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# The ELMA Unfinished Business Project in South West Uganda

## Closing the Adult- Pediatric Treatment Gap

### Background

While Uganda achieved significant reduction in new HIV infections among children by 2014, pediatric antiretroviral therapy (ART) coverage has been slow. By June 2014, 27% of HIV-infected children were receiving ART, compared to 52% of HIV-positive adults in Uganda.<sup>1</sup> By December 2014, only 42% of children and adolescents estimated to be living with HIV were enrolled in care and treatment programs in Uganda.<sup>1</sup> Factors contributing to the low rates included poor levels of pediatric HIV testing services in facilities; only 56% of HIV-exposed infants were tested in 2012 and 2013. There was limited knowledge regarding pediatric and adolescent provider-initiated HIV testing and counseling (PITC) among health workers, and lack of standard protocols in health facilities to guide implementation of PITC.

To close the adult-pediatric HIV treatment gap, the ELMA Foundation provided funds to support implementation of activities that would accelerate pediatric HIV case identification, ensure linkage to ART, and improve the quality of chronic HIV care and treatment services for children and adolescents. In October 2015, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) in partnership with the Ministry of Health (MOH) of Uganda, launched a two-and-a-half-year Unfinished Business (UB) project to improve pediatric HIV care and treatment in six priority districts of Southwest Uganda, contributing to increased parity between pediatric and adult HIV treatment in the country by 2018. The priority districts were Bushenyi, Isingiro, Kabale, Ntungamo, Rukungiri, and Sheema. Guided by the number of children in HIV care in relation to estimates of HIV-positive children living in the catchment area of health facilities within the six districts. The MOH identified 34 health facilities with the widest gap in pediatric HIV care, and these were referred to as “priority health facilities”.

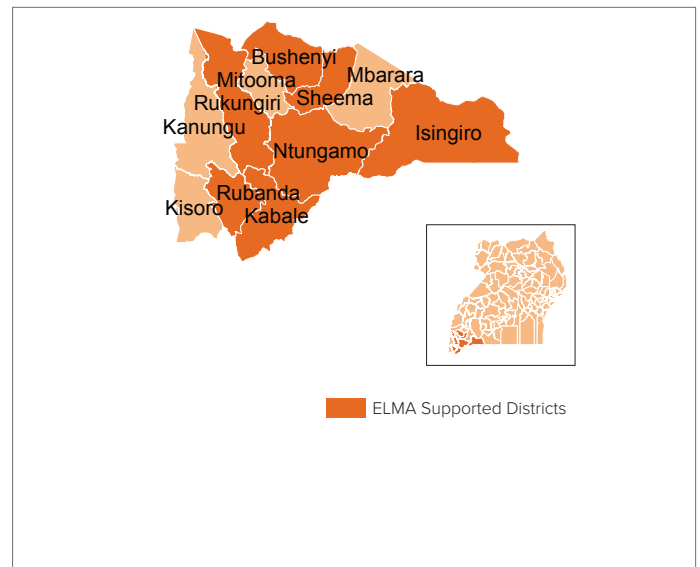


Figure 1: Map of southwest Uganda showing districts supported by the Unfinished Business project

### Objectives of the UB project

1. Promote earlier diagnosis of children and adolescents living with HIV by increasing screening, testing, case finding, and linkages to treatment and support.
2. Increase access to quality HIV treatment for children and adolescents.

