

## PROGRAM BRIEF

# Using Data to Understand and Address Gaps in the Treatment Cascade for HIV-Positive Infants and Young Children:

Experiences from Lesotho, Malawi, and Swaziland



# ACKNOWLEDGMENTS

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The Elizabeth Glaser Pediatric AIDS Foundation would like to acknowledge the Lesotho, Malawi and Swaziland Ministries of Health as well as Denis Tindyebwa, Lisa Bohmer and Colleen Murphy for their guidance and support of the project described in this brief. The activities described in this brief were made possible by the generous support of ViiV Healthcare. The contents are the sole responsibility of the Elizabeth Glaser Pediatric AIDS Foundation and do not necessarily reflect the official views of ViiV Healthcare.

# BACKGROUND AND INTRODUCTION

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More than 1,000 children are newly infected with HIV every day. More than half will die before their first birthday if they do not access antiretroviral therapy (ART).<sup>i</sup> As untreated HIV in infants and young children (IYC) can lead to rapid illness and death, it is imperative that HIV infection be quickly diagnosed and that HIV-positive IYC be initiated on treatment as soon as possible. Despite the rapid progression of HIV in IYC, only 23% of the 2.02 million children in need of ART received it in 2010, compared with 51% of adults.<sup>ii</sup> Furthermore, only an estimated 6% of infants born to HIV-positive women receive an HIV test within the first two months of life.<sup>iii</sup> These challenges, combined with the fact that many caregivers of HIV-positive IYC never receive their HIV test results, mean that many go undiagnosed, and therefore untreated.

As efforts to eliminate new HIV infections among children continue to scale up, it is important to ensure that HIV-exposed children are tested, that their caregivers receive results, and that HIV-positive IYC access HIV care and treatment services. However, in many resource-limited settings, measuring performance of early infant diagnosis and treatment (EIDT) is difficult due to an emphasis on measuring delivery of services rather than quality of services. As a result, gaps often exist in determining how early infants are tested for HIV, how quickly test results are given to caregivers, and how soon infants are initiated on ART. Additionally, use of data for program improvement is often not emphasized at the facility level, resulting in staff not being aware of possible gaps in service delivery for HIV-exposed infants. Collecting and using this type of information is central to gaining a deeper understanding of pediatric HIV within the context of prevention of mother-to-child transmission (PMTCT) and for ultimately improving the quality of EIDT service delivery.

In June 2010, ViiV Healthcare (ViiV) awarded funds to the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) for a two-year pilot project to improve EIDT access for HIV-positive IYC at 13 sentinel sites in Lesotho, Malawi, and Swaziland. The project's specific objectives were to: 1) increase early detection and initiation of ART for HIV-positive IYC; 2) to strengthen government leadership and policies; 3) and to use strategic information to understand what works and apply this understanding to improve programs. The ViiV pilot project complemented existing EIDT activities already being supported by EGPAF through funding from the U.S. Agency for International Development (USAID) and other donors in the three countries. This program brief focuses on a component of the third project objective, examining how the selection and use of five indicators highlighted gaps in the implementation of EIDT. The brief also describes how the data were used to understand and address these gaps to improve the quality and delivery of service for HIV-exposed IYC.

# MONITORING AND EVALUATION APPROACH

Prior to project implementation, gaps in routinely collected EIDT data were reported in national monitoring and evaluation (M&E) systems in Lesotho, Malawi, and Swaziland. For example, the disaggregation of age groups to track information on the earliest periods of childhood was not available in existing data. Also, it was impossible to determine how many caregivers received results and, of the results that were received and positive, how many of these IYC were initiated on ART. The project teams assessed existing data collected by sites to establish whether it was possible to measure the number of infants who were tested and received ART early. After a thorough review, some countries found the sites were not summarizing this information in national summary forms, yet the information existed in the national registers. Therefore, the project first identified key indicators that were relatively easy to collect within the existing ministry of health (MOH) registers, yet were robust enough to ascertain key gaps in and progress toward improving EIDT. EGPAF M&E staff in each country conducted an indicator mapping of national summary forms and registers to identify relevant indicators for the project that focused on the quality of care, as opposed to solely the number of infants reached. All stages of the treatment cascade for HIV-positive IYC were also taken into account when choosing project indicators. Table 1 summarizes the five selected indicators and the rationale for their selection.

