

Long-Term HIV Treatment Adherence for Key Populations:

Program Considerations

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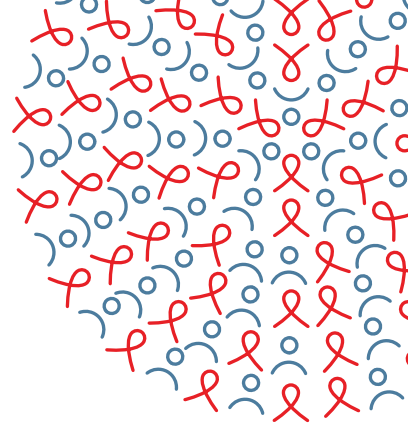
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Acronyms

ART	antiretroviral therapy
CASG	community adherence and support group
CBO	community-based organization
CHAMP	Continuum of HIV/AIDS Prevention, Care and Treatment for Most-at-Risk Populations program
CHW	community health worker
COP	Country operational plan
CSO	care and support officer
DSD	differentiated service delivery
DTG	dolutegravir
EID	early infant diagnosis
EFV	efavirenz
EPiC	Meeting Targets and Maintaining Epidemic Control project
FDC	fixed-dose combination
ICAP	Columbia University's International Center for AIDS Care and Treatment Programs
KP	key population
KPIF	Key Population Investment Fund
KPLHIV	key population member living with HIV
LTFU	loss/lost to follow-up
M&E	monitoring and evaluation
MMD	multimonth dispensation
MSM	men who have sex with men
NGO	nongovernmental organization
ORA	Online Reservation App
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	people living with HIV
PrEP	pre-exposure prophylaxis
PWID	people who inject drugs
S&D	stigma and discrimination
SDART	same-day antiretroviral therapy
SOP	standard operation procedure
SW	sex worker
TB	tuberculosis
TLD	tenofovir, lamivudine, and dolutegravir
U=U	undetectable = untransmittable
USAID	United States Agency for International Development
VL	viral load
VLM	viral load monitoring
WHO	World Health Organization



INTRODUCTION

Background

On a global scale, antiretroviral treatment (ART) is working. Rapid expansion of ART has changed the nature of the epidemic from one associated with fatal illnesses to a life-long but manageable chronic disease [1]. For the first time, nearly two-thirds of all people living with HIV (PLHIV) are on ART, and the number is growing [2]. The epidemic is also transforming: in 2018, over half of all new HIV infections were among key populations (KPs)—sex workers (SWs), people who inject drugs (PWID), gay men and other men who have sex with men (MSM), transgender (TG) people, and prisoners—and their partners. While KPs comprise a small proportion of the general population, they are at much higher risk of HIV infection. Available data suggest that the risk of HIV acquisition among gay men and other MSM was 22 times higher in 2018 than it was among all adult men. Similarly, the risk of acquiring HIV for PWID was 22 times higher than for people who do not inject drugs, 21 times higher for SWs than other adults ages 15–49 years, and 12 times higher for trans people than other adults ages 15–49 years [3].

The UNAIDS report, *Fast Track: Ending the AIDS Epidemic by 2030*, outlines ambitious targets to end the AIDS epidemic by 2030 [4]. The approach includes an agenda for accelerating the delivery of high-impact HIV prevention and treatment services and using innovation to increase service access, address needs, and focus on locations and populations with the highest HIV burden. The Fast-Track drives global 95-95-95 goals: that by 2030, 95% of PLHIV know their HIV status, 95% of people who know their status are receiving treatment, and 95% of people on HIV treatment have a suppressed viral load (VL). However, limited population-based data show that testing and treatment coverage among KPs remains disproportionately low, with no KP group close to achieving 90-90-90 targets by 2020 [5].

Stigma, discrimination, and criminalization have led to increased fear among KP members, preventing many from visiting health care services. Those who do go may be reluctant to disclose their sexual histories for fear of rejection, derision, or other negative reactions from providers [6-8]. In addition, violence against KPs is frequent and often severe. Experiences of violence not only increase their risk of acquiring HIV, but also affect their desire and ability to test for HIV and adhere to treatment [9-10].

Long-term and successful treatment outcomes among KPs and other PLHIV will depend on life-long adherence and sustained viral suppression [11]. While high levels of adherence have been reported in some lower- and middle-income countries, these findings contrast with other studies reporting increasing treatment failure, low retention, and high mortality rates [12-15]. Sustained epidemic control will not be possible if clients, whether new or long-term, fail to stay on treatment.

Vision for epidemic control

The treatment goal for achieving global 95-95-95 targets by 2030 is durable viral suppression that reduces morbidity and mortality and prevents HIV transmission. Key to achieving this goal is the provision of client-centered, differentiated services in which the health system and community-based organizations facilitate continuous, lifelong ART in a manner that is responsive to KP members' changing circumstances.

Purpose

While the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the World Health Organization (WHO), UNAIDS, the International AIDS Society, and other stakeholders have outlined a number of strategies for strengthening ART retention, there remains a gap in guidance specific to KP programming. This guide provides a summary of policies and practices at the structural, network, and site levels which, combined, can optimize epidemic control for KPs. It includes recommendations on the provision of services across the treatment cascade that can speed up links to treatment; enhance differentiated, peer- and community-driven service delivery in partnership with facilities; and improve monitoring, tracking, and reengagement of individuals lost to follow-up (LTFU) to achieve viral suppression. The guide also includes a number of links to guidance documents, tools, and examples to support program design, adaptation, implementation, and monitoring.

Audience

The primary audience for this implementation guide includes HIV program managers and implementers at both facility and community levels. This guide also may be valuable for technical working group members, national HIV guideline committees, and other stakeholders contributing to the development of long-term adherence strategies to achieve viral suppression.

Structural elements

Members of KPs and other PLHIV face a variety of barriers to adherence in treatment at both facility and community levels, including distance to services, congestion at public-sector sites, long wait times, and formal or informal user fees. Individual and social barriers include fear of disclosure; HIV- and KP-related stigma and discrimination (S&D); past and current violence, including sexual violence; depression and anxiety; and lack of social support. Specific behaviors, such as drug use, and characteristics, such as young age, high mobility, homelessness, and incarceration, also are correlated with difficulties in adherence. Among youth, exposure to violence at home, school, and clinics is a major and cumulating risk for adolescents' nonadherence to ART [16].

Successful long-term adherence requires a multifaceted response to barriers at the individual level, supported by an enabling environment. There are a number of national policies and practices that have been demonstrated to remove barriers to treatment initiation, adherence, and retention, and to accelerate achievement of downstream cascade goals for KPs. Programmers should begin with a review of national policies, strategies, and guidelines to gauge to what degree they align or differ from current recommendations to support long-term adherence goals (e.g., WHO's [Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations](#); and PEPFAR's [Country Operational Plan 2020 Guidance](#) [17-18]).

The following sections describe strategies that address structural barriers to long-term adherence. These include differentiated service delivery (DSD), scale-up of tenofovir, lamivudine, and dolutegravir (TLD), rapid and same-day initiation of ART, multimonth dispensation (MMD), decentralized distribution in the private sector, and viral load (VL) scale-up.

FIGURE 1. Key elements in differentiated approaches to HIV care

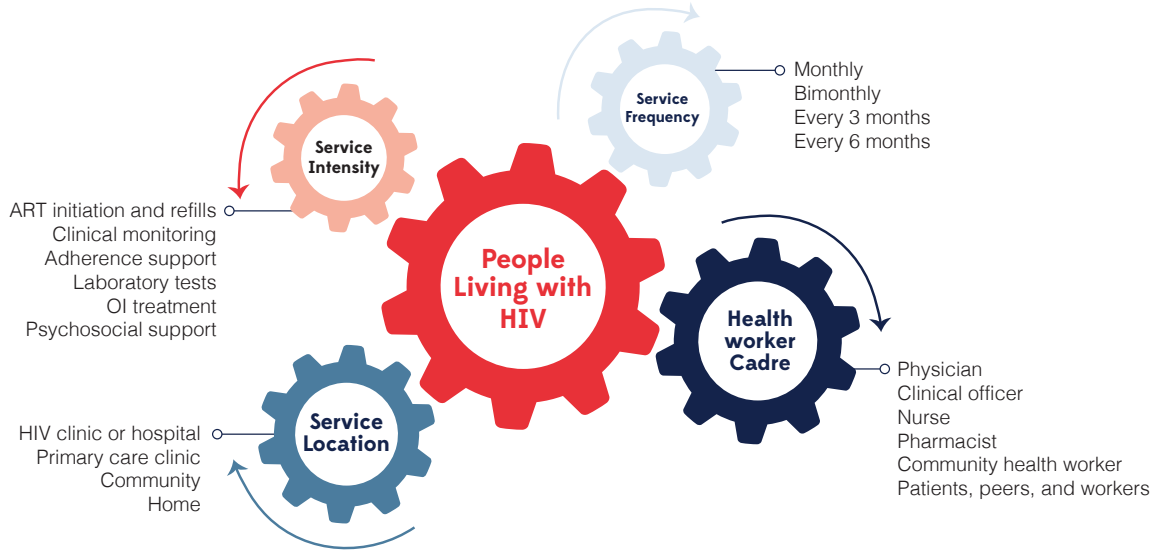
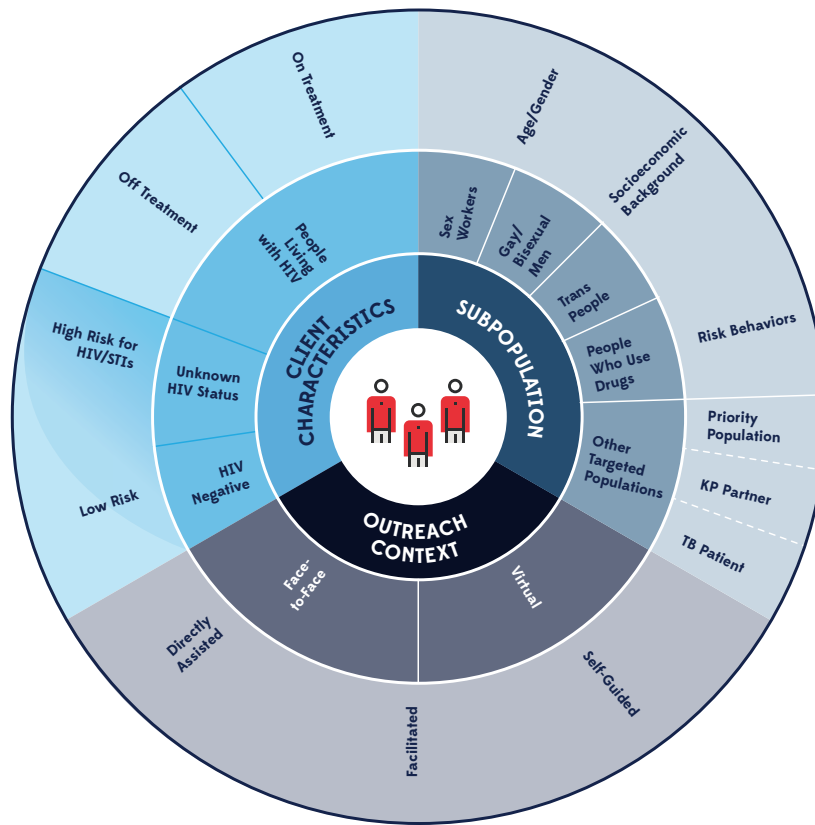


FIGURE 2. LINKAGES DSD Model



Differentiated service delivery

DSD is a client-centered approach that simplifies and adapts HIV services across the cascade to reflect the needs and preferences of KPs (and other PLHIV), while reducing unnecessary burdens on the health system. Implementing DSD can reduce barriers to HIV service access for KPs and allow the health system to refocus resources as needed [19]. By adapting, building, and harmonizing DSD models between the public and private sectors, countries can expand ART access to community settings, integrate community-to-facility models, speed up links to treatment, and improve adherence and viral suppression for KPs. It is important that KP members are able to access services relevant and critical to their needs, when they need them. DSD models can be integrated with facility, community, and mobile interventions based on KP preferences.

National DSD responses will benefit from enabling policies that support decentralization of services. These can include community initiation and dispensation of ART (i.e., at community-based organizations [CBOs] or private sector pharmacies) and decentralized models for increasing access to VL diagnostics (i.e., point-of-care VL or transportation of blood samples). Figure 1, from *WHO's Consolidated Guidelines on the Use of Antiretroviral Drugs For Treating And Preventing HIV Infection* (2016) highlights many of the elements that factor into differentiated support for ART [20].

A number of other tools can be used to develop DSD policies and models for KPs and priority populations to suit each country's context. WHO's [Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations](#) contains guidance on what kinds of service delivery models to develop [17]. Figure 2, the LINKAGES DSD model, guides programs to consider three elements when determining for whom differentiated ART will be provided: **client characteristics, subpopulations**, and the **outreach context**. Each element carries additional considerations that can be incorporated in the model.

The International AIDS Society's [Differentiated Service Delivery: a Decision Framework for Differentiated Antiretroviral Therapy for Key Populations](#) provides a step-by-step approach on how to plan the provision of ART services for KPs and adapt/build differentiated ART delivery models [21]. With considerations based on the three key elements in Figure 2, countries can adapt or develop new DSD models using four building blocks: **When** is care provided (time of visit and visit frequency)? **Where** is care provided (location)? **Who** is providing care (service provider/peer)? **What** care is provided (service package)?

The building blocks for clinical consultations, ART refills, and psychosocial support may be different for each individual, and some services may be more readily decentralized than others. For example, while a client may be clinically stable and require a clinical consultation every six to 12 months while collecting ART refills every six months, they may be experiencing isolation and social rejection and benefit from more frequent psychosocial support. This kind of support can be provided through peer groups or networks (including virtual platforms) of members of KPs living with HIV (KPLHIV), one-on-one adherence counseling with health care workers or peer navigators (discussed below), and/or home visits. Community-based programs can work jointly with district health teams and clients to determine the “where,” “who,” “when,” and “what” building blocks that respond to KP and community needs.

Below is an example of the building blocks of differentiated ART delivery for clinically stable trans women from a community-based, key-population-led care and treatment program supported by PEPFAR/USAID and the LINKAGES program in Thailand. More examples like these are provided in the [Decision Framework](#) [21].

Differentiated ART delivery for KPs should not be limited to clients who are clinically stable. DSD can be a way of increasing access to HIV services for KP members who are experiencing challenges to adherence and providing choices for service delivery models based on clinical needs and individual preferences.

A DSD approach should be applied across the care continuum – including differentiated approaches for prevention (e.g., delivery of pre-exposure prophylaxis [PrEP]), testing, linkage, and retention.

ART DELIVERY THROUGH KP-LED HEALTH SERVICES FOR TRANSGENDER WOMEN, THAILAND [21]

In Thailand, health service delivery models were designed to improve HIV service uptake among trans women and MSM, and to address low rates of linkage to care and high rates of LTFU. Clients were eligible for ART maintenance through community-based KP-led health services if they were clinically stable. Three models of differentiated ART delivery were developed in collaboration with CBOs. In the “one-stop shop CBO model,” doctors visit KP-led CBOs to support ART initiation. Once clinically stable, KP-community health workers (CHWs) support clients for ART maintenance. In the “hospital to CBO model,” CBO staff accompany clients to provincial ART network hospitals for initiation; once clinically stable, clients are referred to KP CHWs at CBOs for ART maintenance. In the “combined hospital to CBO model,” treatment initiation and maintenance can occur at a hospital, as well as a CBO, depending upon client preferences. The models are examples of out-of-facility individual models of ART delivery.

	ART Refills	Clinical Consultations	Psychological Support
WHEN	Monthly or every three months During regular business hours for doctor led visits, additionally during evenings, and/or weekends for KP-CW led visits	Every three months During regular business hours for doctor led visits, additionally during evenings, and/or weekends for KP-CW led visits	Every three months, or as needed During regular business hours for doctor led visits, additionally during evenings, and/or weekends for KP-CW led visits
WHERE	Alternately hospital and CBOs, or all visits at the CBO, depending on client preference and local circumstances	Alternately hospital and CBOs, or all visits at the CBO, depending on client preference and local circumstances	Alternately hospital and CBOs, or all visits at the CBO, depending on client preference and local circumstances
WHO	Alternately doctors and KP-CHWs	Alternately doctors and KP-CHWs	Care and support officers (CSOs)
WHAT	Doctors: ART rescripts, clinical consultation KP-CHWs: ART refills, comprehensive health check, adherence check and counseling, and referral to doctor as needed	Doctors: ART rescripts, clinical consultation KP-CHWs: comprehensive health check, adherence check and counseling, and referral to doctor as needed	CSOs: psychosocial support, safe sex counseling and referral for additional counseling if needed

Scale-up of tenofovir, lamivudine, and dolutegravir

WHO recommends that countries should transition all eligible patients to ART regimens that contain dolutegravir (DTG) in place of efavirenz (EFV). DTG-based ART regimens are associated with fewer side effects, drug interactions, and discontinuations; rapid suppression of VL; and a high genetic barrier to resistance. Rapid VL suppression is particularly important for KPs, who may have multiple partners. Having a high barrier to resistance is critical given lower adherence rates among KPs. The higher efficacy and tolerability, combined with the availability of an economical, fixed-dose combination (FDC) tablet, make TLD an optimal first-line regimen [22]. The FDC tablet can help improve adherence by reducing the number of pills a person must take each day. TLD is also recommended as a second-line regimen for patients failing on EFV- or nevirapine-containing regimens, or for those failing a non-DTG-containing first-line regimen.

Because TLD is better tolerated and has fewer side effects, treatment adherence and retention should be higher, especially if patients are properly educated and prepared. LINKAGES has produced a brief guidance document titled [Tenofovir, Lamivudine, And Dolutegravir \(TLD\) Transition: General Information for Clients, Clinicians, Counselors, and other Service Providers](#) that provides an overview for orienting programs to TLD transition, and special considerations for transition [23]. Recommendations on the use of TLD are available from [WHO](#) and PEPFAR's [COP 2020 guidance](#) [18,24].

Planning for the rollout of TLD includes several decisions at the country level, taking into consideration clinical risks and benefits, and practical programmatic issues. Many of these decisions are country-specific and may change over time as new evidence emerges. Governments usually develop a national policy for TLD transition while updating the HIV treatment guidelines. For guidance to inform some of the practical decisions that countries should consider when rolling out TLD, refer to OPTIMIZE's [Considerations for the Introduction of TLD in National Programs: PEPFAR Guidance on Developing Clinical and Programmatic Recommendations](#) [22].

Rapid and same-day initiation of antiretroviral therapy

In 2017, WHO produced recommendations on rapid and same-day ART based on evidence from several randomized controlled trials and observational studies indicating that these practices can improve patient outcomes [25]. WHO recommends that programs offer rapid ART initiation (within seven days of diagnosis), including same-day start (SDART), to all PLHIV after confirmed HIV diagnosis and clinical assessment, and that people with advanced HIV disease should be given priority for assessment and initiation. The provision of rapid ART initiation is especially important for KPs, who often face additional barriers and challenges to accessing, initiating, and adhering to treatment. KP members presenting for the first time, or those returning to care after being LTFU, should undergo assessment to treat opportunistic infections, such as tuberculosis (TB) or cryptococcal meningitis, before ART is initiated or re-initiated. Although CD4 testing is not a requirement to determine ART eligibility, a baseline CD4 cell count can be used to determine whether the patient has advanced HIV disease. ART should be offered on the same day to people who are ready to start [25]. In line with WHO recommendations, all PEPFAR-supported programs are required to offer same-day initiation of ART to all newly diagnosed HIV patients who have no contraindications to rapid or same-day ART initiation, independent of place of diagnosis [26].

Data from countries implementing rapid ART initiation have shown rapid increases in ART uptake and diminished LTFU. Programs may prevent loss by employing a case management approach, task-shifting services from physicians to other health care workers, and decentralizing from specialized HIV



SAME-DAY SUCCESS STORIES

Tanzania's FIKIA program employs a DSD approach that includes a two-week starter pack of ART at diagnosis. The program doubled ART initiation among KP members who tested HIV positive from ~40% to ~80% using a same-day HIV diagnosis and ART initiation model in community settings, staffed by Ministry of Health providers.

In Thailand's KP-led health services model, clients expressed high acceptability of same-day initiation (~90%), and of these 77% were able to initiate. Additionally, 94% were virally suppressed after one year, and those who had initiated same-day ART were 2.2 times more likely to be virally suppressed than those in the standard care model.

Source: PEPFAR COP 2020 Guidance [18]

treatment centers to primary care or KP/community clinics to support ART initiation and maintenance for KPs. Approaches that are focused and organized around the health needs, preferences, and expectations of KPs, and that uphold individual dignity and respect, will be more likely to retain their clients [18]. Programs should engage and support KP members and their families to play an active role in their own care through informed decision-making. For programs that support links to treatment via referral, it is critical to confirm that clients initiate ART and to provide ongoing treatment and adherence support, as needed.

Community-based partners and facilities can work in tandem to develop robust models to decrease the time between diagnosis and treatment initiation. Core components of the 2016 WHO-recommended good practices for links that support retention, with additional inputs, include the following [20]:

- Integrated services, where HIV testing and treatment are packaged with other services such as screening and treatment for sexually transmitted infections and TB at a single site
- Intensified post-test counseling and education
- Assessment and mitigation of real and perceived barriers to HIV care
- Options for treatment support, including peer navigation with personal escort to HIV care registration and support through viral suppression. Others such as social workers, and friends/family may also provide PLHIV adherence support.
- Assistance with transport, such as transport vouchers
- Follow-up by telephone/message, reminders, and contact tracing if treatment was not initiated
- Brief (<90 days) peer-delivered, linkage case management
- Ongoing individually differentiated counseling, psychosocial support, and links to peer support
- Informational and motivational counseling on the benefits of disclosure, testing of partners and biological children, and ART initiation and adherence
- Decentralized ART provision and community-based distribution of ART
- Systematic monitoring and evaluation of enrollment in HIV care and ART initiation outcomes, including monitoring of first drug pick-up



INNOVATIONS IN LINKING CLIENTS TO ART

Programs can be creative in developing approaches to increase the speed and effectiveness of linkage. The *Continuum of HIV/AIDS Prevention, Care and Treatment for Most-at-Risk Populations* (CHAMP) program in Cameroon provides a variety of options for clients to initiate treatment when they are diagnosed HIV positive. Many of the program's FSW and MSM clients are tested during evenings and weekends when many facilities are closed. To improve links to treatment, CHAMP couples outreach teams with peer navigators so that newly diagnosed individuals in the field can be linked immediately to a navigator, who will guide them to ART services during facilities' operating hours. The program also couples outreach teams with clinicians during mobile testing, or offers newly diagnosed individuals the opportunity to speak with a clinician on the phone during evening and weekend hours, as a means of establishing an immediate relationship with a provider. Peer navigators on the program have developed close relationships with public facility nurses, who are on call to open their facilities in the evenings to initiate clients on treatment if they test positive during community testing. These efforts have helped the program maintain consistent ART linkage rates at 95% or above for both FSW and MSM clients.

Programs should incorporate enhanced pre-test counseling and education to ensure that clients hear positive messages about HIV testing, including the benefits of knowing one’s status and early treatment initiation, and “undetectable = untransmittable” (U=U) messaging. More information is provided in the subsection on U=U below. The [PEPFAR Solutions Platform](#) also provides additional community-based examples to improve linkage [27].

Technical guidance on same-day initiation of ART, including recommendations on the timing of ART initiation in the presence of TB and cryptococcal disease, is available in WHO’s [Guidelines for Managing Advanced HIV Disease and Rapid Initiation of Antiretroviral Therapy](#) [25]. For a complete list of recommended and desirable diagnostic tests for people initiating ART, refer to WHO’s [Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection](#) [20].

Multimonth dispensation (MMD)

MMD is a facility- and community-based DSD model in which individuals who are stable on ART receive three months of medication or more at each visit, enabling their appointments to be spaced at less frequent intervals. In the COP 2020 guidance, all those who are clinically stable are required to be provided six months of MMD. In many countries, MMD is combined with appointment spacing and fast-track approaches (i.e., bypassing clinical visits to pick up drugs directly from a pharmacy) to minimize the amount of time that clients need to spend at health facilities. Research has shown that the model creates efficiencies for the health system and improves retention in care [28]. The provision of this service for KPs is critical because of the compounded challenges they may face in accessing services (e.g., SWs’ schedules may make it challenging to make appointments during facility working hours; higher likelihood of mobility among KPs; increased likelihood of perceived/experienced stigma in the health care setting).

In its *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection*, WHO recommends less frequent clinical visits (three to six months) for people stable on ART, and less frequent medication pick-up (three to six months). Current PEPFAR guidance notes that an estimated 80% of PLHIV on treatment will be eligible for six-month MMD [20]. The guidance recommends that those eligible should be offered six-month MMD with the option for fast-track refills, and that in every case, clients should receive ART for multiple months at a time (a minimum of three months’ worth of medication) [29]. For clinically stable KP clients, facility or community-based sites should have the capacity to dispense ART for six months at a time. The COP 20 guidance also recommends that clients who enter DSD without a documented suppressed VL should be prioritized for VL testing, adherence assessment/counseling, and repeat VL testing. Peer navigators can play a critical role in checking in / supporting adherence [20].



ADDRESSING KPs’ MOBILITY

With support from the U.S. Government’s Key Populations Investment Fund (KPIF), the Centre for Sexual Health and HIV AIDS Research Zimbabwe (CeSHHAR) Cross Border Collaboration project is examining ways of providing DSD for FSWs who travel between Botswana, Mozambique, Zambia, and Zimbabwe. The program will develop a regional referral system to ensure continuity of care, and train providers to discuss travel preparedness as part of routine consultation. Regional partner providers will offer clients “safe travel packs” containing a buffer supply of ART (or PrEP) and a transfer letter. The program is also developing a monitoring system to gauge and improve the effectiveness of referral, linkage, adherence, and treatment outcomes.

Eligibility for MMD in the PEPFAR guidance is no longer linked to a VL suppression benchmark, given low coverage of VL testing in many countries. However, many national guidelines require that PLHIV who receive MMD be defined as “stable,” and one criterion for a “stable” designation is a suppressed VL result. Country programs will have to review guidelines, VL coverage rates, and other factors to decide if national policies and programs should be revised.

Planning and implementation of MMD for KPs requires close coordination between KP CBOs, peer navigators (discussed more below), and clinical and supply chain staff. Programs should plan logistics carefully based on the number of expected KP clients on MMD. Of note, mobility is not a criterion for limiting access to MMD, and in fact, can be a valid reason for eligibility. KP individuals who are migrant workers or likely to travel will benefit from MMD the same as PLHIV who are not members of a KP group. A monitoring and evaluation (M&E) system will need to be developed, and pharmacy monitoring systems adapted, to track MMD KP clients and oversee inventory management. USAID’s Supply Chain for Health team has created an ARV planning calculator and guidance tool to help countries plan for MMD implementation. The tool and guidance can be accessed at Differentiatedcare.org [30]. Programs may also wish to access IAS’s [Differentiated Service Delivery: A Decision Framework for Differentiated Antiretroviral Therapy for Key Populations](#), for additional guidance specific to planning MMD for KPs [21].

