HIV/AIDS Programme

RETENTION IN HIV PROGRAMMES

Defining the challenges and identifying solutions

MEETING REPORT
13–15 SEPTEMBER 2011, GENEVA

World Health Organization

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1. INTRODUCTION

WHO convened a global consultative meeting on retention in HIV care from September 13-15, 2011, in Geneva, Switzerland.

Despite significant success in scaling up ART programmes worldwide, many people living with HIV (PLHIV) start ART late in the progression of HIV infection, resulting in high rates of early mortality on ART *(1)*. Currently, the majority of PLHIV remain undiagnosed and many do not access HIV care and treatment despite a positive test. PLHIV are lost at every step along the continuum of care, particularly in the period between HIV diagnosis and initiation of ART. It is now recognized that poor retention of patients in care – especially in the pre-ART period (*Steps 2-3 on the continuum of care; please see Glossary of Terms, p40*) – is a major driver of this poor programme performance and increased morbidity and mortality.

'Retention in HIV care' can be defined as continuous engagement from diagnosis in a package of prevention, treatment, support and care services. 'Retention in care' can be defined from the moment of initial engagement in care, when a person with HIV is linked successfully to services, to assessment for eligibility, initiation on ART and retention in lifelong ART care. However, in other studies and reports it sometimes includes the period from diagnosis to successful linkage to care. This first stage is most problematic to describe and document as people can be tested in a large number of different settings both in the community and in clinical facilities. Linking people to ongoing care from clinical settings may be easier to facilitate and document than from community settings which may not have effective links to services or efficient ways of tracking and documenting linkages. In the meeting, four **stages of retention in the continuum of care** starting from a positive HIV test to enrolment in care, enrolment in care to ART eligibility, ART eligibility to initiation of ART, and finally continuation of lifelong ART, were described and discussed. Retention is critical to reduce HIV-related morbidity and mortality, reduce the incidence of new infections in children and adults, and reduce development of ART resistance.

Preparatory work for the meeting identified a significant challenge with inconsistencies in, confusion about and lack of consensus on how key steps were defined along the continuum of care and the conceptual distinction between 'loss to follow-up' and 'disengagement from care'. A most useful definition of 'loss to follow-up' should refer to patients with *unknown outcomes*. 'Loss to follow-up' should point to gaps in knowledge and information systems. 'Disengagement from care' reflects patient issues for those who cease to access care – and demands a service delivery response. Although these concepts are overlapping, they cannot be considered synonymous without hindering discussion. In other words, knowing the outcomes of the lost (which will differ along the continuum of care and across settings by transfers, deaths, early deaths, leaving care altogether and by reason), is requisite for a data-driven response to loss to follow-up and disengagement from care.

Historically, strategies to address retention have focused on the ART period.[1] Retention on ART is better documented and currently this is the area given the greatest attention and for which systems and resources are prioritized. For patients who have received an HIV diagnosis, the obstacles to enrolment in care, retention in care until eligible for ART and initiation of ART are greater, and this area – retention of patients in care prior to ART initiation – was also an important focus of this meeting. Retaining patients in care in the pre-ART period is especially important as early initiation of ART reduces HIV-related mortality, can support women in the reproductive age group providing an opportunity to expand PMTCT coverage and partner involvement, and may have an impact on HIV transmission, both sexual and vertical. Furthermore there is an opportunity to provide other clinical services in the 'pre-ART' period such as interventions to reduce morbidity and mortality (e.g. co-trimoxazole (CTX) prophylaxis and, isoniazid preventive therapy (IPT)) and HIV prevention interventions.

As background for this meeting, a review of published literature was carried out and loss to follow-up (LTFU) at each stage noted *(2)*. Despite the fact that there may be considerable bias in data from published literature as this often reflects data collected from well-resourced and well functioning programmes, it is worth noting that the highest rates of LTFU occur between testing and enrolment, *(3)* and up to 80% of patients diagnosed with HIV infection may be LTFU between testing and initiation of ART *(4)*.

The key objectives of this meeting were:

1. To highlight the challenges around retention of patients between HIV diagnosis and enrollment and ongoing participation in HIV care with a focus on country-specific issues.
2. To highlight the importance of diligent monitoring and evaluation to improve HIV care programmes.
3. To identify gaps in documenting and monitoring LTFU.
4. To propose standardized definitions for key terms such as loss-to follow-up, and retention, including standardized period definitions.
5. To share country experiences and propose strategies to enhance retention in care with a focus on improving service delivery as part of Treatment 2.0.

The outcomes of the meeting are expected to serve as a foundation for future WHO normative guidance and to strengthen future programme support for retention in care.

The meeting brought together a wide range of experts working in the field of retention (see full participant list and agenda pp 36–42).

1 Indicators to monitor retention on ART, as defined by UNGASS, include the percentage of adults and children with HIV known to be alive and on treatment 12 months after the initiation of ART.

This meeting report summarizes the presentations given by key researchers in the field and the presentations from a number of countries and specific programmes (all presentations and background papers are available on the retention meeting EZcollab website). Summaries of the discussions from the working groups are also presented in this report.

Prior to the meeting a country survey *(5)* was also carried out. This qualitative survey, administered online or by telephone, aimed to gauge views and experiences on retention along the continuum of care. Responses were provided by a wide range of HIV care programmes with input from WHO country staff, Ministry of Health officials and clinicians. At least 2 representatives from each of the 22 priority HIV countries provided input. Meeting participants were also invited to share unpublished data from their country programmes. (Full details from the survey and additional programme information is also available on the website).

2. DEFINING THE PROBLEM

Identifying people with HIV, timely initiation of ART and lifelong care are key elements of the WHO/UNAIDS HIV/AIDS strategy towards achieving universal access. Patient retention is critical to these strategies and also serves to reduce transmission of HIV, through effective adherence to ART and the linkage to HIV prevention services. However, challenges to retention in care in resource-limited settings are numerous, and although there are some common issues at all stages, various factors contribute differentially at each stage along the continuum.

The problem of retention in care among patients with HIV is further complicated by the fact that meaningful measurement of retention in care is a formidable challenge, particularly in high burden countries with generalized epidemics. The scale of the global roll out of HIV/AIDS care means that comprehensive information systems to capture outcomes of the enormous numbers of patients entering care cannot easily be achieved. The speed of the rollout, including rapid decentralization also means that many patients access care at increasingly peripheral sites – and this movement is often poorly captured. Deaths are informally and incompletely reported. To date, assessments of 'retention' frequently report retention in a particular clinic, and this may represent a poor proxy for retention in care. Future strategies to optimize retention require investment in methods to better ascertain patient outcomes (e.g., universal identifiers, regional integration of clinic databases, sampling based tracking studies).

It is also important to consider an assessment of retention that accounts for the timing of patient deaths and can therefore enable targeting the right response to the right patient. Some patients die soon (i.e., within days or weeks) after their last clinic visit. Others die after a long period of absence from care. In the first case, the patient essentially died 'in care', whereas in the second the death was due to lapse in care. The appropriate public health responses differ: to address patient deaths "in care", earlier ART initiation, better point of care diagnostics and empiric treatment protocols can help. For patients who died due to a lapse in care, outreach and addressing transportation, stigma and poverty are needed. Maximizing retention may require both medical and socio-behavioral strategies.

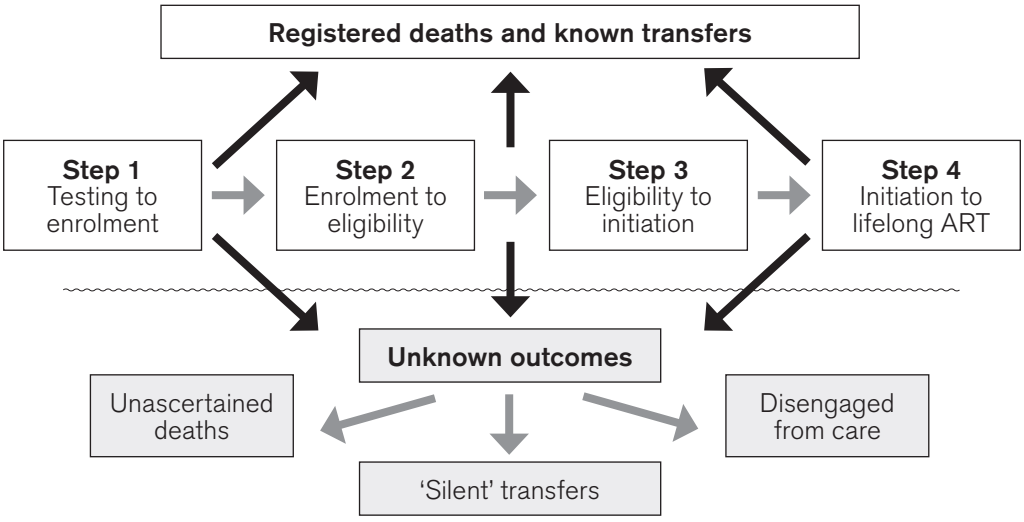
A new prevention-treatment paradigm recently introduced by WHO and UNAIDS is the Treatment 2.0 strategy *(6)*. This reflects the evolution in HIV management from emergency response to chronic disease management. There are 5 key elements to the Treatment 2.0 strategy:

- **Optimizing drug regimens** currently in use through harmonization across different patient populations (including the ideal 1st line regimen of a single pill for once-daily administration).
- **Advancing point of care diagnostics and other simplified diagnostics and monitoring tools** to increase access and reduce waiting times for diagnosis and initiation of ART.
- **Reducing costs** – deliver high-quality HIV care and treatment services through the lowest possible cost.

- **Adapting service delivery systems** with an emphasis on assessing whether appropriately integrated and decentralized HIV care and treatment, and increased community engagement in service delivery, leads to better patient outcomes including improved retention in care.
- **Mobilizing communities to engage and support PLHIV** through advocacy and empowerment, in the demand creation, planning, delivery and evaluation of quality-assured, rights-based HIV care and treatment.

HIV prevention, treatment and care programmes comprise a range of interventions from support for increased diagnosis to the commencement of lifelong ART and beyond. In 2010, WHO published a revised guideline on when to start ART in children, adolescents and adults *(7)*. The continuum of care can be divided into four steps, thereby defining points at which patient attrition (the opposite of retention) occurs. This is summarized in Figure 1 *(5)*.

Fig 1: The 4 steps along the continuum of HIV care and treatment. Patient loss may occur at all 4 steps along this continuum.



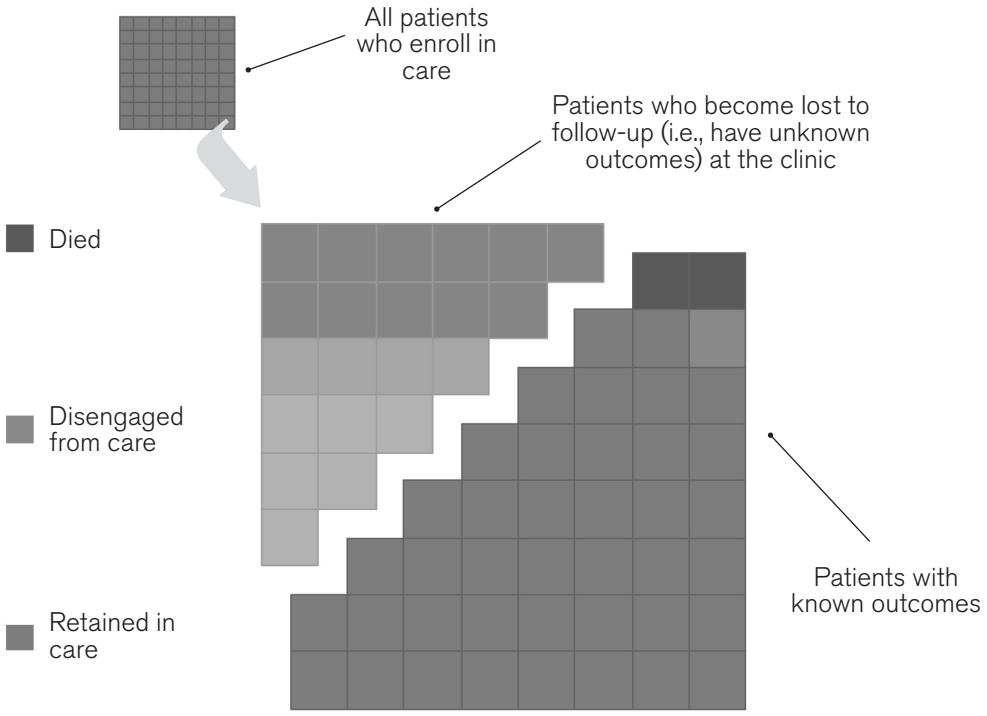
Step 1 – HIV testing to enrolment into care services

Step 2 – enrolment in care to ART eligibility (may be very short if person has WHO clinical stage 3 or 4 or a low CD4, or may be years for someone with a high CD4 count)

Step 3 – eligibility to initiation of ART

Step 4 – initiation to life long ART

Fig 2: Understanding patient outcomes. Elvin Geng, MD MPH, University of California, San Francisco



Linkages to care and the pre-ART period

Studies on the pre-ART period have demonstrated significant levels of patient attrition, particularly in step 1 (prior to the formal definition of the pre-ART period), resulting in only 20–33% of those initially identified as HIV-positive being known to have been retained in pre-ART care to initiate ART *(8)*. These results must be interpreted with caution due to variation in study design, definitions and patient follow-up. A study from South Africa highlighted the particular challenges to this step. It found that only 63% of people who tested positive from clinical and voluntary counselling and testing faculties were linked to initial HIV care *(9)*.