<sup>1</sup> UAC (2015), The National HIV Strategic Plan, 2015/2016- 2019/2020

## Key Accomplishments

- Recruitment of human resources for health.** EGPAF used UB project funds to recruit and place counselors in priority health facilities to improve pediatric and adolescent HIV case finding through provision of pre- and post-test HIV counseling. Counselors were also responsible for improving treatment outcomes through ongoing adherence support; strengthening family psychosocial support to HIV-infected children and adolescents in care; client appointment tracking, and active follow-up of those who missed their clinic appointments. By May 2018, the UB project supported 59 counsellors in the 34 priority health facilities.
- Capacity building of health workers.** Using a quality improvement approach, EGPAF supported training and mentorship of more than 893 health workers in pediatric and adolescent PITC in the 34 priority health facilities. By close of the second year of the UB project, staff at 23 health facilities had been trained and mentored in pediatric and adolescent PITC, and staff at an additional eleven facilities were trained during year three of the project. This effort facilitated the integration of pediatric and adolescent PITC eligibility screening and testing in the routine package of services provided at service points. EGPAF also trained adolescent peer educators to strengthen the provision of psychosocial support and follow-up of children and adolescents with treatment adherence challenges. Within the region, EGPAF built the capacity of 20 regional MOH pediatric HIV trainers and mentors to provide ongoing technical assistance to health facility staff.
- Improved access to HIV testing services, especially among orphans and vulnerable children (OVC).** Uganda's MOH recommends routine provision of HIV testing to OVC. The average HIV positivity yield among OVC of ages 0-18 years in five districts of Southwest Uganda was 0.5%, second to 1.4% yield for children from routine PITC in out-patients departments. Following the training and mentorship of health workers in pediatric and adolescent PITC, HIV screening and testing of children and adolescents became routine at the different service points, which included out-patients departments, in-patient wards, OVC outreaches, young child and ART clinics.
- Introduction of the pediatric and adolescent PITC eligibility screening tool** (Appendix 1). The screening tool currently being validated under the DELTA project serves as a quick guide to identification of children at risk of HIV, who should access HIV testing services. It prioritizes targeted HIV testing among children hence improve yield and case identification. The UB project supported introduction of the tool and provided copies at service points in the targeted health facilities.
- Strengthened partnerships and collaboration with other implementing partners.** During the implementation of the UB project, EGPAF worked closely with various partners in the region. These partners included OVC partners, community-based organizations, people living with HIV (PLHIV) networks, civil society organizations, and district local governments.

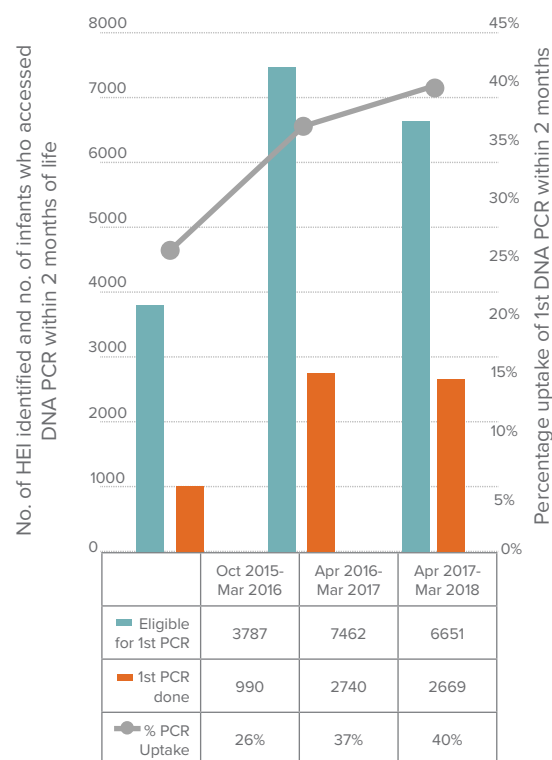
## Key Achievements

The project has achieved progress in improving pediatric and adolescents HIV treatment indicators in the supported districts.<sup>2</sup>