Decentralized distribution in the private sector

Decentralized distribution of ART through the private sector (e.g., through community pharmacies or automated models using teller machines or lockers) can expand access for KPs by increasing the number and convenience of distribution points. Potential benefits include proximity to individuals’ homes or workplaces, more convenient opening hours, and elimination of queues at facilities. Alternative access points integrated with non-HIV medications can also reduce stigma and concerns about confidentiality. Clients who are not eligible for MMD (e.g., unstable) may benefit from easier access while continuing to obtain clinical care at a health facility. Additionally, clients who may not want or be able to store a six-month supply of ARVs at home, or those who move frequently (e.g., FSWs and MSM), would have more convenient options for picking up their medications at a frequency and volume that suits their preferences.

Viral load scale-up

Given the significant risks of HIV transmission among members of KPs with unsuppressed viral replication, policy and programmatic efforts should be directed at implementing services tailored to the specific needs of KPs, who generally share structural determinants of risk including marginalization, increased risk of violence, and mobility. National policies that favor culturally and clinically competent services will foster improved treatment coverage and sustained adherence necessary for epidemic control [31]. Identification of stable KP patients who can be referred to less intensive monitoring and clinical follow-up can also reduce costs to clients and congestion in facilities. When clients have a suppressed VL, clinicians have an objective measure of adherence that can support less frequent clinical consultations (e.g., once every six to 12 months) [32].

Countries should aim to scale routine viral load monitoring (VLM) to 100% national coverage for KPs to ensure early detection of virologic failure. In planning for scale-up, programs should develop a comprehensive assessment of existing systems and detailed plans for each step in the “VL continuum” in order to minimize “leaks” and ensure adequate turnaround time of results. If national implementation is not feasible, countries can implement a phased approach, whereby limited or targeted VL testing is conducted in regions/facilities with the highest HIV prevalence and patient volume, as the structure and systems for routine monitoring are developed and applied [33].

At minimum, countries should advocate for aligning country VL guidelines with WHO guidelines, and address KP-specific needs. This might involve working with an in-country technical working group to plan, review, and make recommendations to the Ministry of Health for implementing VL monitoring, and developing operational models and standard operating procedures (SOPs) for VL testing that cater to KP clients. Where applicable, programs can advocate for and support the use of a laboratory management information system hosted by the Ministry of Health to access VL testing results from relevant laboratories and facilities to help with information exchange.

To protect the rights of participants engaging in activities that may be illegal and for whom the use of names or national IDs may increase risks, KP programs can incorporate unique identifiers, such as aliases or identification numbers. Unique identifiers can be generated by the KP client and provider based on a set of questions only the client can answer. This may also be important for trans populations, for whom sex and legal names on official identifications may not match clients' gender or used name. Alternatively, biometric identifiers offer a technological solution that can be secure and encrypted.

Decentralized models that offer VLM along with HIV testing, ART provision and management, STI screening and treatment, and TB treatment in a stigma-free venue may have better HIV service outcomes for KPs [26]. KP CBOs can play a critical role, including disseminating information on routine VL testing and U=U messaging (demand creation), explaining the significance of results, employing peer navigators who encourage VL testing and ensure KPLHIV get their results, and clinical management of clients who have an unsuppressed VL. Adherence clubs and CBO HIV and mobile services can serve as venues for VLM; they have the potential of providing point-of-care VL diagnostics as they become available or sending dried blood spots to reference laboratories.

CBOs can also support data entry, the development of M&E systems, and data management. KP-dedicated programs are well positioned to support community monitoring and quality assurance, potentially resulting in increased use of VL results in patient management. As an example, people who use drugs or alcohol often experience suboptimal adherence, and consequently higher treatment failure. These prompt the need for more frequent VL monitoring to identify treatment failure early, further preventing the development and onward transmission of resistant strains [31].

VL data can play a pivotal role in advocacy for human rights. For example, the burden of unsuppressed VL on a population compared to if that population had access to VL testing can be used to demonstrate the need for services, support equitable allocation of resources, and evaluate progress toward realization of the right to health for KPs. Comparing viral suppression between KPs and the broader population in different countries can help identify inequities and focus areas for programming [31].

Treatment literacy, including training of providers and frontline staff, is an important part of making VLM effective. LINKAGES has developed a technical brief titled [Reaching the Third 95: Viral Load suppression among Key Population Individuals Living with HIV](#) that outlines considerations for improving access to and uptake of VL testing, as well as for using VL results, within KP-focused HIV programs [32]. PEPFAR's VL/early infant diagnosis (EID) community of practice (COP) group has developed a [VL/EID Reference Manual](#) that offers innovative tools, best practices, and proposed solutions to address VL challenges that are common across programs and can be used to accelerate VL scale-up [33]. In addition, Columbia University's International Center for AIDS Care and Treatment Programs (ICAP) has developed a number of training and implementation tools to support VLM and VL tracking. They can be found here: [ICAP VL Monitoring Tools](#) [34].

Network and site-level elements

Service sites within a network may include public or CBO-led facilities, drop-in centers, and private providers. In this section, we discuss KP clinical care and support competencies, case management, physical space attributes, and client flow within the network of services which, collectively, impact long-term retention.

It is important to foster relationships and coordination between facility and community activities to meet clients' needs. There are a number of measures that programs can take at the network and site levels to increase access to and uptake of adherence and retention services, and to use data effectively to determine the root causes of LTFU. Network and site-level adjustments should be based on clients' needs. Trust and confidentiality are key in encouraging individuals to visit and return to a facility.

Staff competencies

S&D in the health care setting, and health systems that are unresponsive to the needs of KPs, form significant barriers to service uptake and retention. Programs should review their training curricula on reducing S&D, ensure that they are up to date, assess who needs to be trained, and develop and implement plans to address gaps. Because public sector sites often experience turnover, plans should include refresher training, KP-specific SOPs, and job aids. Health care worker training should also include clinical competencies for KPs, based on each population group and their associated needs and risk factors.

It is also important to track and monitor KP experiences with providers at various levels, including assessing the friendliness and competencies of treatment sites, enlisting guidance from KP individuals and organizations throughout. KP-led CBOs can play a key role in facilitating KP sensitization health care worker trainings and establishing safe spaces within health facilities. LINKAGES has created a guide called [Health4All](#) to increase health care workers' empathy, clinical knowledge, and interpersonal skills to improve KP-friendly services [35]. Programs can also incorporate feedback from KP clients and organizations through client surveys, the [Community Scorecard](#), or other quality improvement approaches to increase the accessibility of their services and optimize client comfort [36].

Physical space and client flow

Given myriad ways that KP individuals experience S&D, and how these experiences can affect adherence and retention, it is important to build welcoming, inclusive spaces. This includes ensuring that sites are accessible and open during days and hours that are convenient to KPs (e.g., evening and weekend hours); administrative and guard staff have been trained not to discriminate against KPs; there are adequate and comfortable seating and private spaces for counseling; the space is brightly lit; there are KP-appropriate information/materials; wait times are less than one hour and there are specific interventions to reduce wait times; and client confidentiality and safety are strictly maintained (among others). In addition, rights and S&D policies and practices should be posted visibly on the walls, addressed in trainings, and enforced. CBOs and facilities can work together to find ways of expanding services outside of HIV that may draw KP clients in, such as screening for noncommunicable diseases, activities for children (e.g., of sex workers), and social events. The scorecard, mentioned above, can also be used to gauge client and provider perceptions of facility spaces and client flow, and to make recommendations for improvement.

Case management

Clients may face several challenges adhering to treatment that require more than one provider to address. These might include barriers to service access, medication side effects, mental health and other psychosocial issues (e.g., depression, substance use, and socioeconomic challenges, or past or current experiences with

violence). Some clients may face KP-related stigma at a referral service site. The case management model can help prevent and address these challenges by coordinating services via a team of providers with different skillsets to provide care tailored to each individual's needs.

Comprehensive case management teams often consist of HIV counselors and program staff including peer navigators, social workers, clinical staff, M&E specialists. Community case management systems (including psychosocial counseling), can help overcome structural and social barriers to partner notification and timely links to treatment, and help newly diagnosed or reengaged ART clients establish and maintain long-term treatment compliance. Where CBOs and facilities work together as part of a case management approach, regular meetings (e.g., weekly/monthly) can serve as forums to discuss individual cases and develop solutions to ensure optimal outcomes for each client.

The case management approach can be separated into two phases: intensive and maintenance. **Intensive case-management** involves frequent, personalized client support and counseling from the point at which a client first enters the health care system until the client sustains viral suppression. During the first 30 days after treatment initiation, and at other times based on need, case management team members work together to help prevent or address missed appointments by conducting regular contact with clients through phone or messaging apps, and communicating with health care personnel (e.g., noting if drugs have been picked up or VL tests conducted). These tasks can be accomplished by peer navigators (discussed below), or other lay team members [18]. Case management can also help clients access more holistic services, such as prevention and response to adverse events (including violence), which can ultimately affect adherence.

The **maintenance phase** begins once the client reaches viral suppression. Check-ins during the maintenance phase can be less frequent and event driven (e.g., to remind of upcoming appointments). Understanding that clients' vulnerabilities and circumstances can shift, especially among KPs, case management teams should provide intensive support for clients who have challenges that impede adherence (e.g., experiences of violence, substance use, homelessness), and for those who have fallen out of care. **NOTE:** KP clients may move between intensive and maintenance designations based on their evolving profile. See below for more information on how programs can tailor support.

Virtual (online) case management

Programs can take advantage of KPs' increasing access to mobile and online platforms by providing virtual case management services. The approach can help reduce transport costs and time required both for clients and providers/support staff. In addition, some clients may prefer to conduct counseling and referral anonymously, or to search for and make appointments at their preferred facility through the Online Reservation App (ORA).

Evidence from multiple settings has shown that virtual case managers can be effective in supporting recently diagnosed KP members to initiate ART without significant LTFU. In India, an online HIV campaign called [Yes4Me](#) (developed by the LINKAGES project), which launched in May 2018, offers online risk assessment and referral to testing via a network of private laboratories. A team of virtual case managers follows up with each client by phone or messenger app (e.g., WhatsApp). The program achieved 100% linkage to ART for clients who tested positive in the first 18 months of implementation. A similar program in Mali, managed by FHI 360, achieved a yield of 17% among KP clients through online reach and recruitment. In Kenya, online outreach workers at an MSM-led CBO called HOYMAS provide online outreach and link clients to services through [Step1.co.ke](#) (an ORA booking platform). Since the launch of [Step1.co.ke](#) in March 2019, the program has achieved a 93% linkage rate for those diagnosed positive (as of March 2020).

While many case management services can be provided virtually, including treatment navigation and counseling, coordination with referral services that are easily accessible and KP-friendly is critical. Online staff will need appropriate training on how to provide virtual services, including interpersonal communication skills, appropriate messaging, referral and follow-up, and adherence to locally adapted SOPs. For more information on how to prepare for and implement a tailored online approach to complement comprehensive HIV service provision, refer to the ORA described in the tools section below, or follow this link: <https://fhi360.org/goingonline>.

Differentiated treatment and adherence support models – who, what, when, and where

From initial assessment for potential enablers and barriers to adherence, through sustained viral suppression, KP clients should be offered differentiated treatment and adherence support options that adjust to their needs. Clients may need more convenient access to medication, or peer support to address self-, perceived, or enacted S&D. KPs may experience additional structural and individual level factors that require more intensive case management. These include mobility (seasonal sex work or migrant labor), violence (e.g., sexual partner, violence experienced at a sex work venue, sexuality/gender outing, disclosure to a partner), and political factors such as crackdowns on KP-related behaviors. Programs will need to have a means of assessing evolving risk factors and vulnerabilities among clients through regular peer navigator or case management sessions, and SOPs in place to address those needs.

There are a number of interventions that community and facility partners can provide to help KPLHIV to adhere to treatment and remain within the services continuum. These include measures to ensure rapid/immediate links to ART at the community/facility level (discussed above); out-of-facility and group-managed models to extend access and convenience, prevention and addressing LTFU; integration of a professional cadre of peer navigators as part of the case management team; provision of differentiated counseling and other services based on age group, sex, KP type/subgroup, and clinical needs at the site level; development and scale-up of locally adapted U=U messaging; and demand creation for and links to VL diagnostics and results.

Client-managed community adherence and support groups

KP peer groups can play an active role in supporting adherence to treatment. In the client-managed model, a member of a group of ART clients who is attending a facility for a clinical or diagnostic visit picks up medications and later distributes them to the rest of the group. The groups generally meet at a location convenient to all members, and the role of distribution is rotated among them [37]. Support groups can also help demonstrate to members that they are not alone and that others face similar challenges. Clients manage the groups themselves, fostering self-care and independence. While client-managed community adherence and support groups (CASGs) do not provide comprehensive services, they are inexpensive to establish and implement and can effectively complement a case management approach. Training and support of the group leaders can be



CASGs IN ACTION

A retrospective analysis of 5,729 adults who joined CASGs between February 2008 and December 2012 in Mozambique during a pilot of CASGs by Médecins Sans Frontières showed rates of retention on ART of 98% at 12 months, 96% at 24 months, 93% at 36 months, and 92% at 48 months (Decroo, 2014). This was substantially higher than national retention, which was around 70% at 12 months in 2012 (at sites with electronic patient tracking systems) [29].

provided, as needed, from a case management team member (such as a peer navigator or case manager) or a CBO. For more information and an example of a tool for establishing CASGs, visit the [PEPFAR Solutions Platform](#) [37].

Facility and out-of-facility models

In the **facility DSD model**, ART refills are separated from clinical visits. When clients come to the facility for a refill, they do not see clinical staff or receive adherence support; rather, they proceed directly to the pharmacy or dispensary for medication refills. This fast-track approach is relatively easy to implement and scale and can reduce costs and facility congestion. However, it requires initial training and coordination between providers and pharmacists. While this model provides more convenient options for clients, it still requires clients to set aside time to travel to a facility (with associated financial costs for transport and time lost from work). This, along with potential S&D at the facility, may still create barriers to adherence, despite the convenience of the fast-track approach.



DSD INNOVATION

All three models (CASG, facility-, and out-of-facility) can include drug storage services for clients who do not want to carry or store large quantities of drugs in their home.

In the **out-of-facility DSD model**, ART refills and, in some cases, clinical consultations are provided to clients outside of health facilities. Some countries have developed facility extensions in the community, which often operate out of small spaces in residential or commercial settings and serve as clinical checkpoints for adverse events, dispensaries, and in some cases, testing facilities. KP CBO drop-in centers can serve this purpose, providing treatment initiation and MMD. As part of the community model, clinical staff can initiate clients on ART during mobile/outreach services. Peer navigators can provide community adherence support, and serve as distributors of ART. This model reduces burden on public sector facilities and providers, and it can bring services closer to clients in the community. However, it requires ongoing coordination between community and public sector counterparts. The model may be best suited for clinically stable clients (i.e., not exhibiting advanced disease). People with additional health conditions are likely to benefit from regular clinic visits in a health facility where they can get the care they need. Examples of how CBOs have implemented out-of-facility models can be found in the document [Differentiated Care for Antiretroviral Therapy for Key Populations: Case Examples from the LINKAGES project](#) [38].

Health care worker-managed groups

Some clients require more intensive monitoring and population-specific adherence support. In the health care worker-managed model, clients receive their ART refills in a group managed by a health care staff member. The groups generally meet at a health care facility, and adherence support is provided by a trained counselor or health care staff member. These groups may be segmented by time since ART initiation, for example, and may be appropriate for individuals who are newly on ART. Similarly, individuals who have advanced disease and require more frequent clinical monitoring may benefit from this service. Viremia clinics for those who fail to achieve virologic suppression can be a type of health care worker-managed group. Held at least one day a month at an existing facility, the viremia clinic uses a multidisciplinary team model and focuses on enhanced case management and a client-centered approach. The model identifies client-specific adherence barriers and tailors interventions to address individual needs. Clients are empowered to make joint decisions with their providers to improve their ART adherence. In between clinic visits, peer navigators can provide multiple support functions, such as serving as case managers, conducting home visits to enhance support, identifying other

factors that could contribute to ART nonadherence, and managing missed appointments. Health care worker-managed groups are relatively easy to implement at existing sites without the need for additional resources; however, they require staff orientation and commitment. They will also benefit from buy-in by the KP community at the outset and should be tailored to local context, with coordinated efforts to monitor results across sites. The [PEPFAR Solutions Platform](#) provides more information [39].

Preventing and addressing loss to follow-up

The first 30 days of ART initiation are critical. A growing body of evidence suggests that individuals who miss appointments early on may be more likely to have health behaviors that lead to increased mortality. Conversely, early adherence is associated with virologic suppression and better outcomes [30-31]. Therefore, identifying individuals at risk for missed appointments and LTFU (i.e., before an appointment is even missed), and providing tailored services based on their needs, are key to achieving epidemic control. Programs can optimize client linkage and retention by assessing individual risk factors for LTFU, developing individualized plans to address potential barriers, and providing active referral and support through peer navigation or case management and appointment reminders to ensure that clients start and stay on treatment. Some practical tools for preventing LTFU are discussed below.

Efforts to prevent missed appointments and LTFU must be coupled with systematic approaches for identifying and locating PLHIV who fail to link to care and initiate ART, or who fail to be retained in care/on treatment. Programs need to build in qualitative and quantitative monitoring and analysis systems to help them to determine reasons clients have missed appointments and/or are LTFU, using a machine learning and/or case profiling approach. The findings can then be used to develop appropriate strategies to prevent LTFU and return individuals to treatment. Peer navigators (discussed in detail below) can play a critical role in tracing individuals LTFU, because they are likely to understand KP needs, behaviors, and mobility. PEPFAR has included a [Loss-to-Follow-Up Tool](#) on its Solutions Platform that outlines procedures for tracking and tracing KP members who have failed to link to treatment, those who have missed appointments, or those who are LTFU [40].

Effective tracking and tracing approaches for PLHIV who have failed to initiate or return, or who are lost from treatment can inform targeted interventions to help return them to care, document their treatment in another setting, or document death or LTFU. Tracking and tracing is a team effort, requiring close collaboration between HIV testing counselors, clinicians, case managers, peer navigators, data entry staff, and M&E staff. ART sites and peer navigators should identify all non-linkers who do not initiate ART the same day they were diagnosed, who missed appointments, or who were LTFU using testing registers, appointment registers, missed appointment lists, tracking logs, and/or LTFU reports from electronic medical record systems (EMRs) where applicable. A team that includes community-based counterparts (e.g., lay counselors and peer navigators)



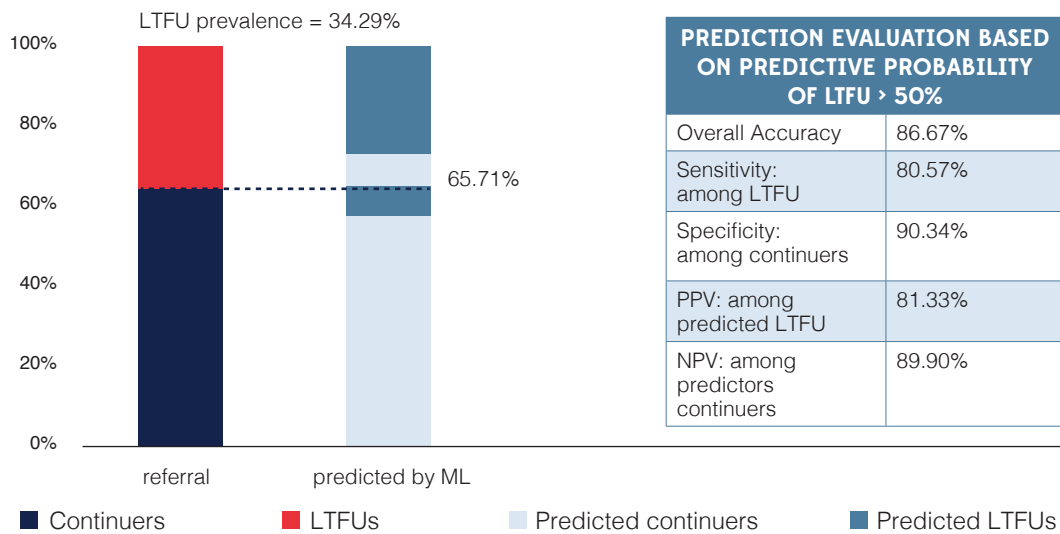
PRACTICAL TOOLS FOR SUPPORTING ADHERENCE

The **Adherence counseling and retention tool**, developed by EpiC with the support of PEPFAR and USAID, is a job aid that counselors, navigators, and providers can use to guide them in providing adherence counseling support for newly diagnosed clients, clients who are experiencing challenges in remaining adherent, and clients for whom treatment is failing. The tool encourages new clients to identify potential barriers to adherence they may face, and to develop a plan and back-up plan to address them if/when they arise. More information on the tool, and its accompanying **Adherence barriers and interventions log**, is provided in the Tools section below.

MACHINE LEARNING TO PREDICT AND PREVENT LOSS TO FOLLOW-UP

Machine learning models have been used in settings including Nigeria and Thailand to test whether it is possible to predict an individual's likelihood of being LTFU at treatment enrollment. In these diverse settings, machine learning models have achieved strong predictive validity (>80%), indicating the potential to strengthen services at enrollment for individuals with a high probability of being LTFU. The machine learning model performed well even where there were gaps in client data.

Identify those patients who were lost to follow-up in 12 months



Identify those defaulters who were LTFU/Stopped ART within the first 12 months of OI/ART service

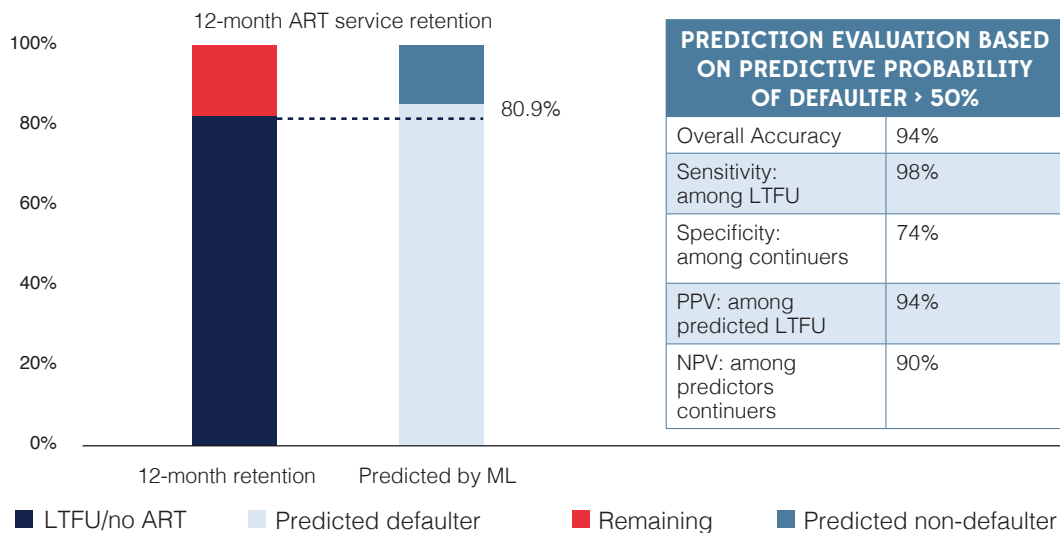
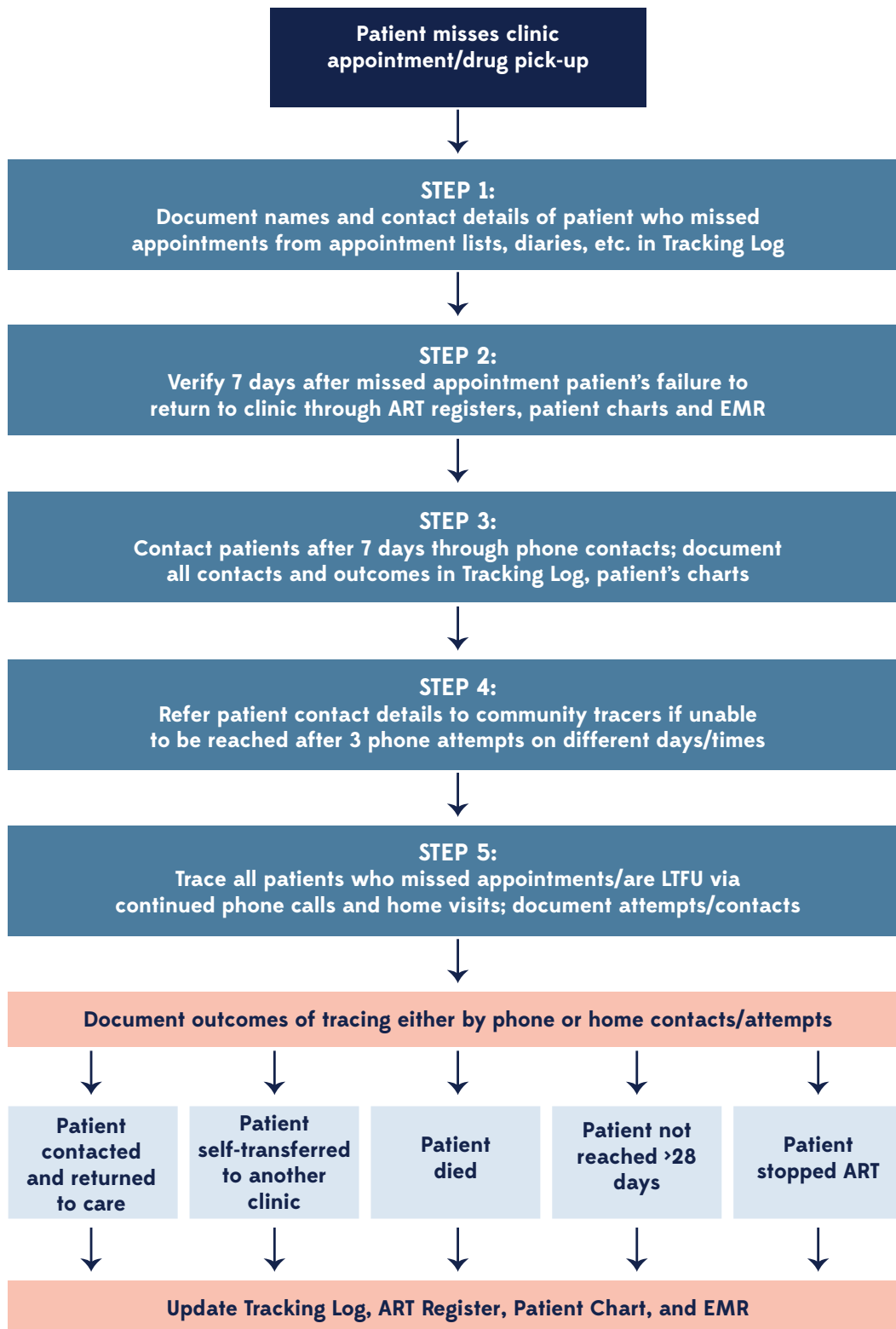


FIGURE 3. Sample algorithm for tracking ART patients who missed appointments



Source: PEPFAR COP20 Guidance

may be more effective at conducting the requisite phone calls and/or visits to hot spots or client-preferred sites that are often required to track clients and reengage them. CBOs can also facilitate support groups headed by ART champions, who can field questions and help those who stopped treatment overcome their ambivalence about starting again. Programs may need to add staff, incentives, transport, and/or communication allowances to support contact and re-initiation efforts. Figure 3 is a sample algorithm for tracking and tracing ART patients who miss an appointment. This, and an example of a LTFU tool and guidance, can be found on the [PEPFAR Solutions Platform](#) [40].

