

BIG IDEAS

ENDING THE HIV EPIDEMIC — SUPPORTING ALL PEOPLE LIVING WITH HIV AND REDUCING NEW TRANSMISSIONS

STRATEGIC CHANGES ARE NEEDED TO STRENGTHEN LINKAGE AND ENGAGEMENT IN HIV CARE

DIAGNOSING, CONNECTING TO CARE, AND PROVIDING A RANGE OF SOCIAL AND CLINICAL SUPPORTS

to facilitate continued engagement in care for all people living with HIV is complex, yet achievable. When the Centers for Disease Control and Prevention (CDC) first published a national estimate of the HIV care continuum (previously called the HIV treatment cascade) in 2010, a little more than a quarter of people with HIV in the U.S. had reached HIV viral suppression.¹ As of 2020, this estimate has more than doubled to 64.6%.^{2,3} Viral suppression in 2020 was much higher, however, for persons who received at least one outpatient medical service (i.e., a physician visit, prescription drugs, etc.) through the Ryan White HIV/AIDS Program, reaching 89.4%, approximately 25% higher than the nation as a whole.⁴

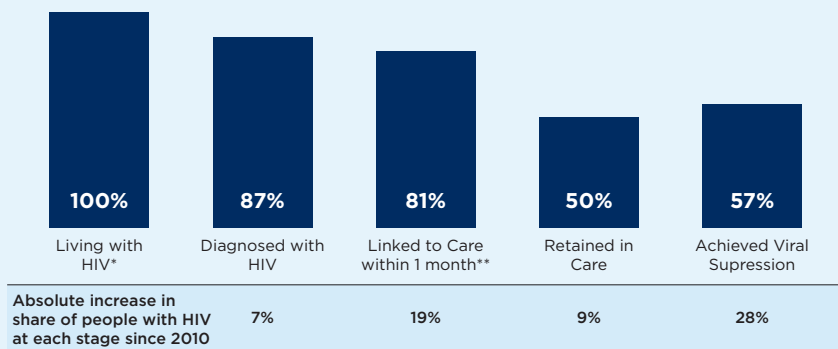
This trajectory of progress, however, belies large disparities in access and outcomes, with varying progress and challenges across the continuum. Three steps that pose especially complex challenges are: 1) linkage to care immediately after diagnosis; 2) sustaining engagement in HIV care over the life course, through major life events and changes in personal and public resources; and 3) monitoring missed clinic visits and

IMPROVING ONGOING ENGAGEMENT IN CARE REQUIRES NEW THINKING

Despite population-level improvements in HIV clinical outcomes, the following new approaches can fuel continued progress:

- Facilitate adoption of differentiated care models that include low-barrier services for specific sub-populations.
- Implement syndemic approaches that can improve HIV outcomes and extend the impact of existing resources.
- Develop monitoring strategies that accommodate differing models of care and evolving clinical practices.

UNITED STATES HIV CARE CONTINUUM, 2019



SOURCE: HIV Surveillance Supplemental Report: Monitoring Selected National HIV Prevention and Care Objectives by Using Surveillance Data – United States and 6 Dependent Areas, 2019, 26 CTRS. FOR DISEASE CONTROL AND PREVENTION (May 2021); Vital Signs: HIV Prevention Through Care and Treatment – United States, 60 MORBIDITY AND MORTALITY WEEKLY REPORT – CTRS. FOR DISEASE CONTROL AND PREVENTION 1618-23 (Dec. 2, 2011).

Notes: *In 2010, it was estimated that 1,178,350 people 13+ were living with HIV in the United States. In 2019, it was estimated that 1,189,700 people 13+ were living with HIV. **This comparison understates the improvement in linkage to care that has occurred: in 2010, 62% were linked within 3-4 months, and in 2019, 81% were linked within 1 month.

other interruptions in care in order to rapidly address barriers to engagement. There are many reasons why people living with HIV may experience interruptions or barriers to care, including due to unreliable and expensive transportation, housing instability, lack of childcare, and other competing life activities, such as employment. Further, stigma and discrimination are additional barriers and can even act to compound other barriers. While there are interventions proven to be effective at engaging and retaining people living with HIV in care, scaling up interventions remains a challenge. Action in three areas can have a large impact:

