

SHORT REPORT

Reach, Acceptability, Feasibility and Impact of a Brief Community Health Worker-Administered Index Case Testing Screening Tool “cICT” on Paediatric HIV Case Identification: Results From Malawi

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ABSTRACT

Introduction: Despite global initiatives to improve access to life-saving antiretroviral treatment (ART), only 54% of over 900,000 children living with HIV (CLHIV) received treatment in 2021, compared to 85% of women (WLHIV). Without timely ART, half of these children could die before age 2. We describe the design, implementation and outcomes of a child index case testing tool (cICT) that identifies WLHIV with untested children and embeds paediatric follow-up into their HIV care to identify and test their untested children.

Methods: The cICT was a card used to gather information about WLHIV and their children, including ages and HIV status (living with HIV, uninfected, exposed or unknown). Community health workers (CHWs) screened WLHIV 15 years and older at 95 ART clinics in Malawi from September 2020 to August 2023 and referred untested children to HIV testing services. De-identified data were entered in SurveyCTO (Dobility, Inc., MA) to determine WLHIV screened, children's baseline HIV status, new HIV testing completed and newly identified CLHIV. Outcomes included reach (percentage of cohort offered screening), acceptability (percentage accepting cICT) and feasibility (percentage screened who completed child testing). Impact measured the proportion of women with untested children at baseline versus study conclusion, proportion of untested children tested; new CLHIV diagnosed and HIV testing yield.

Results: Of an estimated cohort of 116,000 WLHIV active in care, 101,273 were offered and screened (87% reach, 100% acceptability), 75,262 had at least one child 0–19 years old, with 24% (18,175/75,262) of women having at least one child with unknown HIV status. At study conclusion, only 5% (4606/101,273) of WLHIV had children with unknown status. A total of 193,402 children were listed among 75,262 WLHIV who identified as having children; 39,124 (20%) of the 193,402 children listed were untested. By study conclusion, 28,808/39,124 (74%) of them were tested. Of these, 27,934 children were confirmed HIV uninfected, while 486 were newly diagnosed CLHIV, a 1.7% testing yield.

Conclusions: The cICT was acceptable and feasible to implement, revealing nearly a quarter of WLHIV had children with unknown HIV status. The tool's simplicity and scalability make it a high-impact approach for HIV programmes to quantify, track and confirm the status of HIV-exposed untested children and facilitate timely identification of CLHIV by embedding ICT screening within routine ART care for WLHIV.

1 | Introduction

Children living with HIV (CLHIV) face significant barriers in accessing life-saving antiretroviral therapy (ART), lagging behind adults. Despite global initiatives to improve access, only 54% of CLHIV received treatment in 2021, compared to 73% of adults and over 85% of women living with HIV (WLHIV) [1, 2]. The consequences for untreated CLHIV are dire, with approximately half dying before age 2 and 80% by 5 [3–6]. In Malawi, while over 95% of WLHIV are on ART, only 58% of CLHIV are on ART [4, 7–9]. Of nearly 60,000 CLHIV not on treatment, one-third are unaware of their status, making case finding through HIV testing the critical first step in improving outcomes.

Global recommendations for identifying CLHIV include several strategies, with index case testing (ICT) the most promising [10–13], contributing 30% of positive diagnoses from just 13% of HIV tests in settings like Malawi [14–17]. Endorsed by the World Health Organization in 2016, ICT focuses on testing contacts of individuals living with HIV (index clients). Successful implementation involves asking index clients about untested contacts (ICT screening) and ensuring follow-up for HIV testing. While ICT focused on creating deliberate linkages between mothers and their children with perinatal exposure seems obvious [18–20], implementation in Malawi has been suboptimal [21]. Malawi's Elimination of Mother To Child Transmission of HIV (EMTCT) programme provides national tools for linkage until 2 years old, but lacks a pragmatic method to systematically track children thereafter [22, 23]. Consequently, there is no national data identifying WLHIV remaining with untested children, nor how many of their children remain untested.

