

**Presidential Advisory Council on HIV/AIDS (PACHA)
65th Meeting**

**Miami Marriott Biscayne Bay
Miami, FL
October 21–22, 2019**

Council Members—Present

Carl Schmid, M.B.A., Co-Chair
John Wiesman, Dr.P.H., M.P.H., Co-Chair
Gregg H. Alton, J.D.
Wendy Holman
Marc Meachem, M.B.A.
Rafaelé Roberto Narváez
Michael Saag, M.D.
John Sapero
Robert A. Schwartz, M.D., M.P.H., D.Sc. (Hon.)
Justin C. Smith, M.S., M.P.H.
Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC (*day one*)

Staff

B. Kaye Hayes, M.P.A., PACHA Executive Director, Designated Federal Officer; Principal Deputy 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., Public Health Analyst and PACHA Committee Manager, OIDP, OASH, HHS

Federal Partners

Tammy R. Beckham, D.V.M., Ph.D., Director, OIDP, OASH, HHS
John T. Brooks, M.D., Medical Epidemiologist, Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC) (*day two*)
Laura Cheever, M.D., Sc.M., Associate Administrator, HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)
Antigone Dempsey, M.Ed., Director, Division of Policy and Data, HIV/AIDS Bureau, HRSA (*day two*)
Neeraj Gandotra, M.D., Chief Medical Officer, Substance Abuse and Mental Health Services Administration (SAMHSA)
ADM Brett P. Giroir, M.D., U.S. Public Health Service (USPHS), Assistant Secretary for Health (ASH), HHS (*day one*)
Maureen M. Goodenow, Ph.D., Associate Director, AIDS Research, Director, Office of AIDS Research (OAR), National Institutes for Health (NIH)

Norma Harris, M.S.P.H., Ph.D., Senior Advisor, Strategic Indicators, Division of HIV/AIDS Prevention, NCHHSTP, CDC
Rick Haverkate, M.P.H., National HIV/AIDS & Hepatitis C Program Coordinator, Indian Health Service (IHS)
Rita Harcrow, Director, Office of HIV/AIDS Housing, U.S. Department of Housing and Urban Development (HUD)
Eugene McCray, M.D., Director, Division of HIV/AIDS Prevention, NCHHSTP, CDC
Harold J. Philips, Senior HIV Advisor and Chief Operating Officer, *Ending the HIV Epidemic: A Plan for America*, OASH, HHS
Sharon L. Ricks, M.A., Regional Health Administrator, Region IV, HHS
Crystal Simpson, M.D., Medical Officer, Office of Medicare, Centers for Medicare and Medicaid Services (CMS), HHS
April Smith-Hirak, Ph.D., Regional Health Administrator, Region II, HHS
Judith Steinberg, M.D., M.P.H., Chief Medical Officer, Bureau of Primary Health Care, HRSA
(day two)

Presenters

Tammy R. Beckham, D.V.M., Ph.D., Director, ODP, OASH, HHS
Guillermo Chacón, President, Latino Commission on AIDS
Laura Cheever, M.D., Sc.M., Associate Administrator, HIV/AIDS Bureau, HRSA
Sandra Miranda De León, M.P.H., HIV Surveillance Director, Puerto Rico Department of Health
Neeraj Gandotra, M.D., Chief Medical Officer, SAMHSA
ADM Brett P. Giroir, M.D., USPHS, ASH, HHS
Maureen M. Goodenow, Ph.D., Associate Director, AIDS Research, Director, OAR, NIH
Norma Harris, M.S.P.H., Ph.D., Senior Advisor, Strategic Indicators, Division of HIV/AIDS Prevention, NCHHSTP, CDC
Rick Haverkate, M.P.H., National HIV/AIDS & Hepatitis C Program Coordinator, IHS
Geraldo Acosta Hernandez, M.D., Patient
José Javier, Capacity Building Assistance Specialist, Latino Commission on AIDS; Program Consultant, Midland Cares, Inc.
Eugene McCray, M.D., Director, Division of HIV/AIDS Prevention, NCHHSTP, CDC
Iván Meléndez-Rivera, M.D., FAAFP, Chief Medical and Operating Officer, Centro Ararat
Scott A. Rivkees, M.D., Secretary and Surgeon General, Florida Department of Health
Vivian Tamayo-Agrait, M.D., Medical Director, Puerto Rico Community Network for Clinical Services, Research and Health Advancement (PRCoNCRA)
Janelle Taveras Ph.D., M.P.H., LGBT HealthLink Project Administrator, CenterLink
Hansel Tookes, M.D., M.P.H., Assistant Professor of Clinical Medicine, Division of Infectious Diseases, University of Miami Miller School of Medicine
Paul Carl Velez, M.S., President and Chief Executive Officer, Borinquen Medical Centers
CAPT Samuel Wu, Pharm.D., Public Health Advisor, Office of Minority Health (OMH), HHS

Day One

Welcome and Remarks from the Co-Chairs

John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chair, called the meeting to order at 1:30 p.m. (This meeting was broadcast live online; the recorded broadcast is available [online](#). Spanish translation was also available in real time.) PACHA advises the HHS Secretary through the ASH. Meeting outside of Washington, D.C., is one way by which PACHA members learn about the communities served and make meetings more accessible for those communities. A focus of this meeting is the impact of HIV on the Latinx community, particularly in Florida and Puerto Rico. Before the meeting, PACHA members toured Care Resource—a nonprofit organization and a Federally Qualified Health Center (FQHC) that provides comprehensive health and support services to pediatric, adolescent, and adult populations—and Latinos Salud, which provides client-centered, culturally competent health education and integrated preventive, screening, and linkage services throughout South Florida.

(Note: The terms “Latinx” and “Hispanic” are used in this report according to speaker preference or in correspondence with data sources cited.)

Dr. Wiesman outlined the agenda for the meeting. He thanked all those involved in organizing the meeting, particularly PACHA member Rafaelé Roberto Narváez of Florida, who was instrumental in setting up the site visits and identifying local presenters.

Carl Schmid, M.B.A., PACHA Co-Chair, thanked the Federal partners for their hard work on *Ending the HIV Epidemic: A Plan for America*. In an effort to broaden the perspectives of people at the table, PACHA has added Federal partners from HUD and CMS to its roster. Mr. Schmid noted that the U.S. House of Representatives approved the budget for *Ending the HIV Epidemic: A Plan for America* in July; the Senate has introduced a funding bill, but funding has not been approved. The current HHS budget relies on a continuing resolution.

Roll Call

PACHA Executive Director B. Kaye Hayes, M.P.A., called the roll.

Welcome

ADM Brett P. Giroir, M.D., USPHS, ASH, HHS

ADM Giroir congratulated Dr. Wiesman, who was recognized by the Association of State and Territorial Health Officials for outstanding work in Washington State. He also noted that Dr. Wiesman and Mr. Schmid were named to the Scientific Advisory Board of the President’s Emergency Plan for AIDS Relief (PEPFAR). ADM Giroir thanked Tammy R. Beckham, D.V.M., Ph.D., and Ms. Hayes for overseeing the restructuring within HHS to create OI DP.

ADM Giroir expressed confidence that circumstances have converged to make this the right time for *Ending the HIV Epidemic: A Plan for America*, which has the full support of the President and the HHS Secretary. He reiterated the basic principles of *Ending the HIV Epidemic: A Plan for America*. HHS has put out notices of funding opportunities in anticipation of funding; if

funding is not approved, implementation will be delayed. Since the initiative was announced in February, the heads of the agencies involved have visited nearly all the jurisdictions targeted in phase 1 to gather critical input from the communities affected, identifying the following themes:

- Access to testing, prevention, and treatment is an issue everywhere.
- Innovation is needed to spur change in hard-to-reach communities.
- Stigma, “the enemy of public health,” is pervasive and must be mitigated.
- Coordination of care requires person-centered care and integration of HIV care into primary care.
- Effective communication is vital to improve care.
- Social determinants of health (e.g., lack of transportation or stable housing and presence of laws that criminalize HIV) must be addressed.
- Resources are needed to bolster the HIV workforce, including community-based organizations (CBOs), community health workers, and navigators.
- CBOs and faith-based organizations can play a significant role in addressing HIV.

Leaders from each of the key agencies implementing *Ending the HIV Epidemic: A Plan for America* form an operations leadership team, and a chief operating officer, Harold J. Phillips, focuses solely on coordinating the initiative. HHS is still finalizing indicators to assess progress; a dashboard will be publicly available that provides data at least quarterly on new diagnoses, linkages to HIV medical care within 30 days of diagnosis, percentage of people with HIV (PWH) who are virally suppressed, and percentage of people with indications who are prescribed pre-exposure prophylaxis (PrEP). ADM Giroir emphasized that if *Ending the HIV Epidemic: A Plan for America* is successful, the number of diagnoses will increase in the first few years.

HHS has directed \$33 million from the Minority HIV/AIDS Fund to support planning. Gilead Sciences pledged to donate PrEP medication to uninsured people at high risk (for up to 200,000 people over 11 years). ADM Giroir stressed that Gilead will receive no HHS funding for its role as a distributing partner, and HHS still must create a mechanism to reach those eligible.

In June, HHS provided grants to jumpstart HIV efforts in Dekalb County, GA; Baltimore City, MD; and East Baton Rouge, LA. In addition, HHS initiated a pilot program in the Cherokee Nation in Oklahoma. Lessons learned from these early initiatives will inform *Ending the HIV Epidemic: A Plan for America*. HHS has already awarded funding to raise awareness about PrEP. It provided \$12 million to local health departments to create community health plans that represent their unique needs. HHS is leveraging the Prevention through Active Community Engagement program to assign three USPHS officers to act as liaisons in key regions.

Finally, HHS seeks to tackle all of the components that influence the HIV epidemic, including substance use disorders (SUDs)—especially opioid use—and sexually transmitted infections (STIs). It is revising the National Viral Hepatitis Action Plan and creating the first Federal action plan for combating STIs. Among the biggest challenges is building bridges across programs to allow a holistic approach.

HIV and the Latinx Community

Guillermo Chacón, President, Latino Commission on AIDS

The Latino Commission on AIDS seeks to raise awareness about the HIV epidemic among Hispanics and the barriers to care. Mr. Chacón was pleased that CDC, SAMHSA, HRSA, and others have recognized that U.S.-born Hispanics face different barriers to health care than foreign-born Hispanics. Many Latinx people are unaware of their HIV status. Testing poses a significant challenge. Offering testing at night and on weekends would help reach more people. The HIV workforce must increase the number of transgender people—in full-time positions that offer health care benefits—to improve integration, service, and training. More efforts should be made to understand the diversity of people of Central and South American descent and to integrate them into HIV services and the workforce. Despite the availability of PrEP, many Latinxs and other minorities are not enrolled in PrEP programs.