1. CLIENT-CENTERED SUPPORTS ARE NEEDED TO SUSTAIN ENGAGEMENT IN CARE

The population of people living with HIV in the U.S. is diverse, yet certain populations are more impacted. This is oftentimes attributed to various unmet needs and can impede ongoing engagement in care. Therefore, varying levels of supports are needed to maintain an effective relationship with a system of care. Some people have been living with HIV for a long time, have been durably virally suppressed, and do not require extensive services to maintain engagement. Others, however, may enter care unfamiliar with or wary of healthcare systems (whether it is because of past negative experiences or because they are from a community that has experienced racism or unequal treatment when accessing health services), thus making it difficult to engage with and trust their providers. Some may require a variety of services (and at varying levels of need), such as assistance with transportation to get to care and access to healthy and nutritious food and other social services, including housing, childcare, and treatment for mental health and substance abuse disorders (SUD). Too frequently, however, a one-size-fits-all approach produces strain on the system and does not match the needs of people who require either more or less support. Looking to strategies initially adopted to scale-up access to antiretroviral therapy (ART) globally can offer insights into how to adapt the U.S. HIV care system in ways that can lead to better outcomes. This approach, called differentiated care, incorporates concepts such as simplification, task shifting, decentralization (i.e., community-based care), and, when appropriate, rededicating saved resources to patients who are in the greatest need for them.⁵ Differentiating among groups and between individuals and matching service models to specific needs could result in a more efficient and responsive system. Those who stand to benefit the most from differentiated care services are populations who have been historically underserved and those that do not receive clinical care on a routine basis.⁶

Innovative programs are being developed in the U.S. that move in this direction. People with a strong relationship with a clinical team and have sustained

DISPARITIES IN OUTCOMES PERSIST ALONG THE CONTINUUM

Despite progress for all groups, large disparities and inequities continue to produce unequal results:

- **People living in high poverty census tracts** have the highest HIV diagnosis rates, the lowest percentages of adults linked to HIV medical care after receiving a diagnosis, and the lowest percentages of adults with suppressed viral load within 6 months of receiving an HIV diagnosis.[1]
- **Rural Black persons** received a higher percentage of late-stage HIV diagnoses than did those in urban and metropolitan areas. Viral suppression within 6 months of diagnoses was highest in metropolitan areas.[2]
- **Hispanic/Latino MSM** have lower adherence to ART when affected by poverty, SUD, depression, or unmet ancillary service needs.[3]

Sources: [1] *HIV Surveillance Supplemental Report: Social determinants of health among adults with diagnosed HIV infection, 2019*, 27 *CTRS. FOR DISEASE CONTROL AND PREVENTION* (2022).

[2] Shacara Johnson Lyons et al., *Care Outcomes Among Black or African American Persons with Diagnosed HIV in Rural, Urban, and Metropolitan Statistical Areas – 42 U.S. Jurisdictions, 2018*, 70 *MORBIDITY AND MORTALITY WEEKLY REPORT – CTRS. FOR DISEASE CONTROL AND PREVENTION* 229–35 (2021).

[3] Stacy M. Crim et al., *Barriers to Antiretroviral Therapy Adherence Among HIV-Positive Hispanic and Latino Men Who Have Sex with Men – United States, 2015 – 2019*, 69 *MORBIDITY AND MORTALITY WEEKLY REPORT – CTRS. FOR DISEASE CONTROL AND PREVENTION* 1437–42 (2020).

viral suppression may be best served with only an annual visit with their HIV care provider. Other related services that require lab work [e.g., viral load and sexually transmitted infection (STI) testing and vaccinations] could be accomplished remotely via self-swab or mail-in, or via drop-in services that do not require seeing a provider. Indeed, prominent HIV treating physicians at a high-burden clinic in Atlanta have called for such an approach.⁷ For such individuals, this has the advantage of reducing the burden of attending medical appointments, creating more opportunities to address non-HIV-related health concerns, and allowing HIV status to recede in prominence in a person's life in a way that can foster well-being. For the health system, it may offer a way to conserve health care resources and staff time that could be redirected to persons with more extensive needs. Current guidelines, however, call for viral load testing every six months,⁸ which typically leads to an in-person provider visit. Efforts to simplify clinical requirements and reduce the frequency of physician

