The State of Engagement in HIV Care in the United States: From Cascade to Continuum to Control

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(See the Editorial Commentary by Rio and Mayer on pages 1172–4.)

The National HIV/AIDS Strategy and the promise of treatment as prevention have garnered considerable attention from the policy, practice, and scientific communities, with the treatment cascade becoming the sentinel image illustrating the domestic human immunodeficiency virus (HIV) epidemic. The cascade depicts prevalence estimates for sequential steps from HIV diagnosis through viral suppression, the most striking of which is that >50% of persons diagnosed with HIV are not in medical care. This heterogeneous group includes individuals not linked to medical care following HIV diagnosis and those entering care who are not retained, requiring reengagement from a range of community settings. This review synthesizes the state of engagement in HIV care in the United States, focusing on research, practice, and policy considerations. Included are conceptual frameworks, a review of health implications, measurement, monitoring, and evidence-based intervention approaches, and a look to the future in addressing the greatest challenge and opportunity facing our domestic HIV epidemic.

Keywords. HIV; access to care; linkage to care; retention in care; treatment cascade.

Initially presented to describe the human immunodeficiency virus (HIV) epidemic in Washington, DC [1], the “treatment cascade” captured the collective attention of domestic HIV stakeholders following adaptation and projection to the national level [2]. Beginning with estimates of prevalent HIV cases, successive bars illustrate the subsequent steps of HIV diagnosis, linkage to care, retention in care, antiretroviral therapy (ART) receipt, and plasma viral suppression (Figure 1). Suppression of HIV-1 RNA is the goal of ART and is associated with maximal clinical benefit and a dramatic reduction in HIV transmission [3, 4]. Initial estimates of viral suppression among HIV-infected Americans were only 19% [2], with a recent update suggesting that 25% of persons living with HIV in the United States have suppressed virus [5]. Whereas upward of 80% of HIV-infected persons in care are virally suppressed [6, 7], dramatic drop-offs in the early steps of the cascade drive the low overall rates of suppression, carrying profound implications for individual and public health outcomes. An estimated 20% of persons living with HIV infection in the United States are unaware of their status, and >50% of those diagnosed with HIV are not engaged in medical care [2, 5], collectively representing the greatest challenge and opportunity facing the domestic HIV epidemic.

The treatment cascade is a powerful image representing a quantitative depiction of discrete steps along the HIV care continuum, consistent with the National HIV/AIDS Strategy [8] and its specific national goals for testing, linkage, retention, and viral suppression. The cascade, however, is largely outcome oriented, showing population-level estimates of where individuals fall...
within isolated pillars. Other depictions of HIV care engagement emphasize process, demonstrating the dynamic and bidirectional relationships that exist between steps along this continuum [9], and may be applied to both individuals and larger populations (Figure 2). In addition, the 3 components of care engagement—linkage, retention, and reengagement—are explicitly represented [10]. The roughly 50% of persons diagnosed with HIV infection but not in medical care distribute heterogeneously across the care continuum; some have not successfully linked to care, others entered but subsequently dropped out of care, and others may be reengaging or transitioning from other settings (eg, corrections, inpatient hospital, emergency departments). A dynamic phenomenon of individuals cycling in and out of HIV treatment has been referred to as “churn” [11].

When considering factors that influence care engagement as well as intervention targets, comprehensive models are available and emerging. An adapted socioecological framework provides greater depth to the myriad of layers influencing care engagement, including individual level (intrapersonal), relationships (interpersonal), community-level, healthcare system, and healthcare policy factors affecting navigation across the care continuum (Figure 3). Other models of care engagement, including adaptations of the Behavioral Model of Health

Figure 1. The human immunodeficiency virus (HIV) treatment cascade in the United States. Beginning with estimates of prevalent HIV cases, successive bars illustrate the subsequent steps of HIV diagnosis, linkage to care, retention in care, antiretroviral therapy receipt, and plasma viral suppression. Initial national estimates were presented by Gardner and colleagues [2], with updated estimates generated by the Centers for Disease Control and Prevention [5]. More than 50% of persons diagnosed with HIV in the United States are not engaged in medical care because of failure with initial linkage and/or subsequent retention. Abbreviations: ART, antiretroviral therapy; HIV, human immunodeficiency virus.

