A Proactive Follow-up Intervention to Improve Linkage and Retention among HIV Patients

Evidence from a DFID-funded evaluation in Uganda

BACKGROUND AND OBJECTIVES

Despite gains in HIV testing and treatment access in Uganda and elsewhere in sub-Saharan Africa, linkage to and retention in care for patients with HIV remains a persistent challenge, particularly for pediatric and adolescent patients. Although several interventions have been put into place to increase linkage/reduce attrition, implementation has been inconsistent across sites. Strong evidence on cost-effective, scalable, and sustainable improvements in the general ART patient population is lacking.

In this study, CHAI in conjunction with the Uganda MOH implemented a proactive follow-up intervention at 20 facilities in Central Uganda with low retention at baseline and assessed HIV patient linkage to care and six-month retention in care before vs. after rollout of the intervention.

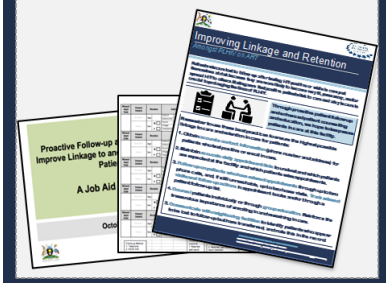
INTERVENTION OVERVIEW

The intervention was implemented in 20 randomly selected facilities across 14 districts in Central Uganda with high ART patient volumes (>120 per year) and low patient retention (35%-75% annually, according to 2015 DHIS 2 estimates) at baseline.

FIGURE 1. INTERVENTION COMPONENTS

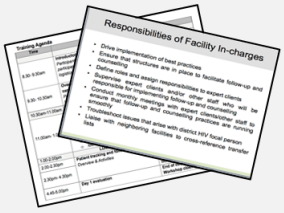
Intervention 1: Expert client training and accountability:

- Training in best practices for linkage/follow-up, clearly defined roles and responsibilities



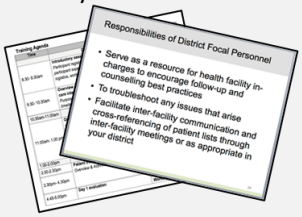
Intervention 2: Facility in-charge training and empowerment:

- Training in best practices for patient linkage/follow-up, clearly defined supervisory roles and responsibilities



Intervention 3: District oversight:

- Strengthening district supervision of patient follow-up at facilities through supervision and monitoring, stronger facility communication



Best practices included:

- Improved tracking of patient appointments, contact information, and follow-up
- Strengthened patient education/counseling services to emphasize importance of staying in care
- Up to 2 phone calls and 2 home visits to patients who missed appointments or did not link to care

Financial and logistical support: Also provided facilities with a cellphone and small amount of monthly funding for phone follow-up/home visits. Optional tools were provided to enhance documentation of patient follow-up.

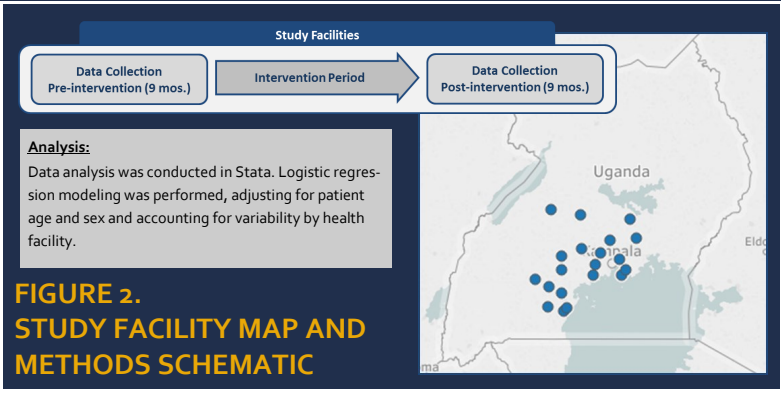
EVALUATION OVERVIEW

The intervention was implemented in November, 2016. Patient records and health registry data from the 9-month periods before and after implementation were compared to assess changes.

The primary outcomes evaluated were:

- ◊ Linkage to care: patient testing positive at the facility enrolled in pre-ART or ART care within 1 month of testing
- ◊ Retention in care: Patient newly initiated on ART who visited the facility at least once over the final quarter of follow-up (months 3-6 of study; MOH definition)

Patient adherence to appointment schedules were assessed as well. Interviews and focus groups with patients and healthcare staff were conducted to assess program success and areas for improvement.



