ENDING AN EPIDEMIC IS HARD. Despite our successes, inadequate attention to responding to the social drivers of health holds the United States back from achieving its HIV prevention and care goals. These social determinants are often connected to inequality and discrimination and require an integrated approach that connects policy, economics, and health and social services. In many communities, HIV exists as part of a syndemic that also encompasses other infectious diseases, as well as non-communicable diseases (such as those that arise from smoking), poverty, unemployment, substance use disorders, and systemic discrimination. A syndemic is characterized by two or more negative health outcomes and/or social factors interacting simultaneously, contributing to excess burden of disease in a population. They have overlapping biological, behavioral, and social/structural components.

Our national approach to monitoring discrete health conditions is outdated, and this makes it difficult to adopt syndemic strategies for improving community health. Data sets held by health care purchasers (i.e., Medicaid, Medicare, and private insurers) and clinical providers are rarely interoperable with public health data systems, thereby limiting the capacity to spot early trends and rapidly intervene to promote population health. Funding for public health is too limited and too siloed, limiting the capacity of health departments to fully integrate their operations across disease states. State and local health departments may have data for HIV (including surveillance, laboratory reports, and clinical information), but it is often disconnected from data related to sexually transmitted infections (STIs), substance use disorders, homelessness, and other threats to individuals’ health that share common risk factors. In a world where a simple online search can lead to integrated profiles of individuals used to target advertisements, the ability of public health to analyze and use population-level data to inform programs and services is decades behind where it could be.

WHY IS DATA MODERNIZATION NEEDED?

In some ways, the case for data modernization is simple: the world has changed, and public health needs to adapt. Further, surveillance and other critical public health activities have been underfunded for...
decades, which has resulted in declining capacity and greater variability across jurisdictions in terms of data quality and how data systems and programs operate, including inconsistent policies governing data sharing throughout the public health ecosystem. Moreover, the changing environment, including more interventions to prevent and treat diseases, changes in clinical practice, a broader recognition of the importance of social determinants of health, and an increasing role of technology in public life, creates new pressures for public health to catch up to digital commerce and other areas of life.

The COVID-19 pandemic has illustrated shortcomings of our current data systems:

- **Not automated and too much lag time:** Too many data systems still rely on paper records and require time-consuming and labor-intensive inputting into electronic systems;

- **Insufficient interoperability and too much variability:** COVID-19 has revealed inadequate standardization across states in reporting data, too little data sharing between the health care and public health systems, and enormous variability across programs in data management capacity; this variability has hindered an effective, integrated nationwide public health response;

- **Not equipped for the exponential growth in volume:** The number of data elements and the number of requests for data are overwhelming the capacity to respond; and

- **Unable to protect against modern data threats:** Technological advances have increased the risk of inappropriate and harmful disclosure of sensitive personal data. Updated data systems can create audit trails and better protect against unauthorized access and disclosure, including from criminal hackers and others.

The U.S. has invested in promoting the adoption of electronic health records (EHRs) within health care settings. A corollary effort is needed to strengthen public health data systems and improve interoperability between health care and public health systems.

**POLICY ACTION: ENGAGE HIV AND OTHER COMMUNITY STAKEHOLDERS IN DATA MODERNIZATION INITIATIVE (DMI) IMPLEMENTATION.**

In 2019, the Council of State and Territorial Epidemiologists (CSTE) and a coalition of related associations and public health stakeholders spearheaded a campaign that is now resulting in new public investments in data modernization. This coalition called for a $1 billion investment over a decade with $100 million in annual funding to sustain these efforts. Through the fiscal year (FY) 2020 federal budget and the CARES Act (COVID-19 relief legislation), $550 million has been appropriated to the Centers for Disease Control and Prevention (CDC) so far for a Data Modernization Initiative (DMI). (For more details on CDC’s approach to the DMI, see the text box on the next page.) CDC and its state, tribal, local, and territorial (STLT) health department partners are beginning to implement the DMI.

