

# **CHALLENGES FOR EARLY INFANT DIAGNOSIS OF HIV IN THE GBEKE HEALTH REGION, IN CENTRAL COTE D'IVOIRE**

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**Abstract**

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In low income countries, 35% of HIV infected infants will die within a year if they are not tested and treated early for HIV infection. Identifying and tracking HIV exposed infants remains a significant challenge for many countries, meaning up to 80% of HIV exposed infants are estimated to be lost to follow up and do not receive critical, lifesaving interventions. This study focused on the facilitators and barriers of early infant diagnosis of HIV at six clinics of the Gbêkê region in Côte d’Ivoire. Quantitative and qualitative methods were used to answer research questions related to community, health system, and individual level facilitators and barriers to accessing early infant diagnosis (EID) services in public health facilities. Key findings reveal that challenges such as unpredictable turnaround time for the return of HIV test results and fear of stigma are important barriers to early infant diagnosis. Facilitating factors include the presence of on-site community counselors, who played key roles in the retention of caregivers into care and treatment services. Recommendations for improving EID services in clinics include

more systematic application of national guidelines related to the organization of onsite services, greater government support for the role of community counselors in public health facilities, and a decentralization of virologic testing machines to reduce the turnaround time of test results for HIV exposed infants.

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## ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral
CDC	Centers for Diseases Control and Prevention
CI	Côte d'Ivoire
CNER	Comité National d'Ethique et de la Recherche (The National Institutional Review Board of Côte d'Ivoire)
CSU	Centre de Santé Urbain (urban health center)
DBS	Dried Blood Spot
DHS	Demographic and Health Survey
EID	Early Infant Diagnosis
FGD	Focus Group Discussion
FSU.COM	Formation Sanitaire Urbaine à base Communautaire (urban community based health center)
HAI	Health Alliance International
HBV	Home Based Visits
HCW	Health Care Worker
HG	Hôpital General (Central Hospital)
HIV	Human Immune-deficiency Virus
IRB	Institutional Review Board
LTFU	Loss To Follow Up
MAP	Men As Partner
MCH	Mother and Child health
MoH	Ministry of Health
MSLS	Ministère de la Santé et de la Lutte contre le SIDA (Ministry of Health and Fight against AIDS)
NGO	Non-Governmental Organization
PCR	Polymerase Chain Reaction
PEPFAR	President's Emergency Plan for Aids Relief
PHP	Public Health Pharmacy
PI	Principal Investigator
PLWHA	People Living With HIV/AIDS
PMI	Centre de Protection Maternelle et Infantile (center for national and child health)
PMTCT	Prevention of Mother-To-Child Transmission of HIV
RA	Research Assistant
HR	Human Resource
UW	University of Washington
WHO	World Health Organization

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## **DEDICATION**

This work is dedicated to my spouse, Adzé Afi MULUH and son, David MULUH, not leaving out my parents in Cameroon; Anyam Paul and Ateh Magdalene. Thank you for your love and incredible support.



## INTRODUCTION

There are about 2.5 million children infected with HIV in the world, with 90% living in low resource settings [4, 5]. In Côte d'Ivoire the prevalence of HIV for the general population is estimated at 3.7% [6] with a resulting burden of 450,000 People Living With HIV/AIDS (PLWHA) [7]. The HIV burden affects women more than men, with two women infected for every infected man, and 50,000 children are HIV infected, with over 16,000 new infections in children each year [8, 9]. According to a study published in 2011 in a remote setting in Thailand on HIV-1 early infant diagnosis by Polymerase Chain Reaction (PCR), 8% of HIV exposed infants in limited resource settings had access to early HIV diagnosis services eight weeks after delivery [10]. A similar pilot study in 2011 in Côte d'Ivoire found that only 2.4% of exposed children had a PCR test [11].

HIV infection of infants and young children can occur during pregnancy, during labor and delivery, or during the postnatal phase through breastfeeding. In breastfeeding populations, 15-45% of infants born to HIV infected mothers acquire HIV infection if no intervention is provided [12]. For non-breastfeeding mothers who follow a PMTCT program, the risk for infection for exposed infants is reduced to 2% and for breastfeeding mothers who received an intervention, the risk of infection is less than 5% [13, 14]. Studies have reported that in developing countries, if no treatment or care is given to HIV exposed infants, 35% will not survive before 12 months and up to 53% will die by the time they reach their 2<sup>nd</sup> birthday [4, 15]. Early diagnosis of HIV among infants is important because it allows health care providers the opportunity to identify and provide critical care and treatment early enough to such children and an opportunity to keep all infected infants and their mothers in care to avoid loss to follow-up (LTFU). Early Infant Diagnosis (EID) also permits the linkage of Prevention of Mother-to-Child

transmission of HIV (PMTCT) and treatment services so as to reduce infant mortality and helps mothers make decisions about infant feeding [4, 14, 16, 17].

WHO recommends a virologic test for early HIV detection at 4 to 6 weeks from birth if the exposure status of babies born from HIV positive mothers is known [18]. The sensitivity for the Polymerase Chain Reaction (PCR) test at this period is >95%. Additionally, to reduce infant mortality rates, most developing countries have chosen to match this period with the early stages of their vaccination programs [19, 20]. If the newborn receives cotrimoxazole as prophylaxis and antiretroviral therapy (ART) early enough after delivery, that child has a greater chance of surviving childhood [21, 22]. These findings underscore the importance of identifying and enrolling HIV exposed infants early into care and treatment programs.

In Côte d'Ivoire, as in most low resource countries, the most common test used to diagnose infants born to HIV infected mothers is the PCR assay, which tests directly for HIV DNA rather than the HIV antibody [23]. From heel stick or finger punctures in infants, whole blood can easily be adsorbed on a filter paper forming Dried Blood Spots (DBS), thus avoiding the use of syringes and vacutainer tubes and eliminating the necessity for sample centrifugation and extraction. Since 2006, EID of HIV has become a priority for the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) that supports the central laboratory in the Ministry of Health (MoH) in Côte d'Ivoire, the only laboratory performing PCR testing through the RETROCI project [6].

Studies have suggested significant LTFU at each step in the EID cascade which has important impacts on the ability to test and treat. In 2009 in Côte d'Ivoire, Leroy and colleagues reported that out of 42 infants who were tested with EID, only 25 families (60%) returned to obtain the test results [16, 21]. In the 2008 study, Kouakou et al reported that when specimens

were received in the laboratory, it took 4 to 8 weeks for the results to be sent back to the care provider and, regarding sample transport to the laboratory, 16% out of 588 specimens collected were rejected due to improper labeling, or missing information [16]. Key barriers to EID exist at testing, receipt of results, and linkage to care services. Since the most significant loss to follow up occurs at the step of the first PCR test, that is, 75-80% at six weeks [24], further research should be devoted towards investigating facilitators and barriers to care at health facilities.

In the past twenty years, Côte d'Ivoire has experienced at least two outbreaks of civil war, first in 2002 and then in 2010-11 following a contested presidential election. Those civil wars had a negative impact on the country's health system including the physical destruction of hospitals and health centers and the displacement of over 80% of health care workers from the Center, Northern and Western regions of the country to safer regions in the South [1]. The political turmoil also contributed to difficulties in Côte d'Ivoire's ability to achieve the Millennium Development Goals related to HIV/AIDS [1-3].

### Research questions:

The main aim of this study was to identify facilitators and barriers to initial access of early infant detection in the health region of Gbêkê, in central Côte d'Ivoire.

The three specific research questions are:

1. What are the health system facilitators and challenges among 6 clinics to obtain initial PCR test results within 6 - 47 weeks?
2. What are the patterns of EID flow from entry points to obtaining initial PCR results at the 6 clinics and how do they differ from high and low performing sites?
3. What are caregivers' perceptions of and experiences with facilitators and barriers to accessing initial infant testing for HIV?

## Literature review:

There have been many publications addressing the challenges and facilitators of early infant diagnosis in resource limited settings including Côte d'Ivoire [18, 25, 26]. However, there was no observable published article on the challenges of EID in Côte d'Ivoire that made reference to the EID cascade or caregivers' perspectives. Search engines such as PubMed and Google Scholar were used with key words such as "early infant diagnosis of HIV, Polymerase Chain Reaction (PCR), Dried Blood Spot (DBS), PMTCT, HIV in Children" were used for the literature review. Several articles focused on barriers to early infant diagnosis of HIV, others focused on facilitators and a few on both, and all made reference to health system obstacles and obstacles related to caregivers. Optimizing ART in infants, health care workers' perspectives towards pediatric testing of HIV, factors associated with HIV testing in infants, and pediatric HIV care in resource limited settings were among the issues discussed.

System challenges related to EID program scale up included the cost of the PCR test to the government as Menzies and his colleagues demonstrated in a study on the cost effectiveness of routine HIV antibody testing in low resource countries to be more expensive than antibody (\$50 vs \$7) testing [14]. Similarly, other studies also focused on ways to improve outcomes and develop cost-effective interventions in low income countries such as Kenya, Tanzania, South Africa, Swaziland, and Malawi. It was documented that non-systematic offering of PCR test at health sites, low acceptance rate of EID among mothers, inaccurate specimen collection, inadequate transport, problems in laboratory processing, delays in reporting of results to the family, inadequate linkage to care, and not informing caregivers of the infant infection status were among identified challenges within the health care system [5, 16, 17, 27, 28]. Community level barriers such as caregivers' lack of knowledge about EID, excuses, (for instance, "I was not

feeling well”, “I was so busy”), were observed in a 2012 mixed methods study carried out in Uganda [5]. Similarly; refusal for testing, or fear, as shown in a study on the dynamics and constraints of EID in rural Kenya in 2012 [4], and the lack of partner involvement were among the themes that emerged in qualitative and mixed studies addressing barriers from the caregivers’ perspective [29].