visits, however, could be contributing to low rates of STI testing and insufficient attention being given to other co-morbid conditions, such as diabetes and hypertension. To illustrate this point, in 2019, fewer than half of all sexually active people with HIV were screened for syphilis, gonorrhea, and chlamydia every three months,⁹ which is the standard recommendation for sexually active gay and bisexual men (the largest share of people living with HIV in the U.S.). Therefore, alternative approaches to STI testing in ways that minimize patient and provider burden without sacrificing the optimal level of care for individual patients should be explored.

For persons not optimally engaged in care, some jurisdictions have developed models of low-barrier services, often for people who are unhoused, transitionally housed, and/or those with a SUD and have not sustained HIV viral suppression. The low-barrier concept means that services are available often on a walk-in basis, so persons are not held to a standard of reporting for a scheduled appointment. The Maximum Assistance Clinic (Max Clinic) in Seattle-King County is available only to persons who are not virally suppressed and/or are no longer taking ART and did not experience improvements in viral suppression after lower intensity outreach and support.¹⁰ Key components include walk-in access to primary care in public health sexually transmitted diseases (STD) clinics, walk-in access to intensive coordinated case management, food vouchers, no-cost bus passes, cell phones, and financial incentives for visits with blood draws and for achieving and maintaining viral suppression. An initial evaluation of the Max Clinic showed that clients were more likely to reach viral suppression than clients in a more traditional HIV clinic.¹¹ Subsequent qualitative research has shown that clients reported that walk-in services lowered experiences of shame and stigma associated with missing scheduled appointments.¹² Adolescent health experts in the Bronx, NY also propose the adoption of differentiated care models for adolescents and young adults, citing the importance of specific practices and needs: frequent and informal communications via text and social media; support services beyond medical care by interdisciplinary staff like mental health and harm reduction services and assistance with housing, transportation, and job training; an LGBTQ-friendly and culturally appropriate service environment; and proactive interventions for adolescents and young adults at-risk for or who have stopped engaging in care.¹³ During the COVID-19 pandemic, people who are transitionally housed likely faced greater barriers to engagement in care than others. The Ward 86 HIV clinic at San Francisco General Hospital, however, compared outcomes for people who were transitionally housed and served by the 'POP-UP' low-barrier, high-intensity HIV primary care program with the general Ward 86 client population. Among the 85 clients assessed, care engagement and viral suppression remained comparable across both groups.¹⁴

POLICY ACTION: FACILITATE ADOPTION OF DIFFERENTIATED CARE MODELS THAT INCLUDE LOW-BARRIER SERVICES FOR SPECIFIC SUB-POPULATIONS.

The Ryan White HIV/AIDS Program can be a central locus of efforts to adopt differentiated care models, but the Health Resources and Services Administration HIV/AIDS Bureau (HRSA/HAB), which administers the program, cannot achieve all necessary policy actions alone:

- **Grantees and Jurisdictions:** Not every clinic should seek to operate a resource-intensive, low-barrier clinic. Therefore, jurisdictions need to be encouraged and supported in planning to adapt their services system to offer more flexibility and support for differentiated care based on current and ongoing needs assessments. Some clinics may primarily serve well-established patients and to simplify their care regimens, should provide them with the option of reducing their own frequency of routine clinical care visits. They also should be supported to expand access to telehealth services (building on experiences gained during the COVID-19 clinic closures) and walk-in services or home-based testing for routine laboratory services and STI testing, which can simplify care seeking for clients and reduce staffing burdens, all while recognizing that this involves overcoming current regulatory and other policy barriers. For low-barrier clinics, having adequate clinical staff available without the predictability achieved by scheduled appointments can be a challenge and must be supported through a trial-and-error process. Health departments and planning councils must play a role in providing an overall vision for how different entities within the community can work together to establish a cohesive system of care. This includes considering ways to ensure adequate revenue for clinics serving clients with various levels of need. Differentiated care models should seek to minimize incentives to provide services that may be only marginally beneficial simply to maintain clinic revenue.
- **HRSA/HAB:** A positive aspect of the Ryan White HIV/AIDS Program is the flexibility in the use of funds and the ability to prioritize services in response to local needs. This can be in tension, however, with the policy goal of achieving a uniform standard for high quality HIV services nationwide. HRSA/HAB should develop policy guidance that affirmatively encourages the adoption of differentiated care models and that identifies strategies and tools jurisdictions can use to move toward greater differentiation. Further, they should consider ways to use the Special Projects of National Significance (SPNS) Program to help jurisdictions and clinics adapt payment models and deploy the use of technology to move toward greater differentiated care.

