FIELD DRIVEN LEARNING MEETING: LINKAGES TO AND RETENTION IN HIV CARE AND SUPPORT PROGRAMS

HOTEL CARDOSO, MAPUTO, MOZAMBIQUE, NOVEMBER 3–5, 2010

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Abstract
From November 3–5, 2010, the U.S. President's Emergency Plan for AIDS Relief Interagency Care and Support Technical Working Group and AIDSTAR-One project held a meeting in Maputo, Mozambique, on HIV linkages and retention in HIV care and support programs. Technical experts from nine African countries presented their countries' perspectives on linking and retaining people living with HIV in care—specifically, expanding the focus of care from those who have begun antiretroviral therapy to also include those who have been diagnosed but have not yet started, or need, therapy. The meeting emphasized specific populations and services, and the relative roles of health care providers, community volunteers, and other stakeholders. Recurring themes in this expanded view included defining HIV services and focusing on clients' needs and perceptions in delivering care. Participants shared their experiences in developing, implementing, monitoring, and evaluating their programs, identifying barriers/challenges and solutions. Participants from each country used information shared throughout the meeting to develop action plans for their own countries.

This report highlights major themes and findings presented at the meeting. Throughout the report, links are embedded to relevant presentations.

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ACRONYMS

ANC	antenatal care
ART	antiretroviral therapy
CBO	community-based organization
CCW	community care worker
CDC	U.S. Centers for Disease Control and Prevention
GBV	gender-based violence
HTC	HIV testing and counseling
M&E	monitoring and evaluation
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PHE	public health evaluation
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
QI	quality improvement
TB	tuberculosis

EXECUTIVE SUMMARY

Linking and retaining people living with HIV (PLHIV) into facility- and community-based care and support programs has emerged as a priority in all countries under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). To date, programs have 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 but who are not eligible or on ART are also linked to health services and retained in care until they need access to ART. On November 3–5, 2010, the PEPFAR Technical Working Group on HIV Care and Support and AIDSTAR-One convened a meeting on this topic in Maputo, Mozambique. Representatives from nine African countries (Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe) discussed their efforts to achieve broader linkage and retention and shared best practices, challenges, and opportunities to reduce the client attrition that occurs between HIV diagnosis and initiation of ART. This report summarizes the discussions from the meeting.

A common theme emerging from the three-day meeting was the need to focus on two critical issues: 1) meeting clients' needs and expectations for health and social services; and 2) addressing those needs through evidence-based approaches. Highlights from the meeting that addressed one or both of these themes include the following:

- **Meeting clients' perceived needs:** Evidence presented at this meeting indicates that the programs with the most significant impact implement systems that allow clients to obtain services where and how they want. Adequately staffed and supplied lower level health centers and community-based programs are important venues for providing convenient services away from congested HIV treatment facilities.
- **Communities and stigma:** Presenters emphasized the community's role in addressing stigma and discrimination. Evidence demonstrates the ability of communities to commit resources to improving care and support programs, both as a means of service delivery and to address stigma and discrimination.
- **Task-shifting:** Task-shifting and task-sharing are important strategies throughout the spectrum of facility and community programs. Many programs and initiatives seek to utilize all available staff to ensure coverage, addressing high staff turnover and variable levels of training and supervision. Programs often engage lay counselors or community workers who support facility-based services by helping to track and reach clients in the community to prevent loss to follow-up. Programs are exploring additional ways to improve the sustainable deployment of community workers, including addressing issues of compensation.
- **New technology:** New technologies are helping to address challenges to linkage and retention. Point-of-care CD4 testing has attracted interest because it addresses a barrier to clinical staging and quickly engages people in clinical care. There are limits, however, to the utility of this intervention, which is not yet appropriate for use of staging two- to five-year-old children; also, the current cost of point-of-care CD4 testing may remain a barrier for many programs. Mobile phones offer many opportunities for follow-up—for example, to remind clients of

appointments, contact clients who miss appointments, deliver test results, and transfer information among different programs to facilitate linkages. Several programs collaborated with telecommunications companies to bolster sustainability.

- **Monitoring and evaluation (M&E):** Participants discussed their approaches for M&E in pre-ART services, including use of patient treatment master cards and pre-ART clinic registers. Challenges included the need for unified definitions of care, support, linkage, and retention; and ways to monitor services provided in or by the community. Staff training and supportive supervision are necessary to effectively implement M&E systems. New technologies have the potential to improve the speed at which monitoring can take place and reduce administrative burden on staff, but the technology will need to be secured to protect confidentiality.
- **Quality improvement (QI) programs:** Many programs are implementing QI programs to focus on systems and strengthen linkages and retention. Participants reported the need for accurate and reliable data sources, clear definitions and measurements, and information sharing to ensure the success of QI programs. Also, assessing client satisfaction poses challenges and requires innovation; satisfaction cannot be fully assessed through a simple client satisfaction survey.

Each day of the meeting, small groups focused on specific themes presented and discussed program information and identified barriers and possible solutions. Highlights from these group meetings include the following:

- Moving from knowing your status to accessing and remaining in services
  - Challenges
    - Lack of infrastructure and equipment; personnel attrition
    - Poor client tracking systems; stigma and discrimination.
  - Solutions
    - Offer a "one-stop shop" approach where equipment and supplies can be shared by different but complementary services
    - Provide confidential (instead of anonymous) HIV testing to help track client transition from testing to care and improve follow-up
    - Engage in informational campaigns to increase knowledge of HIV in the community and address persistent stigma and discrimination
    - Expand client literacy activities to improve access and retention.
- Services for women and children
  - Challenges
    - Increased demand for HIV, antenatal care, and immunization services
    - Transport to health centers
    - Poor facility preparedness to address such challenges as gender-based violence and substance abuse, especially of alcohol.

  - Solutions
    - Conduct community outreach to reach more women and children and assist in follow-up of mother-child pairs
    - Train youth as peer educators to increase the reach of services to young mothers and older children.
- Community structures to retain people in care
  - Challenges
    - How to define HIV care, support , linkage, and retention
    - How to define the package of services provided.
  - Solutions
    - Update definitions of HIV care and support
    - Move from an emphasis on hospice services for terminally ill persons toward broader care and support services to retain PLHIV in care
    - Shift the focus of community services according to this change in emphasis, and involve the community in decisions on the shift
    - Put in place systems that enable communication and collaboration between facilities and communities
    - Administer program evaluations of both facility- and community-based services from the *client perspective* to maintain quality.
- Peers and community working together
  - Challenges
    - Defining the functions and responsibilities of peer and community structures
    - Communicating and advocating effectively.
  - Solutions
    - Tailor peer education to the needs of targeted peer groups, taking age, gender, education level, and other factors into account
    - Work with traditional leaders to bolster the acceptability of HIV messaging by lending authority, voices, and faces to communication campaigns
    - Work with public health leaders and health care workers; recognize peer educators as an important cadre of workers in HIV programming.
- Defining linkage
  - Possible definitions
    - The enrollment or engagement of PLHIV into an integrated network of community and facility care according to client priorities