All ART facilities should include a tracking log or missed appointment register. These should capture information needed to track clients, methods, and timing of attempted contact, and outcomes of each attempt. Recording two methods of contact has been shown to improve patient tracing and should be requested at registration from all patients. Phone numbers can be verified in advance by calling/texting them while the client is in the clinic, and contact information should be updated/verified at every visit. The tracking log structure should allow for easy tabulation of outcomes to help with monitoring and reporting, partner management, program monitoring, and specifically reporting on PEPFAR's TX_ML indicator (the number of ART patients with no clinical contact since their last expected contact). More information about how to implement a tracking log, and what information to collect, can be found in PEPFAR's [Monitoring, Evaluation and Reporting \(MER\) Guidance](#) [41].

Peer navigation and treatment support

Public sector facility staff often have limited time and resources to provide comprehensive support to KP clients. Peer navigation bridges the divide between members of KPs who are living with HIV and the health systems in their communities that provide care and treatment services. Although approaches vary, peer navigators are often HIV-positive, medication-adherent role models who are from KP communities. Because of peer navigators' personal connection to the people they work with, they are best equipped to understand the needs of KP peers and can adequately convey how to access and use prevention, care, and treatment services for PLHIV, and their partners, loved ones, and children.

Programs that incorporate peer navigation can more effectively deliver differentiated services to help clients overcome structural and social barriers to partner notification, decrease time for linkage to ART, and improve retention. The USAID- and PEPFAR-supported LINKAGES project's publications, [Peer Navigation for Key Populations Implementation Guide](#) and [Peer Navigation for Key Populations Facilitator's Guide](#), provide detailed information on how to recruit, train, and support peer navigators to engage and retain KPLHIV in the health care system [42-43]. Peer navigators can be drawn from a pool of peer outreach workers and should receive additional training on topics that include HIV care and treatment, local health care, social and legal systems, motivational counseling, S&D, and violence prevention and response. They should also have knowledge of available facility- and community-based services. Ideally, navigators are PLHIV who have an intimate knowledge of the services network from personal experience. Where possible, clients should be given the option of having a navigator who is either drawn from their KP community, or someone who is not (i.e., where social networks are compact and concerns about confidentiality may pose barriers to service uptake).

Peer navigators' duties might include making active links to treatment; fast-tracking newly diagnosed clients at facilities; providing referrals to clinical, psychosocial, and other care and support services; scheduling appointments and accompanying clients to appointments (including support with transportation); providing adherence support and routine appointment reminders; supporting clients to get VL testing; following up on missed appointments; and tracking individuals LTFU. Navigators generally handle a caseload of 20 to 40 individuals living with HIV, depending on a combination of factors (e.g., the stage of the epidemic, quality of health services, and case complexity). Properly trained navigators can also provide basic psychosocial support

and help address personal factors, such as violence and substance use, which may hinder care-seeking behavior. Together these components help KP members to initiate ART quickly, improve treatment literacy, and achieve undetectable VLs through treatment adherence. Table 1 summarizes peer navigator duties across the HIV services cascade, including PEPFAR MER and custom indicators that navigators might support.

Programs that do not already implement peer navigation, or are seeking to scale the intervention, might begin by formalizing the role that peers play in achieving 95-95-95 targets in collaboration with government counterparts. Examples to formalize the peer navigation role include recognizing peer navigators as a cadre of health care staff, integrating PN in national programs and guidelines, integrating peer navigators into facility case management teams, and having PN support community ART distribution models. Examples of two PEPFAR-supported programs that have successfully implemented the recommended package of linkage services are featured on the PEPFAR Solutions Platform. The [Bukoba Combination Prevention Evaluation](#)

TABLE 1. Key peer navigator duties across the HIV services cascade, including PEPFAR MER and custom indicators

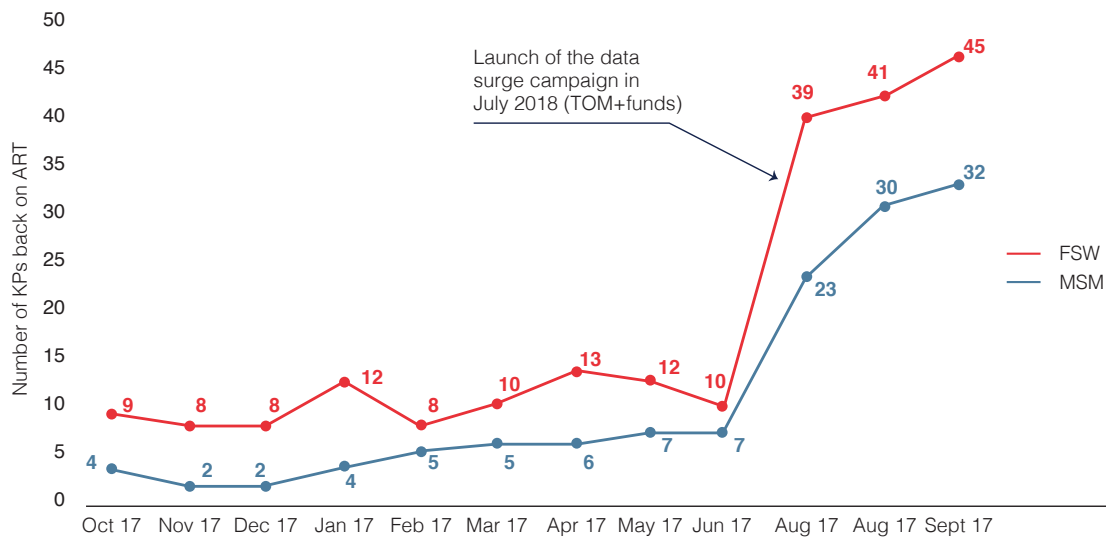
	LINK KPLHIV TO ART (SDART)	SUPPORT RETENTION			SUPPORT VL SUPPRESSION
		IMPROVE ADHERENCE	IMPROVE ATTENDANCE AT APPOINTMENTS	TRACE LTFU	
NAVIGATOR RESPONSIBILITIES	Accompany KPLHIV to treatment after a positive diagnosis	<ul style="list-style-type: none"> • Counsel on medication adherence • Refer KPLHIV with side effects to clinic provider • Generate demand for MMD and TLD • Serve as medication-adherent role model • Facilitate group support 	<ul style="list-style-type: none"> • Remind about appointments • Facilitate communication with clinic providers • Help KPLHIV interpret lab results 	<ul style="list-style-type: none"> • Communicate regularly with providers on missed appointments and trace defaulters 	<ul style="list-style-type: none"> • Generate demand for VL testing • Support attendance for regular VL diagnostics • Communicate with providers to ensure results are reported back • Help clients interpret VL results
PEPFAR MER INDICATORS	TX_NEW	TLD_MMD	TX_ML	TX_ML TX_NET_NEW	TX_PVLS
CUSTOM INDICATORS	TX_LINK_NEW	COMM_SUPP_RET	COMM_SUPP_RET	TX_LINK_RETURN	VL_ELIGIBLE

showed a stark improvement in linkage rates with deployment of a program in Tanzania, in which peers linked clients to services and provided case management, and a similar package of services brought treatment initiation rates above 96% in [eSwatini](#) [44-45].

RAPID RETURNS – THE ROLE OF PEER NAVIGATION IN TREATMENT RESUMPTION IN HAITI

In the last quarter of PEPFAR's 2018 fiscal year, LINKAGES partners used available funding to improve links to and initiation on treatment. Partners analyzed prior fiscal year data to determine who among those newly diagnosed were on treatment (at any site), and then implemented a variety of strategies to reinstate those who remained LTFU. **Haiti** dramatically increased the number of individuals returned to care (from 35 FSWs and 20 MSM in Q3, to 124 FSWs and 85 MSM in Q4). This was achieved through three strategies: (1) provision of performance-based incentives to peer navigators per patient tracked, and those who reinstituted ART; (2) reinforcement of the use of a *patient linkages and retention tool* in all the sites that helped the case management teams to conduct and track phone calls and home visits; and (3) provision of transportation fees for individuals for whom transportation was the main cause of LTFU.

LINKAGES program treatment resumption – Haiti (October 2017 – September 2018)



Source: LINKAGES Haiti

Determining peer navigation case management services based on need

Some countries have faced challenges adopting or operationalizing WHO-recommended test-and-start policies. In addition, individual factors, including clinical and psychosocial, may affect the timing for initiation of treatment among KP clients. As a result, at any given time, programs will have a mix of clients on ART and those who have not yet initiated. KP clients' needs may also change over time, depending on emerging issues that can affect their ability to start and/or stay on treatment.

Newly diagnosed clients who have not yet initiated ART

KP clients who are not yet on ART may be experiencing several challenges that need to be addressed to ensure that they effectively initiate and remain on treatment. Due to the increased S&D that KP clients face, and their individual circumstances, they may be at heightened risk of violence, denial, mobility, or homelessness. Some clients may not be earning income or will struggle to make appointments. They may need to meet with a case management team member more often, and/or require multiple referrals, accompaniment to appointments, or more frequent checking in.

Clients on ART

KP clients on ART may also have diverse needs depending on their circumstances. WHO has developed a classification system for individuals on treatment that determines whether their treatment is stable or unstable.

WHO defines newly diagnosed individuals on ART as *stable* if they have ALL the following characteristics [28]:

- On ART for at least one year
- No current illnesses or pregnancy
- Good understanding of lifelong adherence and evidence of treatment success (two consecutive VL measurements below 1,000 copies/mL; or, in the absence of VLM, rising CD4 counts or CD4 counts above 200 cells/mm³ and other objective measures of adherence)

Long-term clients are considered stable if their most recent VL is suppressed.

WHO defines individuals starting on ART as unstable if they have the following characteristics [28]:

- CD4 count < 200 CD4 cells/mm³ OR WHO Stages 3 and 4 defining illness
- OR comorbidities that require more, or more frequent, clinical care



WHO CLINICAL STAGING OF HIV AND CASE DEFINITION

The clinical staging and the case definition of HIV for resource-constrained settings were developed by WHO in 1990 and revised in 2007. Staging is based on clinical findings that guide the diagnosis, evaluation, and management of HIV, and it does not require a CD4 cell count or VL. Clinical stages are categorized as 1 through 4, progressing from primary HIV infection to advanced AIDS. These stages are defined by specific clinical conditions or symptoms. For a complete list of Stage 3 and 4 conditions and symptoms, refer to Annex 10 in the 2016 WHO [Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection](#) [46].

With increasing focus on return-to-care initiatives, whereby members of case management teams contact clients who are either LTFU or designated eligible for treatment, programs may have a mix of newly diagnosed clients (e.g., within the past month) and those already established in the service network (e.g., known HIV-positive status for at least one month). Among these individuals, some will not be on treatment for various reasons, and some will have initiated treatment. Tables 2, 3, and 4 provide guidance on the frequency and kinds of support new and existing beneficiaries might require. Programs should refer to national guidelines to adapt these recommended approaches to the local context. This document also includes additional information on differentiated services drawn from the [Decision Framework for Differentiated Antiretroviral Therapy Delivery for Key Populations](#) [21].

TABLE 2. Differentiated care for individuals diagnosed HIV-positive but not yet on ART

ALL CLIENTS NOT YET ON ART	Follow up as often as necessary to ensure that basic needs are met and that client is not LTFU (e.g., every day or every few days as needed in person, by phone, or by messenger app).
	Ensure that client is effectively referred to relevant services (e.g., violence prevention and response, substance use, social insurance/protection, and psychosocial support/counseling).
	Call client one day before an appointment (accompany if necessary); call within 24 hours of a missed appointment to reschedule/provide support.

TABLE 3. Differentiated care for newly diagnosed clients on ART

NEWLY DIAGNOSED	First 30 days: Support for intake assessment, initial diagnostics, and adherence planning, including assessment for current or potential violence; follow-up meetings as needed or requested by client; check-in at 30 days; referral to relevant services (with follow-up to gauge effectiveness/value of referral).
	Months 2-3: Follow up by phone, message app, or in person at least once per month (up to weekly for clients who need more regular contact). Clients with side effects should be referred to a clinician.
	After Month 3: Follow up by phone, message app, or in person once every three months (or monthly for clients who need more intensive support).
	Call client at least one day before each appointment date; call within 24 hours of a missed appointment.
	Follow up on VL/CD4 diagnostics. Goal: Two consecutive undetectable viral measures.

TABLE 4. Differentiated care for established clients on ART

	STABLE	UNSTABLE
ESTABLISHED CLIENTS	Every six months: Follow up by phone, message app, or in person.	Months 1-2 (or 3 if needed): Follow up by phone, message app, or in person every one to two weeks.
	Call client the day before each appointment.	After Month 2 or 3: Follow up by phone or in person once every two to three months until client has two consecutive undetectable VL measures.
	Follow up on VL/CD4 diagnostics.	Refer clients with side effects to clinical provider; reassess health status shortly after referral.

Differentiated messaging using case profiling

Just as clients may need tailored services based on their needs, programs can optimize treatment initiation, adherence, and retention by developing and providing differentiated messages according to the profiles of their clients. Messaging can be differentiated across a range of categories, including KP group, age, sex, and other characteristics. For example, a young man who has sex with men who is just starting treatment and who wants to maintain an active sex life warrants different messages than an older man who has sex with men, who is married with children. A younger FSW who is interested in having children will benefit from messaging about sexual and reproductive health, family planning, and ways that she can safely ensure that her child is born free from HIV. PWID will need to understand how their drug use may affect their treatment and may appreciate tips on how to ensure that they can remain adherent when using drugs. Transgender women will benefit from messaging about possible drug interactions with hormone therapy.

Messaging will also differ based on each individual's ART status (e.g., new client not on ART, new client on ART, established and stable, established and unstable), as described in the previous section. Counselors, navigators, and providers can use the Adherence Counseling and Retention Tool, in the annex, to guide them in providing appropriate messaging to support adherence planning for newly diagnosed clients, and problem solving for clients who are experiencing challenges in remaining adherent and clients for whom treatment is failing. More information on the tool, and its accompanying Adherence Barriers and Interventions Log, is provided in the Tools section below.

Scale-up of Undetectable = Untransmittable (U=U) messaging

An overwhelming body of clinical evidence has established that someone living with HIV who is on treatment and has an undetectable viral load cannot transmit HIV to a sexual partner. The global Undetectable = Untransmittable (U=U) campaign was launched after four large studies conducted from 2007 to 2016 among thousands of serodiscordant couples resulted in zero sexual HIV transmissions from a virally suppressed partner. Two of the studies included serodiscordant MSM cohorts. U=U messaging has the potential to:

- Reduce shame and fear of sexual transmission and open up the possibility of conceiving children without alternative means of insemination
- Reduce HIV stigma at the community, clinical, and personal levels (including self-stigma)
- Increase demand for HIV testing and ART
- Encourage PLHIV to start treatment early, remain adherent, and obtain their VL results
- Offer a strong public health argument for universal access to diagnostics, treatment, and care to save lives and bring countries closer to ending the epidemic

LINKAGES has produced a “[U=U: Undetectable = Untransmittable](#)” brief to help orient programmers on the ways in which U=U can be integrated in KP programming [47]. Programs should train frontline team members—including outreach workers, peer navigators, counselors, and clinicians—on treatment literacy, including U=U messaging and the significance of an undetectable VL. National campaigns that incorporate common messages and branding can also bolster community and facility efforts. Some programs have created short videos uploaded to YouTube that can be shared via social media or viewed on tablets at clinical facilities. Examples of these can be found on the [POZ website](#) [48]. The LINKAGES program in Cambodia recently developed low-cost [U=U promotional videos](#) for World AIDS Day working with medication adherent PLHIV role models [49]. Similar videos can be developed locally with little investment. Programs can also use a crowdsourcing approach to encourage community members to make and post their own videos as part of a contest. The Prevention Access Campaign has developed a [user-friendly website](#) that offers a wealth of information, resources, tools, and news on U=U messaging and programming that can be used to develop campaigns, promotional materials, and messages [50].

Demand creation for, and links to viral load testing

Peer navigators or other community lay workers can play a key role in generating demand for VL diagnostics. Coupled with locally adapted messages; information, education, and communication materials; and where applicable, support from national campaign efforts, community partners can ensure that clients receive U=U messaging, understand the meaning of a suppressed and undetectable VL, and know where, how, and how often to obtain their results. With clients' consent, they can provide reminders about upcoming VL appointments, escort clients to the test, and contact them to report back their results.

KP CBOs can also serve as community-based hubs for obtaining dry blood samples, transporting them to central labs, and ensuring that the results are delivered to clients. To save cost and time, community partners can provide results via phone or messaging applications. Programs can also extend VL access by including point-of-care VL testing at community or public sector sites in strategic locations. It is important to ensure that there are quality control measures in place, and/or that a trained lab technician is on staff. While dried blood



spots do not require refrigeration, samples can still degrade if not dried and stored properly. Furthermore, it is important to have clear agreement and procedures in place between CBO sites and reference labs so that samples are transported, processed, and results made available in a timely manner. For programs that use phone or messaging apps to inform their clients of their results, it is important to ensure that confidentiality is maintained. Clients should have options for how they would like the information to be sent, and precautions must be made to ensure that clients' HIV status or other personal information are not revealed.

Tools

Program designers and implementers can use a number of tools to develop appropriate differentiated services for KPs and to support adherence planning, counseling, and problem solving. In addition to those described below, a list of tools, links, and references to the annexes in this guidance can be found at the end of this section.

Standard operating procedures

Development and adaptation of SOPs for adherence and retention services are critical for ensuring that all members of the case management team and partner agencies/service sites understand their roles, responsibilities, and contributions for each step. A set of SOPs for adherence and retention might including the following components:

- Recruitment
 - » Criteria for relevant case management team positions
 - » Job descriptions (i.e., peer navigators, counselors)
- Composition of outreach/testing teams
- Steps for outreach/testing/screening
- Links to treatment
 - » Timing and expectations for immediate/same-day/rapid links
 - » Site locations, focal points, days/hours of operation
 - » Transportation
 - » Back-up steps in cases where immediate linking is not possible
 - » Follow-up of clients not yet initiated on ART
- Adherence planning and counseling
 - » Intake
 - » Support for adherence planning to address barriers and challenges within the first 30 days after ART initiation
 - » Screening for violence, and referrals
 - » Screening for specific needs and referrals to appropriate services
 - » Problem solving and enhanced adherence support
- Case management and follow-up
 - » Differentiated care and support (MMD, CASGs, etc.)
 - » Planning for and reminding of appointments

- » Responding to violence
- » Responding to clinical emergencies
- » Referral services (legal, sexual and reproductive health, family planning, psychosocial, etc.)
- » Clinical care and diagnostics
- » VL testing and monitoring
- Client tracking and monitoring
- Recording, analyzing, and reporting data
- Quality assurance and improvement
- Confidentiality, safety, and security
- Ongoing training and mentoring

The list above is not exhaustive and can include additional elements based on the local country context.

An example of an SOP on linkage and retention from Cote d'Ivoire can be found in Annex A. It is entitled *Linkage to, Initiation of, and Retention on Antiretroviral Therapy for People Living with HIV*. It includes details on procedures and the roles of each player on the case management team. It also includes schematics of a linkage to treatment protocol, and an ART retention protocol.

Treatment literacy, adherence planning, and problem solving

The [International Treatment Preparedness Coalition](#) has developed a number of tools to support treatment education and treatment advocacy with a focus on KP communities [51]. The [Advocacy for Community Treatment \(ACT\) Toolkit](#) can be used to support and train community activists to advocate effectively and passionately for access to treatment for PLHIV, including those from KPs [52]. The [Activist Toolkit for Routine Viral Load Testing](#) can be used to enable and mobilize PLHIV and activists to use science and evidence to advocate to decision-makers and service providers for access to, and availability of, affordable routine VL testing for PLHIV [52]. Their [website](#) also includes additional articles, references, and tools on community demand creation for VL testing, the community treatment observatory model, DSD, and PrEP, among others [53].

The *Adherence Counseling and Retention Tool* (Annex B) includes a flipchart with guided messaging to support PLHIV to plan and achieve their treatment adherence goals. It can be used in the first or second counseling session to introduce a client to treatment and develop plans for adherence, or in subsequent sessions when challenges arise that affect viral suppression (i.e., enhanced adherence counseling). When used in conjunction with the Adherence Barriers and Interventions Log, it can help counsellors determine if a client may be at risk for missed appointments or LTFU, identify supportive interventions, and track progress. The tool can be used with people who

- Have not yet started ART
- Have recently started ART
- Are established ART clients facing adherence challenges
- Have returned to care after having stopped treatment
- Are established ART clients experiencing treatment failure (virally unsuppressed)

The tool is tabulated so that users can navigate to the appropriate sections based on their clients' needs. The first section of the tool provides common treatment literacy messaging on ART and the benefits of an undetectable VL. The second section addresses common barriers to adherence. Counselors can address specific barriers raised by their clients, and develop plans and back-up plans together. The remaining section focuses on follow-up adherence counseling and special circumstances (tips for taking meds, returning to care, and managing unsuppressed VL).

Risk assessment for LTFU

The *Adherence Barriers and Interventions Log* (Annex C) is a paper-based tool that helps providers/counselors determine if a client is likely to need additional support to avoid missed appointments and LTFU. When used in conjunction with the *Adherence Counseling and Retention Tool*, or independently, it can serve as a log for barriers discussed and plans developed by the client to address those barriers. It also guides providers/counselors to consider potential risk factors that the client may not have raised but that may pose challenges to adherence. It offers suggested interventions that the provider/counselor can offer to help bolster client plans, such as appointment reminders, routine check-ins, referral to appropriate services, or MMD (e.g., in the event that the client plans to travel away from home). The log is intended to be kept in the client's file and ideally coordinated with the standardized client tracking log used at the facility of CBO site.

Viral Load Monitoring Toolkit

Columbia University's ICAP program and the U.S. Centers for Disease Control and Prevention (CDC) developed a [package of tools](#) to support clinical counseling on VL and the use of VL test results to improve patient management [534]. The toolkit contains:

- A 1.5-day training curriculum on VLM and enhanced adherence counseling
- A set of VLM and enhanced adherence flipcharts
- Tools and job aids for health workers

The training curriculum is intended to build the capacity of health workers to conduct VLM and enhanced adherence counseling. It contains eight modules and can be conducted over the course of one-and-a-half days. The flipcharts are intended to help health workers provide information about VLM to patients and to explain the meaning of VL results. In addition, they guide the provision of enhanced adherence counseling to patients with elevated VL. They were developed for a range of health care workers (e.g., adherence counselors, doctors, nurses, pharmacists, community health workers) who work with patients living with HIV and their families in settings where VL testing is being performed.

Online Reservation App with case manager functions

The ORA, developed in 2017 by the LINKAGES project in Thailand, is now used in more than 10 countries and includes tools to support ART retention. The newest version of ORA allows for complete cascade tracking for all program beneficiaries (routine clients and those reached online), including referrals, clinic-based reporting on 10 key PEPFAR MER indicators, and tracking and reporting by outreach workers and case managers. ORA includes advanced case management functions for programs to assign client cases to outreach workers and case managers for routine follow-up for ART and PrEP clients and reporting on TX_NEW, TX_RTT, and TX_PLVS. The system can be used by virtual case managers or peer navigators to provide client support through phone or other mobile platforms. Additional details on ORA and how to plan a comprehensive online HIV outreach program can be found at the following link: <https://fhi360.org/goingonline> [54].

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Guidance and tools

REFERENCE/TOOL	OBJECTIVE/CONTENTS	AUDIENCE
PEPFAR Country Operational Plan (COP) 2020 Guidance	PEPFAR mandate, principles, strategies, and detailed technical guidance on the provision of the full cascade of services and monitoring and reporting requirements.	U.S. Government agencies and implementing partners.
WHO Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection, 2016	Guidance on the diagnosis of HIV infection, the use of ARV drugs for treating and preventing HIV infection and the care of PLHIV, structured along the continuum of HIV testing, prevention, treatment, and care.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs, PLHIV, communities, and CSOs
WHO Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations	Unifies existing WHO guidance relevant to five KPs: MSM, PWID, people in prisons and other closed settings, SWs, and transgender people. It includes a number of new recommendations and updates existing guidance and recommendations.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs, PLHIV, communities, and CSOs.
Differentiated Service Delivery for HIV: a Decision Framework for Differentiated Antiretroviral Therapy Delivery for Key Populations	Step-by-step guidance on how to prioritize and plan DSD approaches for KPs, with a focus on differentiated ART delivery.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs, PLHIV, communities, and CSOs.
Tenofovir, Lamivudine, and Dolutegravir (TLD) Transition: General Information for Clients, Clinicians, Counselors, and other Service Providers	Overview of rationale behind TLD transition, client eligibility, guidance on how to educate people about TLD transition, and special considerations for transition.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs, PLHIV, communities, and CSOs.
Considerations for the Introduction of TLD in National Programs: PEPFAR Guidance on Developing Clinical and Programmatic Recommendations	Guidance to support country programs to develop clinical guidance and implementation plans for the introduction of the fixed-dose combination tablet of tenofovir, lamivudine, and dolutegravir (TLD).	HIV program managers, technical working group members, national HIV guideline committees, and other stakeholders contributing to the development of national normative guidance for HIV treatment and planning for the rollout of TLD.
Guidelines for Managing Advanced HIV Disease and Rapid Initiation of Antiretroviral Therapy	Guidelines provide recommendations outlining a public health approach to managing people presenting with advanced HIV disease, and to provide guidance on the timing of initiation of ART for all people living with HIV.	Primarily national HIV program managers who are responsible for adapting the new recommendations at the country level; also relevant to clinicians and to other stakeholders, including PLHIV, national CSOs, implementing partners, NGOs, and domestic and international funders of HIV programs.

