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April 21, 2022

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Identifying Key Gaps in Service for HIV-Exposed Infants within USAID Supported PEPFAR Programs

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Global Health
2022

Abstract

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By Hanna Amanuel

Background: HIV-exposed infants (HEI) are vulnerable to HIV acquisition and high rates of mortality if they are not tested early and linked to appropriate treatment. Programs supported by the President's Emergency Plan for AIDS Relief (PEPFAR) have implemented interventions aimed at the prevention of mother-to-child transmission (PMTCT) of HIV, scale-up of pediatric case identification through family index testing, increasing ART optimization, and providing comprehensive care to children living with HIV (CLHIV). Despite efforts to improve care for HEI, significant gaps exist in retaining mothers within prevention services, timely infant HIV diagnostic testing, and enrollment into comprehensive care services. An analysis of country-specific priorities, initiatives, and barriers is needed to support country teams to improve HEI outcomes across the clinical cascade.

Methods: A 17-question survey was developed and sent to all United States Agency for International Development (USAID) headquarters (HQ) country backstops within the Pediatric and Maternal Branch (PMB) and Orphans and Vulnerable Children (OVC) Program, Mission PMTCT and OVC point-of-contacts, and Implementing Partners (IP). The survey aimed to elicit information from respondents about current gaps in services for HEI and their mothers across all PEPFAR/USAID-supported countries. Survey responses were extracted into Google Sheets and a qualitative review of responses was conducted with job title and country disaggregated, as appropriate, for comparative analyses.

Results: Survey data from 40 eligible respondents were analyzed, including five USAID HQ colleagues, 15 mission point-of-contacts, and 20 implementing partner staff members across 19 different countries. Barriers identified by respondents were summarized and used to inform the development of a technical consideration document, screening tool, and job aid for country team distribution. An in-depth qualitative analysis of country responses was provided to country backstops for programmatic use.

Discussion: The survey gathered insight on technical assistance needed at the country level to strengthen coordination and inform how to close gaps in service for HEI. Data suggested a need for country programs to prioritize comprehensive care by improving clinical and community partner collaborations. Challenges in providing care to HEI are country-specific and require programmatic revision to ensure adequate targeting and contextual consideration.

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Acknowledgments

I would like to express my deepest appreciation and gratitude to all who made this thesis process possible. First and foremost, I would like to give a sincere thank you to my committee chair, Dr. Kenneth G. Castro and committee member, Amy E. Aberra for their expertise, leadership and devoted time.

Many thanks to the OVC and PMB branches within USAIDs Office of HIV/AIDS, specifically the OVC/Peds and EMTCT/HEI technical units. The technical units feedback, encouragement, and commitment to improving HEI outcomes has played a massive role in the survey rollout. To Aimee Rurangwa, thank you for brainstorming with me, teaching with kindness, and helping birth the idea for this survey. I have been blessed with the opportunity to work under such brilliant individuals in this field and it is because of their guidance, I have truly found my niche.

Finally, to my friends and family, thank you is not enough! To my parents, who are my biggest cheerleaders and greatest inspiration. Thanks mom for calling me after every all-nighter to make sure I made it home safely, praying with me and being my voice of reason when things seemed overwhelming. To my siblings, life-long friends, and community for never failing to support me.

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Chapter 1: Introduction

For more than forty years, the human immunodeficiency virus (HIV), the retrovirus that causes the acquired immunodeficiency syndrome (AIDS), has plagued society and claimed the lives of an estimated 36.3 million people globally since the first reported case in 1981 (UNAIDS, 2021). Today, HIV/AIDS still remains a major global health issue, despite significant efforts to reduce its global burden through prevention, treatment, and care initiatives. It is important to acknowledge the disproportionate impact this epidemic has on low income and low-middle income countries, currently two-thirds of all people living with HIV (PLHIV) reside in Sub-Saharan Africa, which remains the most impacted region in the world (KFF, 2021).

The United States (U.S) Government through PEPFAR is the largest contributor by any nation to address a single disease in history and has contributed over a billion dollars to the global HIV/AIDS effort since its inception in 2003 (U.S. Department of Health & Human Services, 2021). PEPFAR funds are implemented by USAID and the U.S. Department of Health and Human Services (HHS) and its agencies, including the Centers for Disease Control and Prevention (CDC), Health Resources and Service Administration HRSA), and the National Institutes of Health (NIH), the U.S. Department of Defense, the Peace Corps, the U.S. Department of Labor, the U.S. Department of Commerce, and the U.S. Department of the Treasury (United States Department of State, 2022).

Globally, it is estimated that 1.7 million children ages 0-14 live with HIV, and only 54% of these children are accessing antiretroviral therapy (ART) (UNAIDS, 2021). Children and Adolescents are often neglected in HIV efforts globally and represent an opportunity for prioritizing testing, linkage to treatment and viral suppression. As one of the key implementers of

PEPFAR, USAID's Office of HIV/AIDS (OHA) has prioritized supporting partner countries' Ministry of Health and implementing partner organizations to leverage facility and community level support. While USAID works to support the clinical cascade across different age demographics, the Agency has prioritized the identification of HIV and facilitating linkages to life-saving ART among children and adolescents (USAID, 2021). PEPFAR has also promoted the integration of pediatric HIV services into maternal and child health settings to strengthen pediatric HIV prevention, early infant diagnosis (EID), and care for HIV-exposed and HIV-infected infants (Abrams, E.J, et al, 2012). PEPFAR further supports the implementation of guidelines for HEI through funding to USAID, which then streamlines funding to implementing partners at the country level.

Problem Statement

Although there have been remarkable efforts to scale-up prevention and treatment for HEI, disparities and gaps still exist in preventing transmission of HIV from the mother to infant. Some of the greatest barriers to providing prevention and comprehensive care to HEI are known, including but not limited to difficulty retaining mothers in PMTCT services, access to timely EID testing and comprehensive care services. While the barriers associated with HEI care are known, it is imperative that research is done at the country level to understand current initiatives and the cause of these service disruptions in order to support country teams according to their specific needs and ultimately achieve better HIV outcomes across the clinical cascade.

Purpose

The purpose of this survey is to assess and identify current barriers to achieving timely EID and comprehensive care services for HEI and their mothers across all

USAID/PEPFAR-supported OVC and PMTCT country programs. The assessment will attempt to identify the gaps in service, identify how well programs are prioritizing HEI as a vulnerable population, and identify where additional technical assistance is needed to scale-up services and improve clinical and community collaboration to further support continuity of treatment.

Main Research Question

What challenges exist in providing comprehensive care services to HIV-Exposed Infants in USAID's PMTCT and OVC programs?

Significance Statement

The progression of HIV differs significantly between adults and infants. On average, an untreated adult is expected to live about 8-10 years from start of infection to death (Gilroy, 2022) while 30% of untreated infants are expected to die by their first birthday and 50% by their second birthday (Mogojwe, 2021), thus emphasizing their extreme vulnerability and need to be prioritized for early identification and life-saving interventions.

In order to prevent infection, ensure timely diagnostic testing, linkage to treatment and retention in lifelong care, there is an immediate need to understand current gaps in clinical and community services/programs and identify new ways to support OVC/PMTCT mission teams and implementing partners to improve HIV outcomes for HEI and their mothers at the country level.

Definition of Terms and Abbreviations

Terms:

Adherence- The extent to which a person takes the agreed-upon medication or other treatment as prescribed.

Antenatal- The period between conception and birth (same as prenatal).

Antiretroviral Drugs- Medication taken to stop the progression or multiplication of retroviruses, such as HIV.

Antiretroviral Therapy- A combination of two or three antiretroviral drugs used to aggressively decrease viral load and halt the progression of HIV disease.

Country backstop- Individual at USAID headquarters serving as a point of contact for a PEPFAR country team and technical area.

Implementing Partner- An organization that implements programs using PEPFAR funds.

MER 2.6- An updated set of indicators used to monitor, evaluate and report PEPFAR data. Program result data is reported using the defined MER indicators to track PEPFAR's progress towards the fight against HIV/AIDS.

Operating Unit- Single country or countries referred to by PEPFAR programs.

Perinatal- The period of time directly before and after childbirth.

Postnatal- The period of time after birth.

Timely EID- Infants having received an initial HIV diagnostic test by two months of age, but no later than ten weeks (this may vary by country guidelines).

Undetectable viral load- The reduction in the amount of virus (viral load) to small quantities, resulting in the inability to detect the presence of the virus with standard viral load testing. This is also labeled when there are fewer than 50 copies of HIV per milliliter of blood.

Vertical Transmission- The transmission of HIV from a mother to child during pregnancy, delivery or breastfeeding.

Abbreviations:

3TC- Lamivudine

ANC- Antenatal Care

ART- Antiretroviral Therapy

ARV- Antiretroviral drugs

AIDS- Acquired Immunodeficiency Syndrome

AZT- Azidothymidine (zidovudine)

C/ALHIV- Children and Adolescents Living with HIV

CLHIV- Children Living with HIV

COP- Country Operational Planning

CTX- Co-Trimoxazole

EID- Early Infant Diagnosis

ePNP- enhanced Postnatal Prophylaxis

FDC- Fixed-Dose Combination

HCW- Health-Care Worker

HEI- HIV-Exposed Infant

HIV- Human Immunodeficiency Virus

HTS- HIV Testing Services

MIP- Mother-Infant Pair

MOU- Memorandum Of Understanding

MTCT- Mother-To-Child Transmission

PMTCT- Prevention of Mother-To-Child Transmission

NAT- Nucleic Acid Test

NVP- Nevirapine

OU- Operating Unit (interchangable with Operational Unit)

OVC- Orphans and Vulnerable Children

PEPFAR- President's Emergency Plan for AIDS Relief

PLHIV- People Living with HIV

POC- Point-of-care

RNA- Ribonucleic Acid

SOP- Standard Operating Procedure

UNAIDS- Joint United Nations Programme on HIV/AIDS

USAID- United States Agency for International Development

VL- Viral Load

WHO- World Health Organization

Chapter 2: Literature Review

Rigorous research has been conducted surrounding HEI, including the life-saving interventions that have been developed over the past 40 years. An infant is considered to be exposed to HIV if the infant's mother is HIV positive during conception, or has acquired HIV while pregnant or breastfeeding. Transmission of HIV from a mother to child is also referred to as vertical transmission and is responsible for over 90% of HIV infections in infants during pregnancy, childbirth or breastfeeding (Elizabeth Glaser Pediatric AIDS Foundation, 2019).