Mr. Chacón described strategies undertaken by the Latino Commission on AIDS, many focusing on creating safe spaces for Latinx people to seek care and tapping into their social networks to promote testing and health care. Engaging religious leaders has been very successful and has helped mitigate stigma. The Commission is collaborating with various organizations to build capacity, raise awareness, and combat stigma. It is working closely with CDC and other Federal partners to organize a national Hispanic/Latinx health leadership summit in 2020.

Discussion

Mr. Chacón urged Federal partners to engage communities in designing the planning process in the jurisdictions targeted by *Ending the HIV Epidemic: A Plan for America*. State-level partners should address the need for campaigns against stigma in counties and cities. Nontraditional partners in the medical community (e.g., the National Medical Association and Black and Latino medical associations) should be encouraged to share their perspectives and to learn more about prescribing PrEP. Ethnic traditional and social media can spread the word about the need for HIV testing.

Eugene McCray, M.D., said treatment as prevention and the science behind the finding that people with an undetectable viral load cannot transmit HIV (i.e., U=U) are important components of *Ending the HIV Epidemic: A Plan for America* and national programs, but grantees are encouraged to use whatever language they deem appropriate to communicate these concepts to their communities. Laura Cheever, M.D., Sc.M., noted that U=U is not always clear to clients. Maureen M. Goodenow, Ph.D., noted that NIH is updating its guidance to include the latest data on treatment as prevention. ADM Giroir pointed out that the HHS Secretary mentions these important tenets of prevention in every talk, and the agency embraces PrEP and other prevention techniques in its policies.

Ending the HIV Epidemic: A Plan for America: Florida and Puerto Rico

Epidemiology of HIV in Florida and the State's Efforts to Address the HIV Epidemic

Scott A. Rivkees, M.D., Secretary and Surgeon General, Florida Department of Health

Dr. Rivkees described the demographics of the HIV epidemic in Florida, highlighting, for example, that the rate of new diagnoses is about twice the national rate and that diagnoses have been increasing since 2013. The State fully embraces the goals and tenets of *Ending the HIV Epidemic: A Plan for America*. To improve detection, it is working to expand HIV testing in emergency departments and referral to local providers. It also is piloting home testing kits.

It is estimated that more than 30,000 people diagnosed with HIV are not in care. To reengage them, the State seeks to identify and address social determinants of health, increase the number of patient navigators, provide clinicians with training in cultural competence, use telehealth mechanisms, and educate more people about U=U.

Only about 20 percent of people eligible for PrEP are taking it. Employing mobile health care units and telehealth technology, educating providers, and informing individuals have been key to increasing uptake. Since 2016, Florida has promoted rapid entry to care for those diagnosed with HIV, which cuts the average time to start HIV treatment and the time to viral suppression. Florida uses molecular surveillance to inform communities about outbreaks and to guide therapy. Syringe service programs provide clean needles and help link people to care. Dr. Rivkees said Florida hopes to build on these and other approaches in place.

Discussion

Asked about barriers to PrEP uptake (which is covered by Medicaid in Florida), Dr. Rivkees explained that individuals need more information about PrEP. The State must minimize stigma, increase access, and reach people where they are through community partners. It was noted that molecular surveillance increases the perception that there are pockets of HIV and raises concerns about criminalization of HIV; at the same time, it helps identify clusters of PWH, which helps guide treatment efforts. Patient confidentiality must be protected, said Dr. Rivkees. He added that communities and organizations can share best practices among themselves and learn from each other. The State is holding workshops to educate communities on how to expand syringe service programs and use mobile health clinics.

Epidemiology of HIV in Puerto Rico and the Territory's Efforts to Address HIV

Sandra Miranda De León, M.P.H., HIV Surveillance Director, Puerto Rico Department of Health

The HIV epidemic in Puerto Rico is different than in the United States, said Ms. De León, and the demographics have shifted significantly over time. Puerto Rico has high rates of retention in care and viral suppression. In 2017, the Territory implemented a 5-year multistakeholder collaborative plan to address HIV using an integrated approach, resulting in a more coordinated response. Prevention services are offered across the Territory by organizations that serve the general population and people at high risk. The Ryan White HIV/AIDS Program in Puerto Rico offers services through a provider network of regional clinics, clinical centers, and CBOs.

Puerto Rico is aligning its 5-year plan with the goals and tenets of the *Ending the HIV Epidemic: A Plan for America*. From 2016 to 2017, Puerto Rico had 979 new HIV diagnoses; to reduce new infections by 75 percent within 5 years and 90 percent within 10 years, the number of new diagnoses in Puerto Rico would have to decrease to 110 or fewer by 2025 and 44 or fewer by 2030. Puerto Rico faces several major challenges to achieving these goals:

- Only two or three providers offer PrEP, and there is little coverage for PrEP prescriptions.
- Electronic laboratory reporting of nucleotide sequences by private laboratories has yet to be fully implemented.
- Ryan White Program personnel cannot contact those newly diagnosed with HIV without a signed consent form.
- It is difficult to reach PWH who received care outside of health departments and who are now out of care.

To address some of these challenges, Puerto Rico will focus on tracing named partners of PWH, offering partner services and links to care for those newly diagnosed in private treatment settings, providing navigation services for those newly diagnosed or out of care, and prioritizing navigation for those most likely to transmit the infection.

Discussion

Ms. De León stated that Puerto Rico lost much of its workforce and patients when many people left the island after Hurricane Maria, although some are now returning. The destruction of infrastructure and loss of workforce hampered laboratories' efforts to implement electronic reporting.

Territory law on contacting PWH must be updated to reflect current needs, and efforts are underway to do so, said Ms. De León. She added that Puerto Rico began a medical monitoring project to identify PWH who are out of care, including those who have left the island.

Panel Discussion: Addressing the Unique Needs in Florida

Facilitator: Rafaelé Roberto Narváez, PACHA Member

José Javier, Capacity Building Assistance Specialist, Latino Commission on AIDS; Program Consultant, Midland Cares, Inc.

Mr. Javier pointed out that CBOs and FQHCs rarely have the time or resources to conduct community assessment to understand how to get more people on PrEP or the community impact of PrEP. Not only do individuals need to know that PrEP is available, they also need to know how and where to get it and how to stay on it. Organizations should create staff positions dedicated to helping people stay on PrEP for as long as they are at risk. More funding is needed specifically for STI screening and the attendant laboratory costs.

Mr. Javier called for grant funding language that requires health care providers to receive cultural competency training. Stigma against PWH and access to PrEP also must be addressed. Mr. Javier said that to implement *Ending the HIV Epidemic: A Plan for America* next year,

Florida's epidemic and its readiness for change must be assessed; key partners must be included in that assessment.

Janelle Taveras Ph.D., M.P.H., LGBT HealthLink Project Administrator, CenterLink

Dr. Taveras acknowledged the long career and many accomplishments of Ron Henderson, who was Florida's Minority AIDS Coordinator since the position was created. He was a strong advocate for Black and Latinx communities who believed in meaningful community engagement and mobilization. True community engagement requires continually measuring, monitoring, and prioritizing community needs; focusing on measures relevant to the community; bringing the community to the table before decisions are made; and holding health department officials accountable for engagement.

Dr. Taveras pointed to the need for open channels of communication through which all stakeholders receive the same information at the same time. Ongoing, honest, intentional, and open conversations with community members and stakeholders are vital. To understand how communities prefer to be engaged, just ask them, Dr. Taveras said. Efforts must involve the most vulnerable populations, and improvement must be measured. Conducting community-based participatory research and giving the community a creative stake in outcomes have been effective in South Florida. Organizations like HealthLink already have representation and relationships in many of the *Ending the HIV Epidemic: A Plan for America* target jurisdictions.

As Florida expands HIV testing and other initiatives, it should collect and evaluate data annually to assess demographic differences and program outcomes. Florida has the resources and capacity to do the work, but it must take new approaches to make a difference, Dr. Taveras concluded.

Hansel Tookes, M.D., M.P.H., Assistant Professor of Clinical Medicine, Division of Infectious Diseases, University of Miami Miller School of Medicine

Dr. Tookes said he is pleased that Florida is embracing evidence-based medicine and allowing counties to establish syringe service programs. When a pilot syringe service program identified a cluster of HIV seroconversions, Dr. Tookes and colleagues determined that those affected were homeless people and injection drug users (IDUs) who were unable to enter HIV care because they lacked identification. The program partnered with the local health department to implement testing and same-day treatment via the local Ryan White Program. Using the wraparound services available, people were linked to care within 20 days of diagnosis, and many achieved viral suppression within 70 days. However, some dropped out of care because they felt stigmatized by staff and other patients.

Dr. Tookes and his colleagues are focusing on lowering barriers to HIV care by reaching out to homeless people to initiate care wherever they are, eliminating the time from diagnosis to treatment. They recently received a grant to promote PrEP in communities where it is underused. Dr. Tookes continues to seek ways to improve care through scientifically based interventions, telehealth approaches to testing and treatment, and increased access to services.

Paul Carl Velez, M.S., President and Chief Executive Officer, Borinquen Medical Centers

Mr. Velez said his organization was the first in the area to use mobile clinics to reach people in the most downtrodden areas of Miami-Dade County, home to some of the poorest communities

in the United States. Many Floridians in need come from Puerto Rico. Mr. Velez noted that a lot of cutting-edge research on HIV has taken place in Florida, particularly in Miami. The Borinquen Medical Centers treat hundreds of specialty patients, but they are seeking more funding to support care. Mr. Velez supported PACHA's draft resolutions on funding *Ending the HIV Epidemic: A Plan for America* and ensuring robust community engagement. He hoped that implementation and research could get underway soon.

Discussion

Dr. Tookes explained that successfully linking homeless people to HIV care involved providing transportation, offering access to showers, and storing medications, so that clients could exchange needles and get HIV medication (and hepatitis C medication, if needed) at the same time. If clients did not show up within a week, staff would seek them out and bring them their medications. The approach requires many resources. With more diagnoses anticipated, the state will need to help organizations that want to reach out to IDUs and others, and organizations must be flexible to meet clients where they are.

Drawing on her own experience working for a health department, Dr. Taveras observed that health departments can do more to engage communities. They must share information in a timely way and invite the community to take part whenever possible. Health departments can encourage staff to represent their own communities. Building relationships takes time, Dr. Taveras stressed. In the meantime, the communities must keep asking health departments to include them. Mr. Javier suggested that health departments take the same approach to engaging communities as they do to engaging their contractor providers. Local input from consumers and providers is needed to ensure that PrEP and other strategies have an effect.

Mr. Velez said the State must increase health department budgets so that they have the resources to involve providers and consumers. Dr. Tookes commented that acknowledging the need to change the status quo has helped level the playing field and has paved the way for new collaborations.