While the DMI is in its formative stages, CDC and its STLT partners should educate community stakeholders more about how public health functions and how and why it uses data, particularly emphasizing the uses of anonymized data that shows population trends without sharing personally identifiable information. CDC also must ensure that the DMI includes meaningful consumer advisory processes that give communities a role in shaping key policy decisions. Without creating a large bureaucracy, CDC should identify lessons from HIV Prevention Community Planning in order to create multiple avenues for community stakeholders to offer input, raise concerns, shape policy development, and monitor the impact of the DMI.

In some cases, people living with HIV have been harmed by their involvement with public health, and many are distrustful of some health departments’ willingness to use both existing data sets and future more integrated data sets to protect individuals and communities. CDC and its other governmental partners should seek to use DMI implementation to foster a new relationship with community groups that is more deeply grounded in mutual respect and collaboration. The Robert Wood Johnson Foundation has established a National Commission to Transform Public Health Data Systems and recently awarded $50 million in grants to ensure that the public health infrastructure does more to promote equity. HIV community voices are especially critical to all of these efforts because of their history of marginalization and experiences with some health departments discriminating against individuals and communities for their sexual and drug using behaviors and other facets of their lives.

**POLICY ACTION: ADOPT A BROADER VISION FOR THE DMI TO INCLUDE WORKFORCE DEVELOPMENT AND INTEGRATION WITH OTHER HUMAN SERVICES PROGRAMS.**

In addition to overcoming technical challenges, the success of the DMI requires that the Initiative be undergirded by a broader vision of what is truly needed to modernize data systems and upgrade how public health data are used. This should encompass both workforce development and integration with other social services programs. Current human and financial resources are inadequate, hampering the
BUILDING A PUBLIC HEALTH DATA SUPERHIGHWAY

WHAT IS THE PROBLEM RIGHT NOW?

Data are needed to identify emerging infectious diseases, promote the health of individuals and communities, and inform how the Centers for Disease Control and Prevention (CDC), other federal agencies, and their state, tribal, local, and territorial (STLT) partners set priorities, fund programs, and carry out their missions to improve the health of the public. Large amounts of data are available, but data sets are often either incomplete, duplicative, not shared appropriately across programs, or simply not used strategically. This results in wasted resources and missed opportunities to improve health outcomes and health equity.

WHAT IS NEEDED TO MODERNIZE OUR NATIONAL PUBLIC HEALTH DATA SYSTEMS?

The Council of State and Territorial Epidemiologists (CSTE) and a coalition of related associations representing health departments, public health laboratories, and others have advocated for a comprehensive and focused approach called the Data Modernization Initiative (DMI). They have called for a $1 billion federal investment over a decade to dramatically reimagine and upgrade the public health data systems ecosystem and increase annual funding to support both CDC and STLT partner efforts. In FY 2020, Congress appropriated $50 million for the DMI; the CARES Act (COVID-19 relief legislation) provided $500 million. CSTE and its partners are asking Congress for $250 million in the FY 2022 budget and to complete the total $1 billion investment in subsequent years, as well as $100 million in annual funding to sustain these investments.

HOW IS THE CDC APPROACHING DATA MODERNIZATION?

The CDC is organizing the DMI around three thematic areas:

- **Data Sharing Across the Public Health Ecosystem** to automate data collection and allow multi-directional data flow across federal and STLT partners.
- **Enhancing CDC Services and Systems for Ongoing Data Modernization** to adopt enterprise-wide infrastructure for data sharing, analysis, and visualization.
- **New Standards and Approaches for Public Health Reporting** to test new standards for accessing data in electronic health records and assess the policy implications of these standards.

The DMI aims to strengthen the whole public health surveillance infrastructure. Critical data systems include:

- **Syndromic Surveillance System**: This system tracks early symptoms before a diagnosis has been made. Implementing the DMI would advance electronic reporting of emergency department visits, which could enable more rapid detection of emerging health threats.
- **Electronic Case Reporting**: Automating the reporting of certain diseases through electronic health records would allow for earlier disease detection and intervention.
- **Notifiable Diseases System**: HIV is one of 120 notifiable conditions for which all cases must be reported by providers, hospitals, and laboratories to state and local public health authorities and which CDC monitors nationally (receiving only de-identified data without names or other identifiers). The DMI would reduce the reporting burden on states by using modernized electronic messages.
- **Electronic Laboratory Reporting**: Complete laboratory reporting has been an essential tool for understanding HIV trends, such as monitoring HIV viral suppression. As the volume of laboratory tests grows, however, updated data systems are needed to support faster, more complete automated reporting from laboratories to local and state health departments.
- **Vital Records**: In a given year, there are nearly 4 million live births and about 3.4 million deaths in the U.S. Updated reporting of these data sets could enable more timely public health responses and quicker notification of causes of death for individuals.

