



# eHealth Interventions for Early Infant Diagnosis: Mothers' Satisfaction with the HIV Infant Tracking System in Kenya

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## Abstract

The HIV Infant Tracking System (HITSsystem) is an eHealth intervention to improve early infant diagnosis (EID) through alerts to providers and text messages to mothers. This study explored mothers' experiences receiving standard and HITSsystem-enhanced EID services to assess perceived intervention benefits, acceptability, and opportunities for improvement. This qualitative study was embedded within a cluster-randomized control trial to evaluate the HITSsystem at six Kenyan government hospitals (3 intervention, 3 control). We conducted semi-structured interviews with 137 mothers attending EID follow-up visits. Compared to control sites, participants at HITSsystem sites described enhanced EID quality; HITSsystem-generated texts informed them of result availability and retesting needs, provided cues-to-action for clinic attendance, and engendered opportunities for patient support. They described improved EID efficiency through shorter waiting periods for results and fewer hospital visits. Participants reported high satisfaction with EID and acceptability of text messages; however, modifications to ensure text delivery, increase repeat testing reminders, include low literacy content options, and provide encouraging messages were suggested. These user experience data suggest improvements in EID at HITSsystem sites when compared with control sites.

**Keywords** Early infant diagnosis (EID) · HITSsystem · HIV · eHealth · Acceptability

## Introduction

Early infant diagnosis (EID) services are essential for HIV-exposed infants in order to confirm HIV status and promptly link HIV-positive infants to care and treatment. In Kenya, mother-to-child transmission remains a significant

contributor to the national HIV burden, with 8000 children newly infected with HIV in 2017 [1]. Yet, EID coverage and antiretroviral therapy (ART) initiation for HIV-positive infants and children are well below the global 90–90–90 targets at 51% and 82%, respectively, according to 2017 estimates [1]. The Kenyan EID cascade of care includes initial HIV DNA PCR testing at 6 weeks of age and then either ART for HIV-positive infants or periodic retesting for HIV-negative infants [2, 3]. Successful EID relies on timely completion of required services by providers and laboratory technicians (sample collection and processing, return of results), as well as timely mother engagement in follow up services (result notification, retesting, ART initiation). Delays or failure at any step in the cascade can hinder achievement of critical clinical targets for early infant testing and ART initiation for HIV-positive infants.

In order to improve the quality (retention and completeness) and efficiency (timeliness) of EID services, we implemented and evaluated the HIV Infant Tracking System (HITSsystem) intervention in Kenya in a cluster randomized control trial (cRCT) [4–6]. The HITSsystem

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is a web-based eHealth intervention aiming to optimize EID outcomes through electronic alerts to providers and laboratory technicians and automatic text messages to caregivers. The HITSsystem tracks infants until they are discharged from EID at 18 months (if HIV-negative) or until initiated on ART (if HIV-positive). Pilot and cRCT findings showed significant improvement in EID efficiency and receipt of “complete EID” among infants enrolled in the HITSsystem compared to standard of care (SOC) [5, 6], while qualitative interviews with providers and laboratory technicians highlighted the HITSsystem’s perceived ease of use and usefulness in improving sample tracking, patient follow up, and stakeholder communication [7].

These findings are consistent with the broader literature indicating the potential of eHealth innovations for HIV and EID service delivery [8–12]. While other studies have evaluated patient acceptability and satisfaction with eHealth interventions for HIV prevention and adherence [13–17], there is a dearth of similar literature in the context of EID. The current study describes the results from qualitative interviews conducted with mothers of HIV-exposed infants enrolled in the HITSsystem as part of the HITSsystem cRCT [4]. This study’s objective is to better understand mothers’ experiences receiving HITSsystem-enhanced EID services, including the text-messaging component of the intervention, in order to assess perceived benefits, general acceptability, and opportunities to improve the HITSsystem intervention for mothers.

## Methods

This process evaluation using qualitative methods was embedded within the cRCT to evaluate the HITSsystem at six government hospitals (3 intervention, 3 control) and the designated central laboratories where study hospitals send their EID samples for processing [4, 6]. Hospitals were matched on geographic region, resource level, and patient volume (high, medium, low); intervention sites began using the HITSsystem in February of 2014.

During this study’s implementation, the Kenyan EID cascade of care included initial HIV DNA PCR testing at 6 weeks of age, then either ART initiation for HIV-positive infants or antibody retests at 9- and 18- months for HIV-negative infants [2, 3]. The HITSsystem sent automated text messages to mothers when a 6-week HIV DNA PCR result was available and when an HIV-negative infant reached 9 or 18 months of age and was eligible for retesting. To avoid unintentional disclosure, text messages simply asked mothers to “please bring baby to the clinic/Tafadhali mlete mtoto kwenye kliniki” with no reference to HIV testing or results.