Panel Discussion: Addressing the Unique Needs in Puerto Rico

Facilitator: Wendy Holman, PACHA Member

Geraldo Acosta Hernandez, M.D., PrEP Patient

Dr. Hernandez observed that in New York City, public messages about HIV testing, PrEP, and protecting against STIs are everywhere; in Puerto Rico, such messages are never seen by the general population. The Territory's citizens—especially young people and the lesbian, gay, bisexual, transgender, and queer (LGBTQ) population—need more education about how HIV is spread and how they can protect themselves. The Puerto Rican government should undertake a huge public education campaign or provide CBOs with the resources and tools to do so. Finding a clinic in Puerto Rico that provides PrEP is difficult, said Dr. Hernandez, but those clinics give excellent service. Many people lack access to clinics that provide HIV care. Needle sharing among IDUs remains a problem. Dr. Hernandez explained that Puerto Rico needs proper funding and management to educate its people; it must bring the various stakeholders together to fight the lack of knowledge about HIV.

Iván Meléndez-Rivera, M.D., FAAFP, Chief Medical and Operating Officer, Centro Ararat

Centro Ararat is a private nonprofit organization that provides integrated HIV and clinical care and wraparound services, including Ryan White Program services, for the underserved. Its clients have very high rates of retention and viral suppression. Among the keys to the organization's success are the following:

- Onsite pharmacies that take part in the Federal 340B Drug Discount Program and other drug assistance programs
- Onsite substance use treatment and mental health services
- Hormonal treatment for transgender people
- Rapid eligibility determination

Among the major challenges are the Territory's economic instability and poor transportation system, high health insurance copays, lack of insurance coverage for laboratory tests, government requirements for frequent laboratory assessments, and delays in access to new medications. Health care providers in Puerto Rico lack education about HIV prevention and early detection, and few advise patients about HIV or other STI testing. The Territory lacks data on where diagnoses are occurring. Stigma is very strong.

According to Dr. Meléndez-Rivera, Puerto Rico has only three clinics that offer PrEP, yet thousands of people at risk should be taking it. Lack of knowledge among the public and health care providers is the biggest barrier to PrEP. More data are needed to understand why some stop taking PrEP. Medicaid in Puerto Rico does not cover PrEP, and private insurers that do cover it require the primary care provider to sign a laboratory statement confirming the patient is eligible. Notably, because PrEP is preventive treatment, the age of consent for PrEP in Puerto Rico is 21 years, and health care providers cannot provide PrEP to those younger than 21 without parental consent. (In contrast, the age of consent for sex is 16 years.) There is skepticism among health care providers and decision makers about the effectiveness of PrEP.

Dr. Meléndez-Rivera called for public education, broad condom distribution, and efforts to train and empower vulnerable communities so individuals can serve their peers. He also called for more active participation from the government and more advocacy to address stigma, develop systems for HIV cluster detection, educate the public and health care providers, and require insurers to cover the costs of laboratory tests for ongoing PrEP.

Vivian Tamayo-Agrait, M.D., Medical Director, PRCoNCRA

PRCoNCRA is a nonprofit CBO that provides compassionate, holistic care to PWH and people at risk for HIV and other STIs, with an emphasis on youth and the LGBTQ and intersex population. It provides Ryan White Program services and recently received funding to become an FQHC. As of 2019, 90 percent of PRCoNCRA's clients have achieved viral suppression. Despite treatment successes, the incidence of HIV infections persists at 2 percent across Puerto Rico. Dr. Tamayo-Agrait noted that people diagnosed with HIV but not in care account for 40 percent of new transmissions. Since 2017, PRCoNCRA has focused on reengaging clients and identifying barriers to retention. Dr. Tamayo-Agrait recommended requiring Federally funded programs to track PWH who are out of care, in conjunction with local health departments. She

also suggested creating pilot projects to implement and assess protocols for rapid initiation of HIV care.

More focus on prevention is needed. Puerto Rico has developed guidelines for implementing PrEP, yet it is still largely unavailable to many and is not provided through the Territory's HIV and STI clinics. Structural barriers include the lack of trained personnel, lack of staff education, HIV stigma, and lack of resources. In addition, most HIV care on the island is provided through Ryan White Program clinics, which cannot serve people who do not have HIV. Access to PrEP is hampered further by the lack of staff to assist with navigation, wraparound services, and insurance coverage. In addition, Puerto Ricans face significant barriers to nonoccupational postexposure prophylaxis (nPEP), which is covered only in cases of sexual assault.

PRCoNCRA surveyed candidates for PrEP and found most (i.e., 80 percent) had heard of it and would consider it, but only a quarter had ever talked about it with their primary care physicians, underscoring the need to train primary care providers in initiating the conversation. With private funding, PRCoNCRA established an HIV prevention and PrEP clinic, which is now self-sustaining thanks to the income generated and clinic's access to 340B drug discounts. However, access continues to rely on assistance programs from manufacturers; public and private insurance coverage is uneven and limited.

Keeping people on PrEP remains a challenge in Puerto Rico, as in the rest of the United States. Dr. Tamayo-Agrait noted that PrEP retention differs from retention in HIV care. People on PrEP are usually healthy, and their risk for HIV might be intermittent. Barriers to access affect retention; increasing service hours, offering free HIV testing, providing wraparound services (including mental health services), and using novel care delivery approaches could mitigate some of the barriers. Evaluating people for PrEP eligibility sometimes reveals indications for nPEP. People who have taken nPEP are at high risk for HIV infection, so they should be considered candidates for PrEP. Improving availability of PrEP and mitigating the risk of HIV involves addressing gaps identified through engagement of local champions and leaders in the field.

Discussion

PACHA members sought clarification about the restrictions on providing PrEP to people younger than age 21 without parental consent. Drs. Tamayo-Agrait and Meléndez-Rivera stated the largest barrier is overcoming the stigma among the public, policymakers, and providers that prevents open discussion about PrEP. No formal advocacy efforts have addressed the government regulations.

Dr. Tamayo-Agrait said most health care providers refer PWH to the Territory's Ryan White Program clinics because they are not comfortable treating them or even treating patients at high risk for HIV. Dr. Meléndez-Rivera pointed out that surveys demonstrate that most of Puerto Rico's health care providers are not interested in providing PrEP or counseling patients about HIV prevention.

Possible Recommendation Development

Mr. Schmid asked that PACHA members and community members provide comments by day two of this meeting on the draft resolution in support of future funding for *Ending the HIV*

Epidemic: A Plan for America that asks the HHS Secretary to work with the President to ensure adequate funding for next year and beyond fiscal year 2020 and to avoid budget cuts to other HIV programs.

A second resolution supporting robust community engagement in *Ending the HIV Epidemic: A Plan for America* asks that Federal partners ensure they gather meaningful input from the community and PWH and provide feedback to those who give input.

Mr. Schmid proposed a third resolution on innovation to end the HIV/AIDS epidemic that would encompass such issues as the need for additional resources to facilitate Gilead's donated drugs, including addressing the required frequency of testing for PrEP maintenance; novel approaches to access; elimination of government-imposed barriers to PrEP and HIV treatment; and initiation of rapid enrollment in PrEP and HIV care. Dr. Weisman agreed to draft a resolution for consideration by PACHA on day two. The meeting recessed for the day at 5:25 p.m.

Day Two

Welcome and Roll Call

Dr. Wiesman reconvened the meeting at 9:03 a.m. and welcomed the participants. Ms. Hayes called the roll.

PACHA Subcommittee Reports

Ending the HIV Epidemic: A Plan for America and the Updated National HIV/AIDS Strategy

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

The Subcommittee reviewed the takeaways from the July PACHA meeting in Jackson, MS. The success of that meeting influenced the decision to hold more PACHA meetings outside of Washington, D.C.—an effort known as PACHA to the People—which should contribute to more community engagement. The Subcommittee has pressed for better communication to PACHA from Federal partners. It also encouraged PACHA to invite new partners from Federal agencies not previously represented on the Council.

Stigma and Disparities

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

The Subcommittee drafted a resolution to support more community engagement. The resolution will be considered by PACHA later at this meeting. PACHA Co-Chairs and Subcommittee Co-Chairs met with the director of the HHS Office for Civil Rights, Roger Severino, to express concerns about a proposed rule regarding potential discrimination against LGBTQ people in health care (Section 1557 of the Patient Protection and Affordable Care Act). Mr. Severino also provided a written response to PACHA (see Appendix A). The Subcommittee hopes to continue the conversation on the importance of eliminating discrimination against LGBTQ people. For *Ending the HIV Epidemic: A Plan for America* to succeed, LGBTQ people should be protected, and Federal efforts should not appear to tolerate discrimination in deed or word. Vulnerable communities should have access to the services they need.

Global

Robert A. Schwartz, M.D., M.P.H., D.Sc. (Hon.), Chair

The Subcommittee seeks to gather lessons from international experiences that can be applied to the United States. For example, Dr. Schwartz has met with HIV experts from South Africa, Botswana, and Poland. Discussions have included new technology (e.g., a vaginal ring for antiretroviral medication) and mechanisms for reducing costs of prevention and care.

Ending the HIV Epidemic: A Plan for America: Work of the Federal Government and Efforts to Ensure Continued Community Engagement

Facilitator: Carl Schmid, M.B.A., PACHA Co-Chair

Ending the HIV Epidemic: A Plan for America: Implementation Overview

Tammy R. Beckham, D.V.M., Ph.D., Director, OIDP, OASH, HHS

Dr. Beckham outlined implementation of *Ending the HIV Epidemic: A Plan for America*. Jurisdictions have received funding to support local planning that heavily involves the community. Given the aggressive timeline for completing plans, HHS expects that jurisdictions will modify plans as needed. To ramp up the distribution of donated PrEP medication, HHS established a 6-month, sole-source contract with Gilead. It estimates providing medication to 4,250 people within the first 6 months, starting in December. HHS will use an open competition process to identify one or more contractors to handle distribution over the long term.

HHS hired a consultant to develop a public awareness campaign around PrEP. Once the campaign begins, HHS will work with jurisdictions to leverage existing resources and respond to community needs. The campaign will focus on the jurisdictions targeted in the first phase of *Ending the HIV Epidemic: A Plan for America*, then expand later on.

To develop the data analysis and visualization system, HHS awarded a contract to a consultant to create a dashboard that shows progress using indicators at the jurisdictional and national levels. An interagency working group is developing the requirements. The initial deliverable will use available data and is expected to launch by the end of 2019; later iterations will integrate new data and support more interaction.

Discussion

Dr. Beckham said HHS is doing market research to determine the best options for distributing the donated PrEP medication at the lowest cost to the government. She added that current estimates are based on current payment rates, but less expensive options might be available. Mr. Schmid asked that Dr. Beckham keep PACHA informed about the distribution of PrEP. Michael Saag, M.D., noted that some sources estimate that distributing PrEP costs \$100 per person per year, totaling \$20 million if all those eligible began taking PrEP. He observed that a different health care delivery system in the United States would be better equipped to support distribution of donated medication.

