

Care as repair, but whose responsibility? Front-line health workers' resourcefulness in implementing a PMTCT tracing policy in Kenya

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ABSTRACT

Defaulter tracing policies for Prevention of Mother-to-Child Transmission (PMTCT) services are vital for achieving the global goal of zero new HIV infections. However, little is known about their implementation. This qualitative study explores the role of tracers—community volunteers, retention workers, and mentor mothers—in implementing such policy across six facilities in Western Kenya. It uses the conceptual lens of 'repair work' to unveil their 'everyday work in keeping systems going' ensuring care delivery to women and their infants. Data were collected through 31 semi-structured interviews with tracers and PMTCT managers, observations, document reviews, and analyzed using thematic network analysis. Our findings reveal significant variability in policy implementation, influenced by integration of PMTCT services to maternal and child health clinics and facility resources. Tracing and retaining women in PMTCT care heavily relied on tracers' adaptive strategies and ingenuity to compensate – through repair work – for systemic shortcomings, resulting in the delivery of differentiated, person-centered care using social networks, personal funds and improvisations. Key challenges included inadequate remuneration, lack of institutional resources and support, and insufficient information and evaluation systems. Our results highlight the social nature of health systems and demonstrate the relevance of 'repair work' for health systems research, used in our paper to unveil the often-unrecognized efforts of tracers in maintaining PMTCT care continuity. To ensure sustainable and effective translation of policy into practice, policymakers, donors and program managers must allocate sufficient resources, and provide formal employment to tracers rather than relying on repair work to keep systems going.

1. Introduction

"I think those were innovations that the healthcare staff developed themselves to ensure services were not interrupted. However, the reason they haven't been institutionalized is that we cannot create a policy that imposes the burden of providing services on someone who has not been

contractually engaged to do so." (Key informant, NASCOP, Ministry of Health)

Trained mentor mothers, who are peers living with HIV, have played a pivotal role in Kenya's efforts to end pediatric AIDS and eliminate vertical HIV transmission, commonly referred to as mother-to-child transmission (Helova et al., 2021; Ministry of Health, National AIDS

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and STI Control Council, 2023; Ligami, 2023). The Kenyan HIV response, particularly in the prevention of mother-to-child transmission (PMTCT) care, relies heavily on community and lay cadres including community health volunteers (CHVs) and mentor mothers for identification, linkage, and retention in care (Ministry of Health, National AIDS and STI Control Council, 2023). This approach and keeping women enrolled in PMTCT care on lifelong antiretroviral treatment (Option B+) significantly increased the uptake of early infant diagnosis between 2015 and 2022 from 56 % to over 98 % (Joint United Nations Programme on HIV/AIDS, 2023).

In East and Southern Africa however, one of the key challenges to achieving the global goal of zero new HIV infections, is women dropping out of PMTCT care, which accounts for nearly one-third of all new HIV infections in children in the region (Joint United Nations Programme on HIV/AIDS, 2023). When women cease adherence to antiretroviral treatment, the risk of vertical transmission increases up to 49 %, why tracing of mother-infant pairs who miss scheduled visits is a key component of retention and successful PMTCT care programs, ensuring the well-being of pregnant and postpartum women living with HIV and their infants (Fernández-Luis et al., 2019; Sellers et al., 2015). This is also referred to as defaulter tracing and usually done via phone calls and home visits.

In low-resource settings, such as Kenya, tracing is commonly carried out by lay cadres, sometimes in collaboration with community organizations and representatives (Joint United Nations Programme on HIV/AIDS, 2024). Lay cadres who serves as PMTCT tracers are typically retention workers, CHVs, or mentor mothers, who serve as vital links between health clinics and communities (Marcos et al., 2012; Cataldo et al., 2018). They have proved invaluable human resources for health, instilling confidence in healthcare services and minimizing stigma (Vogt et al., 2015; Lunsford et al., 2015; Murray et al., 2015), by leveraging their deep understanding of the communities they serve and through their lived experiences (Olaniran et al., 2017).