REFERENCE/TOOL	OBJECTIVE/CONTENTS	AUDIENCE
Reaching the Third 95: Viral Load Suppression among Key Population Individuals Living with HIV	Outlines key considerations for improving access to and uptake of VL testing, as well as use of VL results, within KP-focused HIV programs.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs; PLHIV; communities; and CSOs.
Viral Load/Early Infant Diagnosis Reference Manual	Offers innovative tools, best practices, and solutions to address VL challenges that are common across programs; can be used to accelerate VL scale-up.	Global Fund recipients and implementing agencies/ governments.
ICAP VL Monitoring Tools	Training curriculum designed to build the capacity of health workers to conduct VLM and enhanced adherence counseling; job aids designed to help health workers provide information about VLM to patients, explain the meaning of VL results, and guide the provision of enhanced adherence counseling to patients with elevated VL.	HIV program managers in low- and middle-income countries; clinicians; adherence counselors; international organizations; NGOs; CSOs.
PEPFAR Loss-to-Follow-Up Tracing and Tracking Tools	Outlines procedures for tracking and tracing KP members who have failed to link to treatment or those who have missed appointments/ are LTFU.	HIV program managers in low- and middle-income countries; clinicians; adherence counselors; international organizations; NGOs; CSOs.
Health4All Training Tools	Guides training of health care workers to increase empathy, clinical knowledge, and interpersonal skills to improve KP-friendly services.	HIV program managers in low- and middle-income countries; clinicians; providers; counselors; international organizations; NGOs; CSOs.
The Community Score Card (CSC): A generic Guide for Implementing CARE's CSC Process to Improve Quality of Services	A two-way and ongoing participatory toolkit for assessment, planning, monitoring, and evaluation of services.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs; PLHIV; communities; and CSOs.
Differentiated Care for Antiretroviral Therapy for Key Populations: Case Examples from the LINKAGES Project	Offers examples of how CBOs have implemented out-of-facility models of differentiated care.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs; PLHIV; communities; and CSOs.
LINKAGES Peer Navigation for Key Populations Implementation Guide	Provides detailed information on how to recruit, train, and support peer navigators to engage and retain KPLHIV in the health care system.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs; PLHIV; communities; and CSOs

REFERENCE/TOOL	OBJECTIVE/CONTENTS	AUDIENCE
Standard Operating Procedures for Providing Services to Key Populations: A Guide for Implementing Partners in Malawi	Offers an example of outreach, navigation, and case management. It includes SOPs on mapping, data use for decision making, microplanning and tracking of clients, roles and responsibilities of peer educators and peer navigators, linkage and referral, clinical outreach, preventing and responding to violence, and other relevant topics.	HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs; PLHIV; communities; and CSOs
International Treatment Preparedness Coalition (ITPC) Advocacy for Community Treatment (ACT) Toolkit	Can be used to support and train community activists to advocate effectively and passionately for access to treatment for people living with HIV, including those from KPs.	Community activists; CSOs; HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs; PLHIV
ITPC Activist Toolkit for Routine Viral Load Testing	Can be used to enable and mobilize PLHIV and activists to use science and evidence to advocate to decision-makers and service providers for access to, and availability of, affordable routine VL testing for PLHIV.	Community activists; CSOs; HIV program managers in low- and middle-income countries; clinicians; policymakers in development agencies, international organizations, NGOs; PLHIV
EpiC Adherence Counseling and Retention Tool	Includes a flipchart with guided messaging to support PLHIV to plan and achieve their treatment adherence goals. When used in conjunction with the <i>Adherence Barriers and Interventions Log</i> , it can help counsellors determine if a client may be at risk for missed appointments or LTFU, identify supportive interventions, and track progress.	HIV program managers in low- and middle-income countries; clinicians; providers; counselors; international organizations; NGOs; CSOs
EpiC Adherence Barriers and Interventions Log	A paper-based tool that helps providers/counsellors determine if a client is likely to need additional support to avoid missed appointments and LTFU. When used in conjunction with the <i>Adherence Counseling and Retention Tool</i> , or independently, it can serve as a log for barriers discussed, and for plans developed by the client to address those barriers.	HIV program managers in low- and middle-income countries; clinicians; providers; counselors; international organizations; NGOs; CSOs



ANNEXES

Annex A

Sample Standard Operating
Procedures on Linkage and
Retention (Cote d'Ivoire)

1. Context

[To be updated according to the local country context]

2. Overall Objective

To ensure the improved performance of project implementation teams in linking, initiating, and retaining key population (KP) members living with HIV on antiretroviral therapy (ART), as well as helping them reach viral load suppression.

3. Specific Objectives

- To ensure timely linkage to treatment for all clients testing positive for HIV
- To ensure initiation on ART within one week of testing positive for HIV among at least 95 percent of clients
- To ensure retention on treatment for all clients who have initiated ART
- To ensure viral load suppression among at least 95 percent of ART clients six months after initiation of ART

4. Standard Operating Procedures

I. Linkage to Antiretroviral Therapy (ART)

A. Key Concepts

What is linkage to treatment?

The process of linking clients who test positive for HIV and are ready to begin ART to a treatment center.

Why is linkage to treatment important?

By linking all clients who test positive to treatment, programs can more effectively ensure positive health outcomes and reduce transmission of HIV in the community, leading to epidemic control.

Objectives for peer navigators (PNs) and psychosocial support workers

- Establish trust with clients using motivational counseling techniques (reflection, affirmation, questioning, etc.)
- Support clients to develop treatment-related goals, to express their feelings, and to make constructive decisions
- Clarify the treatment modalities, constraints, and relevant challenges, and find solutions
- Help clients become autonomous actors regarding their HIV infection

When is linkage to treatment done?

Linkage to treatment begins after post-test counseling and communication of a positive test result. It ends once the client presents at a treatment center.

How is linkage to treatment done?

According to the standard operating procedures described below.

B. Standard Operating Procedures

The procedure for linkage to treatment includes the following steps:

- Post-test counseling
- Pre-treatment therapeutic education counseling, including the benefits of early initiation of treatment and messaging on undetectable=untransmittable (U=U)
- Link to a treatment center (“handshake”)
- If the client would like to confirm their first test result, include the following steps:
- Pre-testing counseling (as needed) on:
 - » U=U and the benefits of treatment and early initiation
 - » Identification of ideally two individuals who can provide support during difficult times
 - » Tailored counseling messages based on KP profile (subgroup, gender, age, etc.)
 - » Explain options for index testing and partner referral (if not already discussed)
- Support client to obtain a confirmatory test
 - » Accompaniment to a facility or active linkage through a facility focal point
- Second post-test counseling (emphasize points below if relevant):
 - » U=U and the benefits of treatment and early initiation
 - » Identification of two individuals who can provide support during difficult times
 - » Tailored counseling messages based on KP profile (subgroup, gender, age, etc.)

SOP 1: Post-test counseling (positive diagnosis)

The session objectives are the following:

- Assess the emotional state of the client.
- Assess the impact of the positive diagnosis on the client’s personal life, professional life, mental and sexual health, sleep, etc.
- Bring up the issue of sharing their status with their partner(s) and assess the advantages and disadvantages (e.g., violence).
- Assess whether the client is capable of communicating with the care team.
- Provide emotional support, i.e., through personal testimony if appropriate.
- Document whether the client has accepted their status.
- Verify that the two people identified during pre-test counseling can be contacted if the peer educator (PE)/peer navigator (PN)/facility cannot make contact with the client. Ask if the client plans to disclose their status to either of the two individuals. Ask if the client would like support for disclosure.
- Provide support to ensure linkage to treatment (active linkage with accompaniment, or liaison with a focal point at a treatment facility).
- Obtain informed consent for index testing services, if desired.

During this session, the PN or psychosocial support worker:

- Introduces themselves.
- Reassures the client about the confidentiality both of their discussion and the services to be rendered.
- Explains their role and how they can help.
- Discusses with the client how they experienced the news of the positive result, as well as its impact.
- Provides emotional support through personal testimony, if necessary.
- Notes in the client file whether or not the client has accepted their status.

Scenario 1a: The client has accepted their serostatus.

The PN or psychosocial support worker:

- Arranges a follow-up schedule for the client
- Provides their contact information, obtains that of the client and a social support person, and verifies contact information (i.e., calls the number to verify)
- Conducts or refers the client for a therapeutic education session (SOP 2)

Scenario 1b: The client has not accepted their status and wants to get a confirmatory test.

The PN or psychosocial support worker:

- Notes the reason for refusal in the client file
- Refers the client for a confirmatory test
- Arranges a second post-test counseling appointment with the client
- Verifies the contact information of the client (telephone number, WhatsApp number, Facebook profile), and that of the social support person

Scenario 1c: The client has not accepted their status and does not want a confirmatory test.

The PN or psychosocial support worker:

- Notes the reason for refusal in the client file
- Refers the client to a psychologist/doctor
- Arranges to be in weekly contact with the client
- Provides their contact information, obtains that of the client and a social support person, and verifies contact information

SOP 2: Therapeutic education counseling prior to treatment

The session objectives are the following:

- Communicate general information about HIV, with an emphasis on care.
- Discuss the objectives of ART, how it works, and the relationship between treatment, CD4 count, and viral load.
- Provide messaging on U=U and the benefits of early initiation on treatment (i.e., improved health outcomes, reduced risk of onward infection, etc.)
- Discuss the specific treatment regimen for the client and any questions the client may have.

The PN or psychosocial support worker is responsible for:

- Assessing the client's knowledge of ART as lifelong and providing therapeutic education
- Explaining the goals of ART and the benefits of early initiation of and retention on treatment
- Discussing possible barriers to treatment and plans and back-up plans to those barriers
- Explaining the side effects of the prescribed medications; discuss how they can influence adherence; inform the client that some side effects could be moderate while others could be serious and require medical attention
- Discussing sexually transmitted infection (STI) prevention and opportunistic infections
- Discussing a healthy diet
- Documenting in the client file their agreement to start treatment

Scenario 2a: The client is ready to initiate ART.

The PN or psychosocial support worker is responsible for:

- Agreeing on a follow-up schedule with the client
- Presenting the various options and helping the client choose the most appropriate ART center
- Asking the client to provide the contact information of a support person and setting aside time for discussion with the support person and client
- Asking the client to provide a map to their residence and setting aside time to make a home visit
- Verifying if the telephone number, WhatsApp number, Facebook profile, and/or emergency contact information are still valid
- Referring the client to a clinician for ART initiation immediately (SOP 3), and referring them to a local support group or treatment champion (if desired)

Scenario 2b: The client is not ready to start ART but agrees to clinical monitoring.

The PN or psychosocial support worker is responsible for:

- Documenting the reason for refusal
- Agreeing on a follow-up schedule with the client
- Verifying that the telephone number, WhatsApp number, Facebook profile, and/or emergency contact information are still valid
- Referring the client to a clinician for clinical monitoring

Scenario 2c: The client is not ready to start ART and does not agree to clinical monitoring.

The PN or psychosocial support worker is responsible for:

- Documenting the reason for refusal
- Agreeing on a follow-up schedule with the client
- Verifying that the telephone number, WhatsApp number, Facebook profile, and emergency contact information are still valid
- Referring the client to:
 - » a psychologist (if available) to assist with accepting their diagnosis and developing a plan to initiate treatment
 - » a local support group and/or offering to link them to a treatment champion

SOP 3: Referral to a treatment center (“Handshake”)

When a client chooses to be on treatment in a facility other than the one with which the PN is affiliated or at a different location, the PN/psychosocial counselor provides support for active linkage to the site (handshake). The objectives of the handshake are the following:

- Refer the client and/or accompany them to the treatment center.
- Ensure that the client is received well at a facility that is KP-friendly, and/or provide support to ensure that the client does not face stigmatization, discrimination, or other barriers to initiating treatment.
- Ensure that the client starts ART effectively and as soon as possible.

The PN or psychosocial support worker is responsible for:

- Logging the referral and including a record of the referral in the client’s file
- Accompanying the client to an ART center, if necessary, and introducing them to a focal point (if available)
- Confirming linkage by documenting the client information (national ID, unique identifier code, etc.) and the treatment center in the referral log
- Making follow-up calls with the focal point (if possible) and the client to ensure that the client has started ART effectively

SOP 4: Pairing

In situations where the person providing HIV testing services (HTS) or post-test counseling is not a PN, clients should be offered the opportunity to receive support from a PN or case manager. Pairing consists of introducing a PN (or other support team member) to a client to provide support as they initiate and remain in treatment (for as long as they would like support). Clients can be paired with a navigator at any time, either at a facility, drop-in center (DIC), or in the community (wherever confidentiality can be maintained, and according to their preference).

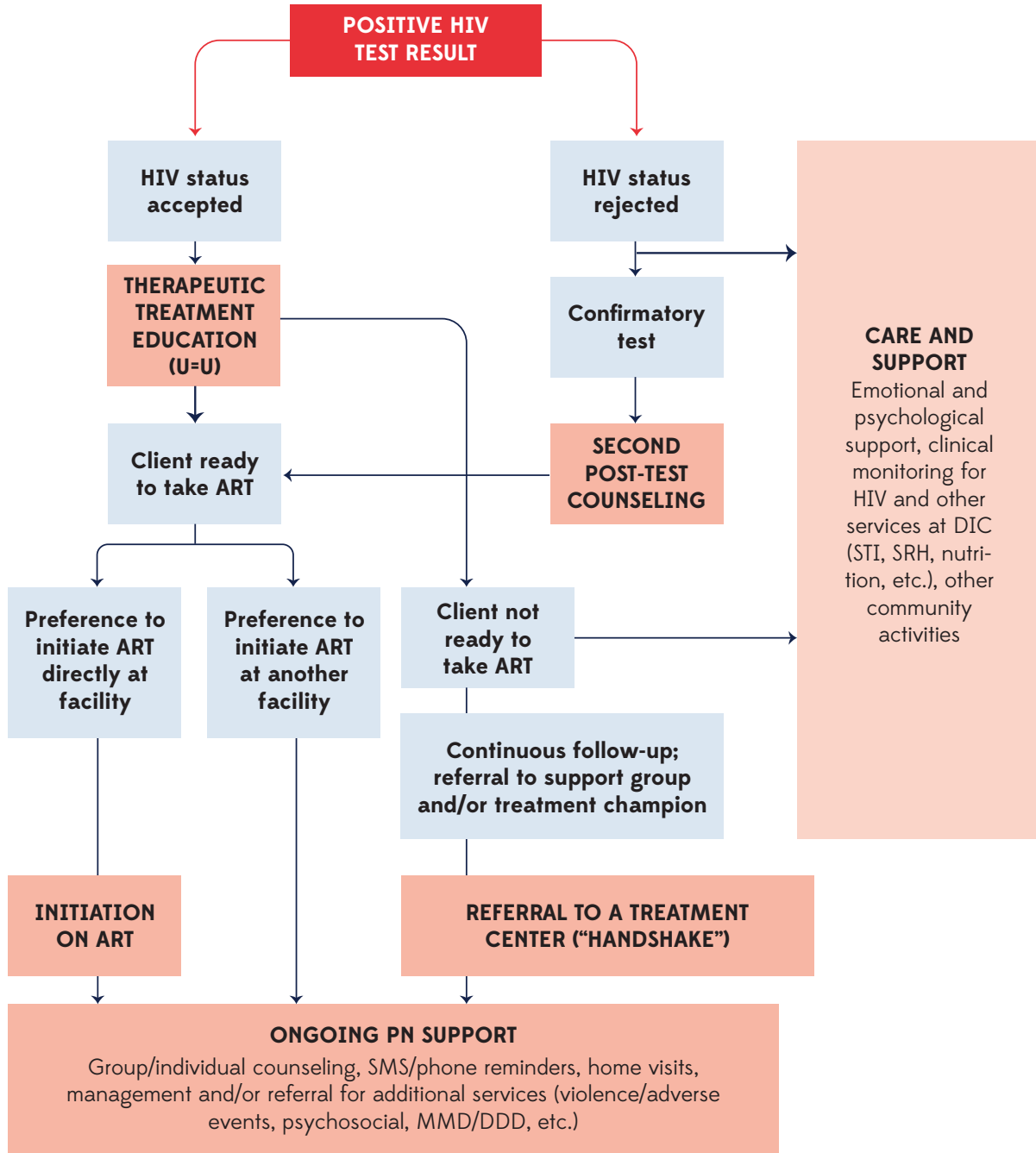
The HTS counselor who does the pairing is responsible for:

- Communicating the benefits of having confidential, tailored navigation support throughout the treatment process (support for understanding their treatment, diagnostics, clinical scheduling, appointment reminders, adherence planning and addressing barriers, linkage and referral to additional services, etc.)
- Asking the client if they want to be paired with a PN or another person on the team to support them to initiate and stay on treatment
- Introducing the PN (or other team member) to the client if desired

In the context of pairing, the PN is responsible for:

- Introducing themselves
- Explaining their role
- Conducting post-test counseling (if appropriate and/or opted for by the client)
- Providing navigation services (refer to the [LINKAGES Peer Navigation for Key Populations Implementation Guide](#) for comprehensive guidance).

FIGURE 1. Flow chart: HIV+ diagnosis to ART initiation



II. Antiretroviral Therapy (ART) Initiation

A. Key Concepts

What is ART initiation?

ART initiation begins once the client is linked to a treatment facility and starts treatment.

Why initiate ART?

The objective is to ensure that at least 95 percent of clients testing positive with HIV achieve and maintain an undetectable viral load.

When should ART be initiated?

ART should be initiated as soon as possible based on national guidelines once a client has given their consent.

How is ART initiation done?

[Initiation processes vary by country, program, and site and should be done according to national guidelines.]

B. Standard Operating Procedures

SOP 5: Therapeutic education counseling at ART initiation

The objectives are the following:

- Verify and reinforce the knowledge acquired by the client.
- Develop a treatment plan based on the prescribed combination and ensure that the client has a good understanding of their treatment and the time they should take it.
- Agree upon a follow-up schedule with the client.

The medical expert is responsible for:

- Assessing the client's commitment to adhering to treatment
- Providing information on U=U and the benefits of treatment and early initiation
- Discussing the medical, psychosocial, and other issues that could have an impact on adherence and discussing the solutions, including tailored messages based on KP profile (subgroup, gender, age, etc.)
- Determining if the client is able to begin treatment (i.e., able to take their meds and without contraindications)
- If the decision is in favor of prescribing, writing a prescription
- Explaining the prescription to the client and ensuring they have understood it
- Agreeing on a follow-up schedule with the client
- Giving the prescription to the client for dispensation at the treatment center
- Involving the navigator in the process, or collaborating with the client to inform the navigator of the session outcomes and next steps

Scenario 5a: The drop-in center does not have a medical expert.

Treatment initiation is done entirely in a treatment center.

Scenario 5b: The drop-in center has a medical expert.

The medical expert is responsible for:

- Discussing with the PN or psychosocial support worker how to prepare the client to begin ART
- Providing therapeutic education
- Prescribing ART
- Giving the antiretroviral (ARV) prescription to the client for initiation

III. Retention on Antiretroviral Therapy

A. Key Concepts

What is retention on ART?

Retention on ART is defined as at least one visit to the clinic in the last three months for resupply of ARVs, medical consultation, and/or laboratory testing (clients who are stable on ART for at least one year may be able to visit once every six months, and can be checked on via phone or SMS between visits). A client is not considered retained on treatment if he/she has transferred out of the program, stopped treatment, died, or is lost to follow-up. Refer to Table 1 for definitions of kept, late, and missed appointments, and loss to follow-up.

TABLE 1. Operational definitions for follow-up appointments

TYPE	DEFINITION
KEPT APPOINTMENT	The client presents within seven days preceding or 48 hours after a scheduled appointment.
LATE APPOINTMENT	The client presents more than 48 hours, but less than seven days after a scheduled appointment.
MISSED APPOINTMENT	The client is between seven and 27 days late for a scheduled appointment.
LOST TO FOLLOW-UP (LTFU)	The client has not presented at the facility/DIC for over 28 days (four weeks) and cannot be located or reached by phone/SMS.

Why is retention on ART important?

The objective is to ensure that at least 95 percent of clients on ART achieve and maintain an undetectable viral load. If clients are not taking their ARVs every day, then their viral load will increase, they will not achieve viral suppression, and they run the risk of getting ill and transmitting HIV to someone else.

When should clients be supported to remain on ART?

It is important to ensure that clients remain adherent to their ARVs from the first day they initiate ART as prescribed.

How is retention on ART achieved?

Clients must remain on ART for life. Retention on ART is achieved by ensuring that clients on ART are able to obtain their medication in a timely manner, that they are conducting requisite diagnostics to determine if treatment is working (and/or if they are able to remain adherent), and that they conduct routine clinical visits based on national guidance. Peer navigators/ psychosocial counselors can support clients to develop adherence goals, identify potential barriers to adherence, and develop plans and back-up plans to address challenges should they arise. Navigators also support clients to stay within the services network and manage barriers including side effects, violence/adverse events, experiences of stigma, potential travel or moving to a new location, referral to appropriate services; and support clients to disclose to their partners, among other things. They can also support clients in transferring to another network/treatment facility if the client chooses to do so.

Clients will vary in terms of the level of support required to remain adherent. Some will face barriers at the outset, whereas others may begin without barriers but experience barriers at a later time. Support throughout the first year of treatment will help ensure clients can manage challenges as they arise. Clients should decide what level of support they need (i.e., frequency of check-ins and reminders, and modality including SMS, phone, etc.).

PNs/counselors should offer or refer clients to the following services:

- Multi-month dispensation (MMD) of ART
- Community adherence groups (CAGs)
- Differentiated drug delivery (DDD) options (i.e., at a network pharmacy, delivered by the PN or a CAG group member, storage and distribution at a CBO, etc.)

B. Standard Operating Procedures

SOP 6: Support leading up to a scheduled appointment

Scenario 6a: The client can be reached by phone, SMS, social media app, or email.

Within 48 hours before the appointment, the PN or other psychosocial support worker is responsible for:

- Regularly consulting their cohort monitoring record to determine who is due for an appointment
- Contacting each client due for an appointment through phone, social media app, or SMS to remind them of their appointment date, time, and location
- Documenting all attempts to contact the client and the outcomes on a contact log

Scenario 6b: The client cannot be reached by any of the methods in 6a.

Within 48 hours before the appointment, the PN or other psychosocial support worker is responsible for:

- Calling one of the client's support contacts to have them pass along the message, verifying that the message has been received, and documenting all contacts and outcomes on a contact form; or visiting the client's home and documenting the visit on a home visit log
- Verifying that the client's telephone number, WhatsApp number, and Facebook profile, as well as the emergency contact information are still valid

SOP 7: Management of kept appointments

If the client presents between seven days before and 48 hours after the appointment date, the PN or other psychosocial support person is responsible for:

- Affirming the client's motivation to keep their appointment
- Documenting the client's actual attendance date on a cohort monitoring log
- Documenting in the client file the reason why they arrived earlier or later than their appointment

- Offering adherence support counseling, if necessary
- Verifying that the client's contact information, as well as his/her emergency contact information, are still valid

SOP 8: Management of missed appointments

The PN or other psychosocial counselor is responsible for using the appointment register to identify clients who have missed their appointments. For clients who do not present within two days after their appointment date, the PN or other psychosocial support worker is responsible for:

- Reviewing the client's file to determine what kind of appointment they missed
- Contacting the client by phone, SMS, WhatsApp, or other modality for which the client has given consent to discuss the reason for their missed appointment and providing appropriate counseling/support if needed
- Arranging a date for the next appointment
- Documenting the calls and/or messages and the outcomes on the contact log
- If contact with the client is not possible, the PN or other psychosocial support worker should:
- Attempt to contact the client at least once per day for the next 48 hours

If the client cannot be contacted thereafter, the PN/counselor should call the client's support person or make a home visit to:

- Discuss the missed visit with the client and their support person, if necessary
- Understand the reasons for the missed visit
- Review the client's treatment adherence goals and plans/back-up plans as appropriate
- Reinforce messaging on the importance of taking ART and keeping appointments
- Identify the client's needs and strategies for surmounting the barriers that prevented them from keeping their appointment
- Support the client and encourage them to start taking ART again
- Discuss again the need to have a treatment support person and the role of the support person if appropriate
- Refer the client for therapeutic education counseling at the clinic as appropriate
- Document the visit on a home visit log
- Verify and register the client's information and emergency contact information

SOP 9: Management of clients with missed appointments

Scenario 9a: The client presents seven to 27 days after the appointment.

The PN or other psychosocial staff is responsible for:

- Recording on a cohort monitoring sheet the actual date the client presented
- Documenting the reason for client's missed appointment in the client file (including asking about violence or other adverse events)
- Conducting therapeutic education counseling and identifying the client's barriers to accessing services
- Referring the client for a clinical consultation or other psychosocial support if necessary (i.e., violence prevention and response, support for disclosure, clinical support for side effects, etc.)

If the client wishes to restart treatment:

- Refer them to the doctor for an ART prescription
- Offer enhanced adherence/navigation services, referral to a support group, and/or referral to other services as needed (violence prevention and response, housing, employment, nutrition, etc.)

If contact is established and the client does not wish to restart treatment:

- Use motivational counseling skills to encourage the client to consider monthly visits at the DIC or in the community until he/she initiates.
- Invite the client to take advantage of other activities/services available at the DIC (educational talks, STI testing, support group meetings, medical consultations, etc.).
- Explain the benefits of participation in a support/discussion group and invite them to join one.
- Agree on a visit to the client's home in the next week.
- Verify that the phone number, WhatsApp number, Facebook profile, and emergency contact information are still valid.
- Document the date of the client's next appointment on a cohort monitoring log.
- Refer the client to another PN or psychosocial worker if personal relations pose a barrier.

Scenario 9b: The client does not present within 28 days after the appointment.