## METHODS

### Study setting:

Côte d’Ivoire is located in West Africa between latitude 4°30’ and 10°30’ north, and covering a surface area of 322,462 km<sup>2</sup>. With an estimated population of about 23.2 million in 2012, the country shares boundaries with Ghana, Mali, Burkina Faso, Guinea and Liberia [6]. In 2002, the country experienced a politico-military crisis which lasted for about 10 years. The country is still rebuilding institutions and infrastructure destroyed during the crisis. In 2001, a special health ministry was created to mobilize national and international resources to ensure a national coordination of the HIV/AIDS response [30]. The US government has provided the greatest financial support to date in terms of response to the pandemic, amounting to about 70% of the funds to combat HIV in Côte d’Ivoire [30]. The US President’s Emergency Plan For AIDS Relief (PEPFAR), and the Côte d’Ivoire Ministry of Health and Fight Against AIDS (MSLS) collaborated to rapidly scale up HIV care and treatment services to ensure the availability of human resources and capacity for HIV care and treatment programs, and to promote sustainability of quality services in collaboration with the private sector and civil society [30].

This study of early infant detection of HIV was conducted in the Gbêkê health region in central Côte d’Ivoire. Gbêkê is one of the health regions supported by Health Alliance

International (HAI); a U.S. based international non-profit organization benefiting from a five year project with CDC/PEPFAR to rapidly scale up and expand access to comprehensive HIV/AIDS care and treatment while strengthening the capacity of national structures and providing sustainable service delivery. HAI, whose central office in Côte d'Ivoire is located in the Gbêkê region, uses a district approach to work in partnership with MSLS institutions and local non-governmental organizations (NGOs) to achieve its objectives. HAI currently supports EID programs by providing technical support to MSLS health facilities, and offers resources and logistic support via a system of specimen transport and delivery of results [31].

The study was reviewed and approved by the University of Washington's Institutional Review Board (IRB) on June 28, 2013 and by Côte d'Ivoire's National Ethics and Research Committee (CNER) on September 27, 2013.

#### **Selection of study subjects:**

Six government health clinics in the study region were identified in collaboration with MSLS and HAI personnel to ensure that the information collected was representative of infants born from HIV positive mothers in the region and who attended PMTCT facilities offering EID services. These sites were: Centre de Santé Urbain (CSU) Koko, CSU Nimbo, Centre de Protection Maternelle et Infantile (PMI) Sokoura, Hôpital General (HG) Béoumi, Formation Sanitaire Urbain Communautaire (FSU.COM) Kottiakoffikro, and CSU Dar-es-Salam. These study clinics were chosen because they had the greatest utilization of ANC services in the region.

We interviewed health care workers (HCWs) and caregivers using two types of purposive sampling methods, key informant interviewing and snow-ball sampling, to recruit participants for the study. They included physicians, midwives, nurses, and community counselors who were all recruited at the sites. Semi-structured questionnaires were administered by the Principal

Investigator (PI) and by the Research Assistant (RA) and each interview lasted approximately 30 minutes. For a HCW to be considered eligible to participate in the study, he or she must have been actively engaged in the EID process at the clinic for at least one year. Caregivers were recruited during support group meetings at the sites and semi-structured questionnaires were also administered to them, with the interviews lasting each for relatively 50 minutes. Eligible caregivers were mothers enrolled at the clinics and having at least an HIV exposed or infected infant whom has done at least the 1st PCR test and received results.

### **Study design:**

This was a descriptive study that used both quantitative and qualitative methods. Quantitative data were collected to provide a description of the EID flow and service utilization rates in the selected health facilities. In collecting qualitative data, we used an interpretivist approach to find meaning in people's words and experiences. This method permitted us to recognize new ideas and themes from an insider's perspective and to generate new concepts or theories about the existing challenges of EID. The choice of the design was justified by the fact that recommendations will be made to improve the EID program of MSLS based on the results of the study.

### **Data collection:**

Both quantitative and qualitative data were collected between October and November 2013. Registry and personnel data for PMTCT activities in 2012 were collected at each study clinic. PMTCT data were collected in collaboration with onsite community counselors and came from PCR registries, onsite delivery registries, and monthly reports found at the clinics. Personnel data were collected from clinic records (electronic data base and filed documents) provided by clinic physicians.

Qualitative methods included participant observations, semi-structured interviews with HCWs and focus group discussions (FGD) with caregivers. The EID patient flow of each of the 6 health facilities were observed and mapped to understand the continuum of services offered at each clinic and how they differed or related to each other. During this process, field notes were taken by the PI.

Next, HCWs identified via key informant sampling methods at the sites were asked by the PI to participate in an in-depth face to face interview. An interview guide adapted from a peer-reviewed and published study on EID in four countries [21] was used to conduct semi-structured and in-depth interviews with HCWs at the sites to explore their knowledge, attitudes and perceptions of the barriers to the PCR1 testing process. The questions focused on exploring bottlenecks along the EID pathway for testing exposed infants and also exploring ways the system could be strengthened. A physician and a community counselor were interviewed at each clinic, for an overall total of 11 respondents interviewed; one respondent did not consent to participate in the study because he was not knowledgeable enough about the topic. The interviews were recorded using digital handheld recorder and transcribed by the PI and a paid transcriber.

Eligible caregivers were informed of the study by their support group leaders or MSLS personnel during their regular visits at the sites, during support group meetings or during focus group meetings organized by their leads. A research assistant from HAI received training from the PI about the study regarding her responsibilities and the study's ethical norms for the focus group exercise. The RA assisted the PI in conducting the FGDs and served as a local language translator as needed.



Recruitment was done at each clinic during onsite monthly support group meetings with HIV positive women and their families. At the beginning of each support group meeting, the RA and the PI were introduced to caregivers by the community counselors who managed the meetings. Caregivers who had been informed of the study by their support group leaders were identified to go over the protocol of the study and consent forms. Participation in the study was voluntary. We used open ended questions on a prepared field guide in the French language during a FGD meeting to explore caregivers' perceptions and experiences with barriers and facilitators to accessing initial infant testing in the last year. One FGD with 5 caregivers was held at each clinic, for a total of 6 FGDs and 30 caregivers.

Audio files were recorded in individual interviews and FGDs and were given a respondent ID code to identify the interview. The codes represented the header of each transcribed interview and were used to label the file in the computer. Each transcript was saved on the computer of the PI as a MS-Word document using the respondent ID to label it, backed up on two separate hard drives of the PI. The audio files were immediately deleted from the recorder once they were copied in the computer of the PI and password protected.

Throughout the data collection process, notes regarding the PI's thoughts and observations were taken to serve during data analysis. In order to assess and assure data quality or consistency, quantitative data collected from each site were compared with data transmitted at the health districts by the sites.

### **Analysis:**

Quantitative and qualitative data were analyzed using deductive and inductive approaches respectively. Quantitative data were uploaded into an Excel spread sheet for analysis. The unit of the qualitative analysis was the individual, specifically health care workers and caregivers.

Interviews with HCWs were conducted by the PI directly in French. FGDs with caregivers were conducted in French and local languages with the help of the RA. Information was audio-recorded and later transcribed by the PI and a paid transcriber who was trained on the ethics of the study and management of transcripts using a French transcription protocol. The transcribed data were uploaded into Atlas.ti Version 7 for analysis in French. Codes that emerged regarding caregivers' knowledge, attitudes and perceptions of the barriers and facilitators to PCR1 testing process along the EID cascade were analyzed by the PI. The same transcription procedure was also followed to analyze HCW's experiences of the clinic system facilitators and challenges to EID services. To ensure reliability of findings, the emerged themes were checked for consistency by study co-investigators.

## **KEY FINDINGS**

### **Section 1: Quantitative findings:**

At each of the six health facilities, we conducted individual interviews with health care workers. Information regarding existing personnel per cadre and which staff had received formal training for EID-related activities was collected. Additional quantitative data was extracted from routine PMTCT and EID registries. These data are presented in Table 1 and Figure 1.

With regard to the types of personnel, each site had at least one physician, one midwife and one nurse on site. There were fewer pharmacists, lab technicians, and data managers. Even sites with large total personnel did not have a pharmacist or lab tech. None of the sites had a specialized health care staff such as a pediatrician or a gynecologist. Of the personnel available per site, generally less than a third said to have received formal training in PMTCT or EID

related activities with the exception of PMI Koko that had over 70% of its staff trained in such activities. The lowest was FSCU.Com Kottiakoffikro with only 1 out of 9 persons trained.

