LINKAGE AND RETENTION IN PRE-ART CARE
BEST PRACTICES AND EXPERIENCES FROM THIRTEEN COUNTRIES

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AIDS Support and Technical Assistance Resources Project
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Abstract
Linkages to and retention in HIV care for people living with HIV has emerged as a priority under the U.S. President’s Emergency Plan for AIDS Relief. Many challenges to retention in care prior to eligibility for antiretroviral therapy persist, but programs are implementing a variety of practices to overcome these challenges. Clear policies and guidelines, and resources to support their implementation, are needed to take promising practices to scale with a focus on quality to meet demand and retain clients in care.

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ACRONYMS

AIDSTAR-One  AIDS Support and Technical Assistance Resources, Sector I, Task Order 1
AIDS    acquired immunodeficiency syndrome
ART    antiretroviral treatment
ARV    antiretroviral
CBO    community-based organization
CDC    U.S. Centers for Disease Control and Prevention
CHW    community health worker
EMR    electronic monitoring record
ETS    electronic tracking system
HIV    human immunodeficiency virus
HMIS  health management information system
HTC    HIV testing and counseling
I ACT  Integrated Access to Care and Treatment Program
LFTU  loss to follow-up
M&E    monitoring and evaluation
MCH    maternal and child health
MNCH  maternal, neonatal, and child health
MOH    ministry of health
NGO    nongovernmental organization
OGAC  Office of the Global AIDS Coordinator
PEPFAR  U.S. President’s Emergency Plan for AIDS Relief
PLHIV  people living with HIV
PMTCT prevention of mother-to-child transmission of HIV
POC    point-of-care
ROM    Reach Out Mbuya
STI    sexually transmitted infections
TB    tuberculosis
USAID  U.S. Agency for International Development
WHO    World Health Organization
EXECUTIVE SUMMARY

Linking and retaining people living with HIV (PLHIV) into HIV care has emerged as a priority under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). Clients eligible for and enrolled in antiretroviral therapy (ART) have been the focus of retention efforts, but those not yet eligible for ART must also be retained in care. Evidence-based approaches must be implemented to meet client needs and expectations to support retention. To learn more about the current state of linkage and retention and identify country evidence and best practices of retention of PLHIV in pre-ART clinical and social support care in the sub-Saharan African region, AIDSTAR-One conducted a desk review of recent literature and an online survey with follow-up interviews, targeting fourteen countries in the region: Botswana, Ethiopia, Kenya, Lesotho, Malawi, Mozambique, Namibia, Rwanda, South Africa, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe.

Findings from the desk review indicate that many HIV programs experience disruptions in the continuum of HIV care, often in the pre-ART phase. Common challenges include loss-to-follow-up (LTFU) or attrition, poor retention, and limited attention to pre-ART services and clients. Distance to health care centers, transportation costs, male gender, younger age, unemployment, and lower levels of education may contribute to attrition in pre-ART care. Another common barrier is stigma and fear of disclosure of HIV status.

Responses from an online survey and follow-up interviews provided additional details on the challenges to retention in pre-ART HIV care, which fell into three overarching categories: human resource (HR) challenges, logistical challenges, and commodities challenges. Lack of financial resources was an issue that cut across these three areas. Other challenges included lack of trained staff or staff attrition, stigma in the communities where clients live, lack of or inadequate client tracking systems, transportation difficulties, problems with infrastructure or equipment, and difficulty in maintaining an adequate supply of laboratory reagents.

Programs are implementing a variety of practices to overcome challenges to retention in pre-ART HIV care. Some of the most common practices reported included task shifting, use of community-based health workers and peer educators, informational campaigns to decrease HIV stigma, collaboration with traditional leaders, client literacy and education campaigns, nutritional programming, income generating activities, legal and child protection programming, use of new technology, point-of-care (POC) services, and employment of supply chain mechanisms.

Three best practices identified in the online survey by all participating countries were: 1) point-of-care services, 2) integration of HIV and maternal, neonatal, and child health (MNCH) services, and 3) use of peer educators or counselors. Other commonly identified best practices included integrating services and increasing male involvement in community-based activities.

From the desk review, survey, and interview findings, recommendations can be made for linkage and retention programs addressing the continuum of HIV care including:

- Develop guidelines and improve strategies to successfully link HIV-positive clients to care.
- Standardize the definitions of LTFU and pre-ART care.
• Improve expand counseling services for newly diagnosed HIV-positive and other pre-ART clients to offer comprehensive psychosocial support, utilizing peer counselors or community health workers, and including adherence support.

• Minimize stockouts of commodities and equipment needed for assessing clients’ eligibility for ART, and scale up co-trimoxazole.

• Ensure timely CD4 testing at the facility-level and in the community, if feasible.

• Employ active monitoring and tracking strategies for pre-ART clients ineligible for ART, both at the facility and in communities. Enhancing client tracking systems may include adapting registers for pre-ART clients transitioning to ART.

• Implement community-based interventions, e.g., mobile HIV services to mitigate client distance or transportation issues.

• Establish electronic tracking systems (ETS) for all clients in HIV care.

• Strengthen human resources, recognize new cadres of health workers, and address current infrastructure.

• Build on achievements in integration.

• Continue implementing client-oriented practices to empower clients and improve retention in care.

• Strengthen the community-facility link.

• Continue to combat stigma.

• Standardize monitoring and evaluation for pre-ART and ART activities.

Challenges to retention in pre-ART HIV care are common across Eastern and Southern Africa. Clear policies and guidelines, and resources to support their implementation, are needed to meet demand and retain PLHIV in care. Programs are addressing challenges to retention but these responses are still in pilot phases or on small scales; programs stand to learn from each other’s experiences. To minimize loss to follow up and poor health outcomes, retention activities need to be strengthened and taken to national scale with a focus on the quality of care.
INTRODUCTION

Linking and retaining people living with HIV (PLHIV) into HIV care has emerged as a priority under the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR). Previously, PEPFAR programs focused on those who are eligible for and on antiretroviral therapy (ART). However, program managers are increasingly aware of the need to ensure that PLHIV who are not yet eligible for ART also remain in care until they need ART. It is also becoming increasingly apparent that HIV care programs need to meet clients’ needs and expectations for services through evidence-based approaches. Programs in different settings across the southern and eastern African region share many similar challenges as well as opportunities to improve retention in pre-ART care (Bergmann 2011).

The concepts of “linkage” and “retention” in HIV care and support programs have varying definitions. In a recent World Health Organization (WHO) report, the authors define linkage to care as the period starting with HIV diagnosis and ending with first enrollment into HIV care and treatment. They define retention in HIV care as engagement in comprehensive prevention, support, and care services regardless of site. Further, the WHO defines four stages of retention in the continuum of HIV care and support: (1) positive HIV test to enrollment in care; (2) enrollment in care to ART eligibility; (3) ART eligibility to ART initiation; and (4) continuation of treatment throughout life (WHO 2012). The definitions of the pre-ART and care phases and what services are available to the client during each also vary. Generally, pre-ART phase involves retaining HIV positive clients into care until they are eligible for and initiate ART (Rosen and Fox 2011; WHO 2012). In this phase, the WHO recommends a package of care, support, and prevention services for clients in pre-ART, and do not consider it merely a waiting period to initiate ART (WHO 2012).

In November 2010, AIDSTAR-One, in collaboration with the PEPFAR Technical Working Group on Care & Support, organized a Field Driven Learning Meeting in Maputo, Mozambique from November 3-5, 2010 on Linkages to and Retention in HIV Care and Support Programs (referred to as the Maputo Retention Meeting in this report). Materials from that meeting are available on the AIDSTAR-One website. The meeting gathered stakeholders from nine countries (Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe) to share their experiences on retaining clients in pre-ART care and to identify next steps to continue to improve retention. Common themes emerged from discussions at the Maputo Retention Meeting:

- Programs need to focus on meeting client needs and expectations of services, addressing these needs through evidence-based practices.
- Service delivery systems allowing clients to access services when and where they want with adequate staff at facilities and in communities have better outcomes.
- Facilities are using different approaches to improve services: employing new technology like POC CD4 testing, using mobile phones for client reminders and follow-up, and focusing on pre-ART care in monitoring and evaluation and quality improvement activities.
- Task shifting is a major strategy to meet client demand and reinforce the facility-community link.
• Communities have different roles to play in HIV care and support, not only delivering services but also committing resources to combat stigma and discrimination against PLHIV. These highlights merit further exploration to improve the design and management of HIV care programs for pre-ART clients.

At the request of the PEPFAR Technical Working Group on Care & Support, AIDSTAR-One conducted complementary follow-up activities to the consultation to identify country evidence and best practices of retention of PLHIV in pre-ART clinical care and social support in the nine countries that participated in the consultation, as well as five additional countries identified by the PEPFAR Technical Working Group on Care & Support and AIDSTAR-One (Ethiopia, Kenya, Rwanda, Tanzania, and Uganda). Initially, a desk review was conducted in September and October 2012 to provide an overview of pre-ART care status and services, and provide an additional basis, along with the Maputo meeting discussions, for the surveys and interviews. An online survey was then sent to the fourteen target countries to identify activities to retain clients in pre-ART care, challenges, potential solutions to address those challenges, and best practices. Information on improving future technical consultations was also solicited from participants along with feedback on the Maputo Retention Meeting and its effect on current activities. In addition to the online survey, several respondents also participated in follow-up telephone interviews. The online survey was administered in October and November 2012 and the follow-up interviews in November 2012. Eleven of the fourteen countries included in the desk review participated in the survey and interviews.