        - Documentation of a client's receipt of pre-ART care in either a facility or through community-based services.
    - Guiding principles in designing and implementing linkage efforts
        - Base client-centered care on evolving client needs—no one referral or care plan will suit all clients
        - Strengthen the capacity of communities to provide, support, and promote linkages and access to care and support as a way to address stigma and discrimination
        - Advocate for the enactment of supportive policies and legislation to provide funding and support, including training and capacity building programs for service providers
        - Deliver multiple services at the point of care, specifically at the HIV testing site (including support groups and patient HIV literacy programs), to facilitate linkage and to diminish loss to follow-up.
- Defining retention
    - Possible definition
        - Ensuring that the client continues to receive appropriate services (from both the client and provider perspective) throughout the continuum of HIV care and support.
    - Guiding principles in designing and implementing retention efforts
        - Prioritize earlier follow-up of clients who are more likely to default, which may help avoid higher costs later
        - Emphasize the client perspective and client satisfaction to address the loss to follow-up that results from clients' view of services and their motivation to use them
        - Be aware of and where possible, address underlying poverty that affects clients' ability to remain in care. Include income-generating activities that increase retention in services and reduce clients' poverty status.

Country teams began developing plans for implementing retention and linkage programs for pre-ART clients including the following:

- Sharing lessons learned and ideas discussed at the meeting with partners in-country
- Placing a greater emphasis on pre-ART care
- Improving links between facilities and communities.

Ultimately, the client must both value and want care and support services to be successfully linked and retained. It is incumbent on service providers, programmers, policymakers, and community leaders to not lose sight of the client perspective. They must also engage the communities in which clients live and work. Continuing to improve linkages to and retention in HIV care and support programs is a complex task, and will require advocacy and raising of awareness to ensure the availability of adequate and appropriate resources. Linkage to and retention in care and support is critical to keeping clients healthy and engaged in services, and for improving their quality of life and clinical outcomes.

INTRODUCTION

Linking people living with HIV (PLHIV) into care has emerged as a priority in all countries supported under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). The need to create, sustain, and improve these linkages applies not only to PLHIV who are eligible for antiretroviral therapy (ART), but also to those who are not yet eligible. Providing consistent HIV care services ensures timely initiation of ART when clients become eligible. Six years into PEPFAR programming, experiences with service implementation in PEPFAR-supported countries are yielding lessons learned about maximizing access throughout the continuum of care. In Maputo, Mozambique, over November 3–5, 2010, the U.S. Agency for International Development, the U.S. Centers for Disease Control and Prevention (CDC), other members of the U.S. Government Technical Working Group on HIV Care and Support, and AIDSTAR-One held a meeting to enable representatives from nine PEPFAR countries (Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe) to learn from each other and develop ways to strengthen linkages to and retention in HIV care and support programs. This report summarizes the discussions from the meeting and is intended to complement the other meeting materials, which are available on the AIDSTAR-One website.

> "A patient's health is not just a product of CD4 counts, but a product of the social and economic environment in which the patient lives. We must create a continuum of care that follows the patient from the clinic all the way home…she goes to a family, a system, that will enable her to remain healthy or not."
>
> – *Ambassador Leslie V. Rowe*

- Field Driven Learning Meeting Materials

SUCCESSES, OPPORTUNITIES, AND CHALLENGES

HIV remains an emergency worldwide. PEPFAR was created as an urgent response program in recognition of that emergency. Despite tremendous progress, including 2.5 million people accessing ART and 11 million accessing care through PEPFAR in 2009 alone, challenges remain. Following PEPFAR's initial rapid response, efforts are now turning from quickly establishing and scaling up HIV programs to improving the coverage and quality of these services. Retention plays a critical role in HIV services, because it engages clients within broad facility- and community-based health and social support systems that offer care and support, helping PLHIV to remain healthy.

A primary consideration of linkage and retention efforts is that the client receives care and support services that they want and need. Support services need not occur solely within a health care facility. Complex and varied systems allow clients to receive a wide range of services in the setting most acceptable and appropriate to the individual. Thus, maintaining a client-centered perspective is critical—and is the correct approach.

- Related presentation: Linkage to, and Retention in Care for Persons with HIV

Focusing on linkage and retention brings up a persistent challenge: how to define and measure linkage and retention in a way that balances the needs of programs with those of Ministries of Health and donors. The challenge of definition and measurement was interwoven into discussions throughout the meeting. Definitions that speak to specific program needs, and the needs of individuals and communities, enhance the capture of programmatic experiences and help to identify successful approaches and new opportunities in HIV care and support.

LINKING AND RETAINING PEOPLE LIVING WITH HIV IN CARE

Evidence presented at the meeting showed that to successfully link and retain PLHIV in care, services must be accessible and acceptable to clients. Programs should support service provision not only in a range of facilities—from high-level hospitals down to small health centers—but also within the community to make sure clients can obtain services where and how they want. Decentralizing services to the community may complicate referrals and their tracking, but presenters reported that they had found ways to document both successful linkages—those that enabled completed referrals—and referrals that failed, and why. For example, when community-based volunteers and clinics use the same client monitoring forms, it is easier for clinic staff to track that a referral was completed. Using mobile phones, clinic- and community-based workers can contact clients who miss appointments to find out why.

Participants felt that it was important that communities and lower level, smaller health care facilities plan for and stock adequate supplies so that services can remain decentralized and perceptions of facility readiness to provide services remain high. Routine communication between providers at facility- and community-based service centers can ensure documentation of clients' access to and utilization of services. Interfacility communication is important, because clients may have multiple residential areas (e.g., a temporary residence near their place of employment and a more permanent residence), which leads them to seek services in several different places.

Related presentations:

- Improving Home and Community-Based Palliative Care Services
- Franchised VCT with Newly Diagnosed HIV

The importance of the community to HIV care and support cannot be overstated. Governments and implementing partners at this meeting emphasized the community's role in perpetuating—but also addressing—stigma and discrimination surrounding HIV. Communities can be significant resources in improving care and support programs, thus helping to address and reduce stigma. Participants reported on such approaches as using communities to help follow clients and engaging communities to provide a venue for peer support and education or training. Fostering a sense of belonging to a broader community can help increase participation by specific populations, such as men, who are often left out of health care services, and pregnant women.

POPULATIONS AND SERVICES

Participants broke into four small groups (discussed subsequently) on the afternoon of the first day of the meeting to discuss populations and services, focusing on specific interventions, lessons learned, best practices, and barriers and challenges.

- Related presentation: Day One Small Group Report Out

The small group dialogue broadened the discussion of what constitutes HIV care and support, and began to examine how HIV programmers and advocates can use existing systems to address challenges and barriers to providing HIV care and support. Identifying specific interventions, best practices, and barriers can help programmers determine the services that are most important to PLHIV, and retain them in care through linkages to those services.