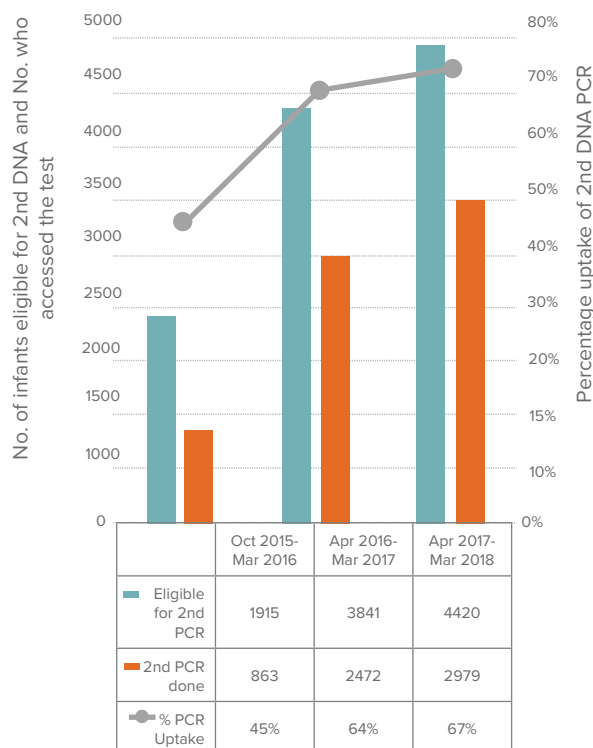
At baseline, 26% and 45% of infants eligible for the 1st and 2nd DNA PCR accessed the test (Figure 2). Following training, mentorship and coaching of service providers in Early Infant retention and Birth

Cohort monitoring, uptake of the PCR tests improved to 40% and 67% respectively by the end of fiscal year 3 of the project. The current gaps in EID uptake are mainly due to continued emigration of mothers after birth, resignation and transfer of trained service providers with replacement by midwives who are naïve to Early Infant retention and Birth Cohort monitoring.

**EID: Access to 1st DNA PCR within 2 months by HEI during FY1, 2, and 3 of the UB project**



**EID: Access to 2nd DNA PCR by HEI during FY1, 2, and 3 of the UB project**



**Figure 2: Uptake of the first and second test via polymerase chain reaction (PCR) diagnosis among HIV-Exposed infants (HEI)**

<sup>2</sup> EGPAF Uganda program data

<sup>3</sup> Ministry of Health (2016). National HIV Testing Services Policy and Implementation Guidelines. 4th Edition

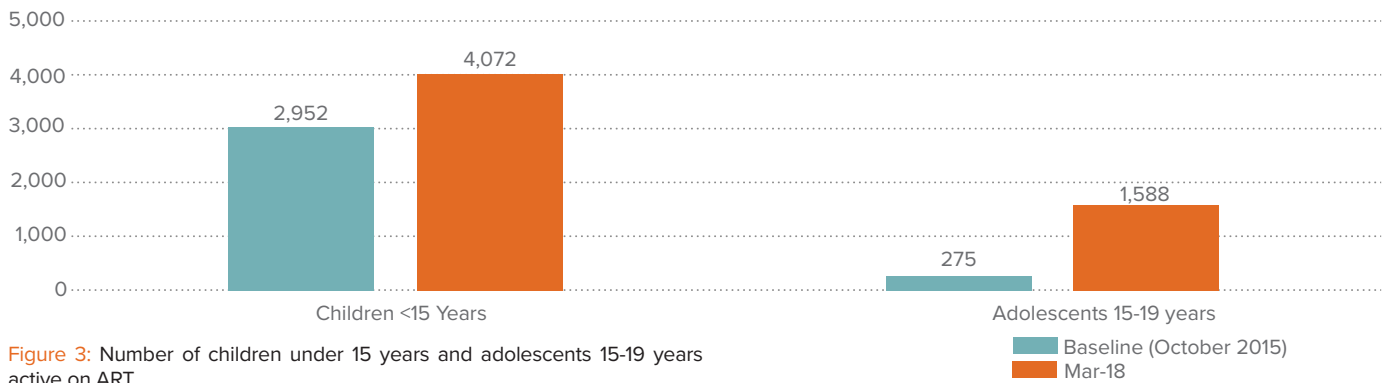


Figure 3: Number of children under 15 years and adolescents 15-19 years active on ART

The project realized a 38% growth in number of children below 15 years active on ART while adolescents 15-19 years increased by 477% (Figure 3). Limited HIV case identification among children <15 years resulted in the observed small increment (38%) of children active in care compared to the 477% growth among adolescents 15-19 years, the age bracket where sexual transmission of HIV often occurs making it easier to identify more cases in the age group and link them to care.