Discussions at the Maputo Retention Meeting included activities specifically targeting women and children. In the desk review, survey and interviews, interventions for pediatric clients or PMTCT clients (mother and/or infant) implemented by HIV programs emerged, but were not a focus of the follow-up activities. Some of the challenges, their potential solutions, and best practices identified in this report are indeed relevant to services for pediatric clients. However, unless otherwise indicated, the challenges and practices to improve retention in pre-ART HIV care discussed below are for the general adult PLHIV population.
DESK REVIEW ON PRE-ART RETENTION ACTIVITIES

METHODS

For the desk review, PubMed/Medline, Google Scholar, Google, and International AIDS Society and Conference on Retroviruses and Opportunistic Infections abstracts were searched to identify both grey and white literature about the status of pre-ART care and strategies to improve retention in the above countries. Articles and findings from 2010 to present were included in the desk review to incorporate new evidence following AIDSTAR-One’s “Field Driven Learning Meeting” in Mozambique in 2010. The majority of evidence about pre-ART care and retention in care gleaned from the literature came from South Africa, Uganda, Kenya, Malawi, and Ethiopia. One country, Lesotho, did not yield any specific findings.

FINDINGS

Overall, many HIV programs experience disruptions in the continuum of HIV care, often in the pre-ART phase. Many studies highlight LTFU or attrition, poor retention, and limited attention to pre-ART services and clients. Factors associated with attrition in pre-ART care include distance to health care centers, transportation costs, male gender, younger age, unemployment, and lower levels of education. Psychological barriers included stigma and fear of disclosure of HIV status (Faal M. et al. 2011; Larson et al. 2010; Govindasamy et al. 2012).

COUNTRY-SPECIFIC FINDINGS

Botswana

According to the National HIV and AIDS Treatment Guidelines, pre-ART care is mandatory for all patients within Ministry of Health units. Pre-ART care is defined as including CD4 testing, clinical staging, and co-trimoxazole for opportunistic infections, with specific considerations for ART-eligible and ART-ineligible clients. The guidelines suggest that pre-ART should include supportive and preventative care as needed, which comprises nutritional interventions for both adolescents and adults (Botswana Ministry of Health 2012). However, limited published evidence was found regarding the extent of implementation of these guidelines. While primarily relating to linkage to HIV care, “The Botswana Combination Prevention Project (BCPP): The Next Phase of HIV Prevention in Botswana” incorporates a PEPFAR intervention to reduce HIV transmission (Makhema et al., 2012). Specifically, CDC/PEPFAR sponsored Prevention-Village Randomized Trials in Africa involved a variety of interventions, some of which contained components that aimed to improve linkages to care and treatment. Interventions included: 1) POC CD4 testing; 2) brief case management and active linkage by community health workers (CHWs); and 3) transportation or cell phone compensation to link to HIV care clinic. The target was for more than 90 percent of newly diagnosed residents to register at an HIV treatment clinic within 30 days after a positive HIV test (Makhema et al. 2012).
Ethiopia
Retention in pre-ART care poses challenges in Ethiopian ART hospitals (Idris et al. 2012). Because of high LTFU, community tracing strategies should be expanded or scaled-up in Ethiopia, and some programs are taking steps in this direction (Mulissa et al. 2010). The desk review identified some strategies aiming to improve pre-ART care. For instance, at Zewditu Memorial Hospital in Addis Ababa, an intervention – the “Plan, Do, Study, Act” strategy – was implemented aiming to improve pre-ART retention, and retention rates were evaluated from July-December 2011. Given low baseline retention levels (35 percent), two strategies were tested: 1) providing adherence counseling prior to enrollment and 2) changing client flow. In December 2011, retention rates significantly improved, reaching 69 percent. Authors suggest that the improvement was associated with implementing the adherence counseling prior to enrollment and changing client flow (Idris et al. 2012). Further, community-based interventions to address high attrition were implemented, including adherence support workers and LTFU (“defaulter”) tracer strategies (Mulissa et al. 2010; Lifson et al. 2012).

A retrospective study of pre-ART clients and staging at a district hospital in southern Ethiopia found pre-ART attrition was high. Of 2191 clients, one quarter was lost to follow-up during pre-ART care. Clients who were lost to follow-up in the pre-ART stage were more likely to be in a recent cohort (i.e., clients enrolled into care between September 2007 and December 2008), rural clients, and with less advanced disease. At the time of the study, no pre-ART client tracing system was used, and results highlighted the importance of community-based interventions to track clients to improve pre-ART retention (Mulissa et al. 2010). Abdulwadud et al. (2011) facilitated a retrospective analysis of ART program data from 2005-09 in accredited private hospitals in Ethiopia. In this study, the number of pre-ART clients was estimated by the number that enrolled in HIV care but did not initiate treatment. Of 10,849 clients enrolled for care, the pre-ART estimate was 13 percent (n = 1,407). Findings suggest that pre-ART programs may be ineffective and should be evaluated (Abdulwadud et al. 2011).

Lifson et al. (2012) facilitated focus groups with pre-ART and ART clients at the HIV Clinic at Arba Minch to understand PLHIV experiences with HIV care, particularly factors that affect retention in care. Focus group participants identified several barriers, including client-related barriers (e.g., misunderstanding of treatment, drug or alcohol use, experience of side effects potentially from prophylaxis drugs or treatment); clinic-related barriers (e.g., client-provider interaction, crowded facilities); social-related (e.g., stigma or lack of support); and contextual and resource-related barriers (e.g., distance to the clinic, competing work priorities, lack of money). Nearly all participants cited social barriers. Based on this research, the authors are implementing a community-based intervention in Arba Minch, aiming to improve retention rates in HIV care. In this intervention, each HIV-positive client is matched with a community adherence support worker (CASW), many of whom are PLHIV and provide client education, counseling (including nutrition counseling), and social support. The CASWs are equipped with mobile phones to communicate with clients and regularly meet with clinic staff. The authors are currently evaluating the community-based intervention (Lifson et al. 2012).

Kenya
Similar to other country findings, retention in pre-ART care is often poor in Kenya, resulting in high attrition. Ensuring client tracking systems or other measures are utilized to reduce client attrition in HIV care is critical (Billingsley et al. 2012; Tayler-Smith et al. 2011). Providing co-trimoxazole prophylaxis to PLHIV, specifically for clients not eligible for ART, is an intervention used in some health facilities (Kohler et al. 2011; Hassan et al. 2012). Kohler et al. (2011) found that providing
free co-trimoxazole prophylaxis for ART-ineligible clients significantly improved retention rates. Clients who were ineligible for ART prior to the intervention were twice as likely to be lost to follow-up as compared with those receiving co-trimoxazole (Kohler et al. 2011). In a rural district hospital, clients ineligible for ART received co-trimoxazole prophylaxis and were monitored every two months. However, 178 clients (33 percent) were lost to follow-up. Being single and residing far from the facility were also associated with higher rates of LTFU (Hassan et al. 2012).

Tayler-Smith et al. (2011) facilitated a cross-sectional study of routine data collected (January 2005-November 2008) on PLHIV eligible for ART at three primary care clinics in Kibera and described factors associated with attrition in care prior to starting ART. Attrition pre-ART included all patients who died in this stage or were lost to follow-up (a client who had not returned to the facility one month or more after scheduled appointment). Tracing systems were only enacted for clients already on ART; there was no tracing system for pre-ART clients. Of 2,471 ART eligible clients, 18 percent were lost to attrition prior to ART initiation, with the majority lost to follow-up. Results indicated that being younger than 35 years old and having an opportunistic infection were associated with attrition; addressing early attrition is critical to improving outcomes (Tayler-Smith et al. 2011). In a large cohort study of adults eligible for ART (n=3633) in Kibera, 77 percent of clients went through the preparation (pre-ART) phase and started ART, yet 15 percent were lost to follow-up in the pre-ART stage. Program implementers need to ensure active tracking systems are used for both pre-ART and ART clients (Zachariah et al. 2011).

While most research has focused on client-level or social factors that affect linkages and retention in care, in one study, a mixed-methods approach mapped critical points in HIV care at the facility level at a hospital’s HIV treatment clinic in central Kenya (Billingsley et al. 2012). Seven linkage points before ART initiation were identified, from testing positive to staging and pre-ART care for ineligible clients. Successful linkages before registering into ART programs are very important, yet poorly understood. Integrated client tracking systems are necessary to improve linkage and retention in care, especially in resource poor settings (Billingsley et al. 2012).

Malawi

The Malawi HIV and AIDS Extended National Action Framework (2010-2012) emphasizes the need for pre-ART care for all PLHIV to complement scale-up of ART. One objective is to increase capacity of sites in Malawi equipped for pre-ART and ART, in addition to providing quality pre-ART care (National AIDS Commission 2009). In rural Malawi, one study suggested that half of HIV-positive clients discontinued pre-ART care within one month of program inclusion, and that only approximately 60 percent of clients had a recorded CD4 count. Mortality rates were also high. Reasons for discontinuing care included dissatisfaction with pre-ART care or health care staff behaviors, stigma, limited knowledge about HIV treatment, and transportation costs (McGuire et al. 2010). Successful linkage to care may depend on a client’s ART eligibility at the time of HIV diagnosis. According to MacPherson et al. (2012), results of a prospective cohort study of newly identified HIV-positive adults (n=280) at the primary care level found linkage to ART high among clients immediately evaluated for ART eligibility (same-day) and found ART-eligible, compared with those who were not assessed the same day. Further, in a large cohort study of adults eligible for ART (n=11,309) in rural Malawi, 74 percent of HIV clients went through a preparation stage and started ART. However, 23 percent (2,649) of clients were lost to follow-up during the pre-ART stage; being male, younger than 35 years old, having advanced HIV/AIDS, and malnutrition were associated with attrition before initiating ART. While attrition was substantial prior to starting ART, programs often only track attrition after clients start ART. Authors suggest identifying a
standardized definition for LTFU in the pre-ART stage, keeping records of those who return for appointments, and implementing tracing systems for all clients (Zachariah et al. 2011).