ability to fully implement the DMI. CDC and its STLT partners should make dedicated improvements to workforce training and capacity building at different levels within public health agencies, including contractors that perform critical public health functions. CDC and health departments also should accelerate their recruitment of new types of public health workers, including persons with expertise in informatics and other technologies.

To incorporate social and economic determinants of health into analyses, interoperable data systems maintained by the Department of Health and Human Services (HHS) need to be able to coordinate with other data systems, including those maintained by the Social Security Administration (SSA), and Departments such as Housing and Urban Development (HUD), Education, and Labor. An issue of critical importance to the syndemic within which HIV operates is to establish uniform standards for the collection of behavioral data (i.e., sexual and drug use histories) along with demographic information related to sexual orientation and gender identity, or SOGI data. The DMI offers a critical opportunity for CDC to standardize and achieve more widespread adoption of behavioral and SOGI data in public data sets through funding requirements as part of the DMI.

HOW CAN INTEROPERABLE DATA SYSTEMS LEAD TO SYNDEMIC RESPONSES?

Modernized data systems could lead to reduced lag time in reporting HIV and other surveillance data and allow earlier identification of trends. The potential benefits of such integration were powerfully illustrated by the well-known HIV outbreak that occurred in Scott County, Indiana in 2014-2015. A community that typically observed fewer than five HIV diagnoses per year experienced an outbreak that led to 235 people becoming newly diagnosed with HIV.13 HIV surveillance systems did not first identify the outbreak. Rather, the state’s STI disease intervention specialists first reported 11 cases of HIV infection. More timely HIV surveillance data, better integration of data systems, and coordinated analysis of such health department data could have identified and interrupted this outbreak sooner.

TIMELY AND COMPLETE DATA CAN FACILITATE SYNDEMIC RESPONSES

Health care providers and public health programs collect a lot of data, but the capacity to bring these data together to quickly identify trends and intervene is often lagging. The following are illustrative examples of how modernized data systems could better meet community needs:

**COVID-19 transmission and adverse outcomes among people with HIV:** The pandemic has raised concerns that people living with HIV could be at an elevated risk of acquiring COVID-19 or are more likely to experience severe cases or long-term effects of COVID-19. Social and structural factors that drive disproportionate risk for HIV also have been observed with COVID-19. Too frequently, however, demographic information, such as race/ethnicity and SOGI status have been missing from COVID-19 data, and our current systems do not make it easy to quickly assess the impacts of COVID-19 on people living with HIV.

**Drug use and the growing crisis of congenital syphilis:** In 2019, there were 1,870 cases of congenital syphilis (infants born with syphilis); from 2018-2019, there were 94 syphilitic stillbirths and 34 infant deaths related to congenital syphilis. The congenital syphilis case rate has risen rapidly, from 9.2/100,000 live births in 2013 to 48.5/100,000 live births in 2019. Much of this increase is associated with increased drug use, in particular, increased methamphetamine use. If databases with drug use and overdose data were linked to STI databases and accessible to perinatal HIV prevention programs, more could be done to reverse these trends.

**Meningitis among people with HIV and MSM:** Meningococcal disease incidence in the U.S. is low, but when persons become infected, even with treatment, morbidity and mortality are high. People living with HIV are at an elevated risk of meningococcal disease, as are men who have sex with men (MSM). Interoperable data systems could enable more rapid identification of meningococcal disease outbreaks in specific communities, especially with improved SOGI data collection.

POLICY ACTION: MAKE SYNDEMIC APPROACHES MORE CENTRAL TO THE DELIVERY OF PUBLIC HEALTH PROGRAMS AND SERVICES.

