

Presidential Advisory Council on HIV/AIDS

Recommended Updates to the National HIV/AIDS Strategy May 27, 2015

Introduction

The Presidential Advisory Council on HIV/AIDS (PACHA) applauds President Obama's ongoing commitment to fighting HIV/AIDS in the United States and his Administration's efforts to update the National HIV/AIDS Strategy (NHAS or Strategy). Over the last 5 years, the Strategy has (a) served as an important catalyst for concentrating and coalescing efforts around a finite set of performance measures (including reducing the number of new infections and improving viral load suppression rates); (b) highlighted and improved our shared understanding of stubbornly persistent HIV-related disparities that transcend gender, geography, race, and age; and (c) challenged a broad cross-section of stakeholders at local, state, and federal levels to improve performance.

As we approach the 5-year anniversary of the release of the original Strategy, we acknowledge the promise of the Patient Protection and Affordable Care Act (ACA) while being soberly reminded of differences between Medicaid and non-Medicaid expansion States, we reflect on the concept that "access is not always access," particularly given the profound influence of social determinants of health on the health outcomes of persons living with HIV (PLWH), even in the presence of categorical Ryan White Program (RWP) funding. We are now more acutely aware of the federal, state, tribal and local regulatory and cost-related barriers to full health care coverage and its impact on the ability to meet the goals of the first NHAS. As such, PACHA maintains that an update to the first landmark Strategy is not only timely, but will serve to (a) further focus our collective energy on the cross-section of communities most impacted by HIV, (b) offer guidance to redirect the investment of domestic HIV resources in a manner that results in dramatic decreases in HIV-related disparities, and (c) place a premium on shared national performance measures and the timeliness, accuracy, and responsiveness of federal measurement gauges. The PACHA recommendations outlined below build on prior recommendations, including those contained in the September 2013 PACHA document, "Achieving an AIDS-Free Generation."

Over the last few months, PACHA and its subcommittees (Access to Care, HIV Incidence, Disparities, and Global Issues) have independently and collectively raised, deliberated, presented, and refined a cross-section of broad and highly-specific recommendations for consideration by the White House Office of National AIDS Policy as it works to update the Strategy. A distillation of these recommendations results in several broad thematic areas including *Access to Health Systems and System Responsiveness*; *Timeliness, Completeness, and Robustness of Tools to Measure Progress*; and *Disparities and Social Determinants of Health*. The broader themes are complemented by specific recommendations tied to *HIV Criminalization* and *Co-Morbidities of HIV Infection*. The recommendations are outlined by theme area; input from all PACHA subcommittees was used to inform each section.

Access to Health Systems and System Responsiveness

The current Strategy was developed before full implementation of the ACA. As ACA implementation has unfolded over the past 5 years, millions of Americans, including thousands of PLWH have benefited from new or expanded health care coverage. Regrettably, the full benefits of the ACA have not been realized as barriers continue to hamper full and complete access to health care systems, including health plans that are only partially responsive to the needs of PLWH.

As such, PACHA maintains that, to meet the stated goals of the Strategy, we must (a) actively remove federal and local regulatory barriers that threaten easy access to high quality HIV care, (b) ensure that all health coverage options fully respond to the health needs of PLWH, and (c) ensure that States with the highest levels of HIV and HIV-related disparities, including those in the U.S. Southeast, expand their respective Medicaid programs. More specifically, we recommend that the updated Strategy address the following issues:

- Promote health plan and health system integrity by “locking formularies,” so that plans cannot be changed after the close of the enrollment period, without just cause, and with the exception of the introduction of newly approved medications;
- Eliminate pharmaceutical coverage concerns by requiring coverage for all HIV medications that are widely accepted in treatment guidelines or clinical best practices;
- Eliminate financial barriers to comprehensive coverage by placing caps on the rates of co-insurance charged to vulnerable individuals with chronic health conditions;
- Eliminate barriers to access for critical RWP resources, including the process and frequency of AIDS Drug Assistance Program (ADAP) recertification, discriminatory third-party payer acceptances, and the complex 75/25 rule waiver process;
- Ensure continued financial and programmatic integrity of the federal Medicaid program and options for Medicaid expansion in all States;
- Ensure that any approved Section 1115 waiver application from a State preserves traditional Medicaid provisions that protect the essential care and treatment needs of vulnerable low-income populations, including PLWH;
- Create a taskforce within the Department of Health and Human Services to actively search for, identify, and inform local, tribal and federal policies and other administrative barriers that threaten publicly funded programs designed to improve responsiveness of HIV prevention, care, and treatment services;
- In an era of patient migration from the RWP to ACA-supported health insurance coverage, ensure that critical ancillary services, HIV clinical specialists, and specialty care teams are supported to preserve HIV treatment success rates and health outcomes;
- Support health services research to track health outcomes of PLWH as they move between payer systems;
- Promote biomedical research to ensure continued advances in treatment, as well as continued efforts to find curative therapies for HIV;
- Ensure a robust health system that provides access without restrictions to treatment advances and, once developed, a cure;