Significant loss to follow up in the pre-ART phase (steps 2&3) is also clearly described for example, in a study from Malawi. Retention in care at 1, 2, 3 and 6 months for those in the pre-ART stage in a hospital-based settling in rural Malawi was 25%, 18%, 11% and 4% vs. 99%, 97%, 95% and 90% for patients who started ART *(3)*.

Retention on ART

Two systematic reviews by Fox and Rosen *(1,8)* demonstrated retention on ART at 24 months of 70-80%. However the two reviews from 2007 and 2010 were not strictly comparable due to variable study methodologies. Of note, in this patient population CD4 counts at initiation of ART were consistently low, averaging 132 cells/mm^3. There is very little published literature on long-term retention on ART (after 24 months), making this an important area for further study. The recent changes in WHO treatment guidelines, recommending treatment initiation at <350 cells/mm^3 , are likely to have a significant impact on retention in the long-term as they should result in people initiating treatment earlier, thus reducing the early mortality currently seen in many programmes during the first year following ART initiation. However there may also be challenges in retaining people who start on ART with higher CD4 counts, who are asymptomatic on ART, and will be on ART for a longer period of time. Currently, however, despite changes in CD4 enrolment criteria, in many countries the majority of people initiated on ART remain those with CD4 <200 cells/mm^3.

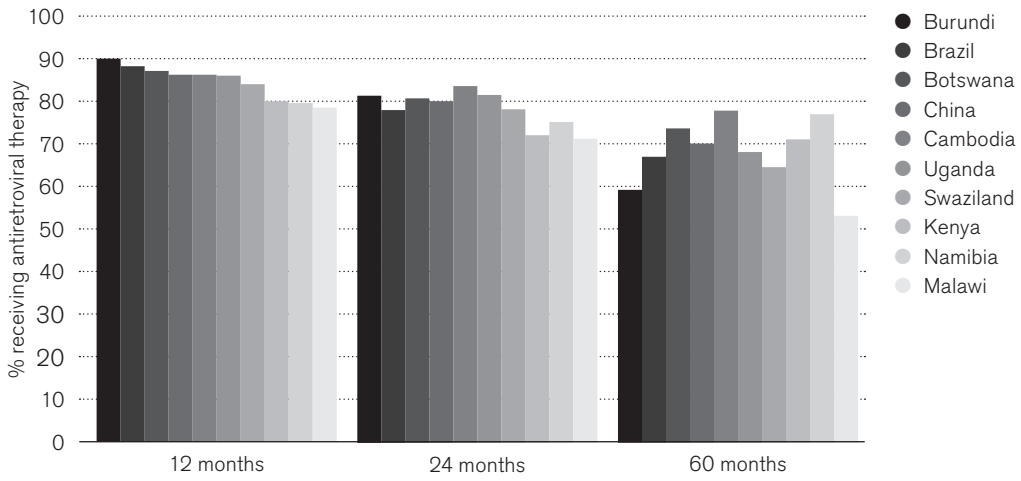
Geng and colleagues performed a tracking study of patients 'lost to follow-up' on ART (for the purpose of the study defined as '*no patient contact for 90 days or longer after the last given appointment*') at a clinic in Mbarara, Uganda *(10)*. Active tracking of a sample of LTFU patients revealed that 29% were deceased (unregistered deaths). Of the remainder, 10% were alive but not in care, 39% were alive but of unknown care status, and 51% were in care at another site. After incorporating the outcomes among the sample of lost patients into the entire clinic population, this study found that a corrected estimate of retention on ART at 24 months was approximately 79% to 86%, as compared to 69% if all lost patients were considered not retained. Other such tracking studies performed on patients 'LTFU' have revealed highly variable retention rates ranging from 6–93% *(11)*.

A pre-ART tracking study by Geng and colleagues at the same clinic in Uganda *(10)* found that from those LTFU, 31% were deceased. Of those who were alive and directly contactable, 37% had disengaged from care, with 63% being retained in care elsewhere. They noted that attrition rates were significant after being assessed as ART eligible, with approximately 21% attrition 12 months after becoming ART eligible by CD4 count.

As discussed above, significant levels of LTFU described are in the pre-ART period. This is likely because of the lack of structure and services provided for people with HIV in this 'waiting period'. The e-survey of the 20+ countries *(5)* demonstrated that during the pre-ART period, apart from some ad hoc opportunistic infection screening and prevention, very little consideration to other services was given. Although there are well-described support packages of care for people with HIV, *(12)* there is little agreement on a start-out set of pre-ART services. In practice this translates to poor retention of clients.

LTFU is often lower, though still considerable, once ART has been commenced and studies have shown significant levels of LTFU on ART particularly during the first 1–2 years, largely due to death and silent (non-documented) transfers. Some data on retention in ART care up to 60 months has been recently included in the WHO progress report *(13)*. A significant investment has been made to improve monitoring of cohorts of patients initiating ART, including retention rates (see Figure 3 below). However, reported programme data are still incomplete and associated outcomes may be subject to biases *(14)*. Importantly, few countries are able to produce consistent data on the full national cohort of patients initiating ART and for the most recent calendar period. For 2010, only Malawi and Ethiopia, among high-burden countries, were able to produce estimates of ART retention at 12 months based on data from over 90% of patients started during 2009. As such, reported data may not be representative of national programme

Figure 3: Retention rates for ART at 12, 24 and 60 months for selected countries.



3. COUNTRY EXPERIENCES WITH RETENTION: RISK FACTORS FOR LTFU

Country experiences with retention are important to document, highlighting the different ways LTFU is identified and addressed. Several country experiences of retention are summarized below in Table 1. A number of factors are common to low- and middle-income countries, whereas some are more specific to particular settings. For example in Eastern Europe criminalization of IDU is a significant factor affecting both access to HIV care and retention. It is important to acknowledge that the experiences of the Latin America and the Caribbean region were not well represented in either the summary of meeting presentations in Table 1 or the e-survey in Table 2 (the e-survey addressed the 20+ high burden countries). Since HIV in this region is concentrated among MSM, people who inject drugs (PWID), sex workers (SW), and those engaged in transactional sex in the region, the risk factors for LTFU that they face are heavily influenced by stigma, discrimination and social exclusion *(15,16).* Similar to the findings described below in Table 1 and Table 2, individuals and communities in Latin America and the Caribbean may elect for traditional healers or home treatment for 'folk' illness versus the modern healer or medical doctor *(17,18)*.

Table 1: Country experiences with retention: A summary of meeting presentations.
(Strategies employed by these and other countries are summarized in Table 5.)

Country	Factors that affect or reduce retention
Malawi (on ART)	• Advanced illness • Unregistered transfers-out • Alternative health beliefs/some faith beliefs/practices • Provision of inaccurate/false personal info by patients • Health service delivery issues: Long distance travel to healthcare facilities, manual data systems making M&E and linkage difficult, suboptimal integration of services, shortage of healthcare workers, weak procurement & supply chain management • Financial issues
Viet Nam (on ART)	• Male gender, WHO clinical stage IV, low BMI (<18.5), low CD4 count (<200) • Heavy alcohol consumption (independent of IDU), depression • Clinic in provinces vs. clinics in urban settings; small clinics (<100 patients) had worse retention than medium/larger clinics
Zambia	• Early mortality • Self-perceived improvement on ART • Stigma • Health service delivery issues: few CD4 testing facilities, distance to ART clinics, poor linkages, overburdened ART facilities, poor treatment counselling/preparation • Alternative health beliefs/some faith beliefs/practices

Country	Factors that affect or reduce retention
Mozambique	• Socio-economic issues: poverty, loss of income, stigma (community and within health care facilities) • Morbidity • Alternative belief systems • Health service delivery issues: prolonged waiting times, unavailability of same day services, pharmacy overload, distance from health facilities, overburdened health facilities. • Shortage of health care workers
Liberia ⇨Pre-ART	• Traditional medicine, religious beliefs, lack of transportation, work responsibilities.
⇨ART	• Traditional medicine, religious beliefs, sick relatives, lack of transportation, moving elsewhere for work, unregistered transfers out.
⇨At all points along the continuum	• Incorrect patient information, poor linkage & tracking, suboptimal system of monitoring and evaluation, nutritional problems, confidentiality, poor staff-patient relationship, overburdened health facilities.
Eastern Europe (12 countries) including Russia & Ukraine. Mainly IDU patient population.	• Mortality • Financial issues • Patient related issues: active drug and alcohol use, migration, imprisonment, psychological factors including depression, adverse drug reactions • Policy related issue: Criminalization of IDU and substitution therapy • Health service delivery issues: inadequate patient monitoring systems, limited sites offering HIV care & ART, inadequate preparation of patients for treatment (counselling), clinical decision to stop ART due to active IDU
India	• **Step 1** – Low index of suspicion for HIV infection resulting in late referral by health care provider (missed opportunity), inadequate post-test counselling, patients' perception of well-being, long distance travel to HIV care facility, loss of income, lack of awareness of ART services, absence of symptoms, stigma, ease or difficulty of locating the HIV care within the hospital • **Step 2** – Generally low LTFU here as all patients enrolled in care undergo CD4 testing, very few fail to collect their CD4 report • **Step 3** – Inadequate pre-ART CD4 monitoring, inadequate provision of CD4 results to patients and pre-ART counselling, patients' feeling of well-being, patients' use of alternative medicine • **Step 4** – Long distance travel to HIV care facility, loss of income, difficulty travelling when sick, stigma and stopping therapy when symptomatically better

Country	Factors that affect or reduce retention
Cambodia	• Socio-economic issues: poverty, job-related mobility, lack of education, loss of income from clinic visit, bad roads, limited public transportation • Health service delivery issues: lack of access to CD4 testing / delays obtaining results, lack of financial motivation for staff, lack of communication and poor tracking systems especially between VCT centre and HIV care facility, overburdened healthcare system

WHO carried out an informal e-survey of retention issues in 22 countries in Africa, Asia, Latin America and Europe. There was a consistent high level of LTFU across all countries, particularly during the first 2 steps in the continuum of care. The duration after the last scheduled clinic appointment to define LTFU ranged from 1–6 months in this cohort.

Table 2. Summary of WHO e-survey findings on challenges to retaining patients in HIV care

Key issues	Retention challenges
Common to most areas	• *Poverty related* – including taking time off work and caring for family, transport costs • *Logistics* – distances, opening hours • *Health service delivery factors* – perceived poor quality of services, health workers attitudes • *Monitoring* – poor monitoring and tracking of patients
Step 1 – **Testing to enrolment in care**	• *Psychosocial factors* – stigma and discrimination, denial of positive status, not ready to accept HIV infection or embark on life long care • *Health service delivery factors* – poor links/referrals from testing to services (may be a particular issue for people who receive diagnoses in community settings, as part of a campaign and in non-clinical settings, though also a significant problem in some antenatal settings), poor/no counselling or support after a positive diagnosis
Step 2 – **Enrolment in care to eligibility testing**	• *Health service delivery factors* – delays in receiving CD4 test results/lack of CD4 testing (including point of care technology), crowded clinics, long lines and distances to clinics • *Psychosocial issues* – lack of understanding or information, especially among those feeling well
Step 3 – **Eligibility to initiation on ART**	• *Perceptions* – disbelief in effectiveness of ART, fear of ART side effects • *Psychosocial factors* – lack of support, non-disclosure • *Health service delivery factors* – waiting lists

Key issues	Retention challenges
Step 4 – **Initiation on ART to lifelong ART**	• *Treatment-related* – stopping ART because of feeling better, pill burden and treatment fatigue • *Death* – especially in first year following initiation • *Health service delivery* – high frequency of appointments, difficult for patients because of transportation costs, missed work and home responsibilities; stock outs • *Migration* – Mobile populations seeking economic and job opportunities • *Undocumented transfers* ('silent transfers') – to other ART service providers; continuation of care problematic for incarcerated patients • *Alternative/spiritual healers* – alternative health beliefs and influences

A significant number of respondents indicated the use of WHO clinical staging to determine ART eligibility rather than CD4 (this may reflect current lack of availability in many settings), although it is well recognized that there is an imprecise correlation between WHO clinical stage and CD4 count. Furthermore few countries had strategies in place to prevent horizontal transmission once an HIV diagnosis was made, either by providing condoms and other prevention support, or facilitating partner HTC. It is also important to acknowledge the recurrent mention of alternative health and healing options through spiritual and traditional medicine, the impact of stigma and discrimination, as well as psychosocial factors in both the meeting presentations and the e-survey conducted by WHO. These and other related factors can have significant influence over individual and community health care-seeking behaviours which can impact linkage to and retention in HIV care and treatment services.