HEI are particularly vulnerable, if not tested and linked to treatment quickly, the risk of mortality for HIV-infected infants during the early period of life can be up to 12 times higher than among uninfected infants. Infants who are infected with HIV are also at higher risk for irreversible poor health outcomes, with increased occurrence of malnutrition, opportunistic infections, and permanent developmental challenges (Ghadrshenas et al., 2013).

The considerable scale-up of PMTCT services, HIV testing services (HTS), antiretroviral therapy (ART) optimization, and HIV prevention services have been associated with an estimated 53% decrease in new pediatric infections between 2010 and 2020 (UNAIDS, 2021). Despite this improvement, targets have not been achieved and children are still acquiring HIV at high volumes. In 2014, The Joint United Nations Programme on HIV/AIDS (UNAIDS) launched Fast Track 95-95-95 targets which state that by 2030, 95% of all PLHIV know their status, 95% of people who know their status are on treatment, and 95% of people on HIV treatment have suppressed viral loads (UNAIDS, 2015). These targets were adapted from the previous 90-90-90 targets by 2020.

In 2016, UNAIDS and PEPFAR launched the Start Free, Stay Free, AIDS Free framework with three main concepts; ensuring children are born free of HIV through MTC

vertical transmission targeted testing and treatment services, applying prevention strategies to ensure children who are HIV negative do not acquire the disease postnatally, and ensuring that those who do have HIV are tested, linked to ART and remain free of AIDS (UNAIDS, 2021a).This framework set the goal of fewer than 40,000 new HIV infections by 2018, but in 2019 there were an estimated 150,000 children ages 0–14 newly infected with HIV. The framework also described the goal of 20,000 newly infected children by 2020 but this goal was also not achieved (UNAIDS, 2020), revealing significant need to prioritize these populations.

Healthy HIV outcomes for HEI is directly related to four key factors; the enrollment and retention of mother-infant pairs (MIPs) into PMTCT programs, timely EID for HEI, linkage to HIV preventive medication or ART, and the comprehensive care for HEI through the collaboration of clinical and community programs. This research thesis aims to understand clinical and community services for HEI and identify any existing barriers to provide life saving interventions within PEPFAR-supported OVC and PMTCT programs. Tools, technical considerations and resources have been developed in order to support country teams close identified gaps and contribute to improved outcomes for HEI.

This literature review sought to identify all relevant extant policies from various national and international agencies that are used to guide PEPFAR approaches to HEI, PMTCT, and OVC services. The online literature search was limited to English language documents and, with few exceptions, did not systematically research primary source documents used as the evidence-basis for extant PEPFAR policies.

PMTCT Program Enrollment and Retention

Preventing transmission of HIV from a mother to infant during pregnancy, delivery and periods of breastfeeding is fundamental to ensure infants are born free of HIV. PMTCT programs

promote adherence among patients with enhanced viral load suppression and improve linkages to other supportive services and retention in care (Vrazo, et al., 2018). According to the World Health Organization, without any intervention, the rate of transmission from mother to child ranges from 15% to 45% (WHO, 2021b). The prevention of transmission is contingent on maternal viral load suppression achieved through ART adherence, thus the knowledge of the mothers' HIV status during pregnancy and breastfeeding is the first step in identifying those who should be targeted or interventions aimed at reducing the risk of vertical transmission.

Studies have shown that challenges associated with women utilization and retention within PMTCT programs fall within the broad constructs of the socio-ecological model of individual, family, society and structural determinants (Onono, 2015). The understanding of mothers' retention within these programs surpasses the personal-level and without examining higher levels of the social and community barriers, our understanding and ability to address barriers to PMTCT is limited (Hampanda, 2013).

Beyond the term of pregnancy, PMTCT programs also provide ART adherence support and mentorship initiatives. Mothers2mothers (m2m) is a peer-based mentorship model that employs local women with HIV to serve as community health workers and mentors called Mentor Mothers (mothers2mothers, 2020). This m2m PMTCT program has been implemented across 10 countries in Africa and serves as a community initiative to help start and maintain women on treatment while pregnant then transfer them to another program that will support life-long treatment. Tracking the retention of mothers within PMTCT programs can be quite difficult, creating a heavy reliance on utilizing community programs, such as mothers2mothers to ensure there is no loss to followup.

The enrollment and retention of women in PMTCT programs after delivery is critical to healthy outcomes but unfortunately loss of follow-up within these programs serves as a potential challenge and heightens the risk of interruption of treatment, which could lead to an increased risk of the infant acquiring HIV. Pregnant adolescents living with HIV are a particularly vulnerable group and are at risk of loss to follow up from PMTCT services, resulting in an increased risk of mother-to-child HIV transmission.

As of March 2021, the World Health Organization (WHO) has released updated recommendations on HIV prevention, infant diagnosis, antiretroviral initiation and monitoring (WHO, 2021a). These updated recommendations include:

- Adherence counseling provided at all antenatal care and postnatal visits to ensure that viral suppression is maintained throughout pregnancy and breastfeeding
- All pregnant women, regardless of ART initiation timing, should have viral load testing at 34–36 weeks of gestation (or at the latest at delivery) to identify women who may be at risk of treatment failure and/or may deliver infants at higher risk of perinatal transmission.
- Pregnant women receiving ART before conception are recommended to have a viral load test at the first antenatal care visit (or when first presenting) to identify women at increased risk of in utero transmission.
- Pregnant women starting ART during pregnancy should have a viral load by three months after ART initiation to ensure that there has been rapid viral suppression.
- All breastfeeding women, regardless of when ART was initiated, should have a viral load test three months after delivery and every six months thereafter to detect viraemic episodes during the postnatal period.

Early Infant Diagnostic Testing

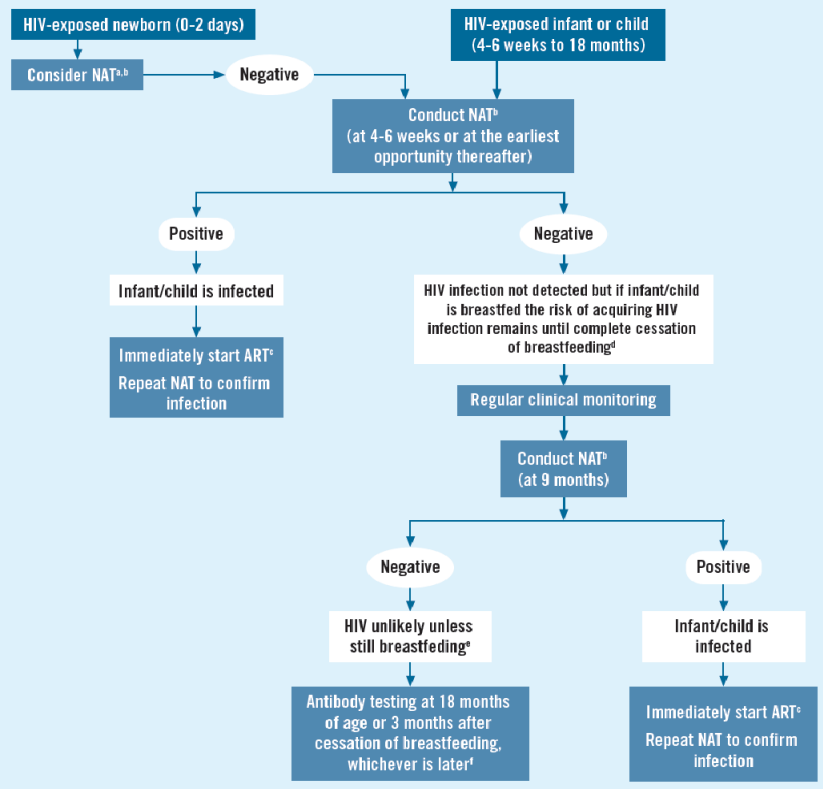
As of 2020 global coverage of early infant diagnosis (EID) was 67%, and while this shows improvement from 57% in 2018 (U.S Department of State, 2022), there is still scale-up needed to achieve global targets. The first step in the UNAIDS 95-95-95 targets states that 95% of PLHIV should know their status, including subpopulations. The achievement of this target is only possible if testing is readily available to all who are at-risk of acquiring HIV. For infants, early infant diagnostic testing is essential to beginning HIV-positive infants on life saving ART and preventing postnatal mother-to-child transmission for infants who are HIV-negative (Cintron, C., Fernandez-Knott, A., Mudhune, V, 2018). The World Health Organization recommends that all HEI are tested within four to six weeks of birth and that results are returned to their caregivers as soon as possible. (WHO, 2021b). Although an infant may test negative during initial EID testing, more than half of new pediatric HIV infections occur during the breastfeeding period (Beyene et al., 2018) and represent a substantial risk of exposure. Further recommendations from the World Health Organization state that infants born to mothers living with HIV should be tested again at 18 months and/or three months after breastfeeding ends to provide the final infant diagnosis, and recommended care.

There are two categories of tests available for infants, serological and virological. Virological testing is used to detect the presence of the virus in a blood sample. Virological testing is suggested at birth and again at 4-6 weeks old and can be done in healthcare facilities with point-of-care (POC) technology or within local labs. POC technology allows for rapid results at the site where clinical care is provided, resulting in same day results to patients and providers. WHO now strongly recommends the use of POC Nucleic Acid Testing (NAT) to diagnose HIV in all infants and children younger than 18 months of age (WHO, 2021a).

Serological testing detects the presence of antibodies and is used to diagnose those over the age of 18 months, or three months after the end of breastfeeding. Serological testing can be done rapidly and is conducted within a laboratory setting.

NAT technologies look for the presence of HIV within the blood sample and can detect the presence of HIV infection 10-33 days after exposure. Comparatively, antigen and antibody tests detect the presence of HIV infection 18-45 days and 18-90 days after exposure respectively (Centers for Disease Control and Prevention, 2020). The ability for earlier detection led to the written recommendation of NAT use at or around birth for earlier diagnosis of HIV in infants (World Health Organization, 2016). The EID algorithm with use of NAT for HEI can be seen in Figure 1.