## Study Participants and Procedures

Between February 2015 and April 2017, we conducted 137 semi-structured individual interviews with a convenience sample of mothers enrolled in the cRCT attending their 9 month ( $n = 74$ ; 40 intervention, 34 control) and 18 month ( $n = 63$ ; 28 intervention, 35 control) EID visits at all study sites. Mothers at control sites were included to contextualize standard EID services during study implementation, allowing for better comparison with HITSsystem-supported EID. Of the 690 mother-infant pairs included in the larger cRCT, all mothers of HIV-exposed infants who returned for their 9 month ( $n = 625$ ; 360 intervention, 265 control) and subsequent 18 month ( $n = 516$ ; 315 intervention, 201 control) EID visits were eligible for recruitment [6]. Participants representing a range of demographic and experiential variation among mothers attending EID at each timepoint were recruited at their infant retesting visits, with an initial target of 10 participants per site at 9 and 18 month visits. Site coordinators conducting the interviews were trained in iterative qualitative data analysis and determined the final sample size at each site based on the quality and saturation (i.e., no newly emergent themes, high coverage of a priori and emergent themes) of the data collected. While not an inclusion criterion nor routinely assessed, some mothers at intervention sites with more than one child reported prior experience with SOC EID ( $n = 11$ ), and thus were able to directly compare their HITSsystem experience to SOC. Interview guides were developed collaboratively by Kenyan and US investigators, piloted among Kenyan-based site coordinators, and then refined based on feedback. Guides assessed basic demographic data (age, number of children, partner status, and HIV disclosure status, see Table 1); the perceived benefits, barriers, and importance of EID; and the patient experience under standard or HITSsystem-enhanced EID conditions (including method of contact for PCR results or repeat testing, turnaround time for results, satisfaction with EID, suggestions for improvement, and issues related to confidentiality). Guides for HITSsystem sites included questions on mothers’ experiences with the text-messaging component of the intervention. Participants were encouraged to share both positive and negative experiences, and guided interview questions were open-ended to encourage free responses and mitigate the risk of acquiescence bias, with probing to elicit rich data on topics of interest.

All interviews were conducted by Kenyan site coordinators trained in qualitative methods and human subjects’ research; site coordinators were familiar with the sites and may have previously interacted with the participants for study-related activities, but were not routinely involved with participants’ care at the facility. Written informed

**Table 1** Participant characteristics

	Intervention		Control	
	9 months (n=40)	18 months (n=28)	9 months (n=34)	18 months (n=35)
Median age (IQR)	30.0 (28.0–35.0)	34.0 (29.0–39.0)	29.0 (24.3–32.8)	32.5 (27.0–36.0)
Median no. living children (IQR)	3.0 (2.0–4.0)	3.0 (3.0–5.0)	3.0 (2.0–3.0)	3.0 (2.0–4.0)
Partner status				
Married	25 (62.5%)	20 (71.4%)	22 (64.7%)	24 (68.6%)
Divorced	–	1 (3.6%)	5 (14.7%)	3 (8.6%)
Partner	4 (10.0%)	3 (10.7%)	2 (5.9%)	6 (17.1%)
Single	4 (10.0%)	3 (10.7%)	2 (5.9%)	2 (5.7%)
Missing data	7	1	3	–
HIV disclosure status				
No disclosure	5 (12.5%)	3 (10.7%)	1 (2.9%)	1 (2.9%)
Partner only	16 (40.0%)	7 (25.0%)	9 (26.5%)	12 (34.3%)
Partner + family	7 (17.5%)	13 (46.4%)	14 (41.2%)	14 (40.0%)
Family/other	6 (15.0%)	5 (17.9%)	5 (14.7%)	7 (20.0%)
Missing data	6	–	5	1
EID entry point				
Linked from PMTCT/prenatal services	29 (72.5%)	21 (52.5%)	17 (50.0%)	30 (85.7%)
Linked during postnatal services	5 (12.5%)	3 (7.5%)	12 (35.3%)	1 (2.9%)
Missing data	6	4	5	4
PCR results contact method				
Text message	25 (62.5%)	Not applicable	–	Not applicable
Phone call	2 (5.0%)		1 (2.9%)	
No contact reported	13 (32.5%)		32 (94.1%)	
Missing data	–		1	

consent was obtained from participants prior to each interview. Interviews lasted approximately 45 min, were conducted in the mothers' preferred language (English, Swahili, or other local language), and occurred in a private setting at the hospital during planned infant retesting visits. Participants received 400 Kenyan Shillings (approximately 4 US Dollars) remuneration for their time. All study procedures were approved by the Institutional Review Boards at the Kenya Medical Research Institute and the University of Kansas Medical Center.

### Analysis Strategy

Interviews were audio recorded, translated and transcribed, and then analyzed. During the first round of coding, transcripts were coded independently by 3 study team members based on a priori themes and emergent themes, using a combination of Dedoose and ATLAS.ti 8 qualitative data analysis software. Informed by a grounded theory approach [18], these initial thematic codes were then combined into axial codes through group consensus, and a second round of analysis using these finalized codes was independently conducted by 2 study team members (see Table 2). In the analysis, we aimed to take advantage

of different positionalities within the research team. Coding was conducted both by researchers who had intimate knowledge of the program through fieldwork and long-term engagement, and newer team members who were less familiar with the project and came with fresh and critical perspectives. Study team members involved included those with direct and indirect roles (e.g. principal investigator, study manager, research associate) in HITSsystem study implementation. The coding team consisted primarily of US researchers (and one Kenyan colleague), though the Kenya-based team offered feedback through participation in debriefing sessions.