The survey findings underscore the importance of increasing retention through better follow-up mechanisms, better pre- and post-test counselling, clinic based support services including ART adherence support, prevention counselling and psychosocial support), and optimizing health service delivery through improved CD4 testing and availability, assessing whether decentralization and integration can support improved retention. However, even with the provision of 'immediate' CD4 results with point of care CD4 testing to newly diagnosed individuals with HIV in South Africa, 52.4% did not report for further care *(19)*. In Kisesa Tanzania, both experienced and anticipated discrimination hindered widespread ART uptake and stigma remained a significant barrier to accessing ART *(20)*.

In Viet Nam the HIV epidemic is a concentrated one, mainly among people who inject drugs (PWID). This has significant implications for retention and strategies employed by healthcare services to keep patients in care and on ART once eligible. Among people who were enrolled in HIV care programme in 2009 and who did not start ART, 11% were deceased at 12 months, and 19% LTFU. There were a further 11% unregistered transfers out, leaving 59% in pre-ART care. At the end of 2010, only 32% reported HIV cases were in care (pre-ART and ART), and

the overwhelming majority of those in care were PLHIV on ART. This is consistent with the findings of Rosen and Geng *(8,10)* in that most LTFU occurs between the diagnosis of HIV and commencement of ART.

However it is also important to consider that vulnerable groups in the population are often marginalized due to specific social and situational factors that contribute to their LTFU, and these should be considered and addressed in programmes. These groups include, but are not limited to, pregnant women, children and adolescents, men who have sex with men, men and women engaged in transactional sex, migrant populations, patients co-infected with HIV/TB, and PWID.

4. RETENTION ISSUES IN SPECIAL GROUPS

4.1 PMTCT

Despite worldwide scale-up of services to prevent mother-to-child transmission (PMTCT), coverage in low- and middle-income countries remains unacceptably low *(21)*. Contributory factors include inconsistent screening of pregnant mothers for HIV infection during antenatal care, if they present to ANC at all, and LTFU. Once identified as HIV-infected during ANC, retention is key to ensure that expectant mothers begin ART, or that they are offered effective prophylaxis for PMTCT *(22)*. In practice this is complicated by the fact that often ANC, screening for HIV and administration of ART for PMTCT are not fully linked or integrated.

In a study of pregnant women in Tanzania and Kenya, Ferguson and colleagues *(23)* found unacceptable rates of loss throughout the continuum of care. Although access to and uptake of maternal and infant ARV prophylaxis for PMTCT was greater than 60% for all positive women identified in ANC, only 18% in Tanzania and 4% in Kenya, of women estimated eligible, received ART for their own health. In both countries the highest rate of loss occurred during the first period in the continuum of care – from positive diagnosis through enrolment in care. A very complicated referral process during the first and second periods starting from the initial HIV screening test to eligibility assessment requiring multiple clinic visits to ANC and ART facilities, multiple adherence counselling sessions and prolonged waiting times of 5–6 hours were significant barriers to retaining patients in care. Enrolment to eligibility assessment (Step 2) averaged 37 days, whilst initiation of ART once deemed eligible (Step 3) averaged 40 days in Kenya. Other significant barriers to retaining patients in PMTCT to ongoing HIV care and ART were low levels of treatment literacy, perceived poor quality of care, costs of services, disclosure to partner and partner's attitude to HIV, and stigma.

Gender issues were also discussed as a complicating factor for retention; these are particularly important for pregnant women. Often, the choices of women to engage in care are influenced by what their husbands, fathers, or mothers-in-law may think or expect within their context. The pressure to conform to these norms cuts across cultures and regions. For example, the oldest man in the household may hold the greatest power over health care decision-making for the family. The importance of understanding and addressing the role of gender hierarchy is a retention issue for pregnant women and issues of gender/power in decision-making were discussed during the meeting.

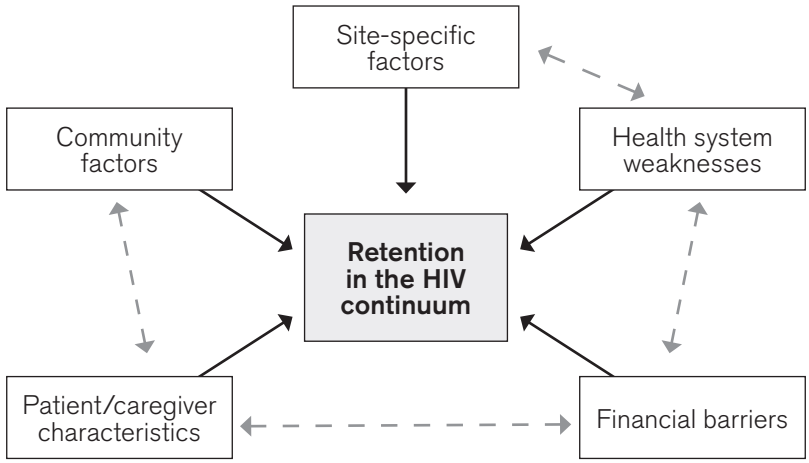
4.2 Paediatrics and adolescents

Diagnosing and retaining HIV-exposed and infected children and adolescents in care present unique challenges. Their vulnerability is heightened by dependence upon a caregiver.

In addition to the factors described above for adults, retention in the paediatric population

is heavily influenced by families/family-ties, other caregivers, the community and financial factors. Due to the *perceived* complexity of care, paediatric ART is often more centralized. Figure 2 offers a schematic overview of barriers to retention in children and adolescents. Site-specific barriers include lack of an age-appropriate comprehensive HIV care package, human resource shortfalls, prolonged waiting times, and lack of adequate counselling and support services. Health system weaknesses reflect longstanding neglect of MCH in general as well as intermittent HIV financing. These include systemic problems such as poor linkage, poor information systems affecting surveillance and tracking, and deficiencies in procurement and supply management. Financial challenges in providing ART services in resource-limited settings also affect retention when service charges are transferred to patients' families – for example, although ART may be supplied free of charge, families may be required to cover other costs such as CD4 and other laboratory monitoring tests. Advanced clinical stage of HIV, concurrent malnutrition and/or TB infection in the patient, and socio-demographic characteristics of the caregiver are important determinants of adherence to care. Social stigma remains a huge barrier to retention following HIV diagnosis and enrolment in care, especially for children who are orphaned.

Fig 4: Interaction of factors influencing retention in HIV care in paediatric and adolescent populations *(24)*.



In many resource-limited settings, paediatric LTFU is a problem even in the first months of life. PCR testing of HIV-exposed infants is inconsistently implemented – globally an estimated 24% of HIV-exposed infants are tested by 2 months of age, and a large proportion of those that do test positive never return for their results. Programme data from the International Center

for AIDS Programmes (ICAP) suggests that infants have the highest risk of LTFU and death even after initiation of ART, with only 60% retained in care at 2 years *(25)*.

Youth (ages 15–24) are the group least likely to attend HTC, and late diagnosis and poor access to ART remain significant problems. This is a particular issue for perinatally infected 'slow progressors' who either did not benefit from PMTCT programmes or were lost to follow-up postnatally, but it is also a concern for adolescents (largely girls) infected horizontally. Young people also have substantial rates of LTFU from pre-ART care with approximately 52% being retained at 12 months, as demonstrated by 2010 ICAP data from 13 sub-Saharan African countries. After ART initiation retention is slightly better at 70%, however youth are twice as likely to be LTFU compared to 11–14 year olds, and 1.6 times more likely to be LTFU than older adults *(25)*. Pregnant adolescents and young women have poorer retention than older pregnant women at 50% and 63% respectively at 12 months following diagnosis. Challenges faced in retaining youth and adolescents in HIV care programmes include poor knowledge of ART efficacy and benefits of adherence, inadequate social support, stigma, prolonged waiting times interfering with school / work schedules, costs and a range of social and emotional factors associated with adolescence.

4.3 Patients with HIV/TB co-infection

Patients co-infected with HIV and TB present a significant public health problem and are also at increased risk of morbidity and mortality as HIV infection exacerbates the progression of TB and TB accelerates the rate of HIV progression. It is imperative to retain these patients in care and ensure that ART is commenced as soon as possible once TB treatment has been commenced, *(26,7)* and that patients on pre-ART care or ART are regularly screened for TB at each clinic visit and receive either isoniazid preventive therapy or appropriate TB treatment. However it is known that there are significant levels of patient attrition ranging from 14–25%, either due to ART non-adherence or non-adherence to TB treatment *(27,28)*.

Risk factors for LTFU in this group can be classified as disease-related, patient-related, environment-related, provider-related *(29)*, or health system-related. Fear of side effects of treatment, pill burden, denial of disease, work commitments, transportation costs and health/ treatment illiteracy are significant causes of LTFU; some patients are too unwell to attend a healthcare facility. As TB is the leading cause of death for PLHIV, some individuals die from untreated TB before they are diagnosed with TB/HIV or before they are able to attend a healthcare facility. Others may choose to seek treatment through traditional or spiritual healers *(30)*. Also, in some regions TB-associated community stigma is also high. This can serve as a barrier for PLHIV and others with TB to engage in care. System-related problems include distance, prolonged waiting times during clinic visit, poor staff conduct and ineffective models of service delivery. Major barriers to providing adequate care to patients infected

with TB/HIV are lack of integrated services and poor linkage – combined with patient and disease factors discussed above. This results in the currently observed high rates of LTFU in this patient population.

MSM, sex workers, migrants are also groups with important social and situational factors that can affect uptake and retention in care. These particular issues were not adequately discussed in this meeting and require follow-up attention.

Summary

Identifying people with HIV, supporting linkage to HIV prevention and care services, and early initiation of ART among those eligible, and lifelong care are key elements of the WHO/UNAIDS strategy towards achieving universal access to treatment for PLHIV. Retaining patients in care along the care continuum of HIV programmes, defined by at least the 4-step schematic, is critical to achieving these outcomes.

Definitions of retention and LTFU vary greatly; some stakeholders refer to 'linkage to care' to describe a concept that others capture within the definition of 'retention.' There appeared to be differences within and between countries in these definitions *(31,32,33,34)*. Consistent definitions of retention and LTFU are required to facilitate communication between programmes, consistent data monitoring and evaluation nationally and globally. The importance of patient 'tracking' as a means of establishing causes of LTFU at a local level in order to improve service provision is also highlighted.

There are many causes of LTFU along the continuum, including stigma in the community and from healthcare staff, patient costs (transportation, loss of income), service delivery factors (prolonged waiting times, high frequency of clinic visits, poor linkage between services, lack of or poor patient monitoring systems, poor integration, stock-outs) patient factors and beliefs (limited perception of treatment issues, denial, alternative health beliefs, lack of disclosure to partner/family), and most importantly, overburdened, under-staffed healthcare systems.

Risk factors for LTFU amongst special populations such as pregnant women, adolescents, children, people who inject drugs, and patients co-infected with HIV/TB are often more complex and reflect the greater vulnerability and multifaceted health and social needs of these groups. The Treatment 2.0 strategy with its 5 pillars aims to address some of these issues.

Currently there are major challenges in the monitoring and evaluation of programmes at patient and health system delivery levels to assess coverage and retention and to allow programmes to identify their problems with retention and address these effectively.