TOOLS AND CHALLENGES IN ADOPTING DIFFERENTIATED CARE

The vision of an HIV healthcare system able to respond to the individual needs of people living with HIV is simple, but adapting our current delivery and financing systems to more flexible approaches is more complex. Critical tools that can enable jurisdictions and clinics to move to differentiated care models include:

Rapid Start of ART: Evidence supporting the significance of the initial clinical interaction at the time of diagnosis is mounting, and starting ART as soon as possible after receiving an HIV diagnosis also may lead to higher rates of viral suppression among some populations.[1] Developing and maintaining capacity to ensure that qualified, culturally-competent, and linguistically appropriate providers are available as needed to provide information and discuss treatment options at the time of diagnosis and ensuring payment for initial ART before insurance or safety-net program eligibility is established, however, is challenging.

Expanding the Dynamic HIV Care Team: Physicians and other clinical providers are often stretched too thin, and people with HIV tend to come to care with a variety of socioeconomic challenges and comorbidities. This calls for renewed efforts and funding to task shift and use nurses, social workers, case managers, and other non-physician providers to the greatest extent feasible.

Self-Sample Collection: Research has shown that individuals are able to reliably collect their own samples for STI testing.[2] The ability to self-collect laboratory samples at home or in the clinic may be an important way to increase STI testing among all populations, especially sexually active individuals, while minimizing clinic burdens.

Extended Prescription Drug Refills: The response to COVID-19 has shown that it is possible to fill prescriptions for 90 days in place of the prior standard of once every one month. By facilitating better adherence to ART and simplifying the demands of remaining engaged in care, this may be beneficial both for individual and population health. It is welcomed by many clients and can reduce costs and staff time. Many commercial and public payors, however, do not offer this option, and if patients lose their supply, replacement costs are even higher.

Telehealth Services: The COVID-19 pandemic revealed the essential role of telehealth and its acceptability and preference for these services by many patient populations. By facilitating the options of telephone visits or full clinical visits by videoconference, telehealth can serve a critical role in overcoming transportation and time barriers to care engagement. Providers also should embrace timely/current modes of communicating with clients, the use of web/app services to schedule and confirm appointments, and texting to reach clients who have fallen out of care.[3]

Social Services: Differentiated care models should not stop within the clinical setting. For example, pilot programs utilizing rideshare services have proven to be effective for patients in areas that lack public transportation, and a variety of innovative models have been developed to overcome non-medical barriers to engagement in care.[4]

INNOVATION IS NEEDED: Moving from small innovative projects to widespread adoption across various settings is challenging. More work is needed with engagement from federal program leadership, health department staff, clinical providers, and community members to tackle complex issues, including developing **payment models** to create more flexibility for providers and patients. New efforts are needed to address **administrative simplification** to make it easier for grantees to comply with competing requirements for different grant programs. Further, new consideration must be given to take successful models and achieve **sufficient scale** across a jurisdiction.

Sources: [1] Jeffrey S. Crowley & Sean E. Bland, *Big Ideas: Leveraging the Ryan White Program to Make Rapid Start of HIV Therapy Standard Practice*, O'NEILL INST. FOR NAT'L & GLOB. HEALTH LAW (Dec. 2018); [2] Carole Lunny et al., *Self-Collected versus Clinician-Collected Sampling for Chlamydia and Gonorrhea Screening: A Systemic Review and Meta-Analysis*, 10 PLoS ONE (July 13, 2015); [3] Jeffrey S. Crowley & Sean E. Bland, *Big Ideas: Integrating Telehealth Into HIV Services Systems Can Help to Sustain Improved Outcomes*, O'NEILL INST. FOR NAT'L & GLOB. HEALTH LAW (Oct. 9, 2020); [4] Nicole Rapfogel & Jill Rosenthal, *How North Carolina Is Using Medicaid To Address Social Determinants of Health*, CTR. FOR AM. PROGRESS (Feb. 3, 2022).

