Ensuring an Effective Continuum of Response and Cascade of Care for Persons Living with HIV in Uganda

From HIV testing to prevention and treatment

The primary goal of the Continuum of Response (COR) approach is to provide clients and their families with the essential prevention, care/support, and treatment services to reduce HIV transmission and disease progression and to maximize health outcomes. Following diagnosis of HIV, the next step along the COR cascade is linking persons living with HIV (PLHIV) to care and treatment, retaining them in care, and ensuring that they receive all recommended services, often referred to as the cascade of care.

Linkage and enrollment into care and treatment involves a range of processes after initial HIV diagnosis, including: patient referral to an HIV clinic or care setting; initial baseline clinical and laboratory assessment (clinical staging and CD4 count); provision of a pre-antiretroviral therapy (ART) care package, such as sexually transmitted infection (STI) screening, tuberculosis (TB) screening, nutrition assessment, counseling and support, and cotrimoxazole prophylaxis; ART preparation and early initiation if eligible; and retention and adherence counseling and support.

Approach to ensuring an effective Continuum of Response

Uganda has adapted modern quality improvement (QI) approaches to improve linkage and enrollment from HIV testing and counseling (HTC) into care and treatment in order to sustain reductions in morbidity, mortality, and transmission of HIV. A continuous quality improvement approach is applied to achieve actual improvement at the site level, complemented by the collaborative improvement approach which establishes a learning environment to facilitate rapid dissemination of successful changes and best practices among a large number of teams. A collaborative is a time-limited, organized effort of shared learning by a network of teams to make changes in support systems and delivery processes to achieve better results and scale up packages of changes that have proven effective.

Part of the first phase of this work includes providing support to 50 health facilities across Uganda through implementing partners funded by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR): USAID, Walter Reed, Department of Defense, The MildMay Center (funded by the U.S. Centers for Disease Control and Prevention), and the QI technical assistance partner, USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project. The facilities, which are testing changes in support of the Continuum of Response, include 18 general hospitals, 23 health center IVs, 8 health center IIIIs, and one health center II. In collaboration with Ministry of Health (MoH), lessons learned on the best practices...
and proven interventions will be scaled up and, where appropriate, will also be used to inform national
guidance and policies.

Community Viral Load suppression (defined as an aggregation of individual viral loads of people infected
with HIV in a specific community) will be used as a benchmark for measuring outcome achievements of
the COR through AIDS Indicator Surveys.

With input from frontline health workers, a simple COR model (Annex 1) was developed that can be easily
understood by the different levels of health professionals in the field. This COR model was developed
through a systematic process:

- A common set of indicators based on MoH standards in each program area was established. These indicators are used as a reference point to assess performance gaps and measure improvements.
- Priority populations that had higher drop-offs along the cascade due to a number of reasons (structural, socio-economic, personal characteristics, etc.) were identified. These included: HIV-positive pregnant women and their babies, children, and TB/HIV co-infected patients.
- The care pathways for the priority population groups, including inter-facility, intra-facility, and facility-community, were identified.
- A system was established to test and develop change packages that if proven effective, can be replicated in other facilities under similar settings.
- Site- and program-level data are reviewed routinely. Improvements are documented and tracked using simple tools, including run charts, dashboards, and narratives in QI team documentation journals.

A large part of the COR and cascade of care is reliant on a strong facility-community linkage. As such, PEPFAR Uganda is supporting the concept of Linkage facilitators as part of our efforts to improve linkage, patient engagement, and retention. Linkage facilitators are members of the community structures already recognized by the government, such as Village Health Teams (VHTs), PLHIV networks, and expert clients, whose role is three-fold, to:

1) Provide care (e.g., nutrition screening, TB screening) and support (psychosocial, linkage to social services) to HIV-positive clients in the community, in order to support them to remain in care and adhere to treatment;
2) Understand reasons for non-adherence if any, and bring that to the attention of health workers;
3) Link the clients who have dropped off the continuum cascade back into care.

**Results**

To effectively measure the gaps along the COR and cascade of care, it was important to address the data
quality issues (accuracy, completeness, and reliability) at each facility as a first step. Some changes
tested to improve these areas were: reorganizing the filing system and assigning specific staff the role to
retrieve files (usually an expert client volunteer); on-the-job mentorship on data recording and reporting;
and assigning a focal person to regularly review the records for completion.