Whereas care givers of children <15 years, and adolescents 15-19 years received on going adherence counseling, the latter had a better improvement in viral suppression rates (11%) compared to children <15 years (1%) Figure 4. This was because children <15 years still relied on care givers for their medication yet some care givers were elderly and often forgot to adhere to the treatment schedules.

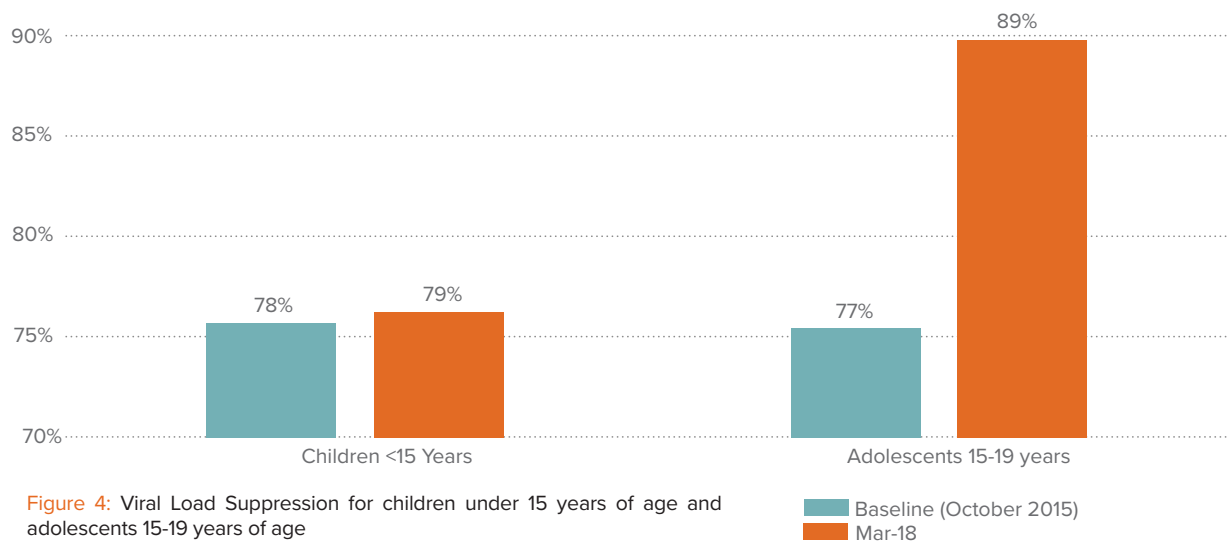


Figure 4: Viral Load Suppression for children under 15 years of age and adolescents 15-19 years of age

## Lessons Learned

- Know Your Child's Status campaigns\* were associated with very low yield and were discontinued
- Routine provision of targeted PITC to children and adolescents in outpatient departments was associated with high yield (1.4%)
- Partnerships with OVC organizations are crucial in enabling improved access to HIV testing among OVC.
- Opening ART clinics all working days to allow same-day linkages and working with linkage facilitators to physically escort newly identified, HIV-positive children and adolescents to ART clinics significantly improve treatment initiation rates.

## Challenges

- Missed opportunities for children and adolescents to access HIV testing were still seen, due to occasional stock-outs of HIV test kits which was most often due to inadequate supplies from the national system
- Missed opportunities to link all newly identified HIV-positive children and adolescents to care and ART, This was mainly observed among children and adolescents newly identified in outreaches and among those whose care givers had the tendency to seek the opinion of the parents before such children

are linked to care. Only a few of such care givers brought back the children for enrolment.