Funded by the United States government through the Presidential Emergency Fund for AIDS Relief (PEPFAR), Baylor's Tingathe ("together we can") programme has partnered with the Malawi Ministry of Health (MOH) for 15+ years and employs community health workers (CHWs) to provide HIV testing and support HIV service delivery [24–27]. The child index case testing tool, or ("cICT"), was developed to address gaps in identifying CLHIV by establishing a baseline of WLHIV with untested children and embedding longitudinal paediatric follow-up into their HIV care to link their untested children to testing. We describe the tool's design, implementation and outcomes—including reach, acceptability, feasibility and impact in Malawi.

2 | Methods

We conducted a retrospective, descriptive study of programmatic outcomes based on experience implementing cICT from 2020 to 2023 in Malawi.

2.1 | Setting and Programme Description

The cICT was implemented at all 95/95 Tingathe-supported health facilities in southeast and central Malawi: five district hospitals, three community hospitals and 87 health centres. Over 200,000 people living with HIV (PLHIV) access HIV care at these facilities, representing ~20% of PLHIV on ART in Malawi.

2.2 | Study Population

All WLHIV over 15 years old attending ART clinic visits were eligible for cICT screening; all children 0–19 years in the household (HH) were listed as contacts.

Prior to study initiation, we quantified the cohort eligible for screening by extracting the number of WLHIV over 15 years active in care from MOH ART records.

2.3 | Design and Implementation Process

The cICT (Figure 1) was a printed card stored with the mother's MOH ART record, designed to be integrated within ART care. During clinic triage, CHWs used cICT to screen WLHIV attending the clinic for their children's HIV status, including WLHIV newly diagnosed and WLHIV collecting refills. CHWs completed cICT and documented in MOH registers per HIV testing guidelines [22, 23].

At a woman's initial "baseline" screening, CHWs recorded information for WLHIV on cICT: date, mother's (index client) name, age, date of initial screen and number of living children 0–19 years (biological and non-biological) in the HH. For each child: name, age, HIV status as reported by mother (living with HIV, uninfected, exposed, unknown) and linkage to care for perinatally HIV-exposed infants (HIV care clinic, HCC) <2 years, or to ART for CLHIV (verified with ART records) [22]. Infants <2 years were classified as "living with HIV" if diagnosed with HIV, "exposed" if enrolled in HCC with ongoing breastfeeding exposure or "unknown" if not HCC-enrolled or enrolled but had missed testing milestones. CHWs referred untested children for counselling and home or facility-based testing. After documentation, cICT was filed alongside the mother's MOH ART record [23].

WLHIV had clinical reviews every 3–6 months. At each subsequent visit, CHWs used cICT to review children's testing status, update the status of previously untested children, provide further counselling and tracing for children remaining untested, and add

Use this tool to document children of index women in ART clinic; all other index clients should be screened as usual and documented in ICT register, but do not need this tool completed. PIN THIS PAGE TO THE CLIENT'S MASTERCARD FOR REVIEW AT THE NEXT CLINIC VISIT.