5. MONITORING AND EVALUATION

Data monitoring and evaluation are an essential part of any healthcare programme for informed decision making and in order to assess the effectiveness, cost-efficiency and acceptability of interventions. Though retention in HIV care is crucial to the success of HIV programmes, there are few indicators used consistently to measure it. In addition to measurement, M&E can also facilitate retention through better patient tracking and linkage.

There are currently 2 UNGASS indicators that primarily measure coverage and 1 that measures retention on ART at 12 months. However, currently retention on ART beyond 12 months of initiation and pre- ART retention are not assessed:

- Percentage of eligible adults and children currently receiving antiretroviral therapy
- Percentage of adults and children with HIV known to be on treatment 12 months after initiation of antiretroviral therapy
- Percentage of estimated HIV-positive incident TB cases that received treatment for TB and HIV

The highest rates of reported attrition occur in the first 12 months of ART and lower rates in subsequent years. However few studies document long-term (>5 years) retention rates on ART.

Although there are few indicators in use for measuring retention, other programmatic data are available which may be used as surrogate markers for measuring retention in HIV care, particularly in the pre-ART period. Depending on the local programme and recordkeeping, the following indicators have already been developed and may be collected by some programmes *(35)*:

- Ratio of new patients receiving pre-ART care or ART services: the number of new patients testing positive for HIV
- Percentage of HIV infected pregnant women assessed for ART eligibility
- Percentage of eligible pregnant women receiving ART for their own health
- Percentage of infants born to HIV-infected women receiving co-trimoxazole prophylaxis within 2 months of birth
- Percentage of infants born to HIV-infected women receiving a test for HIV within 2 months of birth
- Percentage of HIV-infected children aged 0–14 years currently receiving ART
- Coverage of co-trimoxazole prophylaxis
- Coverage of IPT and screening for TB at last visit
- Pharmacy stocks of ART
- Percentage of TB patients screened for HIV

There is a lack of markers, even surrogate markers, to represent Step 1 between diagnosis and enrolment in care. Additional work is needed to address this gap; if the success or failure of this step is not measured, it may not be clear to programme planners that they need to focus specifically on improving linkages to care and Step 1.

M&E activities often represent additional workload for already overstretched healthcare systems, limiting quality results. Additional workload may be offset by utilization of randomized sampling methods *(36)*, electronic recording and monitoring systems and better communication systems.

Another issue is that data are often collated and analysed centrally with little feed back to the sites where data were collected. This is a missed opportunity – programme data are valuable to key stakeholders who can use the information to support continuous quality improvement efforts in terms of programme effectiveness and efficiency as well as staff ownership and empowerment.

Table 3: Summary of country experiences with M&E strategies

Country	M&E strategies
India	**Care and treatment records & registers for patient monitoring** *OPD attendance register, pre-ART HIV care register, patient treatment record (white card), ART record (green card kept by patient), ART enrolment register, CD4 lab register, line list of PLHIV referred for TB treatment, ART centre register of HIV exposed infants & children, tracking & tracing through CD4 due list/ daily clinic due list/ tracker format* **Stock management registers for supply of drugs** *ART drug stock & dispensing registers, OI drug stock & dispensing registers, expired drug disposal registers, CD4 kit and consumable stock register* **Formats for referrals and linkages** *ICTC to ART triplicate referral form, TB-HIV duplicate referral form, exposed infant/child referral form, transfer out form, SACEP referral form for treatment failure, LAC referral format* **Programme performance monitoring reports** *Monthly ART centre report including CD4, monthly LAC/+ report, monthly 2nd line ART report, TB-HIV report from ART facility, quarterly private sector report, monthly EID report from ART facility*

Country	M&E strategies
	Supervision, quality assurance and feedback M&E formats *Formats for assessing ART facility (feasibility, preparedness, supervisory checklist with summary recommendations), format for assessing CCC/CCSC, format for assessing linkage of ART facility (LAC feasibility visit format, supervisory checklist with summary recommendations), tour report format for CST officials* **Step 1** – referral slips (triplicate white referral slip) with feedback mechanisms, paediatric referral workers, monthly district level coordination meetings, tracking system for non-registrants **Step 2** – linkage of patients with DIC/positive network/CCC to ensure kept in active care **Step 3** – importance of pre-ART LTFU emphasized, ICTC report of confirmed HIV infection, proof of address and phone number of patient + 1 caregiver, 2 passport sized photographs, green book to patient detailing CD4 count, treatment, appointments etc., monthly CD4 due list at ART centre with phone reminders **Step 4** – daily due list of patients, tracker formats, LTFU list linkage within programme, supervision of peripheral ART monitoring systems
Cambodia	**Patient monitoring system: paper +/- electronic databases** • *Support patient management (appointments, co-management of TB/HIV, PMTCT etc* • *Monitor progress on ART coverage - LTFU, deaths, transfers out, new starters on ART* • *Survival and retention on ART - short & long-term* • *HIV drug resistance monitoring including early warning indicators (EWI)* • *Quality improvement of treatment and care* **Continuous Quality Improvement (CQI) indicators** • *Mortality indicators – % on ART or pre-ART (with OIs) who died or were LTFU* • *Quality of service indicators – pre-ART care (starting ART within 60d of eligibility, CTX/fluconazole prophylaxis, new registrants screened for TB); ART care (% who kept all appointments in last quarter, % still on 1st line regimen at 12 or 24 months)* • *Case finding and prevention indicators – % patients with new OIs with baseline CD4>350, % new TB patients who received HTC, % pregnant women receiving HTC, % pregnant women known to be HIV pos, % HIV pos pregnant women receiving PMTCT*

Country	M&E strategies
South Africa	**3-tiered M&E system** **Tier 1:** *Paper-based ART register, ideal for smaller facilities with low clinical load; can be implemented whilst awaiting procurement of computer hardware.* **Tier 2:** *Electronic (offline) version of paper-based register, allows rapid retrospective capture of paper-based data, relatively quick and inexpensive to scale up.* **Tier 3:** *Electronic (networked) medical record system, captures a larger dataset and can be used in sentinel surveillance or research. If utilized correctly at sentinel sites this can reduce the workload at central HIV care centres.*
Ethiopia	**M&E at micro (patient), meso (health facility), sub-macro (district) and macro (national) levels** • *Number of patients tested, linked, enrolled in care, eligible for ART, started on and currently on ART* • *Via routine reports, catchment area meetings, multidisciplinary team meetings, review meetings at different levels* • *Sharing of best practices; establishing strategic framework and case management guidelines; provision of training with training manuals; mobilizing resources*

India has established a comprehensive system for M&E through multiple referral and linkage formats, optimized by unique patient identifiers enabling effective tracking. Excess workload poses challenges to system maintenance, however current staff are managing to maintain this programme.

Cambodia is scaling up an HIV programme with strong linkages between HIV testing centres, ART services and associated facilities (e.g. STI centres, TB, reproductive health/PMTCT and laboratory services) and community support groups, namely MMM or the Mundol Mith Chuoy Mith programme (Friends Help Friends). MMM is a model in which PLHIV meet on a monthly basis with HCW at referral hospitals to strengthen the synergy between the community and healthcare facilities for HIV care *(37)* and promote access to HIV services for all clients. Due to scaling up of a Patient Monitoring System (PMS) and definition of Continuous Quality Indicators (CQI), staff workload for M&E is a significant problem, and data quality is poor. Furthermore TB screening, TB status and treatment monitoring are not integrated into the PMS in some areas resulting in falsely low coverage data on TB/HIV. Disaggregates of some ART coverage indicators are also incomplete, such as MARPS data, pregnancy status and children's age groups. Again, the importance of better linkage, tracking and communication is illustrated here.

In South Africa, as in many other countries, rapid expansion of ART programmes and progressive decentralization of service delivery have created challenges with programme monitoring and evaluation. Complex and bulky electronic medical record systems, parallel

monitoring systems involving different software products, unwieldy paper-based registers and variable infrastructure contribute to these difficulties. Earlier this year the South African Ministry of Health approved a 3-tiered M&E pilot programme *(38)* that is currently under evaluation and shows considerable promise. This programme aims to simplify M&E through targeted methods for facilities based on local infrastructure and skills, implementing a range of systems from simple paper-based to networked electronic medical records. All the methods being used measure retention in care, signal the need for interventions (e.g. alerting healthcare staff to missed appointments), and facilitate linkages for ongoing care. Programme analysis from South Africa stresses the importance of maintaining a single, simple M&E system with a few key indicators that can be utilized and modified to local requirements.

Ethiopia carried out a linkage assessment, cohort analysis and quality assessment of its ART programme between 2007 and 2010. Of individuals receiving a positive diagnosis, there was evidence that 73.2% had been referred to care, but only 47% of those had registered for care, and 53% of registrants were found to be eligible for ART. Of those who started ART, 66% were retained in care at 24 months, the remainder having died or been LTFU. Some issues identified through evaluation were repeat-testers, self-referrals, lack of systematic monitoring of ART eligibility, different modalities of service delivery and lack of care coordination with M&E processes. The findings resulted in new approaches to programme improvement based on a national strategic framework for linkage *(39)*.

M&E of HIV/TB programmes is fraught with challenges due to frequent dependence on referral between services rather than service integration. Existing HIV clinic registries may not have monitoring indicators for TB infection/ treatment and vice versa, and data collection is often inconsistent.

M&E is a key element of HIV programme evaluation and improving retention at all points along the care continuum. Generation of comparable data depends on consistent use of clearly defined indicators with clear definition of variables such as LTFU. Challenges to effective M&E include unwieldy paper-based registries in the face of large patient volume, crossover from one type of clinic to another without M&E linkages between the two, lack of infrastructure, multiple monitoring systems and overburdened healthcare systems. Priority areas for intervention include development of clear contextual M&E definitions, establishment of a single straightforward M&E system that can be utilized in all settings regardless of available infrastructure, and reduction of staff workload through a simple user-friendly electronic medical record.

6. WORKING GROUPS – M&E

There is limited consensus around terms such as retention and loss to follow-up, and there is an urgent need for standardized terminology, definitions, and time intervals particularly in reference to the pre-ART period. In order to achieve consensus in a number of key areas related to M&E including definitions of terminology, and to identify M&E indicators that are missing, the meeting divided into working groups to discuss 4 key areas:

1. Glossary of terms
2. Period definitions
3. Missing data
4. Data generation and simplification

6.1. Terms

One of the working groups attempted to reach consensus on terminology and definitions including period definitions. It was recognized that consensus was not achieved for many of the definitions and further discussion will be required – this is planned for a follow-up meeting in 2012.

The continuum of care with 4 steps was endorsed as an appropriate framework to guide approaches to retention in HIV care.

The majority of participants agreed the term 'defaulter' (borrowed from the TB programme) cannot be applied to HIV care programmes due to the requirement for a patient to be on treatment and to have stopped treatment of their own volition or due to toxicity or death, or the decision to take a period free of treatment ('treatment holiday'). It was also noted that this term excludes pre-ART patients, and may have negative connotations from a patient's perspective, particularly when ART has to be ceased due to toxicity. Furthermore it does not account for patients returning to the care programme after a variable period.

Working group participants noted that definitions will need further consideration and may need to be flexible, reflecting patient, provider or programme perspective. The definitions below were provided by the working group as a start, but it was acknowledged that further work was required to achieve a consensus on useful definitions that could be adopted broadly.

Loss to follow-up (LTFU): Loss of patients from the care continuum. Often used interchangeably with 'attrition' including death (registered or unregistered), unknown outcome ('true' LTFU) and transfer to another facility. Some working group participants expressed discomfort with this term as no one is truly 'lost to follow-up'. Therefore loss to follow-up could be defined more precisely as referring to **patients with unknown outcomes**. Patients who cease to engage in the continuum of care because of their own wishes or beliefs or because

of barriers to continued access to care (due to transportation, sigma, resources, etc) could be called **'disengaged from care'**.

Pre-ART care: That part of HIV programmes that patients enter into after enrolment at an HIV care site, but before initiation of ART. These services should include for example, HIV prevention and family planning support, PMTCT, co-trimoxazole prophylaxis, TB screening, INH, insecticide treated bednets (where appropriate), safe water and nutritional assessment.

Pre-ART period: Consensus was not achieved on this definition. Some participants described this period from enrolment to HIV care and support to provision of ART and others from testing positive up to initiation of ART (this paper generally defines the pre-ART period as Steps 2-3 in continuum of care).

Retention in care: Engagement in a comprehensive package of prevention, support and care services irrespective of the particular clinic site.