**Table 1. Project Indicators and Reasoning Behind Selection**

INDICATOR	REASONING BEHIND SELECTION
<b>1. Number of infants born to HIV+ women who received an HIV test at eight weeks of age or less using DNA PCR testing</b>	DNA PCR testing ideally should occur between four and eight weeks of age due to the vulnerability of this age group. This indicator monitors improvements in whether HIV-exposed infants are being tested early.
<b>2. Number of infants born to HIV+ women who received an HIV test between eight weeks and six months of age using DNA PCR testing</b>	This indicator monitors whether exposed infants who are not tested by eight weeks of age (which is optimal) are eventually being tested by six months of age.
<b>3. Percentage of HIV-exposed infants (&lt;12 months of age) testing positive on DNA PCR who received results within eight weeks of testing</b>	Due to infrastructural and logistical issues, DNA PCR results are often not returned to the caregiver in a timely manner. It is critical that results (especially positive ones) be received as soon as possible. This indicator monitors whether results are returned by eight weeks (although the international recommendation is four weeks).
<b>4. Percentage of HIV-exposed infants (&lt;12 months of age) testing positive who were initiated on ART</b>	The WHO recommendation is to initiate ART for all HIV-infected infants diagnosed in the first year of life. This indicator monitors progress in initiating HIV-exposed infants during that critical period.
<b>5. Percentage of HIV-exposed children between 12 and 24 months of age testing positive who were initiated on ART</b>	Without effective treatment, an estimated half of infected infants will have died by two years of age. This indicator monitors the HIV-exposed infants who were initiated on ART between 12 and 24 months of age.

To assess progress pre- and post-intervention, baseline data were collected from existing information in the health registers from the sentinel sites and estimated to reflect the year prior to the ViiV project. These baseline estimates permitted the EGPAF country teams to set realistic targets for the first and second year of project implementation. Data were then collected, analyzed, and used on a monthly basis from the 13 ViiV-supported sentinel sites. The next three sections detail key systems gaps highlighted by the indicators and illustrate how data were used in the three pilot countries to improve service delivery and the quality of crucial pediatric HIV services.

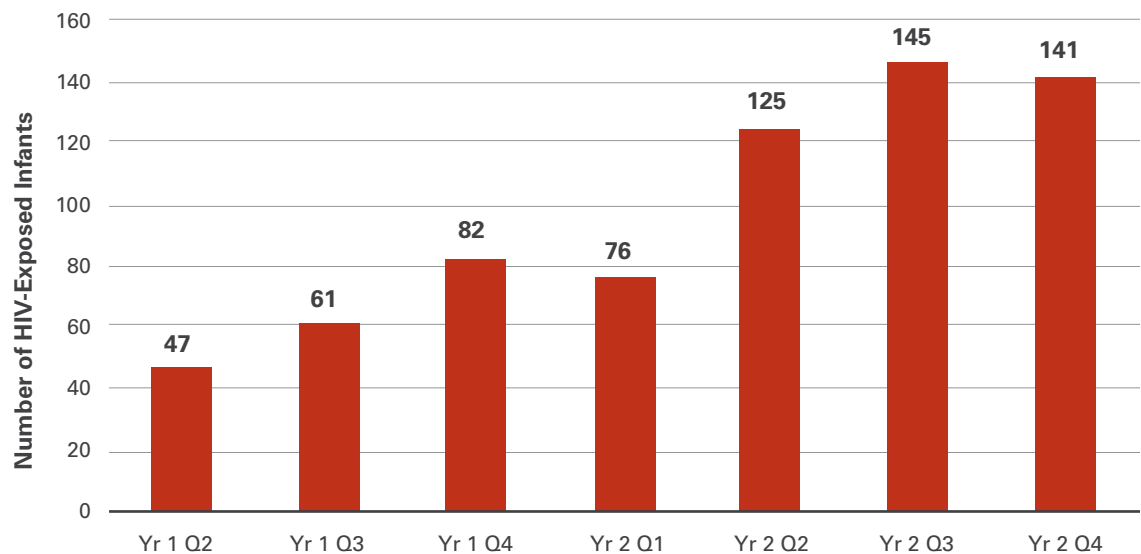
## Monitoring Improvements in Early Infant Diagnosis: Indicators 1 and 2