Index Client Name: _____ Index Client Age: _____ Date of Initial Screen: ____/____/____ ART Number: _____ Number of Living Children in Household 0-19 years: _____ Write the names of these children below and complete the "HIV status" column. Document ART # and ART start date for children living with HIV (CLHIV) in the "ART status" column. Have ALL of these children had an HIV test*? Circle Y or N : If Yes * → tool is complete. Check "tool complete" box to right and date and continue ICT screening. *circle yes if an exposed infant had ANY DBS or rapid test, even if their HIV status is "exposed." If No → offer FRS for each untested child and enter woman into ICT register with all contacts.						CHW: ☐ Tick box when tool is complete Date tool opened: ____/____/____ Date tool complete: (date that all children on tool have documented status): ____/____/____ For new infants born: Date new infant added to card: ____/____/____ Data Clerk: UNIQUE ID ASSIGNED: _____ Card OPENED: date entered into database: ____/____/____ Card COMPLETE: date entered into database: ____/____/____ New infant born: date entered into database: ____/____/____	
Client Linkage – Active in Care? (complete only ONE of the sections below for each child)							
Date child first entered on this card	Name of Child 0-19	Age (Years)	Has child been tested for HIV ever? (by the time of opening card) (Circle Yes or No)	Date of HIV Test	Child's HIV Status (circle one) (I=infected, U=uninfected, E=exposed)	CLHIV - ART status Document ART# and ART START DATE for CLHIV: If HIV uninfected write "NA"	Exposed Infants only Active in care? Circle Y/N If no, make a plan with mother/guardian today to enroll in care
			Y N		I E U	ART # ART start date	Y N
			Y N		I E U		Y N
			Y N		I E U		Y N
			Y N		I E U		Y N
			Y N		I E U		Y N
			Y N		I E U		Y N
Enter any new infants born after CHILD ICT Card was closed here* (write date new infants added to card above):							
Date infant entered on this card	Name of Infant	Date of birth	Has child been tested for HIV yet? (Circle Yes or No)	Date of HIV Test	HIV Status (circle)	CLHIV only- ART status	Active in care? Y/N If no, make a plan with mother/guardian today to enroll in care
			Y N		I U E	ART # ART start date	Y N
			Y N		I U E		Y N
			Y N		I U E		Y N

FIGURE 1 | CHILD index case testing tool (cICT).

new HH members; once all children were tested, the card was marked complete and entered into a SurveyCTO (Dobility, Inc., MA) database by programme staff. Women were then re-screened at annual viral load visits for new children who had joined the HH. CHWs provided counselling and testing referrals for newly identified untested children.

In August 2020, 1 month prior to implementation, programme staff led facility-based orientations (3–4 h) for clinic staff to practice cICT administration and integration into clinic flow, referral provision and follow-up tracing for testing. Orientations concluded with focused sessions to establish integrated clinic flow to prevent duplication and promote sustainability.

2.4 | Data Collection

De-identified monthly cumulative data were integrated into existing performance dashboards to provide monthly feedback on screening and testing. Facilities with low screening coverage implemented continuous quality improvement cycles by identifying and addressing gaps in clinic flow and counselling/tracing.

At study conclusion, cumulative de-identified data were abstracted for analysis. We defined the initial cICT screen for each WLHIV as baseline and used the last follow-up screen for each woman during the study period to describe the status of her children at study conclusion.

2.5 | Measures

We define reach as the percentage of the cohort of eligible WLHIV offered screening with cICT.

Acceptability assessed the percentage of women offered screening with cICT who accepted.

Feasibility assessed the percentage of screened women who completed all child testing by study conclusion.

Impact was assessed by the proportion of eligible WLHIV with untested children at initial screening, with all children tested by study conclusion; the proportion of children with unknown HIV status at baseline who received HIV testing; and the number and proportion (yield) of children with previously unknown HIV status who newly tested positive.

2.6 | Statistical Analysis

We used counts and proportions to describe categorical variables and means and standard deviations to summarize numerical variables. Children's ages by HIV status were compared using one-way analysis of variance. We assessed whether having untested children at baseline was associated with having all children tested at study conclusion using Student's *t*-test. All tests were two-sided; alpha ≤ 0.05 was considered statistically significant. All analyses were performed in Stata 19.

