judgment, criminalization, or confidentiality violations. Funding for EHE should be contingent on meaningful community engagement and a commitment to end institutionalized stigma. It is also critical that the HIV Plan prioritize decriminalization as adjustments are made to EHE plans. To rectify the harms enacted in the name of public health, funding strategies should favor jurisdictions that apply a racial and gender justice lens and those working explicitly to address criminalization.

Murray Penner, U.S. executive director of the Prevention Access Campaign, pointed out that CDC estimates that only 63 percent of PWH in the United States are virally suppressed, which means that some 400,000 people, many of whom are people of color and transgender people, do not achieve optimal health because their HIV is not suppressed. This figure is unacceptable. The reasons vary, but holistic support increases viral suppression, as demonstrated by the Ryan White program's 88-percent suppression rate. Achieving viral suppression and undetectable levels of HIV has tremendous benefits, from improving physical health to greatly improving social and emotional well-being, reducing HIV stigma, reducing anxiety associated with testing, and motivating treatment uptake, adherence, and engagement in care. Recent data support these benefits. Mr. Penner put forth the following recommendations for ending HIV in the United States, drawn from a series of articles in *The Lancet*:

- A national, culturally competent effort is needed to raise awareness of the U=U campaign as a promising approach to reduce HIV stigma.
- Health care professionals must inform patients about U=U to improve personal health, as well as public health.
- Advocates should be equipped to use the so-called public health argument about U=U in advocacy to increase access and remove barriers to quality health care, as the Prevention Access Campaign is doing.

In addition, PWH must be included as EHE plans are designed and implemented. PWH should be hired to serve as local treatment navigators, similar to PrEP navigators. When PWH are consulted and engaged in these efforts, they must be compensated fairly for their work. Mr. Penner urged PACHA to ensure that U=U is central to the HIV Plan and the EHE initiative.

Jose A. Rodriguez, senior policy and advocacy manager of the HIV Medicine Association (HIVMA), observed that the HIV Plan is comprehensive in scope but will require a significant investment of resources for implementation. HIVMA offered the following recommendations to address HIV workforce shortages:

- Update the Ryan White program and enforce a USPSTF grade-A recommendation for PrEP to improve the implementation of the HIV Plan.
- Strengthen the proposed strategies to bolster the HIV workforce by leveraging the development of a more robust public health workforce for HIV and other urgent public health needs, including viral hepatitis, STIs, substance use disorders, and chronic disease screening.
- Collaborate with CMS to ensure adequate reimbursement for infectious disease and HIV care and related cognitive specialties to ensure a pipeline of physicians caring for PWH.
- Increase attention to the role of physicians and nurse practitioners in HIV care to support and foster growth of this critical center of the HIV medical workforce.

The steady increase in HIV infections associated with injection drug use since 2014, especially in rural communities, needs urgent attention, including specific training for the chronic care workforce in these areas. Stronger national guidance is needed to set expectations for States to reduce barriers to services by streamlining certification and recertification processes for Ryan White ADAPs through electronic submissions, eliminating in-person attestation requirements, and not requiring the submission of CD4 counts and HIV RNA levels every 6 months. These policies result in countless avoidable treatment disruptions and are barriers to achieving the goals of the HIV Plan and the EHE initiative. The USPSTF grade-A recommendation established PrEP as a highly effective prevention tool. Full implementation of the USPSTF recommendation is critical to meet the ambitious plan to scale up PrEP access. The ability to fully leverage telemedicine to reach patients where they are and to provide PrEP and care and treatment services can further play a critical role in meeting the goals of EHE. Integrating the principles of equity in every step of the process would help meet the goals of the President's Executive Order on advancing racial equity.

Venita Ray of the Positive Women's Network commented that the Federal domestic response to HIV must center on racial equity, meaningful involvement of PWH, and an understanding that HIV is a symptom of multiple intersecting injustices and oppressions. First, metrics and indicators must be created to ensure that PWH are involved in all areas of the national response. Funding for EHE plans should be contingent on jurisdictions' meeting clear, transparent metrics and indicators of meaningful engagement. These metrics and indicators must be written into the HIV Plan's implementation plan in partnership with networks of PWH. The implementation plan also should create standing seats on PACHA, CHAC, and other Federal advisory bodies for representation of networks of PWH. The Office of National AIDS Policy should be required to

have leadership from communities most affected by the epidemic and have a process to regularly engage with networks of PWH.

Second, neither the HIV Plan nor EHE mentions sexual and reproductive health for PWH. It is essential that any implementation plan ensure quality and nonstigmatizing sexual and reproductive health for PWH. People of all genders and ages with HIV experience stigma and discrimination from health care providers when seeking HIV care. For transgender PWH, it is especially important that gender-affirming care be provided and that providers and clinicians be well versed on the options and rights of transgender people.

Oscar Lopez, CEO and national director of policy for Poderosos, noted that people who use methamphetamines have been underprioritized in HIV prevention efforts nationwide, despite greater attention in recent years to the opioid crisis and the rise of HIV transmissions related to injection drug use. More effective public health approaches are needed to address methamphetamine use among gay, bisexual, and same-gender-loving men, especially within Latino and African American communities. The use of methamphetamine to enhance sex is a major factor driving HIV transmission and facilitating condomless sex with more partners.

Mr. Lopez went on to note that currently one in two new infections occurs among people who inject drugs, including gay and bisexual men; however, in the last 2 years, research has emerged showing that methamphetamine use outranks all other drugs for negative HIV health outcomes. Methamphetamine use contributes to the inability to suppress the virus, to people falling out of care, and to nonadherence to medical regimens. As a result, these people lose their housing, and providing care for them becomes more difficult. An estimated 10 to 27 percent of gay and bisexual men have used methamphetamine within the last year, which is 20 times that of the general population. More concerning are studies that show that methamphetamine users have higher viral loads and that methamphetamine use affects the immune response and increases HIV replication, even in a person taking HIV medication.

Because methamphetamine use is a growing concern among Black and Latino gay and bisexual men, building and maintaining support for an effective HIV response should address methamphetamine and other drug use, said Mr. Lopez. Syringe services and other harm reduction and health services for people who use drugs must be expanded. More important, contingency management—which rewards positive behaviors—has been found to be the only successful intervention for people who use methamphetamine, and no medical-assisted treatment currently exists for methamphetamine users. Contingency management programs must be paired with PrEP awareness and access. Addressing methamphetamine use, stigma, and other SDH is critical, especially during the COVID-19 pandemic and particularly for people of color.

**Derrick Flowers** observed that HIV and AIDS have had a profound impact, bringing out the best in people when communities and governments band together to provide access to prevention, treatment, care, and support for whole persons, restoring the humanity and dignity that the disease has taken away. HIV and AIDS bring out the worst in people when peoplecentered care and treatment is replaced by profit margins of "AIDS, Inc." and when individuals turn their backs on the real science of harm reduction and syringe exchange. The HIV epidemic has evolved over the last 40 years and is now concentrated in socially marginalized and

disenfranchised communities. The health disparities in these communities are striking, caused by structural racism, income and gender inequalities, and poverty of all forms.

HIV has a complex relationship with poverty, Mr. Flowers continued. He noted that the United States' response has achieved historic, unprecedented progress. Those most involved in advocacy are PWH. Activists and their allies have changed social norms and attitudes, driving the Federal government to form partnerships, with inclusion and not tokenism, and with a sense of urgency. Mr. Flowers described his first job in the United States at the National Association of People with AIDS, which worked to change language around HIV to recognize that people who have HIV or AIDS should not be painted as victims or even patients dependent on care. He insisted that meaningful involvement and participation of people with AIDS at all levels is necessary to shape the implementation and evaluation of the country's national response. Special focus must be placed on young people, recognizing that in 2018, people between the ages of 13 and 34 years accounted for 21 percent of HIV infections.

Jada Hicks, supervising attorney at the Center for HIV Law and Policy, called for an end to irrational, inconsistent government policies on HIV. State and Federal authorities continue to endorse investments in HIV prevention, care, and harm reduction while tolerating laws that exclude PWH from military service and prosecute people for their health status and consensual sexual relationships. Federal agencies, such as CDC, should require that State recipients of Federal prevention funding certify that their State's policies do not disadvantage PWH or allow the sharing of identifiable surveillance or health information with law enforcement authorities. Any plan to end the HIV epidemic must commit to ending the use of the criminal law to address social and public health challenges. Research shows that behavioral and social determinants directly affect health goals and outcomes, as well as an individual's risk of acquiring HIV. Explicit Federal and State government support is needed for the following:

- Decriminalization of sex work
- Decriminalization of syringe exchange and addiction
- Substantially increased investment in inpatient and outpatient drug treatment programs that eliminate waiting lists in many States

Ms. Hicks further stated that public health organizations should be leading the charge on HIV decriminalization. Sensationalist media reports should be met immediately by corrective statements from public health authorities on the actual routes, relative risks, and realities of living with HIV. Perhaps the most significant common denominator to discriminatory and stigmatizing policies is the profound, near-universal lack of sexual health literacy. The problem of sexual health ignorance and the discomfort many providers express with LGBTQ patients and discussions about sex represent an unaddressed and serious public health issue. Federal prevention funding should prioritize jurisdictions that (a) require sexual health literacy training in all schools and training programs for direct service health care providers or (b) require training in sexual health literacy as a condition of licensing for health care professionals. Also, it is time for a new Surgeon General's letter to the American public on HIV and STIs that states the facts of these epidemics and that promotes universal sexual health literacy.

Lastly, said Ms. Hicks, the real causes of the HIV epidemic cannot be addressed by looking only at HIV. Decriminalization of HIV must incorporate decriminalization of other infectious diseases as well as victimless disfavored behavior, such as sex work and possession of drugs or syringes. Policy discussions about prevention, including PrEP, need to start centering those at risk for HIV who have remained seronegative. It is unrealistic to expect people to engage in ending the dual epidemics of HIV and STIs without institutionalizing broad sexual health literacy programs across the country. It is time to consider more creative strategies for a truly intersectional approach to all of the work on behalf of those most affected by HIV and most alienated from the systems purportedly created to serve them.

Dwayne Steward, director of prevention at Equitas Health, suggested that the actions needed to meet EHE's goals are simple. Ending health inequity today will end the HIV epidemic tomorrow. Marginalized communities with historic lack of access to care because of institutionalized oppression in health care systems are not reaching viral suppression at the same rates as the general population. PrEP uptake remains very low among Black and Latinx communities, especially in the Midwest, because of lack of education and perceived cost barriers. To end the HIV epidemic, it is time to enact policies and programs thought to be unallowable or impossible. Free HIV testing and free condom distribution need to be integrated into all care models, from large health care systems and FQHCs to emergency rooms, recovery centers, syringe service programs, prison health care systems, and all reentry programs, among others. Prescription drug costs for antiretroviral medications must be made more affordable. Additionally, medications and health care services must be paired with transportation, child care, and food voucher assistance, as well as other social services that fully address SDH. PrEP must be made more affordable and more easily accessible to increase its use in low-income communities. Over-the-counter access and drug assistance programs are just two pathways that should be standardized nationally. PrEP also needs to become a medication that every primary care provider understands how to prescribe, much like diabetes and hypertension medication.

Mr. Steward called for destigmatizing HIV by mandating comprehensive and inclusive sex education in schools and by a Federal mandate that decriminalizes HIV nationwide. HIV criminalization laws are furthering stigma and keeping those on the ground from making radical progress. Radical access for all, in all circumstances, is how to achieve the end of HIV, he suggested. Mr. Steward quoted Nelson Mandela: "Poverty is not an accident; like apartheid and slavery, it is manmade and can be removed by the actions of human beings." The health inequity that fuels HIV transmission and suppression is also not an accident, Mr. Steward stated. It is uplifted daily by the institutional barriers that keep marginalized communities from accessing the care and services they need. Mr. Steward said the country must make the impossible possible and the unrealistic a reality to end this epidemic, and dismantling health inequity is how to do so.

Nancy Lyons, vice president and chief pharmacy officer for Health Mart, which supports a network of locally owned, independent community pharmacies across the country, observed that many of the critical needs the country is facing are being met by the local health care provider at the center of the community who is among the most visited providers—the community pharmacist. Community pharmacies have played a part in COVID-19 testing and vaccine administration, reinforcing their critical role in meeting the unique needs of their communities, particularly in underserved and marginalized communities. More than half of Health Mart

pharmacies are located in communities identified as socially vulnerable, and many are located in areas where access to any health care provider is limited.

Among the most meaningful actions that can be taken to implement the HIV Plan and EHE, Ms. Lyons said, are focusing on prevention and expanding the Ready, Set, PrEP program. Pharmacists can dispense PrEP medications at no cost to patients, but they could also do more. Discussions have occurred about allowing pharmacies to conduct HIV testing to identify those eligible for PrEP, but no path to payment is in place. Addressing payment is a critical solution that would reduce barriers and stigma. Pharmacists could initiate therapy and ensure adherence among patients who choose to avoid visiting a medical provider. Pharmacies can help reduce stigma and save costs. Insurance coverage is needed so that critical initiation services could begin conveniently at the pharmacy and so that sustainable services are consistently available. Pharmacies can help meet the needs of underserved communities, especially if they have the authority to provide services and receive payment. Initiating care in the community pharmacy can reduce stigma and expand reach with directed communication, plans, and programs. Payment for services delivered at the pharmacy is a path forward and must include options for identification, testing, and initiation of therapy at the community pharmacy.

See Appendix A for all written public comments submitted.

## **PACHA Resolution on Health Equity**

Mr. Smith presented the draft resolution of the Subcommittee on Stigma and Disparities on ensuring equity and justice in ending HIV, which describes steps the Federal government can take to improve equity. Dr. Wiesman proposed the following revisions:

- Recommend more prominently that PWH and persons with a history of drug use be hired to ensure the diversity of the White House Office of National AIDS Policy staff.
- Suggest that the Federal government work with Tribal nations and Tribal epidemiology centers to better collect, analyze, and report data on AI/ANs; decolonize the data; and adequately fund the HIV work of the IHS and CBOs serving AI/ANs.
- Suggest that Federal funding of broadband access should include urban and frontier communities and specify funding for broadband infrastructure and access.

Mr. Schmid proposed clarifying that in addition to fully funding and implementing the HIV National Strategic Plan, HHS also should leverage and coordinate with the resources and programs of other parts of the Federal government.

Dr. Wiesman commented that the resolution's suggestion to collect data at a more granular level should speak to PACHA members' concerns about the lack of detailed information on small racial and ethnic populations. The proposed changes were accepted following agreement on rewording.

Michael Saag, M.D., asked whether the contents would have more impact if divided into shorter, more targeted pieces. Ms. Hayes noted that targeted letters to the HHS Secretary and ASH can be very effective. Mr. Smith proposed considering the resolution as written a blueprint for PACHA to use in crafting more focused resolutions, and PACHA members agreed.

#### Vote

The Council voted unanimously in favor of finalizing the resolution, as amended.

See Appendix B for the final resolution.

## **Closing Remarks from the PACHA Co-Chairs**

Mr. Schmid thanked the speakers, panelists, Federal participants, and PACHA members. He also expressed gratitude to Ms. Hayes and Caroline Talev, M.P.A., for their outstanding support of PACHA. Mr. Schmid expressed optimism, noting that programs are making progress against HIV and the new administration is taking on SDH and social and racial justice. Dr. Wiesman added his thanks to all the participants for helping to strengthen PACHA's contributions as it seeks to advise the Federal government. Ms. Hayes thanked the consultants who support PACHA: audio engineer Ramon Reyes, meeting reporter Dana Trevas, and meeting coordinator Mark Dennis. The meeting adjourned at approximately 5:10 p.m.