### Results

Due to HITSsystem-driven improvements in EID quality and efficiency, intervention participants described enhanced EID benefits and mitigated challenges. Overall, HITSsystem participants indicated HITSsystem-generated text-messages were acceptable, even as they gave feedback on suggestions for HITSsystem experience improvement.

**Table 2** Results: A priori and emergent themes

Research context
Participant characteristics (see Table 1)
EID benefits
Conclusive knowledge of infant HIV status <sup>a</sup>
Protection of infant health <sup>a</sup>
Early ART initiation <sup>a</sup>
Perceived importance of EID
EID barriers
Limited resources <sup>a</sup>
Competing responsibilities <sup>a</sup>
Fear of stigma <sup>a</sup>
Fear of unintentional disclosure <sup>a</sup>
EID experience: Efficiency
Turnaround time for DNA PCR test results
Length of time to results
Number of facility visits for results <sup>a</sup>
EID experience: Quality
EID experience
Satisfaction with services
Anxiety <sup>a</sup>
Suggestions for improvement
How contacted: test results and/or appointments
Text message
Phone call
Community health worker
No contact
Contact preferences
HITSytem text message acceptability (intervention sites only)
Text message effect
“ <i>Informed</i> ” <sup>a</sup>
Anxiety/reduced anxiety <sup>a</sup>
Reminder <sup>a</sup>
Cue to action <sup>a</sup>
Prompted partner support <sup>a</sup>
Engagement in care <sup>a</sup>
Encouragement <sup>a</sup>
Text message challenges
Failed delivery of texts <sup>a</sup>
Language/literacy challenges <sup>a</sup>
Unintentional disclosure
Confidentiality <sup>a</sup>
Suggestions for text message improvement
Timing <sup>a</sup>
Frequency <sup>a</sup>
Additional content <sup>a</sup>

<sup>a</sup>Emergent themes

## Benefits of HITSytem-Facilitated EID

Mothers at intervention sites described how the HITSytem-driven improvements in EID efficiency and quality helped them remain engaged in care and achieve the full benefits of EID.

### Improved Efficiency

HITSytem participants described greater EID efficiency via faster time to result notification. This reduced the occurrence of wasted follow up visits at the clinic to check for results as compared with control site participants.

**Reduced Time to Result Notification** Mothers at intervention sites recognized that HITSytem-generated texts to inform them when their infants’ 6-week test results were available reduced the time to notification. Whereas participants at control sites described being told to “come back after 1 month” to check for results, regardless of actual result availability, those enrolled in the HITSytem received a text message as soon as results became available, prompting them to come to the facility. While a few HITSytem-site respondents delayed returning to the hospital for their infants’ results due to challenges, most respondents reported coming as soon as possible, either “immediately” or within the first week after receiving the text. This led to earlier clinic attendance for result notification, as one woman described “I was to come on Tuesday, but I came on Monday instead because of the text message” (Participant 49, Intervention Site 1, 9 Month Visit), and also led to greater satisfaction with the EID experience given the reduced waiting time: “[the text messages] helped remind me when I can come to the clinic to get the results...I didn’t have to wait indefinitely” (Participant 16, Intervention Site 2, 9 Month Visit).

**Reduced Hospital Visits for Results** Text messages confirming result availability also improved EID efficiency by reducing the number of visits needed to check for results, thus mitigating the opportunity cost and resource strain of EID participation. Mothers from HITSytem sites described coming once to the facility to receive their infant’s results, allowing them to carry on with other activities: “I receive a text and bring the baby...then I can go my way and attend to other things” (Participant 13, Intervention Site 2, 9 Month Visit).

This was in contrast with the accounts of multiple control site participants who reported making repeated monthly visits to check for results, coming “many times” before results were available:

I: What other advice did they tell you when you got to the clinic and the results were not back?

R: They told me to be patient and that the results will eventually come.

I: How many times did you come to the clinic before you got the results?

R: I came in January and February and finally got the results in March.

(Participant 27, Control Site 1, 9 Month Visit)

### Improved Quality

In addition to more efficient services, mothers at HITSsystem intervention sites described enhanced EID service quality through greater information provision, reminders/cues to action for clinic attendance, and opportunities for improved patient support and engagement in care.

**Improved Information Flow/Reduced Anxiety** Mothers reported feeling more “informed” throughout the EID process via HITSsystem-generated texts, whether regarding result availability or repeat testing reminders. Many mothers at both intervention and control sites expressed constant anxiety regarding their infants’ health status, from the time of birth and through each subsequent EID appointment. As one mother described waiting for results at 9 and 18 months, “It made me sweat. You see, the child escaped intrauterine infection at 6 weeks. Now the infection from breastfeeding... oh my...now I did not know...” (Participant 95, Intervention Site 2, 18 Month Visit). Thus, it was confirmation of infants’ HIV status that provided the surest relief and clearest way forward, whether “how to take care of my infant after finding out that my child is HIV negative and how to continue with care until the baby is done with his/her tests” (Participant 54, Intervention Site 3, 9 Month Visit), or for HIV-positive infants, allowing ART initiation, “early as recommended, not wait until it’s too late” (Participant 21, Intervention Site 2, 9 Month Visit). Text messages indicating result availability helped “get rid of that anxiety” by reducing the waiting period for results, “if I didn’t receive the SMS, I would have just been waiting, not knowing” (Participant 40, Intervention Site 1, 9 Month Visit), and by providing surety that results would be available upon mothers’ clinic visit, “I can prepare myself to go to the hospital because I know tomorrow will be the day I get the results. Even though it’s difficult I...make it there knowing with certainty I’ll get the results” (Participant 90, Intervention Site 2, 18 Month Visit).