Given the common programmatic and research usage of the phrase 'linkage(s) to care', the meeting attendees acknowledged the importance of defining 'linkages to care', but did not have sufficient time to address this during the meeting.

6.2 Period definitions

No final consensus agreement of period definitions was made at the meeting. It was proposed to convene a technical working group to focus on period definitions to serve as a normative basis for future guidelines. The current WHO definition for LTFU once on ART is as below:

LTFU is 90 days after the last scheduled appointment. This period definition should be adjusted to a reasonable time frame within the relevant phase in the care continuum, particularly in Step 1 when there is a clinical urgency to review patients early (e,g, within 2 weeks) after diagnosis. Furthermore at other points along the continuum, the period definition must vary according to the local schedule for monitoring stable patients on ART or pre-ART.

The period definition must elapse before a patient is considered LTFU for purposes of M&E classification. However it is important to distinguish period definitions for M&E purposes from period definitions that influence clinical management – for example, failure to attend medication pick-up or clinic requires contacting the patient/family within a few days in order to prevent complications of non-adherence.

6.3 Missing data

Retention on ART beyond 12 months
Most studies report retention rates at 12 months and some at 24 months but very few have data on patient retention beyond 24 months. It will be important to support collection of data on long-term follow-up as ART is inevitably lifelong treatment, and factors such as 'treatment fatigue' or inability to tolerate adverse effects may become more relevant when patients have been on treatment for longer periods of time. Conversely, familiarity with treatment regimes, simpler monitoring and fewer clinic visits for patients who are stabilized on treatment may improve retention.

The WHO Universal Access report for 2011 will for the first time include data on follow-up at 12, 24 and 60 months.

Retention in care for children, adolescents and key populations
There are less data on retention and LTFU for children and adolescents (disaggregated data needed), and for people from 'key populations' such as PWID, MSM and SW. It is important to collect these data where services for these populations exist so that specific problems can be identified and services developed and improved to support retention.

Retention in PMTCT programmes
Although considerable coverage data are collected, there are limited data on retention throughout PMTCT interventions and on access to ART for treatment as well as longer-term retention on ART for pregnant women eligible for treatment for their own health.

Mobile and incarcerated populations
Attention must be given to mobile populations who may transfer (or not) to other services, people in emergency settings such as refugee camps who may be particularly vulnerable to interruptions in treatment, and people who move between prisons and detention centres and the community.

Pre-ART (including Step 1) retention data
As identified in many of the presentations, the most significant LTFU in the continuum of care is from testing to treatment. This reflects three distinct stages: testing to enrolment, enrolment to eligibility, and then eligibility to treatment. Whereas some interventions to improve retention on ART have been evaluated, few interventions to improve retention in pre-ART care have been evaluated, and are largely limited by the lack of consistent health information systems, clear definitions of the components of pre-ART care and support and measurable indicators. Programmatic experience is however described from sub Saharan Africa *(40)*.

6.4 Indicators

Table 4. Some proposed area and indicators for consideration (pts = patients)

⇨ Top level information to be reported nationally
⇨ Other data to be shared at facility level as part of QI programme

Period	Indicator (or proxy indicator)
Pre-care	# of pts in care (pre-ART and ART)/# of pts tested[a]
Pre-ART	# of pts receiving CTX prophylaxis
	# of pts receiving IPT
	# of pts receiving CD4 count (at enrolment and then annually or semi-annually)
	# of patients retained in pre-ART care (NB: account for pts who have 'transferred' to ART care once eligible)
ART	% eligible adults and children currently receiving ART who are eligible for ART[b]
	% adults and children with HIV known to be on treatment 12 (24, 36, etc months after initiation of ART)
	% and # of patients initiating ART with CD4 count < 100 cells/mm^3
Cross-cutting	Ratio of new pts receiving pre-ART care or ART services: the number of new patients testing positive for HIV
	% new pts receiving pre-ART care or ART services with unknown outcomes at 12, 24, 36 etc months
	pt mortality per annum in pre-ART, ART
PMTCT Maternal	% HIV infected pregnant women assessed for ART eligibility
	%eligible pregnant women receiving ART for their own health
	%eligible pregnant women with HIV known to be on treatment 12 (24, 36, etc months after initiation of ART)
PMTCT Infant	% infants born to HIV-infected women receiving co-trimoxazole prophylaxis within 2 months of birth
	% infants born to HIV-infected women receiving a test for HIV within 2 months of birth
	% infant with HIV known to be on treatment 12 (24, 36, etc months after initiation of ART)
	% infants receiving ART services with unknown outcomes at 12, 24, 36 etc months

a Existing indicator for field testing in the HTC M&E guide.
b Already an UNGASS indicator – see UA 2011 report.

Other areas where indicators are available:

- TB M&E guidelines
- Early warning indicators (of drug-resistant HIV)

Unique patient identifier

Many stakeholders recognized the importance of a unique identifier as one of a number of tools that could help to improve the tracking of patients through the continuum of care. In addition, a networked system that communicates between HTC sites and ART facilities could improve patient care and monitoring. Given that HTC often occurs in systems (e.g NGO, CBO, private sector) and settings (mobile, home, stand alone VCT sites) that are separate and distinct from HIV treatments and care systems, in many cases it will be difficult to develop networked systems across these various types of settings.

Follow-up for indicator development and definition development

Follow-up work on indicator and definition development was recognized as an important activity based on discussions at the meeting.

7. RESPONDING TO LOW RETENTION

7.1 Country experiences with strategies to improve retention

Presentations from the meeting suggested that goals to improve retention could be divided into those that reduce patient costs (e.g. making it easier to access care financially or otherwise) and those that increase patient benefits (e.g. improving quality of services) *(41)*. A summary of the county examples is presented in Table 5. This is not a comprehensive picture and does not adequately reflect experience from all regions.

Table 5: Country experiences with strategies to improve retention

Country	All steps	Step 1	Step 2	Step 3	Step 4
Rwanda	CHW: community education/ health promotion, malnutrition screening, community IMCI, ANC delivery, TB screening and DOT Networks of positive people: collaborate with the health system and improve decentralization and access to HIV care				
Lesotho, Zimbabwe, Malawi, South Africa (MSF experience)	Decentralization of care to primary care facilities or health posts[c,f] Integration of ANC/ PMTCT with ART[c,f] Integration of TB/HIV Community support groups	Decentralization of testing			Network of 22 decentralized ART clinics[a] Primary care clinics providing ART[b] 6 monthly appointments of stable patients with CD4 >300[c] Annual clinic visits + HIV VL in South Africa (long-term adherence clubs) for stable patients on ART[d] Community ART groups[e] Early initiation of ART[f] Revision of 1st line ART[f] All pregnant women placed on ART regardless of CD4 countf

Country	All steps	Step 1	Step 2	Step 3	Step 4
Kenya		Active case finding of HIV positive patients through home-based testing Linking them into care			High risk express care with weekly nurse + monthly CO reviews for patients with CD4<100 initiating ART Low risk express care with monthly nurse + 3-monthly CO reviews for stable adherent patients on ART Community Care Coordinators (CCC) and Cooperatives
Cameroon	Decentralization of service to district level networked, clear guidelines for all levels of care Mobilize local funds Task shifting Integration of services				Agreement with pharmaceutical company to reduce costs of ART, generic drugs
Viet Nam	Prevention and care peer educators Linkage Mental health services Drug dependence services Testing, ART & Tb, MMT integrated	HIV rapid test algorithm VCT care site tracking system		Shorten ART preparation period once eligible	

Country	All steps	Step 1	Step 2	Step 3	Step 4
Cambodia	Patient-level: reminders via SMS, unique identifier system HCF level: improve linkage within and between HCF and community-based support services – e.g. better communication through SMS	Improve laboratory services - access to CD4 tests, reduce delays		Reduce complicated eligibility criteria for starting ART (number of adherence counselling visits, ability to read/write etc).	Reduce frequency of stable patient visits Provide longer drug supplies (>1 month)
Mozambique	Community Adherence Support Groups Decentralization of care to primary care facilities				Patient level: reduce transport costs since patients only have to attend clinic once in 6 months HCF level: • Reduce number of stable ART patients accessing the health facilities • Increase capacity of a health facility to enroll new patients • Increase amount of time staff can dedicate to sick or complex patients • Decrease congestion at the pharmacy • Decrease acuity of consultations and admissions due to earlier access to health services • Improved reporting on patient outcomes Primary care clinics providing ART increasing entry points to HIV care

a H Bygrave, MSF experience, Zimbabwe
b H Bygrave, MSF experience, Lesotho
c H Bygrave, MSF experience, Malawi: 3 monthly drug refills, stable adherent patients on ART
d H Bygrave, MSF experience South Africa: clinic and community-based clubs for stable patients with counsellor/ PWHLA as facilitator; group screening; 2–3 month drug refills. ->97.5% retained in care at 2 years.
e H Bygrave, MSF experience Mozambique: groups of 6 stable (adult) patients on 1st line ART >6 months, with CD4>200: 6 monthly clinic reviews with monthly drug refills. 97.6% retained in care at 12 months.
f F Chimbwandira, MoH Malawi

In Rwanda a programme developed with support from Partners in Health (PIH) has resulted in impressive outcomes, with 55% reduction in under-5 mortality and excellent PMTCT coverage resulting in 94% HIV-free child survival42 at 18 months. Recognizing the general under-utilization of CHW has led to training and performance-based financial compensation of CHW, to retain 92.3% PLHIV on ART at 24 months and zero paediatric LTFU at 6 years. The key to the success of the PIH programme is integration of the community with all levels of the healthcare service.

Accompaniment of patients (DOT, clinics, psychosocial supports, medicine pick-up, material supports including nutrition) results in better coping skills and reduced stress, increased hopefulness, and reduced stigma leading to clinical recovery (through ART adherence) and psychosocial recovery *(43)*.

MSF has supported a trial of decentralization in Lesotho and found considerable success in retaining patients on ART (both adults and paediatrics), with retention rates of 76% and 85% for adults and paediatrics respectively *(44)*.

In Cameroon, the Global Fund supported decentralization of HIV care. A network of district level healthcare facilities with clear guidelines was established, and treatment was largely managed by doctors, while pharmaceutical companies supported the procurement of generic drugs to reduce costs of ART. Evaluation revealed that there were higher levels of patient satisfaction on the quality of care received at district hospitals compared with central facilities, particularly due to shorter waiting periods. Adherence to national treatment guidelines by medical staff, and change in CD4 counts were no different at 1 month between central and district centres, although this needs to be followed up for a longer period of time. Adherence and quality of life were better at district (local) level. Some of the challenges faced in Cameroon to sustain the programme in the long-term include dependence on international funding, persistence of a vertical programme, staffing shortages, and current weaknesses within the health system with regards to M&E and management of ART. Areas for improvement include mobilization of local funds, integration of services and task shifting.

A highly innovative strategy introduced during this meeting was the Community Adherence Support Group (CASG), developed by patients themselves. This has been piloted in Tete Mozambique45 and involves 6 adult PLHIV supporting each other on ART. A nominated member attends clinic once a month to report back to the HCF on the other 5 members, collect drug supplies for all, submit their own blood samples for CD4 testing and retrieve the CD4 results from the previous month's attendee. This arrangement requires each individual to attend clinic only once in 6 months, unless there are pressing clinical indications to attend more frequently. Key eligibility criteria for membership in a CASG include being stable on ART for >6 months and having a CD4 count of >200 cells/mm^3. CASGs have the added benefit

of reducing workload at a healthcare facility level. However, CASGs are not appropriate for all people. In this programme approximately half of the patients preferred to continue to access their care as individuals. In general when developing programmes to support retention in care, the views of patients themselves should be sought and considered. It should also be recognized that different approaches will be needed for different groups, and patient autonomy and empowerment will be key factors enabling patients to be retained successfully along the continuum of care. The Mozambican government will be piloting this approach in all provinces within the country, based on the experience in Tete-Kebba. The meeting attendees had a high level of interest in the success of this community-based, patient-led approach that supports retention in care.

7.2 Decentralization and integration

Of the many potential strategies to improve retention in HIV care, **decentralization** may be pivotal, assuming that a number of conditions are in place including a strongly linked network of quality care and support services and adequately trained staff. At the International AIDS Society conference in Rome (July 2011), point of care diagnostics, task shifting to nurse-led primary care facilities, community support groups and integration of services were recommended for adapting service delivery as part of Treatment 2.0. A Cochrane review published in 2011 on strategies for integrating primary health services in low- and middle-income countries at the point of delivery mentions only some evidence that 'adding on' services (or linkages) may improve the utilization and outputs of healthcare delivery. Currently there is no published evidence that a fuller form of integration improves healthcare delivery or health status.

