

**UNITED STATES OF AMERICA
BEFORE THE DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Request for Information (RFI): Improving Efficiency, Effectiveness,
Coordination, and Accountability of HIV and Viral Hepatitis Prevention,
Care, and Treatment Programs**

**COMMENTS OF WHITMAN-WALKER HEALTH ON THE NATIONAL HIV/AIDS
STRATEGY**

Submitted via Electronic Communication to HepHIVStrategies@hhs.gov

In response to the Request for Information issued on February 8, 2019, 84 Fed. Reg. 2883, Whitman-Walker Health (Whitman-Walker or WWH) submits the following comments on updates to the National HIV/AIDS Strategy.

Whitman-Walker supports the recently announced initiative to dramatically curtail the HIV epidemic by 2030, and offers these suggestions for updates to the National Strategy to further that goal. We agree that the specific goals of reducing new infections by 75% within five years and by 90% within ten years are achievable – with the commitment of substantial new federal funds that target those communities and states, and those specific populations, that are most affected by HIV. Federal funding and initiatives should not only focus on those counties, cities, states and territories that have been specifically identified, but on fully engaging people of color, gay and bisexual men, transgender women, and injection drug users within those areas.

INTEREST AND EXPERIENCE OF WHITMAN-WALKER HEALTH

Whitman-Walker Health is a Federally Qualified Health Center serving greater Washington, DC's diverse urban community, including individuals who face barriers to accessing care, and with a special expertise in HIV care and serving lesbian, gay, bisexual, transgender and questioning/queer (LGBTQ) populations. We empower all persons to live healthy, love openly, and achieve equality and inclusion. WWH services include primary

medical care, HIV and LGBTQ specialty care, oral health, mental health care, substance use disorder treatment services, psychosocial support, medical nutrition therapy, early intervention services, public benefits and insurance navigation, nurse-focused case management, HIV and STI screening, legal services, youth programs, and two onsite pharmacies – one in Northwest DC and one in Southeast DC. WWH has achieved Level 3 Patient Centered Medical Home accreditation from the National Committee for Quality Assurance. Our team provides high quality, affirming health care to more than 20,000 individuals annually and is the medical home to more than 10,000 patients. The center has five sites and a team of more than 280 highly educated and practically experienced staff. Our diverse patient populations include African Americans; Latinx individuals; gay and bisexual men and lesbian and bisexual women; individuals with substance use disorders; and low-income and homeless individuals. Transgender and gender non-binary individuals comprise a substantial and growing part of our patient and client base: approximately 6% of all those receiving health services; 13% of medical patients; 20% of persons receiving mental health services; 8% of those receiving substance abuse treatment services; and 20% of our legal clients.

Whitman-Walker has been a nationally recognized leader in HIV treatment and prevention for almost four decades. In calendar year 2018, we provided health care to 3,505 people living with HIV. We serve more than 25% of the District of Columbia's reported HIV-positive population, many of them low-income or members of otherwise underserved communities. Eighty three percent of our patients living with HIV are virally suppressed – a success rate much higher than the national and DC averages for people living with HIV, and comparable to the success rate for Ryan White-funded programs.

Whitman-Walker's Medical, Behavioral Health and Community Health Departments have been at the forefront of HIV education and prevention since the earliest days of the epidemic. In 2018, we provided HIV tests to 7,787 individuals, and our walk-in Sexual Health and Wellness clinics, which offer STI and HIV testing, served 1,719 individuals. In 2017, our STI testing program diagnosed approximately 9% of the new HCV cases, 27% of the new cases of primary and secondary syphilis; more than 18% of the new cases of gonorrhea; and more than 9% of the new cases of chlamydia in the District of Columbia. Whitman-Walker also has more than 1,000 patients on PrEP, and has instituted a low-barrier "PrEP clinic" to make it easier for individuals who would benefit to start and remain adherent to the therapy.

Increasing numbers of our patients are being diagnosed with HCV; many of them are duly diagnosed with HIV and HCV, and Whitman-Walker medical providers have become experts in HCV care. In 2018, they cared for 341 patients living with HCV.

WWH has been conducting clinical research since 1987, when the first HIV treatments were being tested. Our studies investigate new ways to prevent or treat diseases in our community, particularly infectious diseases. Whitman-Walker has engaged in a wide range of research studies including; improved methods to screen for anal cancer; HIV and heart health; PrEP for HIV prevention; and HIV and cognitive impairment. Our research priorities also include new treatments for opioid addiction, the health and wellness priorities of LGBTQ youth, and improving HIV prevention and treatment for sex workers. WWH's current research studies include clinical trials that test the long term effects of HCV treatments, how well new medications work, and the safety and efficacy of treatments for HIV and HBV co-infected adults; as well as behavioral studies that look at such topics as disease prevention and medical adherence.