One intervention was identified related to tracking clients and retention in care for PLHIV in Malawi. “Call to Action” provides postpartum CD4 testing at a prevention of mother-to-child transmission (PMTCT) site for women who are HIV-positive, yet not eligible for ART. Information and emotional support received through counseling were identified as critical for successful provision of repeat CD4 count testing (Gilles et al. 2011). Strategies are needed to empower HIV positive clients and introduce task shifting to reduce health care workers’ workload burden (McGuire et al. 2010). These interventions are likely also relevant to the general adult population.

Mozambique
A partnership framework between the Government of the Republic of Mozambique and the United States Government to support the national HIV/AIDS response (2009-13) in Mozambique includes objectives to strengthen pre-ART care, including providing basic care, tracking systems, and promoting retention in care (PEPFAR 2010). However, the desk review identified limited literature about pre-ART in Mozambique. In an observational cohort study in primary care clinics, POC CD4 count testing was implemented, and findings found it improved clients’ retention rates before initiation of ART, likely due to less time between enrollment and completion of staging. POC CD4 testing identified more clients eligible for and, thus, initiating ART (Jani 2011). Timely CD4 testing, in addition to POC testing, is necessary to improve retention in pre-ART care (Lahuerta et al. 2012). Employing electronic tracking systems (ETSs) may also improve data collection of clients in HIV care. While not specific to pre-ART clients, ETSs used to collect and manage data for clients receiving HIV treatment in central Mozambique were found very accurate in comparison with paper records (Lambdin et al. 2012). Médecins San Frontières and provincial leaders in Tete Province implemented an ART distribution, adherence support, and monitoring program led by community ART groups (CAG). CAG patients were responsible for facilitating monthly ART distribution to other members, offering adherence and social support, monitoring outcomes, and ensuring each member attended a clinical appointment at least every six months. Of the patients that remained in the CAG between February 2008 and May 2010 (n=1,301), over 97 percent remained in care. While primarily relevant for patients on ART, some patients ineligible for ART joined monthly meetings and benefited from peer support and education, which may help improve pre-ART retention in care. Future steps will determine how this approach can be applied across the HIV care and treatment cascade (Decroo et al. 2011).

Namibia
While pre-ART services are not standardized in Namibia, the importance of pre-ART services is recognized (Namibia Ministry of Health and Social Services 2010). Pre-ART services vary both operationally and by care and support provision. A majority of facilities implement pre-ART care integrated with ART (i.e., in the same setting), while others offer stand-alone services. Additionally, pre-ART services vary from completing a register to offering comprehensive psychosocial care. The only stand-alone pre-ART facility, at Oshakati Hospital, was found essential in improving quality of client care. Limited human resources and poor infrastructure, among other factors, are associated with poor retention in pre-ART care. Namibia aims to improve quality of care for PLHIV prior to starting ART, and to increase the percentage of PLHIV retained in pre-ART care until eligible for ART to 80 percent by 2012/13 and to 90 percent by 2015/16 (Namibia Ministry of Health and Social Services 2010).
Rwanda
The desk review found limited literature on pre-ART retention in care for Rwanda. The “Rwanda National Strategic Plan on HIV and AIDS, 2009-2012,” defines key targets to maintain quality in HIV treatment, including ensuring that PLHIV receive social and psychosocial care and support (National AIDS Control Commission 2009). Retaining PLHIV ineligible for ART in care was not a defined outcome in the Strategic Plan. Data collected on clients diagnosed with HIV from March to May 2009 in eight health facilities found that of 482 clients diagnosed with HIV, less than 50 percent enrolled into HIV care and treatment within 90 days, and of these clients, only 48 percent were immediately eligible to start ART. Strategic efforts to improve pre-ART care and retention are critical (Kayigamba et al. 2012).

In a study of Rwandan female sex workers who were tested for HIV (n=800), those who tested HIV-positive (n=192) were referred to care (i.e., given instructions to return to the clinic in two weeks for CD4 count testing then referred to health center for treatment eligibility). The women were invited to return at least one year following diagnosis to evaluate linkage to care and treatment experiences. One hundred forty one women returned for the follow-up study, all of whom were referred for care and treatment eligibility. Of these women, 85 percent reported they had enrolled in care. Perceived good health or a high CD4 count, or believing care was unnecessary, were the most common reasons for not enrolling in care (Braunstein et al. 2011).

South Africa
Although published evidence on pre-ART care remains generally limited in sub-Saharan Africa, greater evidence was found for South Africa. Overall, desk review findings suggest retention in pre-ART care in South Africa is poor and data is not routinely collected. Pre-ART is considered a “broken link” in many health care programs (Govindasamy, 2012; Larson et al., 2010; Lessells et al., 2011; Scott et al., 2011). However, the National HIV Guidelines in South Africa recommend a wellness program for those not yet eligible for ART (Govindasamy et al., 2011). Pre-ART services in South Africa vary. Faal et al. (2011) found poor enrollment rates into ART programs for clients who required pre-ART care (ineligible for treatment). Immediate knowledge of CD4 count did not increase client enrollment in further care. In a rural setting (KwaZulu-Natal, South Africa), the pre-ART services at the clinics include: counseling, advice on healthy living, encouragement of disclosure, partner notification and testing, risk reduction, and family planning services; clients were also invited to join peer support groups at the clinics (Lessells et al., 2011). However, not utilizing POC CD4 count testing, clients were expected to return for results two-weeks post testing. Less than half of clients returned for subsequent CD4 count testing within 13 months. Similar to other pre-ART retention evidence in the region, males and younger cohorts were less likely to be retained in care in rural South Africa (Lessells et al., 2011). Among ART-ineligible clients from four primary health care clinics in KwaZulu-Natal, South Africa identified common barriers to pre-ART care including: misinformation about treatment; limited perceived social support for attending the clinic; community stigma; and wait times and transportation costs. Perceived barriers differed by clinic, indicating that clinic-specific interventions are needed to improve pre-ART care (Smith et al. 2012).

In a large public health care clinic in Johannesburg, 69 percent of clients who were registered in pre-ART care did not return to follow-up medical appointments within one year, impeding monitoring disease progress to initiate eligible clients on treatment in a timely manner and improve clinical outcomes (Larson et al. 2010). In most public primary care services in Cape Town, South Africa, the
pre-ART care phase is defined, yet not fully applied. Pre-ART services in these facilities still included prevention, early detection, monitoring of ART eligibility, and social services, yet there is poor continuity and limited programmatic support (Scott et al. 2011).

A few interventions have been implemented in South Africa in an effort to improve retention of PLHIV in pre-ART care. Strategies included employing lay counselors to track LTFU clients; mobile HTC and CD4 count testing; additional counselor training; client support programs; co-trimoxazole prophylaxis; and periodic audits of health facilities (Diesel et al., 2012; Clouse et al., 2012; Tembo et al., 2012; Jones et al., 2012; Myer et al., 2012; Scott et al., 2011). Training and sending lay counselors to track LTFU clients in the Eastern Cape, South Africa was determined as a feasible and cost-effective measure to trace clients. Almost half of the defaulting clients reported attending specialized HIV clinics; however, despite approximately 20 percent returning for a follow-up visit within six weeks, 10 percent did not return to care (Jones et al., 2012).

With HIV testing and counseling (HTC) services and HIV treatment services in the same location, nearly 78 percent of newly diagnosed HIV positive clients had a CD4 count, however, only 47 percent were clinically staged because this step occurs in pre-ART care phase (Scott et al. 2011). Following a mobile HIV testing program, individuals who tested HIV positive received a referral letter to a health care provider to initiate HIV care. CD4 count results were delivered to clients by phone or home visits, or alternatively, a letter was sent if not reached by the previous methods. Of 192 individuals, nearly 73 percent received CD4 count results; among these clients, just over half accessed HIV care. A majority of these clients reported that the referral letter assisted their linkage to care. Factors associated with receiving a CD4 count result were being a woman, having access to a cell phone, and a lower CD4 count (Govindasamy 2011). An integrated HIV and TB mobile service in Musina, South Africa for migrant farm workers provided CD4 count testing to assess ART eligibility. Eighty-one percent of 594 clients received their results. Mobile HIV care improved pre-ART retention in care, which may be associated with no transportation costs and not losing pay to take time off of work. Matambo et al. (2012) suggest that providing POC CD4 testing will further enhance pre-ART care.

South African HIV guidelines recommend co-trimoxazole for clients with a CD4 count ≤ 200 or WHO stages II, III, or IV. Clouse et al. (2012) evaluated the effect of co-trimoxazole on ART initiation within the first year (following CD4 count and staging) at primary health care sites in Johannesburg. Of 491 clients who initiated co-trimoxazole, approximately 96 percent later enrolled in ART; however, 91 percent of clients who did not initiate co-trimoxazole (138 of 151) did not later initiate ART (three-quarters were lost to follow up and 17 percent died). Co-trimoxazole may improve client retention and probability of initiated ART, and may be a cost-effective intervention to improve retention (Clouse et al., 2012).