Subsequently, through data reviews, quality gaps and barriers to linkage and retention were identified
along the different care pathways. Each facility prioritized their improvement aims and developed
improvement plans to address those gaps. Multi-disciplinary QI structures were established where they
were non-existent, and existing QI teams received refresher training on applying the QI methodology to
improve linkage and retention along the care cascade.

**Improving HIV testing**

Provider-initiated HIV testing and counseling (PITC) is a key pivot for the PEPFAR Uganda program.
Facilities carry out PITC at key entry points within the facility (outpatient department, inpatient
department, TB clinics, child health clinics, maternity wards and antenatal care points). Family members
of HIV-positive individuals are also tested at the facility and at community outreaches. Those identified as HIV-positive are referred to HIV care and treatment centers of their choice. Those found to be HIV-negative are counseled on staying negative and linked to preventive services such as Safe Male Circumcision (also called Voluntary Medical Male Circumcision) and condom distribution points and encouraged to re-test for HIV based on their risk assessment. As shown in Figure 1, HIV testing in 15 of the 50 sites that prioritized HTC increased from 2517 clients in May 2013 to over 10,000 clients in November 2014.

Successful changes tested were:

- Creation of more testing points within the facility.
- Engaging more staff members in HIV testing beyond the laboratory staff.
- Routine review of HTC, pre-ART and ART registers to ensure accuracy and completeness.

Figure 1: HIV testing among adult across 15 facilities in Uganda, May 2013–January 2015

Improving linkages

Clients tested HIV-positive are being linked to HIV care and treatment clinics either within the health facility (intra linkage) or other facilities, based on the preference of the client. Referral forms have been introduced for inter facility linkage, while linkage facilitators have been assigned the role of physically escorting the HIV-positive clients to the HIV care and treatment centers within the facility. On arrival, clients are enrolled into care and assigned a pre-ART number, counseled on positive living, initiated on cotrimoxazole prophylaxis, assessed for eligibility (using the WHO clinical staging or CD4 count), screened for TB, opportunistic infections (OIs), and nutritional status, and given an appointment date for follow-up care. ART-eligible clients are offered ART adherence counseling, and once ready, are initiated on HAART. Figure 2 shows results from three facilities for linking and enrolling newly-diagnosed HIV-positive clients into care.

Examples of changes tested by the facilities to improve linkage include:

- Tagging HIV care cards of eligible clients with easily identifiable stickers.
Transferring the HIV testing point from the laboratory to a designated room at the outpatient department and other key entry points.

■ Placing posters on the walls as reminders for staff to update the HTC registers at testing points.
■ Written referrals for new HIV-positive clients to ART clinic.
■ Physically escorting newly diagnosed HIV+ clients to the ART clinic; done by expert clients.
■ Enrolling-HIV positive patients into care on the same day, especially when testing is done on HIV clinic days.
■ Placing reminders for the health workers to update patient records, especially the clinical staging and CD4 sections of the care card, once results are received from the laboratory.
■ Eligible clients are immediately registered in the counseling register, which the clinicians then use to identify clients ready for ART. This register is used to quantify and place orders for antiretroviral drugs needed for the next cycle. This information is also used by the facility teams to re-allocate staff time for the HIV clinic to ensure adequate staff are available to initiate eligible clients on ART.

Of these changes, two seemed to have had the most impact on linkage more patients into care: 1) Physically escorting newly diagnosed clients and 2) same-day enrollment.

Figure 2: Percentage of newly tested HIV-positive clients linked and enrolled into care in three health facilities, October 2012–November 2013

Early initiation of ART-eligible clients

To minimize the time it takes to initiate eligible clients on ART, a number of process improvements were undertaken to address barriers identified and reduce ART preparation time. These included:

■ The use of file stickers marked ‘ART eligible’ that are placed on patients’ files to easily identify eligible clients.
■ Use of a counselor register to note that eligible clients were started on ART
■ Changing the sequence of ART counseling sessions for eligible clients to reduce the pre-ART sessions from three to one but add at least two individual-focused sessions with a clinician and
subsequently regular adherence counseling sessions with expert clients (when a client is already
started on ART).
- Reinforced implementation of the MoH HIV pediatric guidelines where all children under 15 years
are to be started on ART.