## **Appendix A: Written Public Comments**

Comments for the Presidential Advisory Council on HIV/AIDS Mark Misrok, Executive Director, National Working Positive Coalition March 9, 2021

I'm Mark Misrok, a person living and aging with HIV, and Executive Director for the National Working Positive Coalition. Our work is focused, in alignment with HIV care and prevention, to strengthen responses to the employment needs of people living with or at greater vulnerability to HIV.

- Our current HIV services infrastructure is weakened by a profound lack of capacity to respond to the employment needs of people living with or at greater vulnerability to HIV across most of the country. Few of the individuals we serve have the opportunity to understand what employment options may be possible for them for optimal physical, mental, and economic health and wellbeing, maintaining or improving their access to health care, medications, housing or economic security. Few HIV care and prevention providers are equipped with this knowledge to accurately share it with those that they serve. For decades now, many thousands of us people living with HIV in the U.S. have advanced through our working years into impoverished older age without, or with only the most minimal and marginal, participation in employment and vocational development. The urgency of our responding to employment needs has only been heightened by the impacts of the COVID-19 pandemic.
- The exclusion of employment services as an allowable supportive service in the Ryan White HIV/AIDS Program helps institutionalize minimal attention, and limited to no response, to the employment needs of people living with HIV by the providers who we are most well-connected to and trust, those who otherwise best understand and care about us. Little to no training is offered through the AETC's on how to understand and respond to employment needs, either directly, or through informed linkage and referral, and the few HIV-focused employment programs developed by HIV service providers with other sources of funding, too frequently struggle or collapse, regardless of their success. It would seem that we don't value economic and employment opportunity for the communities we serve, we don't see connections between addressing employment needs to racial equity and to health equity, or we believe that there are no models for how employment needs can be addressed within our own service delivery infrastructure.
- Employment services help to level the playing field for job seekers who do not and have
  not had equal opportunities. People living with or at greater vulnerability to HIV deserve
  and need non-stigmatizing, non-discriminatory, affirming, health-promoting employment
  services, located in the programs where we access care and prevention services, to
  address social determinants of health and for a more just quality of life and wellbeing.
  Thank you.

## **Testimony Transcript**

Hello, my name is Nancy Lyons. I am the Vice President and Chief Pharmacy Officer for Health Mart. Health Mart is a franchise that supports a network of locally owned, independent community pharmacies across the country and is the fourth largest pharmacy chain in the US. I want to thank the Council for the opportunity today to speak with you about the critical roles that independent community pharmacies play in ending the HIV epidemic.

As we are continuing to work through the many public health issues that the COVID-19 pandemic amplified, including a delay in progress in achieving the goals of the HIV epidemic, many of the critical needs the country is facing are being met by the local health care provider who is in the center of our communities and is one of the most visited providers- the community pharmacist.

With each of the health care challenges identified over the past year, pharmacies and pharmacists have been called upon multiple times to be a part the solution. The role community pharmacies have played in covid testing and vaccine administration has reinforced the critical role community pharmacies play in meeting the unique needs of their communities where the population lives, particularly in underserved and marginalized communities.

That is where independent pharmacies can make the largest impact. More than half of our Health Mart pharmacies are located in moderate and high socially vulnerable indexed communities. In addition, a large number of Health Mart pharmacies are located in care deserts or areas where access to any health care provider is limited.

In addressing the first question posed to the panel regarding the most meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of the Ending the I have these thoughts:

The first is to focus on prevention and expand or extend HHS Ready, Set, PrEP HIV prevention program, particularly with the role that community pharmacists can play. Right now pharmacists can dispense PrEP medications at no cost to patients. But there is so much more that these accessible providers can perform. We all know that it is critical that the individual who begins PrEP therapy has a negative HIV test before initiation, but this creates a barrier. There has been discussion previously around potentially opening up testing at pharmacy but no path to payment is in place currently. This must be addressed as it is a critical solution that would reduce barriers and stigma.

Pharmacists could also be a collaborative extension to initiate therapy and ensure adherence in patients who choose to avoid the stigma that visiting a medical provider can have. Pharmacies can reduce this stigma and save costs. Each of these efforts would require coverage so critical initiation services could begin conveniently at the pharmacy and that sustainable services are consistently available.

Pharmacies can also make an impact in meeting the needs of underserved communities. As I stated before, this is a particular forte of Health Mart Independent pharmacies. To enable this, authority to provide services and receive payment is critical. Continue and strengthen

partnerships with community pharmacies that serve and live in these underserved communities. Initiating care in the community pharmacy can reduce stigma and expand reach with directed communication, plans and program. Payment for services delivered at the pharmacy is a path forward and must include options for identification, testing and initiation of therapy to occur at the community pharmacy.

Thank you for your time today.

Good afternoon, members of PACHA. My name is Tyler Barbarin and I am the Coordinator for the Health Not Prisons Collective, or HNP. HNP is 5 national organizations: The Counter Narrative Project, The Positive Women's Network, The United States PLHIV Caucus, The Transgender Law Center, and The Sero Project that have come together to tackle the issue of HIV decriminalization on a national scale.

HNP contends that the most meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of the Ending the HIV Epidemic initiative are to: 1) elevate the focus on racial equity in the HIV response, 2) end the practices of HIV criminalization 3) declare an immediate moratorium on molecular HIV surveillance and 4) protect the rights of sex workers, who are at disproportionate risk of criminalization and, 5) to consider criminalization as a priority in Ending the Epidemic funding strategies.

High levels of health risks and poor health outcomes are inseparable from the race-driven criminalization and incarceration patterns The HIV National Strategic Plan and End the Epidemic efforts must take a leadership role in ending the use of incarceration to deal with poverty, public and mental health conditions, because incarceration only exacerbates the problem.

Criminalization of HIV occurs even outside the targeted laws that make engaging in consensual sexual acts with a positive status illegal. The Plan can rectify the lack of attention paid to underrepresented and minoritized communities by addressing enacted, internalized, interpersonal, community, and institutional stigma. HIV stigma comes in many forms. HIV criminalization is one form of institutionalized stigma, and the language on HIV criminalization as a problem must be strengthened.

The practices of molecular HIV surveillance, (also called cluster detection) is the sequencing of HIV genomes without consent from the individuals involved have come under immense scrutiny in recent years and as networks representing PLHIV we strongly oppose these practices. These practices create vulnerabilities for inadvertent disclosure, stigma, risks to physical safety, employment, and housing, and even criminal liability for PLHIV. Molecular HIV surveillance must be stopped immediately and have no place in a national HIV plan.

The Plan must uphold sex worker rights and ensure that sex workers are meaningfully engaged in HIV prevention and care activities. Sex workers are at elevated risk for community violence and service delivery settings often marginalize sex workers. The Plan should assure that competent and non-stigmatizing HIV services are provided to sex workers and that sex workers can participate in HIV services without fear of judgment, criminalization, or confidentiality violations.

Funding for EHE plans should be contingent on meaningful community engagement and a commitment to end this form of institutionalized stigma which impedes HIV prevention and care efforts. It is also critical that the national strategic plan on HIV prioritizes decriminalization as adjustments are made to Ending the Epidemic plans. As funding strategies are created, they should give favor to jurisdictions applying a racial and gender justice lens, and those working explicitly to address criminalization if it is to rectify the harms done in the name of public health.

Thank you to the Council for the opportunity to provide public comment. We hope that these concerns about the role of criminalization in the public health response will be taken seriously.

Good afternoon, Members of PACHA. My name is Venita Ray and I speak to you today as a WLHIV and on behalf of Positive Women's Network-USA, a national membership organization comprised of women and people of transgender experience living with HIV. In support of our mission to strengthen the strategic power of all women living with HIV, we submitted a comment on the draft HIV National Strategic Plan with detailed concerns and recommendations. Today I will focus on two key concerns and I invite you to read our full comment available at pwn-usa.org.

The federal domestic response to HIV must center racial equity, the meaningful involvement of people living with HIV, and an understanding that HIV is a symptom of multiple intersecting injustices and oppressions. It is critically important that people living with HIV are centered in the response in a way that is distinct from other community input. It is quite literally impossible to end the epidemic without us and the federal response must work for us too. We would like to highlight two steps that must be taken to effectively implement the domestic HIV response.

First, metrics and indicators must be created to ensure that people living with HIV are involved in all areas of the national response. Funding for Ending the Epidemics plans should be contingent on jurisdictions meeting clear, transparent metrics and indicators of meaningful engagement. These metrics and indicators must be written into the Implementation Plan in partnership with PLHIV networks. The Implementation Plan should also create standing seats on PACHA, CHAC, and other federal advisory bodies for PLHIV network representation. Finally, ONAP should be required to have leadership from communities most impacted by the epidemic and have a process to regularly engage with PLHIV networks.

Second, neither HNSP nor EHE mentions sexual and reproductive health for people living with HIV. It is essential that any Implementation Plan ensures quality and non-stigmatizing sexual and reproductive sexual health for people living with HIV. People of all genders and ages living with HIV experience the greatest stigma and discrimination from health care providers when seeking this kind of health care, making its absence from the Implemention Plan especially problematic. For transgender people living with HIV, it is especially important that genderaffirming care is provided and that providers and clinicians are well-versed on our options and rights.

We stand ready to partner with PACHA and the Biden-Harris administration on these and the other solutions provided in our written comment. Thank you for the opportunity to speak with you today.



March 09, 2021

Co-Chairs and members of the Presidential Advisory Council on HIV/AIDS (PACHA):

The HIV Medicine Association (HIVMA) is pleased to provide testimony specific to implementing the National HIV Strategic Plan (NHSP) and the Ending the HIV Epidemic (EHE) initiative. HIVMA represents nearly 6,000 physicians, researchers and other health care professionals who provide HIV prevention, care and treatment and conduct research in communities across the U.S.

## **National HIV Strategic Plan**

The NHSP is comprehensive in scope but will require a significant investment of resources to support implementation. HIVMA offers the following recommendations to address HIV workforce shortages, update the Ryan White HIV/AIDS program and enforce the U.S. Preventive Services Task Force's (USPSTF) Grade A recommendation for PrEP to improve the implementation of the plan.

### Strengthen the HIV Workforce

While the NHSP acknowledges HIV workforce shortages as a significant challenge to meeting the goals of the plan, the suggested actions for addressing shortages are insufficient and fail to address the root causes of these workforce shortages. We strongly recommend strengthening the proposed strategies to bolster the HIV workforce by leveraging the development of a more robust public health workforce for HIV and other urgent public health needs, including viral hepatitis, sexually transmitted infections, substance use disorders, and chronic disease screening.

HIVMA encourages collaboration with the Centers for Medicare and Medicaid Services to ensure adequate reimbursement for ID/HIV care and other cognitive specialties so that there is a robust pipeline of physicians caring for people with HIV. In addition, we urge increased attention to expanding the role of physician assistants and nurse practitioners in HIV care, to support and grow this critical segment of the HIV medical workforce. The steady increase in HIV infections associated with injection drug use since 2014, especially in rural communities, needs urgent attention, including specific training for the primary care workforce in these areas.

An essential step to implementing the plan will be to integrate training centered on culturally competent HIV treatment and prevention for primary care trainees and providers. Moreover, a well-financed public health workforce to provide community-based comprehensive outreach prevention and health care services would mitigate the effects of structural racism and the social determinants of health that drive healthcare disparities.

Lastly, engaging the academic, public health and private workforce intentionally and collaboratively is needed to raise awareness of the NHSP and to elicit feedback on ways to implement the plan in health care education and practice across the U.S.

### Innovate the Ryan White HIV/AIDS Program (RWHAP)

Stronger national guidance is needed to set expectations for states to reduce barriers to services by streamlining RWHAP AIDS Drug Assistance Program (ADAP) certification and recertification processes through electronic submissions, eliminating in-person attestation requirements and not requiring the submission of CD4 counts and HIV RNA levels every six months. These policies result in countless avoidable treatment disruptions and are barriers to achieving the goals of the NHSP and the EHE.

#### Enforce New Pre-exposure Prophylaxis (PrEP) Coverage Requirements

The U.S. Preventive Services Task Force's (USPSTF) Grade A recommendation for PrEP released in June 2019 was a game-changer in establishing PrEP as a highly effective prevention tool. Full implementation of the USPSTF recommendation is critical to meet the ambitious plan to scale up PrEP access. HIVMA urges federal and state regulators to ensure that coverage of PrEP and associated recommended screenings and laboratory monitoring recommended by the Centers for Disease Control and Prevention are available without cost-sharing.

## **Ending the HIV Epidemic Initiative**

The success of the EHE Initiative will require fundamentally changing HIV prevention and care delivery to engage more persons with HIV and at risk of HIV in treatment. Many Ryan White programs have developed innovative solutions, including the use of telemedicine, to provide prevention and care services during the COVID-19 pandemic. It is critical to address the digital divide so that people in greatest need can benefit from telehealth services, focusing on digital equity. Offering these services to people with HIV and at risk for HIV has the potential to transform HIV prevention and care to be more patient-centered, accessible, collaborative and less bureaucratic.

The ability to fully leverage telemedicine to reach patients where they are, to provide PrEP and care and treatment services could play a critical role in meeting the goal set forth by the Ending the HIV Epidemic Initiative to reduce new infections in the U.S. by 90% in 2030. HIVMA recommends reducing physical barriers to PrEP access by ensuring reimbursement for telemedicine visits by both telephone and video (the former because not all patients have video access); incentivizing states to authorize data-sharing agreements between agencies; and incentivizing reciprocity across state lines for telemedicine visits, including for advanced practice providers and supervised trainees. Clinical research also is needed to identify patients for whom telehealth works well, assess if it reduces barriers to care such as transportation and stigma and determine the right balance between in-person and telehealth visits.

Other forms of prevention, such as syringe services programs, must receive more federal support as well as state-level strategies to combat the spread of HIV through injection drug use.

By integrating principles of equity in every step of this process, this would help meet the goals of the President's Executive Order Advancing Racial Equity. Thank you for the opportunity to provide input on meaningful actions that can be taken to improve the implementation of the National HIV Strategic Plan and meet the goal of the Ending the HIV Epidemic initiative of ending HIV. Please contact HIVMA senior policy & advocacy manager Jose A. Rodriguez at <a href="mailto:JRodriguez@hivma.org">JRodriguez@hivma.org</a> to schedule a meeting to discuss our recommendations.

Office of HIV/AIDS and Infectious Disease Policy Department of Health and Human Services Attention: Tammy Beckham, Nate Fecik, Leith States, et al.

#### RE: FINAL INPUT TO 2021-25 NATIONAL HIV/AIDS STRATEGY

The Beyond AIDS Foundation is herewith submitting (just "under the wire") recommendations for enhancement of the above document, specifically the portions devoted to Goals 1, 2, and 4. Many of our recommendations are based on the findings and summary recommendations in our article, "HIV Prevention/Practices and Non-Federal Funding Among U.S. States and Non-State Regions: A Survey of HIV/AIDS Directors," published in AIDS Education and Prevention, February 2019, 31(10, 82-94, 2019 and attached to our cover email.