Adaptation of service delivery is a multifaceted process and the different interventions need to be assessed separately for acceptability and impact: decentralization of HIV care into the community; integration of diagnosis with prevention and treatment in a chronic care model; integration of stand-alone ART services with ANC, TB care, and drug-dependency treatment services and primary level services; expansion of HTC; strengthening procurement and supply systems; and most importantly, partnership with the community through bidirectional linkages and referral for services between communities and facilities, as well as advocacy and empowerment *(46)*. There are important opportunities to work with communities to create an enabling environment to support linkage to and retention in care through stigma reduction, strengthened capacity to provide, support, and promote linkages and access to prevention, care and support. The role of community-based organizations, community leaders, PLHIV, or other community structures in linkage to and retention also needs acknowledgement and analysis.

The objective of decentralization is to improve access to care locally (increasing entry points to HIV care), thereby potentially improving integration of care and patient outcomes. Training

and empowering staff in primary care health facilities and mobile clinics to provide HTC, CD4 testing, ART prescription, basic clinical care and ART adherence support will be essential strategies to assess where there are shortages of trained medical staff in high HIV prevalence settings.

Integration of health services may also result in better retention by providing patients with the user-friendly care they need at a 'one-stop shop'. Service and program integration can also occur without physical co-location or integration services. For example, integration of facility-based and home-based services that have service provision in different locations, but still provide integrated services.

7.3 WHO guidance for adapting HIV service delivery: to improve patient and population health outcomes

WHO guidance for adapting HIV service delivery includes set of 9 PICO[1] questions to guide a systematic literature review to assess patient and population outcomes including retention in HIV care. The PICO questions fall into 4 categories and aim to assess the effectiveness of approaches: HTC and linkage to care, decentralization, integration, and task shifting. It is important that service delivery models are adapted to reduce morbidity and mortality, promote early diagnosis and timely ART, and retention in HIV care in order to maximize health at patient and population levels. In developing guidance in this area review of the literature will enable the development of recommendations for evidence-based approaches.

HTC and linkage to care:

1. For people living in generalised or concentrated HIV epidemics **(P)**, should community HTC be provided by non-physician providers **(I)**, compared to providing only facility based HTC **(C)**, to increase knowledge of HIV status and increase links to access to HIV prevention and treatment **(O)**?

2. In countries with an HIV prevalence ≥ 5%, should community-based HTC and PITC by non-physician providers be offered once a year to the general public?

Decentralization:

3. For HIV-infected people eligible for ART in generalised or concentrated epidemics, **(P)**, does the **initiation** of ART and HIV care in clinics providing general services in the community **(I)**, compared to referral to specialised HIV clinics for ART initiation **(C)**, result in comparable health and programmatic outcomes **(O)**?

1 PICO (**P**opulation, **I**ntervention, **C**ontrol, **O**utcome) is framework by which questions are constructed for review as part of the methodology WHO uses when assessing evidence according to the WHO Guidelines Review Committee.

4. For HIV-infected people eligible for ART in generalised, or concentrated epidemics (P), does the provision of **maintenance** ART and HIV care in clinics providing general services in the community **(I)**, compared to referral to specialised HIV clinics for maintenance ART **(C)**, result in comparable health and programmatic outcomes **(O)**?

5. For HIV-infected people eligible for ART in generalised or concentrated epidemics **(P)**, does **initiation** of ART by appropriately trained non-physician healthcare workers **(I)**, compared to initiation by physicians **(C)**, result in comparable health and programmatic outcomes **(O)**?

6. For HIV-infected people eligible for ART in generalised or concentrated epidemics **(P)**, does the provision of **maintenance** ART by appropriately trained non-physician healthcare workers **(I)**, compared to the provision of maintenance ART by physicians **(C)**, result in comparable health and programmatic outcomes **(O)**?

Integration:
7. In countries with a high burden of TB/HIV co-infection, **(P)** do ART and HIV care services provided at the TB clinic **(I)** compared to referral to specialized HIV clinics **(C)** result in comparable health and programmatic outcomes **(O)**?

8. In countries with a high burden of TB/HIV co-infection, **(P)** does TB diagnosis and treatment at specialized HIV clinics **(I)** compared to referral to TB clinics **(C)** result in comparable health and programmatic outcomes **(O)**?

9. For pregnant women and infants in generalized epidemics **(P)** does **initiation or maintenance** of ART and HIV care services within ANC/MCH clinics **(I)**, compared to referral to specialized HIV clinics **(C)**, result in comparable health and programmatic outcomes **(O)**?

In plenary it was suggested to include PICO questions for integration of HIV in drug dependency treatment settings. It was also suggested that refinement of PICO questions and systematic review in this area be taken forward.

8. RETENTION STRATEGIES (WORKING GROUPS)

Several working groups comprising country and international experts reached consensus on suggested strategies for retention along the continuum of care. These strategies are summarized in Table 6 below. The working group outcomes will serve as a baseline for future technical reviews and development of WHO guidance.

8.1 Retention in special populations

Working group participants identified a number of issues and approaches to consider in support of retention in special populations.

TB/HIV

Given the close association between HIV and TB, screening for HIV in TB patients/TB suspects in clinical settings is recommended. In general TB patients with HIV should be started on ART within 8 weeks following initiation of their TB treatment but within two weeks for those with profound immunosuppression (e.g. CD4 count less than 50 cells/mm^3). Upon completion of TB treatment, effective referral to HIV care/ART services for continuation of ART should be ensured. Alternatively, TB clinics could consider continuing the provision of ART especially if ART centers are centralized at higher level of care ART is recommended for all patients with TB irrespective of CD4. For people living with HIV who are screened for TB and found not to have TB, assessment for ART is recommended as well as initiation of isoniazid preventive therapy to prevent TB. PLHIV can be screened for TB in HIV clinics and at home as screening relies on a symptom algorithm.

Countries use different service delivery models depending on the local prevalence of HIV and TB, their health care delivery systems, and disease burden.

A major priority for 'integration' of HIV care/ART services should be in TB clinics in settings where both infections are prevalent as immediate initiation of ART is recommended for co-infected patients.

- If ART is initiated in TB clinics, the follow-up of ART once patients are discharged from TB services can be continued at the same site. If continued ART services at the TB clinic are not available, it is important to manage closely the linkage process from the TB clinic to the HIV care and treatment clinic for continued care after completion of TB treatment.

- *Integration of care*

  Providing a 'one-stop shop' TB and HIV service has been shown to result in a significant reduction in time to ART initiation without negatively impacting TB treatment outcomes. In addition, integration can lead to improved clinical skills and record keeping, outcomes

and quality of care. Integrated services are urgently needed *(47)*.

Key components include:

- HTC counsellor (pre- and post-test counselling; screening for TB; HIV prevention; partner testing)
- HIV counsellor to address ART issues including adherence
- Integrated HIV/TB data clerks
- Integrated mobile doctor to initiate ART, attend to complicated cases, diagnose smear negative/ extra-pulmonary TB
- Integrated nurse to stage HIV (including CD4 count), screen for OIs and drug toxicities, IPT; diagnose and treat smear positive TB; STI management/ prevention/ family planning
- Integrated community strategies for direct observation of therapy
- Revised forms based on the 3ILPMS to support integrated monitoring and evaluation

ANC/HIV care and ART

HTC is now a routine component of many ANC services, based on the PITC approach. Although this has resulted in a significant increase in the identification of HIV positive pregnant women and coverage of PMTCT interventions, there are still major gaps in providing ART for eligible women for their own health *(48)*. Key challenges are:

- Provision of CD4 testing and determination of eligibility for ART for maternal health
- Follow-up once discharged from PMTCT services to continuation of ART initiated in ANC or timely commencement of ART for women when eligible
- Follow-up family planning services

Examples of successful programmes to support an integrated approach, discussed at the meeting:

- mothers2mothers programme
  - Core intervention relies on HIV positive women who have previously been enrolled in PMTCT programmes to serve as peer educators and supporters, working with patients and health care workers.

- DREAM (Drug Resource Enhancement against AIDS and Malnutrition) strategy:
  - Comprehensive health education
  - Full immunologic and virologic monitoring
  - Electronic medical records (DREAM software)
  - Nutritional support
  - Strong linkage system between pharmacy, laboratory, PMTCT centre etc

- Shorten the chain between assessment and commencement of PMTCT/ lifelong ART
- Commencing ART for all HIV positive pregnant women regardless of CD4 count (the option B+ approach) has been adopted in DREAM programmes and may offset LTFU post-ANC and delays in lifelong ART initiation post-PMTCT. This may result in reduced maternal mortality *(49)*, and may be cost-effective *(50)*.

Mobile populations

In some settings, a significant proportion of patients are mobile, such as seasonal workers, migrant workers and people moving across borders or internally displaced due to conflict. The following were suggested as important considerations for people in these contexts:

- Proactively ask about travel plans
- Identify ART facilities near area of travel
- Peer support groups for testing and treatment literacy
- 'Temporary transfers out' – provide a formal transfer letter to another ART facility, provide 3 month supply of drugs
- Patient passport

Paediatrics and adolescents

Loss to follow-up is most acute in paediatric and adolescent populations. The following areas were considered to be potentially important in improving services and retention:

- Peer HIV+ve support groups for adolescents
- Child- and adolescent- friendly clinic schedules; take in to account school schedule when making appointments and if possible consider after school/evenings or weekend clinic openings
- Train healthcare workers to support adolescents through adherence and regarding other issues (alcohol, drugs, family planning, disclosure and recognizing adolescent emotional problems and needs for support)
- Ongoing adherence counselling – different models will be needed for children, children transitioning to adolescents and adolescents
- Functional tracking system to identify adolescents who miss appointments
- Decentralize care in a paediatric/adolescent appropriate manner
- Integrate paediatric care with family-based HIV care

For data monitoring purposes, there is a need to define age groups clearly - adolescent vs. youth.

Insufficient attention was given during the meeting to the retention needs of key populations, for example, **migrants, internally displaced persons, people who inject drugs, MSM, people engaged in transactional sex**, and other key populations at high risk for and vulnerability to HIV infection. Insufficient time was available to discuss the important and specific needs of key populations; this should be a prioritized for further consideration and work as the challenges associated with reaching and retaining people in these key populations are considerable.

Table 6: Suggested retention strategies at each step along the continuum of care

	Step 1: HIV testing to enrolment in care	Step 2: Enrolment in care to ART eligibility	Step 3: Eligibility testing to enrolment in ART	Step 4: ART enrolment to lifelong retention
Patient level	Adequate pre- and post- test counselling Point of care CD4 testing Linkage to prevention services including condoms, needle/syringe program, OST, peer educators Education: health, reduction of stigma Post-test messaging Smart card/ unique identifier for better patient tracking	Patient education, empowerment, advocacy, treatment literacy SMS messaging Remove user fees for lab services POCT Mobile HTC services Reduce frequency of visits and waiting times CTX/ INH prophylaxis Drug prescriptions to match visits Reimburse transport costs STI prevention & treatment services Nutritional support Smart card/ unique identifier for better patient tracking	SMS messaging Community/ Peer support groups Community Health Workers (CHW) Smart card/ unique identifier for better patient tracking	SMS messaging Community/Peer Adherence Support Groups Reduce drug toxicities Single daily pill containing ART Drug subsidies Drug prescriptions to match visits Nutritional support Reimbursement of transport costs Smart card/ unique identifier for better patient tracking

	Step 1: HIV testing to enrolment in care	Step 2: Enrolment in care to ART eligibility	Step 3: Eligibility testing to enrolment in ART	Step 4: ART enrolment to lifelong retention
Healthcare facility level	Decentralization of HTC Address staff attitudes and improve interactions with patients Involve community leaders (e.g. tribal leaders) Integration of services - e.g. HIV testing in TB centres; STI services, drug dependence treatment services Engagement of community partners, peer educators	Decentralization Integration of services Reduce clinic waiting times by fast-track system based on negative screening tools (triage) Address staff attitudes and improve interactions with patients Performance-based incentives for staff	Decentralization Integration of services Address staff attitudes and improve interactions with patients Performance-based incentives for staff	Decentralization Integration of services Address staff attitudes and improve interactions with patients Performance-based incentives for staff Integrate/link with drug dependence treatment Link with community & home-based care
District/ National level	Healthcare policy reviews to increase availability of POCT De-stigmatization De-criminalize HIV and IDU/ OST	Healthcare policy reviews	Healthcare policy reviews	Funding for ART programmes Healthcare policy reviews, remove legal barriers to employment De-stigmatization

9. SUMMARY AND CONCLUSIONS

9.1 Steps towards better patient retention across the continuum of care

Increased access to HTC

It is important to consider retention along the whole continuum of care – with diagnosing the undiagnosed persons with HIV as the critical starting point. Although there has been an impressive increase in access to HTC, coverage remains uneven in many settings and linkages to care inadequate. Supporting greater access to HTC will allow the more than 50% of people with HIV who are unaware of their infection to know their status; however this is of little benefit if linkage to care, prevention and support is not achieved.