Challenges in the delivery of early infant diagnosis (EID) for HIV-exposed infants are reflected in M&E systems. Polymerase chain reaction (DNA PCR) testing ideally should occur between four and eight weeks of age (usually at the first immunization visit) for the diagnosis to be considered “early.” However, indicators in national summary tools focus on monitoring the overall number of HIV-exposed infants tested with DNA PCR by one year of age and do not differentiate between infants who are tested early (younger than eight weeks) or late. This makes it impossible to assess performance of health facilities in delivering EID services to infants in this critical age group.

The ViiV project was an opportunity to pilot indicators that monitor performance of EID services at the ViiV-supported sentinel sites as well as to address gaps in M&E systems for EID. Due to the dearth of data regarding infant testing by eight weeks, all three ViiV-supported country programs started collecting data on the number of infants born to HIV-positive women who received an HIV test at eight weeks of age or less using DNA PCR testing (Table 1, Indicator 1), either through new data collection tools or by summarizing existing data from health-facility registers. In addition to collecting data related to infants tested by eight weeks, it was necessary to monitor the number of infants born to HIV-positive women who received an HIV test between eight weeks and six months of age using DNA PCR testing (Table 1, Indicator 2) at the ViiV-supported sites in the three country programs. Though testing of an HIV-exposed infant is optimal by eight weeks, this second indicator monitors whether HIV-exposed infants are eventually tested by the age of six months; it also enables data collectors to track the rate of reduction in testing in this age group as more infants are tested earlier.

Figure 1 below illustrates the indicator on the “Number of infants born to HIV+ women who received an HIV test at eight weeks of age or less using DNA PCR testing” and its resulting data were critical to identifying and addressing gaps in EID service delivery at the pilot sites in Malawi.

**Figure 1. Number of Infants Born to HIV+ Women Who Received an HIV Test at Eight Weeks of Age or Less Using DNA PCR Testing at Five ViiV-Supported Sites in Malawi: September 2010–May 2012**



In January 2011 (Year 1 Q2), Malawi's Likuni Hospital reported testing three to five HIV-exposed children each month; after reviewing data that revealed 40 to 50 HIV-positive women delivering each month, HCWs realized that the vast majority of HIV-exposed infants were not being identified or tested. The data enabled HCWs to specify areas of weakness in identifying HIV-exposed children. HCWs engaged in review meetings, where they developed strategies and action plans to address these challenges by enabling lay health surveillance assistants (HSAs) in the "under-five" clinic and outpatient department (OPD) to use child health cards to identify HIV exposed children and by helping community health workers (CHWs) to provide caregivers with DNA PCR results more rapidly. HSAs were assigned to be responsible for transporting samples, following up with central laboratories, carrying out community awareness programs on the benefits of EID, and introducing pediatric HIV testing and care within their catchment populations. Training of HCWs and HSAs, site-level orientations, mentorship, data review and use, community mobilization, and staff commitment to improved quality of services contributed to increases in the number of infants tested by eight weeks of age in Malawi's five ViiV-supported sites.