Figure 1. *World Health Organization simplified EID algorithm for HEI*



(Source: World Health Organization, 2018)

Table 1. *Recommended EID testing method by age*

Age	Recommended EID test
Birth (0–2 days) if recommended by national guideline	HIV **virologica**l testing using NAT, as per national guidelines
4–6 weeks of age, or as soon as possible	HIV **virological** testing, using NAT
9 months of age	HIV **virological** testing, using NAT
18 months of age or 3 months after the end of breastfeeding (whichever occurs later). To determine final HIV status	HIV **serological** testing if 18 months of age or older

(Source: World Health Organization, 2018)

USAID measures EID testing coverage among PEPFAR-supported Operational Units (OUs) using the monitoring, evaluation and reporting (MER) indicator PMTCT_EID at both 2 months and 12 months. The benchmark target for EID testing coverage by 2 months is 95% but has unfortunately been missed by the majority of supported OU's.

Despite guidelines, targets and programmatic intervention for testing, EID has remained stagnant with approximately 50% of exposed infants receiving an HIV test within the first two months of life (WHO, 2021a). It is critical that the barriers to accessing EID are understood and specific interventions are made to address this.

Prophylaxis and Treatment:

Prophylaxis

Once initial testing outcome is determined, all HEI should be linked to an ART or Antiretroviral (ARV) medication depending on HIV status and level of risk acquiring HIV perinatally. All infants who test positive for HIV should be immediately initiated on ART. Infants who test negative for HIV should be linked to an ARV regimen depending on level of transmission risk. ARV prophylaxis can be defined as the administration of ARV drugs to a

newborn who has no documented HIV infection, in order to reduce the risk of HIV acquisition (National Institute of Health, 2021). ARV regimens recommended by WHO are based on risk of perinatal transmission, and include single ARV medications or enhanced postnatal prophylaxis (ePNP). This second option (ePNP) is an ARV regimen intended for infants with higher risk of vertical transmission and is used to improve HIV prevention amongst HEI who have not acquired HIV (WHO, 2018).

The WHO 2018 guidance on HIV Diagnosis and ARV use in HEI states that infants with a lower risk for perinatal transmission should be given standard nevirapine (NVP) or zidovudine (AZT) prophylaxis for a total of four-six weeks (WHO, 2018). Low risk of perinatal HIV transmission is attributed to mothers who received ART during pregnancy and achieved viral load suppression, defined as a confirmed HIV ribonucleic acid (RNA) level fewer than 1000 copies/mL (PEPFAR, 2021) and/or has been on ART for at least 4 weeks prior to delivery.

Infants who are at highest risk for HIV acquisition are recommended to receive ePNP; a dual regimen of AZT and NVP for six weeks, but are able to extend to a total of twelve weeks depending on the on-going risk of transmission from breastfeeding (U.S Department of State, 2022). The additional six weeks of treatment for breastfeeding infants may include the original dual regimen or NVP alone. Clinical trials have shown that the use of a two or three regimen ARV prophylaxis, or ePNP, has a significant reduction of MTCT in high risk infants, compared to the use of the standard one ARV prophylaxis (Nielsen-Saines et al., 2012). Furthermore, this clinical trial concluded that the two-drug combination regimen of ART and NVP had less toxicity than the three-drug regimen which included lamivudine (3TC).

PEPFAR's 2022 Country Operational Planning (COP22) guidelines further defines an infant being at high risk for perinatal HIV transmission if the mother meets the following criteria:

- Viral suppression was not achieved prior to delivery
- Late initiation of ART in pregnancy (i.e., received less than 4 weeks of ART at time of delivery)
- First identified as infected with HIV in the peripartum or postpartum period
- Newly infected with HIV during pregnancy or breastfeeding (with or without a negative test prenatally).

Antiretroviral Therapy

The timely initiation of ART amongst infants is crucial to their survival and works to prevent the development of AIDS. Infants are to be initiated on ART after their first HIV-positive test and a confirmatory test is typically collected shortly after (UNAIDS, 2014). Research suggests that if HIV-exposed infants begin ART within the first 12 weeks of their life, they are 75% less likely to die from an AIDS-related illness (Violari et al., 2008).

Among adults, Dolutegravir (DTG) has been a first-line ARV and has been connected to high rates of viral load suppression, shortened duration to achieve viral suppression, ability to be used in children on TB treatment, cost-effectiveness, palatability, minimal side effect profile, and ability to use once-daily dosing (U.S. Department of State, 2022).

In June 2020, WHO introduced the new FDA approved pediatric formulation of dolutegravir (pDTG). This breakthrough drug initially presented as 5mg dosage and was later updated to include a 10mg tablet for use in both infants and children/adolescents living with HIV (C/ALHIV) (World Health Organization, 2020).

> *"Children are among the most vulnerable and disproportionately affected populations in the HIV epidemic. The lack of optimal antiretroviral medicines with suitable pediatric formulations has been a longstanding barrier to improving health outcomes for children living with HIV, contributing towards low treatment coverage, and poor virological suppression,"*
>
> - Dr Meg Doherty, Director of Global HIV, Hepatitis and STI Programmes, WHO.

Comprehensive Care for HEI

The comprehensive care for HEI includes close clinical and community collaboration to ensure the entire wellbeing of the HEI is accounted for. Comprehensive care includes, but is not limited to the identification of HIV-exposed infants through EID, providing preventive and routine infant care, linkage to ART (for HIV-infected infants) and other HIV-related conditions, and family support. While the clinical realm protects the health of HEI by providing direct medical treatment, community programs can support retention within PMTCT programs by providing easier access to care and adherence support.

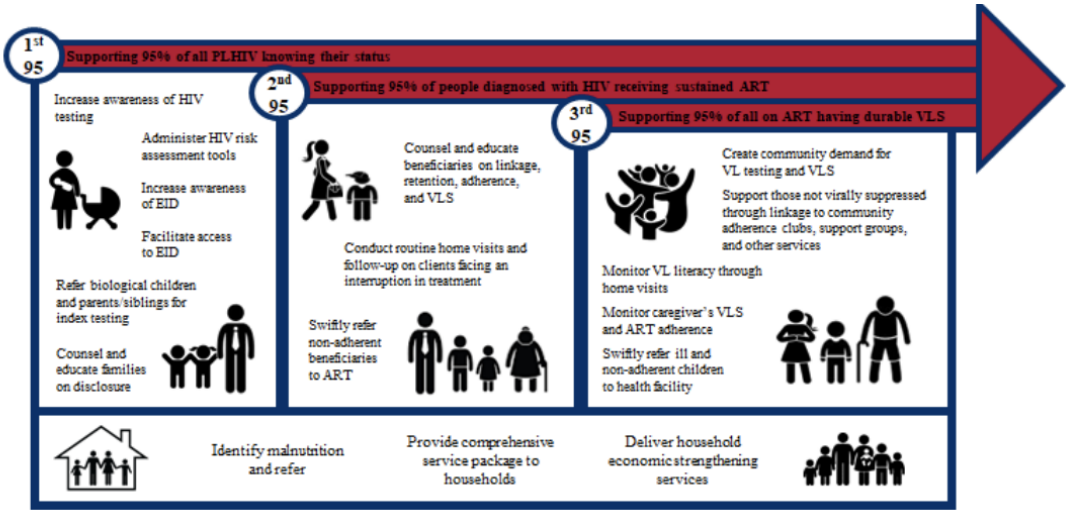
The OVC program at USAID utilizes a comprehensive, needs-based service delivery model to access the needs of HEI and their mother, then provide specific, client-centered care. The overall goal of the OVC program is to build the resiliency of families and children affected by HIV/AIDS so that they can meet their health, economic, education, and social development needs (PEPFAR Solutions, 2021).

The collaboration between health facilities and OVC implementing partners (IPs) play a critical role in the continuum of care for MIPs. OVC IP's contribute to the continuum of care through their case management approaches in the community; these approaches include increasing awareness of HIV testing, counseling on adherence/viral load suppression, administering HIV risk assessment tools, increasing awareness and facilitation of access to EID, monitoring outcomes and referring back to the clinical sites (PEPFAR Solutions, 2021).

OVC programs can provide support through the PMTCT platform to pregnant women living with HIV and their infants most at risk for interruption in treatment or missing EID, such as pregnant adolescents (U.S Department of State, 2022). PEPFAR's COP22 guidance further supports this by stating "Mother-infant pairs at risk of not meeting PMTCT benchmarks (e.g., timely return for EID) should be prioritized for enrollment into the OVC program, especially for adolescent/youth mothers living with HIV". The successful coordination between community OVC programs and clinical partners can only be established through the development of a Memoranda of understanding (MOU) in order to delineate the roles and responsibilities of each partner.

The OVC program supports UNAIDS 95-95-95 targets by utilizing comprehensive case management. OVC's contribution to each 95 target can be seen in Figure 2.

Figure 2. *USAID OVC Comprehensive Program contributing to each of the UNAIDS 95-95-95 targets*



(Source: PEPFAR Solutions, 2021)

Historically, the OVC program has also partnered with other community programs to provide additional support to MIPs. In 2018, Plan International released a technical brief detailing the USAID-supported project titled Nilinde. This OVC project, in partnership with

mothers2mothers, utilized the Mentor Mothers approach and worked to support caregivers and communities to improve the overall welfare and protection of children affected by HIV and AIDS, while also improving support to OVC by strengthening social systems (Plan International et al., 2018). Nilinde's comprehensive case management approach was able to ensure 87% of children living with HIV within their program were adherent to HIV treatment, compared to the national average of 66% (Plan International et al., 2018).

In conclusion, the review of existing policies from various sources emphasizes HEI vulnerability to adverse HIV outcomes and the need to prioritize fast, equitable access to testing and treatment. To successfully eliminate the vertical transmission of HIV in Sub-Saharan Africa, there needs to be accessible HIV testing and care services to all pregnant women and children. In order to ensure services are being provided to pregnant women and HEI, the gaps in services must be identified and addressed for all PEPFAR supported countries. Although current guidelines and research identify the potential challenges associated with providing service for HEI, it is imperative to understand country-specific challenges and address programmatic gaps in accessing service.