Figure 2. Blueprint for human immunodeficiency virus (HIV) treatment success. Inclusive of the steps in the treatment cascade following diagnosis, this illustration demonstrates the dynamic and bidirectional nature and relationships among steps and explicitly identifies the 3 processes of engagement in HIV medical care—linkage, retention, and reengagement. Abbreviations: ART, antiretroviral therapy; HIV, human immunodeficiency virus.
Services Utilization and of the Information, Motivation, Behavioral Skills model, situated to initiation and maintenance of care, have been proposed to inform our understanding and guide intervention development [12–14]. This review synthesizes the current state of engagement in care in the United States, including health implications; measurement and monitoring considerations; and evidence-based intervention approaches, with an eye towards the future.

**THE IMPACT OF ENGAGEMENT IN HIV CARE ON INDIVIDUAL AND PUBLIC HEALTH OUTCOMES**

Numerous studies have evaluated associated factors and health implications of poor engagement in HIV care. On balance, linkage and retention has been generally worse among younger persons, females, and racial/ethnic minorities [5, 11, 12, 15–17]. In addition, lack of health insurance, mental illness, substance abuse, HIV stigma, and unmet needs for supportive services including housing, case management, mental health and substance abuse services have been consistently associated with poor HIV care engagement [18]. At a system level, passive referral to care following diagnosis and testing positive in a nonmedical setting has been associated with delayed or unsuccessful linkage to care [19, 20].

At an individual level, poor care engagement has been associated with delayed ART receipt and nonadherence, the emergence of antiretroviral resistance mutations, and inferior CD4 count and viral load outcomes [17, 21, 22]. Moreover, suboptimal retention has been associated with an increased risk of clinical events and death [22, 23]. At a public health level, differential engagement is a contributor to racial disparities in health outcomes and plays a prominent role in HIV transmission. Reductions in sexual risk transmission behaviors have been observed among persons with better retention [24]. Furthermore, more timely and sustained receipt of ART, improved adherence, and durable viral load suppression have notable implications for treatment as prevention initiatives [25]. Although enthusiasm has been bolstered by the findings of the HIV Prevention Trials Network (HPTN) 052 study, which demonstrated a dramatic 96% prevention benefit of early versus delayed ART [26], the success of treatment as prevention approaches is contingent upon successful diagnosis, linkage, and longitudinal retention in continuous HIV medical care to allow for uninterrupted ART receipt and sustained viral suppression. Accordingly, “treatment” must be interpreted in a broader context than ART alone.

**MEASURING ENGAGEMENT IN HIV CARE**

Linkage to HIV care has typically been defined as attendance at an initial outpatient medical care visit with a provider with medication-prescribing authority following initial HIV diagnosis. The National HIV/AIDS Strategy [8], Institute of Medicine (IOM) [27], and US Department of Health and Human Services (DHHS) [28] provide health policy guidance for measuring HIV care engagement. There is consensus to include linkage to medical care within 3 months of HIV diagnosis as a core indicator. Programmatically, many agencies and jurisdictions target a shorter time frame, although evidence is lacking to define an optimal period for linkage to care following HIV diagnosis.
Operationalizing measurement of retention has proven more complex. Individuals are scheduled for medical care visits at varying time intervals based upon clinical and psychosocial factors, and patient preference. In terms of what to quantify, both presence (“kept”) and absence (“missed”) of care visits have been used to compute various retention measures (Table 1) [29]. For retention, the IOM included the Health Resources and Services Administration (HRSA) HIV AIDS Bureau measure as a clinical core indicator. The DHHS recently adopted an alternative retention indicator among 7 measures for monitoring funded HIV services and programs (Table 1).

