Presidential Advisory Council on
HIV/AIDS

December 15, 2015

The Honorable Barack H. Obama
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Mr. President:

On behalf of the Presidential Advisory Council on HIV/AIDS (PACHA), we respectfully ask for your full and unwavering support of our recommendations to address stubbornly persistent disparities in HIV-related clinical outcomes through the implementation of standardized HIV clinical performance measures.

Background

Despite significant progress in the prevention and treatment of HIV and AIDS in the United States over the last decade, vulnerable sub-populations continue to be disproportionately affected by HIV, including experiencing significant differences in clinical outcomes and mortality tied to this disease. A closer examination of the root causes of these disparities shows that income, gender, age and race/ethnicity are factors that contribute to unequal health outcomes, as are differential access to HIV treatment programs, varying utilization of health care services and systems, and still unequal access to health insurance despite the early success of the landmark Patient Protection and Affordable Care Act.[1]

In the absence of universally understood and accepted performance measures intended to drive improved clinical outcomes, clinicians may unknowingly contribute to disparities in access to comprehensive, state-of-the-art HIV care. In parts of the country where HIV specialty physicians are scarce, many primary care providers do not have HIV specialty training or the experience necessary to effectively treat HIV disease and may be less likely to initiate appropriate antiretroviral therapy (ART), implement routine health maintenance screening for people living with HIV (PLWH), provide prophylaxis and/or treatment for opportunistic infections, offer routine and necessary vaccinations, provide education on prevention of transmission, or provide support services to improve retention in medical care.[2] These issues underscore the importance of integrating and standardizing HIV quality metrics across health care programs and insurance plans with an end goal to reduce disparities in clinical outcomes.

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[1] C. Brooke Steele, Lehida Meléndez-Morales, Richard Campoluci, Nickolas DeLuca, and Hazel D. Dean. Health Disparities in HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis: Issues, Burden, and Response, A Retrospective Review, 2000–2004. Atlanta, GA: Department of Health and Human Services, Centers for Disease Control and Prevention, November 2007. Available at: http://www.cdc.gov/nchhstp/healthdisparities.

[2] Rand Health Research Highlights, HCSUS Study Consortium. Disparities in Care of HIV Patients, 2006, www.rand.org/health.

[3] Michael A. Horberg, Judith A. Aberg, Laura W. Cheever, Philip Renner, Erin O'Brien Kaleba, and Steven M. Asch. Development of National and Multiagency HIV Care Quality Measures, Clinical Infectious Diseases, 2010 Aug Epub.

In the Unites States, while many organizations measure the effectiveness and quality of their HIV clinical outcomes, there is a lack of standardization across health care programs and insurance plans. The New York State Department of Health AIDS Institute (NYSAI) developed the HIV Quality of Care Program in 1992. This program is responsible for monitoring medical care quality and support services provided to PLWH in New York's hospitals, long-term care facilities, community health centers, drug treatment programs, community-based organizations, and managed care HIV Special Need Plans. Subsequently, the Health Resources and Services Administration (HRSA)-supported Ryan White Program developed a set of performance indicators, called HIVQUAL, based on the NYSAI measures. HIVQUAL sought to assess and improve the quality of care delivered to PLWH through the federally funded programs.[3] Separately, Kaiser Permanente, the largest private provider of HIV care in the United States, began an HIV care quality measurement and improvement program in 2006, measuring HIV diagnosis, access to and retention in care, care processes, and outcomes, leading to HIV care quality improvement programs at Kaiser Permanente.[4] Finally, the Veterans' Administration, the largest public provider of HIV care in the United States, conducted HIV care quality improvement and measurement research and implemented its own system in 1999. Despite the broad reach of these health plans and federal programs, none of these measure-development efforts are standardized or coordinated, and in some instances, achieving the performance benchmarks are neither mandated nor incentivized.

With the increasing number of quality measures for HIV care, there is an emerging acknowledgement that a better-coordinated effort is critical and could help improve quality of care, in addition to reducing the administrative burden of duplicative and conflicting reporting requirements. A 2012 report from the Institute of Medicine made it clear that a standard set of measures could more easily be applied across multiple delivery platforms (public, private, large and small clinics), allowing for informative comparisons and tracking. More important, PACHA offers, standardization of measures would be a significant catalyst to eliminating decades-long disparities in health outcomes among different groups of persons living with HIV.