Whitman-Walker has seen great success in testing and linking people with HIV, HCV, and (often co-occurring) substance use disorders to treatment and to prevention services, for one primary reason: we provide care with the core principle of dignity at the forefront. This principle of dignity respects the uniqueness of every individual and motivates us to provide care in ways that celebrate uniqueness, rather than shame people for their gender identity, sexuality, race, ethnicity, age or other characteristics. Any efforts to improve the health and wellness of communities that are clouded by efforts to disenfranchise those same communities will not be successful. The leadership within the HIV and HCV communities knows this all too well and we urge this Administration, and all agencies of the federal government, to do more to protect the rights and dignity of people living with, or at risk for HIV, HCV and HBV.

COMMENTS ON THE NATIONAL HIV/AIDS STRATEGY

Whitman-Walker supports the Administration's efforts to update the National HIV/AIDS strategy to provide a more detailed roadmap to guide our ongoing journey to end HIV. We are encouraged by the announced intention to accelerate and focus the tools at our disposal to dramatically reduce new infections and improve the health and well-being of people living with HIV: testing to ensure that everyone knows their HIV status; antiretroviral medication to help those living with HIV to become and remain virally suppressed; expanding the use of PrEP among those at significant risk of becoming infected; and identifying emerging clusters of new infections for rapid response.¹

Realizing the promise of our biomedical tools will require substantial new federal investments that target not only those geographic areas most affected, but also those communities most affected: Black and Latinx people; gay and bisexual men, especially young

¹ Fauci A.S., Redfield R.R., Sigounas G., et al. Ending the HIV epidemic: A plan for the United States. JAMA. Published online Feb. 7, 2019. <https://jamanetwork.com/journals/jama/fullarticle/2724455>.

men of color; transgender women; and injection drug users. A fundamental concern of Whitman-Walker, therefore, is federal actions that undercut efforts to engage these key populations in HIV testing, prevention and treatment. As discussed in more detail below (pages 10-11), policies and actions of the Administration that curtail legal protections for LGBTQ people and for individuals and families seeking to immigrate to or enter the U.S., and that have the effect of further alienating and stigmatizing people of color, foreign-born people and LGBTQ people, will make it more difficult to engage those communities in HCV testing and medical care.

Moreover, we are greatly concerned by developments in the Administration that threaten the health insurance programs that are essential to providing millions of Americans with access to affordable health care. As discussed in more detail below (pages 13-15), policies and actions that restrict Medicaid, Medicare, and the health insurance reforms accomplished through the Affordable Care Act, threaten to undermine the progress we have made in the fight against HIV, by making health care more costly, or by erecting barriers to accessing drugs that are medically indicated for many living with HIV.

In addition to this fundamental concern, Whitman-Walker offers the following comments and suggestions in response to the questions posed in the Request for Information.

Question (1a) asks:

What components of the NHAS do you think should be maintained? What changes should be made to the NHAS? This may include changes to the structure, goals, and indicators, key areas of focus and/or populations, and annual reporting processes by federal agencies. This may also include areas of the current strategy that should be scaled back or areas of the current strategy that should be expanded or scaled up.

With reference to **Goal 1.A.2**, the updated NHAS should maintain – and, indeed, increase – the focus on the most vulnerable and marginalized populations. Gay and bisexual men of

color, transgender women of color, people who inject drugs, and people who lack secure housing have a greater risk of contracting HIV and less access to effective treatment and prevention.

With reference to **Policy and Action Step 3.B**, we recommend that the updated NHAS scale up interventions that address social determinants of health to keep those living with HIV engaged in care, on medication, and virally suppressed. We recommend using the model, and increasing funding specially for, wrap-around social supports available through the Ryan White HIV/AIDS Program (RWHAP) to provide housing, transportation, and food assistance.