**Table 1: Health care workers per site**

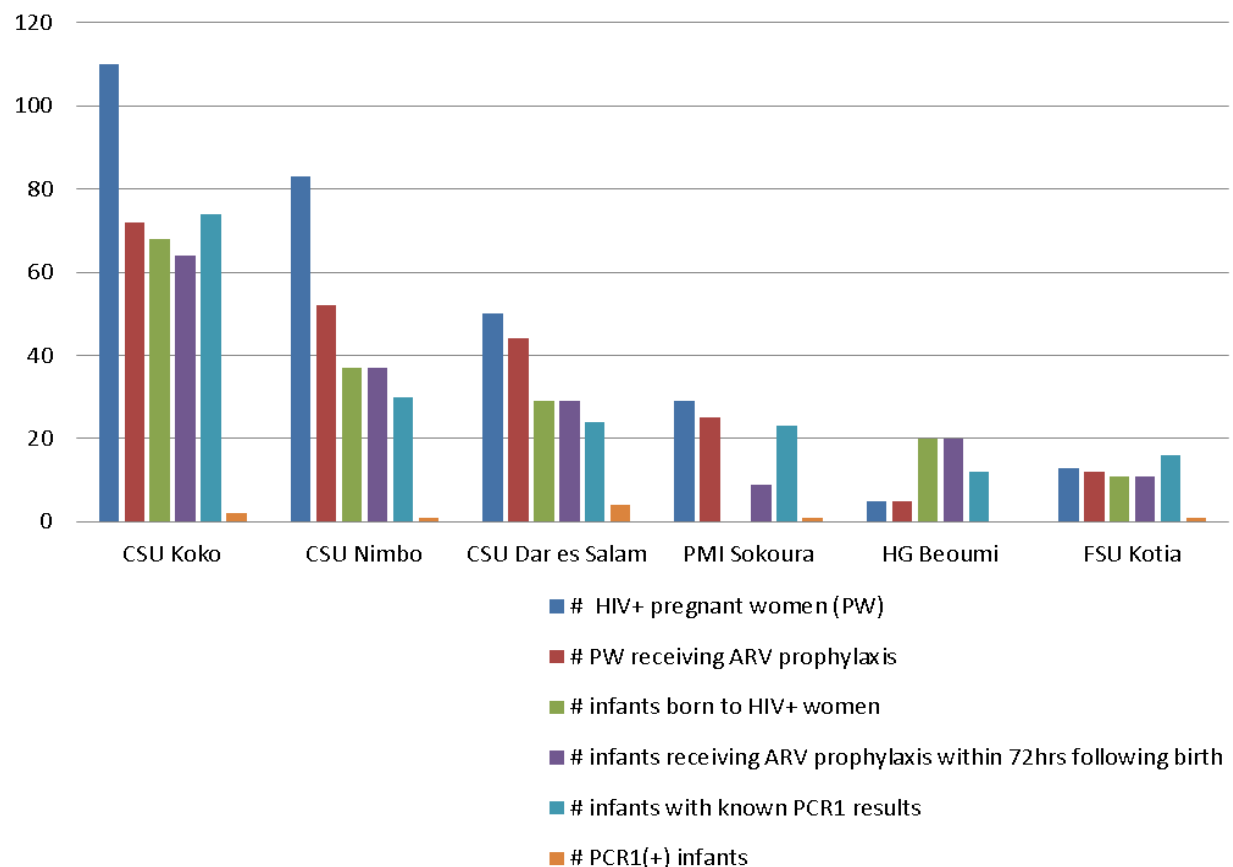
Site	Physician	Midwife	Nurse	Nursing aid	Pharmacist attendant	Lab Tech	Community counselor	Data manager	Ward aid	Total staff	Total PMTCT/EID trained staff (%)
HG Beoumi	4	6	8	9	2	2	2	1	4	<b>38</b>	<b>10 (26%)</b>
CSU Koko	2	6	6	8	0	0	3	1	6	<b>32</b>	<b>8 (25%)</b>
CSU Nimbo	2	4	4	10	0	0	3	0	6	<b>29</b>	<b>6 (21%)</b>
CSU Dar-es-Salam	2	3	5	9	1	0	1	0	3	<b>24</b>	<b>5 (21%)</b>
PMI Koko	1	5	4	0	0	0	2	0	1	<b>14</b>	<b>10 (71%)</b>
FSU.COM Kottia	1	1	1	3	1	0	1	0	1	<b>9</b>	<b>1 (11%)</b>
<b>Total</b>	<b>12</b>	<b>25</b>	<b>28</b>	<b>39</b>	<b>4</b>	<b>2</b>	<b>12</b>	<b>2</b>	<b>21</b>	<b>146</b>	<b>40 (27%)</b>

Information was also gathered regarding the types of services offered at each site. Besides PMTCT/EID services, most of these sites also offered vaccination services, nutrition services, delivery and post natal care services, HIV treatment, support and care services.

Figure 1 below shows an overview of 2012 registry data collected at each site and the number of women accessing services at each step of the EID cascade, from when the mother first tests positive for HIV to when the infant receives a PCR test result. For the majority of the sites, there is a large gap between the number of pregnant women tested HIV positive and the number of exposed children born and registered with the health facility. For example, at CSU Koko, CSU Nimbo, and CSU Dar-Es-Salam, the gap was respectively 33, 64 and 52 percent.

Not all sites provided all of the services along the EID cascade. For example, PMI Sokoura did not offer delivery services so caregivers who visited this facility for ANC had to visit other sites to seek delivery services. HG Béoumi had stopped offering ANC services after January 2012 because another facility opened nearby and so, caregivers who came for ANC visits at HG Beoumi were now referred to this new facility. Nine months later, HG Béoumi re-opened its ANC services and registered five HIV positive women at the ANC clinic for prophylaxis in the year. Of the four health sites with at least 20 exposed children during the study period, the majority of these children received the first PCR test with known results.

**Figure 1: Early Infant Diagnosis cascade of services, 2012.**



## **Section 2: Patient flow mapping:**

Patterns of patient flow at each of the six study sites were mapped in collaboration with health care workers to understand patient movements and the average duration at each stage. Overall, the resulting EID flow map varied slightly from one health site to the other and different sites had different types of health personnel or infrastructure available for the activities.

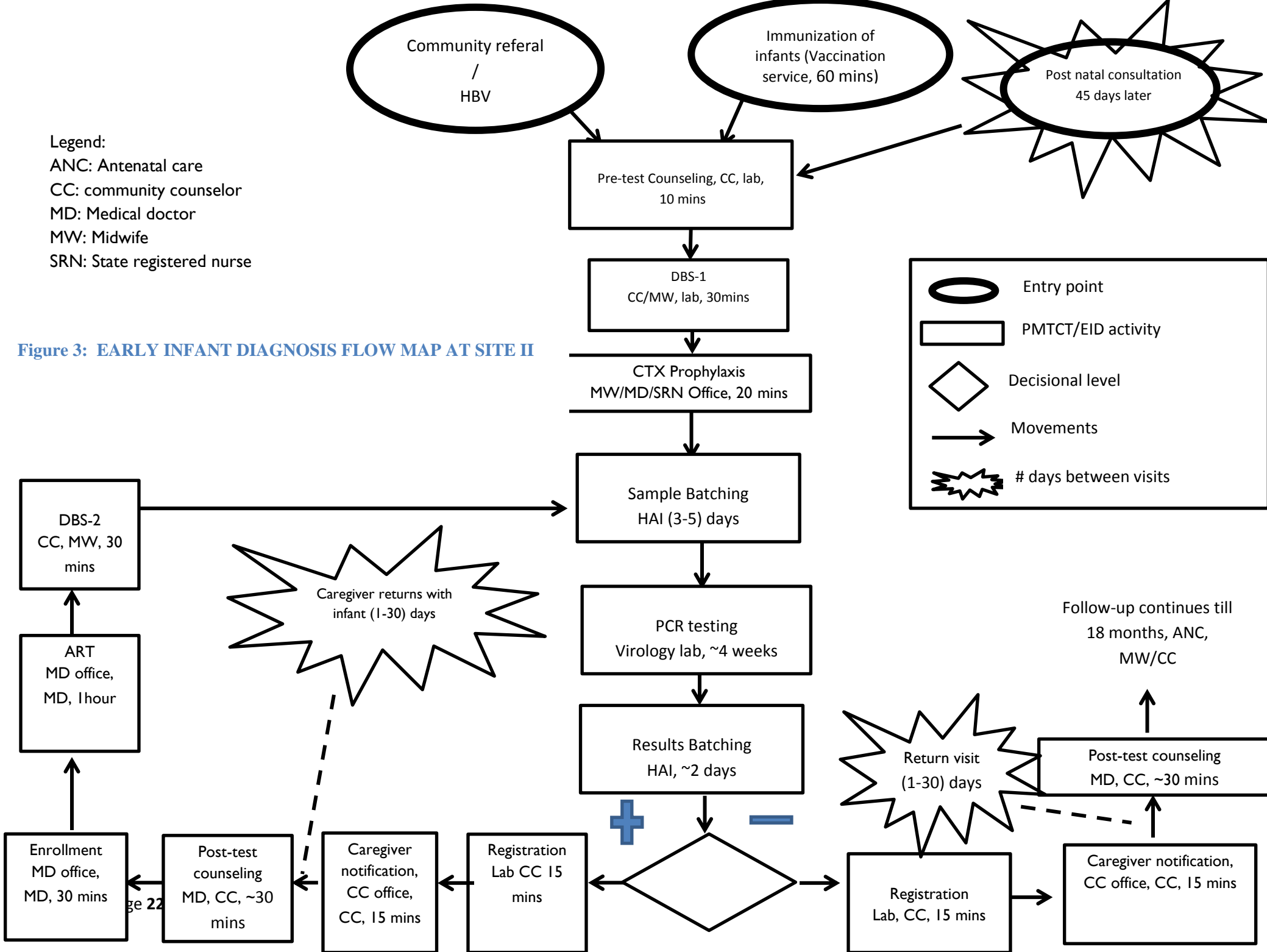
Figures 2 and 3 illustrate the variability of the organization of services in two of the sites, CSU Koko and FSU.COM Kottiakoffikro. While both of these sites had several entry points into EID services (such as vaccination clinics, nutrition services, community referral), these points were not the same for all the sites. At some sites, providers' consultation offices were not observed as entry points into EID services (Figures 2 and 3). However, they had an identical number of required return visits of the caregiver with the infant to the facility; for instance, 45 days after post natal care, pre- and post-test counseling to get results and for an infant who tested positive at PCR1, the caregiver also had a required return visit to the clinic.

