

**Presidential Advisory Council on HIV/AIDS (PACHA)
57th Meeting**

Ronald Reagan Building and International Trade Center

Washington, DC

September 15, 2015

Council Members—Present

David Holtgrave, Ph.D., Vice Chair

Jeffrey S. Akman, M.D.

Ada A. Adimora, M.D., M.P.H.

Oliver Clyde Allen III

Gina M. Brown, M.S.W.

Ulysses W. Burley III, M.D., M.P.H.

Vignetta Charles, Ph.D.

Cecilia C. Chung

Michelle Collins-Ogle, M.D., FAAP,
AAHIVS

Yvette Flunder, D.Min.

Grissel Granados, M.S.W.

Gabriel Maldonado, M.B.A.

Douglas A. Michels, M.B.A.

Ligia Peralta, M.D., FAAP, FSAHM,
AAHIVS

Mario Pérez, M.P.H.

Harlan H. Pruden

Scott A. Schoettes, J.D.

Vanessa D. Sharp, M.Div., MACM,
MATM

Lawrence A. Stallworth II

Elizabeth Styffe, M.S.N.

Mildred Williamson, Ph.D., M.S.W.

Council Members—Absent

William H. Collier

Lucy A. Bradley-Springer, Ph.D., R.N.,
ACRN, FAAN

Robert Greenwald, J.D.

Nancy Mahon, J.D., PACHA Chair

Staff

Kaye Hayes, M.P.A., PACHA Executive
Director

Caroline Talev, M.P.A., Public Health
Analyst

Chynna Cole, B.B.A., ORISE Fellow

Federal Liaisons

George Fistonich, M.P.H., Policy Assistant, White House Office of National AIDS Policy
(ONAP)

Michael Goldrosen, Deputy Division Director, Division of State HIV/AIDS Programs,
Health Resources and Services Administration (HRSA)

Jennifer Kates, Ph.D., Liaison, Centers for Disease Control and Prevention (CDC)/HRSA
Advisory Committee on HIV, Viral Hepatitis, and Sexually Transmitted Disease
Prevention and Treatment

Eva Margolies, M.P.A., Associate Director for Planning and Policy Coordination, National
Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease
Control and Prevention (CDC)

Ronald O. Valdiserri, M.D., M.P.H., Deputy Assistant Secretary for Health, Infectious
Diseases; Office of HIV/AIDS and Infectious Disease Policy, Office of the Assistant
Secretary for Health, U. S. Department of Health and Human Services (HHS)

Presenters

Cassandra Ackerman, National AIDS Housing Coalition Board Member, Consumer Advisory Board Chair

Allison Lorna Agwu, M.D., Assistant Professor of Infectious Diseases, Johns Hopkins University School of Medicine, Division of Pediatric Infectious Diseases

Arturo Bendixen, Executive Director, Center for Housing and Health, AIDS Foundation of Chicago

Rusty Bennett, Ph.D., Chief Executive Officer, Collaborative Solutions, Inc.

Mary Bowman, Policy and Advocacy Associate, The Women's Collective

Douglas Brooks, M.S.W., Director, ONAP

Michael Horberg, M.D., M.A.S., FACP, FIDSA, Director, HIV/AIDS, Kaiser Permanente; Executive Director, Research and Community Benefit, Mid-Atlantic Permanente Medical Group; Director, Mid-Atlantic Permanente Research Institute

Twiggy Pucci Garçon, Program Officer, True Colors Fund

Hailie Sahar, Lesbian/Gay/Bisexual/Transgender (LGBT) Activist

Marsha Smith, M.D., M.P.H., Medical Officer, Quality Measurement and Value-Based Incentives Group, Center for Clinical Standards and Quality, Centers for Medicare and Medicaid Services (CMS)

Benjamin Young, M.D., Ph.D., Senior Vice President, Chief Medical Officer, International Association of Providers in AIDS Care

Welcome

PACHA Executive Director Kaye Hayes, M.P.A., called the meeting to order at 9:07 a.m. PACHA Vice Chair David Holtgrave, Ph.D., welcomed the members of the Council and meeting attendees. (PACHA Chair Nancy Mahon, J.D., was unable to attend.) He extended special thanks to Mario Pérez, M.P.H., who has completed his service as a PACHA member, and presented Mr. Pérez with a certificate of appreciation. Mr. Pérez called his time on PACHA one of his proudest achievements and thanked the Administration, PACHA staff, and PACHA colleagues for the opportunity to serve. He trusted that PACHA would continue to work toward ending HIV in America.

Dr. Holtgrave thanked the PACHA staff for their hard work in support of PACHA; he said PACHA could not ask for better partners in the Administration than Ronald O. Valdiserri, M.D., M.P.H., and ONAP Director Douglas Brooks, M.S.W.

Roll Call

Ms. Hayes called the roll.

Overview of the Agenda

Dr. Holtgrave outlined the agenda. He hoped that feedback and ideas from recent events—the U.S. Conference on AIDS, at which PACHA held a public input session; the North American Housing and HIV/AIDS Research Summit, at which PACHA held a town

hall meeting; and a joint meeting of the PACHA Access to Care and Disparities Subcommittees—would be part of the discussion. For example, at the Housing and HIV/AIDS Research Summit, a group of transgender activists presented a list of “demands” related to the rights of transgender people; the list was sent to PACHA members by e-mail.

Scott A. Schoettes, J.D., presented a letter to the ONAP director, drafted by the Disparities and Access Subcommittees, recommending that social determinants of health (SDH) be addressed by Federal agencies developing their updated National HIV/AIDS Strategy (NHAS) implementation plans. The updated NHAS addresses the role of SDH and also highlights the need for coordination across agencies, so the letter underlines the importance of tying those two concepts together. Ms. Hayes said the letter from PACHA should be addressed to HHS Secretary Sylvia Burwell, who would send it to ONAP. PACHA members suggested that the letter address barriers to care for immigrants and for people living with HIV (PLHIV) in the southern United States. It also should be worded more strongly. Dr. Holtgrave asked that PACHA members provide Mr. Schoettes with comments, and said that PACHA would revisit the letter and vote on it at the end of the day.