While previous studies in Kenya have explored combination interventions to improve PMTCT outcomes, such as defaulter tracing, mobile health (mHealth), and enhanced adherence and psychosocial support (Odhiambo et al., 2024; Finocchiaro-Kessler et al., 2021; Kanyuuru et al., 2015; Fayorsey et al., 2019a; Larson et al., 2023; Dicarolo et al., 2018; Njoroge et al., 2017; Odeny et al., 2019), as well as outcomes of tracing policies and programs (Rachlis et al., 2015; Thomson et al., 2011), there is a paucity of research on the processes of implementing the policy. Exploring policy implementation in action provides valuable insights into how a policy is adopted, the fidelity to its guidelines, and the overall sustainability and feasibility of the policy (Peters et al., 2013).

In this paper, we investigate the role of both PMTCT tracers and managers in implementing national defaulter tracing policy across six health facilities in Western Kenya. Using the theoretical lens of “repair work” described below, we explore their adaptation and resourcefulness as they navigate the interplay of policies, guidelines, stakeholders, and resource scarcity. Extending the work of Vernooij et al (Vernooij et al., 2022). and Livingston (Livingston, 2012), we critically discuss the ‘politics of repair’ and the gap between policy and practice, questioning whose responsibility it is exactly. Such information is critical to better understand how healthcare workers navigate policy changes, including adaptive strategies they may use to ensure continuity and quality of care in complex and changing systems.

1.1. PMTCT care provision in Kenya

PMTCT care in Kenya is a collaborative effort involving the Ministry of Health (MoH), external donors, and implementing partners. National guidelines and plans are developed by the National AIDS Control Council and National AIDS and STI Control Program (NAS COP) and are updated to reflect global policy changes and socioeconomic shifts at both national and global levels (National AIDS Control Council, 2021a).

Funding relies heavily on international donors, who covered 69 % of expenditures in 2018/2019, down slightly from 72 % in 2016/2017, while the government contributed 24 % (Health Policy Plus, 2022). However, the share of county government spending within overall government funding rose from 32 % to 38 % during the same period (Health Policy Plus, 2022).

Mentor mothers and tracing are part of a broader package of changes to the Kenyan PMTCT landscape during the last decade. Option B+ was introduced in 2014 (Ministry of Health Kenya, National AIDS and STI Control Council, 2014) and following the devolution of healthcare to county governments, PMTCT care was integrated into maternal and child health (MCH) clinics between 2015 and 2017. Previously, services were provided through comprehensive care clinics (CCC) dedicated to all people living with HIV (Ministry of Health Kenya, National AIDS and STI Control Council, 2016). From 2016 donors pushed county governments to gradually take over PMTCT services and implement differentiated care models for long-term sustainability (Ministry of Health Kenya, National AIDS and STI Control Council, 2016; PEPFAR, 2016). In 2020–2021, a people-centered care approach was adopted to further progress towards zero new infections (PEPFAR, 2020; National AIDS Control Council, 2021b).

The Kenyan defaulter tracing policy, introduced in 2012 as part of the mentor mother program (Ministry of Health Kenya, National AIDS and STI Control Council, 2012) and further supported by standardized tools and mechanisms in 2016, was emphasized as a critical strategy to enhance retention and adherence in PMTCT (Ministry of Health Kenya, National AIDS and STI Control Council, 2016). Upon a woman’s initiation into PMTCT care, her contact information is recorded, and she is asked to consent to tracing via phone and/or home visits. Tracing begins when a woman misses a scheduled visit. Mentor mothers use diaries and client logbooks to identify these women and should contact them via phone or SMS within 72 h of a missed visit. If there is no response or no-show after seven days, a community health worker (such as mentor mothers or retention workers) is tasked with home tracing, filling out a home visit report detailing the outcome (Ministry of Health Kenya, National AIDS and STI Control Council, 2016). Contact with the women should involve counselling, assessment of adherence and readiness for lifelong antiretroviral treatment, addressing social or medical concerns, and evaluating existing support systems, including the need for linkage to community or facility-based support such as income-generating activities or support groups.