Mr. Sapero questioned why HHS is creating a huge program to support distribution of the free drug when it is already available and often paid for through manufacturers' patient assistance programs. CBOs have indicated they need more navigators and other supports to link people to PrEP. Dr. Beckham agreed that community navigators play an important role; grants from Federal partners and the Minority HIV/AIDS Fund might address the supports needed to increase PrEP uptake. However, HHS wants to make the most of the donation from Gilead. Mr. Narváez appreciated that HHS will seek out other contractors for PrEP distribution through an open competition, which addresses some concerns raised by the community.

HRSA HIV/AIDS Bureau Update

Laura Cheever, M.D., Sc.M., Associate Administrator, HIV/AIDS Bureau, HRSA

The Ryan White Program has succeeded in building systems of care for PWH, and HRSA brings that experience with robust community engagement to *Ending the HIV Epidemic: A Plan for America*. Dr. Cheever presented demographic and outcomes data on Ryan White Program clients in Puerto Rico and Florida. Both areas have achieved very good suppression rates among PWH engaged in care, and both see disparities in maintaining viral suppression among youth and those who are temporarily or unstably housed, particularly among the Hispanic population. Both areas are doing great work to meet the needs of Hispanic transgender people engaged in care.

Listening sessions have emphasized the need for *Ending the HIV Epidemic: A Plan for America* to better address social determinants of health, including housing and transportation; leverage community strengths; employ new and novel approaches; and address stigma, distrust, and HIV criminalization. The Ryan White Program is focusing on improving care for existing clients, linking more people to care, and improving retention and reengagement. With increased flexibility in funding, Ryan White Program providers have been able to pilot new approaches, such as one targeting people exiting the criminal justice system and one that seeks to identify roommates and family members of PWH in the same household who would benefit from care.

HRSA is updating policies and incorporating new strategies to better meet the needs of the Latinx population. For example, HRSA seeks not only to identify which interventions work but also to better disseminate them and to promote their use by developing methodologies and paying clinics to implement them. It will fund leadership development of PWH so they can represent their communities. Efforts are underway to improve the processes for Ryan White Program eligibility and recertification, reimagine Medicare Part D, and get insights from expert panels on subpopulations of PWH. HRSA is building capacity by funding efforts to link SAMHSA-funded programs with Ryan White Programs. New or updated guidance will address rapid eligibility, correctional settings, and housing resources.

SAMHSA Update

Neeraj Gandotra, M.D., Chief Medical Officer, SAMHSA

People with mental health issues or SUDs are at twice the risk for HIV infection as the general population. SAMHSA seeks to improve prevention efforts, increase testing, and provide linkages to HIV care as part of mental health and SUD treatment. Mental health disorders, SUD, and HIV/AIDS are interrelated; PWH are twice as likely as others to suffer from depression, anxiety, and SUD. Stigma persists and poses barriers to treatment for all three conditions. Novel approaches—such as requiring all those seeking medical licenses to be trained in caring for PWH

and to undergo education on opioid addiction and treatment—have helped chip away at stigma, said Dr. Gandotra.

Mental health, HIV, and SUD interact in complex ways. For example, depression and drug use both affect adherence to HIV treatment regimens. However, those who seek SUD treatment are more likely to seek treatment for HIV or mental health concerns. SAMHSA will provide new guidance to help grantees address HIV and link PWH to care.

Through collaboration, SAMHSA seeks to promote HIV prevention and offer pre- and posttest counseling, education, and referrals to care through community settings and in mental health and SUD clinics. It recognizes the need to provide wraparound services that address the social determinants of health so that people can take advantage of available resources. SAMHSA offers its national network of technology transfer centers to all nonprofit organizations, not just grantees, to improve HIV screening and assessment for those seeking behavioral health services. It also provides training and technical assistance to primary care providers about the importance of mental health concerns and SUD among PWH or those at risk for HIV. Dr. Gandotra described some SAMHSA-funded efforts to address mental health issues and SUD among the Hispanic population in the United States.

Thanks to a new policy, every SAMHSA grantee can require HIV and hepatitis testing for people who enroll in mental health and SUD programs, and programs will track linkages to care. The more people who get mental health or SUD treatment, the more who are likely to engage in other preventive treatment, Dr. Gandotra concluded.

Ending the HIV Epidemic: NIH Work to Ensure Continued Community Engagement

Maureen M. Goodenow, Ph.D., Associate Director, AIDS Research, Director, OAR, NIH

OAR coordinates HIV research and activities across NIH's many Institutes, Centers, and Offices. NIH's priorities around HIV, particularly reducing HIV incidence and developing new therapies, align with the pillars of *Ending the HIV Epidemic: A Plan for America*. Research is conducted along a continuum, from basic research to public health policies. NIH research fuels the pipeline of discovery and informs policymaking.

For *Ending the HIV Epidemic: A Plan for America* specifically, NIH seeks to fill knowledge gaps and build on opportunities to leverage resources and expertise. It is implementing a new strategic plan and HIV/AIDS research priorities. NIH continues to track, monitor, and evaluate direct and related NIH research activities to achieve *Ending the HIV Epidemic: A Plan for America* goals. It also has convened stakeholder listening sessions, which identified strong support for Federal coordination and collaboration to facilitate HIV prevention, treatment, and care and the need for more communication of NIH-supported research.

NIH's Centers for AIDS Research and the National Institute of Mental Health's AIDS Research Centers support implementation science and facilitate collaboration with partners funded by CDC, HRSA, IHS, and SAMHSA to identify best practices and to collect and disseminate data on the effectiveness of approaches supported by *Ending the HIV Epidemic: A Plan for America*. NIH has provided some short-term resources to jumpstart these efforts, focusing particularly on delivering evidence-based interventions to populations at high risk for HIV. Dr. Goodenow

described some targeted support for HIV research in Puerto Rico specifically and among Latinx communities on the mainland, as well as some supplemental funding for research on sexual and gender minority populations.

Ending the HIV Epidemic in Indian Country

Rick Haverkate, M.P.H., National HIV/AIDS & Hepatitis C Program Coordinator, IHS

Mr. Haverkate presented information on American Indians/Alaska Natives (AI/ANs) with HIV, but cautioned that the data are incomplete because Tribal health care sites that are not Federally operated are not required to share their data. At IHS facilities, HIV screening should be offered at least once to all clients. About 53 percent of AI/ANs with HIV are in care, but many facilities do not provide care because they lack practitioners or are perceived as lacking sufficient patient privacy protections. Retention in care in IHS facilities is lower than the national average.

IHS has received funding to prepare for *Ending the HIV Epidemic: A Plan for America*; some of it will be used to expand staff and support planning. The Cherokee Nation pilot project has had great success treating HIV and curing hepatitis C. That project should be a model for others on how to plan programs, drive political will to address HIV, and raise awareness about testing, PrEP, linkages to care, and retention. The Cherokee Nation pilot included educating providers about the need to discuss sexual health and link patients to PrEP. With Minority HIV/AIDS Fund support, IHS is educating providers about the concept of “two-spirit” people—a term used to describe a person of AI/AN descent who embodies male and female identities—and culturally competent approaches to treating LGBTQ people in IHS facilities. It also will fund Tribal epidemiology centers to look at disease outbreaks and the effects of new interventions by gathering and assessing community-specific data. IHS has embarked on Tribal consultations and listening sessions to better understand what communities want.

IHS is developing guidance and tools for clinicians on treating HIV at the local level and providing PrEP. It revised the core formulary for pharmacies to include two new HIV medications and PrEP medications so that prescriptions are available immediately. In addition to the need for more education, IHS is considering how to cover the high cost of medications. Mr. Haverkate said IHS is always working to reduce stigma around HIV, LGBTQ people, and two-spirit people; recently it produced two relevant videos. It also made available the Northwest Portland Area Indian Health Board’s online curriculum for health care providers that addresses transgender people and sexual and gender minorities.

Ending the HIV Epidemic: A Plan for America—CDC’s Role

Eugene McCray, M.D., Director, Division of HIV/AIDS Prevention, NCHHSTP, CDC

Among other efforts, CDC is working to increase HIV testing among people at high risk through new approaches that use technology and existing systems to make testing easy and accessible. To prevent HIV, CDC relies on proven interventions, including PrEP, and is training health care providers, increasing availability of PrEP in community health centers, bolstering outreach to people at high risk, and updating PrEP guidelines. It maintains an up-to-date online PrEP provider locator system. Dr. McCray pointed out that knowledge about PrEP has not translated to uptake among people at high risk for HIV.

CDC and SAMHSA are working together to increase community support for, access to, and use of syringe services programs. Buy-in can be a challenge, especially in rural States. CDC seeks to address gaps in staffing, data management, community support, and other resources that prevent sufficient response to identify outbreaks and interrupt transmission. It wants to enhance the clinical and nonclinical HIV workforce—for example, by matching early-career public health professionals with job opportunities in jurisdictions targeted by *Ending the HIV Epidemic: A Plan for America*. CDC hopes to implement an STI clinic at each of the sites engaged in a jumpstart pilot program.

Grantees in targeted jurisdictions have already received funding to develop their community plans for *Ending the HIV Epidemic: A Plan for America*. CDC will soon publish a funding notice that reflects input from communities about the need for resources to support wraparound services for HIV care and PrEP. Other 2020 funding will address implementation and workforce needs. CDC is updating its education and communications materials to include the latest science and to align with the *Ending the HIV Epidemic: A Plan for America*. It recently unveiled HIV Nexus, a hub for providers to find all CDC education, guidelines, and recommendations on HIV and PrEP.

Discussion

The high success rate of Ryan White Programs in achieving viral suppression demonstrates that investing in addressing barriers to housing, transportation, SUD treatment, and other factors works, so money should target such services for people who are not in Ryan White Programs.

Dr. McCray noted that CDC's new guidance spells out how communities should broaden and deepen engagement to support planning. It was suggested that statewide primary care associations be involved in planning at the local level. Digital platforms could be used to gather community input outside of meetings. More attention is needed to providing feedback to community participants about how their input informs programs and services. Planning should include the voices of PWH who are not in care or who have not achieved viral suppression. CBOs should receive funding or other resources to support the extra time and effort required for community engagement. It is important that community input be gathered from the outset, not once plans have been drafted.

Dr. Cheever hoped that new funding for the Ryan White Program would provide some flexibility to focus on jurisdictions outside its current authority so that it can promote more rapid start initiatives. Dr. McCray said CDC is assisting providers in building capacity to provide rapid initiation of treatment. Judith Steinberg, M.D., M.P.H., added that HRSA is sharing promising practices from community health centers on rapid-start programs and fast-track clinics and is providing funding training and technical assistance for implementation of such programs. Dr. Saag suggested framing the opportunity as a same-day option, because some people are not comfortable making an immediate decision about care after they receive a diagnosis.