Beyond AIDS Foundation is a national organization that has been working for two decades to improve the public health policy and response to HIV/AIDS, and to thereby drive down incidence. Our Web site is <a href="www.beyondaids.org">www.beyondaids.org</a>. We were early and effective advocates for name-based HIV reporting, treatment as prevention, and opt-out testing consent. Our leaders include former big city HIV/AIDS and STD directors, infectious disease and preventive medicine specialists, and other HIV clinicians and educators. We provided extensive input, including meetings in your office, in 2014 (with Dr. Valdiserri et al.) for the 2015-20 NHAS. I more recently corresponded about the pending update of the NHAS with Dr. Beckham in February 2019, and shared our survey article referenced above. Over the years, we have met with several HHS HIV/AIDS Policy directors, and several national directors of HIV/AIDS Policy (when that office existed). We have shared strategy proposals at a CDC-sponsored "listening session" and at International HIV/AIDS Conferences. We were not invited to OIDP's National HIV Prevention Conference in March 2020, but would welcome future invitations to be represented at such opportunities.

Our proposals below are scientifically sound and proven to be effective, and we believe them to be necessary to achieve at least 3 of the 4 major overall goals of the NHAS. Almost all have been successfully used in some locations, so we are advocating nationwide implementation, which in most cases can be achieved by relatively minor redistribution of existing funding.

Please insert the following ideas in different parts of the plan if your staff members think that would produce a better fit. Should any of our proposals not ultimately be inserted into this NHAS, we nevertheless strongly recommend that they become activities for its implementation. We are available for virtual meetings and/or presentations with OIDP, OASH, PACHA, the NHAS Steering Committee, CDC's Division of HIV/AIDS Prevention, HRSA, and the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment (CHACHSPT).

#### **GOAL 1: PREVENT NEW INFECTIONS**

Objective 1.2 on testing should be expanded by adding more detail to strategies 1.2.1 and 1.2.2, or by adding strategy 1.2.5: **The plan should include coordinating and combining screening for HIV, viral hepatitis, and other STDs when appropriate** Since HHS is trying to develop a national STD strategy, with rates of STDs skyrocketing this year; and more universal screening for viral hepatitis, especially hepatitis C, is a simultaneous objective, we should move away from isolated screening for only one disease, and work toward simultaneous screening for all three categories of infection. When indicated, antibody testing for COVID-19 can be coordinated as well.

Strategy 1.2.4 and in other places, all diagnosed patients should be interviewed for partner services; or merge into 1.3 as proposed below. This must be a condition for HIV prevention grants, and states that delegate such activities to local jurisdictions must be accountable for assuring that those services actually are performed by those local jurisdictions. Beyond AIDS Foundation did a separate, unpublished survey of California counties a number of years ago, in which we found that some counties were so small that they had no staff to perform partner services, not only for HIV but also for syphilis and gonorrhea. However, the state was not aware of this and assuming that everything was being done.

Add strategy 1.2.5: Increase routine HIV testing nationwide in adult and juvenile correctional facilities, emergency departments and urgent care, substance abuse clinics; and promote screening by primary care providers. California already has a law requiring most primary care providers to offer opt-out HIV testing if blood is to be drawn for other purposes. Routine ER testing has been successfully utilized in New York City, but there has been reluctance in California (where a study at a few hospitals was approved by the legislature) and other locations. This screening should be combined as appropriate with screening for other STDs and viral hepatitis, as per our other recommendations.

Objective 1.3: In actual public health practice, there are some gaps in linking public health receipt of diagnoses and outreach to patients and providers. In our published survey, we found that 60% of jurisdictions routinely contacted providers, and 80% routinely contacted patients. Neither was usually contacted in 14% of states and territories. When contacts occurred, there was some inconsistency of what was discussed. Sometimes, the main topic asked of providers was information to complete the diagnosis report. We recommend adding more detail to strategy 1.3.3 or adding strategy 1.3.6, striving for routine and standardized public health outreach following a new diagnosis, to help assure linkage to care and partner services among any other topics in every jurisdiction. More uniform follow-up of HIV diagnoses should be incorporated into CDC guidelines, and should be a condition for HIV prevention funding. When a diagnosis report indicates that the patient is a drug user, appropriate referrals for that aspect should be included, and other relevant topics of discussion may be optionally included, as our published survey showed that some states are doing.

Strategy 1.3.3: With respect to PrEP, efforts should be made to assure that condoms are still strongly encouraged to prevent STDs, and that periodic STD screening always takes place per CDC guidelines.

### GOAL 2: INCLUDING HIV-RELATED HEALTH OUTCOMES OF PERSONS WITH HIV

Objective 2.1: To achieve earliest possible initiation of care, expand strategy 2.1.2 or add a strategy 2.1.3, to train primary care providers to initiate HIV treatment at the same time a patient is informed of diagnosis, if the patient is willing. There might be some skepticism, but I have successfully delivered 1 to 1.5 hour lectures (copies of PowerPoints and of a Webinar are on the Beyond AIDS Foundation Website at <a href="http://www.beyondaids.org/resources.html">http://www.beyondaids.org/resources.html</a>). This minimal training prepares resident physicians and other providers to do this, including the use of HHS-recommended starting regimens with little if any drug resistance, and assuring that blood is drawn for the initial (pre-treatment) recommend panel of tests, but without waiting for results. Then when the patient returns and the test results are back, the provider has 3 choices: continue full care of the patient (easy if the CD4 count is high and the patient is tolerating the medication well); refer for HIV consultation or even referring all the HIV care but retaining the primary care; or totally referring the patient to an HIV specialist.

Objective 2.3: Improve retention in care by adding strategies.

Add strategy 2.3.6: For HRSA to establish the responsibility of funded HIV care providers (including those receiving Ryan White subsidies), to follow-up by contacting patients for missed appointments. HRSA should also establish a system for monitoring patient progression through the HIV Care Continuum, depending either on providers to report aggregate data to HRSA, or on public health to expand surveillance for this purpose.

Add strategy 2.3.7, to require states and cities receiving CDC grants to establish surveillance of MISSED viral load results from diagnosed patients, e.g. none coming in over the course of a year. The reasons for missed viral loads include 1) that the patient is not in care or has dropped out of care, and outreach is needed; 2) that the patient has moved to another jurisdiction, which should be notified about the patient; or 3) that the provider is not monitoring viral load or the lab is not reporting, either of which deserves public health outreach. In our published survey, this was an area we studied, and 38% of jurisdictions claimed that they were already doing this, with more considering it. In a few states, viral loads were not reportable by labs to public health, and if there are still any in this situation, CDC should work with the public health agencies to request authorization, by the development of legislation or regulations. In most states, the reportability of a positive HIV test is interpreted to include a viral load.

Objective 2.5 needs to be added to the plan. This draft of the NHAS does not seem to deal with the potential problem of increases, either widespread or localized, in viral resistance to commonly used medications. There needs to be a national surveillance system for genotypes (and the rare phenotypes), with reports being forwarded to CDC for analysis. So far, CDC obtains only a sampling from a few states with special grants. In our published survey, only 38% of jurisdictions said that genotype results were reportable to public health, and in most, health departments were not doing anything with the data. If that percentage has not increased much since the study, implementation of a national database will take a lot of work with the jurisdiction. However, grant applications could say that if genotypes are already being received

by public health, they should be tabulated and passed on to CDC. If genotypes are not being received, the jurisdiction would need to document efforts to get these tests reportable.

GOAL 4: ACHIEVE INTEGRATED, COORDINATED EFFORTS THAT ADDRESS THE HIV EPIDEMIC

Objective 4.2 deals with federal-state-local and private sector coordination, and strategy 4.1.3 mentions funding. In our published survey, we asked whether states had other sources for HIV prevention funding besides CDC. None of the territories did, however the percentages to follow refer to all respondents, most of which were states: 72% reported some funding for HIV prevention from the jurisdiction, and 28% reported that funding had been raised in at least one local jurisdiction (one state required all local jurisdictions to provide such funding, and altogether had the highest non-federal HIV prevention funding); 12% had at least some private sector funding. Some states had seen their HIV prevention funding disappear during the Great Recession of 2009, and a number of these had not had any of those funds restored since the economy had recovered.

Add strategy 4.2.5 to require each funded jurisdiction to attempt to raise some of its own funding for HIV prevention. A supplemental portion of CDC grants could require matching funds.

Add strategy 4.2.6 to call on CDC and HRSA to monitor whether goals of grants are actually accomplished. If there are deficiencies or failures to fulfill objectives or projects promised in the grant applications, the next grant should include a requirement that they use part of the money to correct those deficiencies. Boilerplate language making all grants read the same should be avoided, so that each grant is adapted to the needs of the funded agency.

Sincerely, on behalf of the Board of the Beyond AIDS Foundation,

Ronald P. Hattis, MD, MPH, Secretary

# HIV PREVENTION PRACTICES AND NON-FEDERAL FUNDING AMONG U.S. STATES AND NON-STATE REGIONS: A SURVEY OF HIV/AIDS DIRECTORS

Ronald P. Hattis, Richel Y. Strydom, Josileide Gaio, and Deanna C. Stover

We surveyed U.S. HIV/AIDS directors or designees in states and non-state regions, regarding factors influencing HIV viral suppression: (1) non-federal prevention funding; (2) contacting newly reported patients and providers, for care linkage and partner services; (3) follow-up of non-received viral load reports, to identify untreated patients; and (4) genotype/phenotype surveillance, to monitor drug resistance. The survey was conducted April–July 2015; 50 (87.7%) participated. Eighty percent of jurisdictions contacted all newly reported patients; 60% contacted all providers. HIV resistance tests were reportable in 38%; 66% contacted providers and/or patients about missed viral loads. Non-federal funding was significantly associated with annual diagnoses (p = .0001) and population (p = .0002), but not with other factors studied. Many jurisdictions lacked non-federal funding (28%), or experienced unrestored reductions since 2008 (33%). Jurisdictions' funding and preventive practices varied greatly. HIV viral suppression could be

Ronald P. Hattis, MD, MPH, is affiliated with Beyond AIDS Foundation and Loma Linda University, Loma Linda, California. Richel Y. Strydom, MD, MPH, is affiliated with Beyond AIDS Foundation and Loma Linda University, Loma Linda, California (the latter through February 2018). Josileide Gaio, MPH, is affiliated with Beyond AIDS Foundation, Redlands, California. Deanna C. Stover, PhD, RN, FNP, CNS, COHN-S, is affiliated with Beyond AIDS Foundation and the Community Health Association Inland Southern Region, San Bernardino, California.

The authors report no conflicts of interest. This study was financed by the authors and by the Beyond AIDS Foundation. The Beyond AIDS Foundation has received two small grants from the Gilead Foundation for conducting educational programs; neither supported this study.

The study was sponsored by and submitted on behalf of the Beyond AIDS Foundation, the educational and research subsidiary of Beyond AIDS, <a href="https://www.beyondaids.org">www.beyondaids.org</a>, a nonprofit corporation. Input was re-ceived from the Foundation's Scientific Committee, and the conclusions were endorsed by the Foun-dation Board, <a href="https://beyondaids.blogspot.com/2016/11/beyond-aids-leaders-for-2016-2017.html">https://beyondaids.blogspot.com/2016/11/beyond-aids-leaders-for-2016-2017.html</a>. No external financial support was received.

The study was approved as a residency project for RYS by the Department of Preventive Medicine, Loma Linda University. The conclusions and views expressed do not necessarily represent that department or the university.

National Alliance of State & Territorial AIDS Directors staff and Centers for Disease Control and Prevention HIV/AIDS Prevention personnel were consulted. Intern Christy Mota transferred and tabulated the questionnaire data to facilitate analysis.

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enhanced by restoring (or establishing) non-federal prevention funding, and by more standardized surveillance/outreach practices.

Keywords: HIV, public health, outreach, funding, surveillance, standardization

This cross-sectional study analyzed data from 43 U.S. states and 7 non-state regions from which the Centers for Disease Control and Prevention (CDC) collected HIV surveillance data. It assessed implementation of three HIV public health practices that could impact viral suppression among HIV-infected persons. These included routine preventive outreach after new diagnoses (to promote linkage to care and partner services), monitoring of expected but non-received viral load reports (to detect patients who may not be receiving treatment and to refer them for antiretroviral medications), and reportability of HIV genotype and phenotype results (to detect emerging drug resistance). These activities were not universally funded or required by CDC, and anecdotal information had suggested that they were not performed consistently in all jurisdictions.

We also studied non-federal (state/regional, local, and/or private) HIV prevention funding, to determine trends (including recession-associated cuts and restorations), and any associations with the three above practices, or with diagnoses or population. We queried uses of all prevention funding, including federal.

Our pre-survey hypotheses were:

- 1. The three public health practices studied were not consistently implemented in all jurisdictions.
- 2. Jurisdictions with more non-federal funding, or more diagnoses, might provide more outreach to patients and providers and expanded surveillance services (the exception being that jurisdictions with very few HIV diagnoses might also find time and staff to perform these functions, without dedicated funding).

In 1996, one of us had anticipated that antiretroviral therapy would prevent HIV transmission (Hattis & Jason, 1996). About 15 years later, suppression of HIV viral load to undetectable levels by medication was confirmed to provide dual benefits: suppressing transmission by at least 96% (M. D. Cohen et al., 2011), and improving health outcomes (INSIGHT START Study Group, 2015). Viral load, a measure of the quantity of HIV RNA in serum, has been the best indicator of both response to treatment and infectiousness (Castro & Lansky, 2013; Department of Health and Human Services [HHS], 2017; Günthard et al., 2016). In 2011, Gardner estimated that only about 19% of infected persons in the U.S. had reached such viral suppression (Gardner, McLees, Steiner, del Rio, & Burman, 2011); CDC's estimate was 30% (Centers for Disease Control and Prevention [CDC], 2016). CDC estimated in 2018 that the prevalence of viral suppression among HIV infected persons had risen to 51% overall, and 59.8% among diagnosed patients, by 2015 when this survey was conducted; however this was still far short of the National HIV/AIDS Strategy goal for 2020 of 80% (CDC, 2018; HHS, 2016b).

HIV treatment recommendations in the U.S. since 2012 have included offering antiretrovirals to all infected persons, and striving for undetectable viral loads (Günthard, 2016; HHS, 2017). President Obama's 2013 HIV Care Continuum (HCC) Initiative (HHS, 2016a) aimed to increase viral suppression.

The HCC stages are screening for initial diagnosis, linkage to care, retention in care, treatment with antiretroviral therapy (ART), and achieving undetectable viral

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loads (HHS, 2016a). With each successive stage, transmission decreases (Skarbinski et al., 2015). Unfortunately, many individuals fail to progress along the stages of the continuum (Gardner et al., 2011).

The CDC has been the major source of U.S. HIV prevention funding, providing grants to all states, the non-state regions in this study, and 8 metropolitan areas (CDC, 2012b; National Alliance of State & Territorial AIDS Directors [NASTAD], 2009, 2012–2013). Smaller specialized grants are given to states and are open to a larger number of metropolitan areas on a competitive basis (CDC, 2013a). The Health Resources and Services Agency (HRSA), has also awarded grants for linkage and retention in care (HRSA, 2017).

Since federal HIV prevention funding levels are archived by the funding agencies and occasionally published online (CDC, 2012b, 2013a), this survey focused on the less-documented additional funding from other sources. Tracking of HIV-related funding from non-federal sources (state/NSR, local, and private) has required surveys like this one. NASTAD conducted two previous surveys on HIV prevention funding as well as testing and prevention programs, in 2007 (NASTAD, 2009) and 2012 (NASTAD, 2012–2013). Those reported that just over a third of HIV prevention funding came from states in 2007, and just under a third in 2012, with great variation among jurisdictions. State and local funding were also found to have decreased substantially between 2007 and 2012, overlapping the major 2008 economic recession.