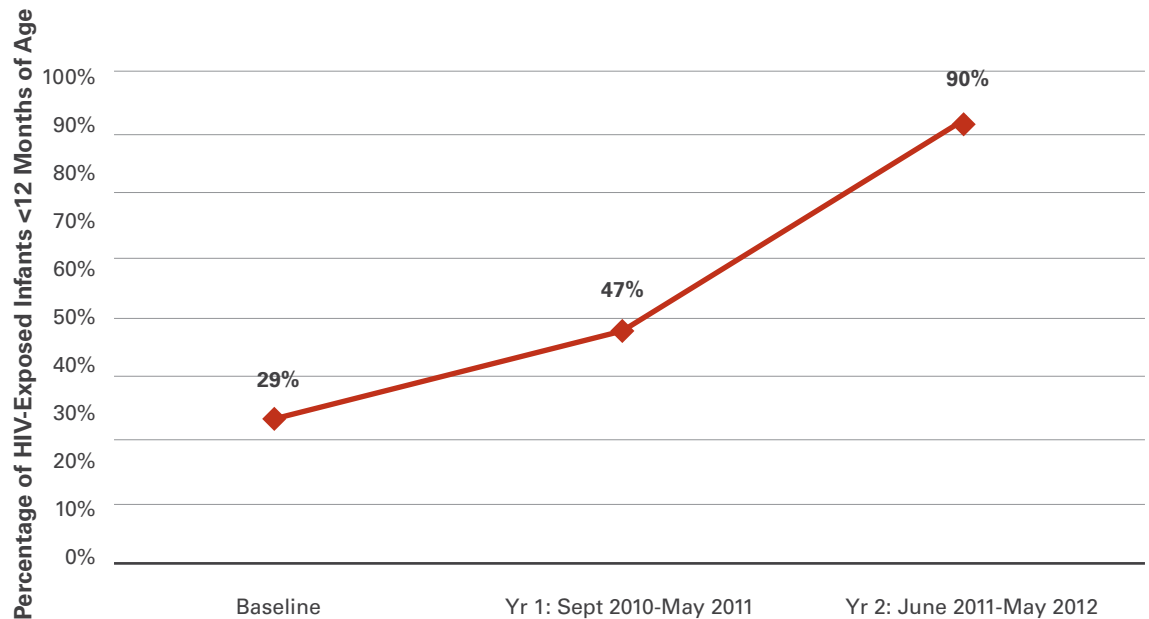
## **Monitoring Improvements in Results Given Back to Caregivers: Indicator 3**

When DNA PCR tests are performed, the results often do not reach caregivers of HIV-positive children in a timely manner due to multiple factors: poor mother-infant follow-up, long turnaround times from the laboratory, and inadequate laboratory and clinic systems for tracking and returning results to the clinic or caregiver. Long distances between facilities and labs also contribute to long turnaround times and loss of test samples and results. Further, economic instability can result in high transport costs, which further complicate transport of DNA PCR samples from facilities to labs.

At the beginning of the project, it was clear through in-depth indicator mapping that returning results to the caregiver was not being reported in national summary tools in Lesotho, Malawi, and Swaziland. If results were being recorded at all, they were often recorded in health facility registers with a "yes/no" response, demonstrating only whether the result was returned to the health facility and not whether it was returned to the caregiver. In addition, there was no information about how soon the result was being given back to the caregiver. The WHO recommends that results be returned to the caregiver within four weeks of an HIV-exposed infant's being tested to enable prompt initiation of ART. Despite this recommendation, the available information in the national summary tools, and in some countries' health facility registers, did not allow for monitoring of results returned to the caregiver.

To address this information gap, all three EGPAF country programs began to monitor results returned at their sentinel sites. The indicator chosen was "Percentage of HIV-exposed infants (<12 months of age) testing positive on DNA PCR who received results within eight weeks of testing" (Table 1, Indicator 3). This indicator monitors the quality of care given to HIV-positive infants in terms of receiving results, measuring both the availability of results at the facility and whether results are returned to the caregiver in a timely manner. It was decided that the indicator would monitor results returned specifically for HIV-positive infants, given the need for this population to begin treatment as soon as possible. Though the international recommendation is for results to be given back to the caregiver within four weeks of testing, there was evidence at the beginning of the project that this was not occurring. Therefore, it was necessary to increase the time period to within eight weeks of testing.