This was in contrast with descriptions from control site participants who were left waiting for results with no information regarding when they would be available, sometimes for many months: “I called the first time and I was told the [6-week test] results were not yet back from Nairobi. I had

a lot of anxiety because...the results took 3 months to come back” (Participant 128, Control Site 2, 18 Month Visit). Others were never notified of their infants’ results, “They told me they would let me know if he has [HIV] or not, and have never told me” (Participant 4, Control Site 3, 9 Month Visit).

While receiving HIV-negative results relieved mothers’ anxiety, some HITSsystem-site mothers reported temporarily heightened anxiety between when they received the text informing them to return to the hospital for results and when they were notified of their infants’ diagnoses. One mother described her reaction to the text message, “I knew that the results would be either positive or negative. So I got on my knees and prayed. I was so scared” (Participant 39, Intervention Site 1, 9 Month Visit). Another participant clarified that it was not the message content that triggered anxiety, but simply that “the results were already out.” Yet, others who received the texts did not report anxiety, only a “strong desire to know the health status” of their infants, whether HIV-positive or negative: “I wasn’t worried because I had already accepted. You know when you give birth to the baby you know he might have the virus or not” (Participant 21, Intervention Site 2, 9 Month Visit).

**Reminder/Cue to Action for Clinic Attendance** Many women from HITSsystem sites appreciated the text messages’ function both as a reminder and cue to action for hospital attendance. Text-driven reminders were essential in light of competing responsibilities and other challenges; as one woman described, “on some days duties can be so overwhelming that you forget [appointments]” (Participant 95, Intervention Site 2, 18 Month Visit) and another said, “based on the challenges, these [text] messages remain helpful...The messages wake us up [alert us]. Like someone who is asleep is woken up” (Participant 97, Intervention Site 2, 18 Month Visit). For others, the text messages when their infants were due for repeat testing or when results became available provided a cue to action to plan for their clinic visit: “the message made me start looking for transport so I can bring my child to the clinic” (Participant 56, Intervention Site 3, 9 Month Visit). While some mothers from control sites reported receiving phone calls from providers, especially to notify them when results were available or to follow up if they were late for services, the level and consistency of provider-initiated contact varied by participant and site. Thus, even when contact occurred at control sites, it was not universal, nor did it always provide the same efficiency advantages of HITSsystem messages: immediate notification of result availability and prompt cues to action when infants were due for repeat testing.

**Increased Opportunities for Patient Support** Women from HITSsystem sites described text message-facilitated opportunities for patient engagement and support. Remain-

ing informed regarding upcoming EID services increased mothers' sense of personal responsibility and engagement in care. When asked how they felt about receiving text messages telling them to bring their infant to the hospital, several women indicated "it was my responsibility to follow up with the hospital" (Participant 54, Intervention Site 3, 9 Month Visit).

The messages also generated new opportunities for male partner support for those women who had disclosed their status to their partner and shared the texts. Male partners were able to facilitate earlier clinic attendance through financial support and encouragement:

"When I received the message, I showed it to my husband, he read it and asked if I was going to the clinic tomorrow, I said no my appointment is near. He said it's ok to go and find out how our baby is doing so we can raise him well" (Participant 53, Intervention Site 3, 9 Month Visit).

While HITSystem text messages were automatically generated, several mothers identified the texts with improved engagement from the health system providers, perceiving the messages as encouragement and reassurance that their infants were being tracked and followed up:

"When I get a text, like the other day I got a text reminding me it's 9 months come back to the hospital, it encourages me because I feel like you guys are concerned too, there are many people not everyone follows up, and you remind us, so you encourage us" (Participant 22, Intervention Site 2, 9 Month Visit).

### HITSystem-Facilitated EID Experience in Context

The improvements in HITSystem-facilitated EID were described in the context of ongoing challenges related to mothers' EID participation: retention despite limited resources and competing responsibilities, and care-seeking in the midst of high HIV-related stigma and risk of unintentional disclosure.

#### Limited Resources/Competing Responsibilities

Mothers at all sites described the high cost of EID attendance in terms of direct costs and opportunity costs. Some women described financial sacrifice to attend their scheduled EID visits, sometimes at the expense of competing priorities: "Sometimes I sacrifice the money that I would otherwise use to buy food and use it as bus fare to get to the clinic when my husband is not around" (Participant 39, Intervention Site 1, 9 Month Visit), or through incurring debt, "sometimes I don't have money [for the clinic visit] and resort to borrowing"

(Participant 99, Control Site 1, 18 Month Visit). For those who could not afford the fare to the hospital, long distances made accessing care more difficult, especially for those in poor health who have to walk a long distance: "Usually when I don't have money I will walk to the clinic. When I walk...I sometimes get to the clinic late. It also takes time... I am usually very tired by the time I get home" (Participant 70, Control Site 3, 9 Month Visit). For women who were working, "daily tasks...become hard to complete because I have to stop and take the baby to the clinic" (Participant 13, Intervention Site 2, 9 Month Visit).