Updated NHAS

Douglas Brooks, M.S.W., Director, ONAP

Mr. Brooks thanked PACHA for its thoughtful input on NHAS; he also thanked those members who moderated or served as panelists for conference sessions to support the rollout of the NHAS. ONAP has received tremendous feedback on the document.

Federal agencies must now develop action plans (combining implementation and operating plans) within 100 days. The President has called on some Federal partners who have not traditionally been included in HIV/AIDS discussions, including the Departments of Education, Homeland Security, Interior, and Defense and the Equal Employment Opportunity Commission, to be part of a robust action plan for the NHAS. Mr. Brooks acknowledged that some topics were left out of the NHAS because they were considered too granular for a broad strategy. However, ONAP is combing through all the recommendations it has received and will include many of them in agency action plans. In some cases, ONAP will direct Federal agencies; in others, the agencies will propose responses. Mr. Brooks said ONAP sees the NHAS as a roadmap for the remainder of this Administration’s term, a transitional document for the next Administration, and, hopefully, a guide for the next Administration.

Discussion

PACHA Subcommittees presented recommendations for the updated NHAS action plans.

Incidence Subcommittee

- Federal agencies should harmonize their definitions of quality HIV care and mandatory quality indicators, e.g., HIV testing and virologic suppression, with those of private and other payers. (For example, some National Committee for Quality Assurance Healthcare Effectiveness Data and Information Set [HEDIS] indicators and HRSA measures concerning HIV screening and testing do not align.)
- Agencies should work together to ensure universal adoption of CDC HIV and hepatitis C virus (HCV) screening guides as part of meaningful use requirements.
- CDC should publish annual estimates of HIV incidence (as other countries do).
- Federal agencies should work together to educate Congress about the efficacy of syringe exchange programs in preventing HIV and HCV and to achieve implementation of effective syringe exchange programs throughout the nation, especially in those areas hit hardest by injection drug use.
- CDC should effectively inform and educate target populations about the existence and benefits of pre-exposure prophylaxis (PrEP), and Federal agencies should work together to enable providers to be paid for PrEP counseling.
- Agencies should work to end disparities in HIV prevention by encouraging all State Medicaid programs to cover routine HIV screening for their traditional Medicaid population (which is currently the only group for whom access to routine HIV screening is not mandatory), especially in States—many of which are in the South—that have not yet expanded their Medicaid programs.
- The National Institutes of Health (NIH) should revise its reprioritization of AIDS research funding to include behavioral and social science research, given the importance of this research in efforts to prevent and cure HIV infection.
- Relevant Federal agencies (e.g., CDC and the Department of Education) should develop State report cards concerning the extent to which each State delivers comprehensive sex education.

Comments

Mr. Brooks and Dr. Valdiserri pointed out that counseling for PrEP is covered in CDC-funded programs, but not in other instances. Ada A. Adimora, M.D., M.P.H., clarified that the recommendation seeks coverage of counseling for PrEP in all settings. PACHA members noted that knowledge about PrEP and access to PrEP are inadequate, so much more communication and education of providers and consumers are needed. Mr. Brooks agreed and urged PACHA to continue to offer advice on how to address four key aspects of the NHAS: widespread testing and linkage to care, universal viral suppression, access to PrEP, and retention in care.

Access to Care Subcommittee

- The Administration should release regulations on the implementation of Section 1557 of the Affordable Care Act (ACA). The nondiscrimination protections of the ACA are critical, and ensure that regulations and practices employed by some

insurers to discourage enrollment or limit coverage for individuals with HIV and others with complex and/or chronic conditions are not implemented. Practices that must be prohibited under the law include having provider networks without HIV expertise, failing to cover antiretrovirals (ARVs) or other commonly prescribed HIV medications, placing all ARVs or other HIV medications on the highest or one of the highest cost-sharing tiers, and not complying with the requirement to accept premium or cost-sharing payments from the Ryan White HIV/AIDS program.

- Qualified health plans should use standardized, streamlined prior authorization processes that require prior authorization for medications and services to be based on clinical evidence, including safety.
- CMS should issue a State Medicaid directors letter on the importance of providing access to HIV and HCV medications across fee-for-service and managed care programs and of taking actions that uphold clinically appropriate use, without limitations, of ARVs, direct-acting antivirals for HCV, and HIV-related services.
- The Center for Medicare and Medicaid Innovation, in conjunction with HRSA, should evaluate models for providing access to case management and other psychosocial support services for HIV primary care providers.
- CMS should work with the Substance Abuse and Mental Health Services Administration and other Federal agencies to implement Medicaid demonstration projects for integration of behavioral health in HIV services, including programs for juveniles and adults in the justice system, and develop Medicaid managed care delivery and financing models that seek to integrate mental and behavioral health with primary and HIV care.

Reducing HIV-Related Disparities Subcommittee

- There should be uniform HIV measures of testing for all patients ages 13–64; the number of annual visits by HIV-positive patients; the frequency of viral load testing; and, most importantly, the percentage of patients achieving viral suppression across all federally supported programs. The Subcommittee also supports adoption of these same standards by private health insurance plans. At the same time, there should be incentives for care and treatment for those who present significant challenges to adherence to ensure that providers do not exclude people who are harder to treat.
- Leverage new Affordable Care Act (ACA) requirements with regard to collection of data related to health-related disparities for the lesbian, gay, bisexual, and transgender (LGBT) population to collect better national data on HIV-related health disparities among this population. The inclusion of sexual orientation and gender identity questions in Federal data collection efforts and surveys of LGBT health-related disparities will help prioritize resources, address stigma, and improve quality of care. We urge CMS, working across Federal agencies, to

ensure that HIV-related disparities across the LGBT community and among racial and ethnic minorities also are captured in Federal datasets.