- In year two, mothers of 36 out of 122 (29.5%) HIV-positive infants identified could not be traced in the communities they earlier indicated as their home villages. Relocation of HIV-positive mothers after birth made it difficult to track infants who potentially seroconvert.
- Between October 2016 and February 2017, the turnaround time of EID results increased from the expected two weeks to two months (on average), due to delays during transportation of dry blood spots from health facilities to the central laboratories where samples were examined. There were also delays in transportation of printed results from the central laboratories to the health facilities. Delays in transportation of samples and results resulted in delayed ART initiation for some newly identified HIV-infected infants. During the period, six of the 122 HIV-positive infants identified in year two had died by the time their results were received in the health facilities.
- The 24-month retention of children and adolescents 2–19 years of age was 78% by the end of year two of the UB project, compared to 71% among adults.<sup>3</sup>

\*Know Your Child's Status Campaigns were activities that entailed mass mobilization of index clients in care to take their biological children for HIV testing at the respective health facilities.



- Stock-outs of pediatric antiretroviral formulations due to inconsistencies in the national supply chain hampered treatment initiation, retention and viral load suppression.
- Poor viral load suppression of 79% among children under 15 years and 89% among adolescents 15–19 years or age, as of the end of September 2017.

### Next Steps

- EGPAF will continue providing technical assistance to health facilities to fully institutionalize pediatric and adolescent PITC eligibility screening and testing at all service points in the priority health facilities and thus improve case identification and the yield from pediatric and adolescent HIV testing services. The technical assistance will also aim at monitoring stock levels of laboratory commodities and pediatric ARV formulations and redistribution to minimize stock-outs.
- Strengthening strategic collaboration with OVC partners with a goal of enhancing integration of HIV testing in planned OVC activities.
- Improving linkages to care by working with linkage facilitators to achieve same-day linkages and active follow-up of HIV-positive children newly identified in outreach.
- Improving retention of children and adolescents in care by facilitating counselors' provision of quality psychosocial support and through routine appointment tracking and active follow-up of those who miss appointments. Counselors will strengthen ongoing adherence counseling support to adolescents and caregivers of children, leading to improved treatment outcomes.
- Supporting Ariel club activities. Ariel club activities are

psychosocial events targeting HIV infected and affected children and adolescents. They are an avenue to engage caregivers in issues of looking after HIV-infected children, and strengthening psychosocial support to children and adolescents with expected outcomes of improved retention in care and viral load suppression.

- Continue working with existing/sustainable structures (district health officers, district health team officials, health workers, peer educators, village health teams, PLHIV networks) to implement the UB project.
- Engaging the 20 trained regional and district MOH trainers/mentors to champion and foster ongoing and future supportive supervision of pediatric HIV activities.
- Building health worker capacity for the provision of quality pediatric and adolescent HIV diagnosis, care, and treatment services.
- Mentoring and coaching health workers, especially those who are new on board to capture and report pediatric and adolescent HIV data using the standard MOH health management information system tools and electronic systems.