With reference to **Goal 1**, we recommend scaling up and expanding federal support for syringe services programs and other harm-reduction steps to address HIV transmission in persons who use injection drugs. Syringe exchange programs are a well-documented, cost-effective method to reduce the spread of HIV. The current NHAS supports the increased access to sterile syringes. We recommend that the federal government support the creation of more needle exchange programs and research into the safety and viability of safe-injection sites as a harm-reduction strategy to reduce HIV infections and overdose deaths.²

In addition, consistent with **Step 3.A.2** in the current NHAS, we recommend lowering the barrier to receiving treatment for substance use disorders, including medication-assisted treatment (MAT), while also receiving treatment for HIV. Requiring patients with substance use disorders to abstain from use in order to access treatment is counterproductive: it drives people away from treatment and reduces the ability to help them become virally suppressed, which improves their health and reduces the risk of HIV transmission to others. Encouraging individuals with substance use disorders to engage with the health care system also increases

² See, e.g., AIDS United, *Statement on Supervised Injection Facilities*, last updated June 29, 2016, https://www.aidsunited.org/data/files/Site_18/Policy/Statement%20on%20Supervised%20Injection%20Facilities%20July%207%202016.pdf.

opportunities to help them reduce or eliminate their substance use, and expands the ability of service providers to deploy treatment as prevention modalities in priority populations.

Marginalized and stigmatized individuals living with HIV should not be required to “prove” they are ready for treatment.

In reference to **Goals 1.C.5 and 3.C.1, and Goal 4**, we recommend expanding federal action to support decriminalization of HIV in state laws. Laws that criminalize sexual activity by people who have been diagnosed with HIV are ineffective and counterproductive, especially as they relate to the specific effort to reduce new HIV transmissions. They generally penalize low-risk or no-risk behavior, are based on outdated information or fundamental misconceptions about how HIV is transmitted, exacerbate stigma, and constitute an incentive to avoid HIV testing. We recommend that the federal government build on previous statements in support of state law reform,³ particularly in light of the prevention benefits of antiretroviral treatment, which render many if not most state criminal laws even more outdated.⁴

We recommend that NHAS include **additional indicators for gender minorities** when updating the NHAS. WWH appreciates the focus in the current NHAS on transgender female communities, recognizing the disproportionate share of the HIV infections in that community. We recommend that the updated NHAS continue to emphasize initiatives that focus on transgender women, and also expand this focus to include transgender men and gender non-binary individuals. There has been very little research into HIV risks in transgender men, and in

³ Lehman JS, Carr MH, Nichol AJ, et al. Prevalence and public health implications of state laws that criminalize potential HIV exposure in the United States. *AIDS Behav* 2014. 18:997–1006. Available at <http://link.springer.com/article/10.1007/s10461-014-0724-0>.

⁴ Barre-Sinoussi F, Karim SSA, Albert J et al. Expert consensus statement on the science of HIV in the context of criminal law. *J Intl AIDS Soc* 2018, 21:e25161. <https://onlinelibrary.wiley.com/doi/full/10.1002/jia2.25161>.

persons who identify as gender non-binary, and too little effort to engage them in testing, prevention and treatment initiatives.

With reference to **Goal 3, Step 3.B.1**, recognizing the role of structural supports in facilitating the care of people living with HIV, we recommend additional funding for supportive services that enable access to health care and remove barriers to care, including legal services, transportation services, and care navigation services. The Ryan White Care Act and the Housing Opportunities for People With AIDS (HOPWA) Program have provided invaluable support, but they are substantially underfunded.

Question (2a) asks for

[s]pecific recommendations you think will improve the efficiency, effectiveness, accountability, and impact of the national response to HIV.

We encourage more funding to replicate programs and strategies that have been found to work, such as incorporating HIV care and treatment into primary care settings. These strategies also positively decrease health disparities by increasing access to care for all diseases, especially important for populations at heightened risk of HIV because they often coincide with other health risks and exposures.

We recommend targeting prevention dollars to the most heavily impacted groups. Currently, gay, bisexual and same-gender-loving men, and transgender persons – especially youth and persons of color – have the highest rates of HIV infection. We recommend continuing to focus attention on engaging youth living with HIV and youth at high risk of HIV, in the continuum of care. We encourage the plan to support research into HIV prevention strategies that mainstream HIV prevention and care to reach these heavily impacted groups.

In alignment with **Recommended Action 1.C.4 and Policy and Action Step 3.B**, we recommend providing youth with accurate information about their sexual health in secondary

and post-secondary education. We recommend that the updated NHAS highlight the structural role that comprehensive sexual education for school-age children plays in eliminating disparities in HIV testing, prevention and treatment by reaching at-risk populations. The federal government can have a powerful role in facilitating and promulgating a medical consensus around sex and sexuality education. We recommend that the federal government promulgate standards for sex and sexuality education that are realistic and non-judgmental, and that provide specific, accurate information about HIV transmission risks and how to avoid them. We recommend that education on healthy relationships and healthy bodies begin in middle school classrooms. At the onset of puberty if not before, students should be provided with accurate information about sexual health and infectious diseases that helps empower them to make fully informed, healthy decisions.