The Integrated Access to Care and Treatment Program (I ACT) was implemented in 2009 in the Eastern Cape, South Africa, to promote referral and retention of newly diagnosed PLHIV by providing support programs led by trained PLHIV volunteers. Trainers used a curriculum on HIV, TB, treatment, prevention, stigma and disclosure, and positive living through employing adult learning principles and interactive techniques. Participation increased from 10,435 to nearly 19,900 from 2009/10 to 2010/11. Generally, 25-49 year old women were most likely to complete the program. The I ACT program may contribute to early linkage and retention in HIV care and further scale-up is being considered (Diesel et al., 2012).
**Swaziland**

According to the “National Strategic Framework for HIV and AIDS, 2009-2014,” Swaziland aims to strengthen pre-ART programs, of which many are in initial stages. Only seven facilities consistently report on pre-ART services and no monitoring system exists to track clients. Linkage from HTC to care and treatment is poor. To improve pre-ART services and retention in care, Swaziland aims to deliver a comprehensive pre-ART program and has set objectives to retain more clients in care (National Emergency Response Council on HIV/AIDS 2009). Few published studies about pre-ART in Swaziland were identified. A comprehensive, nurse-led pre-ART care intervention in a district hospital in Swaziland was assessed for impact on the quality of care. The intervention’s goals were to provide comprehensive care, active follow-up of clients, and task-shifting of responsibilities for pre-ART care. The intervention included counseling, regular review, clinical staging, early ART initiation, psychosocial support, and prevention and management of opportunistic infections; additionally, three registers were included specific to pre-ART care. Prior to the intervention, a third of clients did not return to collect CD4 counts and many clients initiated ART in advanced stages of the disease. Following implementation, a greater proportion of HIV clients were assessed for ART; in which a greater proportion of those eligible began ART and more received pre-ART care (Burtle et al., 2012). Task shifting to nurses and lay counselors improved the client linkage and cost effectiveness in a resource limited setting (Burtle et al., 2012).

**Tanzania**

HIV services in Tanzania track clients in pre-ART using registers to monitor progress (Tanzania National AIDS Programme 2012). Loss to follow-up among pre-ART was assessed by reviewing adult client data from 42 clinics in five regions and from five annual site assessments (2005-2011). Client records were reviewed by ART eligibility or unknown eligibility (missing WHO stage or CD4 count). Among nearly 36,000 pre-ART clients enrolled in June 2010, 38 percent of unknown eligibility was lost to follow-up after one year (27 percent of ART-ineligible and 19 percent ART-eligible). Support, peer education, and community outreach at facilities were associated with lower LTFU rates. Many clients were lost to follow-up before ART eligibility was determined; ART-ineligible clients had higher LTFU rates than ART-eligible clients, highlighting a need to determine eligibility early and provide quality care (Kovacs et al. 2012).

**Uganda**

Comparable to previous county findings, high rates of LTFU occur among pre-ART clients in Uganda (Muhamadi et al. 2010; Lubega et al. 2010; Scheibe et al. 2012). Lack of incentives for PLHIV and health care workers, long waiting times at health clinics, and inadequate counseling were associated with late ART initiation (Muhamadi et al. 2010) and a high drop-out rate of pre-ART care (Lubega et al. 2010). Additionally, high attrition rates in pre-ART care in eastern Uganda were also related to competition with traditional healers, transport costs and gender inequality; however, quality counseling was motivation to return to care (Lubega et al. 2010, Muhamadi et al. 2011a). Increasing the number of health care workers with counseling skills, specifically in pre-ART care has been identified as necessary to improve retention (Lubega et al. 2010). However, in an analysis of a prospective cohort of clients initiating ART, pre-ART counseling did not significantly benefit clients, compared with those who received counseling on the same day as beginning treatment. Authors agree in the importance of counseling clients, yet suggest that it should not delay initiating treatment, especially for those with advanced HIV and because pre-ART attrition is high (Siedner et al. 2012).

In a community-based ART program, pre-ART care was found associated with risk of dropping out of care. The pre-ART care included multiple mandatory counseling sessions, disclosure of HIV status to family, support through a community treatment support, and signing a treatment
agreement. While client tracing was adapted to include pre-ART clients, clients described the program as too lengthy and demanding (Alamo et al. 2012). In a cross-sectional retrospective study that assessed barriers to women in Kampala encounter accessing HIV care, one factor was the delay between testing HIV positive and seeking treatment. Women may return or enrolled for care only when symptomatic (McGrath et al. 2012).

With the evidence of poor pre-ART care and poor retention rates in care, some programs and interventions to address these issues were implemented. In a randomized controlled trial to assess the effectiveness of pre-ART care in eastern Uganda, HIV-positive clients (n=400) were assigned into the standard care—post-test counseling with clinic staff, lacking basic counseling skills—or counseling with trained counselors (the intervention). The intervention also included monthly home visits by community support agents to provide further counseling. Clients in the intervention were 80 percent more likely to accept and/or return for pre-ART care (Muhamadi et al. 2011b). A socioeconomic support, community-based ART program in Uganda, Reach Out Mbuya (ROM), was evaluated using data from 2001-2010. Support options included school fees, money for rent or providing housing, employment at ROM, interest-free loans, adult literacy education, income-generating activities, transport, skills-building activities, and food assistance. Community health workers intensively followed up and traced pre-ART and ART clients; no significant differences in LTFU between the pre-ART and ART groups were identified. However, pre-ART clients were 1.4 times more likely to die than ART clients. LTFU or death was significantly higher in clients receiving no support interventions, compared with those who received some support (Talisuna-Alamo S. et al. 2012).

Client data for children from three hospitals in Uganda’s National Pediatric ART Program were randomly selected to assess continuity of care. Retention for pre-ART children was 45 percent, compared with 80 percent among ART clients; one-third of pre-ART loss to follow-up occurred during the first six months. LTFU was associated with disjointed clinical care, poor linkage and data management, inadequate knowledge of health care workers, among others. Following these findings, interventions have been implemented to address gaps in care, including revising training curricula, data tools and job aids, and implementing phone follow up and improving pre-ART services (Elyanu et al. 2012).

**Zambia**

Zambia’s National AIDS Strategic Framework (2011-2015) aims to improve referral systems within HIV services, specifically to refer PLHIV who are ineligible for ART to pre-ART care. Pre-ART services include: screening and treating opportunistic infections, prophylaxis, education about treatment, counseling (including for nutrition) and viral load monitoring (Zambia National AIDS Council 2010). Limited published literature about pre-ART services in Zambia was found in the desk review. While only one published article was obtained, two abstracts were found relevant to pre-ART care. In Zambia, retaining clients in care was prioritized, particularly since HIV services were decentralized in 2007 (Utsushikawa et al. 2012). In a retrospective study of 146 clients enrolled into HIV care in Kalomo district, nearly 40 percent were enrolled into pre-ART care. Client retention was poor; non-disclosure of HIV status to a close family member, partner, or friend was associated with loss to follow-up when compared with those who disclosed their status. Time and financial constraints were reported as reasons for loss to follow-up. Pre-ART retention was poor even though services were close to the community. Further, in a comparative analysis of HIV service at rural health center and district hospital in rural Zambia, Miyano et al. (2012) found that retention in pre-ART care was poorer in the rural health center compared with the district hospital. However, client retention once on ART was comparable at the sites. Time from diagnosis to
enrollment in care was longer in the rural health center. Even without a laboratory, a greater number of CD4 counts were measured at the rural center (Miyano et al. 2012). HIV care, pre-ART, and ART, require standardization at all health facilities.

**Zimbabwe**

In Zimbabwe, PLHIV enrolled in pre-ART and ART programs are considered priority populations in the National HIV and AIDS Strategic Plan 2011-2015. The strategy indicates the following pre-ART services: screening and treating opportunistic infections, prophylaxis, viral load monitoring, education on treatment, and psychosocial and nutritional support (Zimbabwe National AIDS Council 2011). Limited published evidence was identified from the desk review. While not specific to pre-ART care, Mtapuri-Zinyowera et al. (2010) assessed same-day POC CD4 testing and voluntary testing and counseling centers in Harare. Both nurses and laboratory technicians performed the tests accurately. Results demonstrated that POC CD4 testing and staging HIV clients can be facilitated in these settings. Because POC CD4 testing yields immediate results and decision-making, it may also increase linkage and retention in HIV care (Mtapuri-Zinyowera et al. 2010).
SURVEY ON PRE-ART RETENTION ACTIVITIES

DESIGN

The survey questions sought to elicit information regarding challenges to retention in pre-ART care, possible solutions to those challenges, and best practices identified in participants’ settings. Questions for the survey and interviews, and answer options for the close-ended online survey drew from the discussions and evidence presented at the 2010 Maputo Retention Meeting. The online survey contained 17 questions, including closed and open-ended questions about pre-ART care. The follow up interview contained 14 open-ended questions that built on the online survey responses to provide additional qualitative information. While the survey and interview tools were focused on pre-ART, some respondents interchanged the concepts, pre-ART and ART, and there are common elements of both in the pre-ART and ART phases of the continuum of care.

PARTICIPANTS

Twenty-seven respondents from eleven countries (Ethiopia, Lesotho, Malawi, Mozambique, Namibia, Rwanda, South Africa, Swaziland, Tanzania, Zambia, and Zimbabwe) participated in the online survey. To gather more information on the programs implemented in these countries, survey respondents were asked to participate in follow-up interviews. Countries were prioritized for interviews based on the desk review. Interviews were conducted with representatives from five countries (Lesotho, Rwanda, South Africa, Zambia, and Zimbabwe).