Figure 3 shows progress in initiating pediatric clients on ART in 49 pilot sites.

**Figure 3: Percentage of pediatric HIV-positive clients started on ART in 49 facilities, October 2012–
September 2014**

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**Retention in care and treatment**

Retention in pre-ART and on ART entails a number of processes, which include the following:

- Ensuring pre-ART and ART clients keep their clinic appointments.
- Ensuring 100% of adults and children in pre-ART care are regularly assessed for ART eligibility
  (either clinical staging or receive CD4 test every six months).
- Ensuring 100% of eligible adults and children are started on ART.
- Ensuring at least 80% of adults and children on ART are retained in care.

In April 2013, PEPFAR Uganda reported overall a lower retention in pre-ART at 67% compared to
retention on ART at 85%. Figure 4 shows improved retention in care at two hospitals in Eastern Uganda.

Examples of changes tested by the facilities to improve retention include:

- Performing a CD4 test immediately upon enrollment.
- WHO clinical staging charts pinned in clinician rooms for quick reference.
- Regularly updating MoH patient monitoring tools, including recording CD4 results as soon as
  these results are received from the laboratory.
- On-the-job mentorship for health workers on how to carry out eligibility assessment.
- Conducting home visits to all the clients that have been linked to community support structures to
  remind them of their appointment dates and address any adherence or retention issues.
- Sensitize and engage local council leaders, religious leaders, and elders in community QI
  activities with particular focus on addressing barriers to retention and adherence.
Figure 4: Percentage of HIV-positive clients keeping their appointments at two hospitals in Eastern Uganda, April 2013–November 2014

Challenges to improving linkage and retention

Because of the chronic understaffing and poor clinic organization, QI work is often perceived as additional work; as a result this affects the sustainability of QI interventions and improvements. The Ministry of Health and the district health offices are considering setting up rewards and motivational initiatives to recognize and reward teams that are performing well.

Recurrent stock-out of essential HIV commodities such as HIV test kits and laboratory reagents impedes improvement efforts.

The issues surrounding stigma and disclosure are also major barriers to accessing testing and care and treatment. The quality of adherence and retention programs is further affected by the limited number of professionally trained counselors and support programs and use of non-professional counselors, such as expert clients. This will need to be addressed if we are to achieve our goals.

The lack of a unique identifier number and poor or non-existent electronic data systems make it difficult to effectively track patients. However, the ongoing national ID registration and scaling up of the electronic patient monitoring systems in high-volume sites will have a positive impact on QI interventions.

Conclusion

Actively linking patients who test HIV-positive to care is important to get a critical number of people with HIV on treatment and care. Subsequently, there needs to be a deliberate and active effort by the care team to retain these patients in care. Going forward, lessons learnt will be spread to more facilities that offer HIV care and treatment. The same lessons can be applied to improve the enrollment on treatment and retention for patients with other chronic diseases like diabetes and cancer.
Annex 1: HIV Continuum of Response

**HIV Continuum of Response**

- **Linkage gap**
  - HIV Testing
  - PMTCT: Mother-baby pairs eligible for PMTCT identified
  - TB-HIV: All TB-HIV co-infected adults and children identified

- **Coverage gap**
  - HIV Care and Treatment: All HIV-positive adults and children identified
  - Treatment initiated (pre-ART or ART)
  - PMTCT initiated (Option B+, mother-baby nutrition assessment and counselling)
  - Treatment initiated (anti-TB drugs and ART)

- **Retention gap**
  - Retained in care (Pre-ART or ART)
  - Retained in PMTCT care
  - Retained on anti-TB drugs and ART

- **Wellness gap**
  - Clinical wellness or viral suppression
  - HIV-free children and clinically well mothers
  - Mothers linked back to HIV clinic at 18 months
  - TB treatment success/cure and clinical wellness

- **Outcomes**
  - Community services including, but not limited to: adherence and retention support, nutrition and TB screening, and home-based care

- **HIV prevention**
  - Safe Male Circumcision; prevention messages and BCC; condom distribution; risk reduction counseling