The total time it took for the caregiver to get through the cascade varied. The process was longer at CSU Koko (about 12 weeks). It was observed that the process was longer (8-12 weeks) for sites that used prenatal care offices to offer counseling and testing services to caregivers and infants (Figure 4 below) and shorter (four to eight weeks) for sites that offered these activities in a laboratory (PMI Sokoura and FSU.COM Kottiakoffikro) as shown in Figure 4 below. These differences in patterns may have impacted how EID services were offered at the sites and consequently, the extent to which infant care and diagnosis was complete.



Legend:  
 ANC: Antenatal care  
 CC: community counselor  
 MD: Medical doctor  
 MW: Midwife  
 SRN: State registered nurse

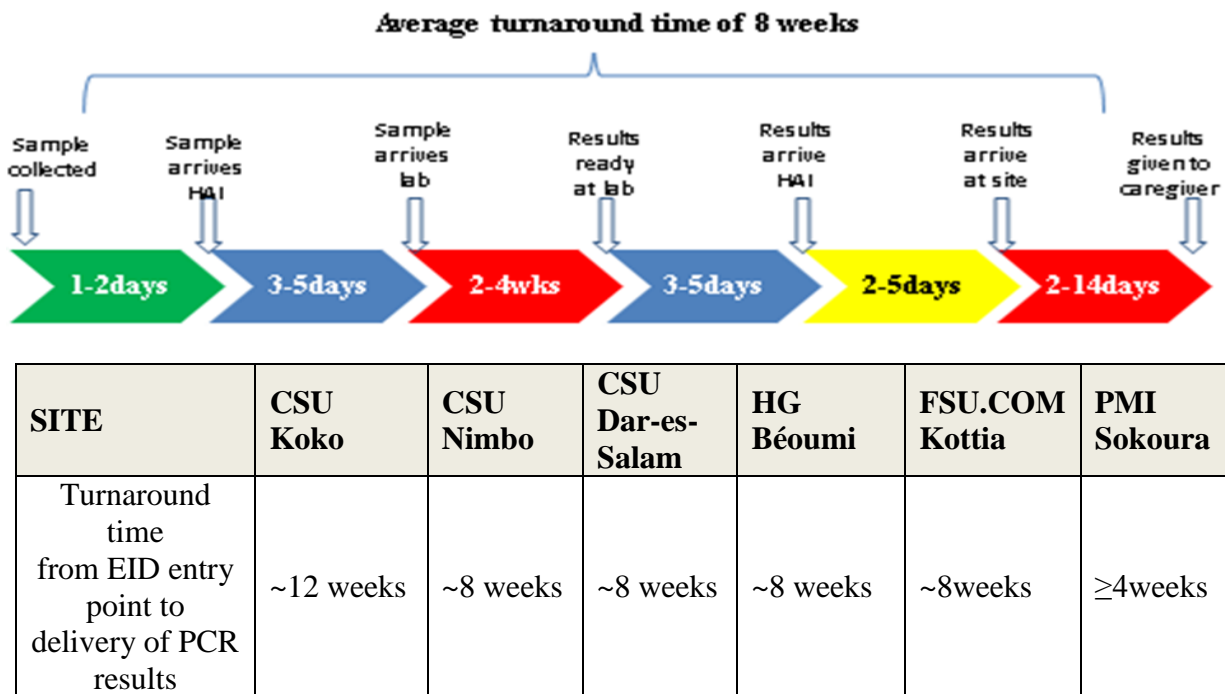
**Figure 3: EARLY INFANT DIAGNOSIS FLOW MAP AT SITE II**



Just as there were small variations in patient flow through EID services across the health facilities in the study, so was the amount of time from infant PCR testing to the delivery of results to the infant's caregiver. Turnaround time was calculated in collaboration with community counselors. Without consulting registries, they reported the amount of time it took from one activity to get to another activity. The total amount of time from entry into the cascade to delivery of results was calculated as the turnaround time for each clinic. Counselors reported that turnaround time for results could be as little as four weeks (such as PMI Sokoura) to as much as 12 weeks (CSU Koko). The variability in turnaround time was related to batching activity, caregiver notification points, and reorganization of services at some clinics. At the batching activity points, results were received earlier at some clinics simply due to the distance. At caregiver's notification points, it took time (from one day to 4 weeks) for caregivers to come back for their results. While some caregivers were quick to respond to the call, HCWs reported that others were reluctant. Many caregivers decide to schedule their return to the clinics with their next appointment date which could take up to a month, as reported by community counselors. At some sites (e.g., CSU Koko), it took time for midwives to deliver PCR results to community counselors due to inadequate communication or negative engagement among health care workers. Some providers filed reports but said they forgot to notify caregivers.



**Figure 4 : Average turnaround time from infant PCR testing to delivery of results.**



### **Section 3: Qualitative findings**

Analysis of interviews with health care providers and community counselors and support group discussions with caregivers revealed key themes that can be organized as facilitators or barriers to initial access to early infant detection programs. Themes were further grouped into sub-themes in three levels (community, health system, and individual) according to where the investigators believed the impact was greatly measurable. See Table 2 for a complete list of facilitators and barriers at each of the three levels.

**Table 2 : Complete list of facilitators and barriers at each of the levels.**

<b>Level</b>	<b>Facilitators</b>	<b>Barriers</b>
<b>Community</b>	<ul style="list-style-type: none"> <li>• Community &amp; media outreach</li> </ul>	<ul style="list-style-type: none"> <li>• Stigma / Discrimination</li> <li>• Traditional/cultural practices</li> </ul>
<b>Health System</b>	<ul style="list-style-type: none"> <li>• Existence of registries for data collection (PCR registries)</li> <li>• Strong logistics systems               <ul style="list-style-type: none"> <li>○ Improved MSLS procurement &amp; distribution systems (reducing stock outs)</li> <li>○ Transport (for DBS samples &amp; results)</li> </ul> </li> <li>• Role of Community Counselors               <ul style="list-style-type: none"> <li>○ Onsite at multiple entry points</li> <li>○ Home based visits</li> <li>○ MCH booklets</li> <li>○ Counseling services</li> <li>○ Outreach to locate LTFU</li> <li>○ Support groups for PLAWHA</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Unpredictable turnaround time PCR test results</li> <li>• Insufficient working space</li> <li>• Negative engagement with health care workers (inadequate communication)</li> <li>• Lack of client contact information</li> </ul>
<b>Individual</b>	<ul style="list-style-type: none"> <li>• Concern for infant's health</li> </ul>	<ul style="list-style-type: none"> <li>• Fear of HIV+ diagnosis</li> <li>• Fear of disclosure to spouse/partner</li> <li>• Associated costs (financial or other)</li> </ul>

In general, the majority of sub-themes emerged at the health system level as both facilitators and barriers while a few were seen only at the community and individual levels. Within the group of facilitators, the most significant findings were seen at the “role of community counselors” within the health system. “Unpredictable turnaround time PCR test results” was the most significant and most mentioned barrier observed within the health system. A few sub-themes occurred at multiple levels; others were linked or seemed to have an impact on other themes. For instance, “stigma” emerged as a barrier in the community and at the facility level, while the “role of community counselors” was linked as a facilitator to the “existence of data collection tools” and to “lack of client contact information” as a barrier.

## **FACILITATORS**

### **Community Level:**

#### **Community mobilization and media outreach**

Respondents revealed that community mobilization by peers and messaging through media outreach were important strategies for bringing women to the clinics. Sometimes this mobilization happened between neighbors or acquaintances, as one caregiver reported.

*“...when I see a woman with a child who is sick, really I advise her to come to the clinic and to accept the HIV test in order to know what the infant is suffering from...” (Caregiver).*

One caregiver said that she wanted to educate the community via radio programs that discuss HIV prevention and treatment, though she wished to do so anonymously.

*“...at times I change my name. I go to the radio and sensitize women who live with HIV and whom are afraid to go for HIV testing at the clinics...that sickness, me I do not consider it, for me it is eating properly, if you do not eat, you have the sickness, if you eat, the sickness is behind you, and you are ahead... so I wish that women should look a little bit at their entourage, don't be afraid to do the test of your infants, in all the case, that is my message...” (Caregiver).*

### **Health System Level:**

#### **Existence of data collection tools**

The presence of improvised PCR registries at all six study sites was one of the key factors attributed to the success of EID activities. These improvised registries, which were not distributed by MSLS but rather created by health workers using a notebook, were used to record patient information such as the date of birth of the child, the patient number, the name of the mother, choice of infant feeding, and PCR test results.