Chapter 3: Methods

Survey Description and Goal

USAID-supported programs in various countries are carrying out impressive work to contribute to reductions in mother-to-child transmission (MTCT), scale-up pediatric case identification through family index testing, increase ART optimization, and support C/ALHIV and their families to reach and sustain viral suppression. A survey was sent out to gather information from colleagues working in the area of OVC and PMTCT about current gaps in

services for mothers living with HIV and their HEI across all USAID/PEPFAR-supported countries. The survey served as an evaluation of current clinical and community coordination and as a needs assessment to collect insight on technical assistance needed at the country-level to strengthen coordination and close gaps in service for HEI.

The survey was designed to measure the degree at which respondents (whether at the HQ, mission or IP level), believe their OVC or PMTCT programs are prioritizing care for HEI, and the improvements they feel are necessary to achieve comprehensive MIP support.

Materials and methods

The HEI/OVC survey was developed and sent to the USAID OVC technical unit and Maternal and Infant Health Cluster team leads for further review and revisions via shared Google Docs. The 17-question survey (see **Appendix A** for the full list of survey questions) was made up of two main sections; the first part had 12 questions specific to understanding respondents knowledge of current interventions and challenges associated with PMTCT programs, EID testing, HEI comprehensive care and their subjective opinion about how well the program and country they support are prioritizing these interventions. The second part of the survey had four questions tailored to participants' knowledge and feelings towards existing PMTCT and OVC collaborations in their supported country, and identifying technical assistance needed to strengthen further coordination. The last question was open ended and allowed participants to express any last remarks they felt were not included within the questionnaire.

Upon making final revisions to the HEI/OVC survey, it was sent to USAID's OVC and PMB Branch Chiefs for final review and dissemination approval. The Google Forms survey link was then sent by email to a USAID listserv containing HQ OVC and PMB backstops, and OVC and PMB mission teams.

The email invitation to prospective participants was sent stating that their involvement was completely voluntary and all respondent identities would remain confidential. Participants were told that the survey consisted of 17-questions and was designed to take less than 20 minutes to complete. Additionally, they were told that the survey aimed to provide HQ with better insight into current OVC/PMTCT-EID collaboration and practices and identify areas where programs may need support to further contribute to HEI outcomes in COP22. Participants were further informed that the analysis of the survey would result in the development of materials and/or tools that would be shared with countries to address gaps and improve outcomes for HEI. Participants were given three weeks to complete the self-administered online survey and were told to contact me directly if they had any questions or concerns.

Once the survey closed, the data were extracted into Google Sheets and an initial qualitative review of responses was conducted. Responses were disaggregated by job title and country as appropriate for comparative purposes. A full oral debrief and visual presentation was provided to USAID, including PMB and OVC mission teams and implementing partners . Materials were developed according to the responses by country teams and an in depth qualitative analysis of country responses was provided to all country backstops for review and programmatic revisions.

Participants

The voluntary survey was sent to all USAID HQ country backstops within PMB and OVC, Mission PMTCT and OVC point-of-contacts, and Implementing Partners (IP). The identity of all respondents is protected and no personal identifiers were requested outside of what country they support and cadre they work in (OVC or PMTCT). Invited participants included 16 USAID HQ OVC backstops, 17 USAID PMB backstops, 92 PMTCT mission contacts, and 95

OVC mission contacts. Direct communication to PMTCT and OVC IPs was challenging due to no readily accessible email LISTSERV directory. All IPs were recruited using the snowball sampling method, where mission team members were asked to invite other relevant survey respondents. This approach was intended to increase the number of respondents, yet made it impossible to track the total number of eligible IP participants enrolled through the snowball sampling method.

Chapter 4: Results

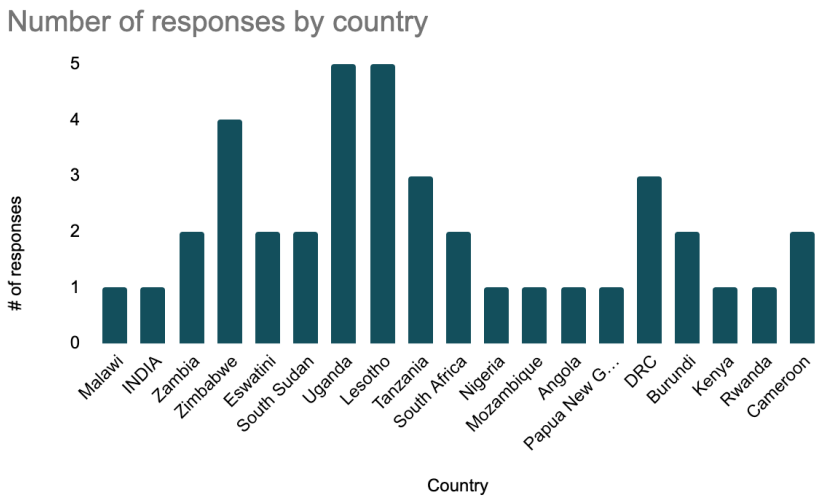
The results section will provide detailed information while also safeguarding the privacy commitment set forth by PEPFAR/USAID communications.

Participant Results

Of the 220 invited participants, there were 42 total survey respondents (19.0% response rate). Two eligible survey respondents indicated their job title as “other” and were therefore excluded from further analyses. Of these 40, five included USAID HQ colleagues, 15 mission point-of-contacts, and 20 implementing partner staff members across 19 different countries. Additionally, the survey respondents comprised 42.5% PMTCT participants and 57.5% OVC participants from all three levels (HQ, Missions, and IPs).

The 19 countries represented by the survey respondents included Angola, Burundi, Cameroon, Democratic Republic of the Congo, Eswatini, India, Kenya, Lesotho, Malawi, Mozambique, Nigeria, Papua New Guinea, Rwanda, South Africa, South Sudan, Tanzania, Uganda, Zambia, Zimbabwe. The number of respondents per country can be seen in Figure 3.

Figure 3. *Survey participants, number by country represented*



The number of total participants in the data analyzed is limited to 40. Twenty three (57.5%) of participants represented OVC and 17 (42.5%) of participants represented PMTCT cadres (Figure 4). When disaggregating by partner level, 20 (50.0%) of respondents were implementing partners, 15 (37.5%) of respondents were part of a country mission team, and 5 (12.5%) of respondents were country backstops at USAID HQ (Figure 5).

Figure 4. *Survey participants, percent from OVC and PMTCT*

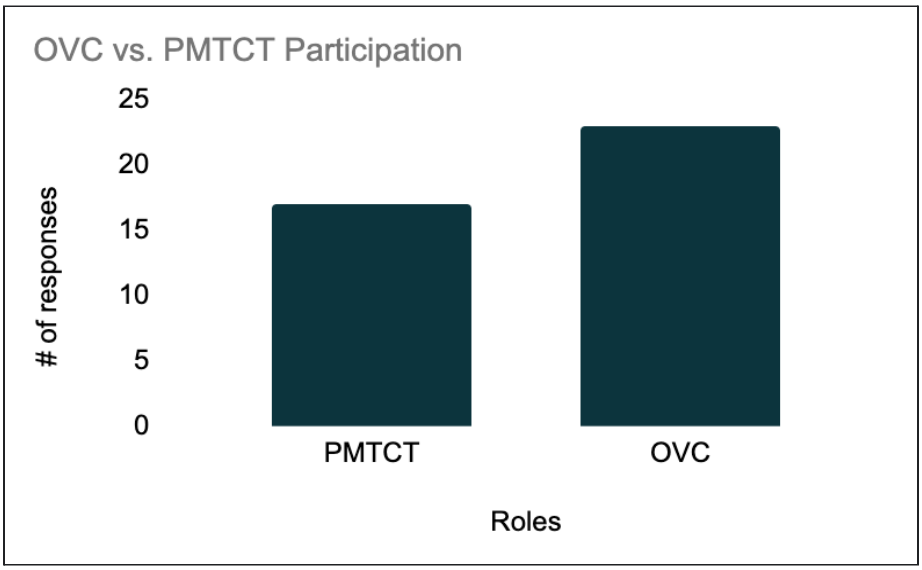


Figure 5. *Survey participants, percent from USAID HQ, country mission, and implementing partner level*

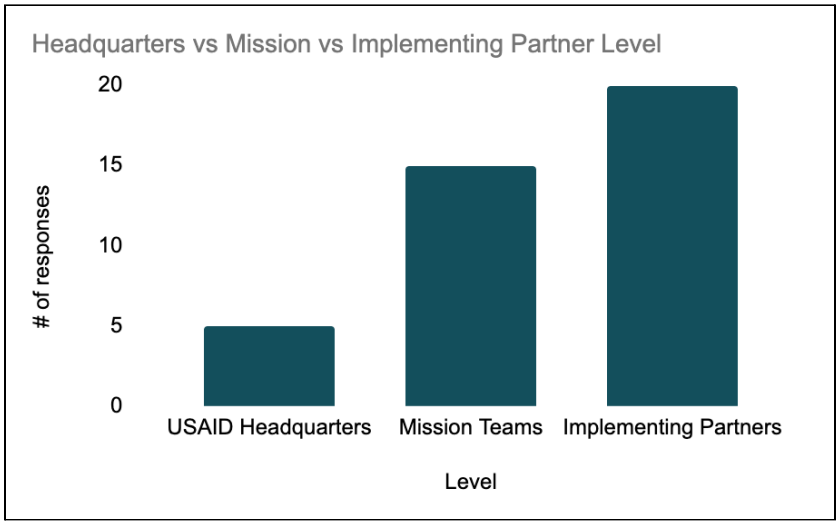


Table 2. *Number of survey participants, number by level and cadre*

USAID HQ PMTCT	**4**
USAID HQ OVC	**1**
Mission PMTCT	**9**
Mission OVC	**6**
PMTCT IP	**4**
OVC IP	**16**
Total	**40**

Challenges Identified in Retaining Mothers in PMTCT Programs

Between the 2019 and 2021 fiscal-year (FY), survey respondents indicated each of the following MIP program interventions as having been implemented within the country they supported to further reduce mothers loss-to-follow-up. The data represents the number and percent of participants who identified each of the barriers among the total 40 survey respondents.