Questions were raised about what new approaches Federal partners are taking to ensure that grantees operate with “cultural humility”—an understanding that some people have not been served well by existing systems. HRSA has encouraged organizations not only to hire from within the community served but also to provide the training and development to grow and retain staff, especially in areas that lack sufficient health care providers. It also has borrowed lessons

from trauma-informed care approaches to make services more LGBTQ friendly and seeks to educate about techniques to enhance cultural sensitivity, such as staff nametags with preferred pronouns. Health departments that are not Ryan White Program participants face structural challenges to hiring, so it is especially important for them to work with and support CBOs that engage the community. Dr. McCray said CDC offers a network of capacity-building assistance for providers that addresses cultural humility and sensitivity to stigma.

Participation in international research has yielded insights that can be applied to rural America, such as the effectiveness of enabling locals to determine and implement their own solutions. Such an approach not only engages the community but also gives community members some accountability. Dr. Cheever observed that the Ryan White Program seeks to include PWH in quality improvement so they can help identify gaps, create solutions, and measure success.

Federal partners are seeking mechanisms to help local and State health departments collaborate with new and different community partners. Dr. McCray said CDC is working with the National Association of County and City Health Officials to reach more stakeholders. John T. Brooks, M.D., added that CDC can work with health departments to identify stakeholders who are not involved but should be. Drs. Cheever and McCray noted that local political processes can be a barrier; for example, local clearance guidelines might prevent Federal partners from learning about implementation challenges. Dr. Weisman congratulated the Federal partners for accomplishing so much despite the lack of congressionally appropriated funding.

Ending the HIV Epidemic: A Plan for America: Performance Indicators for Tracking the Initiative

Norma Harris, M.S.P.H., Ph.D., Senior Advisor, Strategic Indicators, Division of HIV/AIDS Prevention, NCHHSTP, CDC

An interagency working group of subject matter experts from various HHS operational divisions agreed on the following six core indicators to assess progress of the initiative:

- Incidence: Estimated number of new HIV infections among people ages 13 years or older in a calendar year
- Knowledge of status: Percentage of HIV infections diagnosed among people ages 13 years or older
- Diagnoses: Number of reported HIV infections among people ages 13 years or older that were confirmed through laboratory or clinical evidence
- Linkage to HIV medical care: Percentage of those diagnosed who had one or more viral load or CD4 tests within 1 month of diagnosis
- Viral suppression: Percentage of people with HIV with a viral load of less than 200 copies per milliliter at the most recent test
- PrEP coverage: Percentage of people estimated to be eligible for PrEP who were prescribed PrEP

Data for all the indicators will be collected from the National HIV Surveillance System. PrEP coverage will be assessed by national pharmacy data through IQVIA Real World Solutions.

The knowledge and tools are available to reduce new infections. The Joint United Nations Programme on HIV/AIDS has established 2030 Fast-Track goals of 95 percent of PWH diagnosed, 95 percent of those diagnosed receiving treatment, and 95 percent of those on treatment achieving viral suppression, with the overall goal of a 90-percent reduction in HIV by 2030. The *Ending the HIV Epidemic: A Plan for America* has an ambitious but achievable goal that by 2025, 95 percent of PWH will know their HIV status, be linked to care, and achieve viral suppression. CDC has refined its initial modeling and will publish more details soon.

Discussion

It was noted that data must be collected and analyzed more rapidly to monitor performance and improve quickly. Dr. Harris said more details on the data schedule will be available once a data analysis contractor is confirmed. She noted that IQVIA has data from about 92 percent of retail pharmacies in the United States, although those do not include prescription data from closed systems, such as the Department of Defense. Dr. Harris cautioned that prescription data rarely include race or ethnicity information, and she and her colleagues hope to address that issue. More work is needed to address barriers to sharing data between clinics and health departments.

Public Comments

Silvana Erbstein of the AIDS Healthcare Foundation said her organization was glad to see a HUD representative at the PACHA table, because housing is a major priority. She summarized the AIDS Healthcare Foundation's work in Florida. To improve *Ending the HIV Epidemic: A Plan for America* in Florida and the rest of the country, Ms. Erbstein suggested looking at existing models that could be replicated within communities, recognizing that one size will not fit all. Efforts must be made to get the resources where they are needed. Reforms to the Ryan White Program should keep the needs of patients in mind, particularly the need for data to determine what works and what does not.

Joey Wynn of Midland Cares, Inc., pointed out that meetings and discussions involving Federal partners often lack adequate community representation from the South. Many southern organizations lack the financial support to attend meetings or the technology to allow for meaningful participation in decision making. Meaningful participation requires communities to be involved from the beginning, not just receiving presentations about decisions already made. Mr. Wynn hoped PACHA would focus on helping Federal partners clarify expectations with grantees, either by sending people to meetings or providing technology to support participation. He specifically suggested that grant funding be allowed to support meeting travel.

Mr. Wynn said he supports the new testing guidelines and believes they will help more providers offer HIV screening. He called on CDC to make a concentrated effort to ensure that local health departments have meaningful discussions with communities about molecular surveillance, because fear of the technology will be a barrier. Communities can assist with identifying the best solutions. Mr. Wynn requested mechanisms to fund training and mentorship for a new generation of PWH, so they can learn from current and past advocates, peers, and leaders who have been working at the community level for years. The next generation needs to learn about the complexities of funding, how to participate in planning bodies, and how to engage in meetings that keep the system moving forward.

Ramin Bastani of Healthvana said his company seeks to help end HIV with innovation and technology. Healthvana empowers people at high risk who are taking PrEP or HIV medications to manage their health on their mobile phones. It is currently focusing on PrEP. Users receive automated reminders and educational messages aimed at retaining them in care. Healthvana seeks to build relationships with users where they spend most of their time—on their phones. The company has seen a growing problem around adherence and retention to PrEP. PrEP works amazingly well, when taken as prescribed, and access is increasing through incredible initiatives such as Gilead’s donation of free medication, California’s move to allow pharmacies to provide PrEP without a prescription or preauthorization, and PACHA’s work to increase access to PrEP through *Ending the HIV Epidemic: A Plan for America*. Mr. Bastani asked that the Council and all stakeholders consider making PrEP adherence and retention as big a part of the initiative as access. Recent published research from interviews with 4,000 Black men who have sex with men found that HIV prevalence in the population on PrEP was 60 percent higher than in those not on PrEP. Mr. Bastani concluded that technology can help.

Marianna Baum of Florida International University said she has been an investigator on several NIH-funded projects involving minority participants in communities and has worked with many CBOs. In one study with 1,500 minority participants, most had HIV, and many were coinfecting with hepatitis. About one fourth of those not infected were at high risk for HIV. Florida in general has a high incidence of HIV coinfection and death from opioids. The main substances of abuse in Florida are cocaine and alcohol, but opioids have been rising, from 5 percent to 50 percent in the past 7 years among research participants. Use of heroin and fentanyl has increased. Opioid use results in behavior change and affects judgment, which might increase risky behavior. In the past 15 years, viral suppression has increased dramatically, but the remaining unsuppressed people are a reservoir of HIV in the community. Ms. Baum stated that community health centers need more funding to make sure all PWH achieve viral suppression so that HIV is eliminated.

Michael Ruppal of The AIDS Institute pointed out that Florida is second only to California in the number of jurisdictions targeted by the first phase of *Ending the HIV Epidemic: A Plan for America*. The epidemic is different in Florida, he said. Efforts must be made to engage communities so that they mobilize. Under the new State administration, good relationships have been developed among community groups, the Surgeon General of Florida, and the State Department of Health. Mr. Ruppal hoped Governor Ron DeSantis would not make the same mistakes as the previous governor. The targeted jurisdictions represent 73 percent of new diagnoses in Florida, and dollars must go where they are most needed. The seven counties involved are very different, so innovative approaches are needed for each. Mr. Ruppal asked that Federal partners also seek to be innovative.

Mariano Kanamori of the University of Miami said that in the past 2 years, as an NIH-funded Center for AIDS Research, the university’s medical school has worked with Latinos Salud to develop a social network model to identify and recruit Latinx candidates for PrEP. It has reached more than 500 people so far, primarily men who have sex with men, bisexual people, and women. Mr. Kanamori hopes that with additional support, the partnership can explore mechanisms to share the model.

Ace Robinson of the National Minority AIDS Council said mountains of data and lived experience have determined where those people disproportionately affected by HIV are and what needs to be done. There is already a roadmap, and new efforts should follow it. He emphasized that community must be at the center of local, regional, and national planning, driving the conversations and creating the programs. The locals should deem what is appropriate. All planning should be evaluated from the lens of a high-risk community. Rather than doing the same things and having the same conversations that have been ongoing since 1981, Mr. Robinson called for more communication through less formal mechanisms (e.g., using webinars to engage more people) with different people involved. Guidance must be timely so that people can do what is needed. Mr. Robinson emphasized the need to change the system that created the current health disparities. In New York, for example, goals of screening, retention, and suppression have been met for White populations but not for non-White groups, so the structural systems must change. People drop out of care for good reasons, so it is important to understand why and adjust as necessary. Mr. Robinson called for wiping the slate clean and starting over.

Sannisha Dale of the University of Miami emphasized that intersectionality must be part of every conversation. Although presenters at this meeting highlighted HIV concerns among Latinx people, Black people—particularly Black transgender women—are affected substantially by HIV in Florida. Ms. Dale cautioned against separating race/ethnicity from sexual identity, gender identity, and immigration status; acknowledging the intersectionality of these issues must be front and center to effect real change. Ms. Dale reported that one CBO told her the *Ending the HIV Epidemic: A Plan for America* planning process felt very rushed, because it allowed only 2 weeks to convene community members, discuss concerns, and create a plan. She questioned whether issues get communicated up the chain with the same conviction and passion with which they were expressed originally. It must be recognized that community stakeholders are asked to come to the table—repeatedly—but are not given any resources to support the extra time and effort required to do so. These representatives need stipends, transportation, and childcare to help them continue to take part. Finally, Ms. Dale said grantees should engage community partners in ways that ensure that the community partners receive some of the resources that come with the grant. The community should be treated as the solution; the epidemic will not be ended unless the community leads the conversation.

Christopher Bates, community member and former executive director of PACHA, said this meeting helped elevate the conversation about the challenges organizations and individuals face in the region. He hoped the region would take seriously the input from the community.

See written submissions in Appendix B.

