

September 9, 2025

Geri R. Donenberg, PhD
Director, Office of AIDS Research
National Institutes of Health
Bethesda, MD

Dear Donenberg:

Thank you for your leadership of NIH's Office of AIDS Research. We are writing in response to the June 26 Office of AIDS Research Advisory Council (OARAC) meeting where the future of NIH's federal HIV treatment, care, and prevention guidelines was discussed. Our organizations represent people living with and affected by HIV and the diversity of health care professionals who care for people living with HIV across the lifespan. **We are writing to request a meeting to discuss the future of the federal HIV guidelines and potential strategies and opportunities for supporting their maintenance at NIH.**

We appreciate that you outlined a coordinated and transparent process during the June OARAC meeting for soliciting input on the future of the federal HIV guidelines and indicated that a final decision on the fate of the guidelines had not yet been made. We would very much like to be a part of that process. As organizations representing individuals that interact with and are affected by the NIH HIV guidelines, we understand their importance and immense value to the care and treatment of people living with HIV and in supporting clinicians in providing the highest standard of treatment.

NIH demonstrated important foresight when the agency recognized it was uniquely positioned to rapidly translate the latest research to clinical practice by supporting the development of clinical practice guidelines. NIH also recognized the importance of responding to unique needs and HIV clinical issues during pregnancy and the postpartum period (including reducing perinatal transmission) for infants, children, adolescents and adults — with specific recommendations for the large and growing population of aging adults with HIV. The guidelines also provide highly specialized guidance for treating the rare but serious opportunistic infections that can occur in children, adolescents, and adults with HIV, particularly those who are not virally suppressed. As a result, people living with HIV in communities across the country, including in rural areas and others with limited infectious diseases or HIV expertise, have benefited from the remarkable HIV treatment advances led by the agency.

The availability, accessibility and timeliness of the HIV guidelines have saved countless lives, and decades later their [utilization](#) continues to increase because of the expertise and credibility that NIH brings to guideline development on complex HIV treatment and clinical issues. The rigorous process also advances NIH's priorities by identifying critical research gaps that inform NIH's research agenda and priority areas for implementation science.

We understand that NIH's proposal to transition away from maintaining the federal HIV guidelines is driven primarily by fiscal constraints. Given that there is not another federal agency with the expertise to maintain the guidelines, this short-term cost-saving measure could come at a high cost in the long term, if people living with HIV experience poorer health outcomes, which also will lead to more costly and intensive care and an increase in HIV transmissions. The potential transition of the guidelines also comes at a time when the HIV prevention and care infrastructure

across the country faces unprecedented threats that will further strain an already insufficient HIV workforce – particularly in rural communities. This is especially concerning as the population of aging people with HIV continues to grow, bringing increased complexity in managing comorbidities, drug interactions and age-related conditions that require evidence-based guidance.

We would greatly appreciate the opportunity to meet with you to discuss these issues and how we may be able to partner with you to support the sustainability of the federal HIV guidelines at NIH. Please contact Andrea Weddle, executive director of the HIV Medicine Association, at aweddle@hivma.org to schedule a meeting.

Respectively submitted by the undersigned organizations:

AIDS United
American Academy of HIV Medicine
American Academy of Pediatrics
American College of Obstetricians and Gynecologists
Association of Departments of Family Medicine
Association of Nurses in AIDS Care
AVAC
Dandelions Inc.
Family Medicine Residency Directors
HIV Medicine Association
HIV+Hepatitis Policy Institute
Infectious Diseases Society of America
International Association of Physicians in AIDS Care
International Community of Women Living With HIV North America
NASTAD
North American Primary Care Research Group
PAC
Pediatric Infectious Diseases Society
Positive Women's Network - USA
Positively Trans
Ribbon – A Center of Excellence
San Francisco AIDS Foundation
SERO
SisterLove
Society for Maternal-Fetal Medicine
Society for Teachers in Family Medicine
Southern AIDS Coalition
The Reunion Project
The Well Project
Transgender Law Center
Treatment Action Group

CC: Leslie J. Marshall, PhD, Acting Deputy Director
Office of AIDS Research, National Institutes of Health