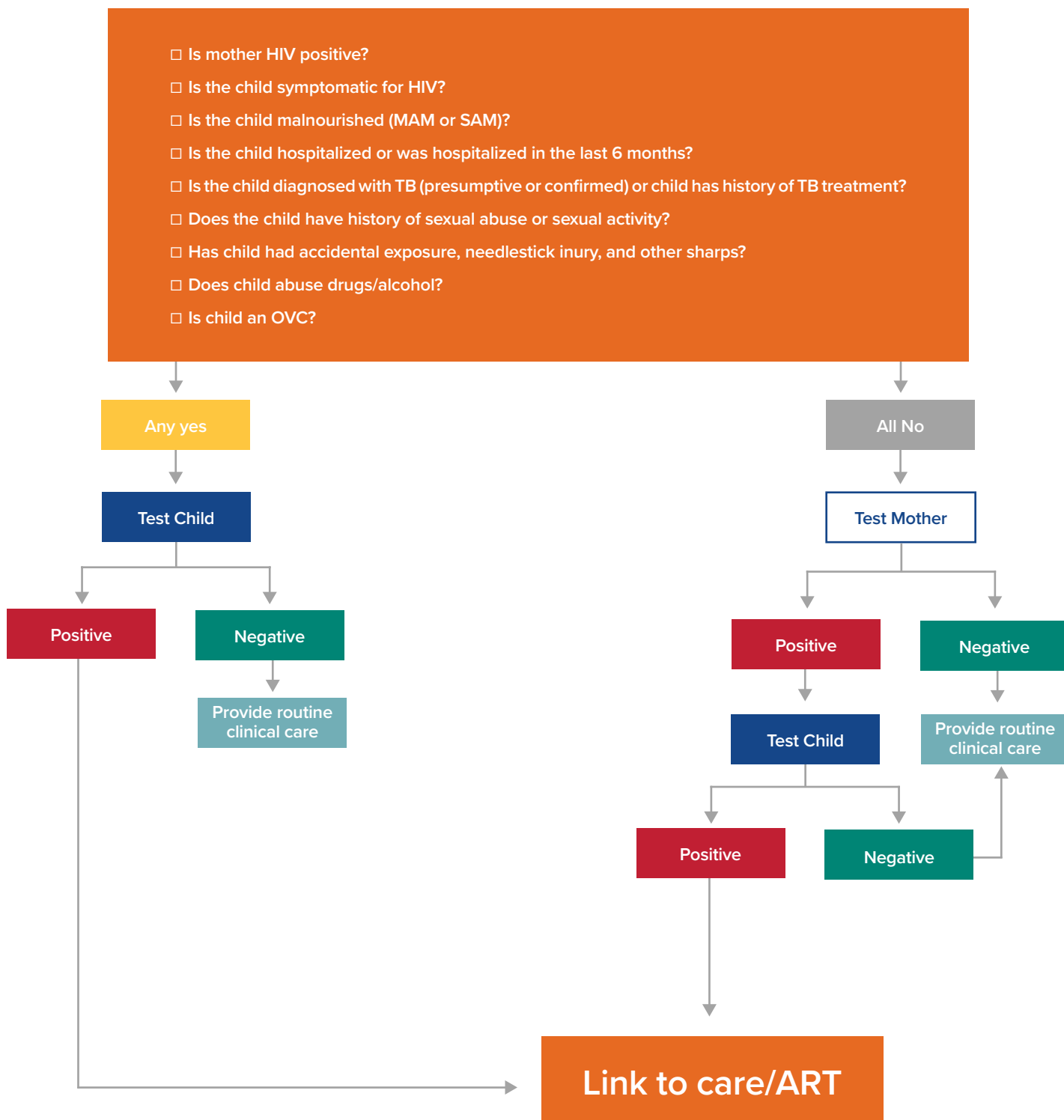
### References:

1. Uganda AIDS Commission (UAC), *The National HIV Strategic Plan, 2015/2016–2019/2020* (Kampala, Uganda: UAC, 2015).
2. GLASER database. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation. Accessed May 6th 2018
3. USAID RHITES SW October 2016 – March 31st 2017 semiannual report. Accessed June 26th 2018



Photo: Eric Bond/EGPAF, 2015

HCT guidance or children and adolescents (18mo-18 years)



All children below 18 months whose exposure status is determined using rapid testing should be re-tested using PCR following the National EID algorithm

**Retesting for children and adults**

Children testing negative should be retested in the following situations: specific incident of HIV exposure within the three months prior to HIV testing, any form of exposure after the previous Negative test, have STIs or TB, are symptomatic of HIV infection, are receiving PEP.

**The following categories of children should not be subjected to an HIV rapid test:**

1. Unaccompanied minors (children less than 12 years); unless for diagnostic or mandatory testing
2. Children and adolescents with known HIV negative status who have not had HIV risk exposure within the last 3 months and do not fall under the categories described above.
3. Known HIV positive children/adolescents