Eliminating Racial and Ethnic Disparities in HIV Prevention and Care

CAPT Samuel Wu, Pharm.D., Public Health Advisor, OMH, HHS

Dr. Wu said OMH acts as a catalyst, promoting policies, programs, and practices around its mission of improving the health of racial/ethnic minority populations. Collaboration with partners and stakeholders outside of government has been key to success. OMH supports

demonstration projects and evaluations of new policies and practices. When those efforts succeed, OMH tries to find partners that sustain them.

The Advisory Committee on Minority Health has a racially diverse membership that represents a broad range of sectors. The Committee is uniquely qualified and positioned to advise the Deputy Assistant Secretary for Minority Health about specific actions for improving health. OMH and ODP sought the Committee's input on *Ending the HIV Epidemic: A Plan for America* implementation. At its August 2019 meeting, the Committee focused on ways to better identify and engage community representatives and mechanisms to reduce stigma. The following themes emerged, and the Committee is drafting formal recommendations:

- Require grantees to address community engagement and stigma reduction in future funding opportunities.
- Prioritize racial and ethnic communities in funding opportunities.
- Engage and empower the communities (e.g., youth/young adults) as collaborators in developing messages.
- Ensure cultural and linguistic appropriateness of communications.
- Employ methods to measure evidence of success to inform outcomes and quality improvement.

PACHA and the People: Discussion with Audience Attendees and CBOs

Facilitator: PACHA Co-Chair John Wiesman, Dr.P.H., M.P.H.

Audience members were invited to weigh in on two specific questions; their comments were captured on flip charts in real time and are summarized here.

Question 1: What is the level of trust you have in the institutions that are serving you and why? What can be done to increase trust in government agencies as it relates to Ending the HIV Epidemic: A Plan for America?

- People in government agencies take a minimalist approach because it is just their job; more PWH, nontraditional organizations, and grassroots efforts must be included.
- Transgender people are tokenized; they must be involved at all levels and have a seat at the table.
- Seek data on PrEP adherence and apply it to the PrEP coverage indicator.

Question 2: How should community and CBOs be involved in Ending the HIV Epidemic: A Plan for America planning, implementation, and evaluation? What types of engagement strategies would work best? How can we build capacity?

Better engage specific communities.

- Include the people who are served. Many peer-led, grassroots organizations have great ideas but lack the funding, support, visibility, and infrastructure to translate them broadly.
- Incorporate the corrections/criminal justice system into *Ending the HIV Epidemic: A Plan for America* (specifically, testing and linkage to care).

- Seek more diversity that better reflects the community.
- Ensure Federal monitoring of the diversity of the input and deliverables, with specific guidelines, expectations, and requirements for collaboration with the transgender community and nontraditional agencies (including financial support for collaboration).
- Fund more work by transgender-led agencies.
- Involve more health care providers.
- Consider the needs of PWH older than age 50 and complications related to aging.
- Young people, particularly young people of color, are missing from the conversation.

Make community engagement easier.

- Hold meetings in neutral, accessible sites (e.g., with no identification required and free parking), promote them to the public in advance, and follow up on the meeting outcomes.
- Ensure that meetings are inviting and not intimidating, encourage people to express themselves in ways they feel comfortable with, and use plain language and clear processes.
- Raise an army of actively engaged people by going into the community and talking one-on-one with connected community leaders (but not necessarily elected officials or clergy); this highly personal approach requires funding and sustained commitment.
- Engage community stakeholders at their convenience—in accessible locations outside of work hours.
- Representation matters; pay people for their time and effort.

Leverage technology for outreach and messaging.

- Seek examples of HIV prevention and technology working well together in Florida.
- Use technology to bring more people into the conversation and direct questions to the relevant communities.
- Empower individuals to communicate with others about HIV prevention using social media so that messages are disseminated in various ways.
- Partner with dating apps to reach millions of people quickly.

Improve messaging.

- Ensure that messages and media are clear and targeted to specific populations; consider consumer issues and barriers.
- Employ broad and large-scale marketing campaigns to promote HIV prevention and treatment messages.
- Health departments should have leeway to produce messaging and materials that are relevant and meaningful to the populations they serve, without censorship from the State.
- Recognize the need for diversity within groups and craft messages appropriately.
- Federal partners can help with messaging by developing templates—that range from conservative to daring—for communities to use.
- The Super Bowl in Miami in 2020 is an opportunity for *Ending the HIV Epidemic: A Plan for America* to make a big splash locally and nationally.
- *Ending the HIV Epidemic: A Plan for America* should address how to get PrEP to people who are not using health services (e.g., immigrants).

Address organizational barriers and build capacity.

- Improve customer service and other structural issues.
- Identify and disseminate best practices for specific issues, such as retention.
- Better align Florida Department of Health contract goals with agencies' expertise.
- Help organizations see how they fit into the initiative so they buy in to it, looking beyond their own funding and requirements to the broader goals.
- To build capacity, clarify expectations about community engagement in position descriptions and grant requirements and address indicators of success, evaluation, and follow up.

Build trust.

- Challenge organizations to be humbler and more sensitive to individuals, to foster authentic connections with clients, and to find and build trust with people who already have strong community connections.
- The party with the power must do the work to build and sustain relationships, acknowledging the other party's preference.
- Ask communities what trust looks like; recognize that building trust requires funding and persistence.
- Public health advocates should support communities but not direct them; seek better mechanisms for joint decision making and ensure that communities receive feedback on the results of their input.
- The Federal government fails to provide sufficient guidance; because of the focus on compliance, States and localities do the minimum.
- Florida's State leadership around HIV does not reflect the diversity of the epidemic in the State, which erodes trust.
- To build trust, create open, consistent lines of communication that deliver messages to communities at the same time.
- The community can sense an individual's lack of passion or investment, which might be the barrier to engagement.

Create tools.

- Develop a stigma index tool.
- Create tools and plans to reach PWH and their partners.

PACHA Member Discussion and Action Steps

Resolution 1

Regarding the resolution in support of future funding for *Ending the HIV Epidemic: A Plan for America* (Resolution 1), Mr. Sapero suggested adding wording that acknowledges that communities will be involved in implementation, as well as the typical grantees and program providers. The amendment was accepted.

Vote

The Council voted unanimously in favor of finalizing Resolution 1, as amended, and sending it to the ASH.

Resolution 2

Regarding the resolution supporting robust community engagement in *Ending the HIV Epidemic: A Plan for America* (Resolution 2), there was agreement to add two-spirit people to the list of those most affected by HIV.

Vote

The Council voted unanimously in favor of finalizing Resolution 2, as amended, and sending it to the ASH.

Discussion ensued about how to make future public PACHA meetings more welcoming and accessible to community members. Future meeting planning will consider how to break down some barriers to community attendance.

The community engagement resolution calls for more transparency, accountability, and feedback, but more discussion is needed about how to measure and report community engagement, and deeper community input is needed on such measures.

It was noted that the audience discussion raised the issue of competition among community groups for funding, which hinders collaboration. Council members thought that funding issues should be addressed at the Federal level, and the planning process for *Ending the HIV Epidemic: A Plan for America* should provide a forum and incentive for communities to overcome the barriers to better collaboration.

Resolution 3

Regarding the resolution in support of innovation to end the HIV/AIDS epidemic (Resolution 3), Council members offered many revisions to clarify the intent and ensure the language is inclusive. The following issues were addressed in the revisions:

- There was discussion about the perceived differences between “cultural competence” and “cultural humility.”
- In some cases, the proposed actions require statutory changes; it was noted that PACHA can encourage the HHS Secretary to (1) work with Congress to change laws and (2) direct Federal agencies to work with States and Territories to address regulatory barriers.
- Council members agreed on the need for Federal partners to provide more technical assistance to improve data sharing.
- Regarding the issue of State censorship, Council members agreed that the Federal government should be encouraged to remove various types of barriers that limit innovation in prevention and treatment. Council members also called more broadly for direct funding of community entities to implement powerful, population-specific prevention and care services and media/marketing initiatives.
- Discussion ensued on whether to include a threshold to define older PWH as a special population; ultimately, it was agreed that specifying age 50 years and older adequately reflects the intent.

Vote

The Council voted unanimously in favor of finalizing Resolution 3, as amended, and sending it to the ASH.

See Appendix C for the finalized PACHA resolutions.

Next Steps and Closing Remarks from PACHA Co-Chairs

Mr. Schmid proposed that PACHA meet next in Washington, D.C., in early 2020, after the President presents his proposed budget. CBOs in Washington, D.C., and nearby Baltimore City might provide some early insights on *Ending the HIV Epidemic: A Plan for America* implementation.

Action Item

PACHA staff will evaluate meeting sites and times in the Washington, D.C., area that allow the public easier access to the meeting and will consider how to publicize the next meeting through community networks.

Council members proposed holding a future PACHA meeting in California, which has the most *Ending the HIV Epidemic: A Plan for America* target jurisdictions, or in Oklahoma in the Cherokee Nation. It was noted that the U.S. Conference on AIDS, which will take place in Puerto Rico in October 2020, might be an opportunity for PACHA to again include representatives from Puerto Rico.

The meeting adjourned at approximately 4:30 p.m.

Appendix A: Letter from the Director of the Office of Civil Rights



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Director
Office for Civil Rights
Washington, D.C. 20201

October 8, 2019

John Wiesman, DrPH, MPH
Co-Chair
Carl Schmid, MBA
Co-Chair
Presidential Advisory Council on HIV/AIDS
330 C Street SW, Room L106B
Washington, DC 20024

OCR Transaction Number 20-000005

Dear Dr. Wiesman and Mr. Schmid,

I sincerely appreciated the opportunity to meet with you and the members of the Presidential Advisory Council on HIV/AIDS on Tuesday, September 24, 2019. Thank you for expressing your concerns about civil rights protections for members of the LGBT community and people living with HIV.

The U.S. Department of Health and Human Services is committed to the principle that discrimination has no place in our Nation's health care system. It has long been the position of the HHS Office for Civil Rights (HHS OCR) that when nursing homes, hospitals, and other health care providers are in compliance with Section 504 of the Rehabilitation Act of 1973, they are characterized by an absence of exclusion, separation or discrimination on the basis of HIV status.

Over the years, we have secured voluntary compliance or corrective action from hospitals who refused to assign patients to rooms without regard to HIV status, assisted living facilities and nursing homes who refused to admit HIV+ patients, state and local agencies who refused to provide personal care services to HIV+ patients, dentists who refused to treat HIV+ patients, and surgeons who refused to operate on HIV+ patients. In 2013, when we could not secure voluntary compliance from a surgeon who refused to operate on an HIV+ patient without cause, we filed an action with the HHS Departmental Appeals Board, who terminated the surgeon's participation in the Medicaid program.