- Medicaid:** Medicaid is the largest payer for HIV health care services in the U.S. and should be encouraged to develop tailored programs to better meet the needs of beneficiaries with HIV. While states operate their own programs, the Centers for Medicare and Medicaid Services (CMS), which administers the program at the federal level, has an important role in describing barriers to linkage and retention, emphasizing Medicaid services options that can be used, and highlighting innovative state initiatives. One option that may offer a promising mechanism for increasing HIV outcomes is the Medicaid Health Home State Plan Option that was authorized under the Affordable Care Act (ACA) and allows states to establish health homes that will coordinate care for people with chronic conditions, including for people living with HIV.¹⁵ As of March 2022, 19 states and the District of Columbia had submitted state plan amendments to create health home programs. At least four of those states (Michigan, New York, Washington, and Wisconsin) have created health homes that offer services to beneficiaries with HIV/AIDS. Michigan, New York, and Washington include HIV among other qualifying chronic conditions for enrollment into the health home.¹⁶ Wisconsin is the only state that has created a distinct category of health homes that are solely dedicated to people living with HIV.¹⁷ New York found success in its Supportive Housing Health Homes Pilot, which from 2012-2018, provided a number of services to chronically homeless people living with HIV.¹⁸ Care coordination; comprehensive transitional care (including appropriate follow-up, from inpatient to other settings); and the facilitation and referral to individual, family support, community, and social support services resulted in decreased likelihood of emergency department visits and hospitalizations and an increased likelihood in the utilization of outpatient services. Other Medicaid options, such as the rehabilitation services option or existing waiver authorities, also may create avenues for state experimentation to strengthen linkage and retention in care.

2. FUNDING, GRANT REQUIREMENTS, AND STAFFING PRACTICES MUST BETTER SUPPORT INTEGRATED AND COHESIVE SERVICES MODELS

Another proposed HIV policy solution is the adoption of a syndemic approach. Factors that increase risk for poor HIV-related outcomes also increase the risk for other infectious diseases and are often associated with mental health (or brain health) challenges and substance use disorders. Syndemics often arise in the context of inadequate health care access and social supports. A syndemic is characterized by two or more negative health outcomes and/or social

SUCCESSFUL INTERVENTIONS FOR IMPROVING RETENTION SHOULD BE SCALED UP

To reduce disparities across populations, evidence-informed interventions for populations disproportionately impacted by HIV need to be developed and evaluated at the local level. The following are illustrative examples of interventions that have been shown to work for Black gay and bisexual men.

Acceptance-based behavior therapy: Newly diagnosed patients receiving therapy had 6.7% disengagement from care compared to 26.7% percent for those not receiving tailored therapy.

Project Identify, Navigate, Connect, Access, Retain, and Evaluate (IN-CARE): Out of care clients were identified through case finding, outreach, and referral partnerships and then provided six to nine months of peer health navigation, peer-led group education focused on retention, and access to primary care, laboratory services, and medication. At follow-up, linkage to care increased from 0% to 90%, and retention increased from 0% to 73%.

Project nGage: This is a social support intervention delivered by social workers. At twelve months, the intervention group was three times more likely to have had at least three care visits and report high adherence to their medication.

Sources: Hilary Goldhammer et al., *HIV care continuum interventions for Black men who have sex with men in the USA*, 8 THE LANCET HIV e776-86 (2021).

factors interacting simultaneously, contributing to excess burden of disease in a population.¹⁹ An ongoing policy obstacle to embracing syndemic strategies is the siloed nature of many federal and state funding initiatives, limited interoperability across federal/state data systems, and the complexity and volume of reporting requirements that have accrued over time to increase accountability and improve the monitoring of outcomes.

