

# The HIV Care Continuum: No Partial Credit Given

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Despite significant scale-up of HIV care and treatment across the world, overall effectiveness of HIV programs is severely undermined by attrition of patients across the HIV care continuum, both in resource-rich and resource-limited settings. The care continuum has four essential steps: linkage from testing to enrollment in care, determination of antiretroviral therapy (ART) eligibility, ART initiation, and adherence to medications to achieve viral suppression. In order to substantially improve health outcomes for the individual and potentially for prevention of transmission to others, each of the steps of the entire care continuum must be achieved. This will require the adoption of interventions which address the multiplicity of barriers and social contexts faced by individuals and populations across each step, a reconceptualization of services to maximize engagement, and ambitious evaluation of program performance using all-or-none measurement. © 2012 Wolters Kluwer Health | Lippincott Williams & Wilkins

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Scale-up of HIV testing, care, and treatment across the world, particularly in sub-Saharan Africa (SSA) where the majority of people living with HIV (PLWH) reside, has been extraordinary with millions of individuals tested for HIV, over 11 million enrolled in HIV care, and more than 6 million initiated on antiretroviral therapy (ART) [1,2]. The impact of this effort is evident in the decrease in HIV-related deaths and rates of mother-to-child-transmission in high prevalence countries as well as in the notable decrease in HIV incidence in several countries in SSA [2–4]. However, the overall effectiveness of HIV programs is severely undermined by attrition of patients across the HIV care continuum, both in resource-rich and resource-limited settings. In studies from the US, only 19–28% percent of PLWH are estimated to achieve viral load suppression [5,6]. In SSA, insufficient data are available on overall viral load suppression given it is not routinely available, but less than one-third of individuals who test HIV positive are estimated to be retained from time of testing through ART initiation [7,8].

Completion of the entire care continuum is essential for optimal health outcomes for PLWH. This continuum begins with HIV testing and continues through multiple steps on the path to viral suppression for those initiated on ART (Fig. 1). The first step is linkage from where a patient received HIV testing to HIV clinics where counseling, clinical and laboratory monitoring for disease progression can be done on an ongoing basis to determine ART eligibility, the second step in the continuum. The subsequent step is prompt ART initiation based on prevailing guidelines. Upon initiation of ART, similar monitoring and counseling is needed to achieve and maintain viral suppression, a critical outcome necessary for attaining individual benefits from treatment [9]. Viral suppression in PLWH has also been associated with a decrease in risk of HIV transmission to sexual partners, an additional benefit from effective completion of the continuum [10].

No single step in the care continuum appears to be the sole bottleneck in the achievement of the entire

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continuum. Linkage from testing to care has not been routinely reported by programs, but limited data suggest that it is poor across diverse settings. In the US, only 48% of PLWH in South Carolina and 77% in New York City linked to care within 3 months of receiving an HIV positive test result [11,12], as compared to the target of 85% recommended by the US National AIDS Strategy [13]. In SSA, median linkage is 59% across an analysis of 28 studies [7]. Determination of ART eligibility and initiation of ART for eligible patients is also suboptimal. In the US only half of PLWH, once enrolled, remained in care and 89% of those eligible were prescribed ART [5]. Results are similar in SSA where less than half of PLWH receive a CD4+ count test result or clinical staging—two critical assessments required to determine ART eligibility [7]. Approximately two-thirds of PLWH who are eligible for ART remain in care to ART initiation [7,8] and 70% of patients on ART are retained in care at 24 months [14].

Improvements in each step of the continuum must be achieved simultaneously to improve outcomes such as achievement of viral load suppression, decreased mother-to-child transmission, and HIV-related mortality. To improve viral suppression in PLWH in the US, it has been noted that only when each step in the continuum is completed with 90% fidelity would the proportion of viral suppression increase from current 19% to 66% [6]. In the context of the programs for prevention of mother-to-child transmission (PMTCT), programs need to perform with 90–95% effectiveness across the various steps in the continuum in order to achieve the ultimate desired mother-to-child-transmission rate of less than 5% [15].

There are multiple reasons for the failure to achieve optimal linkages and retention including structural, biomedical and behavioral barriers. In a meta-analysis of 17 studies evaluating loss to follow-up in ART participants, the most common reasons reported were lack of money, improving or deteriorating health, and transfer to another HIV care site [16]. In a study from Uganda, reported reasons for loss to follow-up included lack of transport (50%), lack of money (35%), work (27%) or childcare (22%), and deteriorating health (6%) [17]. Stigma also continues to be a barrier, particularly in marginalized populations such as men who have sex with men (MSM), and has been associated with non-disclosure of HIV status and poor retention [18,19]. To address these challenges, interventions such as use of point-of-care CD4+ cell count testing at time of receipt of positive HIV test result [20,21], case managers [22], counseling, mobile technology [23,24], and financial incentives [25] offer encouraging results for enhancing various steps in the continuum; however, no single intervention to date has been able to substantially impact all steps in the continuum. Combination approaches which evaluate the feasibility of multiple interventions are being explored with a focus on overall adherence with all steps in the continuum [26]. However, interventions be tailored to

the social context and characteristics of the specific patient populations they serve. For example, MSM in resource-rich settings are likely to face different barriers as compared to pregnant women in resource-limited settings.