Notably, only “missed” visits that were not canceled in advance by patient or clinic have typically been used for calculation of missed visit–based measures (“no show” visits). In a recent study, a wide range of “retention” (33%–77%) was observed among the same study sample during a 12-month observation period depending on the measure used [30]. Although retention measures based on kept visits and those based on missed visits were strongly associated with viral suppression, they were not highly correlated with each other. These findings suggest there is no clear gold standard, and that different measures may tap into different domains of retention in care. Of note, it is imperative to look closely at the measure(s) employed to ensure comparability when evaluating retention across studies and settings. For research purposes, this paper suggested that measures should include one quantifying kept visits and one operationalized by missed visits.

**MONITORING ENGAGEMENT IN HIV CARE**

Recently published evidence-based guidelines for entry into and retention in care and ART adherence include recommendations for systematic monitoring of successful linkage into and subsequent retention in care for persons living with HIV [31]. While relatively straightforward conceptually, programmatic implementation to systematically determine whether individuals diagnosed with HIV are actively engaged in medical care is quite challenging. For example, determining whether a patient lost to care at a given medical clinic has engaged in care at another treatment facility is not always easily ascertained. Elegant epidemiological research conducted in resource-limited settings demonstrates that many patients lost to a specific medical clinic are not necessarily lost to medical care [32].

A number of data systems can be used to monitor entry into and retention in care including surveillance, medical and supportive services utilization, and administrative and claims databases. Studies have demonstrated the value of data system integration to improve systematic monitoring of care engagement [33, 34]. Despite the noted challenges in comprehensive monitoring, quantifying steps in the cascade at the state and

| Table 1. Approaches to Measuring Retention in HIV Care |
|---------------------------------|-----------------|----------------|
| **Retention Measure** | **Description** | **Notes** |
| Based on missed clinic visits | | |
| Missed visits | Number of “no show” visits accrued during a measurement period | Used as a dichotomous or a count measure |
| Visit adherence | Proportion of kept visits/scheduled visits (kept + “no-show” visits) during a measurement period | Visit nonadherence also used for this measure, which is the only single retention measure incorporating both missed and kept visits |
| Based on kept clinic visits | | |
| Visit constancy | Number of time intervals with at least 1 kept visit during a measurement period | Time intervals have typically ranged between 3 and 6 mo to assess for at least 1 kept visit during a longer measurement period (eg, 12 mo) |
| Gap in care | The time interval between sequential kept visits during a measurement period | Time intervals have typically ranged between 4 and 6 mo to define a gap in care during a longer measurement period (eg, 12 mo) |
| HRSA HAB measure | 2 kept visits separated by ≥ 90 d during a 12-mo measurement period | Identified as a clinical core indicator by the Institute of Medicine |
| DHHS measure | At least 1 kept visit in each 6-mo period during a 24-mo measurement period, with ≥ 60-d between visits in adjacent 6-mo periods | Among 7 common core indicators for monitoring DHHS-funded prevention, treatment, and care services |

By convention, only scheduled clinic visits with an HIV medical care provider with medication prescribing privileges are used to calculate retention measures. “No-show” visits are defined as visits not canceled in advance of the scheduled appointment by the patient, provider, or clinic. Use of CD4 counts and viral loads reported to surveillance have increasingly been used as proxy measures for HIV medical care visits, and can be used to calculate kept visit–based retention measures only.