The PN or other psychosocial support worker is responsible for:

- Contacting the client every two weeks to reestablish contact and schedule a new appointment as soon as possible
- Documenting all telephone calls on the call log
- Contacting the support person every two weeks if the client cannot be reached
- Making a home visit with the support person to reestablish contact and schedule a new appointment as soon as possible
- Documenting the visit on a home visit log

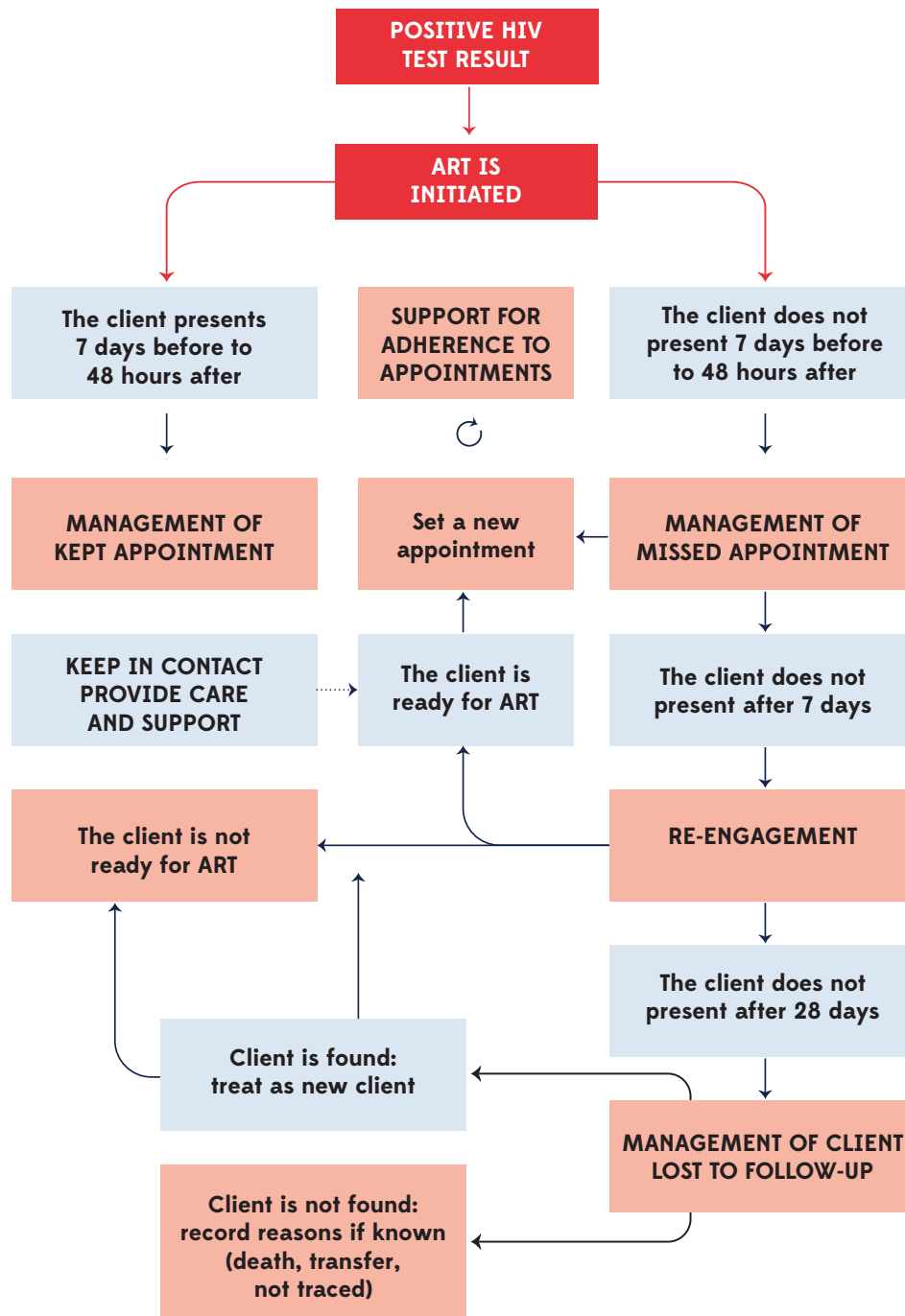
After 90 days, if the client cannot be reached, the PN or other psychosocial support worker should classify their file as either lost to follow-up, died, or transferred out. Files should be archived in a dedicated location. It is also important to note if no attempts were made to contact the client.

SOP 10: Management of a client lost to follow-up

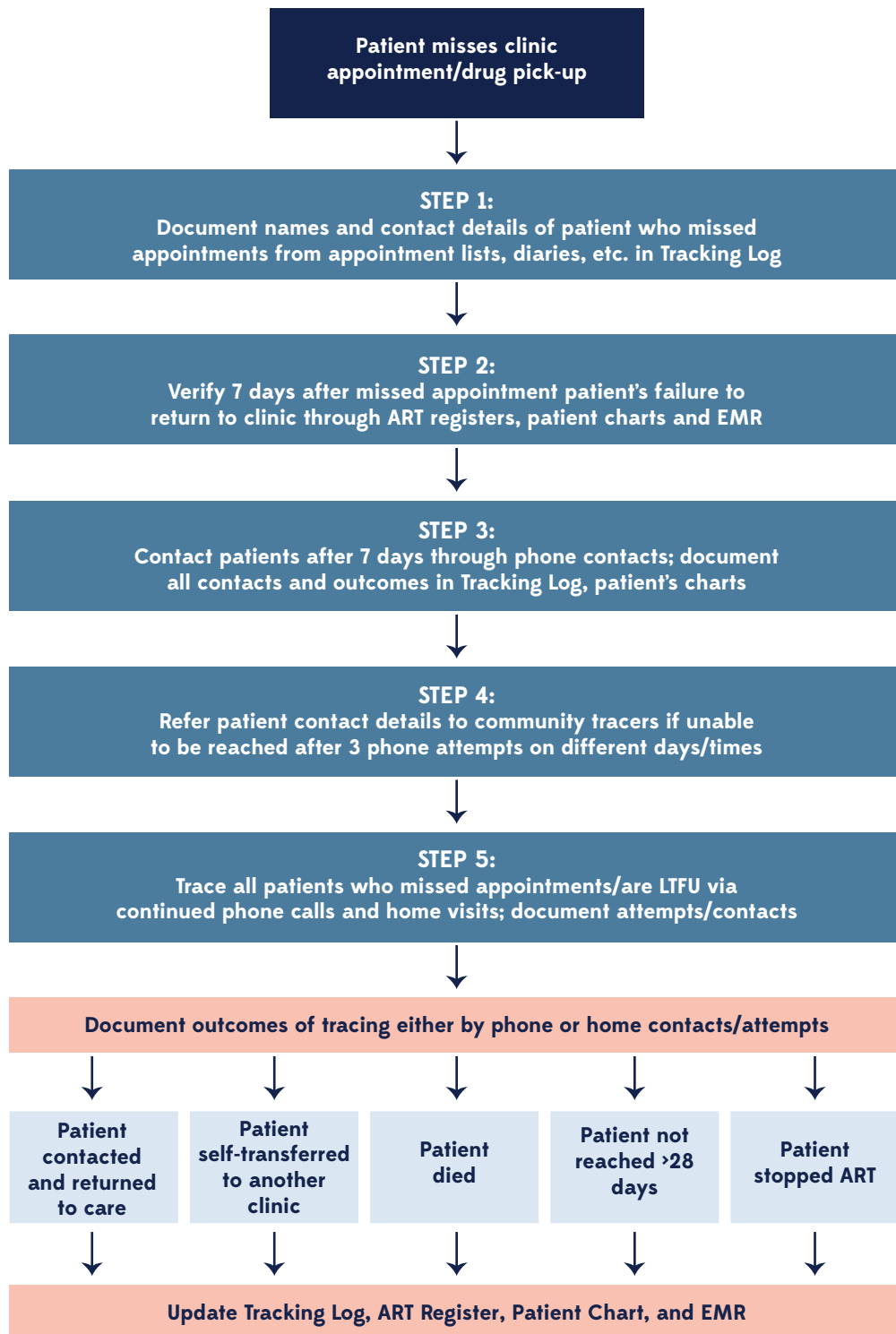
Scenario 10a: The client lost to follow-up presents.

The PN or other psychosocial support worker retrieves the client file and treats the client as a new client, following SOPs for clients initiating treatment.

FIGURE 2. Flow chart: management and follow-up of treatment appointments



Sample algorithm for tracking ART patients who missed appointments



Source: PEPFAR COP20 Guidance

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Annex B

Adherence Counseling and Retention Tool

July 2020

HIV Treatment Adherence Counseling and Retention Guide

A job aid for counselors and providers working
with people living with HIV



This tool was adapted from the Life Steps for ART Adherence tool developed by Lena Anderson, John Joskin, and Steve Safren, and the Viral Load Monitoring Tool developed by ICAP at Columbia University.

It was developed with funding from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID) under the terms of the Meeting Targets and Maintaining Epidemic Control (EpiC), led by FHI 360, cooperative agreement # 7200AA19CA00002. Its contents are the sole responsibility of the authors and do not necessarily represent the views of the U.S. Government.

The tool is intended for use by counselors and providers in order to inform and support people living with HIV to plan for and remain on lifelong treatment.



How To Use This Tool

The purpose of this tool is to guide people living with HIV (PLHIV) to plan and achieve their treatment adherence goals. It can be used in the first or second counseling session to introduce a client to treatment and develop plans for adherence or in subsequent sessions when challenges arise that affect viral suppression (i.e., *enhanced adherence counseling*). When used in conjunction with the **Adherence Barriers and Interventions Log**, it can help counselors determine if a client may be at risk for missed appointments or loss to follow-up, identify supportive interventions, and track progress.

Structure

The tool has three different sections. Each section focuses on a specific topic or potential challenges clients might face in maintaining adherence.

Section 1. Introduction to HIV treatment. Slides 13-23 introduce clients to HIV treatment, resistance, and viral load; helps clients determine their own reasons/motivation for starting and/or staying on treatment; and helps clients identify challenges they have faced or may face in remaining adherent to their treatment.

Section 2. Addressing barriers to adherence. Slides 24-46 help guide clients to discuss potential barriers they have experienced or may potentially experience, and formulate a plan and backup plan for each barrier. Not all slides may be relevant for a given client.

Section 3. Returning to care and special situations. Tabs 47-67 are designed to guide clients through specific situations, such as unsuppressed or high viral load, or what to expect when returning to treatment after having stopped.

Directions

The flipchart should be positioned on a desk or table so that the client can see the pictures while you see the side with notes.

Each card contains one or more of the following elements:

- Talking points to prompt and guide discussions – each point is optional (clients will tire quickly if all points are read to them)

- Key messages** to convey to the client (printed in **bold**)

- Provider instructions* with specific guidance on how to optimize messaging and/or counseling

- A *Let's Review* box with questions to assess the client's understanding of what was discussed, and provide opportunities for motivational interviewing techniques to address misconceptions

- A *Document* box with instructions on the use of additional tools

The **Adherence Barriers and Interventions Log** tool can be used in initial and follow-up counseling sessions to document findings from the discussions. It should be included in the client's file, and updated with each session.

Card Topic (also shown on client card)

KEY MESSAGES

Also shown to the client



Let's Review

Points to guide review with the client

TALKING POINTS

- Notes to prompt and guide discussion
- Suggested steps for follow-up
- **Key points in bold**



Document

Tells providers which forms to use to document discussions with the client



Provider Instructions

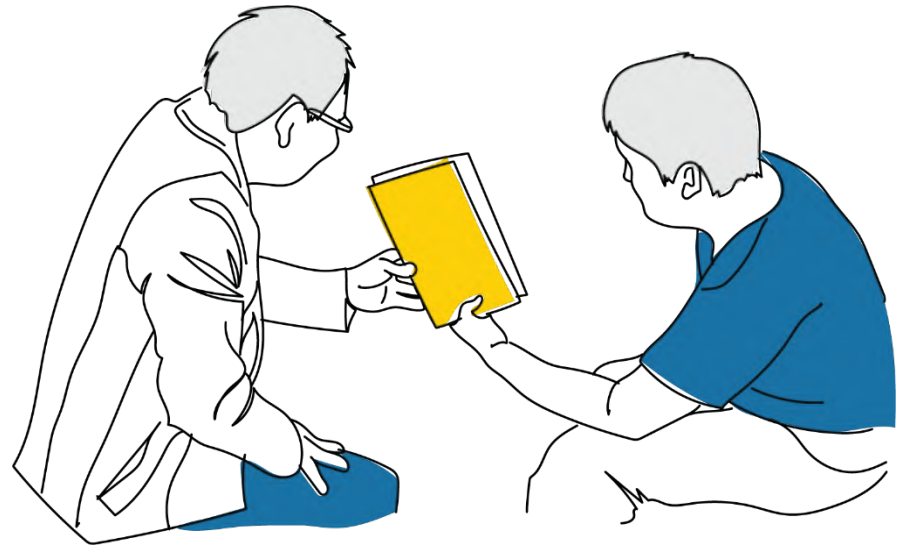
Gives providers specific instructions about their interaction and conversation with the client

Setting the stage for a productive session

Steps you can take to ensure your client is comfortable sharing, planning, and problem solving with you.

- Choose a quiet, private space.
- Sit face-to-face, make eye contact.
- Speak clearly, respectfully, and in a non-threatening voice.
- Use terms the client can understand.
- Explain the limits of confidentiality. You will not tell the client's information to others unless you are concerned for their health and safety or the health and safety of others.
- Don't assume your clients lack knowledge. Before you present information, check what they already know.
- When presenting new information, stop frequently and seek the client's understanding of the material.

Maintain focus on the client's needs and motivations.



Motivational interviewing (MI) and communication skills

Communication skills are critical for supporting clients to initiate and remain on treatment. Use the following MI techniques where appropriate (example language provided below):

A. REFLECTIVE LISTENING (use “you” statements; interpret non-verbal signs to gather information, guide the conversation, and reinforce the client’s motivations for change)

- *You’re wondering if it matters if you take your meds.*
- *You are so overwhelmed that your health is the least of your problems right now.*
- *Let me see if I understand. You want to start treatment, but you are worried your partner will find out. You want to tell him or her, but this does not feel like the right time. Is that right?*

B. AFFIRMATION (accentuate the positive, recognize client’s worth, support, and encourage)

- *I appreciate you for being honest about the challenges you are facing taking your meds.*
- *You are clearly a resourceful person to manage so many challenges.*
- *You’ve worked really hard to take your medications despite these challenges.*

C. QUESTIONING (use open-ended questions that seek information and the client’s perspective)

- *What makes it difficult to take your meds everyday?*
- *What have you already done to try to take your meds every day?*
- *What do you think is likely to happen if you keep taking your meds as you are now?*

Motivational interviewing and communication skills

D. ASK-TELL-ASK (ask what the client knows; ask permission to offer new information; ask what the client thinks of the new information)

- *I get that question a lot. First, let me ask you, what have you heard about this?*
- *I understand you're feeling concerned about how your partner might react.*
- *Many people have felt the same way when they first encountered this problem.*
- *We've found that there are effective ways to talk to your partner about this.*
- *Would you like to hear more about that?*

E. RECOGNIZE WHEN CLIENTS TALK ABOUT CHANGE

- *When clients express desire, ability, rationale, need, plan, or commitment to change*

F. STRENGTHEN WHAT CLIENTS SAY ABOUT CHANGE (reflect, affirm, ask for examples, summarize)

- *Use the confidence/importance ruler; ask questions about desires, abilities, needs, or reasons for change*

Avoid communication “traps”

Avoid these:

- Assuming you know the client better than they know themselves
- Telling the client why they should change or pushing the client to agree to change when they aren't ready
- Arguing with the client
- Ordering or commanding the client to do something
- Blaming, shaming, or judging the client



Try these instead:

- Use open-ended questions to understand the client's knowledge, experiences, and challenges
- Learn about the client's own reasons for making a change
- Explore reasons why the client is resistant; shift the focus to something else if necessary
- Use simple and double-sided reflection when the client is not sure about a decision
- Involve the client in problem solving
- Emphasize the client is free to make decisions for themselves



Counseling Cue Cards Flipchart

- A. Introduction to counseling
- B. Starting ARV treatment
- C. Viral load basics
- D. Adherence planning
- E. Follow-up adherence counseling visit
- F. Returning to care after having stopped treatment
- G. Tips to improve taking meds
- H. Your viral load is low
- I. Your viral load is high
- J. ARVs are not working

COUNSELING CUE CARD TOPICS

Introduction to counseling

1. Starting ARV treatment

2. Resistance

3. Viral load: Undetectable = Untransmittable (U=U)

4. Why start and stay on treatment?

5. Planning to stay on treatment

6. Transportation to the clinic

7. Keeping appointment dates and obtaining medication refills

8. Making a daily medication schedule

9. Storing medications

10. Traveling away from home

11. Identifying social supports

12. Coping with side effects

13. Communicating with the treatment team

14. Substance use

15. Handling missed doses

16. Review and summary of adherence planning

17. Follow-up adherence counseling visit

18-20. Returning to care after having stopped treatment

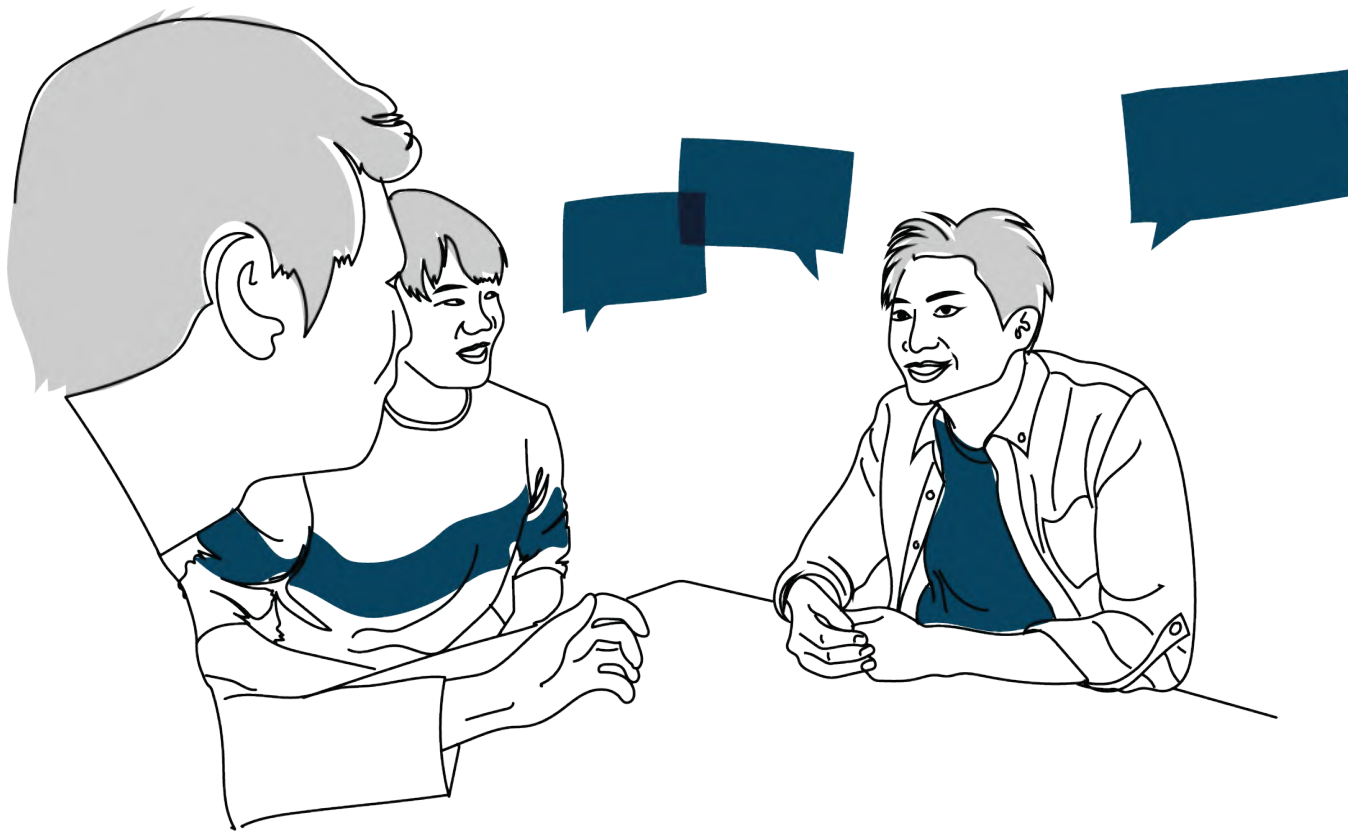
21-23. Tips to improve taking meds

24. Your viral load is low

25. Your viral load is high

26. ARVs are not working well

Introduction to counseling





KEY MESSAGES

- Treatment is a process and we are here to provide support.
- It can feel like a lot at first; feel free to ask questions at any time.
- If I don't have the answer, I will try to find it for you by our next session.

TALKING POINTS

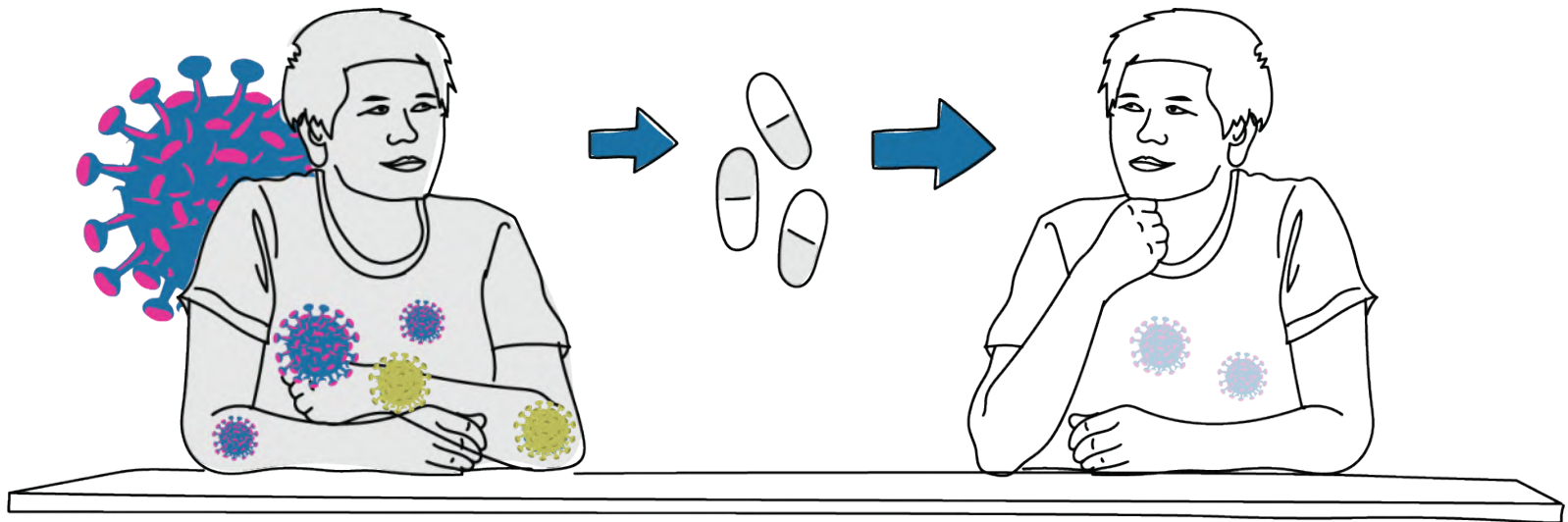
- Thank you for coming. It shows you are serious about taking care of yourself.
- My name is _____, and I am a [Title] working here at [Name of site].
- Today I would like to help orient you to your HIV treatment.
- My role is to support you to take your medication as you were advised and to help you live free from illness and the worry of passing HIV on to someone else.
- We are going to meet a few times over the next ___ months to ensure your treatment is working and to address any challenges along the way.
- You can contact me anytime you have a question or would like support.
- How does that sound to you?
- To begin with, what would you like to get from our discussion today?

SECTION

1

Introduction to HIV
treatment

1. Starting treatment

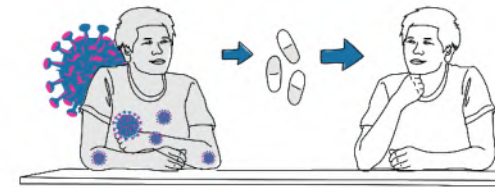


HIV treatment **stops HIV from making more copies of itself**, allowing you to stay healthy.

While treatment **will not cure HIV**, when you stay on it, **the amount of the virus in your body becomes very low and remains hidden.**

It is important to **take your meds every day** as prescribed.

1. Starting treatment



KEY MESSAGES:

- HIV treatment stops HIV from making more copies of itself, allowing you to stay healthy
- While treatment will not cure HIV, the amount of the virus in your body becomes very low and remains hidden
- It is important to take your meds every day as prescribed.



Let's Review

- In your own words, what does treatment do?
- What medicines do you take and when?
- What do you think may be hard about taking your meds every day?

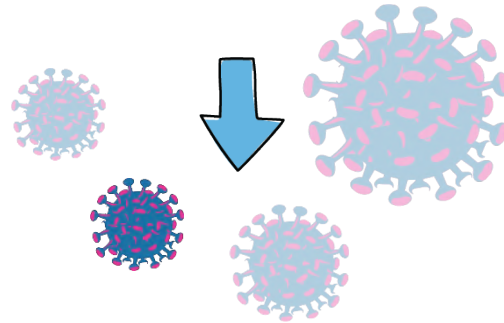
TALKING POINTS:

- What do you know about HIV treatment?
- When **HIV** is in your body without treatment, it makes **more of itself** which can make you **sick** and more likely to **spread HIV to sexual and injecting partners**, and from mother to baby during pregnancy, during delivery, and breastfeeding.
- **Treatment stops HIV** from making more virus and prevents you from getting sick.
- When there is enough medicine in your blood, HIV almost disappears from your body, remaining hidden.
- If you forget to take your meds or run out of medication, the virus makes more of itself and can lead to illness.
- **Treatment does not cure HIV**, which is why you must continue taking your meds even if you are feeling well.

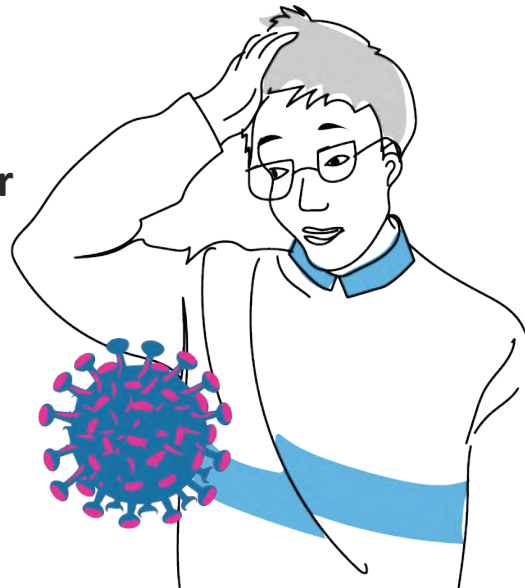
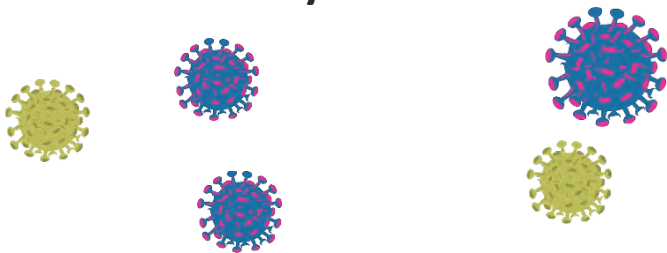
2. Resistance



Takes meds everyday = very low levels of the virus in the body



Misses doses = virus produces more of itself and your meds may no longer work as efficiently



If you miss too many doses of your medication, it will be harder to stay healthy and protect your loved ones.

2. Resistance



KEY MESSAGES

- If you miss too many doses of your medication, the virus can change and your treatment may no longer work.
- This can make it harder for you to stay healthy and protect your loved ones.