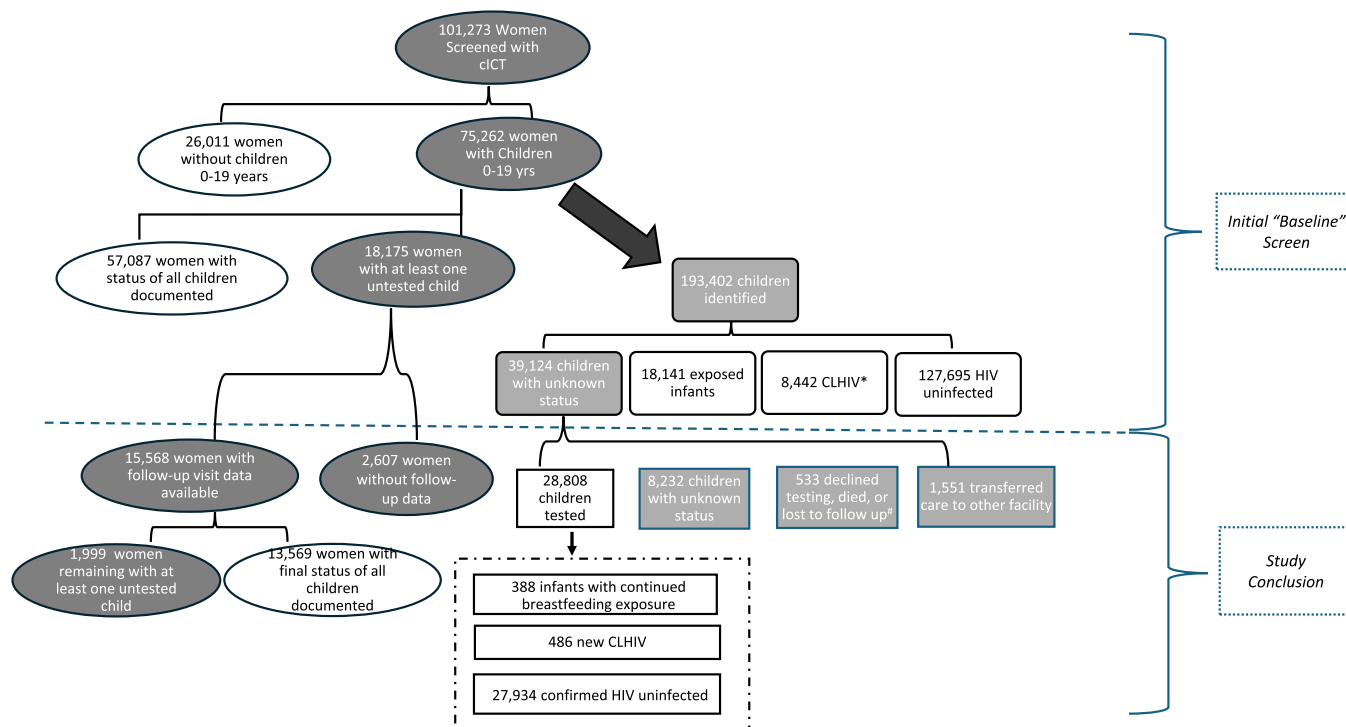


FIGURE 2 | Women screened, children identified.

2.7 | Ethical Approval

This analysis was approved by the Malawi National Health Science Research Committee (protocol #688) and the Baylor College of Medicine Institutional Review Board (protocol H-26099).

3 | Results

3.1 | Reach, Acceptability and Feasibility

In August 2020, before cICT introduction, 110,597 WLHIV were in care at the 95 facilities, with a 4.5% cohort increase to ~116,000 WLHIV by August 2023. Between 1 September 2020, and 31 August 2023, 87% (101,273/116,000) of WLHIV were offered cICT screening, and 100% (101,273/101,273) had baseline data captured on cICT. By study conclusion, the proportion of women with all of their children's HIV statuses confirmed was 95% (96,667/101,273), up from 82% (83,098/101,273) at baseline. Follow-up continues for the 5% of WLHIV (4606/101,273) with children still requiring testing. All 95/95 facilities adopted cICT within 2 months of orientation and continued through manuscript completion.

3.2 | Impact

Of WLHIV screened, 74% (75,262/101,273) reported any children 0–19 years old in the HH (Figure 2), and 24% (18,175/75,262) had at least one child with unknown HIV status. Most women (52% [39,499/75,275]) had 1–2 children (range 1–10). The mean age of WLHIV with children was 35.4 (± 8.9) years. Among WLHIV with at least one untested child, 15,568 (86%) had at least

one follow-up visit by study conclusion, with follow-up more common among women with more untested children at baseline ($X^2(9) = 179$, $p < 0.001$). Of women with at least one follow-up, 87% (13,569/15,568) had documentation of the HIV status of all children.