Funding silos and differences in perspective and culture have hindered much-needed integration between HIV and other infectious disease programs. It is likely not desirable to completely dissolve distinctions between existing programs, but what is needed is a more strategic focus on how to leverage separate programs to improve overall community health. One component is to ensure that different disease data systems can talk to each. The CDC Program Collaboration and Service Integration, or PCSI Initiative, is one model.15 The PCSI Initiative allows a small, defined percentage of health department funding for one infectious disease to be blended with funding for another condition to support activities that improve coordination of prevention responses across conditions. It also seeks to develop common standards for data security and data sharing across infectious disease programs, a critical component of the DMI that can both improve the flow of information and better protect the confidentiality of personal health information. A greater focus on streamlining the delivery of services and reducing duplication at the client-level is also needed. Stories of individuals being contacted by two separate contact tracers if they are concurrently diagnosed with HIV and syphilis exemplifies duplication and reduces trust in public health. Better and more integrated data systems could reduce such occurrences. Newer technology also allows for the adoption of privacy preserving record linkage (PPRL), which aims to link records across databases without revealing any sensitive information about the individual subject of the record.16 CDC, working with other federal agencies and STLT partners, should lead an effort to develop guidance and technical assistance for STLT partners to standardize and encourage (and possibly require) data sharing and program coordination rather than simply permit it. While many in public health see the need for syndemic approaches, now may be the moment to elevate the urgency of this issue to lead to transformative change.

HOW CAN THE DMI BOLSTER TRUST WITH COMMUNITIES AFFECTED BY HIV?

People living with HIV, and the communities in which they live, frequently face extensive stigma and discrimination by society at large, by public health agencies, and the health care system.17 This has contributed to mistrust and active harm that is interwoven with continuing discrimination on the basis of race/ethnicity, sexual orientation, gender identity, and economic status.18 Even though these communities often have the most to benefit from data modernization, many see data collection as a form of intrusive monitoring that invades privacy, encourages discrimination, and can result in criminal prosecution.19 Additionally, the marginalized communities that make up the HIV community never have been adequately resourced, and there is a concern that increased integration could mean less funding for HIV services and less funding for critical community-based providers. Seeking community input at every stage could ensure data collection, privacy, and transparency policies are equity driven, call out the influence of structural racism on inequities on health, and ensure local voices are involved in making informed decisions.20

POLICY ACTION: ENHANCE DATA PROTECTION STANDARDS AND RESTRICT LAW ENFORCEMENT’S ACCESS TO PUBLIC HEALTH SURVEILLANCE DATA.

Many community concerns with strengthening data systems stem from those health departments that use shaming, sometimes under the guise of promoting public health or enforcing “community standards” in ways that delegitimize low-income people, sexual minorities, people who engage in sex work, and others. A critical step in implementing the DMI should be to adopt standards for what data are collected and prohibit federal funding from being used to support such harmful practices.

Thirty-two states have HIV criminal laws that are still being used to this day to prosecute individuals, typically for failure to disclose their HIV status before having sex (or for behaviors that have negligible risk for transmission).21 These laws often do not reflect the science of HIV transmission and disproportionately impact low-income people of color.22 Some states also have criminal laws that cover other infectious diseases. Data accessed and used by health departments for public health purposes should be protected from disclosure to law enforcement. CDC’s Security and Confidentiality Guidelines already encourage that data release be limited for public health purposes or when required by law.23 CSTE and other leading public health organization also recommend that health department legal counsel be trained on surveillance technology and the science of HIV transmission to arm them to resist voluntary disclosures of public health information to law enforcement.24 We have previously called for CDC to use the next funding announcement for health departments that will run from 2023-2028 to establish new data protection requirements.25 In funding state and local health departments through this core funding program and for the DMI, CDC should consider financial incentives to encourage states and STLT partners to enact laws or policies to prohibit disclosures of surveillance data to law enforcement and modernize HIV criminal laws.
THE TIME IS NOW

Modernizing the public health data infrastructure is urgently needed not only to strengthen the HIV response, but to create a platform to respond nimbly to both longstanding and emerging health threats. It must be implemented, however, in the context of a history of often fraught engagement between health departments and marginalized communities. Building in a robust commitment to strengthening community partnerships and addressing syndemics within communities is essential to the DMI’s success.

ENDNOTES


19. See id.


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