Participants represented PEPFAR agencies, ministries of health, and implementing partners. Four PEPFAR agencies, the U.S. Agency for International Development (USAID), the Centers for Disease Control and Prevention (CDC), the Department of Defense (DOD), and the Office of the Global AIDS Coordinator (OGAC) participated. With the exception of Zambia, a PEPFAR agency from each participating country provided input.

RESULTS

Challenges to Retention

Challenges to retention in pre-ART HIV care were grouped into three overarching categories: human resource (HR) challenges, logistical challenges, and commodities challenges. Lack of financial resources was a common challenge across these three areas, but other trends across multiple countries also emerged. These challenges tend to be greater in rural areas, with HIV services in urban areas better resourced and organized.

The most common challenges identified to retaining clients in pre-ART HIV care were: 1) lack of trained staff or staff attrition, 2) stigma in the communities where clients live, and 3) lack of financial resources. Nine of the eleven countries reported these challenges. Seven of the eleven participating countries reported stigma in healthcare facilities and lack of support for HIV care services among community or traditional leaders.
Staff challenges varied across the participating countries, but there were some common themes regarding challenges in retaining trained staff and linking staff in different components of the HIV care continuum. Lesotho reported a lack of policies to retain staff once they have been trained. Tanzania also reported issues with staff attrition after training, as well as a lack of motivation to implement the knowledge and skills imparted during training. South Africa suggested that poor HR infrastructure overall contributes to the challenges of retention in HIV care. Rwanda and South Africa also indicated clinic staff have competing priorities and possibly focus more on the ART patients. Malawi, South Africa, and Tanzania specified that staff shortages affect community outreach programs, with a lack of staff to follow up on defaulter clients in the communities where they live and poor coordination between facility-based and community-based staff.

<table>
<thead>
<tr>
<th>Human Resource Challenges to Retention</th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
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</thead>
<tbody>
<tr>
<td>Lack of trained staff or staff attrition</td>
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<tr>
<td>Stigma in healthcare facilities</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>Stigma in communities where clients live</td>
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<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Lack of support for HIV care services among community/traditional leaders</td>
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<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Lack of financial resources</td>
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<td>X</td>
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<tr>
<td>Other human resource challenges</td>
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<td>X</td>
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</table>

Related to the challenge of having too few or poorly coordinated staff to follow up with clients, especially in the community, was the challenge of lacking or inadequate client tracking systems. Ethiopia specified that they do not have tools to track pre-ART care clients and that pre-ART clients do not receive unique identifier numbers. Lesotho and South Africa described challenges with tracking highly mobile clients who migrate frequently for work. South Africa reported difficulties with the pre-ART registers currently in use—the baseline information is not collected as staff members face competing priorities, and subsequently do not follow up on this information. South Africa also reported poor referral systems between communities and facilities as a challenge, with pre-ART care poorly defined and scarce tracking systems at the community level. Problems with referral systems between HTC programs, communities, and facilities in Tanzania stem from their vertical design and independent reporting requirements.

Transport was a logistical challenge reported by most (nine of eleven) countries. Client transport was a challenge, as clients experienced difficulties attending routine visits in facilities, either form a lack of resources to pay for transport or because they live in rural areas and must travel long distances over difficult terrain to reach the facility. Transport was also reported to be an issue for laboratory testing and supplies. Ethiopia, Lesotho, South Africa, and Tanzania all specified challenges with transporting specimens from facilities with inadequate or with no laboratory testing equipment to other facilities. Delays in specimen transport or analysis lead to longer wait times for test results for clients which may create the need for additional clinic visits, burdening clients and creating additional opportunities for missed appointments, as well as potentially impacting clinical care.
decisions. An additional logistical challenge was described by a participant from Zimbabwe—facilities lack space to accommodate their client loads. Many clinics were built to serve a smaller client population, and there is little support to expand the physical space needed to attend to clients.

<table>
<thead>
<tr>
<th>Logistical Challenges to Retention</th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
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<tbody>
<tr>
<td>Lack of transport to clinics</td>
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<tr>
<td>Lack of pre-ART service availability at lower-level (primary or secondary level) facilities</td>
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<td></td>
<td></td>
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<tr>
<td>Lack of infrastructure or equipment</td>
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<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Lack of or inadequate client tracking systems</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>Lack of financial resources</td>
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<tr>
<td>Other logistical challenges</td>
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</table>

Nine participating countries reported problems with infrastructure or equipment as a challenge to retention. CD4 testing was reported to be particularly problematic, as facilities were reported to lack the necessary equipment to perform the CD4 counts, or if equipment was in place, it was often nonfunctional. Transporting commodities to facilities was reported as challenging. Having to travel for laboratory testing—or re-testing, in the case of malfunctioning equipment—contributed to transport challenges for clients. Although HIV services may be free for clients, laboratory testing often comes with a cost. Zimbabwe noted the challenge that user fees created for PLHIV to have laboratory work or paperwork processed.

Maintaining adequate supply of laboratory reagents was a common difficulty. Nine of eleven countries reported shortages or stockouts of medical or laboratory supplies as a challenge to retention. Shortages or stockouts of other commodities, including other medications such as co-trimoxazole and supplies such as mosquito nets, were also challenges reported by five and eight countries, respectively. Other examples of common shortages or stockouts included nutritional supplements and medications to treat tuberculosis in South Africa and home-based testing kits in Tanzania. A participant from Zambia noted that nutrition services overall are a challenge.

<table>
<thead>
<tr>
<th>Commodities Challenges to Retention</th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
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</thead>
<tbody>
<tr>
<td>Shortages or stockout of medical and laboratory supplies</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
</tr>
<tr>
<td>Shortages of other care and support medications (e.g. co-trimoxazole, pain medications)</td>
<td>X</td>
<td>X</td>
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Commodities Challenges to Retention

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<tr>
<th></th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
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<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shortages or stockouts of care and support commodities (e.g., mosquito nets, soap, and other WASH commodities)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Other human resource challenges</td>
<td>X</td>
<td>X</td>
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</table>

It is noteworthy that respondents from Namibia and Rwanda did not indicate commodities challenges to retention in ART care. The one commodity challenge reported by a respondent from Namibia was the occasional shortage of home-based care kit used in community outreach programs based out of primary healthcare facilities.

Practices to Overcome Challenges to Retention

Programs are implementing a variety of practices to overcome challenges to retention in pre-ART HIV care. Survey respondents noted that for the majority of the practices in place, they are still being implemented as pilot activities and need to be scaled up, with appropriate resources and stakeholder support.

Three practices reported to overcome human resource challenges in retention were reported by most countries participating in the survey: 1) task shifting, 2) use of community-based health workers, and 3) use of peer educators in client education and service provision. An example of task shifting was described by a participant from Zimbabwe: primary care counselors now have the authority to provide HIV services, increasing the opportunities for testing and linkages to care.

Giving peers a role in programming was common, with eight countries reporting use of peers in education or service provision. The I ACT (Integrated Access to Care and Treatment) program in South Africa is improving linkages between PLHIV by bringing peer groups together to create a community of support. It was initially developed by the CDC, but the South Africa National Department of Health is currently adapting the program with the hopes of bringing it to scale nationwide. The Médecins Sans Frontières (MSF) program in Malawi has adapted their model for community-based ART support groups originally implemented in Mozambique.

1 More information can be found on the I ACT website: [http://www.iactsupport.org/](http://www.iactsupport.org/)
<table>
<thead>
<tr>
<th>Human Resource Practices to Overcome Challenges to Retention</th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
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</thead>
<tbody>
<tr>
<td>Task shifting in clinics</td>
<td>X</td>
<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td></td>
</tr>
<tr>
<td>Use of community-based health workers</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Informational campaigns to decrease HIV stigma</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Use of peer educators in client education and service provision</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Collaboration with traditional leaders in the community</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Other human resource practices</td>
<td>X</td>
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</tbody>
</table>

Most countries (nine of eleven) also reported using informational campaigns to decrease HIV stigma. Collaboration with traditional leaders in the community was reported by seven countries. An example of another type of human resource practices: support for staff is taking place in Malawi, with pharmacy managers at the health center and district hospital levels receiving mentoring. South Africa elaborated on these human resource practices, cautioning that many of these activities are being led by poorly resourced CBOs.

<table>
<thead>
<tr>
<th>Community-based Practices to Overcome Challenges to Retention</th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of community-based volunteers and/or community-based health workers</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
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</tr>
<tr>
<td>Education campaigns on care and support activities in the community</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
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</tr>
<tr>
<td>Increased involvement of PLHIV</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community-based approaches to improve retention</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other community-based practices</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
</tbody>
</table>

All but one participating country (Zambia) reported client literacy and education as a practice being implemented to overcome challenges in retention. Nutritional programming was another common client-oriented practice, reported by participants from nine countries. Eight countries reported income generating activities and seven countries reported legal and child protection programming.
## Client-oriented Practices to Overcome Challenges to Retention

<table>
<thead>
<tr>
<th></th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income generating activities</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutritional programming</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal and child protection programming</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client literacy and education</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client satisfaction evaluations</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other client-oriented practices</td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Only three countries, Ethiopia, Lesotho, and Namibia reported use of client satisfaction evaluations, although several participants commented that quality improvement and client satisfaction should be areas of focus. In Namibia, part of the HIV Qual intervention includes a consumer forum to solicit client perspectives on the quality of services. PEPFAR has supported programs in Rwanda to incorporate quality improvement into services, an activity that is being transitioned to the MOH. In participating sites, retention has improved to over 90 percent after one year. In Lesotho and Swaziland, discussions are underway for mothers2mothers to examine the quality of counseling pregnant mothers received in their programs.