At baseline, a total of 193,402 children 0–19 years were identified by cICT with a mean (SD) age 8.9 (± 5.2) years; 20% (39,124/193,402) had unknown HIV status (Figure 2). Of 154,278 children with known status, 12% (18,141/154,278) were infants <2 years with ongoing HIV exposure, 5% (8442/154,278) were CLHIV and 83% (127,695/154,278) were HIV uninfected. The average age of children with unknown status was 10.2 [95% CI = 10.2–10.3] years, significantly higher than for children who were known CLHIV (9.6 [95% CI = 9.5–9.7] years) or children who were HIV uninfected (9.6 [95% CI = 9.6–9.7] years) ($F(2) = 344$, $p < 0.001$).

At study conclusion, 74% (28,808/39,124) of children with an initial unknown HIV status were reported as tested. A total of 486 CLHIV were newly identified, representing an HIV testing yield of 1.7% (486/[486+27,934]). Most newly identified CLHIV were less than 15 years old: 70 (14%) 2- to 4-year-olds, 167 (34%) 5- to 9-year-olds, 166 (34%) 10- to 14-year-olds and 72 (15%) 15- to 19-year-olds. cICT use also facilitated the identification of 388 infants with ongoing exposure who were linked to HCC. Over 70% of children with previously unknown status were confirmed HIV uninfected (71%, 27,934/39,124). Among 10,316 children with unknown status at study conclusion, 27 died before HIV status was ascertained, 267 were lost to follow-up (mother missed ART refill and CHW traced unsuccessfully), 1551 transferred to other facilities and 239 declined HIV testing; 8232 continued being traced for testing by CHWs (Table 1).

TABLE 1 | Children's HIV status at mother's initial screen and at study conclusion, by age group.

	Age group (years)					Total
	<2	2–4	5–9	10–14	15–19	
Panel 1: Status of all 193,402 children at mother’s initial screen						
Children living with HIV	384	1049	2399	3096	1514	8442
Children who are HIV uninfected	10	22,113	41,038	40,303	24,231	127,695
Infants with ongoing perinatal HIV exposure	18,141	0	0	0	0	18,141
Children with unknown HIV status	412	5831	12,039	13,620	7222	39,124
Panel 2: Status at study conclusion of 39,124 children with unknown status at mother’s initial screen						
Children living with HIV	11	70	167	166	72	486
Children who are HIV uninfected	0	4451	8451	9853	5179	27,934
Infants with ongoing perinatal HIV exposure	388	0	0	0	0	388
Still with unknown HIV status	0	1073	2760	2877	1522	8232
Died	0	4	11	6	6	27
Children lost to follow-up	1	39	97	86	44	267
Declined HIV testing	0	16	78	88	57	239
Transferred out to another facility	12	178	475	544	342	1551
Panel 3: Status of all 193,402 children at study conclusion						0
Children living with HIV	418	1119	2566	3262	1586	8951
Children who are HIV uninfected	0	26,527	49,425	50,098	29,387	155,437
Infants with ongoing perinatal HIV exposure	18,450	0	0	0	0	18,450
Children with unknown HIV status	0	1073	2760	2877	1522	8232
Died	7	5	13	8	6	39
Children lost to follow-up	3	39	103	88	46	279
Declined HIV testing	6	17	81	94	59	257
Transferred out to another facility	63	213	528	592	361	1757

Note: Some children were lost to follow-up because the mother was either lost to follow-up or the mother had died.

4 | Discussion

Using the cICT approach, over 87% of women enrolled in HIV care in a routine programme setting were offered screening, identifying that ~25% had children with unknown HIV status, representing over 39,000 untested children. Although multiple studies have estimated that roughly one-quarter to one-half of children exposed to HIV remain untested, this is the first study we are aware of that has identified and clearly documented how many perinatally HIV-exposed children remain untested in Malawi [14, 19, 28–34]. cICT implementation had a broad reach, was highly acceptable and feasible, easily integrated into routine service delivery across a range of facilities, and facilitated efficient identification and testing of most children. At study conclusion, 8232 children remained untested. With an HIV positivity rate of 1.7% in this cohort, about 140 CLHIV remain undiagnosed—a number considerably smaller and easier to target for HIV testing efforts compared to the initial 193,402. Notably, cICT

use continued despite implementation during an extraordinarily challenging period with multiple COVID surges when WLHIV were receiving multi-month refills and accessing facilities less frequently. The tool is still in use at all facilities, demonstrating sustainability.

