COMMUNITY ACCESS NATIONAL NETWORK

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RE: Docket Number CDC-2025-0519

The **Community Access National Network (CANN)** is a 501(c)(3) national nonprofit organization focusing on public policy issues relating to HIV/AIDS and viral hepatitis. CANN's mission is to define, promote, and improve access to healthcare services and support for people living with HIV/AIDS and/or viral hepatitis through advocacy, education, and networking.

While CANN is primarily focused on policy matters affecting access to care for people living with and affected by HIV, we stand in firm support of all people living with chronic and rare diseases and recognize the very reality of those living with multiple health conditions and the necessity of timely, personalized care for every one of those health conditions.

We submit what follows in response to the RFI regarding the National HIV Surveillance System (NHSS).

RFI is Timely, Necessary, and Communicates a Commitment to Collaboration

The proposed collection of information is indeed necessary for the proper functioning of the CDC regarding HIV data collection. We are supportive of the efforts. The National HIV Surveillance System (NHSS) should indeed be continued and strengthened, prioritizing areas of need in a systemic and science-driven fashion. Studies show that the United States is not on track to meet the Ending the HIV Epidemic initiative goal of a 90% reduction in new HIV infections by 2030. This is especially true in specific geographic and socioeconomic populations, such as the South, that are disproportionately affected by HIV.

Recent federal funding proposals poised to drastically reduce public funding for HIV treatment and prevention efforts make surveillance, monitoring, and assessment essential for the beneficial advancement of public health. Moreover, as vulnerable populations face challenges to healthcare access due to Medicaid cuts and the affordability challenges of significantly increased insurance costs, there is strong potential for increases in transmission incidence rates.

At the state level, local health departments use their limited resources to monitor and trace HIV trends. However, continued national HIV surveillance is imperative to ensure data does not remain siloed. Centralized standardized data not only facilitates the identification of HIV clusters but also enables comparisons across demographic groups and geographic areas to identify which efforts are or are not successful and the reasons behind the outcomes. States learn from one another, and thorough surveillance analysis indicates where federal resources should be allocated. Continued surveillance will reveal data on issues such as the uptake, utilization, and success of new HIV treatments, such as long-acting injectables that are new to market.

HIV monitoring and surveillance have existed since the advent of the HIV epidemic. Continued development and evolution of the NHSS are essential for holistic bolstering of public health from rural areas to large urban centers and all places in between. To improve monitoring efforts and enhance the quality, utility, and clarity of information and collection processes, we offer several recommendations.

Proper Data Governance Monitoring and Protections is Paramount

The NHSS Assurance of Confidentiality Statement dated October 2019 is a definitive statement of confidentiality protections for the data collected and the individuals whose protected health information informs it. Going forward, vigilance regarding confidentiality needs to be exercised.
The October 2019 document states explicitly:

"In particular, HIV surveillance or research information that could be used to identify any individual or institution on whom a record is maintained, either directly or indirectly, will not be disclosed for commercial purposes, nor disclosed to the public; to family members; to parties involved in civil, criminal, or administrative litigation; or to non-health agencies of the federal, state, or local governments."

There has been increased scrutiny regarding the public trust of recent trends in the manner in which citizens' sensitive data has been handled. This is especially true regarding the federal utilization of A.I. in various endeavors. It is imperative that guidelines to protect citizens' HIV related health data are explicitly established, and governance remains monitored. The October 2019 document also states:

"Only authorized employees of DHAP in HICSB, BCSB, the Quantitative Sciences and Data Management Branch and Laboratory Branch, their contractors, other authorized staff and other authorized agents granted access, guest researchers, fellows, visiting scientists, authorized external collaborating researchers, research interns, and graduate students who participate in activities jointly approved by CDC and the sponsoring academic institution, and the like, will have access to the information.'"

This level of access requires dedicated oversight to prevent any unauthorized access or utilization of HIV surveillance data.

Data Improvement on Social Determinants of Health

HIV surveillance data collection needs greater integration of social determinants of health (SDOH). SDOH research is not propaganda or ideological discourse. It is objective, evidence-based data that provides additional context for issues that may drive transmission trends. Topics such as health literacy, health center deserts (areas with inadequate access to health services due to a lack of facilities or providers), HIV-related stigma, and more are part of the holistic reality of people living with HIV and those at high-risk of infection. The local health

departments that feed data to the NHSS have the means to obtain some of that data that may not be currently utilized.

Information Should Remain Timely

Information gathered should remain timely and presented in clear formats that are easily digestible by many different stakeholders. Everyone, from legislators creating public policy to medical practitioners and lay members of the public, needs to be able to understand and act upon what is presented.

Above all, the entire ecosystem of stakeholders involved in surveillance, data collection, and analysis needs to be effectively supported. On the state and local level, especially, this requires resources. Funding, policy infrastructure, educational resources, technological frameworks, and any weakness analysis need to be reinforced for effective HIV surveillance to occur.

Respectfully submitted,

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On behalf of
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