

National HIV Surveillance System (NHSS)

Attachment 2(c)

Comment 2

Public Comment on Establishing National HIV Surveillance System (NHSS)

<https://www.regulations.gov/document/CDC-2022-0041-0001>

Docket No. CDC-2022-0041

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Background

Human immunodeficiency virus (HIV) is a health concern affecting populations disproportionately in the United States (CDC, 2022). Current data collection activities may not meet the increasing recognition of sexual orientation and gender identity, the rapid development of test technologies and the associated test history, and the desire to improve the formatting and usability of surveillance forms to improve patients' health outcomes (*Regulations.Gov*, 2022). To collect more comprehensive data to monitor the HIV burden in the United States and ease the data collection process, the Centers for Disease Control and Prevention (CDC) proposed the information collection project titled NHSS to continue and promote information collection, calculation, and analysis. Based on the gaps and needs mentioned above, this proposal should be supported and implemented.

Problem Description

Ever since the first HIV case diagnosis in the United States, about 1.2 million people in the U.S. have been diagnosed with HIV (KFF, 2021). In 2019, there was 36,801 HIV diagnosis in the United States (CDC, 2022). About 13% of those with HIV were unaware of being infected and thus needed testing (KFF, 2021). Over 700,000 people have died from HIV-related illnesses (KFF, 2021).

Moreover, HIV affected the population disproportionately (HIV.gov, 2021). The majority of the incidence of HIV occurred in the south (HIV.gov, 2021), with an HIV diagnosis rate of 15.2 per 100,000 population (CDC, 2022). Among southern states, Florida (42.2 per 100,000), Texas (23.7 per 100,000), and Georgia (22.8 per 100,000) had exceptionally high HIV diagnosis rate (KFF, 2021). Upon analyzing by race, Black/African American and Hispanic/Latino people were most affected (CDC, 2022). Despite accounting for 13% of the population, Black/African American people accounted for 42% of new HIV diagnoses (CDC, 2022). Similarly, the Hispanic/Latino people accounted for 18% of the total population but 29% of new HIV diagnoses (CDC, 2022). Black people also accounted for 43% of HIV-associated death (KFF, 2021), and survival after an AIDS diagnosis was also the lowest (KFF, 2021). By age, people who are 25 to 34 years old had the highest number of diagnoses (CDC, 2022), and the number of HIV diagnoses has increased among people of reproductive age since 2015 (HIV.gov, 2021). Compared with men, women accounted for 22% of all people living with HIV (KFF, 2021). But unlike men, the HIV incidence rate among women did not follow a decreasing trend (KFF, 2021). Black women also accounted for more than half of the new HIV diagnoses among women (KFF, 2021). The highest incidence of HIV occurred among gay and bisexual men in the U.S., accounting for 69% of the new HIV diagnoses and 86% of diagnoses among males (CDC, 2022). To continue the surveillance and care to the disproportionately impacted population, a surveillance system would greatly help the process.

Rationale

A well-developed surveillance system is needed to cater to the needs of these patients with different characteristics. However, the Census has a well-developed HIV/AIDS Surveillance Data Base for countries globally yet excluding data for the United States (Bureau, 2021). Such a gap reflects that the United States needs a platform to collect high-quality data about HIV to facilitate surveillance and research needs. To better care for and prevent HIV, states have started implementing their data collection and surveillance methods to identify people with HIV infection who need medical care and improve overall health outcomes (Sweeney et al., 2018). With the implementation of the surveillance and data collection, states including Illinois, Louisiana, Tennessee, and Virginia were able to identify HIV patients who were care needed, virally suppressed, eligible for follow-up, and adhering to services (Sweeney et al., 2018). Using the information collected, the state health departments subsequently managed to improve linkage to medical care and thus health outcomes for these patients (Sweeney et al., 2018). The results reflected a 68% improvement in viral suppression among the patients who received treatment adherence services (Sweeney et al., 2018). However, better coordination is necessary for the combined impact of surveillance, care, data sharing, and addressing limitations on data (Sweeney et al., 2018). Thus, to reach a better outcome on a national scale, the diffusion of innovation approach can scale up the success in these states (Emani et al., 2012). In order to achieve better coordination for this outcome, we need a comprehensive and national HIV surveillance system (Emani et al., 2012).

Feasibility and Rebuttal

Given the former examples of data collection platforms and surveillance systems for other infectious diseases and epidemiology, the feasibility of the NHSS is not a concern to the CDC, yet they should consider potential ethical issues. Considerable ethical challenges have been embedded in public health surveillance (Klingler et al., 2017). Some challenges include failure to acquire informed consent and information leakage, leading to stigmatization and discrimination against the patients (Klingler et al., 2017). These ethical caveats persist mainly due to the sparse ethics guidance and training (Klingler et al., 2017). However, despite the current documents being scarce in quantity, failing to provide real-world guidelines to address ethical concerns, and only focusing on specific diseases, HIV/AIDS is one of the diseases that have been addressed (Klingler et al., 2017). Other than guideline documents, privacy training and enforcement is another area that can help mitigate ethical concerns (Mbonihankuye et al., 2019). The Health Insurance Portability and Accountability Act (HIPAA) is compliance to secure patient information and privacy (Mbonihankuye et al., 2019). Thus, it should be required and enforced that any employees who have access to identified patient information should receive and complete HIPAA training. People who will work on the NHSS should be obligated to finish the training before handling the surveillance assignments, to continue updating their HIPAA status throughout the process, and be aware of the consequences of violating the HIPAA.

Thus, given the discussion, I would strongly urge the CDC to support and approve the NHSS to close the gaps we face and improve HIV patients' health outcomes and quality of life.

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