



EVALUATION OF THE ELMA  
'UNFINISHED BUSINESS'  
PEDIATRIC AND ADOLESCENT HIV  
PROGRAM IN SOUTH AFRICA

Executive Summary

June 2019

Submitted by Itad

In association with the ELMA Foundation

# Executive summary

## Introduction

Since 2013, the ELMA Foundation has invested heavily in the 'unfinished business' (UB) of accelerating HIV testing, treatment, and retention in care for infants, children, and adolescents in targeted, high-burden areas in Africa. In this context, since 2015, ELMA has been funding implementing partners in South Africa to introduce and support strategies to identify infants, children and adolescents with HIV and link them to care.

The UB program takes place in five priority districts which include the City of Johannesburg and four districts in KwaZulu-Natal (KZN): eThekweni, uMgungundlovu, Zululand, and uMkhanyakude. The initiative is being implemented as a collaborative by groups of partners<sup>1</sup> funded to increase strategies to find untested children; link them into care and onto Anti-Retroviral Treatment (ART); and retain them in care. It aimed to have a catalytic effect, building on the strengths of other HIV programming and current momentum in South Africa to reverse low rates of testing and care.

Itad has been commissioned by the ELMA Foundation to undertake an evaluation of its UB program in South Africa. As defined in the Terms of Reference, the objectives of this evaluation are:

- To assess the outcomes of ELMA's investment in the UB program.
- To inform future investments and the direction of ELMA's HIV portfolio.

## Methodology

The evaluation is focused on interrogating a theory of change for the UB program. This has provided a framework to explore whether the intended program outcomes have or have not been achieved and to examine how and why change has happened. The evaluation methodology included:

- A review of key program and contextual documents
- Analysis of quantitative program data in relation to outcomes across the HIV cascade of care.
- Primary, qualitative data collection at 12 participating health facilities and with key stakeholders at the local, national and international level.

Qualitative and quantitative data sets were analyzed separately, with partner engagement throughout the process, allowing for a robust reflection on the evidence base from each.<sup>2</sup> During the report drafting process, the two datasets were brought together, allowing for triangulation of the data, and reflection on common themes, patterns and differences to generate the findings, conclusions and recommendations.

---

<sup>1</sup> Partners for Johannesburg Health District: Wits Reproductive Health and HIV Institute (WRHI), Anova Health Institute, Right to Care, CARE, HIVSA, with WRHI as the lead on data management. Partners for KZN: Zoë-Life, Maternal Adolescent and Child Health (MatCH), Health Systems Trust, AIDS Foundation of South Africa (AFSA), Networking HIV & AIDS Community of Southern Africa (NACOSA), National Association of Child Care Workers, Mothers to Mothers (m2m), with Zoë-Life the lead on data management

<sup>2</sup> Data was provided by the UB partners and sourced from the District Health Information System (DHIS), the Tier.net electronic patient management system, National Health Laboratory Service (NHLS) HIV-PCR<sup>2</sup> Results for Actions (RfA) reports, USAID-DATIM, or provided directly by implementing partners, including both facility and community-level data.

## Key Findings and Conclusions

The evaluation provided both summative and formative insights which will be useful for the ELMA Foundation and South African partners to design the next phase of programming to bridge the gap to linking children and adolescents into treatment and care, as follows:

- **ELMA's support to UB has mobilized political will and focus on the issue of low rates of testing, initiation and retention of children and adolescents in HIV care and treatment.** Key stakeholders agree that this has had an effect in focusing resources on children and adolescents, at a time (under UTT) when attention was still predominantly focused on reaching untested adults.
- **The numbers of children tested for HIV has increased significantly over time.** A range of community testing approaches have been used across different geographic areas, including both broad-based approaches and targeted interventions that have resulted in increased early identification of children and adolescents living with HIV. ELMA has added significant value to the response through its support to several innovative testing approaches, notably the mix of index tracing with screening tools, and through the engagement of additional adolescent peer educators. The proportion of children who tested HIV positive (the yield), however, decreased over time.
- **The ART initiation rate increased over time (after an initial drop in JHD) and was higher in UB versus non-UB sites in KZN.**
- **However, the number of children under 15 years of age remaining on ART, as well as viral load suppression, has unexpectedly decreased in both JHD and KZN over the course of the program.** Despite this occurrence, stakeholders reported that the ELMA-supported interventions had been of significant value, notably clinician-focused tools, community support groups, educational tools and programs for children and adolescents aged 10–19, and psychosocial support for children and adolescents, parents, and caregivers. Nonetheless, the data raise significant concerns as to the overall effectiveness of the program approaches and ELMA's added value over the long term.
- **There is some evidence that ELMA-supported interventions have worked to overcome both personal and structural barriers to children, adolescents, and caregivers accessing and demanding HIV services.** There is also some evidence of ELMA's support being used to improve the accessibility of services for adolescents through targeted opening hours, and mothers with babies, by installing child play areas – these factors are closely related to patients' perceptions on quality of care. However, this support has benefited only a small number of facilities to date.
- **ELMA's flexibility in working with partners led to key innovations, but there is now a need to harmonize high impact tools across the care pathway.** Partner-led innovations included the Screening Tool and the Viral Load Suppression Checklist. Allowing partners to innovate has been considered by the partners to be one of the strengths of the program. However, this flexibility meant that each partner worked according to its own strengths, without a standard set of interventions in place from the start of the program. There is now a need to harmonize approaches which have worked into distinct packages which can be rolled out to other areas.
- **While there are limited prospects for programmatic sustainability over the short to medium term, there is some evidence of ELMA-supported activities being integrated** in some of the highest HIV burden districts through support provided by other donors, mainly USAID/PEPFAR.

## Recommendations

The following recommendations were developed by the evaluation team in collaboration with program partners during a workshop which was held in South Africa in November 2018, on the basis

of joint review of the evaluation findings. The evaluation team and the ELMA-funded partners have identified issues and opportunities for the next phase of UB programming in South Africa.

### *Overall recommendations*

- **Identify and lobby government partners to adopt “high impact” practices which have significantly contributed to raising testing rates, linkages, and retention in care for children and adolescents.** Examples highlighted in this report included Zoë-Life’s KidzAlive Family Support Intervention, provision of psychosocial support to adolescents, and the work of linkage officers to identify those lost-to-follow-up.

### *Reducing gaps in testing of children and adolescents*

- **Refine the suite of HIV testing strategies implemented across clinics and community-based facilities.** Funding for resource-intensive community testing strategies with low yield (such as door-to-door and general community testing) should be balanced with more targeted HIV strategies which have higher yields. More investment should be made in training nurses and community health workers to deliver targeted index patient testing in partnership with CBOs. Efforts should be made to scale up mobile testing, particularly in rural areas.

### *Improve Initiation of children and adolescents onto treatment*

- **Systematically design and implement clinic-to-community referral and linkage networks and processes.** Linkage Officers and other outreach workers had a significant impact on increasing ART initiation, retaining children on treatment and providing access to psychosocial services. This clinic-community continuum of care system can be expanded and enhanced by including a workable back-referral system and process for both clinics and CBOs, by funding more linkage officers and lobbying the DoH to devote more social workers to some of the duties currently undertaken by linkage officers.
- **Invest in working with organizations who lobby the National Department of Health to strengthen the child and adolescent ART initiation modules in the Nurse-Initiated Management of Antiretroviral Therapy (NIMART) training and increase the number of skilled nurse mentors to increase the capacity of nurses to initiate children, especially infants.**

### *Improve retention in care of children and adolescents*

- **Work collaboratively with government and other stakeholders to provide adolescent and child-friendly services.** Facilities should operate with rooms specially designed for children to help them feel comfortable and be interested in returning for care. Saturday opening hours, extended weekday hours, “Wellness days”, nurse mentoring, and other initiatives shown to boost retention among children and adolescents in school should be maintained and expanded.
- **Consider including simpler and more applicable means of viral load monitoring, such as the use of dried blood spot.** Introduction of dried blood spot (DBS) would mean that nurses without child phlebotomy skills could also monitor viral loads, improving the monitoring of treatment adherence.
- **Increase partnering with PEPFAR as it scales up supplemental health worker staff for the next two years, including counselors, nurses and doctors trained in pediatric and adolescent HIV support, to enhance the optimum access of children and adolescents to HIV programming in the joint ELMA-PEPFAR districts**