- Maintain the integrity of Medicaid programs by ensuring that any approved Section 1115 Medicaid expansion waivers preserve essential Medicaid protections, such as premium and cost-sharing protections and requirements, and reject proposals that include work requirements. We strongly support expansion of Medicaid programs in every State, but not at the expense of the integrity of the programs and the low-income and vulnerable people that they serve.
- Direct HHS to require all health care facilities and education programs that receive government funding to adopt training, policies, and plans to ensure that LGBT people and PLHIV are treated fairly and respectfully by all health care staff and students.

Global Agenda Subcommittee

The Global Subcommittee does not have recommendations but is working with the other Subcommittees to shine a light on the best practices internationally that may inform domestic efforts.

Comments

Mr. Brooks said the State Department is required to provide a list of best practices in the global arena, and ONAP is working closely with Deborah Birx, M.D., Ambassador-at-Large, who oversees AIDS programs and global health diplomacy for the State Department. Mr. Brooks hoped that ONAP and the State Department would have something ready for World AIDS Day.

Young Voices: The State of Youth and HIV/AIDS

Introduction

Grissel Granados, M.S.W., PACHA Member

Ms. Granados described the impact of HIV on young people and poor outcomes for young people across the continuum. To address disparities, young people need funding, policies, and interventions that are age-specific and responsive to developmental needs. It is not okay to lump young people in with adults, stressed Ms. Granados. Young people must be involved at every level of policymaking and program implementation, because they are affected the most. Ms. Granados hoped the discussion today would lead to concrete actions that PACHA and Federal partners can take to meet the updated NHAS goals.

Moderators

Gabriel Maldonado, M.B.A., and Lawrence Stallworth II, PACHA Members

HIV/AIDS Among Adolescents and Youth: State of the Epidemic and Urgent Needs

Allison Lorna Agwu, M.D., Assistant Professor of Infectious Diseases, Johns Hopkins University School of Medicine, Division of Pediatric Infectious Diseases

Despite decreases in HIV infection in other groups, rates of new diagnoses are increasing among those 13–24 years old, and most young people do not know their HIV status. Several factors may explain why youth are at increased risk, including biology, brain development (most notably the continued brain development into the mid-20s), cognitive development that limits the ability to perceive consequences, risk-taking and experimentation, psychosocial development, and decreased parental and adult supervision. Dr. Agwu pointed out that these factors can sometimes have a positive influence (e.g., spurring novel thinking and creativity) but also can lead to teen pregnancy, sexually transmitted infections (STIs), and substance abuse.

Young PLHIV face numerous psychosocial challenges related to their status. A range of clinical considerations come into play in treating them, with unique clinical considerations for those who were perinatally infected. Because those ages 18–24 are often lumped in with older adults, data are slim, but evidence indicates that young adults are less likely than older adults to initiate treatment and more likely to discontinue treatment. They are less likely to reach viral suppression or continue in care. Many young people are lost in the transition from pediatric to adult care providers.

National and international authoritative bodies recognize young PLHIV as a special population, but much more research is needed to understand their unique needs. The Adolescent Trials Network for HIV/AIDS Interventions (ATN) was formed to address behavioral and clinical questions, with the goal of improving HIV prevention and treatment for teens. Its achievements include the Connect to Protect program, which focuses on building community infrastructure for primary prevention among youth, and the Strategic Multisite Initiative for the Identification, Linkage, and Engagement in Care of Youth with Undiagnosed HIV Infection (SMILE), which links ATN sites with local health departments.

Dr. Agwu pointed out that the ATN is ideal for collecting needed data on biomedical and behavioral interventions among youth and adolescents. Plans are underway to restructure the ATN before the next round of NIH funding, discontinuing the Connect to Protect and SMILE programs by early 2016. Dr. Agwu raised concerns about the potential implications of the restructuring. She hoped the changes would maintain the effective components of ATN while optimizing those that need improvement.

Mr. Stallworth asked how to get more young people involved in community advisory boards for research studies in ways in which they are not simply “token” members who do not benefit. Dr. Agwu responded that young people should be invited to consult on

protocols during development, not after they are designed, and that they should be paid for their time (e.g., through incentives such as gift cards).

House... Ball... Home

Twiggy Pucci Garçon, Program Officer, True Colors Fund

Mr. Garçon outlined the history of balls, beginning in the 1920s, in the gay community. Over time, the Harlem drag balls evolved into house balls to provide support for those ejected from their homes because of their sexual orientation or gender identity. Among homeless youth, 40 percent identify as LGBT, compared with 7 percent of their peers who have homes. Family rejection leads the list of reasons why LGBT youth are homeless or at risk of becoming homeless (either because they ran away or were forced out). The other most common reasons are abuse, aging out of foster care, and financial or emotional neglect by the family.

Mr. Garçon said youth inform all the work of the True Colors Fund, which supports advocacy, education, research, community building, and youth collaboration. He noted that one cannot expect young PLHIV to adhere to PrEP or treatment when they do not have a place to live. In such circumstances, treatment is not a priority. Therefore, efforts to address homelessness are a very important part of treating HIV/AIDS.

Mr. Stallworth asked whether organizations like the True Colors Fund have played a role in shaping prevention and intervention strategies that concentrate on the house and ball community, such as HHS' sponsorship of the Latex Ball, and whether these strategies have been undertaken in culturally sensitive and meaningful ways. Mr. Garçon said that in the case of the Latex Ball, input was provided to GMHC, which organizes the event. In other cases, the interventions were pushed on to the community with no input. Sometimes the community creates its own initiatives, but efforts to disseminate them are not always successful.

Insights on Transgender Youth

Hailie Sahar, LGBT Activist

Ms. Sahar said she is a young, proud, minority transgender woman who first experienced the ballroom scene at age 16. She had run away from home, and she did not know who she was or why she felt that she was in the wrong body. Through the ballroom scene, she met people like her and began to understand why she had felt disconnected from her own body as early as 3 years old. It took running away and rebelling against her mother to discover herself because there was not very much information available to her.