All participating countries reported using community-based volunteers and/or health workers and most (ten of eleven) reported some other type of community-based approach to improving retention. All countries except Rwanda reported increased involvement of PLHIV and most (nine of eleven) reported educational campaigns on care and support activities in the community. Countries are making efforts to best match peer counselors and educators as possible; for example, in Lesotho, peer educators in the military community are providing outreach. The National African Patients Living with HIV is a network throughout the Southern African region that provides support as people move around the area. Participants noted that community-based activities need to be better resourced and organized.

To strengthen the linkages between facilities and communities, lay counselors provide adherence and retention support in clinics in Namibia. Ethiopia is working to strengthen the referral system between community-based organizations, faith-based organizations, and facilities; this may lead to improved pre-ART care at the community level. In Tanzania, home-based care volunteers are also placed in facilities, and a comprehensive care package to link clinical (facility-based) and community-based care has been designed, while a joint linkage strategy between facilities and communities is under development to reduce loss to follow up and increase adherence. In South Africa, a network of hospices connects to a parent organization (facility) to provide home-based care, and community health workers are being trained to deliver services such as nutritional counseling. However, the client load is often very high and this may affect the quality of services delivered.

Logistical practices to overcome challenges to retention were also characterized as poorly coordinated, but more limited than community-based practices. Although in some cases other participants from their countries responded differently, participants from Ethiopia, Namibia, South Africa, and Zambia indicated that programs in their settings were not implementing any logistical practices to overcome retention challenges.
All countries except Ethiopia reported use of new technology. Mobile phones are being used to send appointment reminders and to improve referrals. Programs in Namibia are using phone calls to follow up with mother-baby pairs in the post-natal period to improve their retention in care. In Malawi, programs are calling clients to remind them of appointments. Programs in Lesotho will send an SMS to clients to remind them of appointments. If the client doesn’t respond, the program will reach out to a “buddy” to help track down the client and follow up.

Countries are working to address challenges related to monitoring and evaluation. Lesotho is working to standardize referral forms and the monitoring and evaluation (M&E) tools used in the community. They are also using an Electronic Monitoring Record (EMR) to follow up on clients. When a client misses an appointment, the system alerts clinic staff so they may know to follow up with him or her. Zimbabwe is also working on improving the tools used to track pre-ART clients, with registers called “waiting lists” at facilities for PLHIV who are not yet on treatment.

Other logistical practices to overcome challenges to retention addressed various issues. Malawi is piloting a motorbike transport system for lab results and POC CD4 counts. In Mozambique, a MOH pilot activity is matching PLHIV into groups to take turns picking up their ARVs and other medications at the health facility to help alleviate transportation challenges. South Africa is decentralizing its HIV services and working to strengthen the primary healthcare system to better integrate HIV programs and services. Malawi, South Africa, and Tanzania are providing free or reduced cost transportation to facilitate attendance in clinics. To help address the challenge of space constraints, some clinics in Zimbabwe have dedicated an area of the facility and staff to pre-ART clients. The flexible hours and designated space and personnel have reduced waiting times for clients and encourage them to attend clinics.

All countries but Ethiopia reported POC services as a commodities practice to overcome challenges to retention, and all countries but Lesotho reported using supply chain mechanisms.
Commodities Practices to Overcome Challenges to Retention

<table>
<thead>
<tr>
<th>Commodity Practices to Overcome Challenges to Retention</th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of supply chain mechanisms</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Point-of-care services (e.g., CD4 counts)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Other commodities practices</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

A few overall patterns emerged in the responses to questions about practices to overcome challenges to retention. Practices were often described as new or concentrated within specific programs, with little long-term data regarding effectiveness or impact. Some participants reported that programs in their countries were not employing solutions to overcome challenges to retention. This may highlight a need to strengthen communication within countries and encourage taking promising practices to scale.

**RETENTION BEST PRACTICES**

There was some ambiguity among participants regarding having a strategy related to retention in HIV care. Participants from Malawi, Rwanda, South Africa, Tanzania, and Zambia provided contradictory responses when asked whether their country currently had a strategy related to HIV care, either stand-alone or part of the national strategy.

<table>
<thead>
<tr>
<th>Country</th>
<th>Is there currently a strategy (either stand alone or related to the national strategy) related to pre-ART and/or ART retention in HIV care in your country?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethiopia</td>
<td>Yes: [related to strategies for] case management enacted in 2009 and basic preventive package enacted in 2008</td>
</tr>
<tr>
<td>Lesotho</td>
<td>No</td>
</tr>
<tr>
<td>Malawi</td>
<td>Yes: enacted in 2007</td>
</tr>
<tr>
<td>Mozambique</td>
<td>Yes: enacted in 2011</td>
</tr>
<tr>
<td>Namibia</td>
<td>No</td>
</tr>
<tr>
<td>Rwanda</td>
<td>Yes: [related to strategies for] task shifting enacted in 2011</td>
</tr>
<tr>
<td>South Africa</td>
<td>Yes: year enacted unknown</td>
</tr>
<tr>
<td>Swaziland</td>
<td>Yes: enacted in 2012</td>
</tr>
<tr>
<td>Tanzania</td>
<td>Yes: focus area within the national strategy for the past 3-4 years</td>
</tr>
<tr>
<td>Zambia</td>
<td>Yes: year enacted unknown</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>Yes: enacted in 2010</td>
</tr>
</tbody>
</table>

Participants identified “best practices” in retention in HIV care, although some activities were not reported as being implemented in their respective countries/programs. Three of these best practices were identified in the online survey by all participating countries: 1) point-of-care services, 2) integration of HIV and maternal, neonatal, and child health (MNCH) services, and 3) use of peer educators or counselors. A participant from Malawi reported a standardized package of pre-ART...
care within the national program that includes CPT, IPT, CD4 testing, and tuberculosis screening and a follow-up program for exposed infants (mother-baby pairs).

Nearly 100 percent (10 of 11) of countries identified integration of services, and increasing male involvement in community-based activities as best practices. In Lesotho, programs are working with traditional leaders and decision-makers (e.g., mothers-in-law) to support male involvement in facility-based services, from PMTCT to sexually transmitted infection (STI) clinics. In Zimbabwe, community mobilization and sensitization efforts have contributed to increased health care seeking by men in the communities, diminishing the gender disparity often seen among clients on ART.

<table>
<thead>
<tr>
<th>Best Practices in Retention</th>
<th>Ethiopia</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania</th>
<th>Zambia</th>
<th>Zimbabwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task shifting, including to volunteers</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offer “one-stop-shop” services</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Point-of-care services (e.g., CD4 testing)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Decentralization of services from facilities to communities</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Integration of HIV and MNCH services</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Use of peer educators or counselors (i.e., PLHIV, adolescents)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Ensuring client satisfaction through feedback mechanisms and quality control</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standardizing referral forms and systems</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Bidirectional referrals</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increasing male involvement in community-based care activities</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>Use of SmartCards for HMIS</td>
<td>X</td>
<td></td>
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<td>X</td>
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<td>X</td>
<td>X</td>
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<tr>
<td>Use of SMS or other technology for client reminders (for appointments or medication)</td>
<td>X</td>
<td></td>
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<td></td>
<td></td>
<td>X</td>
<td>X</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other activities</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
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</tr>
</tbody>
</table>

There were some differences between what countries considered to be best practices and the activities they were currently implementing. Without definitions of pre-ART care at the national level and policies to support resources for implementation of care services, it may remain difficult for programs to address the challenges they face in retaining clients in care and implementing best practices.
FUTURE MEETINGS TO IMPROVE RETENTION PROGRAMS

Of the 17 people who answered the question, “Did you find that the Maputo Retention Meeting improved your understanding of key issues involved in linkage and retention?” 15 respondents said “yes.” The two people who responded “unsure” did not attend the meeting; participants overwhelmingly felt the technical consultation contributed to their knowledge of retention issues.

Country teams at the Maputo Retention Meeting created action plans to increase linkage and retention efforts in their countries. Survey participants reported on the retention activities that have been implemented in their settings in the two years since the meeting.

<table>
<thead>
<tr>
<th>Activities Implemented in HIV Pre-ART Care Programs to Improve Retention Since the Maputo Retention Meeting</th>
<th>Ethiopia*</th>
<th>Lesotho</th>
<th>Malawi</th>
<th>Mozambique</th>
<th>Namibia</th>
<th>Rwanda*</th>
<th>South Africa</th>
<th>Swaziland</th>
<th>Tanzania*</th>
<th>Zambia</th>
<th>Zimbabwe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standardization of the package of basic pre-ART care services</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Integration of services (e.g., HIV, MCH, TB)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Prioritization of clients at greater risk for loss to follow up</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strengthening linkages between facilities and communities</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Task shifting in healthcare facilities</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Use of point-of-care services (e.g., CD4 testing)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using technology (e.g., text messaging) for client follow up</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensitization training for providers (e.g., stigma and discrimination)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other activities</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

* Country teams that did not attend the Maputo Retention Meeting.
Survey participants provided suggestions for improving similar technical consultations in the future. In general, participants were keen to see additional programmatic evidence or data from community-based interventions and from programs that have successfully retained their pre-ART clients in care. Another requested topic for future technical consultations was how to incorporate quality improvement, or methodologies for doing so. They suggested follow-up on the recommendations from the meeting; one of the objectives of this survey was to do that. Participants also requested follow-up meetings at regular intervals to maintain momentum and facilitate the exchange of ideas and information. An every-other-year schedule was suggested, with opportunities for ongoing facilitated communication and (south-to-south) technical assistance in the interim.
**RECOMMENDATIONS WITHIN THE FOUR STAGES OF RETENTION IN THE CONTINUUM OF CARE**

The patterns and themes emerging from the desk review and survey and interviews suggest that care programs need to build on progress to date. AIDSTAR-One developed recommendations for improving client retention based on the desk review and survey and interview findings. Challenges to retention in HIV care programs have been recorded, and programs have implemented activities to address these challenges, documenting their success. Based on the experiences of some country programs to date and results from pilot activities, recommendations can be made to strengthen retention throughout the four stages of the continuum of care.