#### Fear of Stigma/Unintentional Disclosure

Many women highlighted the significant fear of disclosure and HIV-related stigma from both neighbors and providers as a factor influencing EID service engagement. Despite the challenges that long distances to the hospital may present, some women described intentionally seeking care at facilities further from home because they were "afraid to be seen by others" from their community or to receive discriminatory care:

"You can go to the dispensaries closest to your home and find a doctor there. If this doctor finds out you are positive, they sometimes tell other people your status and people become afraid of you. Instead of the doctor teaching you about how to take care of your infant, they don't want you because of the possibility of spreading the infection" (Participant 55, Intervention Site 3, 9 Month Visit).

### HITSystem Acceptability and Suggestions for Improvement

Most HITSystem participants reported satisfaction with the services and text messages they received, and most control site participants indicated they would appreciate receiving text messages as part of future EID engagement. However, HITSystem participants highlighted various challenges related to the current text messaging strategy including considerations for message confidentiality in the context of HIV-related stigma, failed delivery of text messages, and challenges with literacy. Participants at intervention sites also recommended improvements to the HITSystem experience through changes in message timing, frequency, and content.

#### Confidentiality

In the context of high stigma and fear of disclosure, no unintentional disclosures from HITSystem participation were reported. Indeed, most HITSystem participants were unconcerned about confidentiality given the neutral message

content, predominant personal phone ownership, and the ability to discreetly read and delete messages. This was in contrast to phone calls, which were perceived as riskier for unintentional disclosure,

“[a text message] is something you can read without anybody noticing. For example, when you are in your business in a market place or in a public service vehicle. A call on the other hand...will never be secretive as such” (Participant 128, Control Site 2, 18 Month Visit).

Others appreciated that the messages were “brief and precise” as part of ensuring confidentiality, especially in households where women have not disclosed to their partner and certain messages could raise suspicion. Though the majority of participants “did not think anyone else would see the texts,” a few remained apprehensive that someone might discover the message and become suspicious of their HIV status: “I was worried...because with a phone someone might borrow to use it, and the message arrives, so someone might see” (Participant 52, Intervention Site 3, 9 Month Visit).

### Failed Delivery of Text Messages

While most participants reported receiving a text as expected, some reported not receiving a text, and a few reported receiving a phone call instead. Of those who did not receive a text, one knew the failed delivery was due to an incorrect phone number entry, and several others reported not receiving a text because they had no phone or had lost their phone. For those from HITSsystem sites who did not receive a text, their EID experience mirrored that of the control group with regards to additional follow up visits to check on results: “I was coming and each time I came I was told, not yet, not yet...I was told that there was a text message that I was to receive but I never got one” (Participant 49, Intervention Site 1, 9 Month Visit).

In order to ensure consistent text message delivery, one mother highlighted the importance of verifying contact information at each hospital visit:

“So it’s good every time we come, you ask us if we have the same number, in case there is something so there is another way to get the message...They might be waiting for a text, and if there is none they think everything is fine...So every time we come, we have to talk about it” (Participant 22, Intervention Site 2, 9 Month Visit).

In case of failed text delivery, others suggested phone calls as an additional means of contact, though one woman emphasized phone calls alone were insufficient because a call might not go through if a phone is turned off, but “with

a text message, once you turn on your phone, you will find it” (Participant 91, Intervention Site 2, 18 Month Visit).

### Literacy/Language Challenges

Although many HITSsystem participants were satisfied with their own experience of receiving texts, several women indicated that texts were not universally appropriate. These women indicated that illiteracy and/or multiple spoken languages could prevent participants from understanding a text message: “As long as you can’t read, there won’t be anything that is easy to understand, even if it is simple” (Participant 95, Intervention Site 2, 18 Month Visit). In these cases, women often recommended a phone call. Likewise, when control site participants were asked whether they would be willing to receive text message notifications for EID in the future, many welcomed the idea, but for others, literacy posed a challenge, “Now for the message, if my husband was around I would ask him to read it for me, but now since he is not and I cannot read I would prefer to come for the results myself or to receive a phone call” (Participant 77, Control Site 3, 18 Month Visit).

### Message Timing, Frequency, and Content

Mothers who were retained through 18 months, those with the most experience with repeat testing-related HITSsystem texts, recommended more advanced and/or more frequent repeat testing reminders to allow more preparation time for clinic visits, saying “the notice was too short.” Several suggested that texts be sent 2 weeks before their infant was due for repeat testing, “I would say send the text 2 weeks prior so that the woman can organize herself and bring the child on a particular date...because of that hustle of looking for money to bring the child (Participant 97, Intervention Site 2, 18 Month Visit). Others recommended texts a month prior or at multiple intervals, “a month before and somewhere in between the preceding month. Even remind me on the day because people have many responsibilities” (Participant 98, Intervention Site 2, 18 Month Visit).