*“...ééh, we use registers because we do not have national data collection tools to collect our information...” (Physician).*

*“...we have PCR registries, we use them each time we receive a woman who comes for the PCR test...when results arrive, they fill in the results, and when we also test the infant at 12 months, and we fill the registry...” (Community counselor).*

MCH booklets are national tools issued to caregivers at their first ANC visit. These booklets contain relevant and comprehensive information regarding the caregiver and the infant for follow-up during pregnancy and after delivery. Caregivers bring these cards with them at each ANC visit and on the first page of the cards, midwives or community counselors assign a code regarding the mother's HIV status. If the caregiver was positive, the code was repeated on the delivery and vaccination pages. Six weeks after delivery, if the caregiver came to the ANC clinic before going through the vaccination service for DT-COQ (Diphtheria, tetanus and whooping cough) a DBS was done on her infant and a code to indicate this activity was written or stamped on the first page of the card. If the caregiver went through the vaccination service before the ANC clinic, aid wards could identify her exposure status by verifying if she has the 3 code stamps in her card and if she has the DBS code on the first page as well. If the DBS test was not noted for an exposed infant, the caregiver is referred immediately to the ANC office for DBS.

*“...at the vaccination which is also an entry point, when they come, we look at the card, we know that it is caregiver coming from PMTCT. During sensitization, we take advantage and verify the cards, if we see a PMTCT code; we tell her that she needs to the PCR of her infant...” (Community Counselor).*

### **Strong logistics systems**

The existence of strong logistics systems for procurement and distribution of commodities was also said to be a key facilitator for EID activities at the health sites. Providers reported that in recent years, changes in the MSLS's procurement and distribution system has led

to a significant reduction of stock outs as compared to the previous years. The MSLS's Public Health Pharmacy at the national level was credited for the improved management.

*"...There was a time when the [EID] kit came separately . . . we had the DBS paper, we had the envelope, and most often there were no gloves, where we were obliged to use ordinary gloves. But now the kit comes in full, with all in, there are no more problems with stock-outs..." (Physician).*

*"... good management of all that is strategic commodity to avoid stock-outs contributes to the achievement of this test, here are some factors I can mention that play a key role in the successful completion of this PCR activity..." (Physician).*

In addition, the implementation of a transport system for the delivery of blood samples to the virology laboratory in Abidjan for testing and return of results to health sites made the EID program more efficient.

*"...let them continue hein, because it is thanks to them hein, the truth should be spoken, it is thanks to them that we survive, if HAI is absent, them there is no intervention, that's it..." (Physician).*

*"...we do not batch samples, there is no batching! For instance, today we do a DBS, tomorrow they could come and collect, whether it is one or two DBS that I have done today, they come and collect..." (Community Counselor).*

### **Role of community counselors**

Health care workers reported that community counselors were important and played significant roles at the facility level. They were recruited by local NGO partners and placed at sites to facilitate services at every entry point of the EID cascade including infant testing, caregiver notification, and patient tracking. .

*"...the presence of community counsellors who are for us, a great strength, that's it, because they are associated in this activity, there are really a great strength to us because most of them have information about PLWHIV, they know about their delivery calendar as well as their locations and at 6 weeks, if mothers don't show up, we could*

*then contact them for testing of their infants. That is how community counselors help us...” (Physician)*

Community counselors were also cited as resources to reduce loss to follow up and retain patients in care and treatment services. They communicated with caregivers directly via home-based visits (HBV) or by telephone to have patients come for their PCR results immediately after the results had returned to the facility.

*“...when we receive PCR test results, then, the parents are called by community counselors to tell them that their results have arrived, and immediately the parents come...” (Physician)*

*“...for community counselors, as they do HBVs, they take advantage to sensitize caregivers for PCR testing at 6 weeks” (Physician).*

Mother and child health (MCH) booklets were also used by care providers to facilitate early infant tracking and testing. Through specific codes in these booklets, HCWs were able to identify HIV exposed infants and referred them to seek EID services.

*“...we can investigate to see if this caregiver is being followed-up or had been tested positive at the clinic where she delivered, if we know that she is positive we could start by doing the DBS of the infant. But if we detect by verifying the booklet, because in the card it is written XXX, these are indications that the caregiver is HIV+, at this time, we could start by testing the infant by doing DBS...” (Physician).*

At all six facilities, regular support groups for HIV positive people and their families were held monthly onsite. These support groups, usually facilitated by a community counselor, are intended to provide psychosocial and adherence support to reduce loss to follow up. The size of the groups varies between 10 to 40 participants depending on the number of patients referred to the groups after post-counselling for HIV- positive test.

*“...thank God we have support groups where we talk about the importance of PCR testing. Pregnant women who attend know that there are others in the groups who have already done the test, so, whether positive or negative, they are encouraged to do it...” (Community counselor).*

*“...for instance, we take an example on a caregiver during support groups if there exist any who has done a PCR since together, we make a family “have you seen that one, she came we gave her advice and she followed them her infant is negative, you too, follow her example”...” (Community counselor).*

Community counselors provided counseling to caregivers to reduce fear and stress that is usually observed at testing and delivery of test results.

*“...we offer advice to reassure her that despite the outcome of the results, the infant will be given care and that the infant can live with it without any problem if the result is positive...” (Community counselor).*

### **Individual Level Facilitators:**

#### **Concern for infant’s health**

At the individual level, caregivers reported that the main reason they seek EID services is to provide better health services for their infants.

*“...there are drugs that exist for your child to do better, so, really, it’s important in any case to do it, to know the status of the infant...” (Caregiver).*

*“...what is important for me is that if I come and do it, the child will have life; . . . . Because if I come and do it, if the child has nothing, I am happy but if the child has something, they will give him treatment. If I don’t do it the child can die, that is what is important...” (Caregiver).*

## **BARRIERS**

### **Community Level:**

#### **Fear of stigma/discrimination**

Caregivers and community counselors reported that fear of stigma or discrimination were major reasons why parents did not seek EID services. Parents feared that others in the community would discriminate against them if their child tested positive.

*“...What is also difficult, for example in the neighborhood people...will look down on you, they [will] insult you with it [HIV status]. Now if I do it and someone knows the result of my children’s test, they will look down on us too...” (Caregiver).*

Some community counselors perceived the fear by caregivers to be more self-inflected than actual.

*“... they self-stigmatize themselves, they say, "if I come while you're taking the blood of my child while other children’s blood is not being taken, people will know that there's something [wrong] ...” (Community counselor).*

#### **Traditional/cultural practices**

In some cases, cultural practices prevent caregivers, particularly women, from seeking timely EID services for their children. For example, according to some traditional practices, new mothers are not permitted to leave the family home with a newborn for a prescribed length of time after birth, which would prevent them from getting a PCR for their infant at the recommended six weeks.

*“...first of all, it is a societal problem...it is not easy to come with infants since a number of months is expected to be observed; for others, it will require them to take 2 months before moving out, and for others, it will take them 3 months...” (Physician).*



## **Health System Level:**

### **Unpredictable turnaround time PCR test results**

Many respondents expressed frustration with both the length and unknown turnaround time between the date the blood spot was collected and when the results of testing are made available for the caregiver. As noted above, health care workers reported that the turnaround time varied between four to 12 weeks at the study sites.

*“...so, for samples, they [the blood samples] go to HAI, Now HAI takes it to Abidjan, from there, so that the results come back, it takes time, often it can be 1 month, 2 months, 3 months, 4 months before the result returns to the center... ” (Community counselor).*

*“...at the minimum it takes 4 weeks but it takes up to 12 weeks before the results get to us...” (Physician).*

### **Insufficient working space**

Many respondents complained that there was insufficient space at the health facility to properly carry out effective and quality services related to EID. Some providers were obliged to carry out multiple services in the same room which created long waiting times for caregivers and thus often discouraging them from attending these services.

*“...we have premises that are insufficient so it makes it that there are a number of activities that take place in the same space, so it creates long waiting times for patients and it creates some inconvenience regarding the quality of services that we offer to our patients” (Physician).*

In addition, health workers reported that conducting several activities in the same room made it difficult to maintain confidentiality, which is one of the baseline principles of counseling and testing.

*“...well, here, it's a problem of space because it is where we do antenatal consultation and then screening for pregnant women and then at the same time we do the PCR for the child too. So like that, because when the woman comes, she finds other people who are*

*there, they wonder "why are they testing that child"? So it's uncomfortable they do not know what is going on and so they are asking the question within them "but what does that child have"? But, if there's a unique room for mothers and they come there and there's a midwife who is only available for PCR, she does her PCR and then she goes..." (Community counsellor).*

### **Negative engagement with health care workers**

Some respondents stated that when service providers do not communicate properly with caregivers, the negative engagement discouraged caregivers from seeking EID services at the health facility.

*"...the principal challenge is at the level of the personnel, there should be adequate communication with our caregivers..." (Physician).*

Furthermore, some community counselors reported that at times, midwives did not show sufficient commitment to caregivers and this was a challenge for them to seek services. According to community counselors, midwives were not motivated in HIV related care services.

*"...people [midwives] lose interest, especially when it comes to HIV; there is no clinic where midwives are fully engaged, even if there is, it's rare..." (Community counselor).*

### **Lack of client contact information**

Community counselors found it hard to contact caregivers in order to retain them into care services and reduce LTFU because a majority of them did not have or did not provide contact telephone numbers. According to the community counselors, some caregivers would provide false numbers just to avoid being contacted.