- 33 (82.5%) - Community/facility mentor mothers
- 28 (70.0%) - Appointment reminders
- 24 (60.0%) - Cohort registration

- 23 (57.5%) - MIP joint services/visits
- 23 (57.5%) - QI approach for EID programming
- 11 (27.5%) - mHealth

Common barriers associated with a mothers retention in care and treatment programs were classified into three socio-ecological levels: personal-level, community-level and system-level (see Table 3). Participants were asked to rank the levels according to what they believe is the greatest challenge associated with retaining mothers in PMTCT programs in the country they support. System-level challenges were identified as the greatest challenge to PMTCT retention in most countries.

- 18 (45.0%) participants identified system-level challenges as being the greatest barrier to retaining mothers in PMTCT programs
- 14 (35.0%) participants identified personal-level challenges as being the greatest barrier to retaining mothers in PMTCT programs
- 8 (20.0%) participants stated that community-level challenges posed the greatest barrier to retaining mothers in PMTCT programs

Table 3. *Barriers associated with PMTCT retention, classified into levels with examples.*

Level Barriers	Description and examples of Barriers
Personal-level challenges	High transportation costs, time lost away from work and/or school, lack of knowledge about care and treatment, fear of disclosure, migration during peri- and post-partum periods.
Community- level challenges	Misinformation about antenatal care (ANC), cultural beliefs about ANC and PMTCT, cultural norms influencing women to not give birth at health facilities, women not attending ANC visits, lack of community support and stigma associated with HIV and treatment
System-level challenges	Far distances from health facilities, shortages in health facility staff and/or providers, long waiting times, stockouts/supply chain issues, COVID-19 restrictions, limited PMTCT services in healthcare facilities, few integrated services at health facilities and referral links.

The data were then disaggregated by countries represented to illustrate the level that each country identified having the greatest impact on PMTCT retention (Table 4).

Table 4. *Countries identifying greatest barrier to PMTCT retention, by barrier levels*

Level Barriers	Country identifying the challenges as high priority	
System-level challenges	• Angola • Cameroon • Mozambique • Nigeria • Papua New Guinea • South Sudan • Tanzania • Zambia • Zimbabwe	• (2) Burundi • (3) Lesotho • (2) South Africa • (2) Uganda
Community-level challenges	• DRC • Eswatini • India • South Sudan • Uganda	• (3) Zimbabwe
Person-level challenges	• Cameroon • Eswatini • Kenya • Malawi • Rwanda • Zambia	• (2) DRC • (2) Lesotho • (2) Tanzania • (2) Uganda

Note. Level barriers with multiple responses from the same country are represented in the far right column with parentheses indicating the number of country respondents. (e.g. two respondents from Burundi identified system-level challenges as having the greatest impact on PMTCT retention).

Early Infant Diagnosis

The survey sought to understand whether PEPFAR-supported programs were adhering to 4-6 week early infant diagnostic testing guidelines, and if there were any observed barriers to achieving timely testing and linkage to ART.

Testing at Four-Six Weeks

When asked if 4-6 week testing was supported in the geographic region the participant

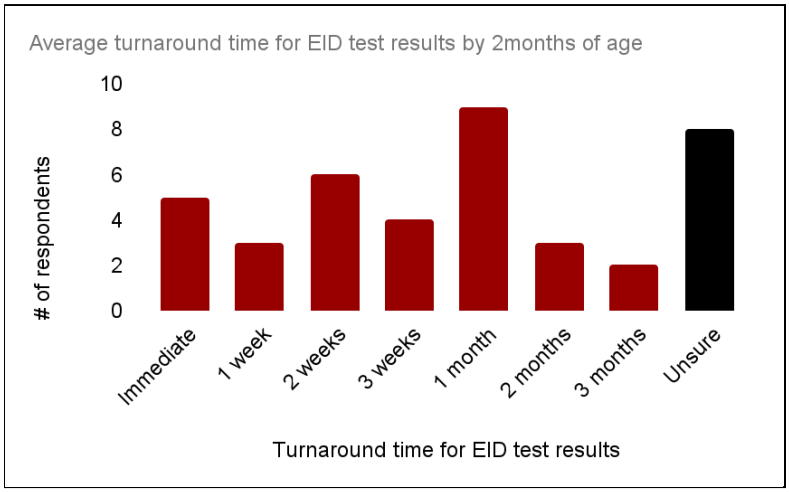
supported, 34 (85.0%) stated that 4-6 week EID testing was conducted, 3 (7.5%) stated no knowledge of 4-6 week EID testing was conducted (respondents representing South Africa and Cameroon) and 3 (7.5%) were unsure of 4-6 week EID testing (respondents representing Kenya, Mozambique and Rwanda).

Barriers to achieving 95% EID testing coverage by 2 months

Key barriers associated with achieving 95% EID coverage by 2 months included:

- Commodities stockouts
- Poor lab systems (machine breakdowns, centralized EID testing, limited lab capacity)
- Mothers not returning for testing
    - Minimal MBP tracking
    - Transportation issues, including but not limited to inaccessible or unreliable transportation and difficulty affording transportation costs.
- Long EID turnaround times
    - Figure 6 shows that turnaround times for 2 month EID results are varied, and differ greatly between countries, but 18 of the 32 participants who reported a known turnaround time identified results being returned at least 3 weeks to 3 months after initial test.

Figure 6. *Percent of respondents indicating specific average turnaround times for 2 month EID test results*



Comprehensive Care for HEI

The greatest challenges to providing comprehensive care to HEI identified by respondents are listed below, with number and percent who identified these greatest challenges among 40 survey respondents:

- 30 (75.0%) - Pregnant or breastfeeding mother retention in PMTCT programs
- 21 (52.5%) - Long turnaround times for EID results
- 18 (45.0%) - Linkage to OVC Programs
- 17 (42.5%) - Linkage to other support structures (including mentor mothers)
- 16 (40.0%) - Availability of diagnostic tests and screening, including EID and TB screening
- 14 (35.0%) - Indicator reporting discrepancies
- 9 (22.5%) - Availability of health facility commodities (including prophylaxis, ART, TPT)

Furthermore, participants were asked how strong they believed current collaboration between OVC and PMTCT programs were in the countries they support, 23 (57.5%) indicated that improvement was needed, 11 (27.5%) stated satisfactory, and 6 (15.0%) stated excellent program collaborations. Disaggregated data for IPs revealed that 100% of those indicating collaboration needed improvement were OVC IPs, and none of PMTCT IPs indicated a need to improve collaboration.

The resources that were mentioned to be essential to improving the provision of comprehensive care for HEI were extensive and country specific. Country disaggregated analyses of resources needed were given to USAID backstops to help identify the needs of each program.

Resources that respondents stated were needed for improving the provision of comprehensive care were:

- EID: Testing commodities, improved turn-around times, decentralized POC EID
- MIP tracking for retention
- Transportation reimbursements for mothers
- Human Resources/ Capacity building
- Strong OVC/Peds collaboration initiatives
- Additional trainings: PMTCT counselors, Human Resources, healthcare providers

Participants were asked if infants newly diagnosed with HIV at health facilities were automatically referred for OVC program enrollment, 22 (55.0%) stated newly diagnosed infants were referred for OVC enrollment while 16 (40.0%) stated no automatic enrollment and 2 (5.0%) said they were unsure.

Technical Assistance

A complete analysis of the survey results revealed the need to provide country teams with additional resources in order to improve the collaboration between OVC and clinic teams and ultimately prioritize the comprehensive care of HEI. Job Aids were the most requested tool, followed by written considerations and training documents for OVC IP's and case workers.

Table 5. *Percentage of total participants requesting technical assistance documents, by type of support requested*

Technical Assistance:	**Percentage of participants who requested this form of aid** (Based on number requesting support/total respondents)
Job aids	77.5%
Written considerations	72.5%
Training documents for OVC IPs and case workers	57.5%
MER Indicator Refresh (PMTCT_FO)	40.0%
Joint webinars with OVC and clinical field teams	30.0%

Chapter 5: Discussion

Prioritizing comprehensive care for MIPs is essential to decrease the morbidity and mortality of children worldwide and helps to ensure that infants are born HIV-negative and stay negative. HIV-exposed infants are at an extreme disadvantage and are often vulnerable to not only acquiring HIV, but high rates of mortality if they are not tested early and linked to appropriate treatment. The clinical cascade for HEI begins with their mothers, making it vital that all pregnant and young mothers are enrolled in PMTCT programs and are not lost to follow up. Programs such as OVC provide a great opportunity for HEI to receive a comprehensive, family-centered approach that pregnant mothers at-risk for interruption in treatment or missed EID are prioritized for enrollment. OVC's community case management coupled with existing clinical care optimizes beneficiaries outcomes and ensures vulnerable populations are healthy, safe, stable and enrolled in school.

Survey data indicated that 13 (32.5%) of respondents believed their country was prioritizing comprehensive care for HEI as either a medium or low priority. These data further support the need for programs to adhere to COP-provided guidance and reevaluate priorities to ensure the most vulnerable are not being missed.

Retaining Mothers in PMTCT Programs

Applying the socio-ecological model to PMTCT retention allowed us to categorize common challenges associated with mothers returning to care into three levels, system, community and personal-levels. For this surveys context, **System-level challenges** were defined as but not limited to: far distances (subjectively defined) from health facilities, shortages in health facility staff and/or providers, long waiting times, stockouts/supply chain issues, COVID-19 restrictions, limited PMTCT services in healthcare facilities, few integrated services at health facilities and referral links. **Community-level challenges** were defined as misinformation about antenatal care (ANC), cultural beliefs about ANC and PMTCT, cultural norms influencing women to not give birth at health facilities, women not attending ANC visits, lack of community support and stigma associated with HIV and treatment. **Personal-level challenges** were defined as high transportation costs, time lost away from work and/or school, lack of knowledge about care and treatment, fear of disclosure, migration during peri- and post-partum periods.

Despite considerable scale up in MIP retention interventions between FY 2019 and FY 2020, barriers in retaining mothers within PMTCT programs remain prevalent at every level, with the system-level posing the greatest challenges across most countries represented. Participant responses were further disaggregated by country in order to account for country

contexts and allow USAID country backstops to tailor future interventions according to the specific needs of the country.