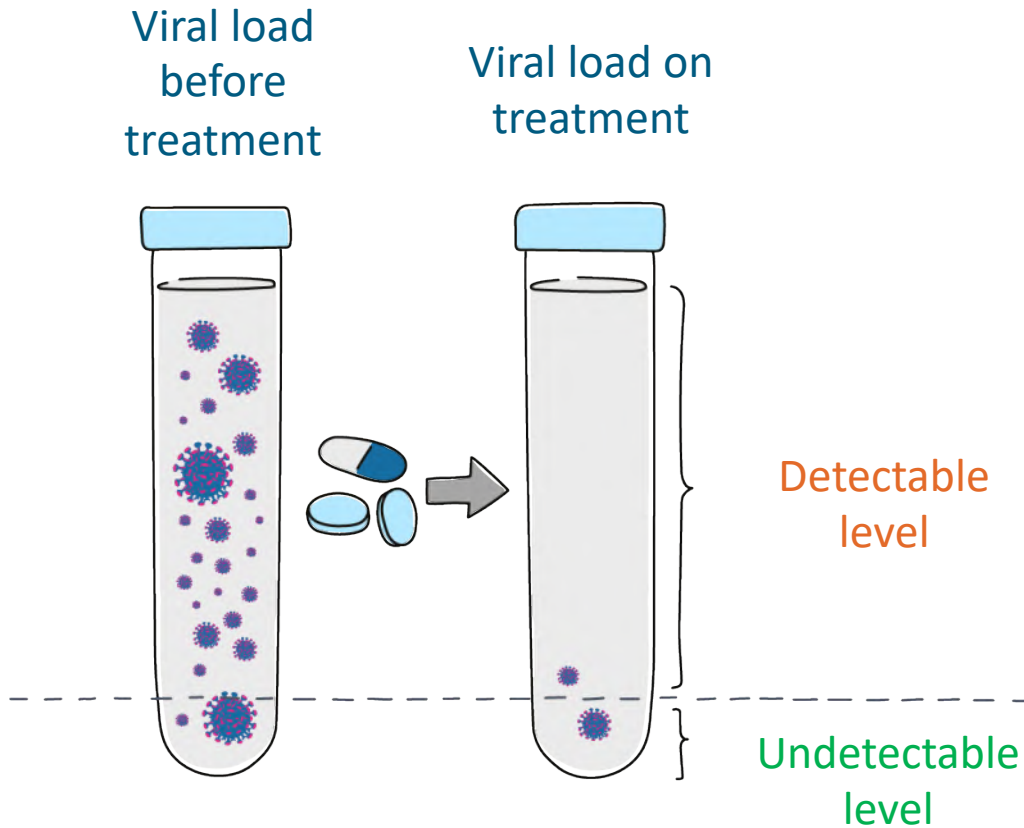
Let's Review

- In your own words, what can happen if you miss too many doses of your medication?
- What does it mean if you develop resistant copies of HIV?

TALKING POINTS

- The picture on the top is of someone who took their meds everyday. The meds stop the virus from making more of itself, and the person has very little virus in their body.
- The bottom picture is of someone who missed doses.
- When you miss doses, the virus can make more of itself. It can also change. See how they look different?
- If the virus changes, the medicine may no longer work. You might pass the new virus to someone else, and the medicine would not work for them either.
- This is why it is important not to miss doses.

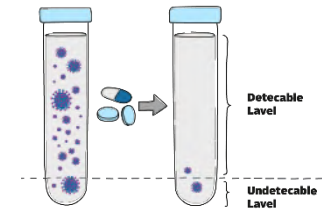
3. Viral load: Undetectable = Untransmittable (U=U)



- For those newly starting treatment, you will conduct a test in 6 months to see how much virus is in your body.
- **If treatment is working, the laboratory may not find virus in your blood. This is called **undetectable**.** HIV is still there, but at a very low level.
- If the virus cannot be detected, then you can no longer give HIV to others through sex.
- It is important to know your viral load results.

Source: <https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/876/undetectable-viral-load>

3. Viral load: Undetectable = Untransmittable (U=U)



KEY MESSAGES

- You will conduct a test in 6 months to see how much HIV is in your body.
- If treatment is working, the laboratory may not find HIV in your blood. This is called **undetectable**. HIV is still there, but at a very low level.
- If it is undetectable, then you will no longer transmit HIV to others through sex.
- It is important to know your viral load results.



Let's Review

- In your own words, what is a viral load?
- What are the benefits of achieving a low viral load?
- For those newly initiated in ART, when will you return for your viral load test?*

TALKING POINTS

- The **viral load** test measures **how much virus** is in your body.
- If treatment is working, the laboratory may not find HIV in your blood. We call this being **undetectable**. It is still there, but at a very low level.
- If you stop your meds, HIV will make more of itself. You may not look sick, but over time, you will get sick and increase the risk of giving HIV to someone else.
- If your meds are working, and you take them every day, your viral load number will usually be less than 1,000 after six months. The goal is a low viral load number.
- **What might be some of the benefits of having a suppressed viral load?**
 - Prevent illness and live longer
 - Fewer hospital visits
 - If undetectable (VL <200ml), PLHIV cannot transmit HIV to sexual partners. However, condoms are important to protect against other sexually transmitted infections.
- Please come back in _____ to check your viral load.
- A late dose is better than a missed dose!

*Refer to national guidelines for appropriate timing and algorithms

4. Why start and stay on treatment?



Benefits of staying on treatment

1.

2.

3.

4. Why start and stay on treatment?



KEY MESSAGES

A simple sticker/notecard system in your home may help you remember why you need to stay on your meds.



Provider instructions

Ask what support the client might need from you, a friend, partner, or loved one to maintain motivation to stay healthy?



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **What could be some benefits or reasons for starting and staying on treatment?**
 - Please write them on a notecard.
- Some people use a system to help them remember their reasons for staying on treatment.
- You can place a reminder (like a sticker, string, or colored piece of paper) somewhere in your home to help you remember:
 - To take your medicine daily and on time
 - The reasons you just identified for taking your medication and coming to your appointments
- **If a sticker/card system might not work for you, what other plan might work for you?**

5. Planning to stay on treatment



Taking meds on time can be challenging.

Making a plan to address possible challenges will make it easier when they arise.

We will:

- A. Identify possible challenges
- B. Develop a plan and back-up plan to address each potential challenge

5. Planning to stay on treatment



KEY MESSAGES

- Taking meds on time can be challenging.
- Making a plan to address possible challenges will make it easier when they arise.



Provider Instructions

- Use MI techniques such as the importance/confidence ruler to gauge the client's readiness and confidence in initiating treatment
- Based on the challenges identified by the client, proceed to the relevant cue cards in this section

TALKING POINTS

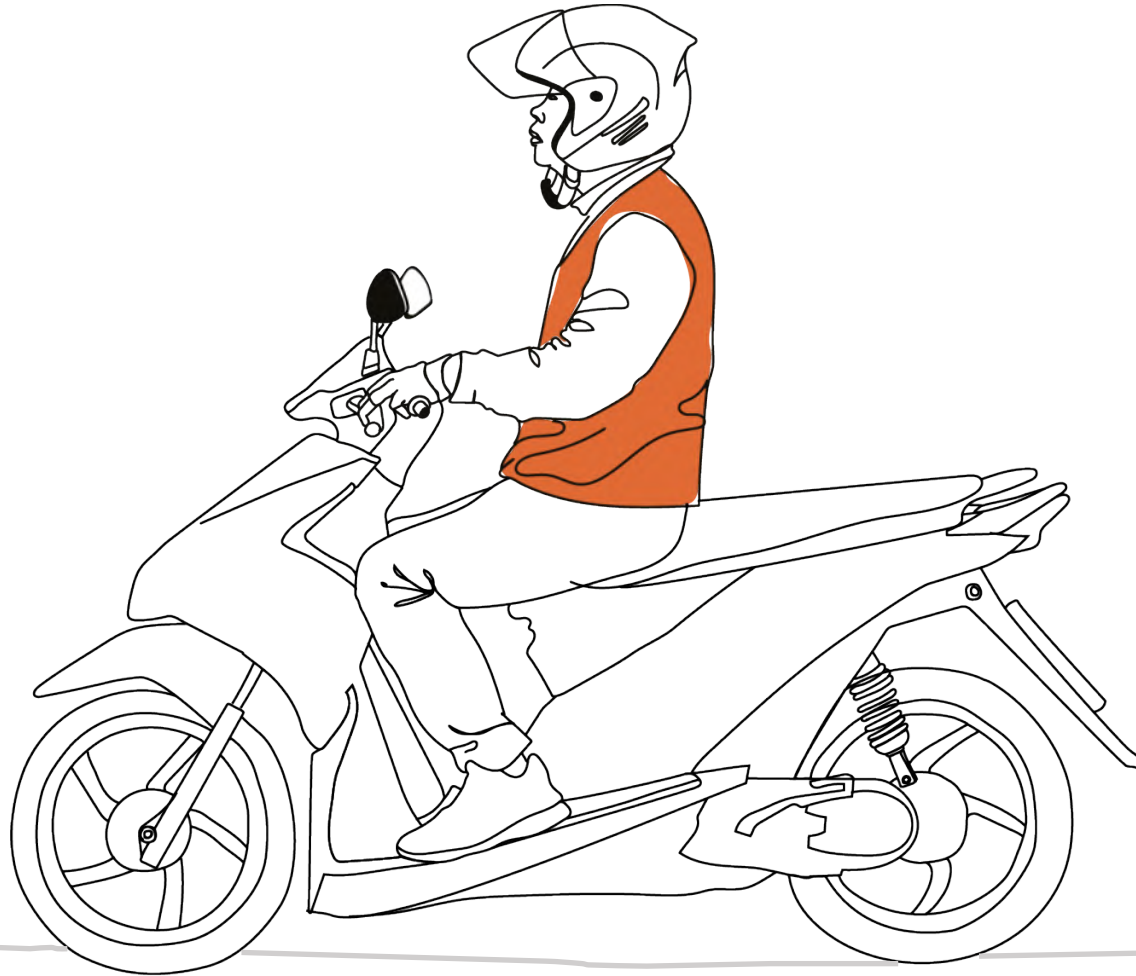
- **On a scale of 1-10 how important is it for you to start and stay on treatment? (1 = not important; 10 = very important)**
 - What makes you a [CLIENT'S NUMBER], as opposed to a [INSERT LOWER NUMBER]?
- **How confident are you that you could do so, on a scale of 1-10?**
 - What might make you more confident?
- **What do you see as some potential challenges?**
- Based on the challenges you identified; we can discuss some methods to help you achieve your treatment goals.
 - With each one we will create a **plan** and **back-up** plan
 - This will help you stay healthy, and live the lifestyle you want to live.
- **How does this sound to you?**
- **Any questions before we talk about those challenges?**

SECTION

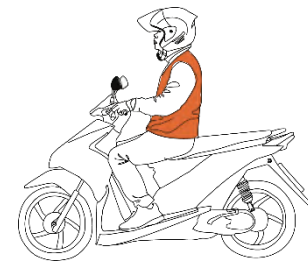
2

Addressing barriers
to adherence

6. Transportation to the clinic



6. Transportation to the clinic



KEY MESSAGES

Transportation challenges are common, but can be overcome by planning ahead.



Provider Instructions

- **Use open-ended questions (for example:**
What support might you need to make it to your next appointment?
- **Identify possible solutions based on potential risks for missed appointments**



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- **How do you usually get to your medical appointments (walk, drive, moto, bus, taxi, friend?)**
- **What is your goal for getting to your appointments for HIV treatment on time?**
- Identify potential barriers
 - **What problems might you experience with transportation?**
 - Examples: Not enough money, rainy season, transport not available at time of appointment, distance is too far, etc.
- **What is your plan and back-up plan to address them?**
 - Client will get to appointments by _____ (walk, bus, taxi, etc.)
 - In case of a problem (e.g., no bus fare, rain, etc.) client will get to appointment by _____

7. Keeping appointment dates and obtaining medication refills



7. Keeping appointment dates and obtaining medication



KEY MESSAGES

We can help you remember your appointments with an SMS or phone call.



Provider Instructions

Use open-ended questions:

- What support might you need to ensure you remember your appointments?
- How can I support you to help you disclose your status to a family member or loved one?
- Remind client of days/hours of operation of clinic.



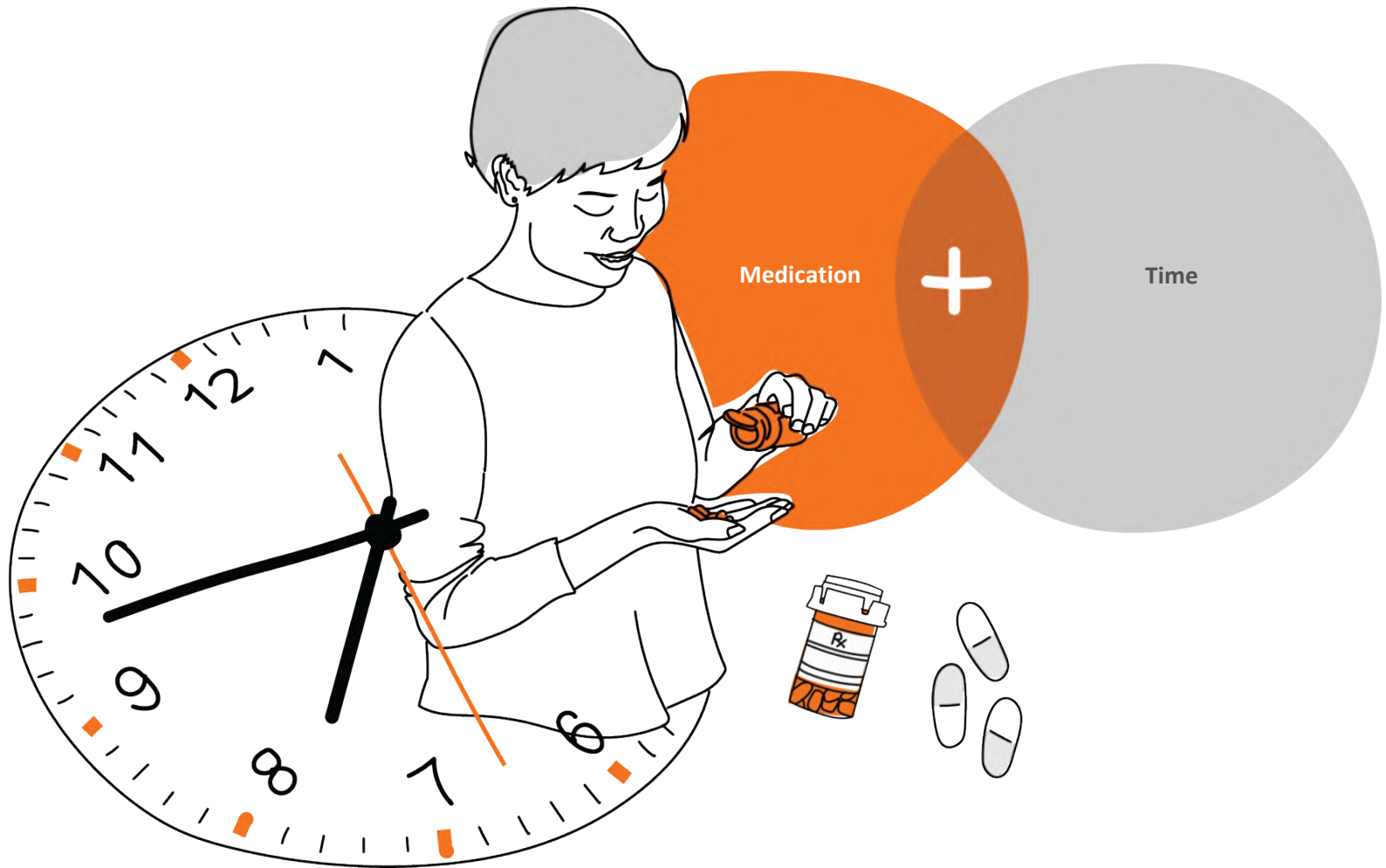
Document

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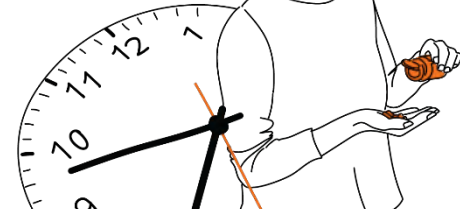
TALKING POINTS

- **What is your goal to keep appointments and obtain drug refills?**
- **What might cause you to miss your appointments?**
 - Illness, child illness, can't get time off work, etc.
 - Plan to change treatment site/moving soon
- **What might happen if people were to learn about your HIV status?**
 - Concerned about violence if HIV status were revealed?
- **Would you like support in disclosing your status to a family member or loved one?**
- **What can you or I do to make sure that you keep your appointment dates and obtain your refills?**
 - SMS/phone call appointment reminders from clinic
 - Have a friend pick up refills
 - Create a physical calendar
 - Set up automatic reminders using a phone or request support from counselor to send SMS reminders/calls

8. Making a daily medication schedule



8. Making a daily medication schedule



KEY MESSAGES

A simple cue in your home can help you remember to take your meds.



Provider Instructions

- **Use open-ended questions for example:**

What support might you need to ensure you remember when to take your meds?

- **Identify possible solutions based on potential risks for missed appointments**



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **How do you plan to take your drugs on time?**
 - We can make a medication schedule together to ensure you take your drugs on time and keep your virus level low.
- **What happens in your typical day from when you wake up to when you go to sleep?**
 - What might prevent you from taking your medication? When might it be harder for you? (identify specific times and situations)
- **What activities can you do at the same time that you take your meds so that each time you do it you will remember to take your meds?**

Strategies:

- Put them somewhere easy to remember, near something you use everyday; take at dinner or during a nightly TV/radio show.
- Place reminders around the house (a piece of tape, a string tied around a door, in the bathroom, etc.)
- Set an alarm on your phone.
- Carry spare meds wherever you go.
- Use pillboxes and a calendar to keep track of when meds are taken.
- Ask for extra meds if you will not be able to return to the health facility in time for your next refill.
- Work with a treatment buddy; request SMS reminders from a counselor.

9. Storing medications



KEY MESSAGES

It may help to have extra meds in a place you can always access them.



Provider Instructions

Use open-ended questions (for example:

- What is a reliable place you can store your meds?
- What challenges might arise if you store your meds in _____?



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **How do you plan to store your meds safely?**
- **What might get in the way of storing your meds properly?**
 - What would happen if other people saw your meds?
 - Are there young children in the house who may open your medication containers?
 - If so, where are some private places in your home that you can store your meds away from children?
 - Where might you keep some extra medicine just in case?

Possible solutions:

- Store extra meds in a purse/handbag, backpack, jacket, special compartment, sealed container, etc.; some place where it is always with you.
- Use an unmarked pill bottle.
- Use pill boxes rather than bottles.

10. Traveling away from home



10. Traveling away from home



KEY MESSAGES

If you plan to travel, you must have a plan for ensuring you do not run out of medication.



Provider Instructions

Assess likelihood of travel:

- Have you worked abroad or in another province in the past?
- Do you have plans in the next 6-9 months to travel to another province or country for work?

Have the client program your/the clinic's number in their phone.

Obtain a back-up number of a friend or family member who will know about the client's status and can help reach them if needed.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **What might prevent you from taking your ARVs while you are away from home?**

- Running out of meds, stolen, arrests, violence, alcohol, not wanting others to see you take your medication, feeling good and not wanting to think about your medication, etc.

- **If you are going on a trip or planning to work away from home, how will you ensure you have enough meds while gone?**

- Plan: _____
- Back-up plan: _____
- Would you be comfortable letting us know if you plan to travel for a long period, or change your number?

Possible solutions:

- A peer, friend, or family member may be able to help get you your medication. Who could do this?
- How could someone send you your medication (i.e., bus, friend, family member traveling to that area, etc.)?

11. Identifying social supports



My treatment supporter:

Plan for asking them for help/disclosing my status:

Back-up plan (second option for treatment supporter):

11. Identifying social supports



KEY MESSAGES

If you plan to travel, you must have a plan for ensuring you do not run out of medication.



Provider Instructions

- **Assess for potential violence that may result from disclosure:**

Would you like to role play disclosing your status to a partner or loved one?

- **Prepare disclosure aides if necessary/appropriate.**
- **Refer individuals for support if they are at risk of or experienced violence.**



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **Who can provide support to you?**
 - Who currently knows your HIV status or is supporting you?
 - If no one, what are the benefits of someone knowing your status?
- **What challenges have you or might you face in identifying someone?**
 - History of violence (verbal, physical, other?); concerns about potential violence.
 - If you currently have a supporter, are you happy with their support?
 - If you don't have a supporter, do you have a friend or family member who can support you?
 - What might make it difficult for this person to provide you support?
- **Who could you ask for support? (Plan)**
 - If you have not told this person about your status, how will you tell them?
- **If the person you ask for support says they are unable to help you with treatment, who else could you ask? (Back-up plan)**
 - You do not have to disclose to anyone, but it may help to have someone close to you to support your treatment plan.

12. Coping with side effects



12. Coping with side effects



KEY MESSAGES

Some people experience side effects, many of which will lessen over time. Keep taking your medication until you see your doctor.



Provider Instructions

If the client has not yet begun taking ARVs, you can discuss potential side effects and develop a plan for addressing them when they arise.

- Who can you contact if you experience discomfort or side effects?



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **What side effects have you experienced before? If you haven't experienced any side effects, what have you heard about side effects related to HIV treatment?**
 - Common side effects: headache, nausea, muscle ache, dreams
 - Stay on treatment even if you are experiencing side effects.
- **What side effects have you experienced that made you stop your medication, or would make you stop if you had them?**
 - What have you done about any side effects you have experienced? Have you talked to your doctor about them?
- **What will you do if you experience any of the common side effects we have discussed?**

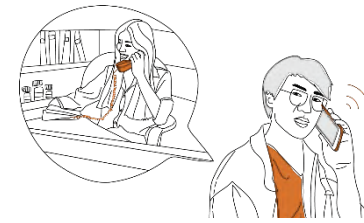
Possible solutions:

- Immediately contact your provider to discuss any side effects, and how you feel about your treatment. The provider will determine the need for treatment discontinuation or regimen change.
- Keep taking your medication until you have seen your doctor.
- Take with food (nausea/headache).
- Take at night (drowsiness/mood).

13. Communicating with the treatment team



13. Communicating with the treatment team



KEY MESSAGES

You should feel free to contact us anytime with questions, especially if you have complications or foresee complications in staying on treatment.



Provider Instructions

Assess ways in which the client feels comfortable making contact when they need support

- Support client to identify feasible options for contacting the health team if he/she has questions.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- **What will you do if you have questions or concerns related to your health?**
- What might prevent you from speaking to the doctor, nurse, or counselor at your clinic about any concerns that you have?
 - Do you sometimes forget questions or problems that you wanted to discuss with the staff at the clinic?
 - Are you planning to travel anytime soon for work? If yes, when?
- **What plan and back-up plans can we develop together in the event that you need to communicate with your treatment team?**
 - Who on your treatment team would you would feel most comfortable talking to?
 - How would you make sure to see this person during your visit?
 - If this person is not at the clinic on the day of your visit, who would you speak to about your concerns?
 - How would you feel about writing down questions for your provider on a piece of paper before your visit; how will you remember to bring this paper into your visit?
 - How do you feel about using your phone to call or send an SMS when you have a question? (provide number if desired)

14. Substance use



14. Substance use



KEY MESSAGES

If you use substances, it is important to ensure that your substance use does not prevent you from taking your meds everyday on time.



Provider Instructions

Refer the client to substance use treatment and counseling if desired and available.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- If you use substances regularly, we can plan together for how you will remember to take your medication while you are using. **What is your goal?**
- **Do you need help or support with stopping substance use?**
- **What aspects of your substance use might make it challenging for you to remember to take your meds?**
 - How often do you drink alcohol or use other drugs?
 - How might this interfere with taking your meds?
 - Do you forget to take medication when you are using?
- **What can you do to remember to take your medicine when you are using?**
 - Who are you usually with and where are you when you are drinking/using drugs?
 - Is there a friend/family member (e.g., support person) who could bring you medicine and encourage you to take it?
 - Would hearing an alarm/seeing stickers help you remember?
 - What if you were to change the time of your medication? Would that help you remember?

15. Handling missed doses



15. Handling missed doses



KEY MESSAGES

It's understandable to miss a dose from time to time. The important thing is that you get back on track as soon as you realize it. Define strategies to avoid missing future doses



Provider Instructions

Clients should never be made to feel foolish for missing one or more doses. Focus on strategies for the future to prevent missed doses.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- Some people forget to take their meds from time to time. Missing a dose is a learning experience.
- We will check in about this at the start of every session.
- What kinds of thoughts do you think may keep you from restarting your medication regimen if you miss a dose?
- **What would be the best way for you to respond when you miss a dose?**
 - What can you learn from missing a dose that will help you avoid it happening again in the future?
- Keep a positive attitude and try to return to your adherence goal as soon as possible.

16. Review and summary of adherence planning



16. Review and summary of adherence planning



KEY MESSAGES

You are taking charge of your own health by making these plans



Provider Instructions

Use MI techniques to reinforce what the client remembers from the discussion.

- Provide support for any items that the client may have forgotten.
- Always end on a positive note.
- Affirm that the efforts the client is making demonstrate how dedicated they are to protecting their health.



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Let's review what we have talked about today:
 - Motivation for starting (or) staying on treatment
 - Potential barriers to staying on treatment
 - Plans and back-up plans
- **Can you tell me the plans and back-up plans we agreed on today?**
 - PROBE ON, AND IF NEEDED, SUMMARIZE ANY PLANS AND BACK-UP PLANS THAT THE CLIENT DEVELOPED
- **Do you have any questions or thoughts about your plans, or anything else?**
- Thank you again for taking time today talk about why adherence to medication is important, and how to stay on treatment.
- I look forward to meeting with you again on _____.
- **Would you like a reminder for our next appointment?**

SECTION

3

Returning to care and
special situations

17. Follow-up adherence counseling visit

Welcome
back!



17. Follow-up adherence counseling visit



KEY MESSAGES

- Welcome back! Returning here shows you are committed to protecting your health.
- Together we will explore ways to help you stay healthy.