- Integrate behavioral health services into traditional health systems that serve PLWH as a strategy to ensure behavioral health parity and to promote comprehensive coverage;
- Promote the integration of trauma-informed approaches into HIV care;
- Promote reproductive justice and broaden family planning options for persons living with HIV, including ensuring that people of all races, ages, gender identities and sexual orientations have access to high-quality, non-stigmatizing, culturally-relevant sexual and reproductive health care that considers the effectiveness of treatment as prevention, conception, contraception, and offers support for serodiscordant couples;
- Promote the integration of food and nutrition services into HIV care delivery systems.
- Developing optimal public and private sector mechanisms to ensure equal access to PrEP for all persons and communities at high risk and therefore at priority for such services.

Timeliness, Completeness, and Robustness of Tools to Measure NHAS Progress

A key element of success in meeting the goals of the Strategy depends on (a) an ability to measure progress in a timely fashion, (b) the completeness of those measures across highly impacted groups and the HIV continuum, and (c) broader access to and use of measurement tools across the country.

As such, PACHA maintains that the updated Strategy must mandate the development, deployment, and use of the most up-to-date and comprehensive data dashboard possible. As a corollary to a more responsive national HIV data dashboard, PACHA also recommends that the new Strategy adopt short-term performance benchmarks to better monitor progress and allow for mid-course corrections. Specific recommendations include:

- Metrics for all groups and communities impacted by HIV, including small but disproportionately impacted groups for whom surveillance data have been lacking in the past, including American Indians/Alaskan Natives and transgender women;
- Metrics must reflect the entire HIV prevention and care continuum, including prevention and testing, referral to care, retention in care, antiretroviral therapy prescription, and undetectable viral load rates;
- The timely release of national dashboard data published within 12-to-18 months of each calendar year's end;
- Building on the current Strategy goal related to the percentage of RWP clients with permanent housing to include a broader cross-section of PLWH and better access to affordable housing.

Disparities and Social Determinants of Health

It has been well documented and is increasingly understood that health and health problems are influenced by health-related behaviors, physical environments, health care access, and quality of care. Further, the social and economic conditions in which people live, learn, work, and play, including education, employment, income, family and social support systems, and community dynamics play a significant role in determining health outcomes. Since 2010, it has become abundantly clear that the social determinants of

health were a significant factor in the collective ability to meet the goals of the original Strategy. More specifically, it is clear that poor social and environmental conditions, coupled with high rates of HIV in “key populations and geographic areas,” contribute to stubbornly persistent and alarming HIV-related disparities including, but not limited to, higher rates of HIV infection, lower rates of access to HIV care, lower HIV viral suppression rates, and higher HIV-related mortality rates for Black and Latino PLWH (especially young Black men who have sex with men), transgender people, and young people.

As such, PACHA maintains that the updated Strategy must explicitly address and consider key issues to ensure meaningful considerations of the role of social determinants of health in achieving the goals of the Strategy and in order to dramatically dampen HIV-related disparities. Responses to these key issues include:

- Re-calibrate the goals for disproportionately impacted groups/areas and mandate adjusted program investment levels consistent with the substantial additional effort needed to eliminate HIV-related disparities;
- Give special attention to the HIV epidemic in Black men who have sex with men given that HIV-related disparities in this group have reached crisis proportions, including mandating the development of a cross-federal agency implementation plan that itemizes clear action steps, aggressive timelines, deployment of resources, and evaluation to assess meaningful progress;
- Give special attention to the HIV epidemic in transgender people and address unique prevention and care needs given the disproportionate impact of HIV on this small but key group; mandate all federal agencies to collect, report, and release demographic information reflective of all gender identities, differentiating between transgender women and transgender men and ensuring that surveillance data on transgender women is not collapsed into MSM categories; actively support more research on the many social and economic challenges facing transgender people including interventional development and translational research efforts;
- Recognize that, although rates of HIV infection in Black and Latina/Hispanic women are decreasing, huge racial disparities among women persist and mandate fully supporting focused biomedical prevention research and active and meaningful involvement of these populations in all phases of research, including research for a cure;
- As a strategy to eliminate mother to child HIV transmission in the US, it is imperative that we continue to sustain and expand the infrastructure for routine HIV screening of pregnant women, particularly as the overwhelming proportion of pregnant women identified as HIV-seropositive are poor women of color, facing multiple, complex socioeconomic challenges;
- Ensure the availability of medically-accurate, age- and developmentally- appropriate comprehensive sexual health education as a critical HIV prevention strategy. In order to maximize impact, comprehensive sex education strategies should not withhold life-saving sexual health information, nor should they include promotion of stigmatizing material such as homophobic, hetero-normative, or shaming information.
- Mandate that a subset of HIV-specific metrics (including HIV diagnosis and viral load suppression) be included as HEDIS and CMS measures given the potential impact of this

structural intervention on a broad cross-section of PLWH who depend on responsive public and private health plans for improved health outcomes;

- Mandate the domestic network of AIDS Education and Training Centers to provide training and technical assistance to public and private health plans to maximize compliance with proposed HEDIS and CMS performance measures.
- Improve access to rehabilitative employment services to ensure that PLWH are active members of the workforce as a means to improve health outcomes and decrease costs.

HIV Criminalization and Other Legal Issues

Proper use of the law can aid and improve public health by promoting health and wellness for all communities. However, punitive laws that are poorly conceived or inappropriately enforced can have unintended consequences that may exacerbate the very problems the laws were designed to address. They may increase stigma, discourage or prevent access to HIV testing and appropriate treatment, and make it more difficult or dangerous for people living with HIV to disclose their status and to seek proper support.

Across our nation, a myriad of laws and statutes continue to criminalize PLWH and hinder public health efforts, including testing for and disclosure of HIV-seropositive status. In fact, many of these laws are incongruent with guidelines released by the Department of Justice, which recommend prosecution only when it can be proven through convincing evidence that the accused had the specific intent to harm the victim.

As such, PACHA maintains that the updated Strategy should clearly and unequivocally strengthen opposition to HIV-based criminal statutes and prosecutions given their role in inhibiting shared progress toward reaching the goals of the Strategy. In addition, federal, state, and local laws should be reviewed and revised to make sure they are consistent with contemporary science and best public health practice, not overly punitive, do not stigmatize specific health conditions, do not harm public health, and protect communities from discrimination.

HIV-Related Co-Morbidities

The current Strategy has explicit language addressing the high rates of HIV and Hepatitis C (HCV) co-infection in subgroups of persons in the United States (i.e., estimated at 50% to 90% of injection drug users). With new curative therapies for HCV and in the spirit of promoting comprehensive care for PLWH,

As such, PACHA recommends that the updated Strategy actively support broad access to HCV treatment. More specifically, we recommend that the updated Strategy include language to eliminate restrictions that are not grounded in the state of the science and would unnecessarily deny treatment to eligible people, such as fibrosis criteria, documentation of abstinence from substance use, requirement of HIV virologic suppression or use of antiretroviral therapy, and excluding Infectious Diseases physicians and HIV care providers from prescribing HCV therapy. Elimination of these

barriers will allow a more holistic approach to the health needs of PLWH and better address the Strategy goal tied to reducing HIV-related mortality.

Capacity Building

The United States has a strong record of support for international HIV/AIDS efforts, particularly through the President's Emergency Plan for AIDS Relief (PEPFAR). This historic investment offers valuable lessons on best strategies to achieve service delivery and enhance health system capacity, particularly in the context of HIV prevention and care scale-up. ***As such, PACHA recommends that these lessons be actively imported and applied to U.S. regions where HIV system capacity continues to be inadequate.*** Failure to do so will only exacerbate the HIV-related disparities described above and further delay reaching the goals of the Strategy.

Behavioral, Policy and Implementation Research

In an era of increasingly complex and evolving health care consumption patterns, health care financing rules, health plan regulation, disparate Medicaid expansion efforts, dramatic differences in regional HIV burden, and other systemic and structural issues, there continues to be an ongoing, if not growing, need for behavioral, policy, and implementation research to better inform domestic HIV control strategies. ***As such, PACHA respectfully requests that the updated Strategy outline a process and time frame to develop a National HIV Research Agenda to complement the goals, objectives, structural interventions, and health system improvement activities recommended for inclusion in the updated Strategy.***