MOVING FROM KNOWING YOUR STATUS TO ACCESSING AND REMAINING IN SERVICES (HIV, TUBERCULOSIS, ETC.)

The transition from receiving an HIV-positive result to accessing and remaining in care relies heavily on the client's environment and facility conditions, including the attitudes of service providers. The small group identified a few key barriers to the transition to continuous care: 1) stigma and discrimination; 2) poor client tracking systems; 3) lack of infrastructure and equipment; and 4) personnel attrition. Programs are implementing interventions to address these challenges, and the group identified a few best practices from current programmatic experiences, which are discussed subsequently.

Stigma: Participants endorsed community HIV information campaigns to address persistent HIV stigma and discrimination. The Zambian Defense Force testing program encourages individuals who are willing to go public with their status to increase the acceptability of HIV testing and disclosure—although it is ultimately the client's choice on where and when to disclose—and involves community leaders for support. Gender-sensitive programs also need to remain cognizant of location and hours, as the schedule of services or available transportation options may favor (or have a discriminatory effect on) men or women.

Client monitoring: Group members identified confidential (instead of anonymous) HIV testing as a way to improve follow-up during the transition from testing to care. To increase coordination across services, providers can use standardized forms across the various systems that provide services. For example, community-based organizations (CBOs) referring to a government-run clinic can use the same referral forms. Participants also recommended decentralizing the data systems that track clients. Use of electronic client records facilitates comparison of records between service delivery points and can feed information into a central system to improve tracking of service utilization at different locations.

Working with the infrastructure: Participants highlighted the one-stop shop approach for meeting the needs of a high volume of clients in an overburdened infrastructure. Equipment and supplies can be shared by different but complementary services. An example from Zimbabwe was the provision of both HIV testing and tuberculosis (TB) referrals in the same program. Acknowledging a client may have multiple health needs providing more than one service at a time increases the focus on meeting clients' needs, and may reduce loss to follow-up.

Related presentations:

- Zambia: Military HIV Services with Mobile C&T, Lower Level CD4 Testing, and Use of ART Adherence Supports to Address Loss to Follow-up
- Mozambique: Use of Home-based Visits, Active Case Finding and Monthly Patient Screenings to Strengthen Retention
- TB Screening of Newly Diagnosed PLHIV and Linkages to TB Diagnostic and Treatment Services in Zimbabwe

Attrition and provider overburden: Participants identified task-shifting as a best practice to move some burden from health care providers and give responsibilities to lay counselors and volunteers. However, providers still need training and some form of acknowledgment of their efforts, through stipends or other remuneration. The Hospice Palliative Care Association of South Africa reported on their experience of using a specific curriculum for counselors. The curriculum uses a structured approach to understanding the evolving needs of a client over time, and facilitates access to services based on these changing needs. Supporting all facility workers—paid clinical staff, lay counselors, volunteers—by providing appropriate training and supportive supervision may help reduce attrition.

Participants also recommended paying close attention to client literacy to improve clients' service use. Low literacy and low knowledge of HIV may prevent clients from seeking services. Representatives from Mozambique shared the experience of targeted counseling to address this barrier. Participants also endorsed partner involvement and education on the importance of services as a way of bolstering the accessibility and acceptability of services.

WOMEN AND CHILDREN

Integration within existing services: Health programs have addressed barriers to accessing centralized services by integrating HIV into existing, much-used health services. Antenatal care (ANC) clinics and immunization clinics both offer opportunities to reach women and children with HIV testing and related HIV interventions. Women identified in ANC as living with HIV may often receive services for the prevention of mother-to-child transmission (PMTCT) in the same facility, including ART for PMTCT, safe delivery, and infant feeding practices. Childhood immunization visits are also an opportunity to reach mothers of unknown HIV status.

Related presentations:

- Access and Notification for Early Infant Diagnosis in Zambia
- Integrating Follow-up of HIV Exposed Infants into Routine EPI Services in a Changing Environment in Zimbabwe: Yes We Can and Why We Should
- Linkages and Retention in Catholic Church HIV Care and Treatment Programs in South Africa
- Improving Quality of Life of PLHIV in Walvis Bay, Namibia

The group identified practices to help address challenges such as increased demand and transport to health care centers. Outreach in the community helps reach more women and children and can assist in follow-up of mother-child pairs who have been lost to follow-up. However, moving services from facilities into communities requires logistical planning and a change in the approach to service provision, as well as support and ownership from local leaders. Training youth as community peer educators is another way to increase the reach of services to young mothers and older children. There should also be support systems ("care for the carers") for counselors and other caretakers. Presenters stressed the importance of government and local ownership to the success of these programs.

Gender: Some challenges still await sustainable solutions. Gender-based violence (GBV) affects the ability of women and children to access HIV services and remain in programs. HIV care and support programs have not been well equipped to deal with GBV to date. Substance use—specifically alcohol abuse—plays a significant role in GBV and is an issue in its own right. Unfortunately, programs have not been prepared to address alcohol abuse in the services targeting women and children. It may be that PEPFAR's new focus on GBV will yield successful experiences in integrating GBV prevention and treatment into HIV services.

COMMUNITY STRUCTURES TO RETAIN PEOPLE IN CARE

The discussion on community-based services included the challenge of defining HIV care and support and the accompanying package of services. Definitions of HIV care are not keeping pace with current need—for example, the definition often centers on palliative services, which were first established before the widespread availability of ART, when life expectancy after diagnosis was short. Many of the hospices established earlier in the epidemic are mostly empty today, with clients living longer, healthier lives on ART. Thus there is a need to shift the services offered following diagnosis to match current needs. Also, with the change in prognosis, the community has a role to play in the care and support of individuals maintaining active lives on ART.

Related presentations:

- South Africa: Community Based Hospice Services
- Malawi: Community Structures to Link and Retain People in Care: Use of Community Support Structures and Cadres to Link PLHIV with Services
- Botswana: Community Volunteer System with Home Visit, Psychosocial Support and Food Basket

Improving communication: Participants identified enhanced communication as a best practice that should be modeled widely, because definitions of what constitutes care and support may vary across CBOs in a given region or country. By improving communication and using the same client tracking or referral forms across organizations, care organizations may overcome a number of barriers, including lack of a standardized definition of care, limited monitoring and evaluation (M&E) systems, and poor coordination and collaboration between organizations that offer complementary services.

Training counselors on available services: Another option is to ensure that HIV testing and counseling (HTC) counselors are thoroughly acquainted with the scope of services available at all health facilities (community- and government-sponsored) that provide services. The same

counselors could serve at multiple facilities and immediately link individuals to care and support at the time of testing, either at the testing site or at a location that is convenient (accessible) and acceptable to the client.

Monitoring and evaluation: Going beyond monitoring programmatic activities, but also evaluating program results and relevance to clients, helps programs keep pace with changes in HIV care as well as changing client needs. The client perspective, including client satisfaction, is an essential element in evaluating service delivery and programmatic priorities. There is a great diversity of service interventions and linkage mechanisms within CBOs. Programs must be able to evaluate all available approaches for the full range of services and populations, so that managers can continue to identify what programs are working best and determine how to apply those practices to other interventions and settings.