The lack of attention to transgender issues is one of the biggest issues transgender people face, even within the LGBT community, where the "T" is often lost. Transgender people have specific psychological and emotional needs, Ms. Sahar said, and the challenges they face have many layers.

People often do not understand that transgender people want what everyone else wants—the American dream, a normal and happy life, and access to health insurance. Young women, especially minorities, often self-medicate. They may turn to sex work for affection or to each other for knowledge (despite the lack of knowledge among peers). Therefore, young women become infected with HIV and involved with narcotics. Ms. Sahar said she knew nothing when she was younger, but by the grace of God and her mother, she sits before PACHA today. More diligent work is needed that is specifically focused on the unique needs of transgender people, Ms. Sahar concluded.

Cecilia C. Chung asked whether Ms. Sahar sees herself in prevention messaging, HIV treatment advertising, or the media's faces of HIV. Ms. Sahar said she did not, nor do her peers. Because transgender people do not see themselves in the media or anywhere else, they lose hope, and so they turn to sex work for affection or to narcotics to numb the pain. Ms. Sahar said she became involved in the ballroom scene and pageants (she is Miss L.A. Pride 2015) so young people can see someone positive.

Reflections on Underserved Young PLHIV

Mary Bowman, Policy and Advocacy Associate, The Women's Collective

Ms. Bowman said she personally represents three communities often overlooked in the conversation about HIV or addressed only as a footnote: black women, lesbians, and the perinatally infected. She echoed Dr. Agwu in calling for inclusion of young people in the groundwork development of prevention strategies and clinical trials; when they are consulted at the end of the process, young people do not feel that their opinions matter.

According to Ms. Bowman, the conversation about LGBT and queer/questioning youth often highlights young men who have sex with men because of their high rates of HIV infection. Lesbians have low rates of HIV/AIDS transmission, but lesbian and queer young women are infected. While growing up with HIV, Ms. Bowman said she went through a phase of experimenting with sex and did not know how to navigate with HIV. There were no programs describing how she could protect herself or her partners. Dental dams were distributed along with condoms but without accompanying information for lesbians.

Ms. Bowman asked that PACHA members relay the importance of including lesbians in clinical prevention studies, because they have HIV, too. Prevention is often male-driven and focused on male condoms. Ms. Bowman said women report that the female condom does not feel good and they do not like it. She wondered how women could be empowered if the only tool they have to prevent HIV is one they do not like.

Mr. Stallworth asked Ms. Bowman to draw on her extensive background using art as prevention to address how media can be used to engage young people and also to

bridge the intergenerational gap. He said it appears that young people are seen as complacent, while in truth, today's youth have never known a world without HIV. Ms. Bowman agreed that art can be used for advocacy, for prevention, and as a tool for healing. She suggested creating more space for other HIV-positive youth to create and use art. The older generation can help promote the work of youth and bring their messages to the world, creating a bridge between generations.

Discussion

Mr. Maldonado asked presenters what they have learned from young people. Ms. Sahar said she has learned that young people are yearning for more. Mr. Garçon said young people are the experts of their own truth and experts on how to solve their problems and move forward. Ms. Bowman said she has learned how to live unapologetically. Dr. Agwu said she has learned about resiliency, noting that she is amazed that young PLHIV manage given the many barriers they face. She added that everyone was young at some time, and individuals either sink or swim, so it is necessary to learn from those experiences how to support young people.

Regarding the roles of young people in implementation of the NHAS, Dr. Agwu stressed the importance of having input from youth about every step of the cascade of care (the drop in PLHIV in care at each stage from diagnosis through viral suppression), and Ms. Sahar and Ms. Bowman agreed. Mr. Garçon challenged whether youth are truly represented, even at PACHA.

Ms. Granados said the key points she gathered from the presentations were as follows:

- Young people are the experts of their own truth and the solution.
- Knowing the history and acknowledging the expertise of the community is important; advice on how to create solutions should be sought early, before decisions are made.
- Leadership must be representative of the epidemic; every meeting should include young people and people of color.
- Communities should drive research, interventions, and practice.

Mr. Brooks thanked the presenters. Because no one has determined how to measure the impact of love, it is incumbent on all of those involved in HIV treatment and policymaking, in conjunction with PACHA and ONAP, to determine how to measure the impact of community, art, and social support, so that the evidence can become part of interventions, he said.

Discussion turned to the challenges of making the transition from pediatric to adult health care providers. Pediatric providers are often reluctant to address issues involving sexuality. Dr. Agwu agreed that health care providers who primarily treat adults need more education on treating young people and being sensitive to their unique needs and

concerns. On the other hand, for some youth, a pediatric provider is the only consistent, stable, long-term adult relationship they have. Dr. Agwu said there is an NIH call for research projects related to provider transitions.

Mr. Garçon said that every major city has a ball alliance that meets regularly, and there is a national house and ball alliance, so there are many opportunities for networking. Regarding employment opportunities, Ms. Sahar said that opportunities for mentoring and entrepreneurship would “change everything” for transgender women, who may have the ability or desire to do more with their lives but do not know how. Mr. Garçon said the True Colors Fund recently completed a report on youth that includes education issues. He noted that some youth are ejected from their homes, yet their families still claim them as dependents on their tax forms, which limits their ability to apply for school funding.

Dr. Agwu said she did not think young people were consulted about plans to restructure the ATN. She stressed that establishing community buy-in was a lot of work, and all that effort could be lost if the program were dismantled. Several PACHA members spoke about the importance of continued funding for ATN programs.

Mr. Garçon suggested reaching youth by being open to nontraditional media, including social media; establishing connections with house parents; and working with leaders within the community. Mr. Maldonado added that Facebook is key for reaching young people. He said that providing incentives for house parents to bring young people to interventions is a successful, evidence-based approach. Dr. Agwu said institutional review boards need education about the appropriate use of Facebook to reach research participants (e.g., through private messaging functions).