In alignment with **Recommend Action 2.A.3 and Policy and Action Step 2.B**, we recommend that primary care providers should exercise their best efforts to ensure that all of their patients are tested for HIV at the onset of engaging in health care services and then annually, and at least annually if they are gay or bisexual men or transgender women, and more often if they are sexually active. Current CDC recommendations for routine HIV testing have a significant flaw, because they are limited to people between the ages of 13 and 64, whereas many people older than 64 remain sexually active. Primary care providers are well placed to diagnose people who may avoid using sexual health services at HIV or STI clinics. They also have access to populations of older adults whose risk profiles are underestimated due to stereotypes about sexual practices of elders. Training primary care providers to integrate HIV prevention and treatment into their regular practice will improve the efficacy and efficiency of the National Strategy.

We recommend expanding access to HIV care through telemedicine programs that allow physicians to practice medicine across state lines. Allowing telemedicine practices would increase access to HIV treatment in rural areas. Currently, these services have been limited because of difficulties around state licensure and payment. Recent legislative action creating opportunities for federal insurance programs to reimburse for telemedicine visits provide a workable framework for future opportunities to increase the efficiency of HIV prevention and treatment efforts in rural areas, especially in Southern states with high levels of HIV incidence and prevalence.

The importance of combatting stigma. Consistent with **Goal 3 and Step 3C** in the current NHAS, we recommend that the federal government increase its efforts to combat HIV stigma and related stigmas – and discrimination in health care as well as in employment, housing and public accommodations. The stigma faced by people living with or at risk for HIV is exacerbated by stigma and discrimination based on age, race, ethnicity, gender identity and sexual orientation. These intersecting stigmas and patterns of discrimination are present in healthcare organizations as widely as they are in the rest of the society and make it more difficult to treat HIV and more difficult for priority populations to access treatment.

The current NHAS, and federal public health leaders, recognize that nondiscriminatory, affirming engagement with sexual and gender minorities, people of color and other HIV-impacted populations is essential. However, many Administration statements and agency actions are having the opposite effect: they are threatening to weaken or eliminate legal protections against discrimination and otherwise stigmatizing these very communities. These include proposed rules and executive actions that ban transgender people from military service; that weaken or eliminate legal protections based on gender identity or sexual orientation in health

care, education and employment; that would encourage health care providers and staff to opt out of their obligations to provide care based on personal beliefs; and that curtail the rights and options of individuals from other countries to immigrate or seek asylum in the U.S. Whatever their intent, these actions are causing great distress among sexual and gender minorities and people of color, and exacerbating distrust and feelings of alienation from the public health and health care systems. They undercut efforts to increase engagement with HIV testing, prevention and treatment by undermining the trust that is necessary for engagement and adherence to care. They also threaten to exacerbate rather than ameliorate the stigma, discrimination and violence that undermine health and encourage health-harming coping behaviors such as self-medication for depression or anxiety with drugs and alcohol and risky sexual behaviors.

Culturally competent programming improves the effectiveness of HIV prevention efforts in outreach, education, and service provision at the local, state, and federal levels. Localized HIV education, testing and prevention campaigns are generally more effective than national public health messaging. **Recommended Action 2.A.5** supports extending technical assistance to local partners who are able to target priority populations with culturally competent messaging and programming. We recommend that the federal government focus increased funding for outreach campaigns for local agencies and provide capacity-building support for education and outreach. Concurrently, to ensure accountability we recommend increasing the transparency around how education and outreach allocations are spent.

In alignment with **Goal 2 and Step 2.B, and Recommended Action 2.A.2** of the NHAS, WWH recommends leveraging community health workers who can go out into the community to test, engage people in treatment, and support patient treatment adherence. We support efforts to expand the ability of health centers to be reimbursed for programs that increase patient adherence

and retention in care. Community health workers, including peer support specialists increase the capacity and the diversity of the healthcare system and providers of clinical care and related services for people living with HIV.