PEERS AND COMMUNITY WORKING TOGETHER

Peers and communities have been shown to provide critical support in that they can help PLHIV communicate their needs and advocate for themselves. Peer educators or counselors can help to address combined challenges, such as when clients confront stigma as well as services that do not meet their needs. Peer education should be tailored to the target group in terms of age, gender, education level, and other factors. Peer support group discussions should explicitly include HIV care literacy, including treatment.

Group members endorsed the use of local leaders in public campaigns; these leaders can provide credible messages about the importance of obtaining and remaining in care. Traditional leaders can bolster the acceptability of HIV messaging by lending their authority, voices, and faces to communication campaigns.

Related presentations:

- Mozambique: Use of Peer Educators for Patient Tracking and Home Visits
- Zambia: Use of Data to Strengthen Community Structures and Their Role in HIV Care and Support
- South Africa: ARTemis and Use of Tracker and Retention

Provider-peer collaboration: The shared experience of the Chá Positivo ("Positive Tea") from Mozambique provided an example of using targeted peer support groups. Health care workers moderate discussions among both adherent and non-adherent clients during monthly meetings, where clients are able to share experiences on numerous concerns such as disclosure, stigma, discordant partners, and children on ART. In this program, peer educators have become better advocates for other PLHIV as they provide comprehensive support, increasing the likelihood that a newly diagnosed PLHIV will link to and stay in care.

Using peer educators is not without its challenges. Clinical staff often do not recognize peer educators as a cadre of equal colleagues with whom they can collaborate. Also, the conditions and terms of engagement in which peer educators operate vary widely. A further challenge is how to effectively engage traditional healers. Clients often turn to traditional medicine and advice, which can interfere with their clinical care. As with peer educators, health care staff often fail to accept traditional healers as colleagues because they operate outside the formal system.

Participants identified standardizing peer educator training and including traditional healers in trainings best practices to address these challenges. Also, given the long or odd hours that peer educators work, and the responsibilities—often emotionally draining ones—that they shoulder, they should receive support themselves. This could be psychosocial support but could also include other forms of compensation or incentive. The incentive need not be monetary; it might include training, materials, or other tangible support.

INNOVATIONS TO MEET DEMAND

As they scale-up and expand care and support for PLHIV, programs are finding ways to adapt local efforts to decentralize services and increase the number of people who receive services. Representatives from programs in the region shared strategies for deploying adequately trained and supervised staff, addressing human resource limitations, and creatively using technology to link and retain more clients in care and support.

HUMAN RESOURCE NEEDS

High staff turnover and variable levels of training and supervision strain the already beleaguered human resources available to health care facilities. This situation often leaves available staff ill-equipped to meet the demand for services, provide high-quality services, and retain clients. As the number of people who know their HIV status increases, client wait time may increase, particularly for those not on ART or without urgent care needs. This may result in situations that make clients less likely to return for services.

Meeting participants mentioned coordination of services between facilities and communities as a major strategy for decreasing the burden on health facilities. They also mentioned task-shifting down the cascade of facility and community programs as a way to utilize available staff and ensure coverage.

Related presentations:

- Mozambique: Retention Strategies to HIV Care and Treatment
- South Africa: Approaches Toward Enhancement of HIV and TB Patient Enrollment and Retention in Care and Treatment Programs: An Integrated Clinic- and Community-Based Support System

Lay counselors: Lay counselors or community workers who do not have formal medical training can play various roles to support facility-based services within the community. Community workers can make home visits to ease the clinic staff's burden of client follow-up, particularly reaching out to clients who have missed clinic appointments. During home visits, these workers ask clients why they missed appointments or did not return to the clinic, reinforce messages on the importance of adherence, and identify client needs and ways to address the barriers that keep them out of care. Appropriately trained and supervised community workers affiliated with independent CBOs can help connect services that are related, but perhaps not integrated, such as HIV and TB, which may still operate as vertical services. A center in South Africa used incentives to increase the credibility of community workers. Clients who presented a referral from a community worker at the clinic would be fast-tracked to see a provider. In Lesotho, PLHIV were trained as a special kind of community worker, called a "focal person." These workers followed clients and provided peer support, while also helping to track clients and retain them in care.

Choosing programmatic partners: Participants discussed considerations for selecting CBOs for collaboration with health care facilities and identifying individuals to be community workers. CBOs that are already involved in some form of community health work, or that have a health focus, may have staff who possess some level of appropriate training. Meeting presenters indicated that community workers should be functionally literate and have some previous experience volunteering in a health care or other facility; these qualifications were critical to ensure that the community workers would report back to the CBO or facility for monitoring purposes.

Sustainability: Sustainability of community collaboration remains a concern. Programs with already stretched financial resources may not be able to continue to provide stipends or other incentives to retain community workers. Continuously identifying and training new volunteers to replace those departing programs generates a significant management burden. Several participants discussed the challenges of training volunteers who often quickly move on to other paid employment with their newfound skills. Where government resources permit, it may be possible to shift employment to government clinics or to have government-employed staff, such as psychologists, support community workers. Including community workers within national and local strategies can ensure the future role of community workers in HIV care and support interventions. Programs continue to explore additional ways to improve the sustainable deployment of community workers.

USING TECHNOLOGY

New technologies are helping to address challenges in the provision of HIV care and support by facilitating linkages and improving retention in various ways. For example, barriers to clinical staging of PLHIV may originate in other HIV-related services, such as laboratory services. Bottlenecks and delays in getting appointments to have samples drawn or in receiving results may delay informed decision making about clinical care.

Point-of-care testing: CDC findings show that because of recent technological improvements, point-of-care CD4 testing can now provide accurate CD4 counts at multiple points, including at sites for HTC, TB programs, and other non-HIV care locations. Point-of-care technology also allows clients to get CD4 counts when they come for other HIV services, such as HTC, opportunistic infection diagnosis and treatment, and PMTCT, which helps providers to make informed decisions about when to initiate treatment. Point-of-care CD4 testing, originally intended to evaluate eligibility for ART initiation to increase access to ART, may also be used to monitor clients already on ART. User-friendly tools are available for the point-of-care CD4 machines, and training for staff takes only a half day.

However, point-of-care CD4 testing alone will not remove all the barriers to timely linkages to clinical services. Programs must still work to address transportation and scheduling, and to make sure that clients are psychologically ready to accept their HIV status and the stage of the disease. At present, the point-of-care test yields an absolute CD4 count, not a percentage, so challenges remain for children between the ages of two and five whose ART eligibility is determined by CD4 percentages. Additionally, the cost may be prohibitively high for sustainable use, but many programs are looking into developing strategies to increase utilization of these services.