Provider Instructions

- **Explore barriers and challenges with the client.**
- **Use open-ended questions**
 - Affirm! Avoid having the client feel they have failed
 - Reframe: *You are really taking your health seriously despite facing a number of challenges.*
 - Note all challenges in the Log.
- **Go to the appropriate cue cards in the Adherence Planning section to review plans and adjust as needed**



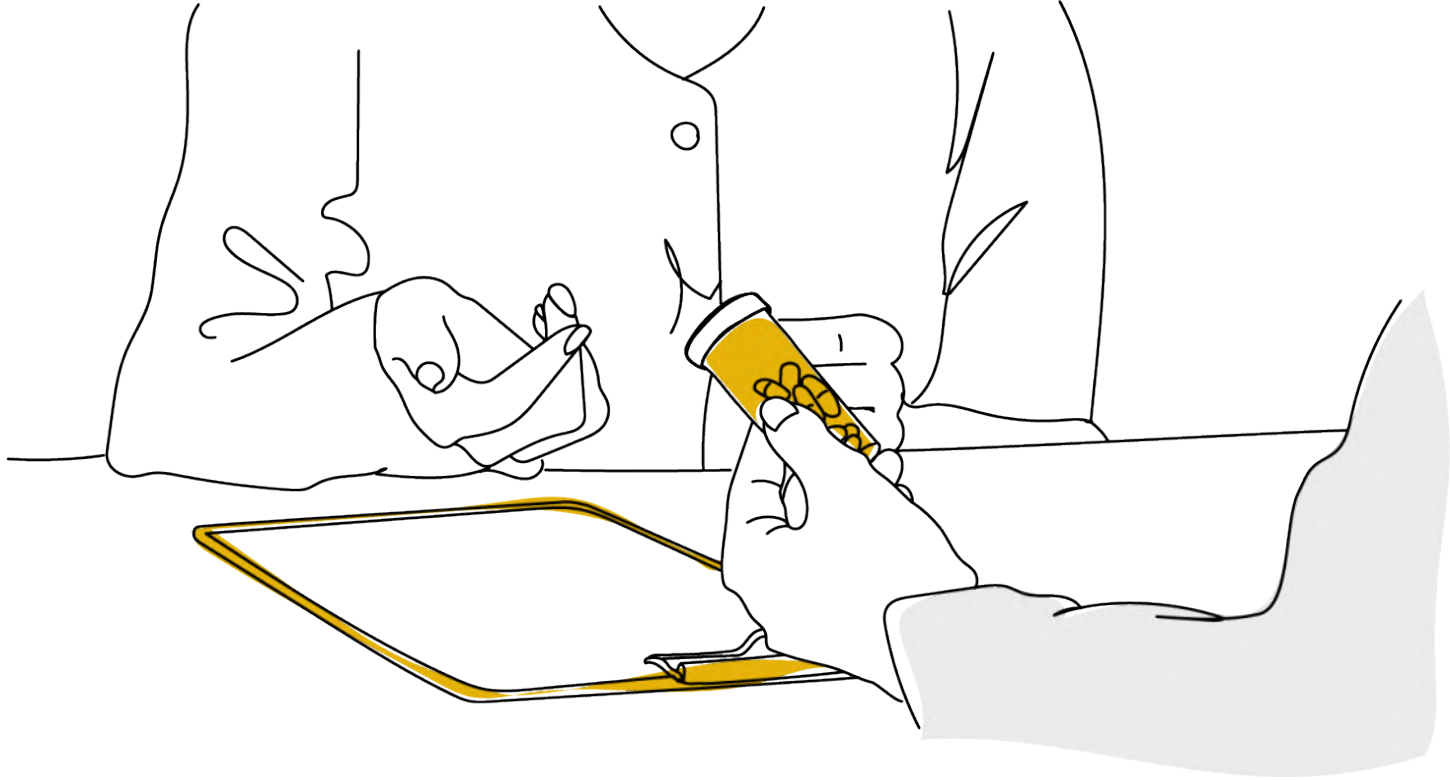
Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Thank you for coming in today. How are you?
- **What issues would you like to be sure we talk about today?**
 - *Address questions and/or note for discussion before the session ends*
- **How are things going with the plans that we discussed last time?** Have you faced any challenges? If so, what challenges have you faced? *Probe for the following as relevant:*
 - **Side effects:** Which? Questions?
 - **Doctor-client communication:** Any issues/challenges?
 - **ART drugs, regimen, and schedule:** Any issues with taking meds on time? Missed doses? Obtaining meds? Keeping appointments?
 - **Social support and disclosure:** Disclosure? Adherence issues?
 - **Violence:** Physical? Verbal? Other?
 - **Substance use:** Challenges to adherence?
 - **Plans for travel:** Any plans? How will they obtain meds?
- Let's explore the **challenges** you mentioned that affected your ability to stay on treatment by looking back at your plan. We might have to make some revisions together. **How does that sound to you?**

18. Returning to care after having stopped treatment



Welcome back!

Returning here shows you are committed to protecting your health.

Together we will explore ways to help you stay healthy.

18. Returning to care after having stopped treatment (1)



KEY MESSAGES

- Welcome back! Returning here shows you are committed to protecting your health.
- Together we will explore ways to help you stay healthy.



Provider Instructions

- **Use open-ended questions**
 - Affirm! Avoid having the client feel like they have failed.
 - Reframe: *You made an effort and faced some challenges. Coming in today shows how much you want to take care of yourself.*
- **Go the appropriate cue cards in the Adherence Planning section to develop or review their plan and adjust as needed**



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Thank you for coming in today and taking charge of your care.
- Tell me about your experience taking your meds so far.
 - What meds were you taking? How were you taking them? What were the effects? When and what were the reasons that made you stop?
- Let's explore the **challenges** that affected your treatment.

BARRIERS	PROBING QUESTIONS TO ASSESS BARRIERS
Knowledge deficit	Can you tell me the names of your meds? What is your schedule/plan to take your ARVs (e.g., what time of day, how many [if pills])? What is your understanding of the purpose of your meds?
Side effects	Have the meds affected the way you feel? Please describe what problems they cause (e.g., nausea, diarrhea, sleep disturbance).
Forgot	Have you ever forgotten or do you often forget to take your meds? Do you take them at a set time of day? What is your method of remembering to take your meds?
Felt better	Do you take your meds even when you are feeling well?
Illness	Have you had illnesses that have prevented you from taking your meds?
Substance use	Do you use alcohol? Do you use drugs? Do you feel this may be affecting your ability to take your meds?
Depression	How is your mood in general? Have you been feeling sad or confused? If yes, has this affected your ability to take your meds?
Health beliefs	Do you believe that taking your meds everyday is beneficial for your health? Have you ever tried other remedies for treating HIV? If so, what?

19. Returning to care after having stopped treatment (2)



19. Returning to care after having stopped treatment (2)



KEY MESSAGES

Let's continue exploring ways to help you stay healthy and happy.



Provider Instructions

Summarize what was learned from the client about any specific barriers identified on this card.

A: Affirmations, for example:

- *I appreciate that you are able to be honest about the way you take your meds.*
- *You are clearly a resourceful person to manage so many challenges.*
- *You've worked really hard to take your medications despite these challenges.*



Document

Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log.**

TALKING POINTS

- How has your experience with the health center been?
- Let's continue to explore any challenges you have faced in staying on treatment.

BARRIERS	QUESTIONS TO ASSESS BARRIERS
Pill burden	Is the number of pills or amount of liquid a challenge for you?
Lost/ran out of pills	Have you lost or run out of your meds?
Transportation problems	Do you have difficulty getting to the health center to collect your meds? If yes, what are the reasons (e.g., long distance, expense, job)?
Scheduling difficulty	Have you been too busy to take your meds? Have you traveled outside of your province/district for work or another reason for long periods of time?
Share with others	Have you ever shared your meds with others?
Fear of disclosure	Have you disclosed your HIV status to your family or your partner? If not, what are your concerns about disclosure? Has your family or partner been non-supportive or kept you from taking your meds? Have you experienced any form of violence, including physical, sexual, or verbal, or are you afraid of potential violence if you disclose your status?
Family/partner relationships	
Inability to pay	Have clinic or other fees kept you from taking your meds?
Food insecurity	Has a lack of adequate food ever been a problem for taking your meds?

20. Returning to care after having stopped treatment (3)



20. Returning to care after having stopped treatment (3)



KEY MESSAGES

Let's continue exploring ways to help you stay healthy.

Provider Instructions



Summarize what was learned from the client about any specific barriers identified on this card.

Use reflective listening, for example:

- *You're wondering* if it matters if you take your meds.
- *So you said you feel angry* when you think about taking your ARVs and that makes it really hard.
- *What I hear you saying is* you are so overwhelmed, your health is the least of your problems right now.

Document



Document the specific barriers you identify with the patient on the **Enhanced Adherence Plan Tool**.

TALKING POINTS

- Let's continue to explore any challenges you may be facing when taking your meds.

BARRIERS

QUESTIONS TO ASSESS BARRIERS

Drug stock-out

Have you ever come to the health facility and found that there were no meds available, or you were only given a small supply?

Long wait times

Have you ever left the health facility before receiving your meds because of long wait times?

Stigma and discrimination

Are you fearful that people in the community will find out about your HIV? Does that prevent you from coming to clinic or taking HIV meds?

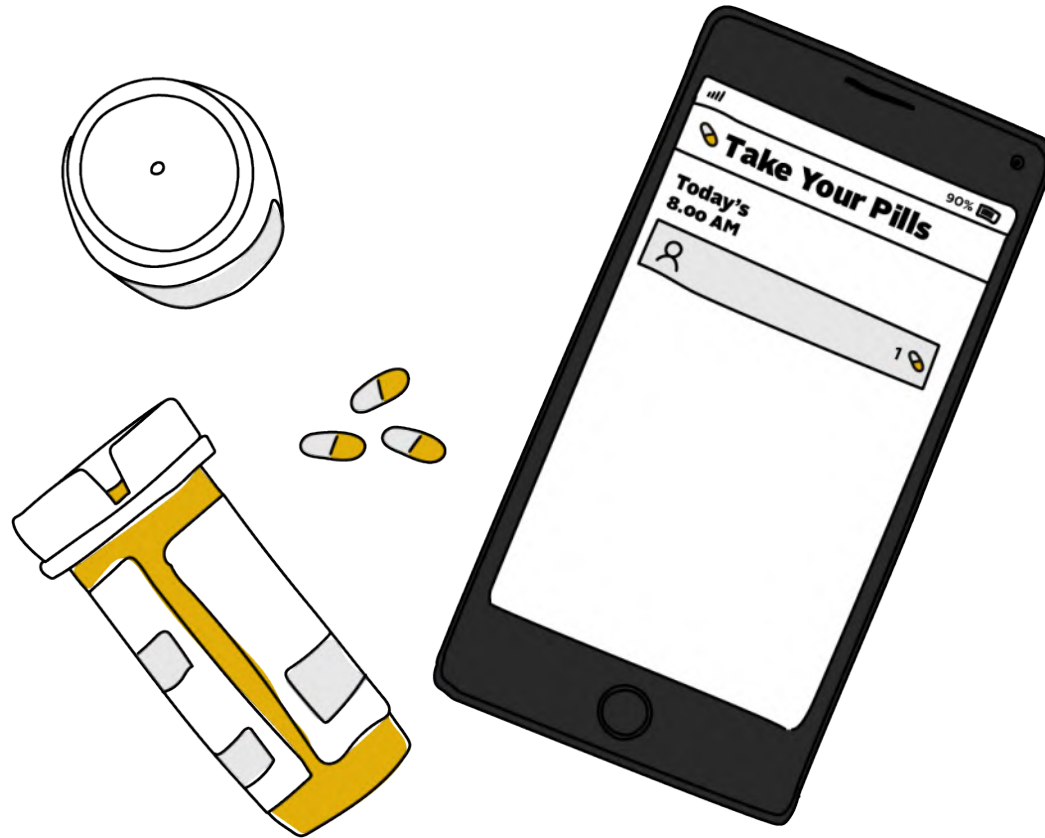
Political crisis/war/natural disaster

Is it ever unsafe for you to pick up your meds from the health facility?

Use summary statements, for example:

- *Let me see if I understand so far.* You are struggling to take your meds because you want to be well and healthy, but you also have other problems in your life that make it difficult to focus on your health.
- *Here's what I've heard you say, let me know if it is right.* You feel fine when you miss a dose and are feeling really uncertain about whether the meds are necessary to keep you healthy.

21. Tips to improve taking meds



Together we will find ways to make it easier to take your meds.

21. Tips to improve taking meds



KEY MESSAGES

Together we will find ways to make it easier for you to take your meds.

Provider Instructions



After giving a tip, ask if it seems helpful or if there are questions:

- How likely do you think it is that this will help you?
- How likely are you to try...?
- What questions do you have about...?

Document



Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- You are taking your health seriously by talking about challenges you have faced taking your meds. *[Summarize main challenges and barriers].*
- What might be the outcome if you regularly miss your doses? *[Use ASK-TELL-ASK if the client does not provide accurate information].*
- Let's explore ways in which we can make it easier for you to take your meds. How might you address some of the challenges you raised?
 - *[Use client's ideas and the tables on next three cue cards, or the Adherence Planning cue cards (D), to come up with solutions.]*

BARRIERS	INTERVENTIONS TO ADDRESS BARRIERS AND IMPROVE ADHERENCE		
Knowledge deficit	<ul style="list-style-type: none"> • Individual counseling for basic HIV/ARV education 	<ul style="list-style-type: none"> • Group counseling/peer support group 	<ul style="list-style-type: none"> • Written instructions
Side effects	<ul style="list-style-type: none"> • Nausea → take with food (refer to physician if persists) • Headache → paracetamol (refer to physician) 	<ul style="list-style-type: none"> • Diarrhea → refer to physician • Fatigue → refer to physician 	<ul style="list-style-type: none"> • Anxiety/depression → take before bed; refer to physician if persists
Forgot	<ul style="list-style-type: none"> • Medication organizer (i.e., pillbox) • Treatment buddy or supporter • Directly Observed Therapy 	<ul style="list-style-type: none"> • Visual schedule (calendar, journal) • Announced pill count at next session 	<ul style="list-style-type: none"> • Reminder devices (e.g., phone calls, SMS, alarm) • Take pills late; do not skip dose
Felt better	<ul style="list-style-type: none"> • Basic HIV/ARV education 		
Illness	<ul style="list-style-type: none"> • Refer to physician 	<ul style="list-style-type: none"> • Directly Observed Therapy 	<ul style="list-style-type: none"> • Treatment buddy

22. Tips to improve taking meds



Together we will find ways to make it easier to take your meds.

22. Tips to improve taking meds



KEY MESSAGES

Together we will find ways to make it easier to take your meds.

Provider Instructions



Collaborate to come up with solutions, for example:

- What have you already tried?
- You have thought a lot about this; what are other ways to solve this challenge?

Document



Document the specific barriers you identify with the patient on the **Adherence Barriers and Interventions Log**.

TALKING POINTS

- Let's continue to explore ways in which we can make it easier to take your meds.

BARRIERS	INTERVENTIONS TO ADDRESS BARRIERS AND IMPROVE ADHERENCE		
Depression	<ul style="list-style-type: none"> • Referral to mental health professional 	<ul style="list-style-type: none"> • Individual counseling • Peer support group 	<ul style="list-style-type: none"> • Treatment buddy
Pill burden	<ul style="list-style-type: none"> • Refer to physician to change to fixed-dose combination if available 		
Lost/ran out of pills	<ul style="list-style-type: none"> • Extra supply of pills 	<ul style="list-style-type: none"> • Community adherence group (to pick up/support taking drugs) 	<ul style="list-style-type: none"> • Educate patient to alert facility if it occurs
Transportation problems	<ul style="list-style-type: none"> • Community adherence group (to pick up/support taking drugs) 	<ul style="list-style-type: none"> • Multi-month dispensation (3-6-month supply when feasible) 	<ul style="list-style-type: none"> • Treatment buddy who can pick up drugs
Health beliefs	<ul style="list-style-type: none"> • Individual counseling for basic HIV/ARV education 	<ul style="list-style-type: none"> • Group counseling 	<ul style="list-style-type: none"> • Peer support group
Scheduling difficulty	<ul style="list-style-type: none"> • Education (combine with daily routine such as bedtime or brushing teeth) 	<ul style="list-style-type: none"> • Reminder devices (e.g., phone calls, SMS, alarm) • ART group 	<ul style="list-style-type: none"> • Treatment buddy • Keep a few doses in different locations for easy access
Alcohol or drug use	<ul style="list-style-type: none"> • Opioid substitution therapy • Individual counseling 	<ul style="list-style-type: none"> • Directly Observed Therapy 	<ul style="list-style-type: none"> • Peer support group

23. Tips to improve taking meds



Together we will find ways to make it easier to take your meds.

23. Tips to improve taking meds



KEY MESSAGES

Together we will find ways to make it easier to take your meds.

Provider Instructions



Offer suggestions to overcome specific barriers that have been identified.

Document



- Document interventions and any needed referrals on the **Adherence Barriers and Interventions Log**.
- Summarize the plans.
- Ask the client if they have any questions.
- Discuss the next follow-up date and its purpose.

TALKING POINTS

- Let's continue to explore ways in which we can make it easier for you to take your meds.

BARRIERS	INTERVENTIONS TO ADDRESS BARRIERS AND IMPROVE ADHERENCE		
Sharing meds with others	<ul style="list-style-type: none"> • Individual counseling for basic HIV/ARV education 	<ul style="list-style-type: none"> • Group counseling 	<ul style="list-style-type: none"> • Facilitate enrollment into care /PrEP for family members
Fear of disclosure	<ul style="list-style-type: none"> • Individual counseling • Treatment buddy • Couples counseling and testing 	<ul style="list-style-type: none"> • Group counseling • Unmarked pill bottle 	<ul style="list-style-type: none"> • Peer support group • ART group
Family/partner relationships	<ul style="list-style-type: none"> • Group counseling 		
Inability to pay	<ul style="list-style-type: none"> • Refer to social worker, peer worker, or NGO 		
Food insecurity	<ul style="list-style-type: none"> • Refer to social worker, peer worker, or NGO 		
Long wait times	<ul style="list-style-type: none"> • Nurse-led or community-based care 	<ul style="list-style-type: none"> • Three month supply where feasible 	<ul style="list-style-type: none"> • ART group
Stigma and discrimination	<ul style="list-style-type: none"> • Individual/group counseling 	<ul style="list-style-type: none"> • Peer support group 	<ul style="list-style-type: none"> • ART group
Political crisis, war, natural disaster	<ul style="list-style-type: none"> • Individual counseling 	<ul style="list-style-type: none"> • Case management 	

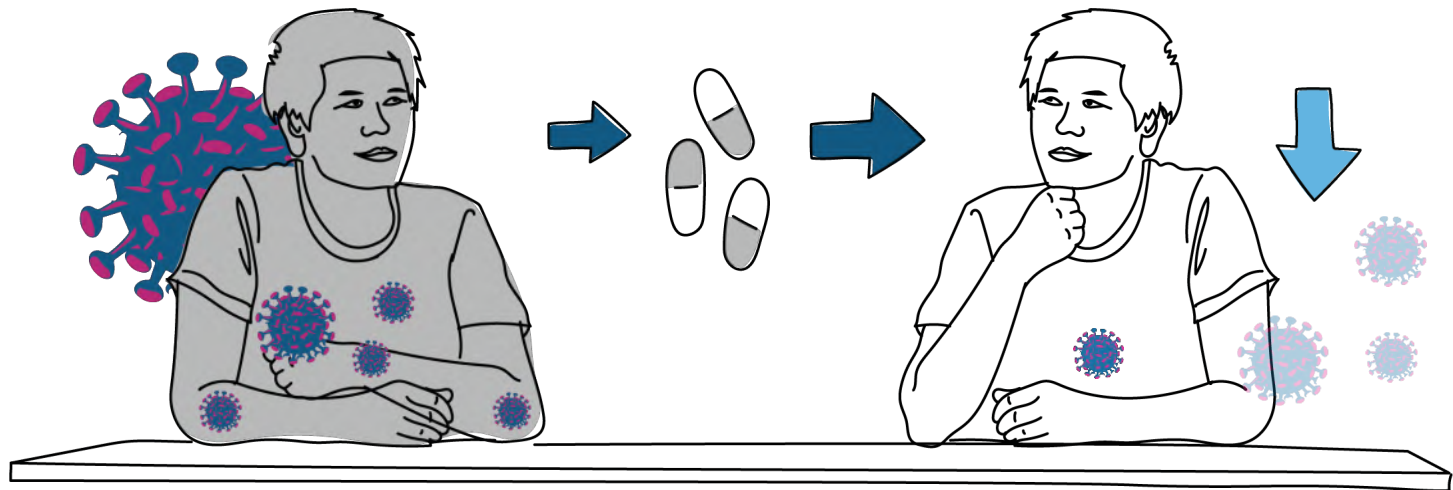
24. You have a suppressed viral load

A suppressed viral load means you are adhering to your medications and they are working.

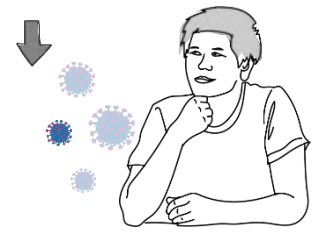
This does not mean your meds can be stopped.

Until your viral load is below 200ml, you can still sexually transmit HIV to your partners.

Continue to take your medication every day.



24. Your viral load is suppressed



KEY MESSAGES

- A suppressed viral load means you are taking your ARVs well and they are working.
- This does not mean ARVs can be stopped.
- Continue to take your ARVs everyday.



Let's Review

- What does a suppressed viral load mean?
- Why is it important to continue taking your meds every day?
- When will the next viral load be checked?
- What medicines do you take and when?

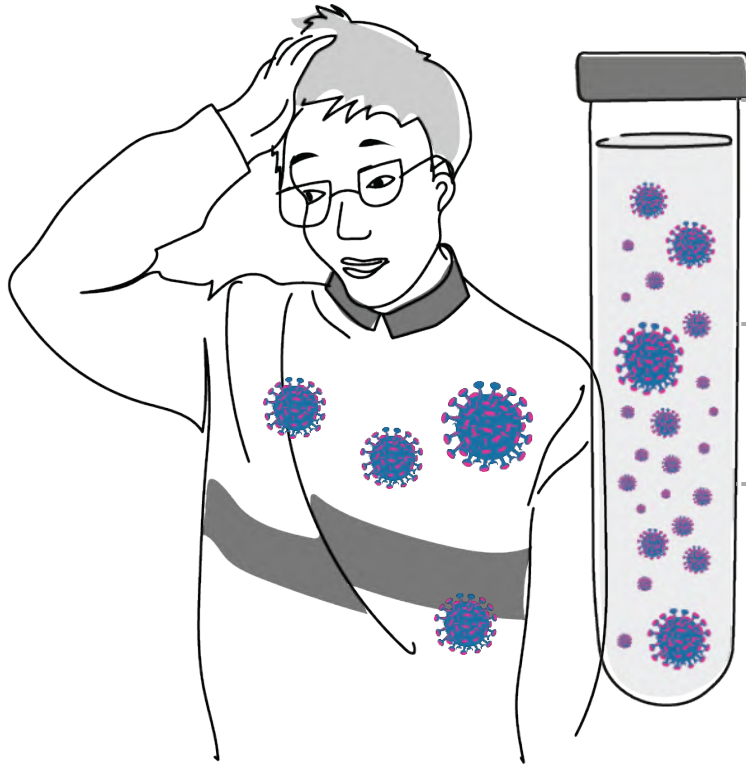
TALKING POINTS

- Your viral load is _____.
- A **suppressed viral load** (<1,000) means you are **taking your meds as prescribed** and they are working. It does not mean you can stop taking your meds or stop using condoms.
- Until your viral load is below 200ml, it is still possible to sexually transmit HIV to your partner.
- A late dose is better than a missed dose.
- Have you experienced any challenges in taking your meds? What has helped you remember to take your meds?

A few reminders:

- It's important to **keep all of your appointments.**
- If you notice that your **meds are running low, come to the clinic** even if you don't have an appointment.
- We will **check the viral load again** in ____ [six months for newly initiated clients and this is first viral load result, or one year for those with more than one low viral load].
- Please let your provider know if there any problems taking your meds in the future, so that he/she can help you address them.
- Your next is appointment is _____. Even if you still have medications, it is important for you to come to your appointment.

25. Your viral load is NOT suppressed



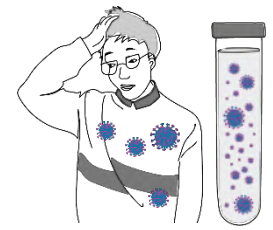
- HIV is making more virus and harming your body.

You may be missing doses of your meds.

Or...

-the virus may have changed and the meds are no longer working.

25. Your viral load NOT suppressed



KEY MESSAGES

- This means that HIV is making more virus and harming your body.
- You may be missing doses of your ARVs.
- The virus may be resistant, meaning it has changed and your meds are no longer working.



Provider Instructions

Remember to use nonjudgmental and respectful language – do not blame or criticize:

- *“I am glad you came to get your viral load results. Now we can help you work toward a low viral load.”*



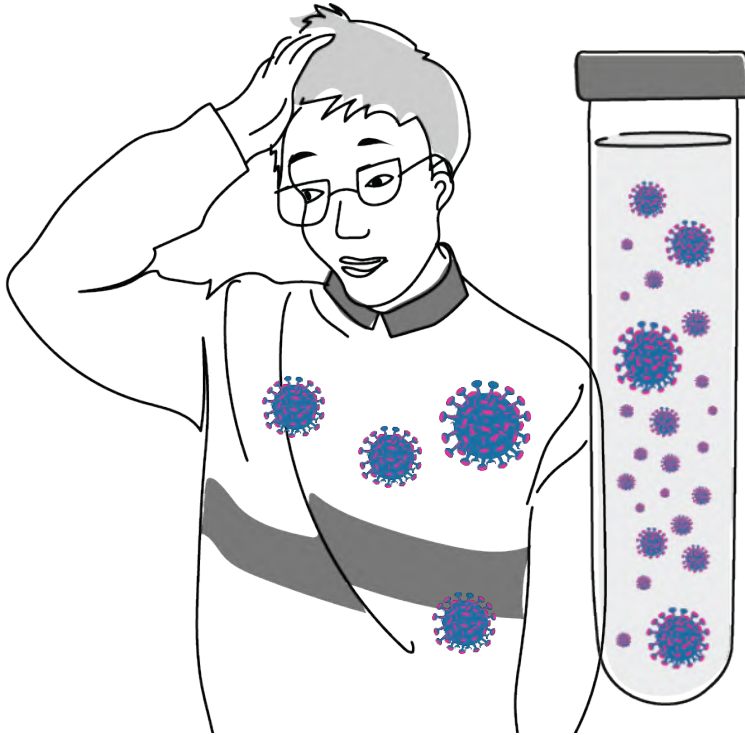
Let's Review

- What are possible reasons for an unsuppressed viral load?
- What can happen when your viral load is not suppressed?
- What is beneficial about having a suppressed viral load? How important is your long-term health?
- What do you think happens if you don't take ARVs regularly?

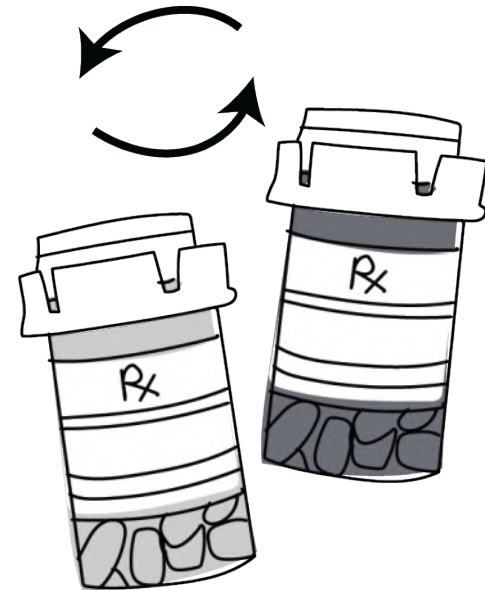
TALKING POINTS

- Your viral load is _____, which is considered unsuppressed.
- The goal is to keep your viral load undetectable, below 200ml.
- Unsuppressed means that **HIV** is making more virus in the body.
- This may be because you are **not taking your meds** as instructed, or because the medicine is not effective for the virus you have.
- With this much virus in your blood, your immune (defense) system becomes weaker. This can affect your brain, heart, liver, and kidneys, and **make you sick**.
- If your meds are not taken properly, the **virus can also change** and become **“resistant” to the meds**, meaning that even if taken properly, they will no longer work.
- With an unsuppressed viral load it's easier to spread HIV to your partner, so it is especially important to use condoms all the time.
- If you were to continue missing doses, what might be some of the outcomes? What is the worst thing that could happen?
- If you were to take your treatment every day, what would you hope would happen?