In our analysis, the term *non-state regions* (NSRs) refers to the federal District of Columbia and six inhabited island areas that are not states but belong to, or are dependent on, the U.S. These have been included as "dependent areas" in CDC tabulations of HIV diagnoses (CDC, 2015c), and as territories in NASTAD rosters (NASTAD, 2015). Legally, Guam, U.S. Virgin Islands, and American Samoa are territories, Washington, D.C., is a federal district, Puerto Rico and the Northern Mariana Islands are commonwealths (Legal Dictionary, n.d.), and Palau is a freely associated republic receiving CDC subsidization for public health (CDC, 2015a).

Jurisdiction refers to either a state or an NSR. "Local jurisdiction" is a subdivision such as a county or city.

### **METHODS**

### STUDY SAMPLE

We contacted all HIV/AIDS directors from states and NSRs listed on the 2014–2015 NASTAD roster (NASTAD, 2015, since updated), or their successors, by email to complete a survey online. Those not initially responding received follow-up emails and phone calls. We collected data from April through July 2015. Analysis began August 2015, continuing into 2017. No human subjects were contacted; there were no clinical interventions.

This type of research was triply exempt from institutional review board review as defined in 45 CFR part 46, on the basis of: no intervention or interaction with living individuals; involving the study or evaluation of survey or interview procedures; and involving study of existing data (HHS.gov). To encourage participation by reluctant directors who were aware of deficiencies in their jurisdictions, we followed the example of the prior NASTAD surveys (NASTAD, 2009, 2012–2013) and assured the participants that their jurisdictions would not be named in any published

paper, although they would be identified in data confidentially shared with NASTAD and CDC.

### **QUESTIONNAIRE**

The multiple-choice questionnaire included 8 substantive multiple-choice and 3 demographic (jurisdiction, job title, and contact information) questions. It utilized SurveyMonkey, Professional Version (SurveyMonkey, San Mateo, CA, 2011). Substantive questions included an other category for comments as a supplemental or substitute response. One state HIV/AIDS director pilot-tested the questionnaire before general release.

### STATISTICAL ANALYSIS

Statistical analysis utilized Statistical Analysis Software (SAS) version 9.4 TS, Level1M1 (SAS Institute, Cary, NC, 2013). HIV diagnoses and rates came from Table 2 of CDC's 2014 surveillance report, the most recent at the time of the data analysis (CDC, 2015c). Annual estimated total diagnoses were prioritized over rates, because patient counts more directly influence sizes and expenses of HIV surveillance and prevention programs. Populations were mid-2014 census estimates (Cox, 2015; U.S. Census, International Programs, 2017).

Jurisdictions were stratified by annual non-federal HIV prevention funding, per survey responses (categories: no funds; more than zero but < \$1 million; > \$1 million). Reported diagnoses, populations, and diagnosis rates were divided by quartiles. The most populous jurisdictions and those with the most diagnoses all placed within the top quarter, while those with low populations and reported cases all placed within the bottom quarter. Two-sided Fisher's exact test of independence was used where > 20% of expected cell frequencies in tables were < 5; otherwise two-sided chi square test of independence was used.

Statistical significance criterion was p < .05. Some survey questions permitted selection of more than one option, so where noted, totals do not equal 100%.

### **RESULTS**

### SURVEY RESPONSE

The overall response rate was 87.7%, including all 7 NSRs and 43 of 50 states. Respondents completed 23 surveys during April–June and 27 in July 2015. Participating jurisdictions accounted for 36,874 (> 82%) of total estimated HIV diagnoses in 2014. HIV/AIDS directors personally completed 32 surveys; knowledgeable assistants such as surveillance chiefs were delegated to complete the remainder.

Respondents included 10 of the 12 states with estimated 2014 diagnoses over 1,000, and 15 of the 16 jurisdictions with estimated 2014 diagnoses under 100. All 50 jurisdictions responded to questions, except as noted.

Of the seven non-participating states, four were refusals (NM, MI, OH, and SD); three were non-responses after multiple contact attempts (FL, IN, and KY). Reasons given for refusals included unfamiliarity with the Beyond AIDS Foundation, discomfort sharing program data, being too busy, having few diagnoses, and/or participation in prior NASTAD surveys.

Apparent inconsistencies or omissions were resolved by phone or email, or by incorporating details added in comments. Twelve of these related to outreach after newly reported diagnoses, seven to funding sources, and one to both. In two

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TABLE 1. Population Size (Mid-2014 Census Estimates, Divided by Quartiles), Stratified Separately by 2014–2015 Non-federal HIV Prevention Funding (in Three Categories), and by 2014 HIV Diagnoses (Divided by Quartiles), U.S. States and Regions

		p value			
	≤ 1,055,173	> 1,055,173, ≤ 3,608,839	> 3,608,839, ≤ 6,731,484	>6,731,484	
	(n = 13)	(n = 12)	(n = 13)	(n = 12)	
	n (%)	n (%)	n (%)	n (%)	
Non-federal Funding					.0002
None $(n = 14)$	7 (53.8)	4 (33.3)	3 (23.1)	0 (0.0)	
> 0 < \$1 M (n = 19)	5 (38.5)	6 (50.0)	7 (53.8)	1 (8.3)	
> \$1 M (n = 17)	1 (7.7)	2 (16.7)	3 (23.1)	11(91.7)	
Annual HIV Diagnoses					.0001
< 61 (n = 13)	10 (76.9)	3 (25)	0 (0.0)	0 (0.0)	
> 61 < 330 (n = 12)	2 (15.4)	7 (58.33)	3 (23.1)	0 (0.0)	
> 330 < 842 (n = 13)	1 (7.7)	2 (16.67)	7 (53.8°)	3 (25.0)	
> 842 (n = 12)	0 (0.0)	0 (0.0)	3 (23.1)	9 (75.0)	

*Note.* Percentages apply only to respective column sections.  ${}^{3}$ Rounded downward to make percentages in this section total 100. Boldface indicates statistical significance (p < .05) found by two-sided Fisher's exact test between population and funding (p = .0002), and between population and annual diagnoses (p = .0001).

cases, the original responder could not be reached, and corrections were provided by other knowledgeable staff. Two additional respondents were contacted to clarify responses on local funding; one provided a correction. Internet-posted documents corroborated two corrections. Information on non-federal funding from two jurisdictions remained inconsistent.

### NON-FEDERAL FUNDING FOR HIV PREVENTION

Lack of any current non-federal funding for HIV prevention was reported by 28% of jurisdictions. State or NSR funding was reported by 72% of jurisdictions, and funding from some but not all local jurisdictions by 28%. In one state, with by far the highest total non-federal funding, all local jurisdictions contributed toward HIV prevention. Some private sector funding for state/NSR or local projects was reported in 12% of jurisdictions.

Of the 48 jurisdictions responding to a question on trends since 2008 in HIV prevention funding from all non-federal sources, 20 (42%) reported that it had remained stable, and 16 (33%) said it had decreased and had not been fully restored to FY2008 levels. Only one jurisdiction (2%) reported that non-federal public prevention funding had been reduced but later fully restored to FY2008 levels. Participants were not asked about increases from baseline.

Population was very strongly associated with annual reported HIV diagnoses (p = .0001 by two-sided Fisher's exact test); see Table 1. Population and non-federal HIV prevention funding were associated almost as strongly (p = .0002). Annual reported HIV diagnoses and diagnosis rates were also significantly associated with non-federal HIV prevention funding (p = 0.0003 and 0.0021 respectively; not in table).

	Call provider always	Call provider sometimes	Do not call provider		Call patient always	Call patient sometimes	Do not call patient	<i>p</i> value
	(n = 30)	(n = 16)	(n = 4)		(n = 40)	(n = 8)	(n = 2)	
	n (%)	n (%)	n (%)		n (%)	n (%)	n (%)	
Non-federal Funds				.26				.06
None $(n = 14, 15)$	6 (20.0)	5 (31.25 <sup>a</sup> )	3 (75.0)		14 (35.0)	1 (12.5)	0 (0.0)	
> 0 < \$1 M (n = 19, 18)	13 (43.3)	6 (37.5)	0 (0.0)		16 (40.0)	1 (12.5)	1 (50.0)	
> \$1 M (n = 17, 17)	11 (36.7)	5 (31.25 <sup>a</sup> )	1 (25.0)		10 (25.0)	6 (75.0)	1 (50.0)	
Annual HIV Diagnoses				.31				.39
< 61 (n = 13, 13)	10 (33.3)	2 (12.5)	1 (25.0)		11 (27.5)	1 (12.5)	1 (50.0)	
> 61 < 330 (n =12, 12)	9 (30.0)	3 (18.75)	0 (0.0)		11 (27.5)	1 (12.5)	0 (0.0)	
> 330 < 842 (n =13, 13)	5 (16.7)	6 (37.5)	2 (50.0)		11 (27.5)	2 (25.0)	0 (0.0)	
> 842 (n = 12, 12)	6 (20.0)	5 (31.25 <sup>a</sup> )	1 (25.0)		7 (17.5)	4 (50.0)	1 (50.0)	

TABLE 2. Public Health Outreach Practices of US States and Regions, to Reported Individual and Provider, Stratified Separately by 2014–2015 Non-federal HIV Prevention Funding (in Three Categories), and by 2014 HIV Diagnoses (Divided by Quartiles)

*Note.* Percentages and p values apply only to each section of respective columns. Two-sided Fisher's exact test performed. No significant relationship was found between the outreach provided to providers or patients, and either annual HIV diagnoses or non-federal HIV prevention funds. \*Carried to additional decimal point to demonstrate that percentages in these sections total 100.

# USES OF ALL HIV PREVENTION FUNDING (FEDERAL AND NON-FEDERAL)

Jurisdictions reported utilization of prevention funding (from all sources including federal) for five purposes of special interest in this study, offered as selections in the questionnaire: linkage to care (92%), partner services (90%), expanded testing (84%), retention in care (60%), and surveillance/monitoring of viral load (42%). Funds were used for all five by 34% of jurisdictions.

Other activities, including those required for CDC prevention cooperative agreements since 2012 (CDC, 2012a) but not listed as selections, e.g., condom distribution, structural initiatives, could be mentioned in optional comments. One jurisdiction commented that prevention funding paid solely for testing, partner services, and condom distribution; while linkage to care was paid from Ryan White funds. Others reported use for syringe access, behavioral interventions, education, interventions for high-risk negatives, community planning, and/or condom access.

### OUTREACH TO PATIENTS AND PROVIDERS FOLLOWING INITIAL HIV REPORTED DIAGNOSES

Following a newly reported HIV diagnosis, the provider (if known) was routinely contacted in 60% of jurisdictions (see Table 2). Some providers were contacted by an additional 32%; while 8% did not indicate that any were contacted. The patient was routinely contacted if possible in 80% of jurisdictions. Some patients were contacted by an additional 16%; while 4% did not indicate that any were contacted. All jurisdictions contacted at least some providers and/or patients, but 14% neither contacted all providers nor all patients. Such contacts were not significantly associated with either annual reported HIV diagnoses or non-federal prevention funding; in fact, a reverse association between funding and calling all patients approached significance (p = .06).

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	(Divided by Quartiles)					
	Contact provider	p value	Contact patient	p value	Do not contact either	p value
	(n = 21)		(n = 20)		(n = 18)	
	n (%)		n (%)		n (%)	
Non-federal Funds		.99*		.97*		.82**
None $(n = 17)$	6 (28.6)		6 (30.0)		5 (27.8)	
> 0 < \$1 M (n = 22)	8 (38.1)		7 (35.0)		7 (38.9)	
> \$1 M (n = 20)	7 (33.3)		7 (35.0)		6 (33.3)	
Annual HIV Diagnoses		.84*		.98**		.27**
< 61 (n = 16)	6 (28.6)		5 (25.0)		5 (27. 8)	
> 61 - < 330 (n = 14)	6 (28.6)		5 (25.0)		3 (16. 7)	
> 330 < 842 (n = 14)	5 (23.8)		6 (30.0)		3 (16.7)	
> 842 (n = 15)	4 (19.0)		4 (20.0)		7 (38.9)	

TABLE 3. Practices for Missed Viral Loads After 12 Months of Diagnosis, Stratified Separately by 2014–2015 Non-federal Prevention Funding (in Three Categories) and by 2014 HIV Diagnoses (Divided by Quartiles)

*Note.* Totals in table exceed number of jurisdictions because nine jurisdictions contact both provider and patient, others only listed a comment. Percentages and p values apply only to each section of respective columns. Two-sided chi-square (\*) and two-sided Fisher's exact tests (\*\*) were performed as shown, and no significant associations were found between annual diagnoses or funds and contacting provider or patient.

Forty-four jurisdictions responded regarding inclusion of three queried topics when providers were contacted. Partner services were discussed by 32 (72.7%), linkage to care by 30 (68.1%), and information to complete reports by 41 (93.2%). All three topics were discussed by 25 (56.8%). In optional comments, 7 jurisdictions listed additional topics, including risk assessment; how to contact patients; informing providers that patients would be contacted; and guidance about managing acute HIV.

Forty-seven jurisdictions responded regarding inclusion of two queried topics when patients were contacted. All (100%) discussed linkage to care; 45 (95.7%) also discussed partner services. In optional comments, 8 jurisdictions listed additional topics, including patient questions on disease course; screening for substance abuse and mental health; insurance status; prevention services; social services referrals; necessary non-HIV services; AIDS Drug Assistance Program; confidentiality; syphilis testing; and case management.

### SURVEILLANCE OF MISSED VIRAL LOAD RESULTS

Missed viral loads (defined as one year without a reported viral load, for a previously reported HIV positive patient) triggered routine communication with all providers in 42% of jurisdictions, and with all patients in 40% (see Table 3). Both were notified in 18%, and neither in 36%.

One additional jurisdiction (not included in Table 3) contacted patients after 15 months. Applying this 15-month criterion, the totals changed to 42% contacting patients and 34% contacting neither. Such outreach was not significantly associated with either reported diagnoses or non-federal funding.

In optional comments, one jurisdiction reported that such a program had just been implemented. Two followed up missed viral loads only for Ryan White clients. This information was not included in Table 3.

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	Report	Do not report	<b>p</b> value		
	(n = 19)	(n = 31)			
	n (%)	n (%)			
Non-federal Funds			.76*		
None $(n = 14)$	6 (31.6)	8 (25.8)			
> 0 < \$1 M (n = 19)	6 (31.6)	13 (41.9)			
> \$1 M (n = 17)	7 (36.8)	10 (32.3)			
Annual HIV Diagnoses			.48**		
< 61 (n = 13)	7 (36.8)	6 (19.4)			
> 61 < 330 (n = 12)	3 (15.8)	9 (29.0)			
> 330 < 842 (n = 13)	4 (21.1)	9 (29.0)			
> 842 (n = 12)	5 (26.3)	7 (22.6)			

TABLE 4. Policies of U.S. States and Regions on Laboratory Reporting of HIV Genotype or Phenotype, Stratified Separately by 2014–2015 Non-federal HIV Prevention Funding (in Three Categories), and by 2014 HIV Diagnoses (Divided by Quartiles)

*Note.* Percentages apply only to each section of respective columns. Two-sided chi-square (\*) and two-sided Fisher's exact test (\*\*) were performed as shown, and no significant association was found between the practice of reporting HIV resistance results, and either annual HIV diagnoses or non-federal HIV prevention funding.

# MANDATORY LABORATORY REPORTING OF HIV RESISTANCE TEST RESULTS (GENOTYPE/PHENOTYPE)

HIV resistance test results were reportable in only 38% of jurisdictions (see Table 4). One additional jurisdiction commented that a regulatory change would soon require reporting. No significant associations with either annual reported diagnoses or non-federal funding were found. Optional comments indicated that resistance data, if received, were not necessarily analyzed for trends.