Public Comment Period

Nicholas Taylor of The AIDS Institute urged President Obama to continue fighting against efforts by Congress to cut funding for HIV/AIDS domestic programs. Such cuts would prevent the attainment of the goals of the NHAS. One proposal would eliminate funding for the HHS Secretary’s Minority AIDS Initiative, which provides resources for collaborative efforts that benefit minority communities affected by HIV. The same proposal would cut funding for Special Projects of National Significance under the Ryan White HIV/AIDS program, which has developed innovative service models for the most vulnerable populations. Other cuts have been proposed for STI prevention, teen pregnancy, family planning programs, and the ACA. The AIDS Institute is pleased to see the loosening of restrictions on funding syringe exchange programs and urges the Administration to work with Congress to ensure that the new language is included in a final spending measure. It also urges the Administration to continue to propose robust funding for HIV/AIDS programs to meet the goals of the updated NHAS.

The following written comments were reviewed by PACHA:

The ATN Youth Community Advisory Board to the Children’s Hospital Colorado Immunodeficiency Program asked that PACHA not support dismantling the ATN and support keeping the current ATN structure, which has allowed young PLHIV to thrive.

Barb Cardell and Kari Hartel, Co-Chairs of the Positive Women’s Network U.S.A.—Colorado Chapter, asked that PACHA not support dismantling the ATN and instead encourage the ATN to broaden the involvement of external stakeholders, advocates, and PLHIV. They did not believe the proposed new structure will better serve those at risk of or living with HIV.

J. Maurice Ka-Mashiriuche of the Youth HIV Advocacy Coalition said that work in the Denver area supported by the ATN, specifically the Connect to Protect Coalition, has served as a critical launchpad for the future of HIV prevention and advocacy on behalf of the target demographic.

Elizabeth McFarland, M.D., and Daniel H. Reirden, M.D., AAHIVS, co-principal investigators of the University of Colorado School of Medicine’s Adolescent Medicine Trials Unit, said the proposed restructuring of the ATN appears to risk the loss of mature community collaborations that have advanced clinical care of both young PLHIV and those at risk. They urged PACHA to support reconsideration of the restructuring proposal given the disruption it would bring to a valuable, community-engaged response to the goal of eliminating HIV among youth.

Moises Muñoz and Melissa Janiszewski, Co-Chairs of Connect to Protect Denver, described how the ATN’s community-based research efforts helped support structural level changes that affect young people and HIV incidence throughout Denver.

Latrice Pichon of Connect to Protect Memphis said that ATN community coalitions have accomplished structural changes in the Memphis community addressing the needs of at-risk youth and have allowed for community input and cross-disciplinary dialogue to strategize and develop solutions to reduce and eliminate HIV disparities.

Mary R. Tanney, M.S.N., M.P.H., CRNP-BC, AAHIVS, of the ATN at The Children’s Hospital of Philadelphia, said the impact of not having core funding to continue the work of the ATN will be devastating to the youth at local ATN sites around the country. The ATN has the infrastructure, scientific therapeutic and behavioral researchers, invested trained personnel, and community partners to lead the way to have an impact on this epidemic in youth in the United States, she noted.

Craig M. Wilson, M.D., of the University of Alabama at Birmingham provided a thorough overview of the impact of proposed infrastructure changes to the ATN and recommended reconsideration of the need to disrupt and dismantle a successful network focused on a key population of the domestic HIV epidemic. He also

recommended opening the dialogue about the concerns and perceived advantages of the proposed new structure.

Discussion

Discussion ensued about possible responses from PACHA regarding funding of the ATN. Concerns were raised that successful models built over many years would be abruptly discontinued, and communities would lose needed services. The programs are a valuable source of community input into HIV responses. The lack of transparency in decisionmaking is concerning, as is the lack of a rationale for ending the programs. It was suggested that PACHA reach out to NIH to request a 1-year delay in the restructuring of the ATN that would allow time to craft a transition plan. It was then proposed that a subset of PACHA members organize a meeting with key NIH staff to better understand the plan and rationale for the restructuring and bring the findings back to PACHA for further discussion.

Action Item

PACHA staff will arrange a meeting with NIH staff to discuss the restructuring of the ATN. The following PACHA members volunteered to take part: Michelle Collins-Ogle, M.D., FAAP, AAHIVS; Yvette Flunder, D.Min.; Grissel Granados, M.S.W.; Ligia Peralta, M.D., FAAP, FSAHM, AAHIVS; Scott Schoettes, J.D.; and Mildred Williamson, Ph.D., M.S.W.

Quality Measures and the Potential Impact on the HIV Care Continuum Initiative

Moderators: Michelle Collins-Ogle, M.D., FAAP, AAHIVS, and Mario Pérez, M.P.H., PACHA Members

Mr. Pérez said the Disparities Subcommittee is seeking a structural intervention that could help level the playing field. The goal of this panel discussion is to consider what performance measures could be helpful and how to use both carrots and sticks to drive progress on HIV-related measures. Dr. Collins-Ogle added that the Subcommittee hopes to spur conversation about a standardized, harmonized set of quality measures.

CMS Quality Measurement

Marsha Smith, M.D., M.P.H., FAAP, Medical Officer, Quality Measurement and Value-Based Incentives Group, Center for Clinical Standards and Quality, CMS

Dr. Smith described the aims and goals of CMS' quality improvement strategy. She summarized numerous principles for measure development at CMS, emphasizing that measures must fill a gap in knowledge. They should be patient-centered, outcome-based, and meaningful to caregivers. Challenges of measure development include defining the right outcome or performance gap, engaging patients in the process, advancing the science for critical measure types (e.g., patient-reported outcomes), and accepting the length of time needed for development.

CMS quality programs fall into three categories: pay for reporting, pay for performance, and pay for value. The Physician Quality Reporting System is a voluntary quality reporting program that encourages individual professionals and group practices to report information on the quality of care provided to Medicare beneficiaries. CMS works with specialty societies to ensure that measures accurately reflect clinical practice.