Early infant diagnosis

Data revealed that 4-6 week testing was conducted in most respondent-supported countries. Two participants representing South Africa indicated no 4-6 week testing conducted, but a review of country EID guidelines later revealed that the South African National Department of Health recommends 10 week testing with a confirmatory test at 18 months (South African National Department of Health, 2019). This finding provides an opportunity to reconcile an important difference between national policy with global guidance.

Barriers associated with achieving the 95% EID testing target by 2 months were largely attributed to commodity stockouts, lab capacity limitations, centralized EID, poor retention caused by poor MIP tracking and transportation difficulties and long turnaround times for EID results. The ability to associate said barriers to testing coverage achievement provides necessary context to prioritize and reallocate efforts to minimizing these gaps.

OVC/PMTCT collaborations

Survey data indicated that 22 (55.0%) of all respondents believe that infants diagnosed with HIV at health facilities are being referred for OVC program enrollment. This finding indicates a gap in enrollment into the OVC comprehensive program and reveals an opportunity to scale-up referrals in order to improve HEI outcomes. COP22 guidelines state that OVC and clinical implementing partners must coordinate to ensure that all HEI are linked to appropriate testing or treatment services, maintain treatment continuity, and are offered enrollment in comprehensive OVC programs (U.S Department of State, 2022).

The multidisciplinary and bidirectional referral system between OVC and Clinical IPs is established through the placement of OVC linkage facilitators in health facility settings. Clinical IP's are not responsible for enrolling patients into OVC programs, but instead are tasked with referring patients to an OVC worker for further community or home-based assessments to identify OVC enrollment eligibility. Clinical IPs should refer all newly diagnosed infants to the linkage facilitator to assess eligibility for enrollment into the OVC Comprehensive Program.

Non-OVC supported USAID districts

While OVC program enrollment should be prioritized in the districts that they are located, not all USAID-supported PMTCT programs have an OVC program within their geographic area. PMTCT programs should consider utilizing clinical case management approaches and partner with existing community-based organizations such as Mentor Mothers, faith-based organizations, young mothers groups, and others to provide MIPs with comprehensive support.

Strengths

This study assessed the known gaps associated with supporting the clinical cascade for HEI and their mothers, and sought to understand the barriers that exist across 19 participating countries. The ability to assess the direct needs from country teams helps to ensure that the materials developed will be directly relevant to closing the service gaps associated with HEI.

As a result of this survey, technical considerations, training and screening tools to prioritize the enrollment of HEI into comprehensive care programs will be provided to the field teams. It is hoped that they can see how their stated training and screening needs were met. It is crucial that these data are used for program performance improvements and that OVC programs

at the mission level continue to utilize these to inform programmatic and targeting considerations to strengthen clinical collaboration to promote healthy outcomes.

Limitations

- The survey data relied heavily on the perspective of IP's and mission teams, not the direct perspective of those this survey is meant to serve. While collecting data from mothers targeted for these services is difficult, future assessments should aim to elicit more specific information from mothers who are experiencing these challenges.
- The survey was sent out in early January and conflicted with Country Operational Planning, this could have reflected the relatively modest response rate at all levels.
- Some challenges identified are outside of PEPFAR's ability to address. (i.e lack of specificity about EID commodity stock outs), and will require partnering with procurement and supply chain authorities in each country. Also, advocacy for improved use of the USAID supply chain division could represent viable next steps to ensure that the identified barriers are addressed.
- Despite the anonymous nature of the survey, unintentional power dynamics and lack of cohesiveness may exist between cadres, which may influence the veracity of responses and potentially subject data to social desirability bias. Respondent-specific data was not shared with USAID HQ staff and no respondent identifiers were collected (email address, phone numbers, names, other), yet survey non-respondents may have questioned the ability to safeguard potentially identifying information.
- The data encompasses three different respondent roles (HQ, mission, IP), differences in responses within the same country could be attributed to perceptions held by different cadres/job roles.

- Small USAID HQ staff response rate impeded role-specific analysis.
- Uneven number of country respondents has the potential to limit generalizability in country-disaggregated analyses (i.e countries with only 1 respondendent cannot represent the entire country).
- Inability to consider differences in cultural context when disaggregating survey results by country limited the analyses.

Implementation Guide/Toolkit

Based on the survey analysis, respondents from the country teams have requested technical assistance to strengthen OVC/PMTCT coordination to improve HEI/MIP outcomes. An implementation guide was created to house all the developed tools and for a coordinated distribution. All documents have been sent to country teams and USAID country backstops. A provisional review of the survey results was presented to the implementing partners, USAID mission teams and HQ staff within PMB and OVC. The developed tools have been excluded from this research thesis in compliance with PEPFAR/USAID internal document sharing guidelines.

Technical Considerations Document

A technical and programmatic considerations document was developed as a resource for PEPFAR-funded OVC and clinical partners to follow COP22 guidance to collaboratively strengthen community-facility linkages, and integrate clinical and OVC services to ultimately strengthen and support continuity of treatment and management of HEI and their mothers. This document also serves to provide targeting enrollment criteria for enrolling new OVC

beneficiaries (including defining “at-risk” MIP), bidirectional referral considerations, and guidance on working with other community programs.

At-risk screening tool

An adaptable screening tool for mission teams and implementing partners to prioritize the enrollment of populations that are the most at-risk of interruption in treatment. COP22 guidance states that MIPs who are at risk of not meeting PMTCT benchmarks (e.g., timely return for EID) should be prioritized for enrollment into the OVC program, especially for adolescent/youth mothers living with HIV. This newly developed tool supports this guidance by allowing clinical staff at health facilities to quickly screen young women for risk factors that may deem them eligible for referral to OVC enrollment. This tool also helps to identify more MIPs and in turn, includes more HEI within the OVC Comprehensive Program.

Job Aids

Three Job Aids were created in order to train and support the coordination between OVC case workers and clinical staff. These job aids provide a “how to” document to clearly illustrate expectations.

- Job Aid 1: OVC case workers in supporting pregnant and breastfeeding women and MIPs
    - This aid outlines what it looks like for OVC case workers to support ART adherence during pregnancy, and advocate for EID and infant ART prophylaxis.
- Job Aid 2: OVC case workers supporting referral to clinical services
    - This aid illustrates when an OVC case worker should refer a beneficiary to the health facility for services.
- Job Aid 3: Clinical staff referral of HIV-positive pregnant and breastfeeding women and MIPs to OVC

- This aid outlines when and how health facility staff should refer the listed population to OVC programs.

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Appendix A: Survey Questionnaire

What country do you support/work in: _____

What is your role: USAID HQ PMTCT backstop, USAID HQ OVC backstop, Mission PMTCT POC, Mission OVC POC, Implementing Partner PMTCT POC, or Implementing Partner OVC POC

1. Is there a PMTCT national strategy in your country? If yes, what is the most recent version you have access to? Short answer
2. Using your knowledge of the challenges in retaining pregnant mothers in PMTCT programs, please rank the below issues in your country from 1 (greatest) to 3 (least). Rank in order
    a. Person-level challenges: transportation costs, time lost away from work/school, misinformation or fear of disclosure, migration from home clinics to family village during peri- and post-partum periods
    b. System-level challenges: distance from HF, not enough HF staff/providers or long waiting times, poor services, stockouts/supply chain, COVID-19 restrictions, limited PMTCT services in healthcare facilities
    c. Community-level challenges: misinformation/cultural beliefs about ANC/PMTCT, women not attending ANC, women not giving birth at facilities, stigma
3. During the FY19 to FY21 time period, did your country implement any of the following mother-infant pair (MIP) retention interventions? Select all that apply
    a. Community/facility mentor mothers
    b. MIP joint services/visits
    c. mHealth
    d. Appointment reminders
    e. QI approach for EID programming
    f. Cohort registration
4. In the country you support, what community-based organizations/interventions currently focus on providing support to mothers living with HIV and their HEI? Select all that apply.
    a. Mentor mothers or m2m
    b. Pregnancy clubs
    c. COVID-19 interventions
    d. Faith-based community programs

   e. Traditional birth attendants
   f. Young mothers groups
   g. Other _____

5. In the country you support, are birth delivery locations, ANC visits, and post-natal follow-up visits integrated within the same health facility?
   a. Yes
   b. No
6. How well is your country prioritizing care for HEI? *(Ex: High priority; country has a national strategy that includes HEI care and funds to implement the strategy; Medium priority: country has a national strategy that includes HEI care but funds depend on external donor support; Low priority: country does NOT have a national HEI strategy or resources for addressing HEI)*
   a. High priority
   b. Medium priority
   c. Low priority
7. Do the geographic areas that you support conduct 4-6 week EID testing?
   a. Yes
   b. No
   c. Unsure
8. What is the biggest barrier to achieving 95% EID testing coverage by 2 months of age? Short Answer
9. What is the average turnaround time for EID test results by 2 months of age in the country you support?
10. Are infants who are newly diagnosed with HIV at a health facility automatically referred to an OVC Program?
    a. Yes
    b. No
11. What challenges in providing comprehensive care to HEI exist within the country you support? Select all that apply
    a. Pregnant or breastfeeding mother retention in PMTCT programs
    b. Indicator reporting discrepancies
    c. Linkage to OVC programs
    d. Linkage to other support structures (including mentor mothers)
    e. Availability of health facility commodities (including prophylaxis, ART, TPT)

f. Availability of diagnostic tests and screening (including EID and TB screening)
g. Long turnaround times for EID results
h. Other: _____

12. In your opinion, what resources are needed to improve the provision of comprehensive care of HEI in your country? Short answer

PMTCT/OVC Collaboration:

13. What services do OVC programs in your country currently offer Pregnant and Breastfeeding Women (PBFW) and HEI? Select all that apply
    i. EID testing referral
    ii. Reminders and tracking for EID testing
    iii. Linkage to ART for babies who test positive
    iv. Adherence support with ARV prophylaxis
    v. Adherence support with Cotrimoxazole prophylaxis
    vi. Nutrition services
    vii. Appointment reminders
    viii. Early childhood development
    ix. Support to ensure tracking through to final outcome (FO) determination
    x. Socioeconomic services (Positive Parenting and Economic Strengthening)
    xi. Other: _____
14. What is your best estimate of the proportion of new babies born within OVC-supported households who received referrals for HIV testing within the last reporting period?
    a. 0%
    b. 1% - 25%
    c. 26% - 50%
    d. 51% - 75%
    e. 76% - 100%
    f. Unsure/cannot estimate
15. How strong do you believe the current collaboration between OVC and PMTCT programs is?
    a. Excellent
    b. Satisfactory
    c. Needs Improvement

   d. Unsure/I'm not aware of any current collaboration

16. What technical assistance is needed to improve OVC and clinical team collaboration to further support HEI/MBPs? Select all that apply
    a. Job aids
    b. Written guidance/considerations
    c. Slides to train OVC IPs/case workers
    d. More webinars
    e. Indicator Refresh (PMTCT_FO)
    f. Other__
17. Additional comments *(additional barriers to providing services for HEI, current initiatives, needed resources or information, etc.)*

Appendix B: Survey Results Presentation Highlights

Importance of Preventing New Child Infections

- Considerable scale-up of prevention of mother-to-child HIV transmission (PMTCT) services, HIV testing services (HTS), antiretroviral therapy (ART) optimization, and HIV prevention services have resulted in a **53% decrease in new pediatric infections between 2010 and 2020** [1]
- However, **global goals have not been met**:
  - In 2019, an estimated 150,000 children ages 0–14 years were newly infected with HIV [1]
- Without treatment, **up to 30%** of infants diagnosed with HIV will die by their first birthday and **50%** by their second [2]
- While there is great opportunity to save infant lives through early diagnosis and linkage to treatment, **gaps still remain** across PEPFAR programs.