### **DISCUSSION**

This study provided new data on post-recession non-federal HIV prevention funding, and on implementation of three public health practices supporting the HIV Care Continuum but not mandated by CDC: outreach to providers/patients after newly reported HIV diagnoses, follow-up of missed viral loads, and reportability of HIV drug resistance. The survey responses represented 43 U.S. States, and 7 non-state regions including the District of Columbia, 5 U.S. island possessions, and an island republic receiving CDC support.

The first study hypothesis, that outreach to providers/patients, follow-up of missed viral loads, and reportability of HIV drug resistance were inconsistent, was confirmed. Contrary to the second hypothesis, neither annual reported diagnoses nor non-federal funding was associated with those practices.

Local public health programs nationwide underwent severe recession cutbacks beginning 2008 (National Alliance of County and City Health Officials [NACCHO], 2014). Reduced state HIV prevention funding to local jurisdictions was estimated to have increased HIV infections in California (Lin, Lasry, Sansom, & Wolitski, 2013).

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Findings on HIV prevention funding were similar though not identical to those of NASTAD in 2012 (NASTAD, 2012–2013). Most jurisdictions reported either reduced non-federal funding for HIV prevention since FY2008 or had no such funding. Only one jurisdiction reported full recovery from recession cutbacks, despite improvement in state budgets from 2012 to 2014 (Torres, Stillwell, & Niquette, 2014). Many health policy advocates outside of government may be unaware of persistent shortfalls. Restoring funding for public health competed with other interests reduced during the recession (Leachman & Mai, 2014). Augmentation of current federal funding, to match jurisdictional funding, could provide an incentive for the latter.

The strongest statistical association found was between population and reported diagnoses. Non-federal HIV prevention funding was strongly associated statistically with population, as well as with estimated annual HIV diagnoses and rates. Theoretically, optimal prevention could be so effective that higher spending would be associated with fewer diagnoses. Results suggested an opposite association.

In FY2012, CDC changed the funding basis for comprehensive HIV prevention grants, giving major consideration to prevalence, i.e., persons living with HIV (CDC, 2014). However, funding based on incidence (diagnoses) would seem more appropriate for testing and services appropriate for recently reported diagnoses (even though some diagnoses may be late reports and not recent infections), e.g., linkage to care and partner services. Immediate treatment initiation, are also related to diagnoses, and could theoretically prevent most transmission and years of preventable life lost (INSIGHT START Study Group, 2015; Granich, Gilks, Dye, De Cock, & Williams, 2009; Hontelez et al., 2013).

Also in FY2012, CDC began requiring that 75% of core prevention allocations to states, NSRs, and local jurisdictions be used for HIV testing, prevention with positives, condom distribution, and structural initiatives (CDC, 2012a). The expanded surveillance and outreach queried in this survey were not among suggested targets for the remaining 25%, and may have required funding from other sources, including non-federal funding, HRSA grants, and competitive CDC grants such as Data to Care (CDC, 2017).

Contacting the patient and/or provider after newly reported diagnoses can facilitate linkage to care, partner services for recently exposed persons (CDC, 2008), and other preventive services. Although all jurisdictions performed at least some such contacts, outreach, and content of discussion were neither universal nor uniform. Jurisdictions that depended on local public health personnel to perform such functions were likely disadvantaged by severe local staffing cutbacks (NACCHO, 2014).

Lack of any viral load report within the past 12 months is an indicator of possible non-initiation or non-retention in antiretroviral treatment. It could alternatively indicate a patient who moved out of the jurisdiction or refused blood testing, provider failure to order the test, or laboratory failure to report results to public health. Only follow-up can differentiate these. A missed test result did not trigger routine outreach to either the patient or provider in 36% of jurisdictions (34% using a 15-month criterion). The remainder contacted provider and/or patient, using varied terminology for such programs.

At the time of this survey, viral load testing was recommended every 3–6 months for patients taking antiretroviral drugs (Günthard et al., 2016; HHS, 2017). The District of Columbia and 42 states required laboratory reporting of all received viral load results (including undetectable) to public health agencies (CDC, 2015b). CDC promoted this, and required it for Data to Care grants. The CDC compilation of state reporting laws lacked sufficient information to enable cross-checking of which

states and NSRs that responded to this survey did not have mandatory reporting of all HIV viral loads, regardless of results (CDC, 2015b). Neither CDC nor state laws required surveillance of non-received viral loads (Castro & Lansky, 2013; CDC, 2012a, 2016; HHS, 2017).

An increase in prevalence of resistance to commonly used medications in any geographical area could have major implications for the HCC. Starting in 2013, CDC collected genotype data from select jurisdictions as a molecular surveillance extension of the National HIV Surveillance System (S. M. Cohen, Gray, Ocfemia, Johnson, & Hall, 2014). "Molecular surveillance" became an optional area for competitive CDC funding (CDC, 2013b), but reporting of HIV drug resistance was not mandatory. This study found that only 38% of jurisdictions required laboratories to report genotype and phenotype results.

### LIMITATIONS

Seven states did not participate in this survey. Cost-effectiveness of recommendations was not studied.

Respondents were not asked whether non-federal funding had increased in jurisdictions that had not experienced cutbacks. In the 2012 NASTAD survey, 11% of programs had reported increased non-federal funding since 2007 (NASTAD, 2012 –2013).

HIV prevention funding was not defined. Interpretations may have varied regarding which grants to count. Amounts were not exact dollar figures, and could have been based on recall rather than record-checking.

Although inconsistent responses were almost all resolved by post-survey contacts and reviews of comments, their occurrence suggested reliability issues.

### **CONCLUSIONS**

After several years of economic recovery, restoration of recession funding cutbacks for HIV prevention was overdue at jurisdictional and local levels. Federal matching of non-federal funds could incentivize this. Restored (or newly established) non-federal funding could help monitor and facilitate progression through the HCC, especially if used in part for outreach to patients and their providers after new diagnoses or if viral load results were not received for a year, and for collection and forwarding of viral resistance data to CDC. However, such services, which were not yet specifically funded routinely by CDC, showed no statistical association with non-federal funding.

Public health practices relating to follow-up of newly reported HIV diagnoses and missed viral load results, and reporting of genotypes and phenotypes, varied widely among states and NSRs. CDC could revise guidelines to encourage a more uniform system of HIV surveillance and monitoring, based on HCC stages and goals.

Linkage to care and partner services were already endorsed by CDC, but inconsistently applied. They could become a required use of CDC prevention funding, with specifications regarding the types of outreach expected.

Public health tracking of non-received viral load results (an indicator of infected persons who may not be in treatment), with outreach to providers and patients, may facilitate two more stages of the HCC: retention in care and antiretroviral treatment. Despite lack of specific funding by CDC, a majority of jurisdictions already claimed engagement in this activity. Patient progression through the HCC could be facilitated

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by making it a required use for CDC and/or HRSA funding. To make this a universal surveillance activity, jurisdictions that do not have mandatory laboratory reporting of all viral loads, regardless of result, would need to institute such reporting.

CDC considered genotype surveillance optional, did not collect phenotypes, and neither was reportable in most jurisdictions. Uniform reporting, with submission to CDC for nationwide analysis, could produce a more complete database for monitoring antiretroviral resistance.

CDC could require grant application objectives to address jurisdiction-specific shortfalls in these areas, and opportunities for improvement.

Surveys like this may prove valuable in increasing awareness among public health advocates about funding gaps and potentials for expanded surveillance and outreach within their jurisdictions. Such awareness could stimulate discussions about policy and any necessary political action.

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### Dear PACHA,

Please see my answers below. If you would like additional information or details please let me know.

1. What are the most meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of the Ending the HIV Epidemic initiative at the national level and in your community to meet the goal of ending HIV?

Intra-coalition building is one of the most promising strategies to implementing the HIV National Strategic Plan particularly ensuring that local organizations have the opportunity to engage with one another and align their missions, strategies, and goals. Too often there are many organizations implementing similar strategies in the same areas. Ensuring that key stakeholders and influencers within target populations are in contact with one another is vital to long term benefits. Building these relationships as well as offering the most recent data and collecting their most recent data that can be collated upwards from local to state to national closes gaps and identifies areas of neglect. Another strategy to consider is conducting Ryan White Planning Council awareness campaigns and recruiting underrepresented and under resourced target populations to participate in meetings and join the councils to represent the interests of their populations and have a decision making voice in how funding is distributed. Equitable representation and intergenerational exchange would both add significantly to the overall goals of the HIV National Strategic Plan. Specific strategies need to be developed for populations such as youth experiencing homelessness, transgender populations, sex workers, chem sex, Southern/rural, and thos living with chronic mental health issues are sorely lacking in large data groups. The sampling of these groups therefore does not often accurately reflect the true needs of these populations.

2. How can domestic HIV/AIDS programs better meet the needs of underserved communities and address the systemic barriers that communities face in order to achieve the goals of the President's Executive Order Advancing Racial Equity and Support for Underserved Communities?

See above for similar strategies. Dignity-based equity and representation must be more than an initiative or addition to a mission statement. In order to truly address systemic barriers organizations must conduct investigations into the role that privilege and systemic barriers have played, which should be conducted by an independent body. As we have seen the blatant rise of white supremacy throughout various reaches of leadership in both the public and private sector it will take significant resources and attention to accountability to address and foster change. Workshops, training, and seminars on privilege and combating white supremacy where these issues have already been identified should be implemented immediately. Reviews and potentially evaluations on understanding the impacts of systemic barriers becoming part of application or recruitment processes could also aid in cultivating a culturally competent staff. The greater challenge is assessment of leadership within organizations. If the leadership is tainted by systemic issues of discriminaton it tends to permeate a culture of fear and silence preventing opportunities for real change. Human resource departments too often value the protection of the organization above the employees further emboldening these practices. There is also a deep need

to assess labor rights when a majority of the population work as at-will employees and have little recourse should they encounter instances of discrimination or prejudice. To uproot generations worth of systemic barriers it will take herculean efforts and commitments by privileged populations (re: white and/or affluent) to teach and hold one another accountable. The burden of this work should not be placed on marginalized groups. However, evaluating gatekeeping and barriers so that qualified underrepresented individuals are put into positions of influence and decision making should become an immediate priority. The system itself must adapt and change if it is to contend with a past entwined so deeply with systemic barriers. The first step is for each of us to look at ourselves, acknowledge that we each have our own set of privileges we were born or raised into, and that the culture we have grown up in has allowed some more than others to benefit off of these inequities. Furthermore, it is imperative that privileged groups listen to those who have been marginalized and discriminated against.

Thank You,

Joseph Varisco Program Director QIO: HIV Impact Education

T: 630.362.2893 Pronouns: He/Him

### To:

Carl Schmid and John Wiesman, Co-Chairs Presidential Advisory Council on HIV/AIDS (PACHA) Current PACHA Membership and Staff, including Kaye Hayes, Caroline Talev

### From:

Ronald P. Hattis, MD, MPH Secretary, Beyond AIDS Foundation 1275 W. Park Ave. #7718, Redlands, CA 92373

Mobile: 909-838-4157

On behalf of the Beyond AIDS Foundation, I wish to express appreciation for the opportunity to submit input at the March 2021 PACHA meeting, to briefly discuss the proposals below. I hope this will include an opportunity to interact with the Council members orally or by video (virtually).

I am enclosing, and attaching to the cover email, some of the Foundation's major current recommendations. We are not strangers to PACHA. The leadership of the Beyond AIDS Foundation includes two Board members who are former PACHA members, Franklyn Judson of Denver and Monica Sweeney of New York City. I have also delivered past testimony to PACHA in person.

We are pleased that PACHA is especially interested in meaningful actions to implement the National HIV/AIDS Strategy (NHAS), the goal of ending the HIV epidemic in the U.S., and fulfillment of the Executive Order on Advancing Racial Equity and Support for Underserved Communities. Our recommendations are particularly addressed toward improving implementation of the NHAS, especially for more effective and integrated HIV/AIDS prevention, and will contribute also toward the other goals.

These recommendations have implications for future grants from CDC and HRSA, for accountability regarding fulfillment of grant conditions, and for programs that do not yet exist in either agency (such as federal subsidies for PrEP and training of primary care providers to initiate HIV treatment). They also could help guide the development of national HIV/AIDS prevention policy and contribute to the HIV/AIDS eradication program. In our judgement, most of our recommendations can probably be implemented without significantly increased federal funding, by re-directng some funds. However, as mentioned below, we also recommend more efforts to raise state, local, and private sector prevention funding to supplement federal resources (while recognizing the current impediments during the pandemic).

Most of the proposals below were also submitted for consideration as revisions to the latest draft for the (NHAS), see attached. We have also notified NASTAD, and are inquiring about the potential of discussing them with CHAC. Many of our recommendations are based on the attached survey of state and territorial HIV/AIDS Directors, published in AIDS Education and Prevention in 2019, including its conclusions/recommendations. That survey revealed significant inconsistencies in policy and practice among the states and territories, and what we considered to be deficiencies in many jurisdictions. I have copied and pasted at the bottom of

this message the response of Dr. Jonathan Mermin to our input to the NHAS and to the list of proposals having to do with CDC specifically.

### Our most important recommendations include:

- That CDC and HRSA, in their RFPs, request more individualized grant applications for HIV prevention and treatment, addressing specific goals and in particular weaknesses and deficiencies of each state/territory/city's HIV/AIDS program, and new policy directions from CDC and HRSA that have not yet been implemented by the respective jurisdictions. The grant recipients should have an opportunity to negotiate with CDC regarding these goals, and then should be accountable for doing their best to achieve them. Any goals that are not reached during a funding period should be emphasized even more specifically in the next renewal grants.
- That CDC goals increasingly stress the need for more standardized outreach to newly diagnosed patients and their providers (if any). If diagnosed persons are not linked to immediate treatment, and if partner services are not done, an early deficiency in the HIV Care Continuum results. Minimum purposes should be to help assure the most rapid possible linkage to and initiation of care, partner services, and referrals for other services as indicated. This need not be absolute uniformity, as we found eight jurisdictions that reported admirable patient outreach "extras" such as screening for substance abuse and mental illness, answering patient questions on disease course or managing acute HIV, ADAP, social services, and assistance in obtaining health insurance. It should remain possible for jurisdictions to continue to fund these out of CDC grants. We are more concerned about the 36% of states and territories that did not routinely attempt to contact either all reported patients or all providers when those existed. Sometimes, in some locations, the main purpose in contacting providers or patients is to complete reporting forms, rather than to assist in overall public health goals.
- That CDC recommend new directions for HIV surveillance (expansion of "data to care") to help monitor and facilitate patient progression along the HIV Care Continuum; and that RFPs indicate that part of the money is to be spent on these activities. As a specific example, many but most states were already tracking MISSED viral load results in diagnosed and reported patients, and we recommend that this become a national expectation. Such testing can promote retention in care. Previously diagnosed patients for whom viral load results have not been received in the past year should have outreach to determine whether they never entered or have dropped out of care (in which case renewed linkage efforts should be implemented), have moved to other jurisdictions (in which case those jurisdictions should be informed), or whether some laboratories are not complying with reporting requirements (in which case jurisdictions should intensify work with those labs). HRSA should meanwhile strongly emphasize the need for monitoring of viral load (as well as CD4 counts) in care funded by Ryan White.
- That HRSA grant recipients, including clinics receiving Ryan White funds, be expected to follow-up on missed appointments, so as to increase treatment retention as part of the HIV/AIDS Care Continuum.