1.2. Conceptual framework: repair work

Inspired by Henke (2000), we take ‘repair work’ to refer to the everyday adjustments, fixes, and improvisations healthcare workers undertake to navigate and mitigate challenges, using in-the-moment judgment and available materials and resources (Henke, 2000). This heightens our attention to the adaptive strategies employed by healthcare workers, emphasizing their informal and often unrecognized efforts to ensure patients receive care despite systemic barriers and complexities (Vernooij et al., 2022). The concept also helps us understand the resilience and adaptability of healthcare systems in low-resource settings including in Kenya (Vernooij et al., 2022). Health systems are viewed as complex socio-technical entities where acts of repair and maintenance are constant and necessary to keep them functional (Jackson, 2013). In this context, repair work explores the critical role people play amid systemic inadequacies and resource limitations, using resourcefulness and improvisation, also referred to by Mol as ‘tinkering’ (Mol, 2008). It draws on the work of ethnographic scholars to highlight the gap between established policies and the socio-material realities in care settings, which necessitate improvisation in delivering these policies (Livingston, 2012; Wendland, 2010), through human labour and ingenuity (Graham and Thrift, 2007).

In line with Mol (2008), we approach care practices as shared work between human and non-human actors, such as cell phones, food, and

income-generating activities. Care practices are socially shared and locally situated (Baszanger and Dodier, 2004), varying according to context, actors, materials, and situations, but informed by frameworks and protocols (Jaffré and Suh, 2016). This creates variability in care practices, such as defaulter tracing, guided by a 'logic of care': what is appropriate or logical in a particular situation or setting (Mol, 2008).

While repair studies highlight the importance of human improvisation (Henke, 2000; Suchman, 1987), we, along with Vernooij et al. (2022), argue that repair work should be understood as a 'relationship of responsibility for the care of others'. We adopt Tronto's (1993) definition of care as 'activities we do to maintain, continue, and repair our world so that we may live in it as well as possible,' viewing care as both a practice and a disposition, always based on the needs of others (Tronto, 1993). Furthermore, we take a critical post-colonial stance, questioning whose burden it is to 'keep systems going' and at what ethical, social, financial, and physical cost.

2. Methods

This research is part of a larger qualitative study exploring care engagement for PMTCT in Western Kenya, aiming to understand policy implementation at multiple levels of the health system. It was nested within the broader WelTel PMTCT trial which took place between 2015 and 2019 to evaluate the effect of an mHealth intervention on retention in PMTCT care and has been described elsewhere (Nordberg et al., 2023). Additional qualitative data were also collected to explore the social realities of women who drop in and out of PMTCT care despite continuous tracing efforts (Submitted for publication). For this paper, we explore implementation of the defaulter tracing policy as it unfolded at six facilities across four counties in Western Kenya, from the perspectives of tracers and PMTCT management. We use the Consolidated Framework for Reporting Qualitative Research (COREQ) (Tong et al., 2007) to report methods and findings.

2.1. Structural context

PMTCT care at the participating facilities was offered through the implementing partner Academic Model Providing Access to Health Care (AMPATH) in cooperation with the MoH via county governments. Before service integration in 2015, AMPATH, funded by the President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID), managed PMTCT care, but during the study period, services were largely integrated into maternal and child health clinics (Berlacher et al., 2021). These clinics run by the MoH, with technical support and extra staff from AMPATH, offered care through a team of PMTCT nurses, clinical officers, mentor mothers, psychosocial workers, and volunteers. Retention-focused services included adherence counselling, financial, and psychosocial support for vulnerable populations, support groups, assisted disclosure, and defaulter tracing.