Increasing linkage from HTC to care

HTC takes place in a variety of clinical and community-based settings. Although there is some data on linkage from testing to care from clinical settings, particularly in ANC and TB clinics, there is little data from community-based HTC approaches such as HTC campaigns and home-based testing. There are potentially greater challenges to supporting and motioning the efficiency and effectiveness of linking people who test HIV positive in community HTC to care, and priority must be given to this if community-based HTC is implemented.

In clinical settings linkages may be better, but are often still unsatisfactory, particularly where clinical services (e.g. outpatient and ART clinics) are not adequately and effectively linked, and systems need to be developed to monitor patient linkages and trace patients who are lost at this stage.

It is important to note that substantial attrition occurs prior to pre-ART enrolment due, in part, to the many individual, provider, health system, environmental, and other barriers to care, including those factors that influence health care-seeking decision-making, and the weak links between diagnosis and care enrolment. Partnerships between the healthcare system and communities, coupled with efforts to understand and address barriers to and facilitators of engagement in care, is critical to addressing these issues *(51)*. Integration of services providing diagnosis and care, where appropriate, may be one approach to help address this issue.

Defining and developing interventions that improve retention in the pre-ART period and providing a 'pre-ART package of prevention and care'

Although there have been many efforts to develop programmes for people with HIV following diagnosis *(11),* insufficient attention has been given to implementation. A beneficial package of care, support and prevention for people with HIV in the pre-ART stage would support people to remain engaged in care throughout this period and facilitate timely assessment of ART eligibility and commencement of treatment.

For example, following a positive diagnosis, if a patient is not eligible to be enrolled in ART

care there are opportunities to offer a range of services which have wide benefits and could prevent loss to follow-up during this period, including provision of HIV prevention services, co-trimoxazole prophylaxis, screening for TB and provision of IPT, safe water, insecticide-treated bednets (where appropriate) nutritional assessment, psychosocial support, support for partner testing, and PMTCT, psychosocial support, family planning and reproductive health services, and linkages to community care and support, in addition to periodic clinical and immunological assessment so that patients can move from pre-ART services to ART care as soon as they become eligible .

Reducing patient loss from eligibility to initiation of ART

Once eligibility for ART is determined, delays in initiating treatment and eventual attrition are due to a range of factors including the requirement for multiple adherence counselling sessions and waiting lists. Patient factors, including a reluctance to start on treatment although eligible if clinically well, anxiety about ART side effects, fear of inadvertent disclosure once on ART because of the need of clinical monitoring visits, need to be addressed through counselling and support.

Reducing patient loss once initiated on ART

Among patients who are retained in care and commence ART, there is a significant level of early death, particularly during the first 12 months of treatment. This is often due to late commencement on ART when the patient is significantly immunosuppressed (see factors discussed above leading to delays initiating ART) and has undiagnosed opportunistic infections. Some patients who feel significantly better on ART, and have inadequate support for adherence and treatment illiteracy, stop treatment of their own volition. It has been noted, however, that undocumented transfers-out to other ART facilities often lead to inaccurately high rates of reported LTFU. Currently there is data on retention in care after 12 months, but countries that report on retention in care at 12, 24 and 60 months have shown significant attrition by 60 months. It will be an important priority to continue monitoring patient retention in the long-term and supporting long-term retention.

9.2 Decentralization and integration of HIV services

Decentralization and integration of HIV services within general and specialist medical care has been proposed as an approach that can improve linkages and retention along the continuum of care. This approach is, however, complex, and success is closely entwined with community factors, the patient population, capacity and training of staff in lower level faculties, patient support and available resources.

Decentralization and integration of services must be judiciously implemented in a contextual manner to avoid adverse consequences. For example, in some settings with low or concentrated

epidemics, there is a potential for increased risk of stigma and loss of confidentiality when services are provided locally, and some patients may have higher levels of confidence in the quality of service provided at larger centres (counselling, physician-lead reviews) than those provided peripherally. Conversely, if carefully planned, decentralized and integrated services may provide more user-friendly care with less patient expenditure. If linked with effective community support and support for greater patient autonomy and participation, local services may also be less congested and less costly.

Integration and decentralization of services should take into consideration the local context, epidemiology of HIV, disease burden and the local health care delivery systems.

In generalized epidemic settings, ANC clinics have made great strides in increasing access to and uptake of ART for PMTCT, but provision of ART for maternal health has been much less successful. In some settings, particularly generalized epidemic settings, ART initiation in ANC services needs to be supported and links between ART care and ANC strengthened. Robust systems must be in place for transitioning care to HIV care/ART service settings for continued care.

9.3 Engagement of community and patients

The key principles of chronic disease management include active engagement of the community and the patients themselves.

Engaging communities and patients in care following a positive test is challenging, and there is significant LTFU. Insufficient attention during post-test counselling to helping clients identify and develop strategies to overcome a range of significant challenges – barriers to uptake of treatment, weak referral systems, logistic and operational challenges, and a range of other personal, provider, health system, environmental and societal factors – contributes to LTFU at this stage. The mix of factors that contribute to loss to follow-up may vary by population and setting, even within the same community. People with HIV are often not included sufficiently in designing and developing services so that they are acceptable and appropriate to their needs. Greater involvement of people with HIV is important so that they feel engaged and empowered in decisions about their care and that their real needs are being taken into consideration.

As the number of new patients eligible for ART and accessing treatment are continually added to those currently receiving ART, there is a danger that services will become further overstretched, possibly compromising quality. There is an urgent need in many settings to develop community systems and engage lay and peer workers to support, among other things, retention in care. Innovative methods of providing HIV care support will be needed to generate, motivate and maintain this community involvement at a patient level. Increasing

patient autonomy, empowerment, treatment literacy, community/peer support and task shifting to lay healthcare workers will be needed. Currently, many lay positions are poorly or not at all remunerated, thereby compromising the long-term motivation and commitment of CHWs and resulting in high attrition of trained lay providers. Acceptable, quality services provided by CHWs require adequate training, mentoring, support and remuneration.

Appropriate, context-specific engagement with other community support structures (e.g. spiritual and emotional leaders and healers, community leaders, chiefs, women's groups, CBOs, village health councils, etc.) should be explored and supported; these structures were identified as key in the e-survey and in the country presentations.

9.4 Health workforce related issues

It is important to increase human resource capacity through multiple approaches, including long-term workforce planning and management, and the standardization and integration of new cadres (e.g. community health workers, lay counsellors). Simplification strategies that reduce burdens on clinics in patients such as simplified clinical monitoring (for 'stable' ART patients) by reduced frequency of clinic attendance using 'peer group' support has been successfully demonstrated in Mozambique.33 This and other models that could reduce the burdens on clinics and patients need to be explored in other settings, but it may not be suitable for all patients and all contexts.

Ways of simplifying follow-up and task shifting for HIV care/ART provision need to be explored to avoid overburdening already overstretched healthcare services, thereby compromising quality of care. However it is also important to consider the potential increase in the burden on the individual/cadre to whom a task is shifted *(52)*.

9.5 Monitoring and evaluation

More effective and simplified monitoring systems with clear, contextual M&E definitions that can be utilized across countries regardless of available infrastructure are vital to evaluating programmatic success in retention. Currently existing international indicators need to be reviewed to ensure retention is sufficiently monitored and evaluated as HIV care and ART expand. A 3-tiered M&E system holds considerable promise for application in resource-limited settings as demonstrated in South Africa *(53)*.

9.6 Conclusions

As discussed in this report, a wide range of challenges to retention of patients across the continuum of care have been identified and interventions that could improve retention are being

implemented; these initiatives (such as involving people with HIV in decisions about their own care, simplifying monitoring and minimizing clinic visits for people who are stable on treatment and in the pre-ART period, and using new communication technologies (e.g. SMS messaging) and more efficient patient tracking (including the use of unique identifier code system) need to be further developed, implemented more broadly and rigorously evaluated. There is an urgent need to standardize definitions to facilitate monitoring and reporting and to allow comparisons between programmes and countries. Early ART initiation and retention are critical to maximize survival and preventive benefits of ART. High-level support by policy makers and community leaders will therefore be needed to prioritize HIV issues, promote testing, support early access to treatment and increase support for integrated care and retention.

10. NEXT STEPS

1. Acknowledging the need for addressing retention at all stages across the continuum of care

WHO will develop a **Strategic HTC framework** to help countries develop an HTC programme to increase access to testing to all those who could benefit – including couples, adolescents, men and key populations by choosing an appropriate mix of facility and community approaches. Promotion of earlier HIV diagnosis and linkage to care is a key aim of the strategic HTC framework as people starting treatment with a low baseline CD4 count is significantly associated with lower retention (due to early mortality and higher LTFU).

WHO, as part of Treatment 2.0 and other initiatives, will support the agenda for increased availability of **point of care HIV diagnosis** where appropriate, developing HIV testing strategies and testing algorithms for rapid HIV tests.

2. Definition and provision of an evidence-based pre-ART package

There are already well-described packages of prevention, care and support for people with HIV.[1] There is a need to support the implementation of such packages that contain a minimum of:

- Periodic screening for ART eligibility
- Ongoing counselling and psychological support, as required
- Screening for TB and provision of IPT
- Provision of co-trimoxazole prophylaxis
- Links to HIV prevention services, including provision of condoms
- Support for partner(s) HTC
- Diagnosis and treatment of OIs
- Malaria prevention
- Safe water
- Nutritional assessment
- Family planning, PMTCT and links with reproductive health
- Clinical and CD4 monitoring of disease progression
- Community-based care and support
- Primary care services for overall health

Programmes must also monitor uptake, acceptability and impact (whether, for example, a pre-ART service will improve retention; reduce morbidity, mortality and HIV transmission in the pre-ART period; and facilitate timely initiation of ART).

1 GNP+ Positive Health, Dignity and Prevention, http://www.gnpplus.net/en/programmes/positive-health-dignity-and-prevention and CDC Prevention with Positives, http://www.cdc.gov/hiv/topics/prev_prog/ahp/AHP-Strategy3.htm

3. Adapting service delivery, including appropriate decentralization and integration of HIV services

WHO, as part of its work on Treatment 2.0 service delivery, is developing comprehensive guidance on the potential role of decentralization and integration in improving access to and retention in ART care, assessing the benefits, risks, costs and feasibility. (Integration and decentralization of HIV care/ART in ANC, TB, primary (including community level) services and drug dependency treatment settings will be assessed).

Systematic reviews of published and gray literature and collection of case studies will support the development of this guidance to describe the possible role of decentralization and integration in improving HIV service delivery by reducing HIV-related morbidity and mortality, supporting timely initiation of ART, retention to HIV care, and adherence.

4. Task shifting

WHO, as part of its work on Treatment 2.0 service delivery, is developing comprehensive guidance on task shifting for the cadres of health and community workers to identify who, in which settlings, can successfully initiate and support continuation of ART.

5. Point of Care CD4 testing and viral load monitoring technologies

WHO, as part of Treatment 2.0 and other initiatives, will support the agenda for increasing access to CD4 testing to assess eligibility for ART. This will include assessment of new strategies and technologies which can be used in decentralized settings and do not require specialized laboratory personnel, and exploration of more efficient sample transportation system and timely delivery of results (e.g. via mobile technologies etc) to facilitate more efficient access to CD4 results.

6. Developing a strategy for improved measurement and analysis of the challenges to and successes in addressing retention in care

Addressing retention in care must also include the formulation of a strategy to get better information about the current problem. Measuring the effectiveness of a public health response relies on defining and collecting considered, accurate and consistent information. Patient outcomes are key data, yet currently approximately 30% of patients after 2 years (whether on or off ART) are lost or have unknown outcomes. Therefore a generalizable measurement strategy to improve knowledge of patient outcomes including retention in care is key. More widespread application of “tracking” studies, in particular of a representative sample of the lost patients, may represent a promising strategy for this goal.