cICT functions not merely as a record-keeping instrument but as a mechanism to integrate paediatric testing within maternal ART care, indicating its potential utility in countries with substantial adult-child treatment gaps like Zimbabwe, Zambia and Tanzania, where >93% of women are on ART and child ART coverage averages only 63–70% [35, 36]. The approach is straightforward: (1) define the cohort of women with untested children; (2) implement cICT to identify untested children and facilitate testing status review at each maternal visit; and (3) follow over time until all are tested. This ensures comprehensive coverage, enhances efficiency and eliminates the need for separate paediatric follow-up, as it is embedded within maternal care, allowing

identification of children who had missed testing through other modalities.

Over the course of 3 years, the cICT approach facilitated HIV status ascertainment of 28,808 children with unknown status, with an HIV testing yield of 1.7%, a high yield among a population with low prevalence (0.9–1.5%), and higher than paediatric testing yields of 0.5–0.6% documented in similar settings in Zimbabwe and Kenya [19, 29, 31, 32, 37–40]. Most notably, nearly three-quarters of previously untested children in this cohort had a documented HIV status by study conclusion, demonstrating that this practical approach can be implemented in various settings and is useful for identifying older children. This is consistent with findings from other studies assessing family mapping approaches in sub-Saharan Africa that have demonstrated promising feasibility and acceptability, and improved identification of child contacts of PLHIV when using tools to map family relationships [27, 41–44]. Unlike previous studies, however, embedding paediatric follow-up within maternal care promotes sustainability as demonstrated by ongoing implementation, endorsement of the cICT tool by the Malawi national programme and adoption by various stakeholders.

4.1 | Limitations

This study has several limitations. Our findings may not be generalizable to countries with lower ART coverage, but testing in these settings would improve external validity and provide insights into cICT's potential impact in countries with varied treatment gaps. The descriptive design limits causal inference. Detailed client-level visit data, including the number and timing of visits per woman, were not recorded in the database, restricting our ability to assess the timeframe for testing completion. Loss to follow-up, client mobility (transfers to other facilities) and deaths hindered our ability to verify the status of some children. Despite these limitations, our study reflects the real-world circumstances faced by ICT implementation and can inform future efforts aimed at closing paediatric ART gaps.

5 | Conclusions

Despite mature HIV programming in Malawi, many perinatally HIV-exposed children remain untested. The cICT approach offers an effective solution. This method is straightforward to implement, integrates sustainably into existing ART programmes and focuses on women accessing HIV services to enhance identification of vulnerable children missed by EMTCT programmes. A key strength of cICT is routine reminders within mothers' medical records, ensuring systematic HIV testing follow-up for their children. By identifying women in care with untested children, cICT supports comprehensive follow-up for a defined cohort needing testing. As part of a comprehensive paediatric case finding approach, cICT can effectively identify and link untested children throughout Malawi and other sub-Saharan African countries with large paediatric care gaps, where the vast majority of the 600,000 CLHIV globally reside.

Author Contributions

KRS and SA conceptualized and designed the study. KRS, EK, RM and LH led the investigation and project administration. AK, EW and SM curated data, performed the analysis and contributed to data interpretation. KRS, SM and SA majorly contributed to manuscript writing and critical revisions, and DV supported review and editing. MHK, BEOB, TAT, RN, SM, CMC, KN and BC provided methodological oversight and assisted in the final review. All authors reviewed and approved the final manuscript.

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Conflicts of Interest

The authors declare that they have no conflicts of interest.

Disclaimer

The contents of this article are the responsibility of the authors and do not necessarily reflect the views of the funders.

Data Availability Statement

The data supporting the findings of this study are available from the corresponding author upon reasonable request.

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