Some participants suggested immediate results via text rather than waiting until the next clinic visit: “I think when texting the mothers to come to the clinic, you can put the results in the text so that the mother doesn’t become anxious. If the baby is not well, they should put this in the text message” (Participant 14, Intervention Site 2, 9 Month Visit). However, others preferred the current setup of receiving their infants’ results “face-to-face” and indicated “the results shouldn’t be released on the phone, at most they should tell you that the results are out, come to the hospital” (Participant 81, Control Site 3, 18 Month Visit). Some women also wanted to receive additional types of messages for encouragement: “They should include encouraging messages that

would give me the will to continue living” (Participant 36, Intervention Site 1, 9 Month Visit).

## Conclusion

This study provides new insight into how eHealth-enhanced EID can mitigate previously identified patient-level challenges to HIV service provision (including limited resources [19], competing responsibilities [20], and fear of stigma/disclosure [19, 21, 22]) and improve the EID experience in Kenya and other low resource settings. HITSsystem participant experiences compared with SOC EID suggest that HITSsystem-generated text messages facilitated improvements in EID efficiency and quality, promoting patient satisfaction and retention. These qualitative findings are supported by cRCT outcomes showing infants enrolled in the HITSsystem had significantly faster TAT for 6-week PCR results and mother notification and were significantly more likely to receive complete EID services compared to SOC (85.2% vs. 61.0%, aOR 3.5) [6]. While mothers at intervention sites may not have been aware of every HITSsystem-driven improvement in EID efficiency along the cascade of care (such as improved sample processing turnaround times), they described how HITSsystem-generated text messages regarding result availability prompted earlier clinic attendance for notification. This has significant clinical implications, as shorter TAT for result notification ( $\leq 4$  weeks from sample collection, per WHO guidelines [23]) has been identified as a significant predictor of ART initiation by 12 weeks of age for HIV-positive infants [24]. By receiving infant results more quickly, mothers are able to provide HIV-status appropriate care, fulfilling a key motivation for EID engagement. Furthermore, as mothers return for results only when they are available (based on text notification), they may also reduce the number of hospital visits to check for results, thus reducing the financial and opportunity cost strain of EID.

With regard to EID quality, HITSsystem-generated text messages increased patient information regarding result availability and retesting needs, thus reducing anxiety and uncertainty. In addition, text messages provided essential cues to action for clinic attendance, allowing greater opportunities for planning and obtaining the resources needed to remain engaged in care. Retention was also enhanced through text-message generated opportunities for patient support, as male partners who saw the text messages encouraged mothers' clinic attendance through instrumental (financial provision for transport) and emotional support, thus addressing the recognized need for male partner involvement for PMTCT/EID [8, 25]. Unlike at control sites, where opportunities for increased engagement were dependent on provider-initiated contact, automated HITSsystem texts

allowed for consistent and widespread patient follow up. Some participants suggested that additional, encouraging text messages would further enhance engagement in care. These findings are consistent with findings by Odeny et al. that text messages to facilitate optimal EID retention serve as important cues to action and should be both informative/educational and encouraging [10].

While most participants expressed high acceptability and satisfaction with the HITSsystem-generated messages, some wanted to ensure alternative means of contact to address message delivery failure or other mobile-related challenge (wrong number, lost phone, etc.) or to lower barriers for illiterate clients. While 95.1% of study participants received texts to their own phone [6], the HITSsystem does accommodate women without access to phones and allows for texts to be sent to a trusted community health care worker on their behalf if preferred or needed due to literacy or privacy challenges. While text message failure remains an ongoing challenge to successful mHealth implementation, in this study a median of 3.0 texts were received per HITSsystem participant, and 73% of text messages were confirmed received by the recipients' phones [6], indicating that most received some benefit from the text message component of the intervention. The HITSsystem also tracks message delivery status, allowing providers to use alternate means of contact in case of delivery failure. In addition, the HITSsystem provides alerts to providers to follow up with patients who have missed services (by manual text, phone call, or through physical tracing), though mothers would not have been able to differentiate between HITSsystem-prompted provider follow up and routine follow up as part of SOC.

Although the HITSsystem intervention does not directly address the challenges posed by fear of disclosure or stigma, there was no unintentional disclosure reported from HITSsystem participation, and many participants felt text messages were more discreet than phone calls, the traditional means of patient contact. Continued participant fears of disclosure and stigma underscore the importance of brief, HIV-neutral messaging as a consideration when developing future text messaging content.

## Limitations

Our study has several limitations. While we interviewed women from each of our study sites (representing high, medium, and low volume facility settings and different regions of the country), our sample is only from six government health facilities, limiting generalizability. Although we attempted to represent a variety of participant experiences and demographics through our targeted sample size, because our convenience sample was small relative to the overall number of study participants at each site, we may not have adequately captured the range of participant experiences. In

addition, because we only captured clients who remained retained in care at 9 and 18 months, this sample is not representative of all mothers with HIV-exposed infants or those engaged in EID; the current sample fails to capture the perspectives of HIV-positive mothers whose infants were never linked to EID or those whose infants were only tested at 6 weeks but were not retained in care. Thus, our data may not adequately reflect the barriers and challenges that prevent (rather than merely hinder) ongoing engagement in EID. In addition, we did not interview mothers of infants diagnosed HIV-positive during EID, thus our findings are only generalizable to the mothers of HIV-negative infants and we were unable to evaluate satisfaction with linkage to HIV care as the final step in the EID cascade for those identified positive.