- That monitoring of genotype results become universal and an activity for which federal money can be used, with results forwarded to CDC for analysis and detection of emerging viral resistance throughout the country to current medications. Currently, this type of surveillance depends on supplemental grants, and is therefore somewhat sporadic, with geographic gaps. Progress in this direction should include encouraging states that are not yet receiving genotype results to work to assure that genotypes be considered as HIV results and thus reportable to public health. The less-commonly performed phenotypes could be added to this program. HRSA's Ryan White program guidelines should meanwhile emphasize the appropriate indications for genotype testing.
- That all jurisdictions, and particularly states, be encouraged, and incentivized (perhaps by making part of the grants be matching funds), to designate some of their own money for HIV prevention, so as to supplement CDC grants. Currently, New York state requires all counties to raise HIV prevention funds and adds a hefty state contribution, but many states have no funds to spend other than their CDC grants. (As promised, the published article does not identify any states or territories by name, but if requested, we can supply a spreadsheet with the survey results identifying responses by jurisdiction; this was already shared with CDC and NASTAD.) We are aware that the COVID-19 pandemic has severely strained state and local resources, without a federal bail-out so far. This makes outreach to the private sector, as done in several jurisdiction, worth considering.
- That the NHAS, as well as the viral hepatitis strategy and the pending new STD strategy, all aim to better coordinate prevention efforts for HIV with other diseases included in specifically other STDs and viral hepatitis. This could begin with more joint screening efforts, and more joint health education about safer sex and avoidance of needle sharing. As we promote PrEP, we should not omit urging condoms, counseling, and frequent screening as indicated, to prevent not only HIV infections, but a whole range of other sexually-transmitted infections.
- That both CDC and HRSA prevention and treatment grants include requirements to address the systemic barriers that communities face in order to achieve the goals of advancing racial equity and support for underserved communities.
- That a way be determined to cover PrEP for uninsured patients. The recent USPSTF recommendation for PrEP should increase insurance coverage, but for those without any, it will not help. Ryan White funds are currently restricted by law to be used only for care of HIV-positive persons. Should a change in the statute by recommended, or can a special category of grants be established by either HRSA or CDC? This is a topic on which we corresponded with Dr. Stoner in 2019.
- That training be made available nationwide to primary care providers on the baseline tests and HHS-recommended starting medications for treatment-naive patients indicated to initiate HIV treatment, without a wait for an infectious disease referral, and without the need to wait for the test results. I have personally provided this training to resident physicians at Loma Linda University, in as little as a 1-hour session. Both short and longer slide presentations are posted on our Foundation's Web site, at <a href="http://www.beyondaids.org/resources.html">http://www.beyondaids.org/resources.html</a>.

Tuesday, December 29, 2020, 10:56 am

Dr. Hattis:

Thank you for the thoughtful input on the new NHAS from the Beyond AIDS Foundation, and for your encouraging comments on our new DHAP leadership. Even in the midst of COVID-19, I believe we will see progress in HIV over the next year.

All the best,

Jono

Jonathan Mermin, MD, MPH
Rear Admiral and Assistant Surgeon General, USPHS
Director, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
Mermin, Jonathan (CDC/DDID/NCHHSTP/OD) <a href="mailto:ihm7@cdc.gov">ihm7@cdc.gov</a>

### HIV National Strategic Plan: Roadmap to End the HIV Epidemic 2021–2025 PUBLIC COMMENT

# MPact Global Action for Gay Men's Health and Rights Fijate Bien Program

If we may start with the statement offered by the Racial Justice Framework Group:

"It is our contention that any struggle for justice or equity in HIV must become a racial justice movement. Health inequities faced by Black, brown, and indigenous people, historically and in our present moment, are structured by historical and present-day racism. If we claim to be leaders in HIV prevention, access to care, or human rights, it is our responsibility to pressure institutions from the clinic to the government, from funders to the courtroom, to act in the service of racial equity and justice, and to divest from the interests of white supremacy.

Already an integral part of the fabric of the HIV community are the principles of meaningful involvement of people living with HIV (MIPA). Meaningful involvement is not and must not be limited to HIV status. We assert that any response to the HIV epidemic is incomplete without leadership, active participation, and guidance of Black and brown people in all aspects of that response."

The Fijate Bien Program at MPact aims to address structural barriers impacting Latinx (including Afro-Latinx and Indigenous-Latinx) gay and bisexual men and other MSM in accessing HIV prevention, care and treatment services. Structural barriers such as homophobia, transphobia, discrimination based on language and country of origin, HIV stigma, nonexistent mental health and harm reduction/treatment services, housing and food insecurity and lack of educational and employment opportunities continue to impact the lives of Latinx gay and bisexual men. To this end, in November of 2019 we released a Technical Brief (enclosed) on the US National HIV/AIDS Strategy Update: Implications for Latinx Gay and Bisexual Men. In it we summarize the different versions and updates that have occurred since the inception of NHAS in 2010. More important we offered actionable targets specific to Latinx gay and bisexual men across 12 of the 13 indicators in the 2016 Indicator Supplement. We hope that some of these targets have or will be taken into consideration and incorporated into the HIV National Strategic Plan.

We acknowledge the inclusion of Latinx gay and bisexual men and other MSM as part of the plan's Priority Populations. Representation and inclusion are important in order to fully address the HIV crisis impacting Latinx gay and bisexual men. Although a good start, we would like a stronger more explicit commitment and propose the following modifications/additions to the plan:

- 1. Center the voices and lived experiences of Black, Indigenous People Of Color (BIPOC) living with HIV and affected by HIV in the further development and implementation of the plan. The top down approach in the creation of the plan via a Steering Committee and then including community voices only through public testimony, contradicts the intention of community ownership and subsequent effective implementation of the goals, objectives and strategies proposed in the plan.
  - a. Convene a national panel of Latinx gay, bisexual and other MSM activists, patients/clients, program implementers and administrators, researchers and policy makers to formulate more specific indicators and targets and inform the implementation process.

- 2. Include in the Vision Statement: "This vision includes all people regardless of.
  .. migration status or socioeconomic status." Multiple studies have shown that one of the biggest barriers to accessing timely HIV prevention, care and treatment services by undocumented community members is fear due to harsh immigration enforcement practices, including possible detention and deportation, and potential negative impact on their naturalization process when accessing services. Given that most new HIV infections among Latinx gay and bisexual men and MSM are among recent immigrant men, if we want to effectively connect them to HIV prevention, care and treatment services, we have to ensure xenophobic barriers are addressed.
- 3. Include and name specific financing mechanism and effective tracking metrics to meet the Targets, Objective and Strategies and ensure the resources reach those intended to reach. Begin by pricing out the costs associated to implement the entirety of the plan and name what Federal, State and Local budgets will need to be decreased in order to reallocate these funds to support the plan. The Steering Committee should keep in mind the economic recession the US has entered, and that Puerto Rico has been in for decades. BIPOC communities will again bear the greatest burden in Federal, State and local budget cuts to safety net programs and services, potentially exacerbating local syndemics.
- 4. Recommend, as part of building the health workforce pipeline, that linguistically competent and culturally humble Latinx gay and bisexual men be considered and hired at the federal, state and local levels. Relocation incentives, competitive salaries, student loan forgiveness programs should be considered when attracting Latinx gay and bisexual professional candidates to health workforce scarce communities.
- 5. Recommend the provision of adequate funding to Latinx specific CBOs that deliver stigma-free, culturally/linguistically competent, evidence-informed and rights-based, comprehensive sexual health programs and earmark funding to support leadership development and community education programming that include capacity building and trainings on planning councils and decision-making bodies. Further allow for language access support and incentives to ensure the active participation of Latinx gay and bisexual men.

In closing, we would like to share some thoughts of one of our fiercest advocates and colleagues:

"My call to our white colleagues in the HIV/AIDS movement is to decide whether you will continue to embrace the exceptionality framework in your individual activism, or would you commit to collective organizing. Would you be able to work in settings where sometimes you would not have the last word, or craft the strategy, pace and tone of projects? Would you be able to learn how to share political imagination, work, and freedom and not be the one in charge? For example, in the work of HIV/AIDS and immigration, I have yet to experience intersectional justice; my grassroots-led work at times feels invisible or is received with less than an open heart. By embracing racial justice, you must learn how to accept discomfort, take risks, and stand side by side with us: leaders of color that work with integrity and have a vision to get things done." - Marco Castro-Bojorquez, Venas Abiertas

Thank you – Fijate Bien Program, MPact
For questions please contact:
Angel C Fabian, MD MNA, Advocacy Coordinator, afabian@mpactglobal.org

Public Comments for PACHA March 9, 2021 by Murray Penner, U.S. Executive Director, Prevention Access Campaign

My name is Murray Penner and I'm the U.S. Executive Director for the Prevention Access Campaign. Today I will briefly discuss meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of the EHE initiative to help meet the goal of ending HIV.

CDC estimates that only 63% of people with HIV in the U.S. are virally suppressed. That means some 400,000 people, many of whom are Black, Brown and of trans experience, aren't able to achieve optimal health because their HIV isn't suppressed. This is unacceptable. The reasons for this vary, but we know when people's lives are supported holistically, viral suppression rates increase. The Ryan White Program is evidence of this as 88% of its clients are virally suppressed. We must endeavor to achieve this outside of Ryan White.

Achieving viral suppression and U=U have tremendous benefits. It not only improves physical health, but it can greatly improve the social and emotional wellbeing of people, reduce HIV stigma, reduce anxiety associated with testing, and help motivate treatment uptake, adherence, and engagement in care. Recent data from the Positive Perspectives 2 study and a South African study back up these benefits.

Goal 2 of the national strategy seeks to improve health-related outcomes of people with HIV. Much work is necessary to improve viral suppression rates in priority populations identified in the plan. An end to HIV can't be accomplished until we end new transmissions in all priority populations, everywhere throughout the U.S.

In a recent series of articles on EHE in The Lancet, the authors suggest several recommendations which I will reiterate as critical for ending HIV in the U.S.

- 1) A national culturally competent effort is needed to raise awareness of the U=U campaign as a promising approach to reduce HIV stigma;
- 2) Health-care professionals need to inform patients about U=U to improve, first and foremost, personal health, as well as public health; and
- 3) Advocates should be equipped to use the so-called public health argument from U=U in advocacy to increase access and remove barriers to quality health care.

We at PAC are doubling down on our efforts to push the U=U public health argument in our advocacy to increase access and remove barriers to quality health care; ensuring that people with HIV have the treatment and support services they need to achieve and maintain an undetectable viral load. This saves lives AND prevents new transmissions.

Lastly, I must mention that people with HIV MUST be at the table (even if it's virtual) in designing EHE plans and implementing programs. People with HIV should also be hired in local jurisdictions as treatment navigators, similar to the PrEP navigators we now regularly see. And as people with HIV are consulted and engaged in these efforts, they must be compensated fairly for their work.

I will include links to the references I've made today in my written testimony, but all point to the need for more knowledge and implementation of U=U as a key strategy to end the epidemic. I urge PACHA to ensure that U=U is a central component of both the national HIV strategy and the EHE initiative.

Thank you again for the opportunity to speak to you today.



# STATEMENT OF THE CENTER FOR HIV LAW AND POLICY TO PACHA ON ENDING THE HIV EPIDEMIC AND ADVANCING RACIAL EQUITY IN HIV CARE AND PREVENTION

I am Jada Hicks, Supervising Attorney at the Center for HIV Law and Policy. I thank you for the opportunity to address PACHA today on strategies that CHLP believes are fundamental to ending the HIV epidemic.

- First, we will never end the epidemic, let alone racial inequities and medical mistrust, until we end irrational, inconsistent government policies on HIV. State and federal authorities continue to endorse investments in HIV prevention, care and harm reduction while tolerating laws that exclude PLHIV from military service and that prosecute people for their health status and consensual sexual relationships.
- Federal agencies such as the CDC should require that state recipients of federal prevention funding certify that their state's policies do not disadvantage PLHIV or allow the sharing of identifiable surveillance or health information with law enforcement authorities.
- Any plan to end the HIV epidemic must commit to ending the use of the criminal law to
  address social and public health challenges. Research shows that behavioral and social
  determinants directly affect health goals and outcomes as well as an individual's risk of
  acquiring HIV. We need explicit federal and state government support for:
  - Decriminalization of sex work
  - o Decriminalization of syringe exchange and addiction
  - Substantially increased investment in in-patient and out-patient drug treatment programs that eliminate waiting lists in many states
- Public health organizations should be leading the charge on HIV decriminalization. A public health issue requires a public health response. Sensationalist media reports (such as the recent reportage of a man living with HIV in Ohio that characterized oral sex as a major risk of HIV transmission justifying his prosecution) should be met immediately by corrective statements from public health authorities on the actual routes, relative risks, and realities of living with HIV.
- Perhaps the most significant common denominator to discriminatory and stigmatizing
  policies is the profound, near-universal lack of sexual health literacy. The problem of
  sexual health ignorance, and the discomfort many providers express with LGBTQ
  patients and discussions about sex, is an unaddressed and serious public health issue.
  Federal prevention funding should prioritize jurisdictions that a) require sexual health
  literacy training in all schools and training programs for direct service health care

- providers; and/or b) require training in sexual health literacy as a condition of licensing for health care professionals. It also is time for a new Surgeon General's letter to the American public on HIV and STIs that states the facts of these epidemics and that promotes universal sexual health literacy.
- Lastly, we cannot continue to operate in a single-issue silo. We cannot address the real causes of the HIV epidemic by making it only about HIV. Decriminalization of HIV as a matter of course must incorporate decriminalization of other infectious diseases, as well as victimless disfavored behavior such as sex work or possession of drugs or syringes. We need to start centering those at risk for HIV who have remained sero-negative in policy discussions about prevention, including PrEP. And we cannot expect people to realistically engage in ending the dual epidemics of HIV and STIs if we do not institutionalize broad sexual health literacy programs across the country. It is time to concretely consider more creative strategies for a truly intersectional approach to all of our work on behalf of those most affected by HIV and most alienated from the systems purportedly created to serve them.

Jada Hicks

Supervising Attorney, Criminal Justice Initiatives

The Center for HIV Law and Policy

March 9, 2021



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March 15, 2021

Re: PWN Public Comment to the Presidential Advisory Council on HIV/AIDS

Positive Women's Network-USA (PWN) appreciates the opportunity to submit a comment to the Presidential advisory Council on HIV/AIDS (PACHA). PWN is the only national organization by and for women and people of transgender experience living with HIV. We have over 3,000 members throughout the U.S., chapters in six states, and a mobilization network in 20 states. PWN's work is grounded in social justice and human rights, and we explicitly apply a racial justice and gender justice lens to address the multifarious barriers people living with HIV face in all aspects of our lives, including economic insecurity, barriers in access to health care, stigma, and more. Our work focuses on building leadership and power among the communities most impacted by the HIV epidemic -- especially transgender women, low-income women living with HIV, and Black and Latinx communities.

In support of our goal to advance policy priorities from women living with HIV, we submitted a <u>comment</u> on the draft HIV National Strategic Plan (HNSP) with detailed concerns and recommendations and previously helped inform and craft the first and second National HIV/AIDS Strategy. Our members and leadership have been members of PACHA, the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (CHAC), the Office of AIDS Research Advisory Council, and played key roles in the implementation of the End the Epidemic plans in local and state jurisdictions.