*"...but [the women] do not even give us numbers, which is why we cannot find them..." (Community counselor).*

*"...we do not know, in such a case, we cannot move to the village in order to seek for her, this is a loss to follow-up..." (Community counselor).*

## **Individual Level:**

### **Fear of HIV+ diagnosis**

Caregivers repeatedly stated that they were afraid of knowing the test results of their exposed children. They reported being afraid to know that their newborn babies could be also infected like themselves.

*“...For me there, to test my children, it scares me, it makes me very afraid to come and take results. . . . it still makes me very afraid because they will come and tell you that your child also has such a problem, ah! For me, I can support [my condition] but for my child I cannot stand...” (Caregiver).*

*“...when I was pregnant, I came to the hospital they told me I was pregnant... and that I was HIV- positive, I took fear...” (Caregiver).*

*“...according to me, I think that it the results that scares because if I come with my infant, I do not know what they [providers] will tell me, if I have a positive results, then it’s really difficult...”(Caregiver).*

### **Fear of disclosure to spouse/partner**

Some caregivers reported that they could not share their HIV status with their spouses due to fear of being sent-off by their partners or spouses and the fear of being denied key spousal or family support. Non-disclosure emerged as a barrier to seeking EID services as it made it more difficult for women to make their health appointments. This affected both care seeking behavior for their own health and that of their infants.

*“...I have shared my status with my mother and my adoptive mother, not with my husband because if you disclose your HIV status with someone who does not care much about you, he will kick you out...” (Caregiver).*

Community counselors expressed similar concerns for the caregivers’ refusal to share their status with their partners.

*“According to me, what prevents them is when the woman did not share her status with her husband. Because she said “well, if I take the test and the test of the child is positive,*

*what will I tell her father"? Because if the test of the child is positive, the child must take medication and it is not at every time she will go on hiding to give drugs to the child. So I think it is the fear of not sharing her status with her husband that pushes them not to go for child screening ...” (Community counselor).*

*“...when the man [husband] is not aware of the status, and due to hiding, all these can prevent them to respect their appointments...” (Community counselor).*

## **Associated costs**

Some caregivers reported that the associated cost of seeking EID services at the health clinic was a barrier. Although infant HIV testing is free, going to the clinic to seek for services required some associated costs, such as paying for transportation. This was more significant for caregivers coming from rural or remote areas.

*“...it is not easy, for instance . . . if the clinic is far from the house that you have to pay transport...you eat only once per day...when you are jobless, even if the child is in need, if the man has not given you money, it’s not working...” (Caregiver).*

*“...it is because their mothers do not have the means to send their children to the hospital before the arrival of their parents; this is why so many children die...” (Caregiver).*

This sub-theme was backed by a community counselor:

*“...now, women who also live in villages when they put to birth you often ask them, it’s transportation because when she is pregnant she can have the money to come for consultations but when they put to birth, the man is not aware of her HIV status, what will she tell her husband in order to come for PCR testing if she does not have the means for herself, so that is the reason they prefer to stay...” (Community counselor).*

## DISCUSSION

The overarching question of this study was to identify keys facilitators and barriers to initial access to early detection of HIV infection among exposed infants in the health region of Gbêkê, in central Côte d'Ivoire.

Findings at the quantitative level revealed that the majority of health facilities in this study had less than a third of their clinic staff formally trained in carrying out PMTCT/EID activities. This is an important finding given the critical nature of the PMTCT/EID program, thus the importance of providers to receive the necessary skills to provide the minimum health package to infected mothers and their infants.

With regards to the cascade of services for EID, we found that there is an important gap between HIV positive caregivers in the PMTCT program and the number of exposed infants born at the health facility during the same period. In general, about one quarter to one third of HIV+ pregnant women in the program did not deliver at that health facility. The data did not permit us to assess whether those women delivered in another health facility or outside of the health system. It is critical for caregivers, particularly those who are HIV+ to have assisted delivery in order to ensure their safety and that of their exposed infants and to minimize the risk of HIV transmission during delivery. Exposed infants also require adequate clinical care and follow-up soon after delivery and these services may not be assured when delivery is outside of the health facility. In HG Béoumi and FSU.COM Kottiakoffikro, we observed that the number of exposed infants was higher than the number of caregivers who entered the PMTCT program. For HG Beoumi, there was a periodic interruption of ANC services due to the opening of a new facility which was tasked to perform all PMTCT activities. The caregivers were referred to that clinic for

ANC visits and only came back to HG Béoumi for delivery. The reason for the unusual observation at FSU.COM Kottiakoffikro is unknown.

Looking at both figures, CSU Koko's highest number of infants who received PCR1 results could be explained by the fact that this clinic is centrally located, and its utilization rate is high despite not having a staff fully trained in PMTCT. By contrast, the general hospital in Béoumi has the highest number of trained PMTCT personnel but the lowest number of PCR1 cases. These contrasting findings on trained personnel and PCR1 out-put have been strengthened in a similar Kenyan study [4].

The patient flow maps demonstrate a variation in turnaround time across the clinics, a slight variation in flow maps, and a unique or centralized testing point at all facilities. Turnaround time from the time a DBS is taken to the return of results to caregivers varies from four to 12 weeks. The centralization of the only virology laboratory in the capital city which is distant from these clinics is said to be the main cause of the delay in turnaround time. However, a shorter turnaround at PMI Sokoura seems to suggest that distance to the laboratory may not be the determining factor. The organization of services within the health facility may play a key role in the turnaround time. It is vital to maintain turnaround time as short as possible, and to be consistent because most physicians rely on PCR test results to initiate care. Clearly, the earlier HIV positive infants receive appropriate antiretroviral treatment, the better the prognosis. Long turnaround times and variation among study sites affecting services to care are also seen in studies carried out in other countries [16, 21, 27].

The slight variation in patient flow map can be attributed to the fact that national policies regarding EID in the region are not respected since they do not tie with realities on the field. With the absence of a reference flow map, each clinic establishes a patient flow circuit based on

the services available at the sites and by convenience. It is important to document that all six facilities have only one DBS collection point within the flow map which according to some studies, has a unique advantage of reducing LTFU, a potential of suppressing infant mortality and giving a good chance of survival to infants. [16, 21]

Qualitative findings revealed that the role of community counselors, turnaround time, and fear were the most important facilitators and/or barriers for EID activities. Community counselors as facilitators play the role of support staff at the health site and by linking clinic services to the community, they help reduce LTFU and retain patients in care. Community counselors also play the role of providing psychosocial support to HIV positive people and their families. Community counselors were observed at every entry point including counseling services, notification points, helping to offer services, and tracking caregivers for follow up visits. They also play significant roles in organizing, at the facilities, support groups which provide an opportunity for HIV+ caregivers to meet peers, share experiences and mutually support each other. These findings are similar with those shown in two studies in Kenya and Thailand [32, 33] that showed the roles community counselors in reducing LTFU and retaining caregivers in care services.

Unpredictable turnaround time was directly linked as a major barrier for EID activities. This concern was expressed by care providers, counselors, and caregivers. Caregivers also reported being afraid to have their infants tested for HIV because they were afraid to find out that their exposed children were infected and were also afraid to be rejected by their own family members. They reported fear at the disclosure of their status or the status of the children to their spouses or partners. If the HIV status of their infants is known, it could indirectly reveal their status and could consequently create risk of problems in the household and family. As a result,

some women preferred not to know the status of the child. The barrier of fear is similar to studies that took place in Thailand and Uganda that showed that fear is negatively associated with early pediatric HIV testing [5, 33].

### **Study strengths and limitations**

The strength of the study was its open nature, using mixed methods for validity, complementarity and triangulation of the findings. Another strength was the existence of support groups that enabled us to strategically meet caregivers for FGDs during meetings organized at the clinics. However, the study had a number of important biases, especially selection biases. We only dealt with health sites already offering EID activities and for logistical purposes; we were not able to access some sites and did not include remote health sites. Another limitation was language barrier. Most caregivers in support groups responded in local languages that were translated into French. The translation could have led to loss of meaning and possibly impacted the themes from caregiver's perspective. The timing of the study was also a limitation, coming at a time when new policies for HIV care and treatment in Côte d'Ivoire are being implemented. We suggest further research in this area should go beyond interviews with providers and caregivers, covering implementing partners and virology laboratory personnel.



## RECOMMENDATIONS

Despite the study limitations, we believe that the findings can assist the Côte d'Ivoire Ministry of Health and Fight against AIDS (MSLS) to improve the EID program in the country. At the health system level, the MSLS could utilize mobile or email technology that could reduce the time it takes to return PCR test results to health facilities. Some countries like Rwanda have implemented this technology and it has proven to be effective in reducing turnaround time. The MSLS could also decentralize the virology laboratory for PCR testing to regional levels in the country. The regional health district could make sure national policies and guidelines reflect field realities regarding the EID algorithm and are implemented to reduce turnaround time. In addition, the government can build up community engagement in the fight against lost to follow up related to stigma and strengthening the link to facilities by developing a program to make community counselors a recognized MSLS staff. MSLS could also develop a more standardized training for community counselors or could provide more resources to increase the number of community counselors.