Standardization of Quality HIV Care Measures and the Impact on the HIV Care Continuum of Care Initiative

Data revealed through the Gardner treatment cascade[5] highlighted gaps in HIV service delivery and retention along the HIV care continuum. The sobering numbers from 2012 show that, although progress is being made: 13% of the estimated 1.1 million PLWH in the United States are still undiagnosed; 19% were not linked to medical care; 61% were not engaged in ongoing care; 64% had not been prescribed ART; and 70% had not reached viral suppression.[6] It has been well established that late entry into care can greatly impact HIV-related mortality; diagnosis and prompt initiation of ART slows progression of HIV disease and prevents opportunistic infections; and routine screening for HIV provides opportunities for early detection and increases entry into care and treatment, thereby decreasing the likelihood of HIV

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[4] Horberg M, Hurley L, Towner W, Gambatese R, Klein D, Antoniskis D, Weinberg W, Kadlecik P, Remmers C, Dobrinich R, Quesenberry C,Silverberg M, Johnson M. HIV quality performance measures in a large integrated health care system: AIDS Patient Care STDS. 2011 Jan; 25(1):21-8.

[5] Edward M. Gardner, Margaret P. McLees, John F. Steiner, Carlos Del Rio, William J. Burman. The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection: Clinical Infectious Diseases (2011) 52(6): 793-800.

[6] White House Office of National AIDS Policy. (2015). *National HIV/AIDS Strategy for the United Stated: Updated to 2020.* Retrieved from https://www.aids.gov/federal-resources/national-hiv-aids-strategy/overview/

transmission to others.[7] Furthermore, the current scientific literature shows that when individuals are aware of their HIV-positive serostatus, they are less likely to participate in higher risk behaviors. Ultimately, viral suppression cannot be achieved unless PLWH are identified early, linked to care, and promptly started on ART.

In the spirit of addressing these HIV-related prevention and treatment realities and to confront the issues raised by Gardener and the promise of "treatment as prevention", the HIV Care Continuum Initiative was established in 2013 to organize federal efforts to coordinate resources to best improve gaps in HIV prevention and care. This initiative supports the concept of integration of HIV prevention and care efforts to decrease barriers in retention and achieving viral load suppression. In fact, standardizing HIV data and core measurements to improve health outcomes along the care continuum is an identified goal for 2016 (Executive Order Release July 15, 2013).

The importance of a standardized set of mandatory performance metrics is further illuminated by the effect of a nearly ten-year-old federal guideline. In 2006, the federal Centers for Disease Control and Prevention recommended HIV testing by all healthcare providers in the public and private sectors, including but not limited to hospital emergency departments, inpatient services, substance use treatment clinics, public health clinics, corrections healthcare facilities, and primary care settings, has been a miserable failure. Even those at greatest risk, such as men who have sex with men and injection drug users, are often not tested in the course of a primary care visit. In a 2014 survey by the Kaiser Family Foundation of gay and bisexual men, 56% said a physician has never recommended an HIV test, and 61% reported they rarely or never discuss HIV when they visit a doctor.[8]

In light of the issues outlined above and the limited progress eliminating HIV-related disparities in the United States, PACHA recommends that the Administration outline a strategy mandating that: 1) all federal programs and agencies supporting and financing HIV services along the prevention, care and treatment continuum (including the Center for Medicaid and Medicare Services, the Veteran's Administration, HRSA, CDC, SAMHSA and the Indian Health Service) adopt a standardized set of mandatory performance measures; and 2) all private health plans supporting HIV services along the prevention, care and treatment continuum conform to a new set of HIV-specific "Healthcare Effectiveness Data and Information Set (HEDIS)" measures.[9] Given their role in improving health outcomes, PACHA

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[7] In 2011, preliminarily published results of the HIV Prevention Trials Network (HPTN) 052 Study demonstrated that when viral suppression is achieved, PLWH are up to 96% less likely to transmit the virus to others. *See* Cohen, et. al., *Prevention of HIV-1 Infection with Early Antiretroviral Therapy:* N Engl J Med 2011; 365:493-505 August 11, 2011. A recent re-analysis of the data from HPTN 052 and preliminary results from the PARTNER study (examining transmission in serodiscordant same-sex male couples when the HIV-positive partner's viral load is suppressed) demonstrate that reduction in infectiousness for those on effective treatment may be close to 100%, cementing the concept that treatment is prevention. *See* HIV Prevention Trials Network, *HPTN 052 HIV Prevention Study Demonstrates Sustained Benefit of Early Antiretroviral Therapy*, July 20, 2015, available at www.hptn.org/web%20documents/PressReleases/HPTN%20052%20Press%20Release%20_07.15.2015_FINAL.pdf (explaining that the eight transmissions occurring after initiation of ART likely were due to recency of ART initiation or treatment failure, either resulting in an unsuppressed viral load); Cairns, G., *No-one with an undetectable viral load, gay or heterosexual, transmits HIV in first two years of PARTNER study*, March 4, 2014, available at www.aidsmap.com/No-one-with-an-undetectable-viral-load-gay-or-heterosexual-transmits-HIV-in-first-two-years-of-PARTNER-study/page/2832748/.