To maintain and improve outcomes along the care continuum in a manner that reduces inequities, it is important to consider the sustainability of the HIV response, including ways to better integrate with other public health and services programs serving the same communities. In prior briefs, we have highlighted the need for more federal funding both for the Ending the HIV Epidemic (EHE) Initiative and the broader HIV response.²⁰ Additionally, it is essential to conserve

HIV discretionary resources (i.e., funding for the Ryan White HIV/AIDS Program and other HIV programs) by maximizing public and private insurance coverage and demanding more accountability from these programs to better structure services to meet the needs of their enrollees. Investing now in services to maintain insurance enrollment, including assisting people living with HIV who may need to recertify their Medicaid eligibility as the public health emergency ends (as early as the fall of 2022), is critically important to minimize cost shifts onto the Ryan White Program. This also underscores the need for all states to adopt Medicaid expansion, as prior research has shown that insured individuals are more likely to be virally suppressed.²¹

POLICY ACTION: IMPLEMENT SYNDemic APPROACHES THAT CAN IMPROVE HIV OUTCOMES AND EXTEND THE IMPACT OF EXISTING RESOURCES.

- **HHS:** Clinics and grantees continually report their frustrations with being unable to operate a cohesive clinic to meet a variety of needs when each funding source (i.e., Ryan White Parts A, B, C, and D, the Minority HIV/AIDS Fund, supplemental EHE funding, etc.) has competing demands and reporting requirements. For many years, numerous stakeholders have proposed permitting blended or braided funding and streamlined reporting, with seemingly limited progress. The Office of Infectious Disease Policy should convene relevant HHS operating divisions (i.e., CDC, HRSA, SAMHSA, IHS, etc.) and HHS, HUD/HOPWA, the Departments of Interior, Labor, Education, and agency budget officials to discuss policy options, including potential legislative proposals, for blending funding and reducing reporting burden. They also should task the President's Advisory Council on HIV/AIDS (PACHA) with providing community and provider recommendations for consideration.
- **HRSA/HAB:** An element of differentiated care is reliance on task shifting to relieve the burden and staffing needs on physicians and relying more heavily on nurses and other health care professionals. While state laws vary, jurisdictions and clinics may need technical assistance to adapt their current service delivery models to expand the range of professionals that are part of the care team. A critical component of such efforts is to facilitate greater use of Community Health Workers (CHWs). Employing workers drawn from the communities in which they work also creates opportunities for more syndemic approaches as they may both better understand the overlapping and inter-related challenges that give rise to multiple adverse outcomes, and they may be better equipped to tap into a variety of community resources to improve health. Whether through hiring CHWs to work in clinics or establishing partnerships

and funding community-based organizations (CBOs), federal and state policy leadership is needed to induce a much greater commitment to integrating CHWs to improve clinical and other outcomes and to ensure that CHWs are paid a living wage with benefits. HRSA/HAB should consider policy guidance, technical assistance, and other actions it can take to lead this change.

3. EFFECTIVE MONITORING CAN GUIDE POLICY INTERVENTIONS TO KEEP IMPROVING OUTCOMES

The HIV care continuum has been an effective framework because it is visually simple to understand and can guide policy action at the national, state, tribal, local, and clinic levels. An unresolved challenge in monitoring HIV outcomes, however, is the tension between simplifying clinical interactions and collecting comprehensive data. Providers have expressed the view that their primary focus in a clinic visit is addressing a client's immediate needs and ensuring that they have access to antiretroviral therapy (ART). This is especially challenging for those with the greatest health care needs or those who face housing instability, food insecurity, cognitive impairments, HIV-related stigma, and other needs not universally addressed by the HIV services systems. Some of the very innovations that allow the health system to simplify the care experience, such as more telehealth services and at-home testing, can lead to data loss. This has been powerfully illustrated with the widespread use of rapid antigen tests for COVID-19. Despite being urged to report results, including negative results, to public health authorities, the vast majority of the roughly 28 million antigen tests performed each week go unreported, thus contributing to the proliferation of a "data black hole."²²

The metrics used for the care continuum have evolved over the past decade and will continue to evolve in the future, yet our ability to adapt metrics has fallen behind. For example, the linked to care metric in the 2010 continuum was based on linkage within 3-4 months, whereas in 2019 it is measured as linked within a month. This is still generally understood to be too long, and the ideal timeframe is linkage within 24-72 hours, so this standard may continue to change. The current definition of sustained engagement in care requires two viral load measurements in a year. As research seeks to evaluate the use of an annual viral load measurement, it is also easy to imagine more frequent viral load screening becoming the norm. In resource limited settings, dried blood spots (DBS) have been shown to be an effective way to measure HIV viral load.²³ Just as fitness trackers and other technology have led to near continuous monitoring of other health metrics that were once measured only periodically, it is easy to foresee a

future where the FDA has approved DBS or other tools that could allow for much more frequent viral load monitoring.