<table>
<thead>
<tr>
<th>Stage 1: From a Positive HIV Test to Enrollment in Care</th>
<th>Additional Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop guidelines and improve strategies to successfully link HIV-positive clients into care.</td>
<td>Policies should support the provision of services that are demonstrating effectiveness in improving linkage to and retention in care, such as POC CD4 testing.</td>
</tr>
<tr>
<td>Standardize the definitions of LTFU and pre-ART care.</td>
<td>Developing a universal definition of LTFU in the pre-ART stage may help focus efforts to track clients before they default. Additionally, pre-ART care should be more systematic and a comprehensive package of services should be available to clients in this stage.</td>
</tr>
<tr>
<td>Improve counseling services for newly-diagnosed HIV-positive clients to offer comprehensive psychosocial support, utilizing peer counselors or community health workers.</td>
<td>Offering disclosure support and peer counseling to clients following diagnosis may provide a cost-effective mechanism to help HIV-positive clients to accept their diagnosis and access care.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 2: From Enrollment in Care to ART Eligibility</th>
<th>Additional Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimize stockouts of commodities and equipment needed for assessing clients’ eligibility for ART, and scale up co-trimoxazole.</td>
<td>Since co-trimoxazole improves client retention and initiation of ART when clients are eligible, ensuring adequate stock will be necessary for improving pre-ART care.</td>
</tr>
<tr>
<td>Employ active monitoring (tracking) strategies for pre-ART clients ineligible for ART both at the facility and in the communities.</td>
<td>Many programs lacked patient-tracking systems for pre-ART clients and only monitored patients who had been initiated on ART. With the high attrition and LTFU rates among pre-ART clients, improving these strategies will be critical to retention in care.</td>
</tr>
<tr>
<td>Ensure timely CD4 testing at the facility level and in the community, if feasible.</td>
<td>As a structural strategy, ensuring timely access to CD4 testing and monitoring may help improve clients’ retention in care and linkage to ART when eligible.</td>
</tr>
<tr>
<td>Recommendation</td>
<td>Additional Considerations</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Stage 3: From ART Eligibility to Initiation on ART</strong></td>
<td></td>
</tr>
<tr>
<td>Utilize client tracking systems, including adapting registers for pre-ART</td>
<td>Many current programs lack tracking systems for pre-ART clients altogether, or their</td>
</tr>
<tr>
<td>patients transitioning to ART.</td>
<td>tracking systems are not systematized. Developing client tracking systems to monitor</td>
</tr>
<tr>
<td></td>
<td>patients, particularly those transitioning into ART, will help improve continuity in</td>
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<td></td>
<td>patient care and data monitoring. Standardizing referral forms designed specifically for</td>
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<td></td>
<td>pre-ART services could help monitor referrals that were followed, and track bidirectional</td>
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<td></td>
<td>referrals between facilities and communities.</td>
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<tr>
<td><strong>Stage 4: Continuation of Lifelong ART</strong></td>
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<tr>
<td>Establish electronic tracking systems (ETS) for all clients in HIV care.</td>
<td>ETS may help improve accurate and complete data collection and quality of care.</td>
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<tr>
<td>Strengthen human resources, recognize new cadres of health workers, and address</td>
<td>Providing additional training, incentives, data tools and job aids for health care</td>
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<tr>
<td>current infrastructure.</td>
<td>workers may help improve retention in HIV care. Providing programmatic support to ensure</td>
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<td></td>
<td>quality may help reduce attrition by other cadres of staff. Using community health</td>
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<td></td>
<td>workers or volunteers in community outreach and client tracking efforts may reduce</td>
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<td></td>
<td>attrition from care programs. Staff and volunteers should receive formal training on the</td>
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<td>new tasks they assume, and be compensated accordingly.</td>
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<tr>
<td>Build on achievements in integration.</td>
<td>Integrating TB testing and treatment, SRH, and other services could provide more of the</td>
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<td>“one-stop shop” approach often preferred by clients. The opportunity to review systems</td>
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<td>can emerge when exploring ways to integrate services and strengthen systems. Sharing</td>
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<td>equipment and commodities as a result of integration may help address the shortages</td>
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<td>experienced by HIV care programs, but improved commodities and logistics management is</td>
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<td>needed to prevent the problem from expanding.</td>
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<td>**Across the Continuum of Care (additional recommendations that span all four</td>
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<tr>
<td>stages)**</td>
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<tr>
<td>Continue implementing client-oriented practices to empower clients and improve</td>
<td>Some programs have recognized the importance of the client perspective in improving</td>
</tr>
<tr>
<td>retention in care.</td>
<td>quality of care. Counseling on specific issues, using treatment buddies, reducing stigma</td>
</tr>
<tr>
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<td>in communities, providing subsidies for transportation to</td>
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</table>
clinics, linking to nutrition and income-generation programs, and creating systems for clients to report feedback on services are ways to keep clients and their needs at the center of programs’ focus. Client literacy activities can empower PLHIV to take a more active role in their own care. Involving PLHIV in program design and management, in addition to including them as peer educators, ensures the voices of PLHIV are heard to identify barriers to their access to care and address their needs.

**Strengthen the community-facility link.**

Improving bidirectional referrals can help clients use complementary activities offered in facilities and communities; it is important clients are aware of and able to access community-based services. Reaching out to traditional and community leaders and implementing education campaigns in communities may help improve support in the community for HIV care and support PLHIV to seek care. Increasing male involvement in HIV programs may increase their support for their family members’ care and also encourage them to seek services, as HIV care and treatment programs remain majority female in many areas.

**Continue to combat stigma.**

In both facilities and communities, stigma against HIV/AIDS and PLHIV persists. Staff should be sensitized and procedures established for violations of non-discrimination policies. Facilities and community-based organizations should have means for clients to report discriminatory experiences, helping make facilities a welcoming place for clients. Sensitization campaigns and outreach activities in communities can help create a more supportive environment and encourage PLHIV to seek care.

**Standardize monitoring and evaluation for pre-ART and ART activities.**

While client tracking systems are more robust in ART programs, many clients are lost to follow-up and documentation of care provided in the community is poor, particularly for pre-ART clients. Improved client tracking systems are urgently needed in many settings. Standardizing the definition of “lost to follow-up” in the pre-ART stage may help focus efforts to track clients before they default. Using new technology (e.g. SMS reminders) and ETS may help improve both client follow-up and the links between facilities and CBOs. With improved documented data from better monitoring of pre-ART care, programs can evaluate their services to ensure they are responding to and meeting clients’ needs in a quality manner.

Programs are already incorporating these activities and strategies in provision of HIV care. Governments and their partners should support improved communications among stakeholders to share experiences. With the appropriate information and planning, promising practices can be taken to scale to improve retention in pre-ART care.
CONCLUSIONS

Challenges to retention in pre-ART HIV care are common across Eastern and Southern Africa. Although smaller-scale activities exist to address these barriers, more support is needed to take them beyond pilot programs and meet demand. Policies and guidelines must strengthen focus on both pre-ART care and treatment activities for ART-eligible clients, to ensure an increasing number of PLHIV access care and support across the continuum and to decrease LTFU.

Many countries are implementing activities to retain clients in pre-ART HIV care. However, the incongruence between activities reported in this survey and the paucity of evidence in the published literature attests to the need to document and evaluate these practices. With knowledge of these experiences, promising practices can be replicated and taken to scale to address the needs of the large number of clients who test HIV positive while linking them to and retaining them in care.

Challenges to retention persist but programs are addressing these challenges and are eager to learn from each other’s experiences. Technical exchange meetings and facilitated communication and technical assistance are promising ways to encourage this sharing of experiences. To minimize loss to follow up and poor health outcomes due to clients accessing care only when they are ill, retention activities need to be strengthened with a focus on the quality of care. Tools and mechanisms developed and tested to improve pre-ART care must be more standardized and shared across programs and countries.
REFERENCES


APPENDIX A

ONLINE SURVEY

Section 1: Demographics and Maputo Retention Meeting November 2010
Attendance/Follow Up

1. Please enter the following information:
   - Name: _________________
   - Title: _________________
   - Agency/organization: _________________
   - Country: _________________

2. I and/or a current member(s) of my PEPFAR country team attended the November 2010 Field Driven Learning Meeting on Linkage to and Retention in Care & Support in Maputo (Maputo Retention Meeting), Mozambique.
   - Yes
   - No (If you check no, then please skip to Question #5 in Section 2)
   - Not sure

3. Did you find that the Maputo retention meeting improved your understanding of key issues involved in linkage and retention?
   - Yes
   - No
   - Unsure