Furthermore, mothers' perceptions of HITSsystem-enhanced EID may have been influenced by their level of experience with EID in a SOC setting, as those going through EID for the first time may not have recognized the benefits of the HITSsystem intervention without a point of comparison. As a result, our analysis of differences in the quality and efficiency between HITSsystem and SOC sites is mostly limited to indirect comparisons between intervention and control participant experiences. While this approach may lend itself to bias in the data collection and analysis phase (inferring only positive comparisons of HITSsystem over SOC), we attempted to mitigate this potential by asking open-ended questions and encouraging negative feedback and suggestions for improvement from HITSsystem participants, while attempting to separate HITSsystem-driven benefits and satisfaction from those associated more generally with EID across both intervention and control sites in our analysis. Indeed, satisfaction with services was high in both intervention and control; however, we found the HITSsystem to be an acceptable intervention to further improve the quality and efficiency of EID. In order to further ensure interpretive validity, we have attempted to support our findings with rich data exemplifying the range of participant feedback, with themes achieving saturation through adequate sampling, and through agreement between independent coders regarding thematic frequency and quality. Though the Kenyan and US-based study staff participated in regular debriefing throughout the data collection and analysis processes, results should be interpreted in light of the positionality of data collectors (Kenyan site coordinators) and coders (primarily US-based study team).

Finally, as part of the study, each intervention site had a designated study coordinator to support HITSsystem implementation and patient engagement. Thus, these data may not reflect the range of mother experiences in programmatic settings.

Despite these limitations, this study provides a qualitative evaluation of patient acceptability and satisfaction

with EID and HITSsystem-enhanced EID in the context of a cRCT, providing support and context for quantitative patient outcome findings showing improved quality and efficiency of EID services. Given high levels of patient acceptability and provider satisfaction [7], the HITSsystem was cited as a best practice for EID by the Kenyan National AIDS & STI Control Programme [26]. Thus, scale up of the HITSsystem and similar eHealth interventions in Kenya and other low resource settings may be an effective way to significantly improve EID quality and efficiency, leading to better individual and system-level outcomes.

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## References

1. Country factsheets: Kenya 2017: UNAIDS; 2017. <http://www.unaids.org/en/regionscountries/countries/kenya>. Accessed 21 June 2019.
2. National AIDS and STI Control Programme (NASCO). Guidelines for prevention of mother to child transmission (PMTCT) of HIV/AIDS in Kenya, Fourth Edition. 2012. [https://www.faces-kenya.org/wp-content/uploads/2012/11/Guidelines-for-PMTCT-of-HIVAIDS-in-Kenya-1\\_2012.pdf](https://www.faces-kenya.org/wp-content/uploads/2012/11/Guidelines-for-PMTCT-of-HIVAIDS-in-Kenya-1_2012.pdf). Accessed 25 Oct 2017.
3. Guidelines on use of antiretroviral drugs for treating and preventing HIV infection in Kenya 2014. Nairobi, Kenya: Ministry of Health, National AIDS & STI Control Programme. 2014.
4. Finocchiaro-Kessler S, Goggin K, Khamadi S, Gautney B, Dariotis JK, Bawcom C, et al. Improving early infant HIV diagnosis in Kenya: study protocol of a cluster-randomized efficacy trial of the HITSsystem. *Implement Sci.* 2015;10:96. <https://doi.org/10.1186/s13012-015-0284-3>.
5. Finocchiaro-Kessler S, Gautney BJ, Khamadi S, Okoth V, Goggin K, Spinler JK, et al. If you text them, they will come: using the HIV infant tracking system to improve early infant diagnosis quality and retention in Kenya. *AIDS.* 2014;28(Suppl 3):S313–21. <https://doi.org/10.1097/QAD.0000000000000332>.
6. Finocchiaro-Kessler S, Gautney B, Cheng A, Wexler C, Maloba M, Nazir N, et al. Evaluation of the HIV infant tracking system (HITSsystem) to optimise quality and efficiency of early infant