[1] UNAIDS Fact Sheet
[2] Point-of-care early infant diagnosis of HIV improves treatment initiation.

RESEARCH QUESTION

What are the current challenges in providing services for HIV-Exposed Infants in USAID's OVC and Clinical Programs?

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Global Summary of Results

High-level overview of participant demographics

19 countries participated

42 people completed the survey

5 USAID HQ staff completed the survey

15 Mission staff completed the survey

20 IP staff completed the survey

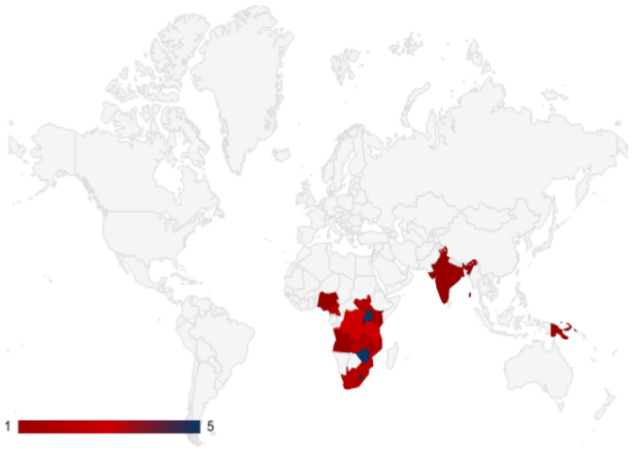
High level of participation

PMTCT Participants	OVC Participants	Other
17	23	2

USAID HQ PMTCT	4
USAID HQ OVC	1
Mission PMTCT	9
Mission OVC	6
PMTCT IP	4
OVC IP	16
Other	2

19 Countries participated

- Malawi
- India
- Zambia
- Zimbabwe
- Eswatini
- South Sudan
- Uganda
- Lesotho
- Tanzania
- South Africa
- Nigeria
- Mozambique
- Angola
- Papua New Guinea
- Democratic Republic of the Congo
- Burundi
- Kenya
- Rwanda
- Cameroon



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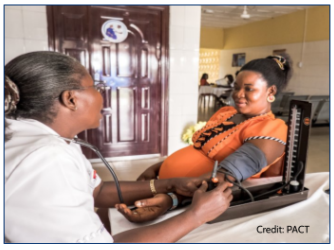
High Level Summary of Survey Results

The greatest challenges in retaining mothers in PMTCT programs were identified at the system level.

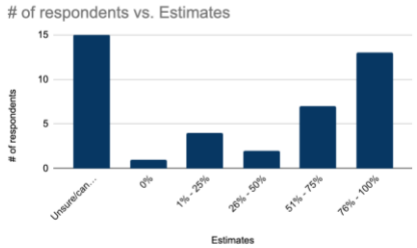
Level	Challenges
Person-level challenges	High transportation costs, time lost away from work and/or school, lack of knowledge about care and treatment, fear of disclosure, migration during peri- and post-partum periods.
Community-level challenges	Misinformation about antenatal care (ANC), cultural beliefs about ANC and PMTCT, cultural norms influencing women to not give birth at health facilities, women not attending ANC visits, lack of community support and stigma associated with HIV and treatment
System-level challenges	Far distances from health facilities, shortages in health facility staff and/or providers, long waiting times, stockouts/supply chain issues, COVID-19 restrictions, limited PMTCT services in healthcare facilities, few integrated services at health facilities and referral links.


Credit: PACT

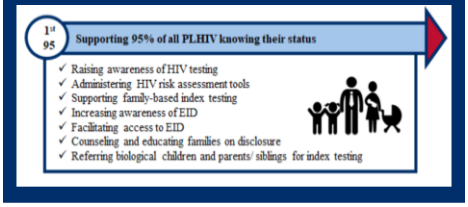
Question: Using your knowledge of the challenges in retaining pregnant mothers in PMTCT programs, please rank the below issues in your country from most challenging to least challenging

45.2% countries identified **system-level**
35.7% countries identified **personal-level**
19.1% countries identified **community-level**

Question: What is your best estimate of the proportion of new babies born within OVC-supported households who received referrals for HIV testing within the last reporting period?



Key Consideration: OVC can support the increase of 2 month EID testing coverage by promoting and referring new infants born within current OVC-supported homes to health facilities for timely EID testing. Proper documentation by case managers can ensure all children are offered testing and linked to ART if presenting with a positive outcome.



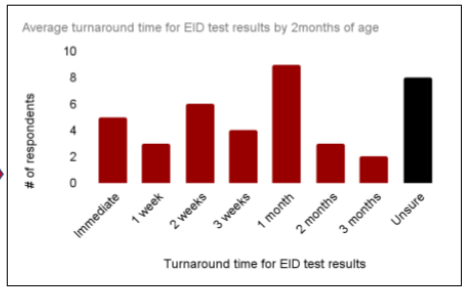
4 - 6 week EID testing within supported geographic areas

- 83.3% stated that 4-6 week EID testing was conducted
- 7.1 % stated no 4-6 week EID testing was conducted (respondents from South Africa and Cameroon)
- 9.5% were unsure of 4-6 week EID testing (respondents from Kenya, Mozambique and Rwanda)

Barriers to EID testing coverage and average turnaround times for 2 month EID

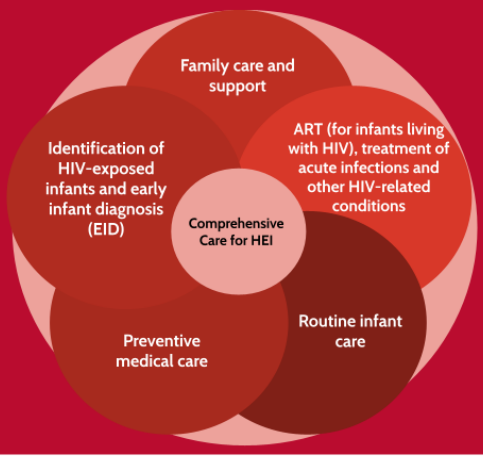
Main Barriers in Achieving 95% EID by 2 months:

- Commodities
- Poor lab systems (machine breakdowns, centralized EID testing, lab capacity issues)
- Mothers not returning for testing
  - Minimal MBP tracking
  - Transportation issues
- Timely EID results



57.6% reported an average turnaround time between 3 weeks - 3 months

— Comprehensive Care for HEI



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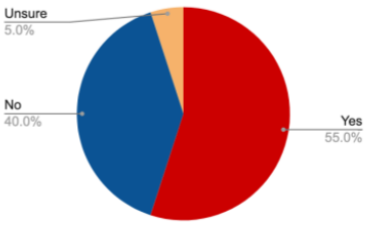
Are infants who are newly diagnosed with HIV at a health facility automatically referred to an OVC Program?



Key Consideration: Facility-based providers should refer all newly diagnosed infants to the linkage facilitator to assess eligibility for enrollment into the OVC Comprehensive Program

Leveraging OVC's Comprehensive Model to provide support to MIPs and improves CoT

The **OVC Comprehensive Model** provides MIPs with needs-based services and support including but not limited to:

- Support for timely EID and final outcome
- HTS referrals
- ART linkage
- ART counseling and adherence
- Nutrition and economic strengthening

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OU Detailed Results (Examples)

UGANDA

High Prioritization of HEI

5

OVC Implementing Partners

Biggest barrier in achieving 95% EID testing coverage by 2 months of age:

- Failure for mothers to attend postnatal care (typically because of transportation limitations)
- In postnatal clinics, mothers are always appointed for 6 weeks immunization but hardly get same day appointment for 1st PCR.

Average turnaround time for EID test results by 2 months of age in Uganda?

- 2 weeks - 1 month

Challenges in providing comprehensive care to HEI exist:

- Pregnant or breastfeeding mother retention in PMTCT programs
- Linkage to other support structures (including mentor mothers)
- Availability of health facility commodities (including prophylaxis, ART, TPT) and diagnostic tests and screening (including EID and TB screening)
- Long turnaround times for EID results
- Some mothers still would like to deliver via health attendants

Resources are needed to improve the provision of comprehensive care of HEI:

- Community structures to increase demand for PMTCT services through referral and linkages
- Availability of diagnostic tests at all EMTCT clinics and strong OVC/EMTCT collaboration.
- Transport and nutritional support to pregnant mothers to attend clinical visits

When asked how strong the collaboration between OVC and PMTCT in Uganda is:

- 60% of respondents stated it needs improvement and 40% of respondents stated satisfactory.
- No respondents stated excellent collaboration.