Analysis:
Data analysis was conducted in Stata. Logistic regression modeling was performed, adjusting for patient age and sex and accounting for variability by health facility.

FIGURE 2. STUDY FACILITY MAP AND METHODS SCHEMATIC

RESULTS

RESULTS: LINKAGE

1900 newly-diagnosed patients were included in the assessment of linkage. Patients who died (N=2) or reportedly transferred to another facility (N=43) during follow-up were excluded from the primary analysis. There were not substantial differences in demographic characteristics of patients in the pre-intervention sample vs. post-intervention sample. At baseline, linkage was low (52.9%) and was slightly higher in men (p=0.06) and lower in adolescents ages 15-<19 years (p=0.003 compared to adults 19-<49 years). Patients who did not link within one week were unlikely to link at all in the 3 months of follow-up. The **cost per** additional person linked within one and three months is **$119** and $108 respectively.

There were small increases in linkage to care after implementation of the intervention, but increases were not statistically significant regardless of the timeframe assessed. Linkage to care did not change substantially over the intervention timeframe and there were not statistically significant increases in analyses stratified by age group.

However, change in linkage to care after implementation of the intervention varied greatly by facility and several facility-level characteristics predicted greater increases in linkage to care, including smaller (level III) facilities, facilities with fewer expert clients, and facilities reporting phone funding as an issue at baseline.

TABLE 1. CHARACTERISTICS OF PATIENTS TESTING HIV+

Characteristic	Pre-intervention		Post-intervention	
	N	%	N	%
Total	928		972	
Female	558	60.1%	586	60.3%
Age <19 years	152	16.4%	148	15.2%
Stage III or IV at dx	25	2.8%	22	2.3%
Outreach	*Not available*	*Not available*	98	10.1%
First HIV test	*Not available*	*Not available*	372	38.3%
Known TB positive	*Not available*	*Not available*	33	3.4%

FIGURE 3. PATIENT LINKAGE TO CARE PRE VS. POST INTERVENTION

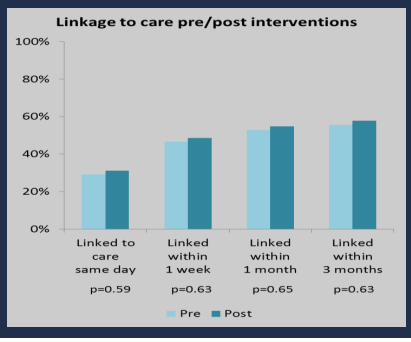
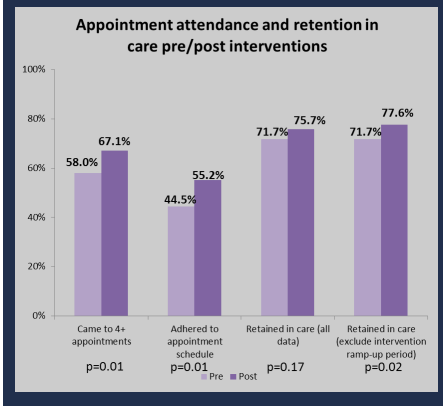
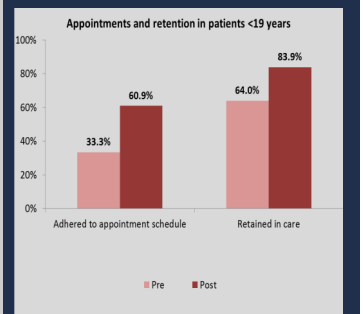


TABLE 2. CHARACTERISTICS OF PATIENTS NEWLY INITIATED ON ART

Characteristic	Pre-intervention		Post-intervention	
	N	%	N	%
Total	678		678	
Female	408	60.2%	446	65.8%
Age <19 years	50	7.4%	62	9.2%
Stage III or IV at initiation	*Not available*	*Not available*	35	5.1%
<3 mos from dx to ART initiation	*Not available*	*Not available*	316	46.6%
Pregnant at initiation	*Not available*	*Not available*	129	19.0%

