Executive Summary

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

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Submitted by Itad
To the ELMA Foundation

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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, ELMA is funding implementing partners in South Africa and Uganda to introduce and support strategies to identify infants, children and adolescents with HIV and link them to care.

Itad has been commissioned by the ELMA Foundation to undertake an evaluation of its UB program in South Africa and Uganda. 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 testing in relation to outcomes across the HIV cascade of care.[1]
- 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. 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.

Key findings and conclusions

The UB program has embarked on an ambitious strategy in Uganda, filling a critical gap in the response. Despite broader gains in the HIV response, progress in addressing children and adolescents has remained slow, hampered by a lack of targeted strategies and resources and the capacity of the system to deliver a tailored response to their needs. In this context, the ELMA UB program is recognized as filling a critical gap, providing targeted interventions to increase demand for and access to testing and improve the coverage of ART services.

The program has demonstrated success in one of its critical goals, with evidence suggesting a contribution of UB interventions to an increase in the numbers of children and adolescents who are tested for HIV. The combination of targeted and generalized strategies through both facility entry points and outreach strategies to access children and adolescents in UB districts has been associated with a demonstrated increase in the number of children tested and identified, particularly in year 2 of the project. Perhaps unsurprisingly, yield has decreased, as those who are easily accessible have been identified and those who are hardest to reach remain, demonstrating the increasing importance of

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[1] We primarily drew on data from DHIS2 to create HIV cascades. In addition, for the polymerase chain reaction (PCR) data, we sourced data from the Central Public Health Laboratories (CPHL) database.

refining strategies to test the hard to reach, which may more intensive and require higher levels of investment.

However, broader trends in improvements in testing mask challenges in losing infants from the EID cascade. While coverage of a first PCR test for exposed infants is comprehensive, there is little evidence to suggest significant improvement in the coverage of a second PCR test among eligible infants with a negative first test, with over a third of these infants lost in both UB and non-UB districts in year 3 of the program. Coverage of an 18-month rapid test has increased over time across all districts; however, UB districts have shown less improvement than non-UB districts. Notwithstanding the challenges with the data available, further interrogation of the EID cascade and definition of intervention strategies to plug the gaps represents an important priority for the program going forward.

Similarly, performance of the program has not been as evident in relation to its second objective – initiation of children on ART. Both UB and non-UB districts have seen a decrease in the number of children initiated on ART, and static or declining performance in relation to the proportion of HIV positive children initiated, as an initial surge of uptake following the introduction of 'test and treat' stabilizes. Following year 1 of the project, UB districts have also shown lower rates of initiation than non-UB districts and in specific UB sites, retention rates show a mixed picture, particularly in relation to adolescents. While this can be attributed to a range of contextual factors, and particularly early gains in UB districts that have left many of the hardest-to-reach remaining, it will be important for the program to reflect on this moving forwards to ensure that gains in testing are matched by gains in treatment.

Quality of care, patient satisfaction and demand for services are intrinsically linked, and efforts by the program to address these are highly valued by both clients and service providers. The program has taken a holistic approach to increasing demand and improving quality of care – combining interventions targeted at clients and caregivers with those targeted at service providers. Patients highly value the 'bolt-on' interventions that are available, notably IGAs, snacks and transport subsidies to address some of the structural barriers to access. Similarly, the introduction of adolescent-friendly services, specific adolescent clinics, and training of providers on how to work with young people are seen as core value additions of the program, mitigating some of the barriers around stigma and allowing adolescents to access services more efficiently. However, challenges in the optimization of quality of care remain: fear of judgement by service providers, concerns about confidentiality, issues of waiting times, and stock-outs of drug supplies are all still evident in some areas.

The introduction of mechanisms for data review have been a key value addition of the program, but there is more work to do in filling evidence gaps and institutionalizing data-driven decision making at the district level. The design of the program has facilitated the use of data at both the consortium level and at the district level to review implementation progress, share learning, and identify priority areas for course corrections. It is clear that, more broadly in Uganda, significant data quality challenges remain, particularly in terms of how to robustly capture individuals who are retained and lost along the cascade of care. Given those constraints, at the facility level, providers valued the contributions of the program through both the data review meetings and the introduction of dashboards for ongoing monitoring. However, review processes are still driven by the program, with more work to be done to institutionalize the routine interrogation of data and translation into tangible action by health decision-makers and providers. From the consortium perspective, while there is significant data being collected and reported by the program, some gaps remain, notably in terms of moving beyond process reporting to monitoring the effectiveness of capacity building and quality improvement initiatives, which would allow future activities to be better targeted.

Sustainability represents a critical ongoing issue for the program. Implementing partners have made deliberate attempts to engage key stakeholders at different levels and build ownership of the program. However, while recognizing the clear contributions of the program, questions were raised about the cost of some of the interventions, and thus the strategy for sustainability and transition to government in the

longer term, in the absence of external funding. This represents an important consideration as the program moves forward regarding ensuring the sustainability of the gains made.

Key Recommendations

1. **Continue to innovate and test targeted strategies to reach the hardest to reach, using data to inform course corrections.** As more and more children and adolescents are identified and initiated on ART, those who remain unidentified and outside the system will be those who are the hardest to reach. Accessing them will necessitate innovative, targeted strategies that are likely to be more resource intensive and may require engagement beyond UB sites; thus, it will be important for the program to effectively, and in an ongoing way, monitor the performance of new strategies and use this data to inform decisions about continuation, adaptation, or cessation. A full sub-national analysis of data along the HIV cascade would allow for improved targeting of interventions. In addition, routine collection of data on the feasibility of innovative testing strategies, such as provider attitudes and any other operational issues which may affect uptake and effectiveness of strategies, will be important in making decisions about which testing strategies to invest in in the longer-term.