The CMS Measures Coordination Workgroup reviews measures and provides input to the HHS Measures Policy Council, which identifies core sets of measures and makes recommendations on their alignment with other measures and programs. By statute, annually, before the Federal rulemaking process begins, a multi-stakeholder group evaluates the HHS' proposed quality measures and makes recommendations. CMS reviews the input and then publishes its rationale for adopting any quality or efficiency measure that is not already endorsed by the National Quality Forum. CMS assesses the impact of the use of its measures and makes that assessment public at least every 3 years.

HIV Quality Metrics in the Private Sector

Michael Horberg, M.D., M.A.S., FACP, FIDSA, Director, HIV/AIDS, Kaiser Permanente; Executive Director, Research and Community Benefit, Mid-Atlantic Permanente Medical Group; Director, Mid-Atlantic Permanente Research Institute

Dr. Horberg likened Kaiser Permanente to a miniature national health system because it serves as the provider, the insurer, and the facilities all at once. Like other private insurers, it serves an increasing number of PLHIV and people at risk of HIV. There is national recognition of the need to standardize and harmonize quality measurements.

A group of national organizations teamed with HRSA to propose standard HIV measures in 2008. Dr. Horberg described some shortcomings of those measures; notably, they do not include measures of testing or access to care and were not intended for use in pediatric care. The process measures include the number of medical visits to track retention in care and require twice-yearly assessment of CD4 cell counts. The treatment measures may be out of date. Despite an "A"-level recommendation by the U.S. Preventive Services Task Force for universal screening for HIV infection for adults ages 15–65 years, there are no nationally accepted metrics to track such screening.

In 2013, HHS created seven key measures for HIV, and a group of national and Government organizations has identified five core metrics. Dr. Horberg presented data from Kaiser Permanente demonstrating the use of measures to guide and improve performance over time.

Dr. Horberg offered numerous issues for consideration. For example, actual results are better than claims data (or estimates). Outcome measures are better than process measures. Tracking patients across systems, the ease of reporting, the number of

metrics, and privacy concerns all pose challenges. Real-time data are better than historic data but more expensive to collect. The costs of data collection and reporting should be taken into account.

Quality Measures and the Potential Impact on the HIV Care Continuum

Initiative: Provider Perspectives

**Benjamin Young, M.D., Ph.D., Senior Vice President, Chief Medical Officer,
International Association of Providers in AIDS Care**

Dr. Young said current HIV-related metrics are not always centered on the cascade of care, but they should be. The NHAS identifies four indicators specifically related to points on the cascade, and any other indicators are superfluous. Measures of CD4 counts and pneumonia prophylaxis will be irrelevant if the goals of testing, treatment, and viral suppression are met.

One in five people with HIV never gets tested, so none of the measures apply to them, Dr. Young pointed out. The measure of gaps between medical visits puts providers at fault when patients stay current with treatment but skip visits. The International Association of Providers in AIDS Care recommends five data elements be collected; these data would be sufficient and reasonable for busy providers:

- Estimated number of PLHIV
- Proportion and number of diagnoses
- Number and proportion linked to care
- Number and proportion on antiretroviral therapy (ART)
- Number and proportion who reach viral suppression

Dr. Young pointed out that existing measures do not align with the NHAS. There is no good definition of retention in care, and CD4 counts may not be needed for stable patients, he noted.

A number of factors should be considered as measures are developed. HIV testing and care occur in a wide range of settings, not all of which are medical facilities or federally funded. Prescription of ART does not necessarily ensure that a patient receives and uses ART. HIV treatment is less complicated and better tolerated than it used to be, so there is a role for primary care providers in prevention and treatment, but primary care providers do not see themselves as HIV providers, and HIV specialists do not see themselves as primary care providers. Ideally, HIV specialists would provide preventive care, but they only see PLHIV. Moreover, HIV specialists are the lowest-paid medical specialists, and their case loads are increasing, while reimbursement for care is decreasing.

Quality improvement requires education of all frontline providers in public and private settings, including those who are not HIV specialists. Dr. Young said. It also requires

tools to integrate HIV testing and care into electronic medical records and meaningful use requirements. There should be effective communication strategies and appropriate incentives related to HIV care. Quality improvement efforts should address HIV care provided in private settings. Dr. Young concluded that ending AIDS is possible with straightforward measures that align with the NHAS and are culturally appropriate for the current HIV care ecosystem.

Discussion

The Disparities Subcommittee drafted a letter to ONAP on HIV care performance measures that can help providers of all types achieve the desired outcomes. Concerns were raised about how metrics can get in the way of providing care by creating disincentives to treat some people. It was noted that indicators are used in different ways and are sometimes mandated by Congress, giving rise to varying definitions and measures.

Discussion ensued about the utility of the measure of the number of visits. Dr. Smith noted that measures are intended to align with clinical practice and that providers give frequent feedback on the measures. Dr. Horberg said there are some data suggesting poorer outcomes among those patients who had only one visit a year, but current measures specify face-to-face visits with an HIV specialist. Several members commented on the need for measures that take a broader approach to identifying and treating PLHIV and recognize the need to tailor treatment to individuals' needs. Metrics must be meaningful, reasonably simple to collect, and aligned with incentives. Concerns were raised about the potential for misuse of measures that include risk adjustment for SDH. Measures must also align with care requirements, such as the requirement to recertify patients every 6 months for AIDS Drug Assistance Program eligibility.

Mr. Pérez pointed out that the goal of the proposed letter is to set an expectation of improving viral suppression and to force a debate about how to achieve it. He hoped PACHA would set a national standard by recommending a mandatory measure for viral suppression. PACHA members noted that more discussion of the letter is needed to reach consensus about issues such as the frequency of medical visits and how to ensure that measures do not run counter to good care being provided in private settings. At the same time, quality measures should align with current, evidence-based guidelines. It was suggested that PACHA could make the case for a national standard measure of viral suppression without specifying what the measure should be.