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## APPENDIXES

### AppendixI-2: Recruitment script for FGDs with caregivers

#### UNIVERSITY OF WASHINGTON

#### RECRUITMENT SCRIPT: FGDs

#### Challenges for Early Infant Diagnosis in the Gbêké region, in central Côte d'Ivoire

My name is Muluh Clifford; I am an MPH candidate at the University of Washington, an affiliate of Health Alliance International (HAI), the sponsor of this focus group meeting. Here is My Research Assistant, Koné Mawa, staff of HAI who will assist to facilitate the discussion. This discussion will principally focus on your perceptions and experiences to accessing initial infant testing for HIV. By so going, we will be able to improve the health care system and help meet the needs of mothers with HIV exposed babies. We value your opinions. Please remember that your participation is voluntary and you are free to not respond to any question or to end the interview at any time.

The focus group will last approximately 1.5 hours. Should you choose to participate, you will receive some snacks for your time and effort if you agree to be part of the FGD. Your decision to participate will not affect the services or treatment that you receive at this clinic.

Would you be interested in participating in a discussion with other women to provide your experiences and perspectives on the challenges of assessing early infant diagnosis of HIV infection at your clinic?

If YES: Proceed to consent process.

If NO: Thank you for your time.

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### ORAL CONSENT SCRIPT: Focus group discussion (FGD) with caregivers

#### Challenges for Early Infant Diagnosis of HIV in the Gbêké region in central Côte d'Ivoire

##### Researchers:

- Muluh Clifford, Principal Investigator, MPH candidate 2014, University of Washington, USA. Department of Global Health. Tel: + (225) 31-63-12-36.
- Ahoua Koné, Clinical Instructor, Côte d'Ivoire Director of Projects, Health Alliance International, USA. Tel: + (1) 206-542-8382.
- Doroux Aristide Billy, Cote d'Ivoire Country Director, Health Alliance International, Cote d'Ivoire. Tel: + (225) 31-63-12-36.
- Robert Martin, International Training and Education Center for Health (I-TECH), USA. Tel: +(1) 206-685-4320
- Serge Aime Dali, National Institute of Public Health (INSP) Cote d'Ivoire, Tel : + (225) 02-20-20-85
- Kouyate Seydou, Program director, Health Alliance International Cote d'Ivoire, Tel: +(225) 49-86-01-51
- Julia Robinson, Clinical Instructor, Cote d'Ivoire Deputy Director of Projects, Health Alliance International, USA. Tel: + (1) 206-542-8382.
- Kone Mawa, Research Assistant, HAI staff in charge of care, and support, OVC activities, Tel: +(225) 49-79-43-45

##### WHAT IS OUR BEGINNING STATEMENT?

We (Muluh Clifford, student at the University of Washington, USA and Koné Mawa, Research Assistant, HAI staff) are asking you to be in a research study. The reason for this information statement is to give you the information you will need to help you decide whether to be in the study or not. You may ask questions about the reason of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the study or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called “informed consent.” We will give you a copy of this form to keep for yourselves.

##### WHY ARE WE DOING THIS STUDY?

Health Alliance International (HAI) and the University of Washington are working together to explore the challenges for Early Infant Diagnosis (EID) of HIV in the Gbêké region. We want to learn more about the things you have done through and what you think concerning these challenges at the health center.

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## **HOW ARE WE GOING TO DO THIS STUDY?**

We are asking you to participate in a focus group research that will last for the next 1 - 1 1/2 hours. We will ask you questions about the difficulties you have gone through as mothers to test your infants for HIV at 6 weeks and would also want to know what you think about the study. An example of the type of question we may ask is, “Do people generally disclose their HIV status to their partners or family members? Why or why not? You may refuse to answer any question at any time, or choose to end the interview at any time for any reason. Your voices will be registered in a machine called audio recorder and later transformed into writing.

## **IS THERE ANY INFORMATION ABOUT RISKS, STRESS, OR EMBARRASSEMENT?**

YES! If you choose to participate in the study, there is a chance that secret information can leak, and/or embarrassment when discussing topics concerning HIV. Some people feel that studies like this will dig into your private matters. We have discussed this point below in this document.

## **ARE THERE ANY BENEFITS?**

There is little direct benefit to you by participating in this study. We hope that your participation will help HAI and the Cote d’Ivoire Ministry of Health, take into account those things makes it difficult for you to bring your infants at 6 weeks for HIV testing. In advance, we think that this study will also help to reduce the number of infants who die because it is not known whether they are HIV-Positive or not.

## **IS THERE ANY OTHER INFORMATION?**

YES! You can choose to end your participation in the focus group at any time for any reason. We will not write your name on any of the study material. Your voices will be kept in the tapes for 12 months after the date of this focus group; but will be destroyed by September 1, 2014. We may use some key information from the focus group to report in our study or make available to the public. If this will happen, nobody will know who has said this or who has said that. If you want to be in the study but do not want your participation to be made known, you may tell the researchers that at any time. A name will be given to this FGD but will be masked and anything that has a relationship with the masked name and participants in the study will be destroyed by September 1, 2014. Even though the researchers will keep your responses secret, we ask that all members of the group keep the information provided during the discussion secret, but we cannot be sure of this for everyone. You will receive something to drink and to chew for your time and effort if you agree to be part of the FGD.

The information you provide will be secret. It will not be shared with your support group leader, your peers or any other worker at the center. Only the researchers listed on this form have access to the information. If you have questions later about the research, you can ask one of the researchers on the list above. If you have questions about your rights as a participant, I can call the University of Washington Human Subjects Division at (+1) 206-543-0098.

This is your copy of the information statement.

## Appendix II-1: Focus group interview guide of caregivers

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### FGD GUIDE: Caregivers

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#### Challenges for Early Infant Diagnosis of HIV in the Gbêké Region, in central Côte d'Ivoire

Date	
Patient ID	
Interviewer Name	
Clinic and district	

#### Arrival

**Step 1.** Participants arrive.

**Step 2.** [Researcher (RA) reads Oral Consent Script, Appendix I-1, to the group. Each participant who agrees to participate signs their initials or an “X” on the form, Appendix I-1.]

#### Introductions

**Step 3.** [Researchers introduce themselves and explain the purpose of the focus group discussion. The RA explains that snacks will be provided to each participant after the focus group is completed.]

**Step 4.** Are there any questions before we begin?

- If YES: take questions from the group.
- If NO: move to Step 5.

**Step 5 (RA).** Let's start by talking a little bit about ourselves. Tell me what you like to do to relax or when you are feeling good

[Participants will respond to the icebreaker question. The purpose of this icebreaker is to make the participants feel at ease with each other and with the researcher.]

#### Questions (by RA)

- Do people generally disclose their HIV status to their partners or family members? Why or why not?



- What makes it easier to talk about HIV with family and friends? What makes it harder?
- What do people do about EID for HIV?
- What makes it easier to get infants tested? What makes it harder?
- Tell me about testing children for HIV, it is that important? What makes a parent choose to or not to test their baby?
- How do you think people feel about knowing the HIV test results of their infant?
- In your opinions, what can be done to facilitate or encourage people for bringing their infants for early testing for HIV?

**Step 6.** [The RA will provide snacks to each individual and each person will sign that they received snacks (see Appendix II-2).]

[Participants are allowed to leave at this time.]

### **Appendix III- 1: Recruitment script for interviews with Health care workers**

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#### **RECRUITMENT SCRIPT: Health care workers**

#### **Challenges for Early Infant Diagnosis of HIV in the Gbêké region, in central Côte d'Ivoire**

My name is Muluh Clifford; I am an MPH candidate at University of Washington, an affiliate of HAI, the sponsor of this study. The principal objective of this discussion is to identify facilitators and barriers to initial access of early infant detection of HIV in the health region of Gbêké, Cote d'Ivoire. After undergoing through your ED cascade and continuum of services, we wish to understand the barriers and facilitators at each step in the ED cascade and, your perspectives on how the system can be strengthened. By so doing, we will be able to improve the health care system and help meet the needs of mothers with HIV exposed babies. We value your opinions. Please remember that your participation is voluntary and you are free to not respond to any question or to end the interview at any time.

The interview may take up to 30-60 minutes. Your decision to participate will not be reported to any clinic staff and should you choose to participate, your responses will remain confidential.

Would you be interested in participating in this interview?

If YES: Proceed to consent process.

If NO: Thank you for your time.

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### HEALTH WORKER INFORMATION STATEMENT

#### Challenges for Early Infant Diagnosis of HIV in the Gbêké region, in central Côte d'Ivoire

#### Researchers:

- Muluh Clifford, Principal Investigator, MPH candidate 2014, University of Washington, USA. Department of Global Health. Tel: + (225) 31-63-12-36.
- Ahoua Kone, Clinical Instructor, Côte d'Ivoire Director of Projects, Health Alliance International, USA. Tel: (001) 206-542-8382.
- Doroux Aristide Billy, Cote d'Ivoire Country Director, Health Alliance International, Cote d'Ivoire. Tel: + (225) 31-63-12-36.
- Robert Martin, International Training and Education Center for Health (I-TECH), USA. Tel: (001)206-685-4320
- Serge Aime Dali, National Institute of Public Health (INSP) Cote d'Ivoire, Tel : + (225) 02-20-20-85
- Kouyaté Seydou, Program director, Health Alliance International Cote d'Ivoire, Tel: +(225)49-86-01-51
- Julia Robinson, Clinical Instructor, Cote d'Ivoire Deputy Director of Projects, Health Alliance International, USA. Tel: (001) 206-542-8382.
- Kone Mawa, Research Assistant, HAI staff in charge of care, and support, OVC activities, Tel: +(225) 49-79-43-45

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#### RESEARCHERS' STATEMENT

We are asking you to be in a research study. The purpose of this information statement is to give you the information you will need to help you decide whether to be in the study or not. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called "informed consent." We will give you a copy of this form for your records.