Abbreviations: DHHS, Department of Health and Human Services; HIV, human immunodeficiency virus; HRSA HAB, Health Resources and Services Administration HIV/AIDS Bureau.
Table 2. Evidence-Based Approaches for Improving Engagement in HIV Medical Care

<table>
<thead>
<tr>
<th>Intervention (Recommendation Grade)</th>
<th>Description</th>
<th>Notes</th>
</tr>
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<tbody>
<tr>
<td>Linkage case management (IIIB)</td>
<td>Grounded in principles of empowerment and self-efficacy, a brief, intense, time-limited interaction focused on fostering linkage to medical care</td>
<td>Evaluated as a randomized controlled trial with formally trained social workers as interventionists; implementation in many settings has employed peer and/or paraprofessionals in this role.</td>
</tr>
<tr>
<td>Medical case management (IIIB, IVB)</td>
<td>A longitudinal relationship to address unmet needs for supportive services including housing, transportation, food insecurity, and mental health/substance abuse treatment among other potential barriers to HIV medical care utilization</td>
<td>Evidence supports recommendations specific to youth (IVB), as well as to the broader population of persons living with HIV (IIIB). Long-standing funding support via Ryan White CARE Act.</td>
</tr>
<tr>
<td>Intensive outreach (IIIC)</td>
<td>Provision of HIV education and support to address stigma and to advocate and access resources to overcome financial and structural barriers to care engagement</td>
<td>Time- and resource-intensive intervention proven effective for women, youth (including MSM of color), and those with mental health and substance abuse disorders.</td>
</tr>
<tr>
<td>Patient navigation (IIIC)</td>
<td>A model of care coordination, patient navigators work with clients to identify unmet needs and available resources across agencies to address their medical and supportive service needs</td>
<td>Typically peers living with HIV, or near peers with a common cultural background, patient navigators share features with advocates, health educators, and case managers, but do not have a home agency.</td>
</tr>
<tr>
<td>Clinic-wide messaging (NA)</td>
<td>Posters prominently displayed throughout the clinic, brochures and brief messages delivered to all clinic patients by all HIV medical clinic providers and staff regarding the importance of retention in care</td>
<td>Low-cost intervention demonstrated modest improvement in retention in care, particularly for new and reengaging patients, and those with detectable viral loads and low CD4 counts.</td>
</tr>
</tbody>
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Abbreviations: CARE, Comprehensive AIDS Resources Emergency; HIV, human immunodeficiency virus; NA, not applicable.

*a Recommendation for this intervention included in recently published Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV [31]. Recommendation grade based on quality of evidence: Excellent (I), High (II), Medium (III), Low (IV); and strength of recommendation: Strong (A), Moderate (B), Optional (C). |

Local level is imperative to inform educational and outreach initiatives, allocation of limited resources, and priority areas for program and service delivery, as well as to iteratively monitor steps on the cascade over time [10].

In recent years there has been a shift toward using surveillance data, notably CD4 counts and viral loads reported to public health departments and the Centers for Disease Control and Prevention (CDC), to monitor engagement in HIV care. Sociodemographic data captured by surveillance further allows for evaluation of disparities in linkage and retention in care, including disproportionately impacted subgroups (eg, young men who have sex with men of color). Whereas >30 states and jurisdictions currently require reporting of these laboratory values to public health, new CDC surveillance initiatives will require electronic laboratory reporting of these variables in all states. This represents a shift in paradigm for use of surveillance data, and recent guidance has been published on the ethical, procedural, and legal considerations, with importance of tailoring to local context within a given state or jurisdiction [34]. Although the use of surveillance laboratory data as a surrogate marker for care engagement may misclassify the number of outpatient clinical visits with an HIV care provider, these data have the advantage of generalizability across care settings (Ryan White providers, Veterans Affairs, private practice, community health centers) without requiring access to multiple diverse electronic medical records. As such, these data allow somewhat standardized estimates of local, state, and national engagement outcomes independent of care setting, but can only record kept visit–based retention measures. Beyond monitoring, surveillance data have been used to identify and make contact with out-of-care patients, provide feedback to providers about patients lost to their medical clinic, and to alert providers at the point of service to out-of-care HIV-infected patients via a health information exchange, in an effort to promote reengagement [34, 35]. These examples demonstrate the value of integrating data systems to enhance systematic monitoring, reduce misclassification of care engagement status, and inform actionable programmatic intervention in healthcare and community settings.