[8] Liz Hamel, Jamie Firth, Tina Hoff, Jennifer Kates, Sarah Levine, Lindsey Dawson; HIV/AIDS In The Lives of Gay And Bisexual Men In The United States: Kaiser Family Foundation Survey, September 25, 2014.

[9] "The Healthcare Effectiveness Data and Information Set (HEDIS) is a tool used by more than 90 percent of America's health plans to measure performance on important dimensions of care and service. Altogether, HEDIS consists of 81 measures across 5 domains of care. Because so many plans collect HEDIS data, and because the measures are so specifically defined, HEDIS makes it possible to compare the performance of health plans on an 'apples-to-apples' basis." NCQA, *HEDIS and Performance Measurement*, available at

recommends that the following quality measures be implemented across all sectors and mandated for those receiving federal funding:[10]

- Percentage of eligible patients tested for HIV at least once annually (eligibility based on age and contact with the healthcare system during the year);
- Percentage of PLWH attending at least 2 medical visits within a year, at least 90 days apart, one of which must be with a physician, physician's assistant or nurse practitioner;
- Percentage of PLWH having HIV Viral Load (VL) measurements at least twice a year;
- Percentage of PLWH achieving Viral Load suppression (VL $\leq$ 200 copies/ml).[11]

Furthermore, we believe that *all* PLWH should be included in the denominator for these measures and that exemptions or exceptions to this should be rare. Because, however, we do not wish to create a system that encourages providers to avoid serving those who are most in need of care and treatment, PACHA further recommends that incentives be created for providers to accept patients with co-morbidities and/or who will otherwise have greater difficulty in achieving these benchmarks, particularly the metric regarding viral suppression. PACHA believes that incentives to care for this population will ensure that the disparities these proposed quality metrics are designed to address will be reduced or eliminated rather than exacerbated by implementation of the recommended quality measures.
PACHA strongly recommends immediate consideration and action tied to these recommendations, particularly in light of the persistent HIV-related disparities, the growing number of Americans entering the healthcare system as a result of the ACA, and the significant human and financial costs associated with high numbers of HIV undiagnosed individuals, poor HIV-related clinical outcomes among PLWH and disparate rates of HIV-related mortality.

We acknowledge the challenge of putting in place these specific performance measures across the public and private sectors, and we recognize that other processes by which HHS is developing indicators designed to tap into similar constructs may be underway. The main point here is less about specific measures and more about developing a standard set of measures across the care continuum so that persons living with HIV may have complete and successful access to care, regardless of the platform through which they are receiving that care; while the details may vary from those given here, we urge all efforts to continue to improve access to HIV-related care and concomitant health outcomes. Whenever and wherever useful, PACHA stands ready to assist HHS in developing, refining, evaluating, and/or interpreting such indicators and resultant data.

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www.ncqa.org/HEDISQualityMeasurement.aspx?campaign=Hedis+Search&group=Hedis+Measures&keyword=%2Bhedis+%2Bmeasures&type=broad+match&gclid=COePnMrs9McCFcaPHwodNH0Cxw#sthash.E5Qyg6J4.dpuf.

[10] It is our understanding that those receiving federal funding to provide HIV-related care currently are allowed to select the quality measures on which they will report, in part because some of the measures no longer reflect the standard of care. Because we do not foresee a time in the near future in which frequency of HIV testing, frequency of medical visits for PLWH and achieving a suppressed viral load would no longer be relevant to improving the results along the continuum of care, we are suggesting that a subset of the quality measures—in particular, those listed above—be made mandatory. The goal of reducing disparities in HIV-related care will be undermined severely if providers are allowed to opt-out of supplying the information sought by these quality measures.

[11] We understand that indicators with respect to STI testing and PrEP are currently being developed within the Health Resources and Services Administration (HRSA). We look forward to the promulgation of those quality measures and strongly recommend that they too be mandated for recipients of federal HIV funding. We further recommend that they be crafted in a manner that makes them easily adopted as new HEDIS measures (e.g., annual vs. bi-annual), so that the standardization of quality metrics across healthcare delivery platforms can be maintained.

Sincerely,

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
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