#### PURPOSE OF THE STUDY

Health Alliance International and the University of Washington are working together to explore the challenges for Early Infant Diagnosis (EID) of HIV in the Gbêké region. We wish to know caregivers' perspectives and experiences in assessing initial infant testing. We will also gather quantitative information regarding clinic systems; registry data from the Health district/HAI's data base. We are also interested in interviewing health care workers who are

directly involved in EID to understand the barriers and facilitators at each step in the EID cascade and, their perspectives on how the system can be strengthened.

## **STUDY PROCEDURES**

We are asking you to participate in a one-on-one interview, which will last approximately 1 hour. We will ask you open-ended questions about your work at the clinic. We may ask you about EID activities, patient flow across the cascade, and barriers to obtain the 1<sup>st</sup> PCR test of an exposed infant. An example of the type of question we may ask is, “Can you describe how the EID system works at this health site: Who does what with the samples?” You may refuse to answer any question at any time, or choose to end the interview at any time for any reason. The interview will be audio recorded and later transcribed (written down).

## **RISKS, STRESS, OR DISCOMFORT**

If you choose to participate in the study, you risk a potential loss of confidentiality and/or discomfort discussing sensitive topics relating to HIV. Some people feel that participating in research is an invasion of privacy. We have addressed your privacy in the Other Information section below.

## **BENEFITS OF THE STUDY**

There is little direct benefit to you by participating in this study. We hope that your participation will help Health Alliance International and the Cote d’Ivoire Ministry of Health make improvements in reducing loss-to-follow up in your EID program at the clinics. We anticipate that this will help strengthen the program and reduce infant mortality.

## **OTHER INFORMATION**

You may refuse to participate and you are free to withdraw from this study at any time without any consequences. In order to protect your confidentiality, we are not recording your name at any point throughout the study. All study materials (signed informed consent document, audio recordings, transcripts, analysis files) will be kept in locked file cabinets at HAI’s office in Bouaké, or in password-protected electronic files accessible only by research staff. Audio recordings will be kept for 12 months following the date of the interview; audio recordings will be destroyed by September 1, 2014. However, we may use quotes from your interview in research reports or study publications. In such cases, no identifying information will be attached to the quote. If you wish to participate in the study but do not wish to be quoted in any documents, you may indicate this to the researchers at any time. A unique identification code will be given to you; any links between this code and direct identifiers will be destroyed by September 1, 2014.

The information you provide will be confidential. It will not be shared with your supervisor or any other staff members at the clinic. Only the researchers listed on this form have access to the data. If you have questions later about the research, you can ask one of the researchers listed above. If you have questions about your rights as a research subject, I can call the University of Washington Human Subjects Division at (+1) 206-543-0098.

This is your copy of the information statement.

## Appendix IV: In-depth interview guide of health workers

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#### INTERVIEW GUIDE: Health care workers

#### challenges for Early Infant Diagnosis of HIV in the Gbêké Region, in central Côte d'Ivoire

<b>Date</b>	
<b>Patient ID</b>	
<b>Interviewer Name</b>	
<b>Clinic and district</b>	

#### **Introductions**

My name is Muluh Clifford; I am an MPH candidate at University of Washington, an affiliate of HAI, the sponsor of this study. The principal objective of this discussion is to identify facilitators and barriers to initial access of early infant detection of HIV in the health region of Gbêké, Cote d'Ivoire.

Before we begin, I would like to state that all of your responses are confidential. Your name and personal information will not be tied to your responses.

[Researcher reads consent form, see Appendix III-2. If participant agrees, he/she signs the consent form, see Appendix III-2.]

Do you have any questions before we begin?

#### **Questions**

##### **Key informant 1: Head of Health facility (Physician)**

Early Infant Diagnosis (EID) system

- Entry point (specifically mention health site HR that interact with women at each point)
- Can you describe how the EID system works at this health site: Who does what with the samples? Who sends them? What do they do next? What data registers are used?
- How long does it take to get samples back from the laboratory? Who receives the results and what do they do next? What data registers do they use?
- Can you describe how the parents of the exposed infants are informed of the testing results? who does that at this site? Is there any follow up with the parent?

### Infrastructure/Procurement system

- How do you get EID tests? Who orders them? What do they do? What data registers do they use?
- How do you describe the procedure for procurement?
- What data registers do they use to register the EID testing?
- Are stock outs major problems for this site? How do you resolve such problems?
- Are there any other infrastructure problems that you encounter as related to EID?

### HR

- Are there major HR needs that could improve the system as relate to EID?
- How sufficient is staffing at this health site?

### Wrap up

- What do you believe are the major challenges of EID? Facilitators?
- What are the key facilitators that you make the EID system function well?
- What recommendations would you have for improving the EID system at this site?
- Are there any facilitators that make the program run well?

### Key informant 2: Staff at the EID care point (DBS collection)

#### EID system

- Tell me about patient circuit or flow at this care point
- How do you identify who to test?
- Is there any pre and post-test counseling service offered? If yes, can you please describe that?
- Can you please describe the process for transportation of samples from and back to the site
- Tell me about EID register management here
- What is the turnaround time for samples? And sample batching?
- What happens with the women getting their results? Who tells them? What do they do? What data registers do they use
- Can you discuss loss to follow-up issues encountered here at the site? What control mechanisms are in place to deal with such issues?
- What are your thoughts about challenges that mothers may face coming to test their infants?

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### Infrastructure/Procurement system

- How do you get EID tests? Who orders them? What do they do? What data registers do they use?
- How do you describe the procedure for procurement?
- What data registers do they use to register the EID testing?
- Are stock outs major problem for this site? How do you resolve such problems?
- Are there any other infrastructure problems that you encounter as related to EID?

### HR

- Are there major HR needs that could improve the system as relate to EID?
- How sufficient is staffing at this health site?

### Wrap-up

- What do you believe are the major challenges of EID?
- What are the key facilitators that you make the EID system function well?
- What advice can you give to face these challenges?
- Are there any facilitators that make the program run well?

Thank you for taking the time to share your thoughts with me. Your input is very much appreciated. If you have any additional thoughts or questions, feel free to contact me.

[Researcher provides interviewee with business card.]

## **Appendix IV-2: Recruitment script for registry data and site identification with**

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**HAI/district staff**

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### **RECRUITMENT SCRIPT: Registry data and site identification with HAI/District**

#### **Challenges for Early Infant Diagnosis of HIV in the Gbêké region, in central Côte d'Ivoire**

My name is Muluh Clifford and I'm a student at the University of Washington, United States. I am working with Health Alliance International, a nonprofit organization currently working in the central region of Cote d'Ivoire, to learn more about the challenges for Early Infant Diagnosis (ED) of HIV infection. Before starting the qualitative aspect of this study, we wish to have quantitative registry and site information on the status of the clinics in the districts that you oversee in order to validate and complement the qualitative part of the research study. This exercise may last up to 2 hours. Your decision to participate will not be reported to any staff and should you choose to participate, this exercise will remain confidential.

Would you be interested in participating in this exercise?

If YES: Proceed to consent process.

If NO: Thank you for your time.

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**Appendix IV: Site identification**

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**SITE IDENTIFICATION**

Challenges for Early Infant Diagnosis of HIV in the Gbêké Region, in central Côte d'Ivoire

<b>Date</b>	
<b>Clinic and district</b>	

Services offered (check if service is available)

- ☐ PMTCT
- ☐ HIV care and support
- ☐ HIV Treatment ( infants and adults)
- ☐ Vaccination
- ☐ Nutrition
- ☐ Counseling and Testing for HIV
- ☐ ANC
- ☐ Delivery
- ☐ Laboratory
- ☐ Pharmacy
- ☐ EID

Year EID activities began:

Personnel on site:

EID staff Position	Number of staff on site	Number of staff that received EID training official/unofficial training in PMTCT/EID
Doctor		
Midwife		
Nurse		

Nursing aid		
Pediatrician		
Roaming Doctor		
Gynecologists		
Pharmacist		
Laboratory Technician		
Laboratory Scientist		
Community counselor		
Health Educator		
Social worker		
Data manager		
Ward aid		

**Appendix VI: Registry data collection form (2012 data)**

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**REGISTRY DATA FORM**

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Challenges for Early Infant Diagnosis of HIV in the Gbêké Region, in central Côte d'Ivoire

<b>Date</b>	
<b>Clinic and district</b>	

	Jan.	Feb.	Mar.	Apr.	May	Jun.	Jul.	Aug.	Sep.	Oct.	Nov.	Dec.
# pregnant women (PW)with known HIV+ results												
# PW HIV+ who received ARV prophylaxis for themselves												
# PW HIV+ who received ARV prophylaxis for their infants												
# life birth infants born from HIV+ women												
# infants born from HIV+ mothers who have received ARV prophylaxis within 72hrs following birth												
# infants with known PCR1 results												
# PCR1+ infants												
# PCR1- infants												

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**FGD-PARTICIPANT SNACK FORM**

[illegible]