Action Item

PACHA staff will organize a public teleconference for further discussion of the need for HIV-related performance measures.

Maximizing Opportunities: New PACHA Business

Because the Subcommittees presented their recommendations on the updated NHAS implementation to Mr. Brooks earlier in the day, PACHA used this time to discuss the proposed recommendation on SDH, the transgender activists' demands, and the NIH's reprioritization of funding for HIV research.

“Mind the Gap”: Trans People State of Emergency and Demands to ONAP

The demands were presented by the head of the Trans Latina Coalition at the North American Housing and HIV/AIDS Research Summit and submitted to PACHA. It was suggested that the activists are likely seeking an opportunity to meet with key leaders and perhaps seeking guidance from PACHA on whom to contact with concerns.

Mr. Brooks pointed out that as special Federal employees, PACHA members can speak with him directly about concerns of the community. He hoped that PACHA members actively corrected any misinformation in their communities, such as the misconception that transgender people are not addressed in the NHAS. He said ONAP is committed to working with the transgender community to gather data to develop indicators for HIV care. In addition, ONAP has committed to convening a meeting with the transgender community to work together to identify recommendations.

Letter to the Secretary on the SDH Framework

Mr. Schoettes presented the revised letter. It emphasizes that all agencies should adopt an SDH framework as part of their updated NHAS implementation plans.

Recommendation

PACHA voted unanimously in favor of sending the letter to Sec. Burwell requesting that agencies adopt an SDH framework as part of their updated NHAS implementation plans. (See Appendix A.)

NIH Reprioritization of HIV Research

Dr. Adimora explained that given the limited funds available for AIDS research funding, NIH restated its priorities, noting that it remains committed to a full portfolio of research. The focus falls mainly on biomedical interventions, and there is little attention to social or behavioral research or the role of SDH. The reprioritization has the potential to undermine the updated NHAS principles. Dr. Holtgrave suggested that members read the NIH director's statement and later discuss options.

Action Item

PACHA staff will include the NIH Reprioritization of HIV Research on the agenda of the proposed PACHA teleconference on performance measures.

Dr. Valdiserri recommended that PACHA describe examples of where validated behavioral, biomedical, and structural interventions are needed. PACHA has the opportunity to give input into the details of the updated NHAS implementation. Mr. Brooks emphasized that the NIH director's intention is not to eliminate behavioral intervention research but rather to prune away from the HIV portfolio research that is not focused on HIV. He added that Dr. Valdiserri is on the search committee for a new director of the NIH Office of AIDS Research.

National HIV/AIDS Housing Coalition Panel

Moderator: David Holtgrave, Ph.D., Vice Chair, PACHA

Perspectives on Homelessness for PLHIV

Cassandra Ackerman, National AIDS Housing Coalition Board Member, Consumer Advisory Board Chair

Ms. Ackerman said she has been living with HIV for many years and has been stably housed for more than 10 years. She hoped PACHA and others would consider how efforts to end the HIV epidemic could be passed on to local jurisdictions. Ms. Ackerman asked whether the Federal Government will initiate some sort of accountability for local governments to institute their own plans.

Case Management for SDH

Arturo Bendixen, Executive Director, Center for Housing and Health, AIDS Foundation of Chicago

Mr. Bendixen said only 20 percent of improvements in population health are attributed to health care; the rest result from changes in SDH. He explained that in Chicago, the annual cost of an AIDS housing unit is \$15,000, which includes a rent subsidy plus services for PLHIV. Since the ACA was enacted, demand for housing has increased, as hospitals and insurers seek to place PLHIV. Studies have demonstrated a direct link between housing and suppressed viral load, which benefits not only patients but also hospitals, private insurers, and Medicaid programs.

Mr. Bendixen described a homeless patient with HIV who had numerous emergency department visits and hospital admissions. The hospital's costs were more than three times the reimbursement they received for the patient's care. Providing housing saved the hospital tens of thousands of dollars within months, and those savings continued over time. A study of homeless people who were high users of Medicaid found that housing resulted in an annual savings to Medicaid of \$38,000.

New York State and Los Angeles County are among the jurisdictions using health care funds to support housing for the homeless, many of whom are PLHIV, because they understand the return on investment. The AIDS Foundation of Chicago recently entered into a contract with the hospital of the University of Illinois at Chicago to house 25 high

users. Leveraging an investment of \$250,000 from the hospital, the Foundation believes it can avert \$750,000 in costs to the hospital within a year.

Housing Is Prevention

Rusty Bennett, Ph.D., Chief Executive Officer, Collaborative Solutions, Inc.

Dr. Bennett said numerous published studies support the connection between housing and health. Stable housing does not just enable PLHIV to link to care; it plays a role in HIV prevention, treatment, and outcomes. Failure to recognize that housing is prevention and treatment is shortsighted, said Dr. Bennett. He stressed that current research findings are sufficient to support investing in and scaling up housing efforts. The HIV epidemic will persist until the HIV community begins talking with housing providers about affordable housing, he stated.

According to Dr. Bennett, the updated NHAS indicator for homelessness for PLHIV is too narrowly focused. He said the indicator should address housing instability so that it better reflects the needs of the community. He proposed that housing advocates work closely with PACHA and ONAP, with collaboration across Federal agencies such as the Department of Housing and Urban Development (HUD), to develop better indicators so that efforts to address housing can be more evidence-based.

Dr. Bennett said Ryan White HIV/AIDS programs need more flexibility to support housing in the communities they serve. He also called for more focus on innovative strategies and models, such as the successful approach of the AIDS Foundation of Chicago. If housing is health care, he said, clinical settings should collect data on housing status (as well as food insecurity and access to transportation) so that providers can make connections across the community. Finally, it is necessary to look at the HIV housing continuum and to change how housing is assessed, because homelessness alone is not a sufficient measure.