FIGURE 4. PATIENT APPOINTMENT ATTENDANCE AND RETENTION IN CARE PRE VS. POST INTERVENTION OVERALL AND AMONG PATIENTS <19 YEARS ONLY





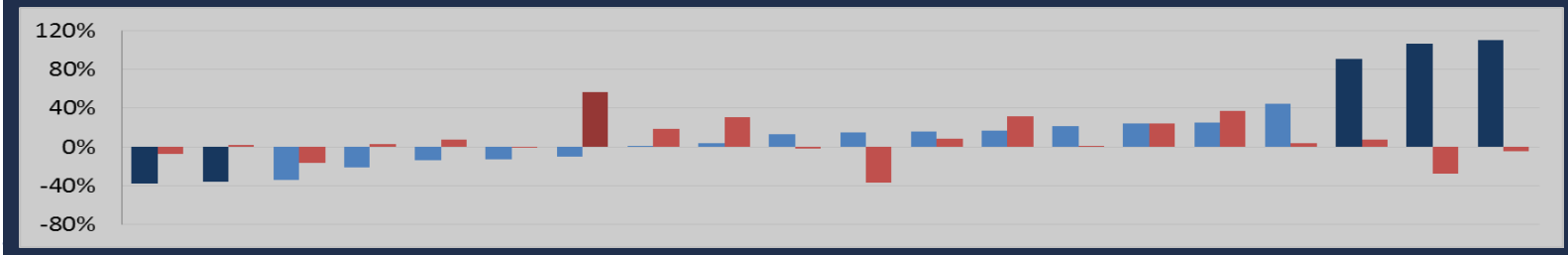
RESULTS: RETENTION

1356 patients newly initiating on ART were included in the assessment of retention. Patients who died (N=28) or reportedly transferred to another facility (N=59) during follow-up were excluded from the primary analysis. There were not substantial differences in demographic characteristics of patients in the pre-intervention sample vs. post-intervention sample. At baseline, retention was slightly higher in men (p=0.03); there were not statistically significant differences by age but statistical power was limited in younger age groups.

Of note, most patients were already falling behind schedule at their first appointment after ART initiation; at baseline, the median time between ART initiation and first follow-up appointment was 28 days (IQR: 27-42) compared to national guideline recommendations of a first follow-up appointment 14 days after initiation..

After the intervention, there were statistically significant increases in patient appointment attendance and adherence to appointment schedules. There was a small increase in the percentage of patients coming for at least 1 appointment in the final 3 months of follow-up—Ministry of Health-defined retention; when data from the period of intervention ramp-up (defined as the first month of the intervention) was dropped, this increase became statistically significant. The increase in appointment adherence and retention was more dramatic for patients under age 19 years.

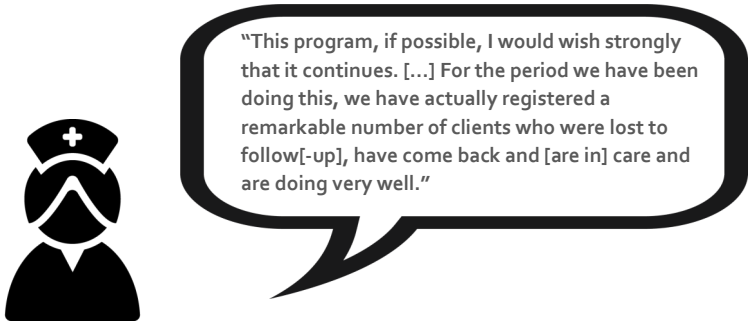
FIGURE 5. CHANGE IN LINKAGE (BLUE) AND RETENTION (RED) ACROSS STUDY FACILITIES



Note: Darker color represents facilities where % change was statistically significant.

PROGRAM VARIABILITY

Change in linkage and retention varied widely by facility, and change in linkage did not necessarily correlate to change in retention. Retention improved more in facilities with stronger leadership and participation in the intervention.



PROGRAM ACCEPTABILITY AND FEEDBACK

Unanimously, healthcare staff and patients had positive feedback about the program and felt strongly that it should continue. Some challenges and areas for program strengthening were identified

Key outstanding challenges included that many patients did not have a phone or were migratory and thus were difficult to reach for follow-up. Some patients also felt stigmatized to be visited at the home, although others indicated that the phone calls and home visits made it clear that the healthcare workers cared about them and strengthened the patient-healthcare worker bond.