In addition to the interventions listed above, a reconceptualization of how HIV services are organized may also be needed to achieve desired health outcomes. For example, HIV testing and HIV care and treatment services have historically been organized and operated separately in disparate physical locations, operated by different staff members sometimes working in parallel and isolation of each other. New models of integrated HIV care should be developed to create networks of testing and care with agile referral systems. Another example is the current organization of HIV services for pregnant HIV-infected women. These services are traditionally based on having PMTCT interventions during pregnancy and delivery provided separately from HIV care and treatment services required by the pregnant HIV-infected women and their infants beyond delivery. Recent studies have shown alarmingly high rates of loss to follow-up for these women, particularly in the transition after delivery, between PMTCT and lifelong HIV care services [27–29]. Integrated HIV care, including provision of ART and antenatal services, whether within antenatal clinics or preferably in primary care clinics that provide continuity care for HIV-infected women and their children may need to be considered.

In addition to the organization of services, another issue that needs particular attention is the manner in which program performance is evaluated. To date, performance indicators largely measure activities within each service, or step, rather than throughout the continuum. For example, HIV testing sites report the numbers of tests conducted or individuals tested rather than the ultimate disposition of those found to be HIV positive. Similarly, HIV care and treatment programs are largely evaluated by the number of individuals enrolled in care or who initiated ART rather than whether individuals were retained across the entire HIV care continuum. Likewise, PMTCT programs have focused on achieving HIV testing in a high percentage of pregnant women attending antenatal care clinics and the number of women and infants who received antiretroviral regimens for PMTCT, rather than based on whether the HIV-infected pregnant women were retained in care beyond delivery and whether their infants were appropriately followed in care until their HIV status is confirmed.

The time is right for HIV programs to be evaluated ambitiously based on the proportion of PLWH who receive a full package, or bundle, of HIV services across the continuum, i.e. in an all-or-none manner with “no partial credit given” for achievement in one step of the continuum [30]. Success would be determined by the

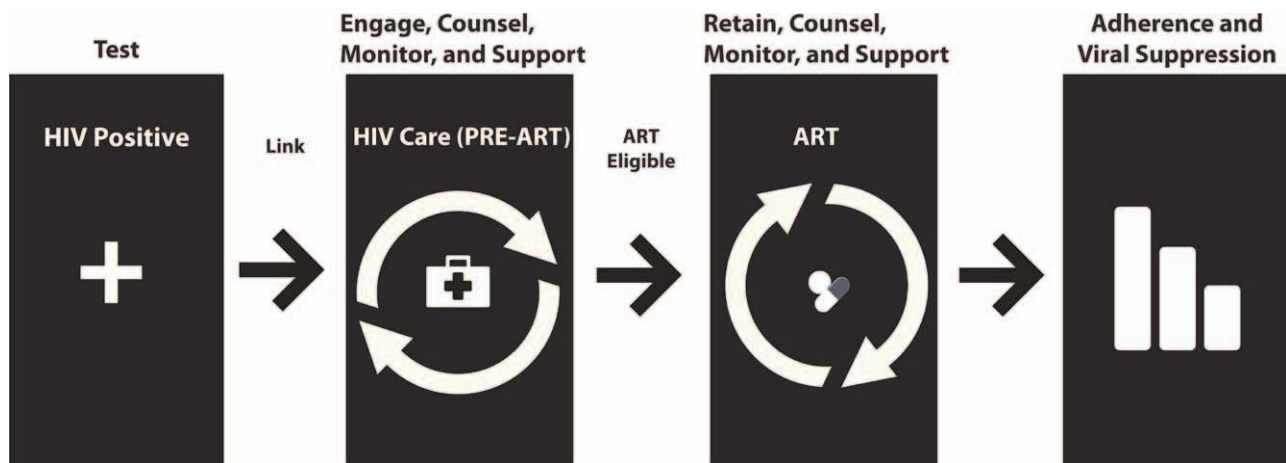


Fig. 1. ????

proportion of patients who received *all* the steps, or all of the care components, for which he or she is eligible. In a 2006 article, Nolan and Berwick articulated the advantages of an “all-or-none” measurement as a patient-centered approach and as a tool to ensure quality, and as a means of promoting a systems perspective [30]. All-or-none measurement is particularly appropriate for chronic disease management, as in the case of HIV disease, given the importance of retention over time and the need for receipt of multiple interventions. In order to operationalize this concept, country and program leadership as well as funders must embrace this approach, while at the same time appropriate data elements must be collected and data management capacity strengthened.

The historic global response to the HIV epidemic has demonstrated the feasibility of establishing large-scale HIV programs in some of the poorest countries in the world. To realize the potential of this extraordinary investment and to enable meeting the remaining challenges will require attention to every step of the HIV care continuum. The loss of program effectiveness is particularly tragic at a time of tremendous potential, immense needs and constrained resources. Attention to the full care continuum coupled with the implementation of creative integrated models of care and ambitious performance measures can go a long way to achievement of an AIDS free generation.

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### Conflicts of interest

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