Related presentations:

- Telephone Follow-Up System: The Swaziland Experience
- Zimbabwe: Point of Care CD4 Testing and Referral for Care and Support

Communication technology: Programs are making innovative use of telephones to follow-up clients who have missed appointments or dropped out of care. Mobile phones can be used to remind clients of appointments, reinforce messages about scheduled medication dosing, or contact clients who miss appointments. Complementing telephone contacts with home visits can augment contact with clients and encourage them to follow-up on referrals. When clients approve in advance, programs give case workers the mobile number of a support person to whom the client has disclosed his or her HIV status in the event the client cannot be reached.

Programs have also used mobile phones to deliver test results and transfer information to other programs, which facilitates linkage by decreasing the amount of time a client must spend traveling to and attending clinics. Some facilities support sustainability by collaborating with telecommunications companies; in a number of countries, cost-sharing partnerships are used to waive text-messaging fees. As use of mobile phones continues to spread, programs are exploring ways to use this technology for client monitoring.

OBTAINING AND USING DATA

MONITORING AND EVALUATION

Tools to specifically monitor pre-ART services are still in development in many settings. Until these tools have been tested and refined, and staff have been trained in their use and have valid and reliable data recorded, programs will use existing information sources. Two tools—the patient treatment master card and the clinic register—are used to track patients on ART who are linked to care and support services. In sites where ART and non-ART services are jointly offered, revision of existing tools may address some of the challenges. Also, improved monitoring of pre-ART clients may lead to earlier access to ART and better clinical outcomes, which can provide a major impetus for adhering to clinical visit schedules in the absence of ART. Examining client data in aggregate and tracking clinic or program performance can also help strengthen linkage and retention efforts overall.

Related presentations:

- Malawi: Data Collection and Factors Associated to Linkages and Retention
- Impact of a Community Based Adherence Support Program on ART Outcomes

Monitoring and evaluation complexities: The need for consistent definitions recurred during the discussion of M&E. Unified definitions of care, support, linkage, and retention are fundamental for programs and, increasingly, for Ministries of Health and donors. It can be difficult to monitor services provided in or by the community. Clinic records do not typically account for community-based services or document them accurately or uniformly, and there may be poor communication between clinics and community organizations about the importance of timely reporting for both patient management and program monitoring. While M&E is essential to program planning and implementation, records and monitoring systems must remain simple and confidential and must not add too many additional duties to already overburdened staff. Staff training is essential and should be followed by supportive supervision; this may help increase the quality of data and its use in program management.

Meeting participants shared their use of new technology such as handheld or other electronic data tracking systems. Mobile phones or electronic databases can help link multiple clinic sites, facilitate monitoring across service provision sites, and provide real-time data for patient management. Using mobile devices may improve linkages between community- and facility-based services, and may help to track the utilization of services across facilities. These new technologies have the potential to speed up monitoring and reduce administrative burdens. Again, programs using new devices must maintain the confidentiality of client information.

QUALITY IMPROVEMENT

Quality improvement (QI) in public health allows programs to focus on systems, examining the organizational system and processes to strengthen services. Incorporating QI into program management requires good data and information sharing between clients and staff. Simple measurements and data tracking systems may facilitate management.

It is vital in the QI process to understand what works for staff and clients; any efforts at system strengthening must be client-focused and client-oriented. A sense of belonging—feeling cared for and having a personal relationship with a service provider—emerges as an important factor in retention. Consistent contact with multiple different service providers or staff may also bolster a sense of belonging, as this may help a client feel more than one person is invested in his or her care.

In QI, as in other service considerations, issues of definition and how to measure QI—and how to replicate successes—present challenges. For instance, varying time intervals may complicate comparison between clinics or measures. Documenting why clients return for services may require a large taxonomy and have overlapping factors. Because quality is often contextual, replicating one clinic's success in another facility may not be feasible, or even appropriate.

Related presentations:

- Measuring for Improvement: Can QI Facilitate Retention in HIV Care?
- Mozambique: Family Health International Experience in Nassa

Clinic rosters: While they may vary in complexity, all clinics have a clinic roster or register. It may be the only consistently available source of client data. However, a single clinic roster will not tell the whole story of whether or not someone is truly retained in care; it may miss those who are not regularly attending clinic or who periodically use services elsewhere. QI initiatives should consider all clients on the roster. Clients who are not registered for recent services may be the most important to find, as they may be the most vulnerable and the most in need. It may be helpful to have staff designated to go between the clinic and the community to monitor linkage and retention.

Quantifying client satisfaction: Assessing client satisfaction also poses challenges. A simple "Are you satisfied with the services you have received?" query is unlikely to capture client satisfaction. Cultural norms and gratitude for free or low-cost services can reduce the likelihood that a client would report anything but satisfaction, much less details on what to improve. Clients may not be aware of standards of care. Thus, client education is important; clients should know their rights to be able to make the best decisions for themselves. Messages on client satisfaction should be culturally appropriate and use terminology familiar to the client. Pre-ART client education warrants particular attention and may require collaboration and coordination between different staff members (e.g., physicians, nurses, and peer case managers). Empowering the client to provide constructive criticism will help strengthen service delivery.

OPPORTUNITIES FOR PUBLIC HEALTH EVALUATION

Recognition of importance of linkages to and retention to HIV programming is growing. Five or six of the thirty-six public health evaluation (PHE) studies currently funded by the U.S. Government, through the National Institutes of Health, focus on linkages and retention. For example, an ongoing

PHE in the Democratic Republic of Congo is tracing clients who have been lost to follow-up; this study may provide lessons that can be used by other programs.

Indicators for public health evaluations: Comparing findings across PHEs is not without its own challenges. Determining which indicators should be used is key. Although models of care may vary across settings, some commonalities may be measured. One potential indicator is the CD4 count at which clients initiate ART. Another could be mortality at ART initiation (measured as observed changes over time). Indicators used for comparison across countries or contexts will have to account for differences across settings and potential mismatches in the time periods used in measurement.

In the future, PHEs can help to find answers to programmatic questions. What helps retain clients in care? Will engaging early defaulters have long-term impacts on clinical and system outcomes? Can a QI-based approach improve retention? How has improved HIV testing effected linkages and retention? PHEs could also help with systematic documentation of community-based activities—much of the information currently available is anecdotal. As more clinics move toward a one-stop shop approach, PHEs could examine the effect on health services, client waiting time, staff burden, and other factors. The hypotheses tested will depend on the local context; in-country decisions should direct PHE approaches. Regardless of their hypotheses, PHEs should expand their focus beyond ART-related care and also examine the pre-ART period.

IMPROVING LINKAGE AND RETENTION

Participants divided into small groups to examine linkage and retention separately, including questions of definition and best practices for both topics. The PEPFAR definition of care includes clinical and non-clinical care, but the stronger emphasis on clinical care may be too constraining and may miss important support services offered through nonclinical care.