**INTERVENTIONS FOR IMPROVING HIV CARE ENGAGEMENT**

In contrast to nearly 2 decades of research and hundreds of randomized clinical trials comparing ART combinations to one another to define best-evidence regimens, relatively few approaches to enhance linkage, retention, and reengagement in care have been rigorously evaluated (Table 2). The sections that
follow describe proven intervention approaches, including recommendations from evidence-based guidelines [31], results of a systematic review [36], and additional interventions recently published in the literature.

**Linkage Case Management**

The CDC-sponsored Antiretroviral Treatment and Access Study (ARTAS) demonstrated the efficacy of a linkage case management intervention to improve initial entry into HIV medical care among recently diagnosed individuals [37]. Grounded in principles of empowerment and self-efficacy, case managers worked with clients to identify their internal assets and skills to promote care entry during up to 5 encounters over a 90-day period. This randomized controlled trial demonstrated 78% linkage to care within 6 months among the case management group, compared with 60% in the standard-of-care control group. Notably, linkage case management should be distinguished from medical case management, as the former is a brief, time-limited interaction focused on fostering medical care entry. In contrast, medical case management represents a longitudinal relationship, tethered to medical care aimed at addressing a wide range of supportive service needs. The ARTAS II study, a nonrandomized effectiveness study [38], demonstrated 79% 6-month care linkage when the intervention was delivered by community-based organizations and health departments.

**Medical Case Management**

Studies have shown that addressing food insecurity, transportation, and housing needs improved retention in care, ART adherence, and clinical outcomes [39–41]. Although evidence supporting this recommendation is largely derived from resource-limited settings, older studies in the United States similarly demonstrated the importance of case management and provision of supportive services to address unmet needs as a means of enhancing care engagement [18]. A second recommendation focuses on medical case management among HIV-infected youth. Observational studies with comparator arms demonstrated improvements in appointment attendance and ART receipt among those receiving individualized, intensive medical case management [42].

**Intensive Outreach**

Funded by an HRSA Targeted HIV Outreach and Intervention Model Development (Outreach Initiative) Special Projects of National Significance (SPNS), a range of intervention approaches were evaluated through observational studies with comparator groups. Evaluation of intensive outreach to provide HIV education and support, to address stigma, and to advocate and access resources to overcome financial and structural barriers to care engagement was conducted among recently diagnosed individuals across 4 study sites [43]. During the 12-month intervention period, participants received an average of 19 outreach visits with nearly 5 hours of contact time per month. Ninety-two percent of participants attended an HIV medical care visit within 6 months of enrollment, and plasma viral load suppression increased from 14% at baseline to 45% at 12-month follow-up. Moreover, a recent report from another HRSA SPNS initiative demonstrated the effectiveness of outreach in promoting engagement in care among young men who have sex with men of color; 87% of participants were linked to care within 90 days and 83% retained at 1 year [20].

**Peer or Paraprofessional Patient Navigation**

Described as a model of care coordination, patient navigation shares features with health advocacy, health education, and case management [44]. Peer or near-peer interventionists often have a shared cultural background with their clients and apply strengths-based principles, but do not have formal training in social work or case management and do not have a home agency. Patient navigators work with clients to identify unmet needs and available resources across agencies to address their medical and supportive service needs. Across 4 studies evaluating patient navigation interventions in the HRSA SPNS Outreach Initiative, retention in care improved from 64% at baseline to 87% at 6 months and 79% at 12 months, with a 50% increase in plasma viral suppression at 12 months [44].