26. HIV meds are not working well

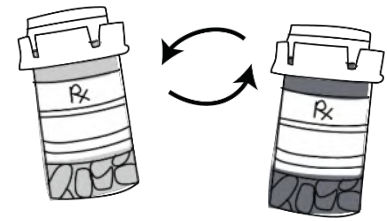


It is likely that the virus has changed and your meds are no longer working.



Switching your medication is recommended.

26. HIV meds are not working well



KEY MESSAGES

- It is likely that the virus is resistant, meaning that it has changed and your meds are no longer working.
- Switching your medication is recommended.

Let's Review



- Can you please tell me what you understand to be the next steps and why your doctor advised changing your medication?
- In your own words, what does resistance mean?
- What are the new meds you are taking, and how will you take them?
- What has helped you to take your meds?
- When is your next appointment?
- We will want to check your viral load again in ____ months to see how the new meds are working.
- Do you have questions?

TALKING POINTS

- Even though you are taking your meds everyday, your viral load result is still high.
- It is likely that the meds are not working well (HIV is 'resistant' to your medication, meaning the medication is not stopping HIV from making copies).
- Your doctor has recommended that you change your medication regimen.
 - *Discuss possible side effects and how to avoid/manage.*
- The new medication should reduce your viral load and keep you well.
- It is important to take your new meds properly.
- Please let your doctor know if you have any trouble so that you can get assistance.
- If you start other medications, such as TB medications, please let your provider know right away.
- Your next appointment is _____.



Provider Instructions

Use relevant cards for adherence assessments and counseling, and explanation of viral load results.



Document

Document new ARVs on the **Enhanced Adherence Plan Tool**.

Annex C

Adherence Barriers and
Interventions Log (LTFU risk
assessment and interventions tool)

CLIENT INFORMATION

CLIENT NUMBER:		HEALTH CENTER:
AGE:		
SEX:		

ARV REGIMEN

_____	Date initiated: DD/MM/YY
_____	Date initiated: DD/MM/YY

ADHERENCE COUNSELING SESSION 1 - CLIENT PLANNING

DATE: DD/MM/YY	LIFE STEPS:	BARRIERS	CLIENT PLAN / BACKUP PLAN
	Transportation		
	Keeping appointment dates and obtaining refills		
	Daily medication schedule		
	Storing medication		
	Travel away from home		
	Social support		
	Violence/threat of violence		
	Coping with side effects		
	Communicating with treatment team		
	Substance use		
	Handling missed doses		

PROVIDER SUPPORTIVE INTERVENTIONS

KEY BARRIERS	SERVICE/TOOLS /SUPPORT
<input type="checkbox"/> Migrant labor	<input type="checkbox"/> Regular phone contact/SMS check-ins. Frequency: _____ <i>Confirm when client plans to travel, record below.</i> <input type="checkbox"/> SMS/phone appointment reminders. Frequency: _____ <input type="checkbox"/> Referral to multi-month ART dispensation (6 months or more) <input type="checkbox"/> Plan for ensuring access to ART while away <input type="checkbox"/> Identify additional contacts in case of travel / migrant labor
<input type="checkbox"/> History of violence <input type="checkbox"/> Concerned about violence with disclosure	<input type="checkbox"/> Violence prevention/response counseling <input type="checkbox"/> Counseling on disclosure/partner notification <input type="checkbox"/> Referral to legal aid
<input type="checkbox"/> Substance use	<input type="checkbox"/> Substance use counseling <input type="checkbox"/> Identification of a treatment buddy/other social support <input type="checkbox"/> Referral to drug rehabilitation
<p>KEY POPULATION SPECIFIC</p> <input type="checkbox"/> Likely to change venue/location for sex work <input type="checkbox"/> History of arrest/imprisonment/police harassment <input type="checkbox"/> KP status not known by partners/family <input type="checkbox"/> Young/adolescent KP <input type="checkbox"/> Compound risk factors (e.g., transgender woman sex worker, homeless, medication interactions with hormone therapy, etc.)	<input type="checkbox"/> Psychosocial counseling by provider trained in KP service provision <input type="checkbox"/> KP-specific violence prevention/response counseling and support <input type="checkbox"/> Referral to legal aid <input type="checkbox"/> Counseling on family disclosure/partner notification and referral <input type="checkbox"/> Referral to social support services (for adolescents, homeless, etc.) <input type="checkbox"/> Referral to specialized clinical care for transgender women
<input type="checkbox"/> Poverty/unable to miss work <input type="checkbox"/> Transportation <input type="checkbox"/> Insurance status	<input type="checkbox"/> Identification of a treatment buddy/other social support <input type="checkbox"/> Referral to community adherence group/dispensation <input type="checkbox"/> Referral to social services (e.g., national insurance scheme)
<input type="checkbox"/> Fear of disclosure	<input type="checkbox"/> Counseling on disclosure/partner notification
<input type="checkbox"/> Depression/mental health	<input type="checkbox"/> Psychosocial counseling <input type="checkbox"/> Referral to professional mental health support
<input type="checkbox"/> Knowledge (understanding ART and HIV) <input type="checkbox"/> Myths/beliefs	<input type="checkbox"/> Education on HIV/ART <input type="checkbox"/> Written instructions <input type="checkbox"/> Weekly pill box for medications (provide/recommend)
<input type="checkbox"/> Lack of social support <input type="checkbox"/> Stigma	<input type="checkbox"/> Psychosocial counseling <input type="checkbox"/> Counseling on disclosure/partner notification <input type="checkbox"/> Referral to community adherence/peer support group <input type="checkbox"/> Referral to legal aid
<input type="checkbox"/> 0 Treatment fatigue/discomfort/side effects	<input type="checkbox"/> Counseling on management of side effects <input type="checkbox"/> Referral to clinician <input type="checkbox"/> Navigation support (accompaniment to appointment with clinician)
<input type="checkbox"/> 0 Non-national	<input type="checkbox"/> Language Interpretation/referral to appropriate services
<input type="checkbox"/> Other:	<input type="checkbox"/> Other:
Priority: <input type="checkbox"/> Higher risk of missed appointments <input type="checkbox"/> Lower risk of missed appointments	Comments:
Referrals:	Follow-up date: DD/MM/YY Estimated time of day: _____ AM / PM (circle one)
Provider Name (Print):	Provider signature:

ADHERENCE COUNSELING SESSION 2	
DATE: DD/MM/YY	
VIRAL LOAD COUNT (IF KNOWN)	
_____ C/MM3 DATE: DD/MM/YY	
PROVIDER SUPPORTIVE INTERVENTIONS	
KEY BARRIERS	SERVICE/TOOLS /SUPPORT
<input type="checkbox"/> Migrant labor	<input type="checkbox"/> Regular phone contact/SMS check-ins. Frequency: _____ <i>Confirm when client plans to travel, record below.</i> <input type="checkbox"/> SMS/phone appointment reminders. Frequency: _____ <input type="checkbox"/> Referral to multi-month ART dispensation (6 months or more) <input type="checkbox"/> Plan for ensuring access to ART while away <input type="checkbox"/> Identify additional contacts in case of travel / migrant labor
<input type="checkbox"/> History of violence <input type="checkbox"/> Concerned about violence with disclosure	<input type="checkbox"/> Violence prevention/response counseling <input type="checkbox"/> Counseling on disclosure/partner notification <input type="checkbox"/> Referral to legal aid
<input type="checkbox"/> Substance use	<input type="checkbox"/> Substance use counseling <input type="checkbox"/> Identification of a treatment buddy/other social support <input type="checkbox"/> Referral to drug rehabilitation
KEY POPULATION SPECIFIC	
<input type="checkbox"/> Likely to change venue/location for sex work <input type="checkbox"/> History of arrest/imprisonment/police harassment <input type="checkbox"/> KP status not known by partners/family <input type="checkbox"/> Young/adolescent KP <input type="checkbox"/> Compound risk factors (e.g., transgender woman sex worker, homeless, medication interactions with hormone therapy, etc.)	<input type="checkbox"/> Psychosocial counseling by provider trained in KP service provision <input type="checkbox"/> KP-specific violence prevention/response counseling and support <input type="checkbox"/> Referral to legal aid <input type="checkbox"/> Counseling on family disclosure/partner notification and referral <input type="checkbox"/> Referral to social support services (for adolescents, homeless, etc.) <input type="checkbox"/> Referral to specialized clinical care for transgender women
<input type="checkbox"/> Poverty/unable to miss work <input type="checkbox"/> Transportation <input type="checkbox"/> Insurance status	<input type="checkbox"/> Identification of a treatment buddy/other social support <input type="checkbox"/> Referral to community adherence group/dispensation <input type="checkbox"/> Referral to social services (e.g., national insurance scheme)
<input type="checkbox"/> Fear of disclosure	<input type="checkbox"/> Counseling on disclosure/partner notification
<input type="checkbox"/> Depression/mental health	<input type="checkbox"/> Psychosocial counseling <input type="checkbox"/> Referral to professional mental health support
<input type="checkbox"/> Knowledge (understanding ART and HIV) <input type="checkbox"/> Myths/beliefs	<input type="checkbox"/> Education on HIV/ART <input type="checkbox"/> Written instructions <input type="checkbox"/> Weekly pill box for medications (provide/recommend)
<input type="checkbox"/> Lack of social support <input type="checkbox"/> Stigma	<input type="checkbox"/> Psychosocial counseling <input type="checkbox"/> Counseling on disclosure/partner notification <input type="checkbox"/> Referral to community adherence/peer support group <input type="checkbox"/> Referral to legal aid
<input type="checkbox"/> 0 Treatment fatigue/discomfort/side effects	<input type="checkbox"/> Counseling on management of side effects <input type="checkbox"/> Referral to clinician <input type="checkbox"/> Navigation support (accompaniment to appointment with clinician)
<input type="checkbox"/> 0 Non-national	<input type="checkbox"/> Language Interpretation/referral to appropriate services
<input type="checkbox"/> Other:	<input type="checkbox"/> Other:
Priority: <input type="checkbox"/> Higher risk of missed appointments <input type="checkbox"/> Lower risk of missed appointments	Comments:
Referrals:	Follow-up date: DD/MM/YY Estimated time of day: _____ AM / PM (circle one)
Provider Name (Print):	Provider signature:

ADHERENCE COUNSELING SESSION 3

DATE: DD/MM/YY

VIRAL LOAD COUNT (IF KNOWN)

_____ C/MM3 DATE: DD/MM/YY

PROVIDER SUPPORTIVE INTERVENTIONS

KEY BARRIERS	SERVICE/TOOLS /SUPPORT
<input type="checkbox"/> Migrant labor	<input type="checkbox"/> Regular phone contact/SMS check-ins. Frequency: _____ <i>Confirm when client plans to travel, record below.</i> <input type="checkbox"/> SMS/phone appointment reminders. Frequency: _____ <input type="checkbox"/> Referral to multi-month ART dispensation (6 months or more) <input type="checkbox"/> Plan for ensuring access to ART while away <input type="checkbox"/> Identify additional contacts in case of travel / migrant labor
<input type="checkbox"/> History of violence <input type="checkbox"/> Concerned about violence with disclosure	<input type="checkbox"/> Violence prevention/response counseling <input type="checkbox"/> Counseling on disclosure/partner notification <input type="checkbox"/> Referral to legal aid
<input type="checkbox"/> Substance use	<input type="checkbox"/> Substance use counseling <input type="checkbox"/> Identification of a treatment buddy/other social support <input type="checkbox"/> Referral to drug rehabilitation
KEY POPULATION SPECIFIC <input type="checkbox"/> Likely to change venue/location for sex work <input type="checkbox"/> History of arrest/imprisonment/police harassment <input type="checkbox"/> KP status not known by partners/family <input type="checkbox"/> Young/adolescent KP <input type="checkbox"/> Compound risk factors (e.g., transgender woman sex worker, homeless, medication interactions with hormone therapy, etc.)	<input type="checkbox"/> Psychosocial counseling by provider trained in KP service provision <input type="checkbox"/> KP-specific violence prevention/response counseling and support <input type="checkbox"/> Referral to legal aid <input type="checkbox"/> Counseling on family disclosure/partner notification and referral <input type="checkbox"/> Referral to social support services (for adolescents, homeless, etc.) <input type="checkbox"/> Referral to specialized clinical care for transgender women
<input type="checkbox"/> Poverty/unable to miss work <input type="checkbox"/> Transportation <input type="checkbox"/> Insurance status	<input type="checkbox"/> Identification of a treatment buddy/other social support <input type="checkbox"/> Referral to community adherence group/dispensation <input type="checkbox"/> Referral to social services (e.g., national insurance scheme)
<input type="checkbox"/> Fear of disclosure	<input type="checkbox"/> Counseling on disclosure/partner notification
<input type="checkbox"/> Depression/mental health	<input type="checkbox"/> Psychosocial counseling <input type="checkbox"/> Referral to professional mental health support
<input type="checkbox"/> Knowledge (understanding ART and HIV) <input type="checkbox"/> Myths/beliefs	<input type="checkbox"/> Education on HIV/ART <input type="checkbox"/> Written instructions <input type="checkbox"/> Weekly pill box for medications (provide/recommend)
<input type="checkbox"/> Lack of social support <input type="checkbox"/> Stigma	<input type="checkbox"/> Psychosocial counseling <input type="checkbox"/> Counseling on disclosure/partner notification <input type="checkbox"/> Referral to community adherence/peer support group <input type="checkbox"/> Referral to legal aid
<input type="checkbox"/> 0 Treatment fatigue/discomfort/side effects	<input type="checkbox"/> Counseling on management of side effects <input type="checkbox"/> Referral to clinician <input type="checkbox"/> Navigation support (accompaniment to appointment with clinician)
<input type="checkbox"/> 0 Non-national	<input type="checkbox"/> Language Interpretation/referral to appropriate services
<input type="checkbox"/> Other:	<input type="checkbox"/> Other:
Priority: <input type="checkbox"/> Higher risk of missed appointments <input type="checkbox"/> Lower risk of missed appointments	Comments:
Referrals:	Follow-up date: DD/MM/YY Estimated time of day: _____ AM / PM (circle one)
Provider Name (Print):	Provider signature:

Annex D

Sample cascade interventions
to prevent and address loss to
follow-up

Linkage to ART level:

- Strengthen pre- and post-test counseling in the facilities and community as well as counseling on treatment literacy messages, including U=U
- Provide newly diagnosed individuals with options of support (i.e., peer navigator, peer educator, social worker, friend/family member) from which they can choose
- Provide accompanied referral to the clinic for ART initiation by a peer navigator or peer educator
- Offer same-day ART or rapid ART initiation options
- Provide transportation fees to ART initiation site
- Explore and advocate for operationalization of community-based ART initiation with National AIDS Control Program (NACP or other national body)
- Support and strengthen the communication and synergy between peer navigators and health care workers

Pre-LTFU activities:

- Offer DSD based on individual ART profile that is defined in SOPs (i.e., newly diagnosed but not on ART, newly diagnosed but on ART, established patient and stable, established patient but not stable)
- Offer DSD for support groups (e.g., varying themes, ART champions) based on individual ART profile
- Team trained peer navigators with KPLHIV to provide emotional, medical, and social support to ensure long-term adherence
- Provide counseling that is specific and based on the person's gender, age, KP type, and ART status
- Offer follow-up and appointment reminders through SMS, phone calls, and home visits
- Provide communication and transportation support for peer navigators to track and re-enroll those LTFU
- Advocate for MMS/MMD for KP individuals who have particular needs (traveling, long distance from facilities, those who express the need)
- Sensitize and encourage KPLHIV to seek official/documented transfer when they move from one area to the other
- Provide first line TLD (national guidance)
- Conduct an assessment to determine likelihood of nonadherence (see pg X, "Machine learning to predict and prevent loss to follow-up")

Lost to follow-up management:

- Encourage collaboration/synergy between community outreach workers and facilities to follow-up with patients who miss appointments
- Conduct daily monitoring of defaulters with active tracking through phone calls, home visits, and social networks
- Hire additional community staff to track, counsel, and re-enroll those who were LTFU
- Provide communication and transportation support for peer navigators to track and re-enroll those LTFU
- Provide support groups and extra peer navigator/psychosocial support for those who dropped out of treatment to help counsel on barriers and define solutions to achieve viral suppression

- Conduct periodic formative assessments to determine the root causes, per site, on why individuals are LTFU and to better understand who is coming back into treatment and why
- Track reasons for missed appointments and shift service delivery as appropriate, including structural, group, and individual levels; report on reasons for LTFU
- Encourage communication among provincial teams on movements of those LTFU if they are identified as moving to different provinces to be enrolled on care.

Annex E

PEPFAR-supported site
requirements for client-centered
services

The following categories include policies, practices, and program activities demonstrated as effective in retaining clients. Operating units (OUs) are expected to address each category at each PEPFAR-supported site and may adapt interventions to the needs of the clients and target those most at risk for LTFU. Programs should identify other factors that contribute to LTFU and newer models and approaches to preserve adherence as the population ages and the size of the HIV community grows. These best practices are categorized accordingly:

Convenient

- MMD and appointment spacing
- Community-based treatment initiation, peer-supported linkage, navigation, and adherence support services
- Measured wait times with specific interventions to reduce them, particularly for working clients (e.g., fast-tracking for those who are working); duration of clinic visits (inclusive of VL specimen collection and related services) and drug pick-up times must be less than one hour from patient arrival to departure
- Extended hours for working clients (including early morning evening and weekend hours)
- More convenient places (e.g., facility extensions into the community) and procedures that support expedited ARV refills
- Transportation support

Hospitable and Friendly

- Creating a welcoming environment and client-centered approaches
- Regular refresher trainings and visual reminders on specifics of human-centered care
- Staff includes patient peers (e.g., patients, males, KP representatives) with an attempt to match patient and staff by peer group
- Rights, stigma, and discrimination policies and practices are posted, addressed specifically in trainings, and enforced
- Full funding and utilization of community CSO groups to ensure the sites are client centered

Supportive and Responsive

- Service referral and linkage system
- Peer outreach and/or case management for linkage and retention with funding and not expected to be done as voluntary work
- Tracking (regular and systematic monitoring and follow-up of patient registers for interruptions in treatment) and expedited reengagement of clients with treatment interruption
- System for pre-appointment reminders with priority to high risk/vulnerable groups (e.g., viremic clients, children)
- PrEP and prevention services offered to those at high risk of HIV acquisition
- Client satisfaction monitored regularly and independently validated by PLHIV CSO groups that are funded
- Tracks for urgent care and walk-ins
- System for calling patients to return lab results or to answer questions
- System developed so 100% of clients 15 years and older, and caregivers for persons under age 14, receive VL results

Accountable and Managed

- Stakeholder engagement: a community advisory board with client representatives
- Inclusion of customer input in service design, monitoring, and improvement
- Regular use of data to analyze retention/LTFU issues, with development of interventions to improve adherence (ongoing operations research)
- Support and assessment of staff performance
- Continuous quality improvement (practices at the site level that engage employees and use client input and program data for ongoing improvements in areas of convenience, hospitality, responsiveness, and effective support)

Return to treatment of clients whose treatment has been interrupted is a high priority for all treatment sites and requires coordinated facility and community efforts.

- Consistent, affirmative “welcome back” messaging that avoids negative consequences of interruption of care and provides positive reinforcement for re-engagement.
- Solutions should be tailored to individual clients. For example, if the issue is distance to the clinic, a client should be supported with six-month appointments and six months of medication with routine phone follow-up. Access to long-term medications should not require clients to prove they are taking their meds and virally suppressed.
- Rapid re-engagement services — patient information systems structured for the rapid identification of clients who miss appointments or drug pick-up dates, outreach and contact with client by appropriate peer and community staff, assessment of client status since last recorded clinic visit including ARV use, current and active symptoms or diagnoses, sexual history for referral of partners to index testing, and case management to identify and address barriers to re-engagement and long term ARV use.
- Transition to treatment – operation protocols and memorandums of understanding to link clients rapidly from home/community to treatment sites, assessment of client readiness by case manager or outreach worker, transportation and accessible scheduling and appointment services, and transmission of client information to facilities to ensure appointment was made.

Annex F

PEPFAR tracking and tracing
standard operating procedures for
linkage and retention¹

1. <https://www.pepfarsolutions.org/tools-2/2019/1/4/loss-to-follow-up-tool>

Missed appointment

A patient who missed an appointment or drug pick-up and for whom seven or more days have elapsed since that appointment

Lost to follow up (LTFU)

A patient for whom four or more weeks have elapsed since their missed appointment or drug pick-up (per PEPFAR MER TX_ML indicator)

Identify all PLHIV who failed to successfully link from testing to ART and those who missed appointments or are LTFU using HIV testing and counseling registers, appointment registers, missed appointment lists, tracking logs, and LTFU reports from electronic medical record systems (EMRs).

Linkage to care (ART initiation)

Review ART registers, EMRs, and patient charts/files to identify all newly identified HIV-positive patients from HIV testing and counseling registers who did not start ART on the same day as diagnosis.

- a. People who did not initiate same day should be appointed to return to clinic for additional counseling and ART initiation by the counselor/nurse or Linkage and Retention Officer within three to seven days, unless patient was not initiated for medical reasons.
- b. If patient does not return, attempt to contact by phone and educate about benefits of ART, solicit reasons for non-attendance at clinic, and encourage newly identified people to come to clinic for appointment and ART initiation within seven days and if no show, contact and reschedule within 14 days of diagnosis.
- c. If patient is not reached by clinic staff within 14 days of diagnosis, refer to community tracer for follow-up so that patient gets to clinic and on ART as soon as possible.
- d. Document attempts/contacts and outcomes of all tracing efforts in tracking log, patient's chart, and EMR.

Missed appointment/defaulters/LTFU:

- e. At the end of each day, appointment logs, diaries, lists of scheduled patients, etc. should be reviewed and all patients who failed to show for their appointment should be added to a tracking log (or missed appointment register); names and contact information should be entered in the tracking log (see country Samples A and B).
- f. If the patient has not returned after seven days, the patient should be contacted by the clinic nurse or Linkage and Retention Officer and rescheduled (time period may vary by country guidelines; however, many patients return on their own within a week).
- g. Where EMRs are available, use them to generate lists of patients who have missed appointments or have not picked up drugs as scheduled within past seven days (missed appointment) and four weeks (LTFU).
- h. Call patients who have not returned to the clinic and give appointments if the patient is reached directly.
- i. Prioritize calls to those with the most recent missed appointments, those most recently initiated on ART, those with high VLs, pregnant women, and children.
- j. Data clerks should verify that lists are up to date, based on patients' charts, and ensure that patients who are enrolled in DSD programs (e.g., external drug pick-ups, CASGs, etc.) and are still current do not appear on these lists (it is helpful to ensure that expected appointment dates for DSD-enrolled patients are entered in EMR).

- k. Clinic nurses, counselors, or Linkage and Retention Officers should attempt to contact patients by phone at least three times to schedule a return visit to the clinic, and all attempts/contacts should be documented in a tracking log.
- l. All outcomes of calls including transfers, death, LTFU, patient returned to the clinic, etc., should be recorded in the tracking log, the patient's chart, and in the EMR.
- m. Check the ART register/patient's chart/EMR to see if the patient has returned to the clinic and was seen in the HIV clinic/initiated/re-initiated on ART.
- n. If unable to reach the patient directly, call the treatment supporter whose details are in the patient's file.
- o. After three unsuccessful phone attempts and patient has not returned to clinic, if possible check national laboratory system to see if patient has HIV-related lab tests (e.g., VL) associated with another clinic. If so, call clinic and verify patient is in care and on treatment at that clinic and complete transfer documentation.
- p. If unable to reach or locate patient, refer patient to community tracers for home visits to try to locate patient and return him/her to care/treatment.
- q. If the patient returns at a later date, update tracking log and ensure that patient chart and EMR have documentation of the patient's visit.

Strategies for tracking and tracing – phone calls

- Ensure that all patients give detailed phone and home contact information and provide the name and contact information of a treatment supporter or trusted family member for future contact.
- Have the patient chart and be familiar with it before making the call, especially the date of the last visit and the purpose for the appointment (e.g. ART initiation, ART refill).
- Stagger calls at different times of day and on different days—during evenings and on weekends if possible, to maximize chances of reaching patient.
- Consider using mobile phones if possible for calls, as many patients do not have or will not pick up landlines.
- If unable to reach and calls go straight to voicemail, send SMS messages (see Sample C).
- If someone answers the telephone, ask their name to ensure that it is the patient or their treatment supporter. The caller should not share patient's information to unauthorized individuals (e.g., those not listed as treatment supporter).
- If the patient is dead, transferred out, or did not consent for home visits (if needed per country guidelines), then record that information (including new treatment facility for patients who transferred) in the tracking log, patient chart, and in the EMR.

Strategies for tracing and tracking – home visits

- After three unsuccessful attempts to reach patient or treatment supporter by phone, or if patient repeatedly does not show up after being reached by phone multiple times, refer case for home visits by community tracer.
- Document referral and date of referral on tracking log and in the patient's chart.
- Community tracers should conduct home visits on different days and at different times, including evenings and weekends where possible, to maximize chances of finding patient at home.
- Conduct home visit for patients who have not linked (initiated ART) or missed appointments at seven, 14, and 28 days post-referral (this may need adaptation to conform with country guidelines or SOPs).

- Continue tracking and tracing patients beyond four weeks to try to get patients back into care/on treatment; follow national guidelines for retention follow-up.
- If contact is made, patient should be counseled on importance of early and consistent treatment and encouraged to return to care; patient should be given an appointment at their preferred clinic for the day and time that is best for them.
- Community tracer should report back to their supervisor at least weekly with status of contacts, when patients are scheduled for appointments, and to receive feedback on who has returned to the clinic and can be closed out.
- Supervisors of community tracers should meet at least weekly with clinic nurse/counselor/Linkage and Retention Officer to compare referrals with ART register, tracking log, patients' charts, and EMR to see who has been contacted and appointed, and who has returned to care/initiated/re-initiated ART.
- Regular communication between facility and community staff is critical for successful tracking and tracing of patients and obtaining outcomes of each referral.
- If the patient is unable to be located through clinic or community contacts, efforts should be made to locate patient through above-site EMRs such as national laboratory systems to see if patient has transferred to another clinic.
- If the patient has a clear outcome (not reachable at home, dead, transferred out, stopped treatment), document the outcome in the tracking log, ART register, patient chart, and in the EMR.

Monitoring and reporting results of tracking and tracing services

A tracking log or missed appointment register should be implemented at all facilities where ART is initiated and/or provided. The log should capture information needed to track clients/patients, the methods of attempting to contact them, and the outcomes of each attempted contact. The structure of the tracking log should allow for easy tabulation of outcomes to help with monitoring and reporting; this is important for partner management and service implementation monitoring, and specifically to support reporting the TX_ML MER indicator.

Tracking logs or missed appointment registers should include columns for contact information, missed appointment dates, contact attempt methods, dates of contact activities, and resulting events for outcomes of interest: died (confirmed), previously undocumented patient transfer (confirmed), traced patient (unable to locate), did not attempt to trace patient. Tracing outcomes can be summarized for the specific reporting period on tally sheets that include counts by age and sex disaggregation.