Collectively, we represent more than estimated 300,000 women and transgender people living with HIV. We appreciate the opportunity to provide both oral and written comments on the two questions PACHA has posed for reflection. In short, our comment can be distilled into three suggestions for the federal domestic response to HIV. The response must center: (1) racial equity; (2) the meaningful involvement of people living with HIV (MIPA); and (3) an understanding that HIV is a symptom of multiple intersecting injustices and oppressions. We will address MIPA and the intersection of injustices and oppressions in our response to the first question and racial equity in our response to the second question.

1. What are the most meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of the Ending the HIV Epidemic initiative at the national level and in your community to meet the goal of ending HIV?

Implementation of both HNSP and the Ending the Epidemics (EHE) initiative will require concrete actions to meaningfully involve people living with HIV and concrete metrics and indicators to evaluate the social and structural determinants of health, including racism. It is critically important that these items are not just an afterthought to the biomedical interventions, which currently are centered in the goals and indicators of both plans. To accomplish this, measurable and meaningful commitments must be made to advance racial equity,

MIPA, and the structural and social determinants of health. Simply reciting that these will be considered is insufficient.

Action must be taken to create metrics and indicators to ensure that people living with HIV are involved in all areas of the national response. It is critically important that people living with HIV are centered in the response in a way that is distinct from other community input. HNSP reduces the concerns of people living with HIV (PLHIV) and the contexts in which we manage our HIV diagnosis largely to treatment adherence and a vaguely discussed notion of stigma. To fully understand not just biomedical interventions, but also include social and structural determinants of health, the people affected by the epidemic must be actively engaged in measurable ways. The federal response must work for us and it is quite literally impossible to end the epidemic without us. PLHIV networks offer a unique engagement opportunity as organizations like PWN build power for PLHIV by speaking in a collective voice and organizing leadership for PLHIV. They should be viewed as essential partners when crafting or changing HIV policy; prevention, care and treatment guidelines; data collection and surveillance practices; the HIV research agenda; in the design of HIV service delivery; and in all aspects of monitoring and evaluation. MIPA requires resources, planning and accountability and we demand that these be included in the plan with commensurate metrics, indicators, strategies, and funding.

Neither HNSP nor EHE mentions sexual and reproductive health for people living with HIV. It is essential that any Implementation Plan ensures quality and non-stigmatizing sexual and reproductive sexual health for people living with HIV. People of all genders and ages living with HIV experience the greatest stigma and discrimination from health care providers when seeking this kind of health care, making its absence from the Implementation Plan especially problematic. For transgender people living with HIV, it is especially important that gender-affirming care is provided and that providers and clinicians are well-versed on our options and rights.

Finally, the implementation of both the HNSP and EHE plans must address the unethical use of molecular HIV surveillance, also known as MHS or cluster detection. PWN, and other PLHIV networks, demand that a moratorium on the use of MHS be put into place. This data should not be collected until consistent state-level data privacy protections and security are put into place, people living with HIV give their informed consent prior to their data being collected, and criminalization concerns are addressed. Without these safeguards, MHS puts already vulnerable people at elevated risk for prosecution and criminalization.

### In sum, we ask that:

- Funding for EHE jurisdictions be contingent on meeting clear, transparent MIPA metrics and indicators
- PLHIV networks are actively engaged and consulted in creating the metrics and indicators for the Implementation Plan
- The Implementation Plan create standing seats on PACHA, CHAC, and other federal advisory bodies for PLHIV network representation
- ONAP be required to have leadership from communities most impacted by the epidemic, including Black gay and bisexual men, Black cisgender women, and transgender women of color
- ONAP must have a process to regularly engage with PLHIV networks

- The implementation plan requires providers to provide sexual and reproductive health care
- The implementation plan requires providers receive ongoing trauma-informed care, racial justice, and trans-sensitivity trainings
- A moratorium on the use of molecular HIV surveillance (MHS)
- MHS policies around state-level data privacy protections and security, informed consent requirements, and criminalization are created at the federal level with the input of PLHIV and their networks
- 2. How can domestic HIV/AIDS programs better meet the needs of underserved communities and address the systemic barriers that communities face in order to achieve the goals of the President's Executive Order Advancing Racial Equity and Support for Underserved Communities?

Racism, especially as it takes shape via anti-Black racism and xenophobia, underpin the devastating history of inequities in the HIV response, and circumscribe a legacy of criminalization and incarceration in the U.S. These interlinked forms of violence disproportionately harm the priority populations identified in the HNSP. High levels of health risks and poor health outcomes are inseparable from the race-driven criminalization and incarceration patterns that disproportionately harm Black and brown communities, as well as those who are transgender, gender nonconforming and non-binary, lesbian, gay and bisexual, immigrant, and sex worker communities, and, increasingly, cisgender women. We ask that:

- The Implementation Plan requires federal, state, and local partners lead the efforts to stop using incarceration to deal with poverty, public health, and mental health conditions
- Key structural interventions are implemented with appropriate tracking metrics including:
  - o Safe and healthy housing for all experiencing homelessness and unstable housing
  - Food and nutrition services
  - o Employment services optimized for communities disproportionately impacted by HIV and the racism-driven parallel of unequal access to quality education and employment
- Invest in, hire, and collaborate with Black leadership in defining priorities for and responses to the domestic HIV epidemic
- Adding sex workers and undocumented immigrants into the implementation plans as distinct constituent groups
- Require ongoing racial justice and trans sensitivity training for all federal employees and all employees at federally-funded programs

By dismantling systems that perpetuate racism and oppression, by upholding human rights and rejecting discrimination, by ensuring that policy recommendations are driven by priorities set by the most impacted communities, and by treating health care as a human right, we could stop the HIV epidemic within our lifetime. We look forward to working with the PACHA to achieve this goal.

### Sincerely,

Venita Ray She/Her Co-Executive Director venita@pwn-usa.org 70th Presidential Advisory Council on HIV/AIDS (PACHA) Full Council Meeting Public Comment Statement

Dwayne Steward, Director of Prevention Equitas Health 1105 Schrock Rd. Columbus, OH 43229 <u>dwaynesteward@equitashealth.com</u> 614-643-6844

Hello, my name is Dwayne Steward, I use he/him pronouns. Thank you to the Presidential Advisory Council on HIV & AIDS for creating this space to speak.

I am the Director of Prevention at Equitas Health, a health system focused on providing a welcoming home to people living with or at risk of HIV, LGBTQ+ people, and anyone wanting a welcoming health care home in Ohio, West Virginia, Kentucky and Texas. I've been a public health advocate and community organizer for 15 years, dedicated to the areas of racial health equity, HIV/STI prevention and research, LGBTQ+ population health and transgender care.

Also, as a black queer-identified male who grew up in the rural Midwest, today I stand in the gap for several underserved communities who are disproportionately impacted by this epidemic.

In Ohio, there are three jurisdictions that have been designated as a part of the Ending the HIV Epidemic Phase 1 rollout, and from my vantage point, the actions that need taken to meet the plan's goals are quite simple. If we end health inequity today, we can end the HIV epidemic tomorrow.

Nationally, average rates of viral suppression have seen increases; however, marginalized communities with historic lack of access to care due to institutionalized oppression in our healthcare systems are not reaching viral suppression at the same rate.

According to 2018 surveillance data in Ohio, 59% of people living with HIV are virally suppressed, however, when broken down by race, 54% of African Americans and 57% of Latinx communities living with HIV are virally suppressed, compared to 64% of white people living with HIV reaching viral suppression. African Americans in Ohio make up 44% of people living with HIV in Ohio, yet are only 14% of the population.

At Equitas Health, we have implemented a patient-centered medical home model that has successfully reached a 91% viral suppression rate among our patients living with HIV. However, even though our viral load suppression rates are much higher than the state and national average for African American (78.2%) and Hispanic (74.12%) communities. These communities still see suppression rates lower than their white counterparts do overall.

The Ryan White program and prescription drug assistance programs help fill some gaps but resource deserts in rural and urban cities, insufficient transportation, homelessness, the criminalization of HIV, ongoing stigma fueled by miseducation, and many other social

determinants of health, keep too many from accessing these services and reaching viral suppression. It all goes back to inequity.

PrEP and affiliated assistance programs have also helped increase impacts on prevention; however, PrEP uptake is still very low among black and Latinx communities. Nationally only one percent of those in the black community, and only 3 percent in Latinx communities, who are eligible actually access PrEP. These numbers are even lower in the Midwest due to lack of education among providers and perceived cost barriers within the community.

Continuing to use the same strategies that we have employed over the last decade will not end this epidemic. Especially as we layer in the devastating effects of the current pandemic. We must ultimately create pathways to enact the policies and the programs we have never done before that we thought were unallowable or impossible.

- Free HIV testing and free condom distribution needs to be integrated into all care models, from large health systems and federally qualified health centers to emergency rooms, recovery centers, syringe services programs, prison healthcare systems, and all reentry programs, just to name a few.
- Prescription drug costs for anti-retroviral medications must be made more affordable. Additionally, medications and health care services must be paired with transportation, childcare, and food voucher assistance, along with other social services that fully address social determinants of health.
- Pre-exposure prophylaxis must be made more affordable and more easily accessible to increase use by low-income communities. Over the counter access and drug assistance programs are just two pathways that should be standardized nationally. PrEP also needs to become a medication that every primary care provider is required to have an understanding in prescribing, much like diabetes or hypertension medication.
- All HIV research studies need to center the inclusion of women, transgender and BIPOC communities from the beginning so that new biomedical interventions reach marginalized communities more immediately once FDA approved. It is often years after a new development is released that it reaches those who need it most.
- Destignatizing HIV early by mandating comprehensive and inclusive sex education in schools and enacting a federal mandate that decriminalizes HIV nationwide. There are still several states where HIV criminalization laws are furthering stigma and keeping those of us on the ground from making radical progress.

These are just a few examples, but as I said earlier, it's quite simple. Radical access for all, in all circumstances, is how we get to the end.

"Poverty is not an accident. Like apartheid and slavery, it is manmade and can be removed from the actions of human beings." Nelson Mandela spoke those important words that still guide my work and the work of many today. The health inequity that fuels HIV transmission and

suppression disparity is also not an accident. It is uplifted daily by the institutional barriers that keep marginalized communities from accessing the care and services they need.

When we live in a world where it's easy for a transgender woman of color who is experiencing a disability, poverty and homelessness, to access care in this country, we will have started to get it right. Because right now, in my work each day, I'm not hearing communities who are experiencing intersecting marginalization tell me that it's easy to access the scientific tools that have brought us to this moment in this epidemic. It's actually quite difficult and sometimes downright impossible.

We have to make the impossible possible and the unrealistic a reality, and dismantling health inequity is how we do it.

Thank you again for your time.

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ACT NOW: END AIDS, March PACHA Meeting Public Comment Submitted electronically 3.16.2021 by Edric Figueroa, anea@treatmentactiongroup.org

Thank you to the Presidential Advisory Council on HIV/AIDS for this opportunity to offer comment on behalf of The ACT NOW: END AIDS (ANEA) Coalition. ANEA is a national coalition of community-based organizations, health departments, and national organizations committed to ending AIDS as an epidemic in the United States. This comment reflects the stances of many of the community-based organizations in ANEA and may not represent the perspectives of our health department partners.

We have linked the public comment ANEA and AIDS United jointly submitted on December 14th, 2020 for the HIV National Strategic Plan below in response to the two questions posed by PACHA—(1) "What are the most meaningful actions that can be taken to implement the HIV National Strategic Plan and improve implementation of the Ending the HIV Epidemic initiative at the national level and in your community to meet the goal of ending HIV? (2) How can domestic HIV/AIDS programs better meet the needs of underserved communities and address the systemic barriers that communities face in order to achieve the goals of the President's Executive Order Advancing Racial Equity and Support for Underserved Communities?"

Our comment highlights several ways both NHAS and the EHE Initiative can remove structural barriers to healthcare for all people living with and vulnerable to HIV– intentionally centering Black, Indigenous, Latinx, and other people of color (BILPOC)– and can be summarized into the following seven key suggestions:

- 1. Meaningfully involve people living with and vulnerable to HIV across all NHAS/EHE leadership sectors.
- 2. Explicitly call out systemic racism in the healthcare sector, and provide concrete strategies to advance racial equity and diversity across the HIV sector.
- 3. Place a much greater emphasis on the needs of older people living with HIV and long-term survivors.
- 4. Provide considerably more resources and focus on the needs of people who use drugs.
- 5. Prioritize the provision of care and allocation of resources to people who engage in sex work.
- 6. Foster collaborations with HUD and create federal housing programs and safety nets that recognize Housing as Healthcare.
- 7. Immediately address the negative impacts of HIV Criminalization.

### Read the full ANEA/AIDS United HIV National Strategic Plan public comment here.

With the recent increase in violence against Asian and Pacific Islander immigrants, it's imperative to explicitly include all people regardless of migration status in public health efforts. We have yet to see a direct commitment to the health of undocumented communities in NHAS or the EHE initiative that acknowledges the present barriers to accessing HIV prevention, care, and treatment services faced by undocumented community members. While the Biden-Harris administration rescinded the Trump-era public charge rule, many immigrants are still wary to access public health services due to the fear imposed by harsh immigration enforcement practices.

Additionally, as several states move to modernize their HIV criminalization laws, federal guidance is needed to assure these legislative changes protect the communities of people living with HIV who experience higher rates of incarceration (BlLPOC and LGBTQ communities). While reducing HIV felony transmission charges to misdemeanors, removing the stigmatizing language, and explicitly defining intent to transmit are steps in the right direction to modernize these laws, this does not go far enough. As long as some version of HIV criminalization laws exists, so will the deterrents to HIV testing, treatment, and care for BlLPOC, sex-workers, people who use drugs, and migrant communities. These laws also form the basis for the mistrust community members have for advancements in molecular HIV surveillance (MHS) and recency testing; until we have a great resolution on criminalization more broadly, ANEA members are advocating for MHS to be deprioritized and removed as a pillar of the EHE response.

It is further urged that the EHE dollars allocated for disruptively innovative partnerships go directly to diverse organizations with demonstrated leadership in the communities they serve. These partnerships are pivotal to reaching communities often neglected by jurisdictional health department efforts; it would further impede EHE/NHAS progress if new collaborations are not actualized. To immediately improve the implementation of EHE, remove any barriers in the funding requirements from health departments to community organizations that would disqualify culturally relevant, community-specific, and under-resourced organizations from applying. To that end, a Community Engagement pillar in the EHE Initiative could foster further jurisdictional accountability to the communities most impacted by HIV.

Such a pillar could ensure that a human-rights approach is centered throughout the bio-medical solutions offered in the Diagnose, Treat, Prevent, and Respond EHE pillars. The detrimental impacts of the COVID-19 pandemic have further isolated and burden community-based organizations and health departments alike while highlighting the severity of racial injustice across public health. A Community Engagement pillar would foster further connections between key leaders and health departments in jurisdictions and build or restore trust in the ambitious EHE goals across diverse communities.

Lastly, the latest COVID-19 relief bill introduced federal funds to bolster syringe services and harm reduction programs across the nation. While this support for harm reduction programs was greatly appreciated, it is imperative that the Biden administration works with Congress to ensure that the ban on federal funding for sterile syringes and other materials is fully lifted. EHE must build upon this landmark commitment to ending HIV and the overdose epidemic in this nation with further research, financial, and community investments in the health of people who use drugs.

We look forward to discussing these topics further with members of PACHA in the future.