Of fundamental importance to the success of the Administration's HIV initiative is **access to HIV treatment and prevention medications**. In order to increase access, Whitman-Walker recommends:

- HHS should exercise its regulatory authority to reduce the administrative burden to access medications through the Ryan White-funded AIDS Drug Assistance Program (ADAP). Our health care providers and legal advocates report that requirements to continuously recertify that participants are HIV positive is stigmatizing and burdensome to patients and onerous to service providers. HIV remains an incurable viral infection for the vast majority of people. The continual recertification of HIV status that ADAP requires is medically unnecessary and bureaucratically wasteful. The reminder of a stigmatizing status creates barriers to care for our patients and can contribute to gaps in treatment up to several months, leading to increased viral loads and heightened potential for HIV transmission.
- The updated NHAS should prioritize steps to lower the cost of PrEP. For those considering PrEP or already taking it, the costs of the medication and required medical visits and tests are major barriers for many, especially people of color, sexual and gender minorities, and youth, who are heavily impacted by HIV and more likely to be lower-income and un- or under-insured. We are concerned about new PrEP modalities may result in the decline of programs supporting access to available treatments.

- We also recommend that that NHAS urge states to clarify or amend their laws to allow minors to access HIV and STI testing, treatment and prevention services, including PrEP, without parental consent. Additionally, state Medicaid programs should work to allow minors to prevent certain data from being shared with parents via explanation of benefit notices that are routinely transmitted. For many young people who are at high risk of HIV, or who may be HIV-positive but are undiagnosed, the prospect of parental involvement is a powerful disincentive to being tested and to taking PrEP if they are negative, because they fear parental disapproval of their sexual activity or sexual orientation. Many state laws that provide minors with the right to testing and treatment of HIV and STIs do not clearly cover prevention modalities such as PrEP – and providers in those states are reluctant to prescribe PrEP without parental notice and consent.
- WWH recommends that all Medicare Part D protected classes of drugs maintain their protected status as recognition of their role in preventing greater disease outbreak and contribution to the continued health and wellbeing of vulnerable populations with particularly virulent and deadly consequences if left untreated. The proposed changes to the Medicare Part D protected classes to allow participating plans to exclude or limit coverage of specific antiretroviral drugs under certain circumstances, or to impose prior authorization and step therapy requirements on those drugs to steer plan participants to cheaper alternatives,⁵ flatly contradict the federally-recognized standard of care for HIV treatment and undercut NHAS goals, and the Administration’s newly-announced initiative to end the epidemic. Step therapy and prior authorization requirements will delay or interrupt effective treatment and upend the treatment cascade and prevention

⁵ Agency Information Collection Activities; Submission for HHS CMS Review; Proposed Rule; Modernizing Part D and Medicare Advantage to Lower Drug Prices and Reduce Out-of-Pocket Expenses, Docket ID CMS-4180-P, 82 Fed. Reg. 62152 (Nov. 30, 2019).

efforts by decreasing viral suppression rates. They will also impose barriers on Medicare recipients who are HIV-negative and would benefit from PrEP.

Question (3a) asks:

What specific actions should the federal government and others take to improve the coordination of funding and delivery of HIV services?

The states most impacted by new HIV cases have not taken advantage of the option under the Affordable Care Act to expand Medicaid, largely at federal expense. Other states are imposing, or considering the imposition of, burdensome Medicaid work requirements that create barriers to care. These efforts have been encouraged or facilitated by the Administration. Expanded Medicaid, made available to low-income persons without proof of disability, has been critical to increasing access to health care – including HIV testing, treatment and prevention – in many states. Efforts to undercut Medicaid will undermine the Administration’s efforts to increase HIV testing, PrEP and antiretroviral treatment in populations most heavily impacted by the epidemic.

Whitman-Walker also recommends that the Administration support the ACA’s protections for people with pre-existing conditions, including people with HIV. Insurance is the primary payor of HIV treatment in our health care system, and the ACA’s protections for coverage of pre-existing conditions, along with Medicaid expansion, are critical to the success of efforts to end the epidemic. The Administration’s actions to undercut the ACA threaten the progress that has been made. For instance, the short term, limited-coverage health plans that Administration actions have encouraged may be attractive to people living with or at high risk of HIV, especially persons with low or limited incomes – and such plans may create financial disincentives for them to be tested for HIV and STIs when indicated; to engage in PrEP if they

are HIV-negative but at significant risk of infection; or to enter into and adhere to treatment if they are HIV-positive.

WWH also recommends that the federal government facilitate coordination and collaboration across health centers in local jurisdictions. Requiring local coalitions of health centers and social support providers to share information on treatment capacity and prevention strategies can facilitate efficient coordination of HIV services. The current NHAS recognizes that local networks are more accountable to communities to produce outcomes and are well placed to strategically reach communities at high risk for HIV infection.

CONCLUSION

Whitman-Walker appreciates this opportunity to contribute to this critical effort. Please feel free to contact us if we can be of assistance in any other way.

Respectfully submitted,



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