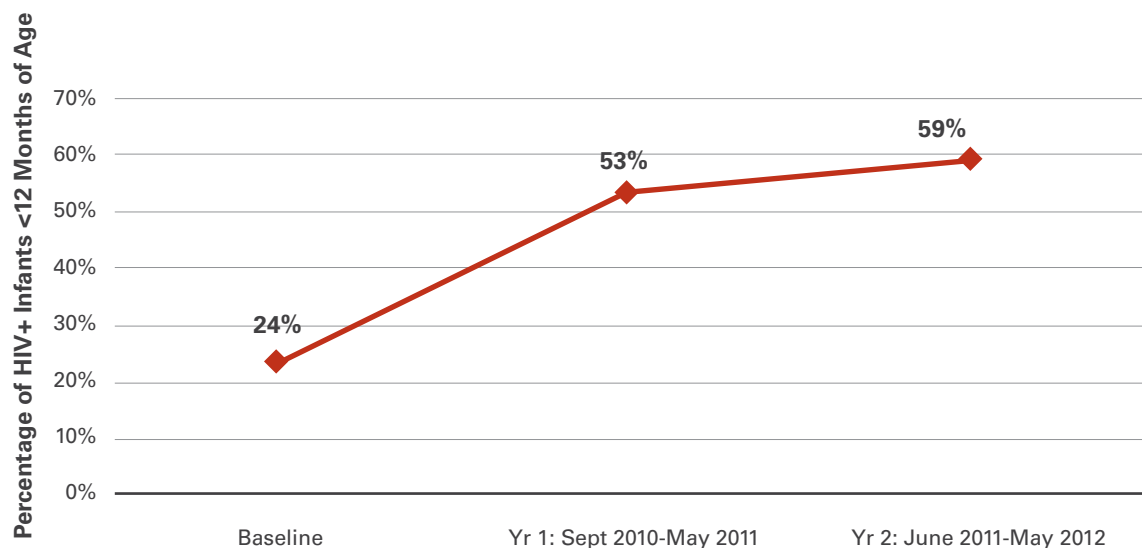
**Figure 2. Percentage of HIV-Exposed Infants (<12 Months of Age) Testing Positive on DNA PCR Who Received Results Within Eight Weeks of Testing at Three ViiV-Supported Sites in Lesotho**



For the three ViiV-supported sites in Lesotho, delays of up to 12 weeks in returning DNA PCR test results to caregivers were observed at the onset of the project. Systems such as distribution of DNA PCR results through mobile Internet were undertaken to reduce the turnaround time. In addition, tracking of HIV-positive infants was strengthened through engaging CHWs. These strategies improved turnaround time and the early initiation on ART of infants who tested HIV-positive to within 7–14 days of the date the results were released. As Figure 2 above illustrates, at baseline, only an estimated 29% of HIV-positive infants were receiving results by eight weeks of testing at the sentinel sites. To address these gaps, the EGPAF/Lesotho team supported the Ministry of Health and Social Welfare (MOHSW) to provide district clinical coordinators with 3G-enabled laptops for lab-facility DNA PCR result communication, as well as client tracing and follow-up. Armed with these tools, plus training and mentorship, the pilot facilities were able to receive DNA PCR results within two to four weeks; they were able to follow up more rapidly with mothers and caregivers, reaching 90% of tested infants with results, and thus initiate infants on ART earlier. Additionally, the MOHSW established a hotline for HCWs to contact the laboratory directly if DNA PCR results are not received.



**Figure 3. Percentage of HIV-Exposed Infants (<12 Months of Age) Testing Positive Who Were Initiated on ART at Three ViiV-Supported Sites in Swaziland**



## Monitoring Early Initiation of ART: Indicators 4 and 5

Historically, enrolling HIV-infected children into care and initiating them on ART has lagged behind that of adults. The WHO recommends that all HIV-infected infants be initiated on ART in the first year of life. This recommendation has been difficult to achieve in many countries for reasons including, policies prohibiting nurses from initiating ART, ART services being available only at a limited number of facilities, and associated loss to follow-up resulting from weak referral mechanisms to and from ART facilities. Compounding these challenges is a lack of age disaggregation in M&E tools to monitor early initiation of ART. Often, there are no pediatric ART age breakdowns in national summary forms, and all children are reported in the “<14 years of age” category. To address this information gap for ART initiation in children in the crucial period of less than one year of age, the ViiV project focused on early initiation of ART as part of the project’s M&E efforts. Two indicators were chosen: “Percentage of HIV-exposed infants (<12 months of age) testing positive who were initiated on ART” and “Percentage of HIV-exposed children between 12 and 24 months of age testing positive who were initiated on ART” (Table 1, Indicators 4 and 5). Indicator 4 was chosen specifically to monitor early initiation of ART, linking to Indicator 3 to ensure few children were missed for ART who had been identified as HIV-positive. The latter indicator was chosen to monitor the remaining population of HIV-positive infants who should have started ART at an earlier date but who were initiated on ART by at least two years of age.