Sincerely,

The ACT NOW: END AIDS Coalition anea@treatmentactiongroup.org



### March 16, 2021

### Re: HNP Public Comment on the Presidential Advisory Council on HIV/AIDS

The Health Not Prisons Collective (HNP) appreciates the opportunity to submit a comment to the Presidential Advisory Council on HIV/AIDS (PACHA). HNP is a group of five national organizations: The Counter Narrative Project (CNP), The Positive Women's Network, The United States People living with HIV Caucus, The Transgender Law Center, and The Sero Project that have come together to tackle the issue of HIV decriminalization on a national scale. Through the meaningful engagement of people living with HIV, we have been able to move HIV legislation in several states, engage leaders of the community in decriminalization work and activate our base nationwide around the connections between the HIV movement and strategies to end the carceral response to public health.

HNP was founded with the central tenet that criminalization is not only a bad public health policy, but that it also stands in direct opposition to public health goals. Interactions with the criminal justice system can be especially dangerous for marginalized communities - causing risk of loss of employment, income, parental rights, isolation, dehumanization and interruptions in health care - and too frequently, even death at the hands of the state. Mass incarceration disrupts communities and families. We believe that an effective national strategy on HIV would be guided by the same principle that carcerality does a grave disservice to our public health strategies. Beyond ending the future criminalization of people, it is critical for a national strategic plan to consider the harms being continually inflicted through current criminalization and incarceration of people living with HIV.

HNP contends that the most meaningful actions that can be taken to implement the HIV National Strategic Plan (HNSP) and improve implementation of the Ending the HIV Epidemic initiative (EHE) at the national level and in your community to meet the goal of ending HIV are to: (1) elevate the focus on racial equity in the HIV response; (2) end the practices of HIV criminalization; (3) declare an immediate moratorium on molecular HIV surveillance; (4) protect the rights of sex workers, who are at disproportionate risk of criminalization, and; (5) consider criminalization as a priority in EHE funding strategies.

### I I. Elevate a Racial Justice Focus in the Federal HIV Response

When we walk about racial justice, we are talking about liberation through addressing the conditions that race - and racism in the US - has wrought on communities of color. Racism, especially as it takes shape via anti-Black racism and xenophobia, underpin the devastating history of inequities in the HIV response, and circumscribe a legacy of criminalization and incarceration in the U.S. These interlinked forms of violence disproportionately harm the priority populations identified in the HNSP. High levels of health risks and poor health outcomes are inseparable from the race-driven criminalization and incarceration patterns that disproportionately harm Black and brown communities, as well as those who are transgender, gender nonconforming and non-binary, lesbian, gay and bisexual, immigrant, and sex worker communities, and, increasingly, cisgender women. The HNSP and EHE efforts must take a leadership role in ending the use of incarceration to deal with poverty, public and mental health conditions, because incarceration only exacerbates the problem.

### We recommend:

- Staffing in the Office of National AIDS Policy must include people openly living with HIV from the communities most impacted by the epidemic, including Black gay and bisexual men, Black cisgender women, and transgender women of color.
- Conduct ongoing and consistent community engagement strategies with Black gay and bisexual men, Black cisgender women, and transgender women of color through the Office of National AIDS Policy.
- Directly address in HNSP, EHE and other federal strategies institutionalized stigma and racism and prioritize policies that will decouple criminalization and incarceration from a public health response.

### **II. End HIV Criminalization**

Criminalization of HIV occurs even outside the targeted laws that make engaging in consensual sexual acts with a positive status illegal. HNSP can rectify the lack of attention paid to underrepresented and marginalized communities by addressing enacted, internalized, interpersonal, community, and institutional stigma associated with HIV criminalization laws.

In terms of criminalization, this stigma can and does result in the inequitable application of punitive laws. Law enforcement practices target communities disproportionately impacted by HIV, including people of trans and gender nonconforming experience, sex workers, people who use drugs, immigrants, people who are unstably housed, people with mental illness, and communities of color.

While we appreciate that there is an indicator designed to address stigma, we are unclear what the baseline survey from 2018 references and it is unfortunate that the Global Stigma Index has not been referenced in HNSP. HIV stigma comes in many forms. HIV criminalization is one form of institutionalized stigma, and the language on HIV criminalization as a problem must be strengthened. HSNP makes a mistake in relegating the harms of HIV criminalization as

stemming solely from HIV-specific criminal laws. People living with HIV are routinely prosecuted for "HIV crimes" under general criminal and public health statutes as well as under provisions of the Uniform Code of Military Justice that do not even mention HIV. Moreover, the phenomenon harms all people living with HIV as well as HIV prevention efforts; it is not a problem affecting only those prosecuted.

### We recommend:

- The HSNP must formalize its stance against criminalization. Guidance should be issued for each federal, state, and local advisory and decision-making body with purview over HIV, and prioritize decriminalization as a necessary measure to achieve positive public health outcomes.
- Indicators must be created that measure stigma and the disproportionate barriers to treatment and prevention that HIV criminalization laws have created. These indicators must then be used to create strategies to directly address the specific harms of criminalization.

### III. Molecular HIV Surveillance

An immediate moratorium of the practice of molecular HIV surveillance should be a top priority for any administration that hopes to bring an end to the HIV epidemic and the disproportionate negative impacts it has on vulnerable populations. The practices of molecular HIV surveillance, cluster detection, and sequencing of HIV genomes without consent from the individuals involved have come under immense scrutiny in recent years and as networks representing people living with HIV we strongly oppose these practices for several reasons. Because it is conducted without knowledge or consent, molecular HIV surveillance undermines trust in the public health system and in individual healthcare providers and clinicians and can reduce willingness to engage in HIV care and treatment.

Communities heavily burdened by HIV are also those with deep distrust of the medical system, for justifiable reasons. The risk of having personal health data taken without consent, then having it sequenced and shared, also without consent, can present a deterrent to people even wanting to access HIV screening and testing. Laws protecting the privacy of this data and permitting sharing and use of molecular HIV data vary widely from state to state and there is no current national standard that would uniformly protect misuse of this data for people living with HIV.

As acknowledged in HNSP, over 30 states have laws criminalizing people living with HIV1. The practice of molecular HIV surveillance, cluster detection, and corresponding public health investigations create vulnerabilities for inadvertent disclosure, stigma, risks to physical safety, employment, and housing, and even criminal liability for people living with HIV.

### We recommend:

- Molecular HIV surveillance and cluster detection practices must be stopped immediately and have no place in a national HIV plan.
- The process of sharing of HIV data is a sensitive issue and must be thoughtfully considered in real, meaningful partnership with networks of people living with HIV, before it is implemented.

1 "HIV and STD Criminalization Laws." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, 21 Dec. 2020, www.cdc.gov/hiv/policies/law/states/exposure.html.

### IV. Include and Prioritize Sex Workers in a Federal Response

The HNSP must uphold sex worker rights and ensure that sex workers are meaningfully engaged in HIV prevention and care activities. Sex workers are at elevated risk for community violence and service delivery settings often marginalize sex workers. Sex work is labor and deserves the same legal protections that other forms of labor are afforded.

The attempts to criminalize sex work reflect a desire to impose morality onto people who are using bodily autonomy for economic gain. This type of carceral imposition of moral codes is illegitimate and only achieves stigmatization, harm and isolation for sex workers. Increasing these things leads to worse health outcomes and disincentives treatment and prevention. HNSP should assure that competent and non-stigmatizing HIV services are provided to sex workers and that sex workers can participate in HIV services without fear of judgment, criminalization, or confidentiality violations. Sex workers should be meaningfully engaged as partners in designing and implementing HIV prevention and care policies and programs.

Often times in an attempt to protect people from the dangers of sex trafficking, harm is done to sex workers through criminalization. To be clear, sex trafficking victims deserve community care and strong legal protections. But sex workers are those who participate in sexual exchanges and are of legal age and have fully consented. They are often caught in the crossfire of the justice system as it attempts to protect people with broad strokes of laws and regulations. Where sex work is decriminalized, sex workers can participate in policy tables freely, partner with law enforcement if they choose, and are subject matter experts in differentiating between consensual sex work and the harms of sexualized violence. In order to create safe environments in which sex workers feel safe to seek affirming and respectful health care, they must be seen, valued and engaged with as experts.

### We Recommend:

- Sex workers, particularly those of transgender experience, should be engaged with as key stakeholders. This engagement should be meaningful, regular and formalized.
- Similarly, sex workers are a part of the population that is most impacted by the epidemic, and therefore should be prioritized as staff positions are created and filled.

### V. Inclusion of HIV Criminalization in the EHE

Local and state EHE plans must include a focus on HIV decriminalization. Funding for EHE plans should be contingent on meaningful community engagement and a commitment to end this form of institutionalized stigma which impedes HIV prevention and care efforts. It is also critical that the national strategic plan on HIV prioritizes decriminalization as adjustments are made to EHE plans.

In order to address the disparate HIV outcomes for communities of color, those of trans experience, sex workers and drug users, the conversation must center decriminalization. The ever-present threat of criminalization and how it is weaponized against vulnerable populations has manifested in the unequal access to prevention and treatment of HIV that this federal strategy aims to address. As funding strategies are created, they should give favor to jurisdictions applying a racial and gender justice lens, and those working explicitly to address criminalization.

Bringing an end to criminalization will bring better health outcomes for many populations that have been gravely impacted by the HIV epidemic. As science advances and the understanding of the negative correlation between criminalization and public health becomes more evident, it is only right that the federal government corrects public policy mistakes that were made previously out of fear and lack of information. The largest beneficial impact that the federal government could make would be to put the weight and power of its funding scheme behind plans that aim to end criminalization of HIV.

### We recommend:

- The HSNP makes formal the consideration of decriminalization as favorable in the consideration of EHE funding.
- EHE plans must be required to demonstrate their commitment to creating a favorable human rights environment for people diagnosed with HIV by including concrete efforts and commitments to decriminalize HIV exposure, transmission, and/or non-disclosure including sentence enhancements predicated on HIV-positive status.

Thank you to PACHA for the opportunity to provide written comment. We look forward to continued opportunities to meaningfully engage people living with HIV in the direction of the federal response to the HIV epidemic. We hope that these concerns about the role of criminalization in the public health response will be taken seriously.

Signed,

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Ronald Johnson, He/Him Chair United States People living with HIV Caucus

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### PACHA Resolution on Ensuring Equity and Justice in Ending the HIV Epidemic

Whereas, Ending the HIV Epidemic: A Plan for America has the ambitious goal of ending the HIV epidemic in the United States by the year 2030;

**Whereas,** the *HIV National Strategic Plan: A Roadmap to End the Epidemic for the United States 2021-2025* outlines a coordinated plan for federal and nonfederal stakeholders to accelerate progress towards ending the *HIV* epidemic in the United States;

**Whereas**, President Biden has issued a Presidential Executive Order on January 20, 2021 entitled, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, and a statement from the National Institutes of Health (NIH) against structural racism in biomedical research was issued on March 1, 2021;

Whereas, bringing about an equitable end to the HIV epidemic in the United States, and ensuring, once achieved, this result is durable for all will require commitment to a bold, equitable, just, whole-of-government and society response that prioritizes the communities that have been the most impacted by HIV, namely Black, Latinx, American Indian/Alaska Native, Asian American and Pacific Islander, and other communities of color (BIPOC). Within these communities, the needs of transgender people, cisgender women, youth, seniors, persons who use drugs, and gay, bisexual, and other men who have sex with men must be prioritized and adequately addressed in the response to HIV;

Whereas, ensuring that prioritized communities have equitable access to high quality and efficacious HIV prevention, treatment, and care services is essential to ending the HIV epidemic, and securing adequate financial and human capital resources from the Federal government is a vital component in improving access;

Whereas, ensuring justice in our HIV response requires that data and evaluation on progress towards ending the HIV epidemic, including measuring progress on addressing social determinants of health in the HIV response, the mitigation of HIV-related stigma and health inequities is collected and reported;

Whereas, these data collection efforts should be co-designed with and have leadership from prioritized communities as to not further harm the very communities that experience historical and contemporary structural racism and health inequities;

Whereas, Pre-Exposure Prophylaxis (PrEP) is a key tool for ending the HIV epidemic, and PrEP uptake among Black, Latinoand American Indian/Alaska Native gay/bisexual and other men who have sex with men and cisgender and transgender women continues to lag due to insurance and financial barriers around coverage of PrEP and PrEP-associated laboratory costs that are not covered through existing programs that provide free PrEP medications or due to other PrEP access issues;

Whereas, ending the HIV epidemic requires leadership from the communities that are most impacted by HIV, including the leadership of people living with HIV;

Whereas, ending the HIV epidemic requires supporting and funding community-based organizations and the Indian Health Service (IHS) led and staffed by members of the communities most impacted by HIV,

### Be it resolved that:

- The White House Office of National AIDS Policy (ONAP) be reestablished and staffed with a diverse group of people, including those living with HIV, and BIPOC, women, LGBTQ+, and persons with a history of drug use;
- Additional PACHA members be appointed who fully represent the communities most impacted by HIV, including people living with HIV who are also transgender, BIPOC, seniors, youth, persons using injection drugs, and women;
- In accordance with the Presidential Executive order on Advancing Racial equity that HIV data be
  collected at a more granular level so that data can be disaggregated by ethnicity within races, by
  inclusive gender identities, by disability type, by primary language spoken, and other
  demographics to better understand disparities, address racial misclassification, focus resources
  and interventions, and understand service reach and health outcomes;
- Work with tribal nations and tribal epidemiology centers to better collect, analyze, and report
  data on American Indians and Alaska Natives and to decolonize the data, and adequately fund
  the IHS and community-based organizations serving American Indians and Alaska Natives for
  their HIV work;
- Performance and outcome measures be monitored at the granular levels noted above, and
  assess whether or not the epidemic is being ended in an equitable manner for all, and if it is not,
  adjust resources and approaches to end the injustice of the disparities;
- Federal funding and technical assistance for EHE should be increased, including the Minority
  AIDS Initiative, and prioritized for community-based organizations and the IHS system that are
  led by and staffed by members of the communities most impacted by HIV and have
  demonstrated trustworthiness and a proven track record of successful service delivery within
  these communities, and hold states accountable for distributing federal resources in this
  manner;
- Once supported via funding and technical assistance, community-based organizations should report data related to their activities in concert with the granular requirements outlined above and be held accountable for their outcomes toward achieving the End of the Epidemic goals;
- The HIV National Strategic Plan be fully funded and implemented, with focused attention and resources devoted to the components of the plan that address the social determinants of health, syndemics (e.g. STIs, hepatitis, substance use, mental health), and stigma, while leveraging and coordinating with the resources and programs of other parts of the federal government;
- Regulations, policies, and procedures that were modified to increase access during the COVID-19 emergency and which are showing positive results, such as allowing payment for telemedicine and allowing home HIV/STI testing for eligibility and follow-up care, be continued after the pandemic;

- Federal funding be directed toward ensuring broadband infrastructure and access nation-wide, with an emphasis on rural and frontier communities in all jurisdictions and other underserved communities;
- Eliminate administrative barriers to eligibility and recertification process for services that could be creating and perpetuating systemic racism;
- Review and modify algorithmsfor PrEP eligibility and treatment services that factor in social determinants of health to increase access to prevention and treatment services for BIPOC persons, persons living with disabilities, transgender persons, and others at increased risk for HIV;
- New HIV medical and service providers who are representative of the communities most impacted by HIV be awarded contracts, organizational development, and capacity-building assistance through dedicated Request for Proposal (RFP) processes supported by Federal agencies;
- Payer barriers to HIV treatment and PrEP be reduced, and ensure ancillary PrEP services are covered with no cost-sharing; and
- Additional incentives be examined to encourage states that have not expanded Medicaid to do so.