7. Monitoring of retention

In 2012, WHO will update the guidelines on M&E, HIV Care and ART and review the recent

M&E guidance for HTC to ensure that it includes attention to linkage to care/retention and work with other organisations to support field testing of the new indicator related to linkages (Ratio of new patients receiving pre-ART care or ART services: the number of new patients testing positive for HIV). Monitoring retention will be a key component of the revision and will include:

- Review and revision of the current recommended indicators for national programmes
- Standardized definition for specific terminology
- Adaptation of the data generation system, including patient monitoring system
- Links with community level, which may include monitoring of community-led interventions and data linkages between the community and health facilities, given that the role communities play for delivering treatment will increase under the Treatment 2.0 initiative

8. Agreement on definitions of terms and periods

There is currently lack of consensus on the definition of the time period that constitutes when a patient is lost to follow-up. WHO will work with others to develop globally accepted definitions.

MEETING AGENDA

All presentations and background documents are on the retention website:
http://ezcollab.who.int/retentioninHIVcare/

Day 1: 13 September – Defining the Challenges of Retention

Session topic /Presenter
Setting the Stage: Defining the problem, addressing solutions **1. Craig McClure: Treatment 2.0 – Where does retention fit in?** *Introducing the importance of retention in HIV care and how retention fits in to the Treatment 2.0 strategy to optimize HIV treatment and care through 5 key elements.* **2. Sydney Rosen: Patient Retention from HIV Testing to Lifelong Treatment: Defining the Issues** *Defining the stages of retention along the continuum of care, highlighting issues with definitions and monitoring systems, strategic interventions.* **3. Elvin Geng: Retention in Care Among HIV-infected Patients in Resource Limited Settings** *Identifying challenges to defining and assessing retention in care and highlighting implications of ascertaining true outcomes among "lost" patients.* **Discussion**
Country Experiences with Retention: Risk factors for loss to follow-up and strategies to improve retention **1. Rachel Baggaley: Survey on Retention in HIV Care: A summary of findings** *An analysis of survey results on retention in 20+ priority countries and barriers to retention at each stage in the continuum of care.* **2. Frank Chimbwandira – MoH Malawi: Retention in ART programme in Malawi** *An overview of issues with retention in Malawi and some strategies being implemented.* **3. Masaya Kato – WHO Viet Nam: Monitoring and promoting retention across continuum of HIV prevention, diagnosis and care in Viet Nam** *An overview of the Viet Nam experience of retention in a concentrated epidemic, mainly IVDU, and the Treatment 2.0 pilot programme* **Discussion**

Country Experiences with Retention: Risk factors for loss to follow-up and strategies to improve retention (contd).

4. Wezi Kaonga, MoH Zambia: Risk factors for LTFU and strategies to improve retention
An overview of risk factors for attrition in Zambia, rollout of a structured tracking system for patients LTFU, and other suggested retention strategies.

5. Kebba M. Jobarteh – CDC Mozambique: Absorption, Retention and Empowerment: Addressing the root causes of attrition through scale-up of Community Adherence Support Groups
An overview of risk factors for attrition in Mozambique, and an introduction to an innovative strategy to improve retention by Community Adherence Support Groups.

6. Yazdan Yazdanpanah: Implementing interventions to decrease LTFU rates in Redemption and JFK hospitals in Monrovia, Liberia
An overview of barriers to retention in Liberia in pre-ART and ART care.

7. Irina Eramova, EURO: Retention in HIV care and ART: data from 12 eastern European countries
An overview of barriers to retention in Eastern Europe, a concentrated epidemic of mainly injecting drug users.

Discussion

Moderated panel discussion with all country representatives to answer questions from floor and discuss challenges to retention in RLS

Day 2: 14 September – Monitoring and Evaluating Retention

Session topic/ Presenter

Setting the Stage: The role of M&E

Jean-Michel Tassie: How better M&E can improve retention. Monitoring retention in the continuum of care
How monitoring and evaluation can impact on patient and programmatic service provision from the point of testing; importance of defining indicators.

Country Experiences with M&E for Retention:
Monitoring and tracking information over the continuum of care; identification of missing patients

1. **B.B. Rewari, NACO India: Enhancing Retention in HIV Care: utilizing M&E systems**
Examples of M&E tools utilized in India to improve retention and suggested strategies for M&E at each Step in the continuum of care from testing to ART and beyond.

2. **Mean Chhi Vun, MoH Cambodia: Systematic Linkages within and between Health and Community Based Support Services to Strengthen Referral and Follow HIV Patients and Retention in ART: Experience from Cambodia**
Examples of M&E tools utilized in Cambodia for continuity of care with a focus on Patient Monitoring System (PMS) and Continuous Quality Improvement (CQI) indicators.

3. **Meg Osler, University of Cape Town: Using a tiered M&E system to enhance linkage, integration and long-term retention in care**
Experience of a 3-tiered M&E system and the potential for linkage with other services, with a focus on the Western Cape.

4. **Yibeltal Assefa, MoH Ethiopia: M&E of HIV/AIDS services and linkage and retention of HIV/AIDS patients in Ethiopia**
Experience of an M&E system in Ethiopia and challenges. Importance of a coordinated M&E system for better linkage and retention.

Discussion

Working groups:
M&E in retention/attrition in the continuum of care.

Objectives: *Split into groups, come to consensus on*
1) glossary of terms
2) period definitions
3) missing data
4) data-generation and simplification

Feedback from morning working groups:
15 minutes per group to present

Retention in PMTCT, Paediatrics, TB/HIV:

1. **Laura Ferguson and Debby Watson-Jones, LSHTM: Care for women identified as HIV positive through PMTCT programmes: Missed opportunities**
Studies of pregnant women in Tanzania and Kenya and causes of LTFU in the care continuum

2. **Leonardo Palombi – DREAM : Multi-country presentation - DREAM: A strategy for retention of women in PMTCT programmes**
An overview of the DREAM project, an innovative strategy to enhance retention of pregnant women in HIV care.

3. **Shaffiq Essajee, WHO: Retention of children in HIV/AIDS programmes**
An overview of challenges specific to retaining children in HIV care programmes and their vulnerability.

Discussion

Retention in PMTCT, Paediatrics, TB/HIV (contd):

4. **Molly McNairy, ICAP, Columbia University: Retention Across the Paediatric Age Continuum: ICAP Programme Level Data**
An overview of ICAP paediatric, pregnant and non-pregnant youth retention data.

5. **Eunice Mmari, CDC Tanzania: Specific issues for adolescent retention in Tanzania**
An overview of the challenges faced with retaining youth in care, and suggested strategies.

6. **Delphine Sculier, WHO: Retention in Specific Populations: TB and HIV**
An overview of challenges faced in retaining HIV/TB co-infected patients and some suggested strategies including integration of care.

Discussion

Day 3: 15 September – Responding to Low Retention: Decentralization and Integration

Session topic/ Presenter

Setting the Stage: Linking decentralization, integration and retention

Eyerusalem Negussie, Chris Duncombe, WHO:
Definitions, plans for normative guidance and an update from IAS, and discussion of proposed PICO questions and methodology for systematic reviews.

Discussion/ 30mins

Decentralization and Integration: Critical interventions to expanding access and improving service delivery

1. **Peter Drobac, PIH: The role of the community in strengthening decentralization**
   Experience of Partners in Health-Rwanda in decentralizing care with a focus on CHW.

2. **Helen Bygrave, MSF: Improving access and retention through decentralization and community models of ART delivery**
   How the community can empower and support patients to enhance retention through decentralization and Community Adherence Support Groups

3. **Paula Braitstein, IU- Kenya: Community testing, decentralization and integration to improve retention: Experience of the AMPATH programme in Kenya**

4. **Elat Bosco Ministry of Health Cameroun: Decentralization of services in Cameroun**

Discussion

Working Groups:
Strategies to improve retention at each stage of the HIV care continuum, within a framework of decentralized, integrated care.
Discuss ways to improve retention at each step.

Group 1: HIV testing to enrollment in care

Group 2: Enrollment in care to eligibility testing

Group 3: Eligibility to enrollment in ART

Group 4: ART enrollment to lifelong retention

Reconvene for discussion of group work/next steps
15 minutes per group to present

Wrap up and close

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In alphabetical order

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ABBREVIATIONS

ART	antiretroviral therapy
CASG	Community Adherence Support Group
CHW	community health worker
CTX	co-trimoxazole (prophylaxis)
EWI	early warning indicators (of developing HIV drug resistance)
HTC	HIV testing and counselling
ICAP	International Centre for AIDS Care and Treatment Programs
IDU	injection drug use
IMCI	integrated management of childhood illness
IPT	isoniazid preventive therapy
M&E	monitoring and evaluation
MARPS	most at risk populations
MMT	methadone maintenance therapy
LTFU	loss to follow-up
OI	opportunistic infection
OST	opioid substitution therapy
PICO	Population, Intervention, Comparison, Outcomes *Framework by which WHO guidelines are developed to address a particular public health issue in collaboration with a Guidelines Review Committee and Cochrane database systematic literature review*
PIH	Partners in Health
PLHIV	people living with HIV
PMTCT	prevention of mother to child transmission
POCT	point of care testing
PWID	people who inject drugs
The 3 I's	Intensive Case Finding (ICF – in HIV/TB care), isoniazid preventive therapy (IPT), Infection Control (in HIV/TB care)
UA	universal access
UNGASS	United Nations General Assembly Special Session (on HIV)

GLOSSARY OF TERMS

This provisional glossary of terms is provided to help with reading this document. Further details surrounding the various terms, definitions and period definitions are provided in Section 6 to better capture the Working Group discussions. As no consensus on terminology was achieved during the meeting these definitions as well as period definitions will be looked at in more detail and agreed upon during follow up work in 2012.

Consistency of terminology is especially important for monitoring and evaluating HIV services which in turn is critical to improving HIV service quality and delivery.

Adherence: Compliance with a prescribed medication or treatment regimen.

Care continuum: The continuum between identification of PLHIV and initiation and maintenance of treatment. This is defined by 4 Steps starting from a positive HIV test to enrolment in care, enrolment in care to assessment for ART eligibility, ART eligibility to initiation of ART, and finally continuation of lifelong ART.

Contact: A patient's contact with the healthcare facility/ programme. This can be a clinic visit (review by a clinician or allied health staff member), medication pick-up, attendance at laboratory services, or telephone review.

Decentralization: usually refers to a political reform, designed to reduce the extent of central influence and promote local autonomy. While this reform is rarely focused on improving health services, it does engender changes in the authority and often financial responsibility for health services. Hence, decentralization can have a large impact on health service performance.

Two forms of decentralization often applied within the health sector are:

- **Deconcentration:** This form of decentralization (sometime referred to as "administrator" or "ministrative," decentralization) transfers authority and responsibility from a central Ministry of Health to field offices of the Ministry at a variety of levels (regional, provincial, and/or local)
- **Delegation:** This form of decentralization transfers authority and responsibility from the Ministry of Health to organizations not directly under its control (i.e. non-governmental agencies).

Follow-up: An intended contact. This includes a formal appointment, telephone contact, or referral.

Integration: The provision of related healthcare services together to facilitate continuity of care and may improve convenience for the patient. Integration may be functional or structural.

Linkage to care: The concept of linkage or linkages to care is variously defined. Some consider linkage or linkages to care as an "ongoing process during which the client comes to assimilate his/her diagnosis, understand the implications of an HIV diagnosis for self and others, to opt for appropriate care and services, and to commit to a regimen that enhances one's own health and protect that of others."[1] Other experts consider it to represent the actions that occur subsequent to HIV diagnosis that support a newly diagnosed PLHIV to successfully engage in HIV care, support, and treatment. In this document, we use the term to specifically refer to the period starting with HIV diagnosis and ending with initial enrollment in HIV care and treatment.

Loss to follow-up: Patients who are lost from the continuum of care with unknown outcomes. This is period sensitive.

Pre-ART period: The concept of the pre-ART period is variously defined. Some researchers consider all points prior to initiation of ART, i.e. Steps 1, 2 and 3 of the care continuum, to be part of the pre-ART period. In this document we use the term to refer to the period between enrolment at an ART clinic and initiation of ART. Pre-ART is a commonly used term reflecting the time between enrollment and initiation – it is important to highlight that a package of HIV prevention, care and support should be available during this time and that it is not viewed as simply as a waiting timeframe for ART.

Retention in care: Ensuring that the client continues to receive appropriate services (from both the client and provider perspective) throughout the continuum of HIV care and support.

Visit: Contact with care.

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