FIGURE 6. SUGGESTIONS FOR PROGRAM STRENGTHENING (most common suggestions underlined)

Training:

- ⇒ More training focus on all aspects of counseling, particularly for pediatric patients and discordant couples
- ⇒ Ensure that all relevant staff from facility are included in follow-up training, such as lab staff
- ⇒ Conduct training on a non-clinic day to allow for maximum focus
- ⇒ Use the local language where possible
- ⇒ Provide more time for the training if possible

Appointment Record Systems:

- ⇒ Ensure that patient contact information is reviewed on a regular basis
- ⇒ Provide appointment books to patients to help them keep track of appointments
- ⇒ Implement SMS reminders or reminder phone calls to patients the day before appointments
- ⇒ Implement electronic appointment systems
- ⇒ Improve staff motivation to ensure completeness, facilitate communication across facilities

Group Education and Individual Counseling:

- ⇒ Facilitate dedicated private space for education and counseling at the facility
- ⇒ Provide dedicated counselors at facilities or more training to lower level staff on counseling
- ⇒ Distribute charts and diagrams to facilitate counseling
- ⇒ Where possible, group clients by age, pregnancy status, and other characteristics to provide tailored counseling

Patient Follow-up via Phone Calls and Home Visits:

- ⇒ Increase funding for phone call and home visit facilitation (funding was inadequate for full follow-up in some facilities) and for expert clients performing follow-up
- ⇒ Test out phone number while the patient is there to ensure that it is correct, explain why phone number and address are needed in order to get the best contact information from patients
- ⇒ Allow for more flexibility in medication pick up (multi-month refills, community adherence groups, pick up at other facilities, transport vouchers) for patients without means for transport to the facility

A key message expressed by staff was that enhanced communication between facilities and more district level interaction would be beneficial for patient care—allowing better coordination of transfers, troubleshooting of challenges, and a stronger sense of community.

SUMMARY AND POLICY RECOMMENDATIONS

SUMMARY OF EVALUATION FINDINGS

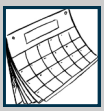
In this pre-/post– evaluation of a strengthened management intervention to improve proactive patient follow-up and enhance counseling practices, the following key findings were observed:

1. **Linkage and retention were low in the study facilities at baseline**
   - Slightly higher in men, lower in adolescents, and highest in older adults
   - Most patients who were lost to follow-up were lost early on
2. **The intervention did not increase linkage to care overall**
   - Numerous contributing factors; only some could be addressed by the intervention
   - However, there were greater gains in linkage at smaller facilities and facilities with fewer expert clients, pointing to gains in efficiency with the intervention
3. **The intervention increased patient appointments, adherence to appointment schedules, and (in some models) retention in care**
   - Improvements were most dramatic for pediatric and adolescent patients
   - Change in linkage and retention varied greatly by facility and were not necessarily correlated to each other within each facility
   - Gains were greater at facilities with stronger observed leadership and greater participation in the intervention
4. **Patients and healthcare workers felt that the program was effective** but noted outstanding challenges and provided suggestions for future program strengthening

POLICY RECOMMENDATIONS

Given the success of this intervention on improving patient appointment adherence and retention in care, particularly for pediatric and adolescent patients, implementation by partners is recommended in facilities with low patient retention, in particular:

Training of district health staff, facility in-charges, expert clients, laboratory staff and other relevant staff at the facility on follow-up and counseling best practices



Strengthened appointment record systems including regular updates to patient contact information, provision of patient calendars, SMS reminders/phone calls to remind patients of upcoming visits

Adequate compensation of expert clients or other staff performing patient follow-up and counseling

Additional focus on patient education and counseling including dedicated private space and materials to facilitate patient learning

Provision of working phones and adequate funding for phone airtime for follow-up of patients who miss appointments and communication with neighboring facilities

Adequate funding for transport to patient homes for home visit follow-up for patients who cannot be reached by phone

Develop facility and ART in-charge directory to aid facility staff in referring patients and tracing self-transfers

With full implementation of the interventions above, facilities may also see improvements in linkage to care in some settings. Issues such as transient patient populations and stigma remain challenges; innovative approaches are needed to continue to address these issues. Finally, additional support/engagement is needed at the district level to further improve facility performance.

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