Technical Assistance requested to strengthen OVC and PMTCT collaboration:

- Job aids, Written considerations, Indicator Refresh (PMTCT_FO), training slides for OVC IP caseworkers

DRC

2
OVC Implementing Partners

1
PMTCT Implementing Partner

High Prioritization of HEI

Biggest barrier in achieving 95% EID testing coverage by 2 months of age:
- Missed appointments at post-natal consultation, transportation cost, MIP high mobility, non-disclosure to partner

Average turnaround time for EID test results by 2 months of age in the DRC?
- 2 weeks - 1 month

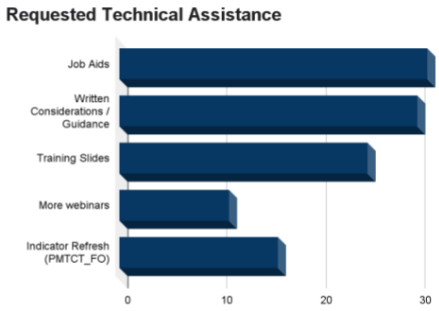
Challenges in providing comprehensive care to HEI exist:
- Pregnant or breastfeeding mother retention in PMTCT programs
- Availability of diagnostic tests and screening (including EID and TB screening)
- Long turnaround times for EID results
- Non-disclosure to partner

Resources are needed to improve the provision of comprehensive care of HEI:
- More skilled providers in both facilities and community
- Insufficient number of community workers
- Turnaround time for EID results

When asked how strong the collaboration between OVC and PMTCT in the DRC is:
- 66.7% stated satisfactory, while 33.3% stated excellent

Technical Assistance requested to strengthen OVC and PMTCT collaboration:
- Job aids, Written guidance/considerations, Slides to train OVC IPs/case workers

What technical assistance is needed to improve OVC and clinical team collaboration to further support HEI/MIPs?



OVC/PMTCT Collaboration

Analyze Results
Total of 40 survey responses representing 19 OUs. Robust data received and analyzed

Webinar
Joint webinar with OVC/PMTCT field teams to discuss next steps, and release the developed toolkit.

HEI/OVC Survey
Developed to identify gaps in services for HEI, current OVC/PMTCT country collaborations and technical assistance needed to improve comprehensive care and treatment of MIPs

Toolkit Development
Survey results revealed technical assistance requests including:
- Written considerations
- Job Aids
- OVC/IP case worker training
- OVC/Peds Webinars

Support OUs
The OVC/Peds TU will be providing support to OUs in the planning and implementation of these tools.

HEI/OVC Toolkit

Job Aids

- OVC case workers in supporting pregnant and breastfeeding women and MIPs
- OVC case workers supporting referral to clinical services
- Clinical staff in supporting HIV positive PBFW and MIPs to be referred to OVC

Considerations Document

- Defining roles for clinical and community collaboration
- Collaborating with PMTCT programs
- MIP targeting considerations for OVC enrollment
- Identifying at-risk young mothers
- Target setting/size estimation.

Training Slides

Training resources for OVC implementing partners and case workers

OVC/Peds Webinar

More details coming soon!

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Thank You!

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Appendix C: HEI/OVC in COP22 Guidance:

Figure 6.6.3.1: OVC Comprehensive & Preventive Program Areas

Program Area	Target Population	Recruitment Modality	Program Approach	Relevant COP22 Guidance Sections
OVC Comprehensive	• Children and adolescents living with HIV • Children of adults living with HIV at risk treatment interruption; children who have lost parents to AIDS • HEI at high risk of treatment interruption (i.e., pregnant and adolescent mothers and their infants) • Children of female sex workers (especially FSWLHIV) • Survivors of sexual violence	• HIV clinical sites (pediatrics, adult treatment, PMTCT) • Child welfare services • Traditional and community leaders	• Family-based case management • Monitor against graduation benchmarks • Provision and/or linkage to supportive socio-economic services	• 6.3.2.2 Case Finding in OVC • 6.6.2.1 Gender-Based Violence and Violence Against Children • 6.5.4 Considerations for Children of Key Populations, Adolescent and Young Key Populations
OVC Preventive	• Boys and girls aged 10-14 years in high burden SNUs	• Schools • Community and faith youth groups	• Provision of single, evidence-based primary prevention of HIV and sexual violence intervention by trained facilitators in group settings • No case management • Not tracked against benchmarks	• 6.2.3 Primary Prevention of HIV and Sexual Violence for 10-14 Year Olds • 6.2.2.2 The DREAMS Partnership

(U.S Department of State, 2022)

6.3.2 Case Finding for Pediatrics

- Mother-infant pairs at risk of not meeting PMTCT benchmarks (e.g., timely return for EID) should also be prioritized for enrollment into the OVC program, especially for adolescent/youth mothers living with HIV.

6.5.4.1 Children of Key Populations

- ***Continuum of Care and Coordination with OVC Comprehensive Program:*** KP, OVC and clinical Implementing partners must coordinate to ensure that children of key populations are included in the bidirectional referral and linkage processes, and that all HEI and CLHIV of key populations are linked to appropriate testing or treatment services, maintain treatment continuity, and are offered enrollment in comprehensive OVC programs

6.6.3 Orphans and Vulnerable Children: Evolving the OVC Portfolio in a Changing Epidemic (p. 498-508)

- **Key Challenges for Children in the AIDS Pandemic:** During pregnancy and breastfeeding, interruption in treatment from PMTCT services greatly increases the likelihood of vertical HIV transmission. Therefore, OVC programs can provide client-centered support to pregnant women living with HIV and their infants most at risk for interruption in treatment or missing EID, such as in pregnant adolescents and adolescent mother-baby pairs.
- **OVC Comprehensive Program:** OVC frontline providers are also essential to supporting both timely testing for HIVexposed infants and the introduction of optimized ART regimens. To facilitate the latter, clinical IPs and facilities should assist in training OVC staff and frontline case workers on the fundamentals of ART and ART

optimization, including new ARVs such as pDTG using language that is understandable by community cadres and members. In continuation from COP21, at least 90% of children (<age 18) in PEPFAR supported treatment sites in high volume clinics within high burden SNUs, should be offered enrollment in OVC programs.

7.3.2 Setting Targets for Accelerated Epidemic Control in Priority Locations and Populations

- *(704)* Subpopulations of focus within the OVC comprehensive program include children of KPs (especially children of FSW living with HIV), children whose parents are living with HIV, children orphaned by AIDS, HIV exposed infants whose mothers are at risk of not returning for timely EID and other key PMTCT benchmarks and child survivors of sexual violence (see Section 6.6.3).
- OVC teams should work with pediatric, PMTCT, and KP colleagues to ensure coordinated planning that results in greater support to children and adolescents living with HIV and **HIV-exposed infants.**

<u>EID Guidance for OVC:</u>

6.1.2.1 Differentiated Service Delivery for Children

- (203) PEPFAR-supported Clinical IPs play a key role in training community (OVC) case workers to build their knowledge in areas such as adherence, CoT, disclosure, ARV transitions and drug administration, viral load testing and suppression, and making referrals for presumed TB. Likewise, OVC IPs can help train clinic staff to understand the broader factors (e.g., socioeconomic, and cultural) that impact health seeking behaviors (**such as EID**, HTS, keeping clinic appointments, adhering to medication, returning for viral load test and results), and to help facility-based staff recognize which families and children/ adolescents would benefit from OVC program support and other community-based services.

6.3.1.3 Infant Diagnosis: Birth Testing, Integrating POC for Early Infant Diagnosis (EID)

- (297) Other strategies to reach infants and older children outside of PMTCT programs will rely on index testing, appropriate PITC (see Section 6.3.2 on Pediatric case finding), and risk based screening in OVC programs and other community-based settings.

6.5.4.1 Children of Key Populations

- (471) Programs should prioritize differentiated care models that improve access to and uptake of **early infant diagnosis (EID)** and PMTCT services (see Section 6.2.4 Prevention for Women and PMTCT)

6.6.3 Orphans and Vulnerable Children: Evolving the OVC Portfolio in a Changing Epidemic (p. 498-508)

- OVC's long-standing and vast community presence coupled with a focus on the socio-economic factors affecting children and families affected by AIDS, are essential to closing gaps for the most vulnerable children. Due to regular interaction with households and communities, OVC programs are able to identify children and families who don't present in clinics or receive appropriate VL monitoring, trace mothers with infants who

don't return for EID and other PMTCT milestones as well as those who experience treatment interruption and provide support to those who struggle with treatment adherence. By employing a case management model that is both child-centered and family-based, PEPFAR's OVC platform helps clients navigate access to health, social, legal, and economic support.

- Identification via clinics should focus on children with poor viral suppression and history of interruption in treatment/returned to care, children newly initiating treatment, infants of mothers at risk of interruption in treatment in the PMTCT cascade or missing EID (especially adolescent mothers during and after pregnancy), adolescents transitioning to adult treatment, and biological children of adult index cases. In addition, CLHIV with biological siblings or biological parents who have unknown HIV status whose households may require support with index testing and linkage to treatment should also be a focus.
- So that roles and responsibilities between health and community services are clear, PEPFAR supported clinics and OVC service delivery organizations (and coordinating implementing partners as needed) should continue reinforcing and operationalizing Memoranda of Understanding (MOUs). The MOUs are required to address key issues such as bi-directional referral protocols, pediatric case finding including index testing, support for ART optimization such as training on the pediatric DTG transition, case conferencing, shared confidentiality, joint case identification and routine and frequent data sharing between the clinics serving OVC beneficiaries and the OVC IPs (related to ART status and regimens, date of last viral load test, viral load suppression status, and index testing where possible), so that OVC IPs have real time and accurate clinical information for the OVC beneficiaries that they serve. This will begin a PEPFAR-wide process of moving the OVC program in the direction of reporting clinically confirmed, rather than self-reported, health information in OVC indicators. In addition, in PEPFAR-supported SNUs, clinical staff and clinical IPs should play a key role in training community case workers to build their knowledge in areas such as ART optimization and drug administration, viral load testing and suppression, continuity of treatment, age-appropriate disclosure, and "Undetectable = Untransmittable" messaging (more information about the role clinical implementing partners should play in supporting training for OVC staff on ART optimization, please see Section 6.4.1.2 Pediatric ART Optimization). Likewise, OVC IPs can help train clinic staff to understand the factors (e.g., socioeconomic, cultural, experience of violence) that impact health-seeking behaviors (e.g., HIV and EID testing, keeping clinic appointments, initiating ART, or transitioning to a new ARV such as pDTG), adhering to medication, and returning for viral load test and results; and to recognize which families and children are most in need of OVC program support.