➢ Related presentation: Day Two Small Group Report Out

INTERVENTIONS AND APPROACHES TO IMPROVING LINKAGES

Broadly, linkage to HIV care and support could be defined as the enrollment or engagement of PLHIV into an integrated network of community and facility care according to client priorities. Under this approach, the initial point of linkage occurs at the time of HIV diagnosis, when a client is referred to care after testing. No one referral or care plan will suit all clients; clients and providers should continually develop service plans centered on each client's evolving need. Another approach to defining linkage is the documentation of a client's receipt of pre-ART care in either a facility or through community-based services. Here, the initial point of linkage occurs *after* HIV testing, when the client is clinically assessed or staged to determine ART eligibility. This definition acknowledges that clinical care services are required to link a client to ART. Despite the multiple ways to define linkage, interventions to improve linkages address similar barriers and challenges.

Stigma and discrimination: Participants identified stigma and discrimination as persistent barriers to accessing services, in both facilities and communities. An unsupportive environment discourages clients from following through with referrals or otherwise seeking services, and weakens linkages to care and support. Low knowledge about HIV and disempowerment among clients and communities compound these challenges. Interventions to address these issues include strengthening communities' capacities to provide, support, and promote linkages and access to care and support. Policies and legislation should be enacted to provide funding and support for these interventions.

Interventions addressing stigma and discrimination include:

- Standardizing appropriate package of basic services
- Mass media or communication programs
- Education programs tailored to different members of the community—leaders, traditional healers, school children, and youth
- Advocacy with professional organizations and coalitions.

➢ Related presentation: South Africa: Basic Care Package: A Continuum of Care and Support for PLHIV

Capacity building: Policy and legislation can also potentially designate funding and establish training and capacity building programs for service providers. However, the norm is that many care and support programs operate under resource and capacity constraints. Using peers and community resources, and moving services out into the community, can help ease the burden of demand that many facilities face.

Interventions addressing resource or capacity constraints include:

- Task-shifting
- Use of expert clients or "focal persons"
- Home- or community-based care.

➢ Related presentation: Role of Community Systems to Retain People in HIV Care in Thyolo, Malawi

Addressing loss to follow-up: Even in supportive, well-resourced environments, loss to follow-up can remain a challenge. Clients may have to invest considerable time and travel long distances to navigate their local health care system. The referral system itself may provide a barrier to locating clients—anonymous HIV testing does not allow providers or community outreach workers to follow-up with patients so that they can begin pre-ART services. In the many places where stigma and discrimination exist in both facilities and communities, disclosure issues may further decrease the likelihood that referrals will be followed. Interventions that make it easier to identify clients and enhance their access to and use of services may help address these challenges.

One strategy for diminishing loss to follow-up was the delivery of multiple services at the point of care, specifically the HIV testing site. This approach can improve clients' access to services at a site they are familiar with until they are ready to transfer to another service delivery location. This approach requires attention to the post-test environment, as follow-up or service initiation may not begin immediately after learning HIV status.

Interventions addressing loss to follow-up include:

- Point-of-care CD4 testing
- Integration of services (e.g., HIV and TB, HIV and Expanded Programme on Immunization)
- Presumptive treatment of HIV-exposed infants
- Follow-up systems using communities (e.g., home visits) or technology (e.g., telephone and text messaging)
- Community support groups.

➢ Related presentation: Access to ART by Pregnant Women in Chitungwiza, Zimbabwe

INTERVENTIONS AND APPROACHES TO IMPROVING RETENTION

As with linkage, retention can be viewed beyond the focus on clinical care. Retention can be defined as the maintenance of contact, from both the client and provider perspective, throughout the continuum of HIV care and support. This contact begins at the point of diagnosis, in post-test counseling. A more service-oriented approach defines retention as client return for continued facility- and community-based services according to national HIV care and support guidelines. This definition also considers the client perspective—services are received based on individual need.

Stigma and discrimination: Many of the barriers to retention in HIV care and support services are similar to the barriers to linkage: stigma and discrimination, and resource and capacity constraints. Clinics and programs may not approach access from an economic perspective, and the inclusion of income-generating activities could help increase retention and reduce clients' poverty status.

Interventions addressing stigma and discrimination include:

- Sensitization training for providers
- Education and treatment literacy
- Income-generating or skills-building programs
- Psychosocial support groups
- Peer educators.

Managing resources: As with linkages, limited resources, including overstretched staff, are a major barrier. Understanding the needs of the client population or community and tailoring services to meet these needs can help direct resources to achieve maximum results. Prioritizing earlier follow-up of clients who are more likely to default may help avoid higher costs later—it is more difficult to locate clients once they have missed several appointments, and their clinical needs may then be greater and costlier.

Interventions addressing resource constraints include:

- Standardizing an appropriate package of services
- Establishing a patient follow-up team to prioritize clients at higher risk for default and clients who have been lost
- Logistics management.

➢ Related presentation: Training District Level Focal People in Care, Linkages, Loss to Follow-up, and Supportive Supervision

Addressing loss to follow-up: Participants also mentioned client satisfaction as a potential barrier to retention. Measuring client satisfaction and using this information to improve services is challenging (see the previous discussions). Providing clients with the services they want and need in one place—such as a one-stop shop clinic—and using their communities—both to track clients and to provide additional, non-clinical support—may help reduce losses to follow-up.

Interventions addressing loss to follow-up include:

- Follow-up systems using communities (e.g., home visits) or technology (e.g., telephone and text messaging)
- Integrated services—a one-stop shop
- Support groups
- Peer educators.

➢ Related presentation: Zimbabwe: Point of Care CD4 Testing and Referral for Care and Support

Clients' perception of the value of services: Another aspect of loss to follow-up is the value clients place on services and their motivation to use them. Information is emerging on the positive benefit of conditional cash transfers in HIV prevention, but little documentation exists to examine their feasibility in care and support programs. At first glance, cash transfers may appear unsustainable, but if they are successful in retaining people in care and keeping their health status high, they could prove more cost-effective than the expensive treatments required by the very ill. The discussion on client perception again focused on the importance of the client perspective. It is critical to accurately assess client satisfaction and respect the client's decision to incorporate the use of traditional or alternative medicines.

Interventions addressing clients' low motivation or value of services include:

- Integration of client satisfaction into program management and service delivery
- Continuous counseling to improve HIV literacy
- Income-generating or skills-building programs
- Adherence programs that use peers or the community
- QI
- Post-delivery and basic care kits.

➢ Related presentation: Malawi: Community Structures to Link and Retain People in Care: Use of Community Support Structures and Cadres to link PLHIV with Services

NEXT STEPS: COUNTRY ACTION PLANS

COUNTRY ACTION PLANS

Building on the presentations and discussions held throughout the meeting, teams from the nine countries drafted action plans to address their country's linkage and retention efforts. Common themes emerging from both the shorter- and longer-term plans included:

- Sharing lessons learned and ideas discussed at the meeting with partners in-country
- Placing a greater emphasis on pre-ART care
- Improving links between facilities and communities.

Some of the key actions the country teams plan to take over the next year are listed subsequently.