Figure 3 illustrates progress in initiating HIV-positive infants on ART at ViiV-supported sites in Swaziland.

Baseline data showed that only 24% of HIV-positive infants less than 12 months of age at the sentinel sites were initiated on ART in Swaziland, largely due to poor referral systems at centralized pediatric ART facilities, as well as existing policies limiting ART prescription to doctors. To address these challenges, the Swaziland team worked with the MOH to establish a nurse-led ART initiation program (NARTIS) and led training of nurses in ART initiation at ViiV and other PMTCT project sites. As a result of the NARTIS program, nurses at local health facilities can now prescribe ART, leading to fewer infants lost to follow-up and more being initiated on ART. The team also developed an “expert client” system, in which HIV-positive expert clients physically escort caregivers to the facility’s ART department, facilitating linkages at facilities where ART is provided. In less than two years, the NARTIS and expert-client approach has more than doubled the number of HIV-positive infants initiated on ART. Additionally, nurses are more empowered in their roles and are able to establish stronger relationships with patients and caregivers, potentially resulting in greater influence over families and caregivers to initiate and adhere to ART services.



# PROJECT IMPACT

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Although only minimally illustrated in this brief, this small-scale project has had an impact in several areas in Lesotho, Malawi, and Swaziland. First, more infants and young children have been diagnosed and initiated on ART, as a result of a comprehensive effort at systems- and skills-building, which in no small part has included a greater emphasis on using data for programmatic decision making at national and facility levels.

HCWs developed their own solutions to address gaps, a potential secondary impact of their recognition of data as an important tool in assessing their own processes and performance. Policies have not been required to make facility-level changes; HCWs' empowerment toward decision making to improve their own performance is potentially a sustainable approach of the project.

Many tools were developed to collect project indicators, with several being integrated into national systems. In Lesotho, tools created for the collection of Indicators 1 and 2 have already been integrated into national systems, and all five indicators have been integrated into the more comprehensive “under-five” register, which was piloted and disseminated with support from ViiV. Current advocacy efforts are underway for the inclusion of EID indicators in the national DNA PCR register and initiation on treatment indicators into the existing ART register. Similarly, in Swaziland and Malawi, these indicators have been incorporated into national PMTCT reporting forms; in cases where they are already included on reporting forms, they are now being better used for programmatic decision making.

Additionally, the Malawi team has reviewed and updated the MOH draft EIDT logbook, including additional key indicators beyond the five presented in this brief. EGPAF/Malawi has begun to use the revised logbook in all 92 EGPAF-supported PMTCT facilities, including the ViiV pilot sites. The team also developed a supervision checklist that has been used to assess achievements and gaps and to agree on action items with site-level staff. In Swaziland, the EID logbook was revised and standardized, and a database using EpiInfo was designed to capture routine EID data. In all three countries, nurses have been trained so that in the future, they can transfer skills and orient new nurses on the data collection tools.

A final impact of this project has been to highlight gaps in progress toward meeting country goals of identifying and treating exposed and infected children. While tools were in place to collect PMTCT and EIDT data, this project demonstrated how shifts in mindset (at the facility as well as at national levels) about which data to collect have illuminated major service delivery gaps. The efforts of this small-scale project will have a larger, long-term impact on more effective implementation of the WHO guidelines, leading to more infants and young children being identified and treated earlier in life—a primary goal of the project countries in their efforts to eliminate pediatric AIDS.

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i UNAIDS. UNAIDS report on the global AIDS epidemic. Geneva. 2010.

ii [http://www.unicef.org/aids/files/PromotingEquity\\_Final.pdf](http://www.unicef.org/aids/files/PromotingEquity_Final.pdf) Promoting Equity for Children in a World with HIV and AIDS. Accessed July 5th, 2012.

iii WHO/UNAIDS/UNICEF. Towards universal access: scaling up priority HIV/AIDS interventions in the health sector. Geneva, Switzerland; 2010.









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