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).