- Botswana
  - Develop and implement the use of a pre-ART register.
  - Explore pilot project opportunities focusing on training linkage and retention counselors and implementing point-of-care services.
  - Mobilize care and support for pre-ART clients.
- Lesotho
  - Make community health workers an accepted cadre within the broader health care system.
  - Bring policies down from central to local levels.
  - Strengthen laboratory systems before moving to additional services, such as point-of-care CD4 counts.
- Malawi
  - Strengthen collaboration between government and community programs.
  - Move from anonymous to confidential HIV testing and registration to improve linkages and retention.
  - Train expert clients to support linkages from HTC through retention services for both pre-ART and ART clients.

- Mozambique
  - Map community-based care and support services to develop a directory for facilities.
  - Conduct a baseline assessment of pre-ART services.
  - Adapt the ART client tracking model for pre-ART clients.
- Namibia
  - Raise awareness of locally available care and support services.
  - Advocate for policies adopting point-of-care CD4 counts.
- South Africa
  - Focus on developing pre-ART programs, identifying the entry point to pre-ART care and the most useful M&E indicators.
  - Develop a trained cadre of community care workers (CCWs), including defining the minimum set of services CCWs may provide.
  - Work with, train, and support providers at all levels to provide quality care.
  - Develop strategies for the care and support of youth and adolescents.
  - Explore synergies between prevention with positives and care and support programs.
- Swaziland
  - Build on success of linking maternal, newborn, and child health and ANC facilities, and strengthen linkages between other types of clinics and health departments, HTC, and care and support services.
  - Strengthen patient education and support groups, possibly through inclusion of health care workers and community leaders in support groups and use of "focal persons."
  - Focus on loss to follow-up and missed opportunities to encourage adherence, narrowing in on missed appointments.
- Zambia
  - Explore point-of-care CD4 testing and the best process for implementation and expansion of services.
  - Develop standards for QI.
- Zimbabwe
  - Document use of referral forms.
  - Use clinic registers to improve follow-up of clients who miss appointments.
  - Improve data recording, documenting daily experience of village health workers (community workers).

FUTURE PROGRAMMING

> "What starts as an idea here will translate to a better life for hundreds of thousands of people in Mozambique, Botswana, Lesotho, Malawi, Namibia, South Africa, Swaziland, Zambia, Zimbabwe, the United States, and beyond."
>
> – *Ambassador Leslie V. Rowe*

Ultimately, successful linkage and retention requires that the client both value and want care and support services. It is incumbent on service providers, programmers, policymakers, and community leaders to keep the client perspective in mind. They must also engage the communities in which clients live and work, because much of the care and support provided to PLHIV, in particular those who are pre-ART, will occur in the community. Community workers may provide substantial care and support services. They may also help locate clients who fail to show for services in facilities, helping programmers understand why clients may default—and how they may be sustainably linked to and retained in HIV care and support.

Continuing to improve linkages to and retention in HIV care and support programs is a complex task. Advocacy throughout the systems—from task management at the service provider level to supportive policy setting at the ministry level—helps divert resources to care and support and prevent pre-ART clients from falling between the cracks. Advocacy can also help maintain the visibility of care and support services, raising awareness of the value of care interventions. Prophylaxis with co-trimoxazole, insecticide-treated bed nets, safe water, and hygiene kits are all examples of cost-effective, evidence-based interventions.

Advocates need only look to existing program experience to make the case for increased resource allocation to care and support services. Ten percent of ART clients die within their first year of treatment in the southern African region. Many of these might have improved survival if they began ART before they became very ill and their CD4 counts plummeted. The justification exists for a move to focus on and improve allocation of resources to pre-ART services, so that clients are linked to HIV services early, and retained throughout the continuum of care.

APPENDIX I

AGENDA

AIDSTAR-ONE REGIONAL CONSULTATION

FIELD DRIVEN LEARNING MEETING: LINKAGES TO AND RETENTION IN HIV CARE AND SUPPORT PROGRAMS

NOVEMBER 3-5, 2010, MAPUTO, MOZAMBIQUE, HOTEL CARDOSO

November 2, 2010

5:00 p.m.–7:00 p.m. **Early Meeting Registration**

If you choose, sign in and pick up your name badge and meeting materials to review.

November 3, 2010

Day 1 Theme: Linking and Retaining PLHIV in Care: Successes, Opportunities and Challenges

7:30 a.m.–8:25 a.m. **Meeting Registration**

Pick up your name badge, meeting materials, and goodies at the Registration table.

8:30 a.m.–8:50 a.m. **Welcome**
Opening Comments: Ambassador Leslie V. Rowe, U.S. Embassy
Moderators: Jon Kaplan, CDC, and Ugo Amanyeiwe, USAID

8:50 a.m.–9:40 a.m. **Linking and Retaining PLHIV: Successes and Opportunities; Voice of Clients and USG perspective. Opportunities and Challenges.**

Overview of why these are important issues, common barriers that interventions try to address, and putting forward a framework to guide the discussion over the three days.

1. *Linkage to, and Retention in Care for Persons with HIV*
   Presenter: Barbara Marston, CDC
2. *Questions and Answers*
   Presenter: Julio Ramos Mujojo, RENSIDA
   Moderator: Jon Kaplan, CDC

9:40 a.m.–10:55 a.m. **Linking and Retaining PLHIV in Care: Country Perspectives**

1. *Telephone follow up system—the Swaziland experience (Swaziland)*
   Presenter: Londiwe Nkambule, ICAP
2. *Role of community systems to retain people in HIV care in Thyolo, Malawi (Malawi)*
   Presenter: Marielle Bemelmans, MSF
3. *Improving home and community-based palliative care services (Namibia)*
   Presenter: Wilhelmina M. Kafitha, Ministry of Health and Social Services
   Moderator: Ugo Amanyeiwe, USAID

10:55 a.m.–11:10 a.m. **Short Morning Break**

11:10 a.m.–12:10 p.m. **Linking and Retaining PLHIV in Care: Country Perspectives**

1. *Basic care package: A continuum of care and support for PLHIV (South Africa)*
   Presenter: Tony Diesel, South Africa Partners
2. *Access to ART by pregnant women in Chitungwiza, Zimbabwe (Zimbabwe)*
   Presenter: Auxilia Muchedzi, EGPAF
3. *Franchised VCT with newly diagnosed HIV. Link to Care and prevention for positives (Zambia)*
   Presenter: Sarah Ngoma, Society for Family Health
   Moderator: Elizabeth Berard, USAID

12:10 p.m.–1:10 p.m. **Lunch**

1:10 p.m.–3:40 p.m. **Small Group Work**

Country/program presentations in areas described below followed by moderated/guided small group work.

Four groups: Participants will sign up for groups prior to arrival, at registration, or during the morning. Country teams would be strongly encouraged to make sure they have representation in each group. All groups will present back to the larger group.