HHS OCR is committed to supporting the full implementation of the National HIV/AIDS Strategy and the President’s initiative, “Ending the HIV Epidemic: A Plan for America.” We serve on the National HIV/AIDS and Viral Hepatitis Steering Committee, the National HIV/AIDS Strategy Federal Implementation Group and the Ending the HIV Epidemic Agency Priority Goal Developmental Workgroup. We support the Department’s HIV/AIDS work by:

- providing training to HHS agencies’ staff members and grant recipients about Federal civil rights, conscience, and health information privacy protections for individuals, including people with HIV;
- working with HHS agencies and programs to provide technical assistance, with the goal of producing educational materials that appropriately inform providers and consumers of Federal civil rights, conscience, and health information privacy laws; and
- investigating complaints of discrimination against individuals with HIV in health care and human services, as well as complaints that a covered entity or a business associate violated the health information privacy rights of individuals, such as people with HIV, or committed another violation of the Privacy, Security, or Breach Notification Rules, under the Health Insurance Portability and Accountability Act of 1996 (HIPAA).
 - For example, in May 2017, St. Luke’s-Roosevelt Hospital Center paid HHS \$387,200 to settle potential violations of the HIPAA Privacy Rule and agreed to implement a comprehensive corrective action plan. The settlement resolved a complaint alleging that a staff member impermissibly faxed the complainant’s protected health information, including his HIV status, to the complainant’s employer, rather than sending it to the requested personal post office box.
 - In FY 2019, HHS OCR developed and implemented a new HIPAA Right of Access Initiative. The right of an individual to obtain their medical records is a cornerstone of the HIPAA Privacy Rule, and fundamental to informed health care decisions and better health care outcomes. For individuals with HIV, timely access to one’s health information is especially important. Access to health information empowers patients to track their progress, monitor their lab results, communicate with their treatment teams, and adhere to their important treatment plans.
 - In September 2017, HHS OCR entered into a resolution agreement with Heritage Hills Living & Rehabilitation Center, LLC (Heritage Hills). The agreement resolved a complaint alleging that Heritage Hills discharged a seriously ill patient from its facility upon learning that she was HIV positive, in violation of Section 504 of the Rehabilitation Act of 1973 and Section 1557 of the Affordable Care Act. Under the Agreement, Heritage Hills reported admissions and discharge data

to OCR for twelve months; appointed a Civil Rights Coordinator; published and posted a new non-discrimination policy; implemented a revised patient grievance procedure and informed patients of their right to file complaints with HHS OCR; required its staff to receive training on HIV and Federal non-discrimination laws; revised its admissions policy to ensure that all individuals with disabilities are provided equal access to its programs; and informed neighboring hospitals that it does not discriminate in admissions on the basis of disability (including HIV).

- o Earlier this month, HHS OCR secured corrective action from the Florida Orthopaedic Institute (FOI), a Tampa Bay comprehensive orthopedic practice employing 40 physicians working in 10 offices and 20 hospitals. The corrective action resolved a complaint alleging that an FOI surgeon, after learning that the complainant is HIV+, canceled his previously scheduled surgery and subsequently retaliated against him for filing a complaint with HHS OCR by dismissing him from the practice. FOI revised its nondiscrimination policies and procedures, as well as its procedures for dismissing a patient from the practice; conducted training for its staff on HIV, Federal non-discrimination laws, grievance procedures, and the requirement to refrain from retaliatory actions; and provided the complainant with referrals to three orthopedic surgeons in the area to prevent further delays in his healthcare.

Although the public comment period on the Section 1557 Notice of Proposed Rule Making has closed, we will carefully review the comments that PACHA members submitted prior to the deadline in their individual and organizational capacities. We appreciate your commitment to eliminating HIV discrimination and promoting equal access to our health care system.

Sincerely,



Roger Severino

cc: Gregg H. Alton, JD
Wendy Holman
Marc Meachem, MBA
Rafaelé Narváez
Michael Saag, MD
John Sapero
Robert A. Schwartz, MD, MPH, DSc (Hon)
Justin C. Smith, MS, MPH
Ada Stewart, RPh, MD, FAAFP, AAHIVS, HMDC

B. Kaye Hayes, MPA
Caroline Talev, MPA

Appendix B: Written Public Comments for the Presidential Advisory Council on HIV/AIDS



Healthvana

Presidential Advisory Council on HIV/AIDS

October 22, 2019 - Miami

Public Comment

Hello, my name is Ramin Bastani, CEO of Healthvana. Our mission is to help end HIV with innovation and technology.

You may not have heard of us, but we're empowering over 300,000 patients who are at high-risk of HIV, already on PrEP or HIV+ manage their health on their mobile phones. And we're doing so by working with clinics in 17 states today - helping them deliver better care at a lower cost. If you go to our website, there is a 1 min video that will show you exactly what we do.

Our recent focus has been on PrEP and by the end of this year we'll have about 5% of all patients on PrEP using Healthvana - and by this time next year we anticipate it to be about ~15%. These patients will receive automated reminders and educational messages such as:

- "You may experience nausea the first few days on PrEP - don't worry, it's normal. If it persists, please click here to send a message to your care team" or
- "It's time to come back in for get your next prescription for PrEP, please click here to schedule an appointment"

The idea is to help build relationships with patients where they spend most of their time - on their phones. And now that you know a bit about our company, I'd like to share a growing problem we're seeing - and it's around adherence and retention to PrEP. No doubt PrEP works amazingly well, when taken as prescribed. And access is increasing through incredible initiatives shared such as:

1. 200,000 patients getting free PrEP from Gilead
2. Pharmacies enabling patients to get PrEP without a prescription or pre-authorization (starting in California)
3. Work by PACHA increasing access to PrEP through support of the Ending the HIV Epidemic Plan

But I respectfully request the council, and all stakeholders, consider making PrEP adherence and retention just as big of an initiative as access. Dr. Lisa Eaton published a paper late last year, highlighting what we're seeing on the ground. And she interviewed 4,000 black men who have sex with men at black pride events, and found that HIV prevalence in the population on PrEP was actually 60% higher than in those not on PrEP. We know that technology can help.

I appreciate the opportunity to address the council. Thank you for the work you do and please know that I am here to help any stakeholders looking to use technology to help end HIV.



PACHA Public Comment

October 21/22, 2019

Miami, Florida

Hello, my name is Giffin Daughtridge. I am a medical doctor and the cofounder of an HIV prevention venture called UrSure. UrSure is focused on improving PrEP adherence and retention. We want to make PrEP work best for those individuals who need it most.

Today I want to talk about why we started this work and the novel data on PrEP adherence and retention that we have generated over the last year.

In 2013, my cofounder, Dr. Helen Koenig, and I started an HIV prevention clinic at Philadelphia FIGHT. We were focused on getting young, men who have sex with men of color on PrEP. We had great success increasing access to PrEP and got almost 200 patients on the drug. But our success was limited by poor adherence and retention. This was especially obvious when several of our patients became HIV positive despite being on PrEP.

As we saw, PrEP access alone is not sufficient. Adherence and retention are also key.

Unfortunately, seroconversions on PrEP were not isolated to our Philadelphia FIGHT clinic. Late last year, Dr. Lisa Eaton at the University of Connecticut published a paper in JAIDS highlighting this trend. She interviewed over 4,000 black men who have sex with men at black Pride events, and she found that HIV prevalence in the population on PrEP was actually 60% higher than in those not on PrEP. We all know that the issue is not PrEP's efficacy. It works when taken, but poor adherence, especially in vulnerable populations, limits its effectiveness.

Today, as we discuss the incredible work PACHA is doing to increase access to PrEP through the support of the Ending the HIV Epidemic Plan for America, I hope we remember all three pillars of PrEP success: Access, Adherence, and Retention.

We have seen a commitment to PrEP access in the Ending the HIV Epidemic Plan, but we would love to see more attention put on adherence and retention.

At UrSure, we have generated some interesting data that could help effectively allocate resources to individuals struggling with PrEP adherence and retention. We make urine tests that measure adherence to PrEP. After running 3,500 tests with over half of those being done at clinics in Florida, we have seen three trends:

1. About 1 in 5 patients self-report daily adherence but have not taken their PrEP in at least 48 hours.
2. If a patient tests non-adherent, they are more than twice as likely to drop out of care in the next 6 months than a patient who tests adherent. This indicates a huge opportunity to identify individuals and intervene before they are lost to care.
3. If a patient tests non-adherent but receives targeted counseling and adherence support, they are recently adherent at their next visit 75% of the time.

Taken together, PrEP adherence and retention can be improved through targeting support to the individuals who need it most. We have an incredible opportunity to end HIV in America, but to do so, we must commit to PrEP adherence and retention in addition to access.

Giffin Daughtridge
CEO, UrSure Inc.
giffin@ursureinc.com
+1.252.287.8215

Greetings distinguished PACHA members. Welcome to Miami specifically, and the great state of Florida overall. My name is Joey Wynn, I am an openly gay, openly HIV positive resident of the South. I've been involved in advocacy and working in HIV for more than 26 years here in Florida; I want to thank you for coming to Miami. Your work is indeed a difficult task - trying to analyze all the data & what it means. Today I'm asking you to remember "Parity Inclusion & Representation"(PIR) from a somewhat different angle.

Too often meetings, conferences & important discussions by Federal partners are held without adequate representation from the south. From the many meetings I occasionally do get to attend, there are usually 1 or 2 people out of 30 or more attendees & somehow those 2 folks are supposed to represent the entire south. I am requesting that you look at the **meaningful representation of people living with HIV, not just in terms of demographics, but in terms of geographic representation**. Please try to increase expectations of geographic diversity in National meetings & deliberations. With the advent of cheaper technology, people can call in, access webinars to see in the conference rooms where meetings are being held, and could very easily participate. The technology is now free or very cheap to incorporate live polling from various local pre-determined outposts, thereby increasing the participation in local level experts in the complex and sometime difficult decision making that needs to occur on a regular basis. I have struggled for years to be involved at the National level, with financial hurdles always being the reason I can't go. I'm sure hundreds of other advocates from around the south have been prevented from participating too. Please ensure meaningful involvement of people living with HIV includes us in proportionate numbers. We do not need National representation from people that do not live here, we can speak for ourselves. There should be some expectation of proportionate representation at national level meetings & conferences as a goal for the future.

I want to thank the Federal government for Ryan White programs that do all the amazing work they have done over the past 3 decades. However, I truly believe in the 21st century we should now be able to **have the Ryan White funds follow the person**. Most of Florida experiences "in migration", with hundreds of people diagnosed elsewhere but the funds staying in their prior homes in other states. Set up a task force to redesign the Care Act to have the funds follow the person, such as Medicaid & Medicare is structured? I know this is a complex, long term goal, but we should begin addressing this topic in 2020. We can update the system without having to deconstruct it. Planning this will take years, so we should stop saying this is not the time to do so.

I also applaud the new **HIV testing guidelines** and the importance these new rules will hold in getting MORE medical providers to get involved in HIV screening.