POLICY ACTION: DEVELOP MONITORING STRATEGIES THAT ACCOMMODATE DIFFERING MODELS OF CARE AND EVOLVING CLINICAL PRACTICES.

There are no simple solutions to the conflict between comprehensive data collection, standardization of metrics, and facilitating ease of clinical practice. Prior federal efforts have incorporated innovation and led to significant improvements. Continued leadership by various parts of HHS can drive the next phase of practice:

CDC: The Centers for Disease Control & Prevention is working with grantees to implement the Data Modernization Initiative. They should work with HRSA and other parts of the Department of HHS and consult with health department and clinical providers to develop strategies for the greater integration of clinical data sets as part of data modernization, including CAREWare, the electronic information management system supported by HAB and the Ryan White HIV/AIDS Program, or any subsequent systems used for Ryan White services data collection. Within the context of HIV prevention, CDC should continue to expand its investment in the Medical Monitoring Project (MMP).

At present, the data set is nationally representative, but not all states participate in MMP. By expanding MMP to more states and jurisdictions, it can continue to build capacity at the state level for improved data monitoring and analysis.

NIH: The National Institutes of Health (NIH), through both the Office for AIDS Research (OAR) and the Centers for AIDS Research (CFAR) network, should conduct a broad stakeholder consultation that includes a diverse array of clinical providers, researchers, participants, and surveillance experts across federal data sets, including MMP, the North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD), and others to consider the issues described. This includes evolving definitions of metrics as clinical standards change and addressing lost data or data gaps that may arise when serving specific patient populations or in specific settings. The NIH should be asked to qualitatively examine these assumptions, make recommendations for immediate policy actions, preview future challenges and opportunities that may arise with technological changes, and invest in research studies to evaluate and validate new or more flexible devices and metrics, like home-testing devices that can communicate with electronic medical records.

HRSA/HAB: Several grantees have reported that CAREWare, which is supported by the Ryan White Program, is a poor means of data management. Critiques have included that it has a clinic-level interface for some, but not all EHRs. It is also said that

PAST POLICY EFFORTS HAVE YIELDED IMPROVED MONITORING

For over ten years, efforts have been made to standardize and improve the monitoring of HIV clinical indicators. In 2010, the White House Office of National AIDS Policy (ONAP) commissioned the Institute of Medicine (now the National Academies of Sciences, Engineering, and Medicine, or NASEM) to conduct a consensus study to identify critical data and indicators related to continuous HIV care and access to supportive services, as well as to monitor the impact of the U.S. National HIV/AIDS Strategy and the Affordable Care Act (ACA) on improvements in HIV care. This led the committee to release two reports in 2012 with recommendations for:

- (1) indicators and data systems[1] and,
- (2) generating national estimates of HIV care and coverage.[2]

In response, HHS identified core indicators for federal programs, streamlined required metrics

for grantee reporting, and established uniform definitions of terms.[3] CDC also made several changes to the Medical Monitoring Project (MMP), a surveillance data set of behaviors and the clinical care experience of people living with HIV in the U.S., to improve the reliability and ability to provide nationally representative data of all people with diagnosed HIV.[4] This included revising data collection methods to allow for the inclusion of persons with diagnosed HIV but not receiving regular HIV care.