4. In the past two years, HIV pre-ART care programs have improved retention by the following activities in my context that you can attribute to your participation at the Maputo linkage and retention meeting (select all that apply):
   - Standardization of the package of basic pre-ART care services
   - Integration of services (e.g., HIV, MCH, TB)
   - Prioritization of clients at greater risk for loss to follow up
   - Strengthening linkages between facilities and communities
   - Task shifting in healthcare facilities
   - Use of point-of-care services (e.g., CD4 testing)
   - Using technology (e.g., text messaging) for client follow up
   - Sensitization training for providers (e.g. stigma & discrimination)
   - Other activities not mentioned above
     - If applicable, please provide brief description of progress made:

_______________________________________
Section 2: What are Challenges to Retention in HIV Care in Your Context?

5. In my context or setting, programs experience the following human resource challenges to retention in care (select all that apply):
   - Lack of trained staff or staff attrition
   - Stigma in healthcare facilities
   - Stigma in communities where clients live
   - Lack of support for HIV care services among community/traditional leaders
   - Lack of financial resources
   - Other human resource challenges that do not fit into one of the above categories
     - If applicable, please describe briefly:
       ____________________________________________
   - There are no human resource challenges to retention in care

6. In my context or setting, programs experience the following logistical challenges to retention in care (select all that apply):
   - Lack of transport to clinics
   - Lack of pre-ART service availability at lower level (primary or secondary level) facilities
   - Lack of infrastructure or equipment
   - Lack of or inadequate client tracking systems
   - Lack of financial resources
   - Other logistical challenges that do not fit into one of the above categories
     - If applicable, please describe briefly:
       ____________________________________________
   - There are no logistical challenges to retention in care

7. In my context or setting, programs experience the following commodities challenges to retention in care (select all that apply):
   - Shortages or stock-outs of ARVs
   - Shortages or stock out of medical and laboratory supplies
   - Shortages of other care and support medications (e.g. cotrimoxazole, pain medications)
   - Shortages or stock-outs of care and support commodities (e.g., mosquito nets, soap, and other WASH commodities)
   - Other commodities challenges that do not fit into one of the above categories
     - If applicable, please describe briefly:
       ____________________________________________
   - There are no commodities challenges to retention in care
Section 3: What are Current Practices to Overcome Challenges Identified in Your Context?

8. Programs in my context are implementing the following community based practices to overcome challenges to retention in HIV care (select all that apply):
   • Use of community based volunteers and/or community based health workers
   • Education campaigns on care and support activities in the community
   • Increased involvement of PLHIV
   • Community based approaches to improve retention
   • Other solutions that do not fit into one of the above categories
     ○ If applicable, please describe briefly:

   • Programs in my context are not employing any community-based practices to overcome challenges in retention in HIV care.

9. Programs in my context are implementing the following client-oriented practices to overcome challenges to retention in HIV care (select all that apply):
   • Income generating activities
   • Nutritional programming
   • Legal and child protection programming
   • Client literacy and education
   • Client satisfaction evaluations
   • Other solutions that do not fit into one of the above categories
     ○ If applicable, please describe briefly:

   • Programs in my context are not employing any client-oriented practices to overcome challenges in retention in HIV care.

10. Programs in my context are implementing the following human resource practices to overcome challenges to retention in HIV care (select all that apply):
    • Task shifting in clinics
    • Use of community based health workers
    • Informational campaigns to decrease HIV stigma
    • Use of peer educators in client education and service provision
    • Collaboration with traditional leaders in the community
    • Other solutions that do not fit into one of the above categories
      ○ If applicable, please describe briefly:

    • Programs in my context are not employing any human resources practices to overcome challenges in retention in HIV care.

11. Programs in my context are implementing the following logistical practices to overcome challenges to retention in HIV care (select all that apply):
    • Use of new technology (e.g., mobile phones)
    • Free or reduced cost transportation to clinics
    • Other solution that does not fit into one of the above categories
If applicable, please describe briefly:

• Programs are not employing any logistical practices to overcome challenges in retention in HIV care.

12. Programs in my context are implementing the following commodities practices to overcome challenges to retention in HIV care (select all that apply):
• Use of supply chain mechanisms
• Point-of-care services (e.g., CD4 counts)
• Other solution that does not fit into one of the above categories
  o If applicable, please describe briefly:

• Programs are not employing any practices to overcome challenges in retention in HIV care.

13. Are there any other current practices to overcome challenges being implemented in your context not mentioned above? If so, please describe briefly:

Section 4: What are Considered Current Priority Areas for and Best Practices in Retention in HIV Care in Your Context?

14. Is there currently a strategy (either stand alone or related to the national strategy) related to retention in HIV care in your country?
• Yes
  o If yes: When was it enacted?

• No

15. What are considered best practices in retention in care in your context? (select all that apply):
• Task shifting, including to volunteers
• Offer “one-stop-shop” services
• Point-of-care services (e.g., CD4 testing)
• Decentralization of services from facilities to communities
• Integration of HIV and MNCH services
• Use of peer educators or counselors (i.e., PLHIV, adolescents)
• Ensuring client satisfaction through feedback mechanisms and quality control
• Standardizing referral forms and systems
• Bidirectional referrals
• Increasing male involvement in community based care activities
• Use of SmartCards for HMIS
• Use of SMS or other technology for client reminders (for appointments or medication)
Section 5: Future Meetings and Follow Up

16. Please suggest how future meetings such as the Maputo Retention Meeting could be improved to increase their value to meeting participants.

_________________________________________________________________
_________________________________________________________________

17. Would you be willing to participate in a brief (less than 30 minutes) follow-up telephone call to provide additional information to your survey responses? AIDSTAR-One would provide the questions ahead of time to help you prepare and keep the interview time to a minimum, and would contact you on a phone number you provide or via Skype for your convenience.
   o Yes
   o No
APPENDIX B

FOLLOW-UP INTERVIEW QUESTIONNAIRE

Section 1: Demographics and Maputo November 2010 Attendance/Follow Up

1. Please confirm your name, title, and agency/organization. (As applicable, read information from online survey.)

2. What changes have you observed in HIV pre-ART care programs to improve retention in your context since attending the Linkages to and Retention in Care Field-Driven Learning Meeting in Maputo, Mozambique (or if not a attendee of the meeting, since late 2010)?

3. Tell me about how HIV care programs have improved in the past two years in your context.
   • Probe using examples from online survey if needed: integration of services, task shifting, point-of-care services, using peer educators, etc.

4. (Only for Maputo attendees) How did the information learned or connections made at the Maputo 2010 field driven learning meeting support progress in retention in HIV care?
   • Probe: Did you get new resources or materials you could use and/or adapt? (If yes) Which ones?

Section 2: What are Considered Current Priority Areas for Retention in HIV Care in Your Context?

5. Tell me about strategies related to retention in pre-ART HIV care in your country.
   • Probe: Is there a strategy specifically for retention in HIV care?
   • Probe: Please describe the main points of the strategy.
   • Probe: Who is responsible for implementing the strategy?
   • Probe: Has the strategy been implemented successfully? Why or why not? What are some of the challenges to implementation?

6. In your opinion, what are the priority areas for retention in pre-ART HIV care in your context?
   • Probe using examples from online survey if needed: defining the basic package of care services, strengthening linkages between facilities and communities, reducing loss of clients to follow-up, etc.
   • Probe: Who determines these priorities?
   • Probe: Who is responsible for addressing these priorities?
• Probe: How have priorities changed in the past two years?
• Probe: How do priority areas for retention vary in your context? By implementing partner, geographical location, client population (adults, pregnant women, children, adolescents)?

7. In your opinion, please describe any best practices in retention in pre-ART HIV care in your context.
   • Probe using examples from online survey if needed: task shifting, offering “one-stop-shop” services, decentralizing services, etc.
   • Probe: Who identifies these best practices?
   • Probe: How are best practices shared?
   • Probe: How are best practices replicated and/or scaled-up?
   • Probe: How do best practices vary in your context? By implementing partner, geographical location, client population (adults, pregnant women, children, adolescents)?

Section 3: What are Challenges to Retention in HIV Care in Your Context?

8. Tell me about the challenges to retention in pre-ART HIV care in your context.
   • Probe using examples from online survey if needed: lack of trained staff, stigma, lack of infrastructure, etc.
   • Probe: How do challenges vary in your context? By implementing partner, geographical location, client population (adults, pregnant women, children, adolescents)?

9. How are challenges documented?
   • Probe: To whom are challenges reported?
   • Probe: Who takes action to make sure the challenges are addressed?

Section 4: What are Current Practices to Overcome Challenges Identified in Your Context?

10. Tell me about some of the practices currently being implemented to overcome challenges identified in your context.
    • Probe using examples from online survey if needed: client satisfaction evaluations, client literacy campaigns, etc.
    • Probe: Who is implementing these practices?
    • Probe: How do these practices vary in your context? By implementing partner, geographical location, client population (adults, pregnant women, children, adolescents)?

11. Tell me about the documentation of these practices.
    • Probe: Who documents the practices?
    • Probe: Who shares these practices? How do they share them?
12. Tell me about the evaluation of these practices.
   • Probe: Who evaluates the practices?
   • Probe: How are the practices evaluated?
   • Probe: How are practices changed as a result of evaluations?

**Section 5: Technical Assistance Needs**

13. Tell me about any technical assistance needs to improve retention in HIV care and related services.
   • Probe: Regarding what areas of retention in HIV care would you like technical assistance?
   • Probe: What is your impression of the most appropriate agency to provide technical assistance in your setting?

14. Tell me about technical assistance you or colleagues from your context could provide in your region related to improving retention in pre-ART HIV care.
   • Probe: Who would be able to provide this technical assistance? (Names, agencies/organizations.)
   • Probe: Regarding what areas of retention in HIV care could they provide technical assistance?
For more information, please visit aidstar-one.com.