Additionally, there needs to be a concentrated effort from CDC to have **meaningful discussions with various communities about Molecular surveillance**, as the vast majority of people do not understand it, or the DOH partners are not adequately trained and expected to involve the community in how it is being used. Fear will make a much larger barrier than the benefits of inclusion in the path forward in how best to use this technology. **Recommit the need for meaningful inclusion of the community to CDC, Local Dept. of Health partners and other grantees**, as the community often can assist in identifying the best solutions.

Finally, there needs to be mechanisms to **fund training & mentorship for a new generation of PLWH** to gain wisdom & hands on experience from the current & past advocates/ peers / leaders that have been working for many years at the local level. We need to begin to teach the next generation how to navigate all the complexities of funding & participation on the planning bodies and other meetings that keep this system moving forward.

Thank you for the ability to speak to you, and your time. I look forward to hearing what you put forward in the future as we all try to improve the HIV Service delivery system here in the USA.

Aging & HIV

Many of us are disappointed that the Aging & HIV problem is not part of the discussion of Ending AIDS, we believe its not possible to END AIDS without adequately addressing the unmet needs for better care & support services for older aging HIV+.

Thanks.

Jules Levin

Exec Dir NATAP

<https://protect2.fireeye.com/url?k=dfa10131-83f40822-dfa1300e-0cc47adb5650-e0362f8030b461b5&u=http://www.natap.org/>

DRAFT

Appendix C: Resolutions

Presidential Advisory Council on HIV/AIDS (PACHA) Resolution in Support of Future Funding for “Ending the HIV Epidemic: A Plan for America”

Whereas, as part of the State of the Union address in February 2019, President Donald Trump announced a bold initiative to end HIV in the U.S. within 10 years by increasing HIV testing, treatment and prevention services, initially focused in those geographic areas most impacted by HIV, coordinated by multi-agencies of the federal government, and implemented by state and local governments along with community-based organizations;

Whereas, in order to accelerate the planning in preparation for rapid implementation, the Department of Health and Human Services (HHS) utilized existing resources from the Minority AIDS Fund and other programs to fund jurisdictions to develop Ending the Epidemic plans, initiate pilot projects, provide PrEP for the uninsured, increase testing and treatment in Native communities, develop research projects and provide workforce training assistance.

Whereas, in order to provide first year foundational support for the Ending the Epidemic, the President included \$291 million in his Fiscal Year 2020 budget. This included \$140 million in new funding for CDC HIV prevention programs, \$70 million in new funding for the Ryan White HIV/AIDS Program, \$50 million to the Bureau of Primary Health Care to provide Pre-exposure prophylaxis (PrEP) for those at risk of HIV; \$25 million in new funding to the Indian Health Service for HIV and hepatitis C testing; and \$6 million for the NIH Centers for AIDS Research;

Whereas, support for the Ending the Epidemic initiative has enjoyed widespread bipartisan support in the Congress, and first year resources have been proposed, but not yet finalized, in both the House of Representatives and the Senate’s Fiscal Year 2020 spending bills;

Whereas, if we are to attain the goals of a 75 percent reduction of HIV in the U.S. in 5 years, and a 90 percent reduction in 10 years by scaling up the diagnosis of HIV, treatment, prevention, including the use of PrEP, the creation of a HIV HealthForce to assist local jurisdictions on the ground, and to overcome the obstacles identified by community and state and local government representatives since the program was announced, jurisdictions will need a substantial increase of resources not only for Fiscal Year 2021 but in future years;

Therefore, be it resolved that PACHA urges the Secretary of Health and Human Services to continue to work with the Congress and the Office of Management and Budget to ensure that first year funding for the initiative is finalized in a timely fashion so that grant awards by the various agencies can be distributed to Ending the Epidemic grantees as scheduled;

Be it further resolved that we urge the Secretary to work with the Office of Management and Budget to ensure that the President’s budget for Fiscal Year 2021 contains the necessary resources to implement year two of the Ending the Epidemic initiative by providing substantial

Approved by unanimous vote of PACHA members on October 22, 2019

increased resources to each of the agencies, programs, and communities implementing the initiative;

Be it further resolved that we urge the Secretary to work with the Office of Management and Budget to ensure there are no proposed cuts to programs such as the Housing and Urban Development's Housing Opportunities for People with AIDS (HOPWA) and other federal government programs that impact the success of meeting the goals of the Ending the Epidemic initiative.

Approved by unanimous vote of PACHA members on October 22, 2019

Presidential Advisory Council on HIV/AIDS (PACHA)
Resolution in Support of Robust Community Engagement in the Ending the Epidemic Initiative

Whereas, robust, meaningful community engagement in the planning and implementation of the *Ending the HIV Epidemic* (EHE) initiative, including people living with and at risk of HIV, is vital to its success;

Whereas, structural and institutional racism and social determinants of health have fueled HIV health inequities in communities of color;

Whereas, historically marginalized communities formed community-based HIV organizations to address the shortcomings of the governmental response to HIV, and minority-focused community-based HIV organizations were established to address the shortcoming of all organizations' responses to HIV in communities of color;

Whereas, the success of the *Ending the HIV Epidemic* plan will not be realized unless the communities most impacted by HIV, including gay, bisexual, and other men who have sex with men, transgender and cisgender women, two-spirit people, and people living with HIV, especially in communities of color, are meaningfully involved in the planning, implementation, and evaluation of EHE plans.

Whereas, as the *Ending the HIV Epidemic* plan is being implemented by various federal agencies through the awarding of grants to state and local governments, along with community-based organizations;

Therefore, be it resolved that all federal agencies involved in the EHE meaningfully involve communities, including people living with and at risk of HIV, in Federal planning and evaluation of the EHE;

Be it further resolved that all federal agencies involved in the EHE require and monitor each grantee for meaningful community engagement of those most impacted by HIV, including established and newer community-based organizations and communities of color, in their state and/or local EHE planning process;

Be it further resolved, that all Federal agencies involved in EHE establish processes for high-quality feedback loops in the planning process that allow for clear, regular communication with members of the impacted communities about progress on EHE initiatives within their jurisdictions and nationally;

Be it further resolved that all Federal agencies involved in EHE ensure that grantee implementation plans occur within organizations that have the trust and engagement of communities at highest risk for HIV and that;

Be it further resolved that all Federal agencies ensure that each grantee and subgrantee has key performance goals tied to EHE goals and quality improvement structures in place to evaluate progress and quickly realign work as necessary.

Approved by unanimous vote of PACHA members on October 22, 2019

Presidential Advisory Council on HIV/AIDS (PACHA)
Resolution in Support of Innovation to End the HIV/AIDS Epidemic

Whereas, the national *Ending the HIV Epidemic: A Plan for America* calls for reducing new HIV infections in the United States by 75 percent in five years and by 90 percent by 2030;

Whereas, we now have the right data, the right tools, and the right leadership to end the HIV epidemic;

Whereas we know that for persons living with HIV/AIDS providing treatment that achieves long-term viral suppression allows for a normal, healthy lifespan and makes HIV untransmittable;

Whereas we know that we have a spectrum of effective HIV prevention tools including Pre-Exposure Prophylaxis (PrEP), HIV treatment as prevention (TasP), consistent and correct condom use, negotiated sexual safety (testing twice, having a sexually exclusive and trusted relationship), non-occupational post exposure prophylaxis (nPEP), and syringe service programs;

Whereas, PACHA is taking its meetings into communities, listening to those on the front lines of ending this epidemic, and gathering information on barriers to success;

Therefore, be it resolved that PACHA urges the Secretary of Health and Human Services (Secretary) in a whole-of-government approach to ending this epidemic to work with all engaged federal agencies to address any financing, legal, policy, system, grant making, contracting, workforce or other barriers that stand in the way of communities implementing their innovation plans to end the HIV epidemic, including efforts to address stigma, discrimination, lack of trust, and social determinants of health (e.g., housing, food, transportation, employment, social support networks);

Be it further resolved that the federal government support and remove financing, eligibility, clinical practice, workforce and other barriers that:

- do not allow someone who is diagnosed with HIV from receiving HIV treatment medication at the same clinical encounter,
- do not allow someone who is HIV negative and screened at risk for HIV from receiving PrEP medication at the same outreach or clinical encounter, and
- do not allow for evidence-based syringe service programs;

Be it further resolved that the federal government support and remove financing, policy, system, grant making, contracting, workforce or other barriers for innovative differentiated models of HIV prevention and treatment, including but not limited to overcoming barriers for:

- service delivery models that make use of telemedicine or telehealth or other technology to reach community,

Approved by unanimous vote of PACHA members on October 22, 2019

- service delivery models that incorporate peer delivered, culturally appropriate service models that include community support activities from trusted community-based providers,
- outreach, testing, and care models that make use of mobile vans,
- outreach, testing, and care models that make use of persons providing services in the field including on the street, homeless camps/shelters, social service offices, cultural events, community events, and the like,
- clinical models that make use of extended hours on evenings and weekends,
- service delivery models that use of self-testing kits for HIV infection,
- service delivery models that make use of pharmacists,
- education being delivered with cultural competency and humility,
- promotion of TasP,
- directly funding community entities to implement powerful, population-specific prevention and care services, and media/marketing initiatives,
- programs that support the health of people who use drugs, are living with mental health disorders, are 50 years of age and older, are trans persons, and/or are living with other disabilities;
- simultaneously addressing the syndemics of hepatitis C, sexually transmitted infections, substance use disorder, and
- service delivery to those who are living in incarceration;

Be it further resolved that the federal government work with all HIV/AIDS related service delivery programs to collect data that is all-gender inclusive to help ensure the best prevention and care programs are reaching transgender persons, and that it ensure this data collection is legally protected from individual disclosure;

Be it further resolved that the federal government work with states, territories, tribes, and local governments to remove barriers that:

- do not allow for the establishment of evidence-based syringe service programs,
- criminalize HIV status,
- do not allow access to PrEP or timely access to nPEP as prevention, including for minors at increased risk for HIV to access to PrEP or nPEP without parental consent, and
- do not allow access to antiretroviral medications for treatment;

Be it further resolved that the Secretary work with federal agencies and the medical community to evaluate the frequency of medically necessary tests to monitor for side effects of PrEP treatments, and that for such medically necessary tests that the federal government identify mechanisms and means to reduce the costs of those tests and to fund the costs of those tests in ways that either eliminate or reduce the cost to the individual;

Be if further resolved that the federal government call upon those states, territories, and tribes that have not mandated the laboratory reporting of HIV viral load testing (detectable and

undetectable) to do so in support of monitoring and evaluating the effectiveness of HIV treatment programs; and

Be it further resolved that the federal government call upon and work with states, territories, tribes, and local governments to remove policy, procedure, and other system barriers that would prevent the quick receipt and use of federal funds to help end the HIV epidemic.