**Clinic-wide Messaging and Culture**

Findings from phase 1 of the CDC/HRSA Retention in Care Project were recently published [45]. This project was a low-cost, clinic-wide health system intervention including posters, brochures, and brief messages delivered by HIV medical clinic providers and staff to all clinic patients regarding the importance of retention in care. It was conducted at 6 HIV medical clinics, and a cross-sectional pretest–posttest evaluation was conducted to evaluate intervention effectiveness during the 12 months following implementation. Overall, there was a statistically significant 3% relative improvement in visit adherence, with larger effects noted for new or reengaging patients (7.6% relative improvement), and those with detectable plasma viral load (5.5% relative improvement) and CD4 cell counts <350/μL (5.1% relative improvement).

**ENGAGEMENT IN HIV CARE: LOOKING TO THE FUTURE**

The call to improve linkage, retention, and reengagement in care is clear, with increased attention generated by the National HIV/AIDS Strategy, recent IOM reports, and release of DHHS indicators [8, 27, 28]. However, the science of engagement in care is in its infancy, with foundational research on measuring,
monitoring, and intervention approaches rapidly evolving, but far from definitive. Service concerns have been raised regarding workforce limitations and the capacity of the existing HIV care system to meet the medical and supportive service needs of individuals currently in care [46], not to mention the roughly 50% not currently engaged in medical care. Moreover, the composition of the HIV workforce is likely to change as service roles are redefined and new gateways to care are made possible by the Affordable Care Act. The coming years will be vibrant and dynamic as the service and science communities work simultaneously to address this most pressing issue facing the domestic HIV epidemic. To maximize health benefits and outcomes for individuals and society, it is imperative that these initiatives are integrated and not conducted only in parallel.

There is urgent need to optimize measurement and monitoring of care engagement by capitalizing on the strengths and overcoming the limitations of surveillance, and assuring the interoperability of administrative and clinical databases, as has been done successfully in many areas [31, 34]. Additional evidence-based interventions are desperately needed. In particular, integrated interventions incorporating public health, community-based and clinical agencies, and addressing several steps on the cascade rather than focusing on a single pillar would be valuable. In addition to randomized controlled trials, practice-based evidence including prospective observational studies with comparator groups may be beneficial and afford “real world” credibility. Engaging patient participation in research and quality improvement endeavors is desirable to inform activities and enhance uptake and delivery. Additionally, dissemination and implementation science initiatives, which already have proved useful in the fields of HIV prevention and drug use [47], are needed. Finally, intervention evaluation spanning multiple layers of the socioecological framework, including individual, relationship, community, healthcare system, and health policy, are needed (Figure 3). Notably, systematic monitoring and evaluation of the impact of the Affordable Care Act implementation, and Ryan White CARE (Comprehensive AIDS Resources Emergency) Act reform on HIV care engagement, are imperative across jurisdictions and around the country.

SUMMARY

Dramatic improvements in ART have impacted both length and quality of life for persons with HIV who are able to access and maintain drug treatment in the setting of sustained medical care. Yet when the majority of HIV-infected individuals are not effectively engaged in the care system, these benefits cannot be achieved, to the detriment of both individual and public health. Increased attention to measurement and monitoring of care engagement provides a needed framework for assessing progress across the care continuum. Evidence-based recommendations are emerging for improving linkage, retention, and reengagement in care, and the scientific rigor of research in these areas is improving. As the United States faces unprecedented changes in its healthcare delivery system, there is increased opportunity to facilitate coordination of the service, science, practice, and policy communities to more efficiently tackle initiatives spanning the continuum of care. As lines between treatment and prevention become more fluid, and silos between and within agencies are less rigid, there are unique opportunities for integration and synergy. Ideally, interventions will be designed to facilitate seamless progression from diagnosis to suppression through collaboration among service agencies, care providers, and researchers. An evidence-based and comprehensive approach to care engagement is now the next frontier in controlling the domestic HIV epidemic.

Note

Potential conflicts of interest. All authors: No reported conflicts.

All authors have submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Conflicts that the editors consider relevant to the content of the manuscript have been disclosed.

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