- diagnosis: a cluster-randomised trial in Kenya. *Lancet HIV*. 2018;5(12):e696–705.
7. Wexler C, Brown M, Hurley EA, Ochieng M, Goggin K, Gautney B, et al. Implementing eHealth technology to address gaps in early infant diagnosis services: qualitative assessment of kenyan provider experiences. *JMIR Mhealth Uhealth*. 2018;6(8):e169.
  8. Ambia J, Mandala J. A systematic review of interventions to improve prevention of mother-to-child HIV transmission service delivery and promote retention. *J Int AIDS Soc*. 2016;19(1):20309 **eCollection 2016**.
  9. Odeny TA, Bukusi EA, Cohen CR, Yugas K, Camlin CS, McClelland RS. Texting improves testing: a randomized trial of two-way SMS to increase postpartum prevention of mother-to-child transmission retention and infant HIV testing. *AIDS*. 2014;28(15):2307–12. <https://doi.org/10.1097/QAD.0000000000000409>.
  10. Odeny TA, Newman M, Bukusi EA, McClelland RS, Cohen CR, Camlin CS. Developing content for a mHealth intervention to promote postpartum retention in prevention of mother-to-child HIV transmission programs and early infant diagnosis of HIV: a qualitative study. *PLoS ONE*. 2014;9(9):e106383. <https://doi.org/10.1371/journal.pone.0106383> **eCollection 2014**.
  11. Gupta RS, Yewale K, Hegde AS, Mulik T, Bamrotiya M, Yadav S, et al. Use of technology in follow-up of HIV positive pregnant women and their babies till 18 months of age- an innovation by Maharashtra State AIDS Control Society (MSACS), India. *Curr Opin HIV AIDS*. 2016;11(Suppl 1):S46–51. <https://doi.org/10.1097/COH.0000000000000265>.
  12. Daher J, Vijn R, Linthwaite B, Dave S, Kim J, Dheda K, et al. Do digital innovations for HIV and sexually transmitted infections work? Results from a systematic review (1996-2017). *BMJ Open*. 2017;7(11):e017604.
  13. Ybarra ML, Mwaba K, Prescott TL, Roman NV, Rooi B, Bull S. Opportunities for technology-based HIV prevention programming among high school students in Cape Town, South Africa. *AIDS Care*. 2014;26(12):1562–7.
  14. Reid MJA, Steenhoff AP, Thompson J, Gabaitiri L, Cary MS, Steele K, et al. Evaluation of the effect of cellular SMS reminders on consistency of antiretroviral therapy pharmacy pickups in HIV-infected adults in Botswana: a randomized controlled trial. *Health Psychol Behav Med*. 2017;5(1):101–9.
  15. Rodrigues R, Poongulali S, Balaji K, Atkins S, Ashorn P, De Costa A. “The phone reminder is important, but will others get to know about my illness?” Patient perceptions of an mHealth antiretroviral treatment support intervention in the HIVIND trial in South India. *BMJ Open*. 2015;5(11):e007574. <https://doi.org/10.1136/bmjopen-2015-007574>.
  16. Nachega JB, Skinner D, Jennings L, Magidson JF, Altice FL, Burke JG, et al. Acceptability and feasibility of mHealth and community-based directly observed antiretroviral therapy to prevent mother-to-child HIV transmission in South African pregnant women under Option B+: an exploratory study. *Patient Prefer Adherence*. 2016;10:683–90. <https://doi.org/10.2147/PPA.S100002> **eCollection 2016**.
  17. Hirsch-Moverman Y, Daftary A, Yuengling KA, Saito S, Ntoane M, Frederix K, et al. Using mHealth for HIV/TB treatment support in lesotho: enhancing patient-provider communication in the START study. *J Acquir Immune Defic Syndr*. 2017;74(Suppl 1):S37–43. <https://doi.org/10.1097/QAI.0000000000001202>.
  18. Charmaz K. *Constructing grounded theory*. 2nd ed. London: SAGE Publications Ltd; 2014.
  19. Boender TS, Sigaloff KC, Kayiwa J, Musiime V, Calis JC, Hamers RL, et al. Barriers to initiation of pediatric HIV treatment in Uganda: a mixed-method study. *AIDS Res Treat*. 2012;2012:817506. <https://doi.org/10.1155/2012/817506>.
  20. Buchberg MK, Fletcher FE, Vidrine DJ, Levison J, Peters MY, Hardwicke R, et al. A mixed-methods approach to understanding barriers to postpartum retention in care among low-income, HIV-infected women. *AIDS Patient Care STDS*. 2015;29(3):126–32.
  21. Adeniyi VO, Thomson E, Ter Goon D, Ajayi IA. Disclosure, stigma of HIV positive child and access to early infant diagnosis in the rural communities of OR Tambo District, South Africa: a qualitative exploration of maternal perspective. *BMC Pediatr*. 2015;15:98. <https://doi.org/10.1186/s12887-015-0414-8>.
  22. Donahue MC, Dube Q, Dow A, Umar E, Van Rie A. “They have already thrown away their chicken”: barriers affecting participation by HIV-infected women in care and treatment programs for their infants in Blantyre, Malawi. *AIDS Care*. 2012;24(10):1233–9. <https://doi.org/10.1080/09540121.2012.656570>.
  23. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: World Health Organization; 2016. [http://apps.who.int/iris/bitstream/handle/10665/208825/9789241549684\\_eng.pdf?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/208825/9789241549684_eng.pdf?sequence=1). Accessed 21 June 2019.
  24. Wexler C, Nazir N, Gautney B, Maloba M, Brown M, Goggin K, et al. Predictors of timely ART initiation among HIV + infants in Kenya. *WHO Bulletin*. Revise and Resubmit.
  25. Mabachi NM, Brown M, Sandbulte M, Wexler C, Goggin K, Maloba M, et al. Using a social support framework to understand how HIV positive Kenyan men engage in PMTCT/EID care: qualitative insights from male partners. *AIDS Behav*. 2019:02451-6.
  26. *Improving the quality and efficiency of health services in Kenya: a practical handbook for HIV managers and service providers on differentiated care*. National AIDS & STI Control Programme 2016, Nairobi.

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