- *Group A: Moving from knowing your status to accessing and remaining in services (HIV, TB, etc.)*
  1. *TB screening of newly diagnosed PLHIV and linkages to TB diagnostic and treatment services in Zimbabwe (Zimbabwe)*
     Presenter: Stephano Gudukeya, PSI
  2. *Military HIV services with mobile C&T, lower level CD4 testing and use of ART adherence supports to address loss to follow up (Zambia)*
     Presenter, Benny Njobvu, Project Concern
  3. *Use of home-based visits, active case finding, and monthly patient meetings to strengthen retention (Mozambique)*
     Presenter: Ruth Bechtel, FGH
     Moderator: Carol Langley, State Department

- *Group B: Women and Children*
  1. *Access and notification for early infant diagnosis in Zambia (Zambia)*
     Presenter: Cathy Thompson, FHI
  2. *Integrating follow-up of HIV exposed infants into routine EPI services in a changing policy environment in Zimbabwe: yes we can and why we should (Zimbabwe)*
     Presenter: Grapper Mujaranji, OPHID/EGPAF
  3. *Linkages and retention in Catholic Church HIV care and treatment programs in South Africa (South Africa)*
     Presenter: Peter Vranken, CDC
  4. *Improving quality of life of PLHIV in Walvis Bay Namibia (Namibia)*
     Presenter: Ochi Ibe, USAID
     Moderator: Sara Bowsky, USAID
- *Group C: Community structures to link and retain people in care*
  1. *Community based hospice services (South Africa)*
     Presenter: Kath Defilippi, HPCA
  2. *Community structures to link and retain people in care: Use of community support structures and cadres to link PLHIV with services (Malawi)*
     Presenter: Ann Akesson, MSF
  3. *Community volunteer system with home visits, psycho social support and food baskets (Botswana)*
     Presenter: Tumelo Tlhoiwe, CDC
     Moderator: Elliot Raizes, CDC
- *Group D: Peers and community working together*
  1. *Use of peer educators for patient tracking and home visits (Mozambique)*
     Presenter: Milena Mello, ICAP
  2. *Use of data to strengthen community structures and their role in HIV care and support (Zambia)*
     Presenter: Bridget Chisenga, AIDSRelief
  3. *ARTemis and use of tracker for retention (South Africa)*
     Presenter: Thobekile Finger, USAID
     Moderator: Barbara Marston, CDC

3:40 p.m.–4:00 p.m. **Afternoon Coffee & Tea Break**

4:00 p.m.–5:30 p.m. **Presentations from Small Group Work**
Moderators: Jon Kaplan, CDC, and Ugo Amanyeiwe, USAID

6:00 p.m.–8:00 p.m. **Evening Event**

November 4, 2010

Day 2 Theme: Systems strengthening to support improved linkages and retention

8:30 a.m.–8:45 a.m. **Preparing for Today**

Please don't miss this chance to hear potentially important news about meeting logistics.

Moderators: Jon Kaplan, CDC, and Ugo Amanyewie, USAID

8:45 a.m.–10:00 a.m. **Implementing Quality Improvement**

1. *Measuring for Improvement: Can QI Facilitate Retention in HIV Care?*
   Presenter: Bruce Agins, HealthQual
2. *Family Health International experience in Nassa (Mozambique)*
   Presenter: Paultre Desrosiers, FHI
   Moderator: Elliot Raizes, CDC

10:00 a.m.–11:00 a.m. **Addressing Human Resource Needs**

1. *Retention strategies to HIV care and treatment (Mozambique)*
   Presenter: Ruth Bechtel, FGH
2. *Approaches toward enhancement of HIV and TB patient enrollment and retention in care and treatment programs: An integrated clinic- and community-based support system (South Africa)*
   Presenter: Peter Vranken, CDC
3. *Training district level focal people in care, linkages, LTFU and supportive supervision (Lesotho)*
   Presenter: Charles Ayayi, State Department
   Moderator: Ugo Amanyeiwe, USAID

11:00 a.m.–11:15 a.m. **Short Morning Break**

11:15 a.m.–12:15 p.m. **Using New Technology to Improve Linkages and Retention**

1. *Improved access to HAART through point care CD4 cell count integrated with CT services in Zimbabwe (Zimbabwe)*
   Presenter: Stephano Gudukeya, PSI
   Moderator: Jon Kaplan. CDC

12:15 p.m.–1:15 p.m. **Lunch**

1:15 p.m.–3:55 p.m. **Small Group Work**

Four groups: Participants will sign up for groups prior to arrival, at registration, or during the morning. Country teams would be strongly encouraged to make sure they have representation in each group. All groups will present back to the larger group.

- *Group A (two groups each): Interventions and approaches to improving linkages (including QI, human resources, and new technology)*
  Moderator A1: Carol Langley, State Department
  Moderator A2: Isaiah Tanui, DOD

- *Group B (two groups): Interventions and approaches to improving retention (including QI, human resources, and new technology)*
  Moderator B1: Barbara Marston, CDC
  Moderator B2: Elliot Raizes, CDC

3:55 p.m.–4:10 p.m. **Afternoon Coffee & Tea Break**

4:10 p.m.–5:30 p.m. **Presentations from Small Group Work**
Moderators: Jon Kaplan, CDC, and Sara Bowsky, USAID

November 5, 2010

Day 3 Theme: Systems, Bringing it All Together & Moving Forward

8:30 a.m.–8:50 a.m. **Welcome to the Last Day**

Please don't miss this chance to hear potentially important news about meeting logistics.

Moderators: Jon Kaplan, CDC, and Ugo Amanyeiwe, USAID

8:50 a.m.–10:00 a.m. **Routine Monitoring and Evaluation for Linkages and Retention**

1. *Monitoring Retention and Mortality in Malawi's National ART Program (Malawi)*
   Presenter: Chirwa Zengani, MOH
2. *Impact of a Community Based Adherence Support Programme on ART Outcomes – KHETH'IMPILO (South Africa)*
   Presenter: Thobekile Finger, USAID
   Moderator: Barbara Marston, CDC

10:00 a.m.–11:10 a.m. **Opportunities for PHE: Lessons Learned and Opportunities**

During this session information will be shared regarding PHE findings related to linkages and retention across the spectrum of HIV programs. Participants will brainstorm to identify PHE questions related to linkages and retention in care and support, including hypothesis generation and identification of possible indicators of importance.

Moderator: Carol Langley, State Department

11:10 a.m.–12:10 p.m. **Country Action Plans: Bringing it all Together and Next Steps**

Participants will develop country action plans to increase opportunities for linkage and retention of PLHIV prior to initiation on ART. This session provides an opportunity to identify/voice STTA needs for help from TWGs, AIDSTAR-One, USAID, CDC and others.

12:10 p.m.–1:10 p.m. **Lunch**

1:10 p.m.–2:30 p.m. **Presentation of Country Action Plans**

Country group work continues, with countries reporting back on their plans.

Moderator: Elizabeth Berard, USAID

2:30 p.m.–3:00 p.m. **Closing Plenary Session**

Moderators: Jon Kaplan, CDC, and Ugo Amanyeiwe, USAID

APPENDIX 2

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