2. **Institutionalize the use of the screening questionnaire in the UB facilities.** The screening tool is considered an effective strategy to prioritize children and adolescents for testing, increasing yield and avoiding missed opportunities for identification of those most at risk. However, there is currently a lack of data on how comprehensively it is being implemented, which is a barrier to the program effectively focusing efforts to encourage its use. The program should introduce mechanisms to document the tool's use and effectiveness, either through the development of a form for staff to document the screening process, or through engaging the MOH in dialogue around incorporating it into the OPD register, and then work with the district health teams and service providers to identify what capacity support (for example, training of OPD staff) is required to institutionalize the use of the tool across facility entry points.

3. **Undertake an in-depth diagnostic and assessment of the barriers to ART initiation and retention.** The trends in ART initiation rates suggest that gains in testing among children and adolescents are not being fully translated into gains in treatment. This presents a critical challenge for the program in achieving its overall objectives and for Uganda in halting the spread of HIV and achieving the global 90:90:90 targets. To mitigate this gap, the program should undertake a detailed diagnostic of why initiation rates are not improving – including identifying if there are common trends in who is being lost and why – and use this to inform a targeted strategy to address the gaps. The introduction and use of the unique identifier to collect cohort data and track linkage, initiation and retention would be a useful contribution to this diagnostic, allowing the program to reflect more holistically on how individuals move through or are lost from the cascade of care. In addition, the lessons learned from UB 1.0 in terms of strengthening facility and community linkage mechanisms should be used to inform future programming decisions.

4. **Explore opportunities to support adolescents who are in school.** Adolescents in school face barriers to adhering to treatment and accessing clinics if they are not willing to disclose their status. Through engaging in dialogue with adolescents and schools to understand the challenges, the program should explore strategies for supporting access to treatment for young people who are in school through existing structures such as school nurses, ideally without the need for disclosure to wider school authorities.

5. **Strengthen adolescent psychosocial support outside the traditional clinic setting, using an adolescent-led model.** Adolescents have highlighted their desire to become more engaged in the design of their own services, and peer-to-peer support has been shown as an effective mechanism of supporting them. Given some of the challenges identified in reaching adolescents, the program should

consider how the scope of its psychosocial support to this group could be bolstered, using adolescent-designed and peer (or near-peer)-led models that engage adolescents in their own environment rather than in clinic settings. For example, this might include facilitation of support groups that are specifically focused on the move of adolescents into adult clinics, drawing on the experience of near-peers (i.e. 20–22-year olds) who have recently gone through the transition and who have been trained to provide support to their peers. In addition, it should include specific training for providing peer support given that the emotional burdens shared by other adolescents could be overwhelming or emotionally challenging.

6. **Increase the scope of socio-economic support targeted at caregivers.** The evidence has shown that socio-economic support, for example, the provision of income-generating activities, can be a powerful incentive for engaging with services, both for initial contact and ongoing retention. However, the package of support for caregivers is currently more limited than it is for adolescents. The program should therefore consider developing a start-up package, linked to income-generating activities, to incentivize caregivers to bring their children for testing and to promote ongoing adherence. This initiative will require the development of an eligibility screening tool and potentially deepening and expanding the scope of partnerships with organizations specialized in the provision of IGAs.

7. **Strengthen data-driven practices among healthcare providers at the facility level.** Encouraging better data use is a key objective of the program, but meeting this goal is still primarily driven by program staff. To strengthen data-driven decision making at the facility level, there is a need to continue building the capacity of health care workers in the interrogation and use of data and to institutionalize the use of performance review meetings. Potential mechanisms for this include:

   - Working with health care workers to prepare for and lead performance review meetings, building their capacity with a view to transitioning from program staff involvement.

   - Documenting the number of performance review meetings that happen and intervening more intensively in facilities where they are not being held.

   - Tracking the implementation of agreed action points that stem from performance review meetings and flagging where no follow-up occurs.

8. **Define new mechanisms to track and report on the effectiveness of capacity building and quality improvement initiatives.** The program has rightly identified the importance of developing health care workers' knowledge and skills and introducing quality improvement initiatives, given the implications for clients' demand for services and the effective care of children and adolescents. However, while these activities are clearly happening, the program is limited in its ability to reflect on their effectiveness and course correct if necessary. Thus, new indicators and tracking mechanisms are needed, moving beyond process reporting and instead capturing evidence of tangible improvements or continuing gaps in staff capacity and the quality of care at the facility level.

9. **Increase the emphasis on sharing learning from the program with other stakeholders to support replication and scale-up.** The ELMA UB program was intended to have a catalytic effect on pediatric and adolescent care in Uganda. While stakeholders clearly value the contributions of the program, sustainability represents an important concern. To maximize wider and longer-term impact, encouraging replication and scale-up by the government and other partners, there is a need to increase the programmatic focus on documenting and sharing best practices and learning about what works and what does not work. Key opportunities for the UB partners to facilitate this include:

   - Generating and sharing knowledge products that reflect on program experience and learning (e.g. best practices, tools and training materials).

   - Undertaking a cost-effectiveness analysis of the various interventions, to inform development of a costed package (or packages) of care focused on implementing the most effective strategies.