Sources: [1] MONITORING HIV CARE IN THE UNITED STATES: INDICATORS AND DATA SYSTEMS (Morgan A. Ford & Carol Mason Spicer eds., 2012); [2] MONITORING HIV CARE IN THE UNITED STATES: A STRATEGY FOR GENERATING NATIONAL ESTIMATES OF HIV CARE AND COVERAGE (Morgan A. Ford & Carol Mason Spicer eds., 2012); [3] Ronald O. Valdiserri et al., *Measuring What Matters: Development of Standard HIV Core Indicators Across the US Department of Health and Human Services*, 128 PUB. HEALTH REPORTS 354-59 (Sep.-Oct. 2013); [4] Linda Beer et al., *A National Behavioral and Clinical Surveillance System of Adults With Diagnosed HIV (The Medical Monitoring Project): Protocol for an Annual Cross-Sectional Interview and Medical Record Abstraction Survey*, 8 JMIR RESEARCH PROTOCOLS (Nov. 18, 2019).

there is a need for greater harmonization of common data elements and that the tailoring of CAREWare for specific uses is often unduly challenging. Given that lack of interoperability is a problem across the health system, HRSA/HAB should work with the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (CHACHSPT) to continue gathering user perspectives and recommendations for short- and long-term strategies for improving CAREWare's utility as a data management system.

THE TIME IS NOW

The doubling of the share of people with HIV who are virally suppressed from 2010 to 2020 shows how the implementation of healthcare best practices and community-centered leadership can drive change. As stakeholders strive to strengthen linkage and sustained engagement in care, reduce inequities across populations, and improve quality of life, strategic refinements to make HIV programs better able to address client needs is necessary. By implementing treatment and care that is integrated with other health and social services and more responsive to differential outcomes across populations, we can continue improving outcomes along the HIV care continuum.

ENDNOTES

- 1 *Vital Signs: HIV Prevention Through Care and Treatment - United States*, 60 MORBIDITY AND MORTALITY WEEKLY REPORT - CTRS. FOR DISEASE CONTROL AND PREVENTION 1618-23 (Dec. 2, 2011), <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a4.htm>.
- 2 *HIV Surveillance Supplemental Report: Monitoring Selected National HIV Prevention and Care Objectives by Using Surveillance Data - United States and 6 Dependent Areas, 2020*, 27 CTRS. FOR DISEASE CONTROL AND PREVENTION 1, 16 (May 2022), <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-27-3.pdf>.
- 3 Please note that data for 2020 should be interpreted with caution due to the impact of the COVID-19 pandemic.
- 4 *Ryan White HIV/AIDS Program Annual Client-Level Data Report, 2020*, HEALTH RES. & SERVS. ADMIN. (Dec. 2021), <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2020.pdf>.
- 5 Anna Grimsrud et al., *Reimagining HIV service delivery: the role of differentiated care from prevention to suppression*, 19 JOURNAL OF THE INT'L AIDS SOCIETY (2016).
- 6 Anna Grimsrud et al., *Evidence for scale up: the differentiated care research agenda*, 20 - Suppl. 4 JOURNAL OF THE INT'L AIDS SOCIETY (2017).
- 7 Lauren F. Collins et al., *The COVID-19 pandemic as a catalyst for differentiated care models to end the HIV epidemic in the US—applying lessons from high-burden settings*, 35 AIDS 337-41 (2021).
- 8 *Table 3. Laboratory Testing Schedule for Monitoring People with HIV Before and After Initiation of Antiretroviral Therapy*, <https://clinicalinfo.hiv.gov/en/table/table-3-laboratory-testing-schedule-monitoring-people-hiv-and-after-initiation-antiretroviral>.
- 9 *HIV Surveillance Special Report: Behavioral and Clinical Characteristics of Persons with Diagnosed HIV Infection—Medical Monitoring Project, United States, 2019 Cycle (June 2018—May 2019)*, 25 CTRS. FOR DISEASE CONTROL AND PREVENTION (May 2020).
- 10 Julia C. Dombrowski et al., *The Max Clinic: Medical Care Designed to Engage the Hardest-to-Reach Persons Living with HIV in Seattle and King County, Washington*, 32 AIDS PATIENT CARE & STDs 149-56 (Apr. 2018).
- 11 See *id.*
- 12 Kristin Beima-Sofie et al., *“It’s Me as a Person, Not Me the Disease”: Patient Perceptions of an HIV Care Model Designed to Engage Persons with Complex Needs*, 34 AIDS PATIENT CARE & STDs 267-74 (May 28, 2020).
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