Discussion

It was noted that rural areas face a lack of housing, while urban areas lack affordable housing. Mr. Bendixen said in some cities, “affordable housing” refers to housing for working people with moderate incomes (e.g., teachers and firefighters); efforts to find affordable housing for PLHIV focus on those receiving public assistance.

It can be difficult to articulate the need for housing for PLHIV as an issue that takes priority over housing for others, such as veterans or single mothers; stronger language is needed to make the case that people in stable housing cost Federal programs less. Dr. Bennett said everyone needs safe, affordable housing. With adequate investment by communities and governments, the dialogue would not be about dividing housing among populations in need. However, to make the case for PLHIV, advocates are working to help communities gather data to demonstrate their own HIV housing

cascade. Dr. Bennett added that unlike other conditions related to high rates of homelessness, HIV is a communicable disease.

Mr. Bendixen pointed out that all homeless people do not have the same needs; sometimes, short-term assistance is all that is needed. For example, some need job training and will eventually graduate out of subsidized housing. Mr. Bendixen said PACHA should continue asking CMS for flexibility in Medicaid spending to fund housing. Mr. Brooks noted that the FY 2016 budget requested funds for CDC to assist with State plans related to housing.

Asked for recommendations about rural housing, Dr. Bennett called for reinvestment in initiatives that build connections, such as transportation. He hoped to see dialogue at the Federal level about HIV in rural communities. Under the Obama Administration, there have been some collaborations across Federal agencies and efforts by Federal entities to get local health care systems more involved in housing, said Mr. Bendixen.

Ms. Chung shared that she held on to her Housing Opportunities for Persons With AIDS subsidy for nearly 20 years and did not seek better-paying employment out of fear of losing the subsidy. More conversations are needed involving Federal agencies and others about how initiatives can empower PLHIV to make the best choices and move on. Dr. Bennett said HUD and the Department of Labor are working on an employment curriculum; he said providers need help addressing the issue of self-sufficiency.

In response to Harlan H. Pruden, Dr. Bennett said he would raise the issue of models for housing Native Americans among peers at the North American Housing and HIV/AIDS Research Summit. It was noted that other special populations include undocumented immigrants with HIV, those reentering society following incarceration, young people aging out of child welfare programs, and victims of domestic violence; there are some research studies and programs addressing these populations.

Mr. Brooks pointed out that the NHAS uses homelessness as an indicator because it can be measured reliably, but he welcomes input on how to measure housing instability. He suggested PACHA consider the following:

- Federal grants for comprehensive programs for young PLHIV have demonstrated success and should be revisited.
- Initiatives that save health care funds should be evaluated and scaled up.
- While more funding for HIV efforts is unlikely to materialize, advocates can look at ways to tap into other mechanisms, such as the White House's place-based efforts that promote housing, economic opportunity, and infrastructure development.

Dr. Valdiserri suggested that PACHA consider public-private partnerships for housing.

Asked about housing shortages in the South, Dr. Bennett said affordable housing is an ongoing problem in every community, and housing and HIV advocates should tackle it together. It was noted that housing providers do not always help their clients link to health care. Without the expectation that clients be actively engaged in clinical care, housing is not really treatment, said Mr. Pérez. Mr. Bendixen agreed that more training is needed for providers on both sides, and the two systems should work together.

Closing Remarks

Dr. Holtgrave and Ms. Hayes summarized some of the accomplishments of this meeting and next steps. Mr. Brooks presented Mr. Pérez with a letter thanking him for his leadership, expertise, and compassion during his three terms of service to PACHA, signed by Mr. Brooks and Cecilia Muñoz, director of the White House Domestic Policy Council.

Adjournment

Dr. Holtgrave thanked the PACHA staff, the members, and participants. He adjourned the meeting at 5:10 p.m.

Appendix A

Presidential Advisory Council on **HIV/AIDS**



September 23, 2015

The Honorable Sylvia Burwell
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Madame Secretary:

Congratulations to the Administration on the recent release of the National HIV/AIDS Strategy (NHAS): Updated to 2020 (“Updated Strategy”). The Presidential Advisory Council on HIV/AIDS (PACHA) is excited and energized by the Updated Strategy and the goals it establishes to address the HIV/AIDS epidemic at the federal, state, and community levels.

During a joint PACHA subcommittee meeting led by Access to Care subcommittee co-chair Vignetta Charles, PhD and Disparities subcommittee co-chair, Scott Schoettes, JD, committee members agreed that meaningful progress toward the goals of the Updated Strategy will require a concerted and coordinated effort from a broad and diverse set of stakeholders and must address the social determinants of health that drive the HIV/AIDS epidemic. The PACHA voted in favor of this recommendation during the 57th Full Council meeting on Tuesday, September 15, 2015.

On behalf of PACHA, I am writing to respectfully request that all federal agencies identified in the Executive Order that accompanied the release of the Updated Strategy adopt a social determinants of health framework as they finalize the development of their respective NHAS-related federal implementation plans. The PACHA maintains that this exercise will maximize our progress against the goals of the Updated Strategy.

While both the importance of the social determinants of health and the need for a coordinated effort from the federal government are underscored in the Updated Strategy, we request that the White House Office of National AIDS Policy (ONAP) explicitly link these two concepts together for the federal agencies identified in the Executive Order. The social determinants of health framework developed by the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention, based on the conceptual framework developed by the World Health Organization, is an example of the type of framework PACHA is contemplating.

I look forward to working with you, the Department, and ONAP to reach the shared goals of the Updated Strategy by ensuring we address the social determinants of health through the federal implementation plans.

Sincerely,

A handwritten signature in black ink, appearing to read "Nancy Mahon".

Nancy Mahon, JD
Chair

Enclosure

CC:

Douglas Brooks, MSW, Director, Office of National AIDS Policy

Anne Reid, MPH, Counselor, Science and Public Health

Karen DeSalvo, MD, MPH, MSc, Acting Assistant Secretary for Health

Ronald Valdiserri, MD, MPH, Deputy Assistant Secretary for Health, Infectious Diseases