Defaulter tracing followed national policy and AMPATH standard operating procedures with mentor mothers attempting phone contact within 24 h of a missed visit and. If unsuccessful after four calls in seven days, cases were referred to home tracing by retention workers or CHVs. At one facility a community health extension worker (trained nurse), coordinated and trained the CHVs, all these actors are collectively referred to as 'tracers' in the paper. Compensation varied with mentor mothers, employed by AMPATH, receiving 10,000 – 15,000 KSH monthly ($\approx$ 77–116 USD), while CHVs and retention workers received minor stipends no or performance-based remuneration depending on whether AMPATH or MoH employed them. Tracers received continuous training, used public transportation or walked for home visits and made phone calls with clinic or private phones and airtime. Initially PMTCT managers at AMPATH oversaw services, including mentor mothers, defaulter tracing, and outreach, but as MoH took on greater responsibility, some roles at AMPATH restructured, leading to role

mergers and task shifting during the study period. The mentor mother program remained under AMPATH.

2.2. Sampling and recruitment

Facilities were selected in collaboration with AMPATH, based on their participation in the WelTel PMTCT trial. Catering for a mix of urban, peri-urban and rural populations, participating facilities comprised four sub-county level hospitals, one national referral hospital and one health centre, three within Uasin Gishu county (Fig. 1). For the semi-structured interviews, we used purposive sampling ensuring broad representation from all facilities and counties. Respondents additionally needed at least one year of experience as PMTCT managers or tracers.

We first approached tracers at the facilities to gain insights into defaulter tracing policy implementation, followed by PMTCT managers from AMPATH, NASCOP or county governments to understand the broader structures and systems. Participants were identified by the first author and the study coordinator and approached in person or by phone. Of the 21 tracers approached, two declined due to lack of interest; of the 14 managers, two declined due to lack of time. Most were female and had worked in their positions for 2–5 years.

2.3. Data collection

The first author spent 7 months in Kenya between March 2016 and September 2018, conducting three rounds of non-participant observations (average 4 h) at the participating facilities to understand PMTCT care structures, daily activities, and interactions between women in care and providers. Informal conversations helped build rapport and contextual understanding of the setting and culture. A total of 31 interviews were conducted: 19 semi-structured interviews with tracers (May - June 2017) and 12 key informant interviews with PMTCT management (September 2017, with two in March 2018) (Fig. 1). Except for one interview held at the respondent's home after work hours upon her request, all interviews took place during work hours, in a location preferred by the participants, either inside or outside health facilities, in private offices, or the study office. Interviews conducted in English (one in Swahili with a translator) following verbal and written consent lasted 39–105 min (tracers) and 19–72 min (PMTCT managers), and were audio recorded. Participants received 150 Kenyan shillings ($\approx$ 1.37 USD) for their participation. Questions to tracers explored their tracing experiences, perceptions of the women they traced and their interaction, challenges and opportunities, and defaulter tracing as a retention strategy. Questions to managers explored PMTCT service organization, integration and management. Policy documents, standard operation procedures, data collection tools and reports were reviewed as complementary sources and some questions to respondents arose from them or concerned their operationalization.

2.4. Data processing and analysis

The first author, KDA, wrote notes and summaries promptly after each observation and interview, which were transcribed verbatim and translated to English where necessary, followed by quality checks by the first and second author (and interpreter). We analyzed data using an iterative approach to thematic network analysis (Attride-Stirling, 2001), coded both inductively and deductively using NVivo 14 (Lumivero, 2023). Notes and transcripts were read multiple times for familiarization, followed by inductive coding and exploration of emerging patterns and themes. After two rounds of coding, we identified "Repair work" (Vernooij et al., 2022) as a fitting theoretical lens, highlighting the resourcefulness of tracers in accommodating tracing policy to provide care through innovation, tinkering, and adaptation. Our coding was thus restructured deductively into five organizing themes, all corresponding to types of "repair work" tracers in our study would engage in to implement the policy: Interpersonal Work, Resourceful Work,

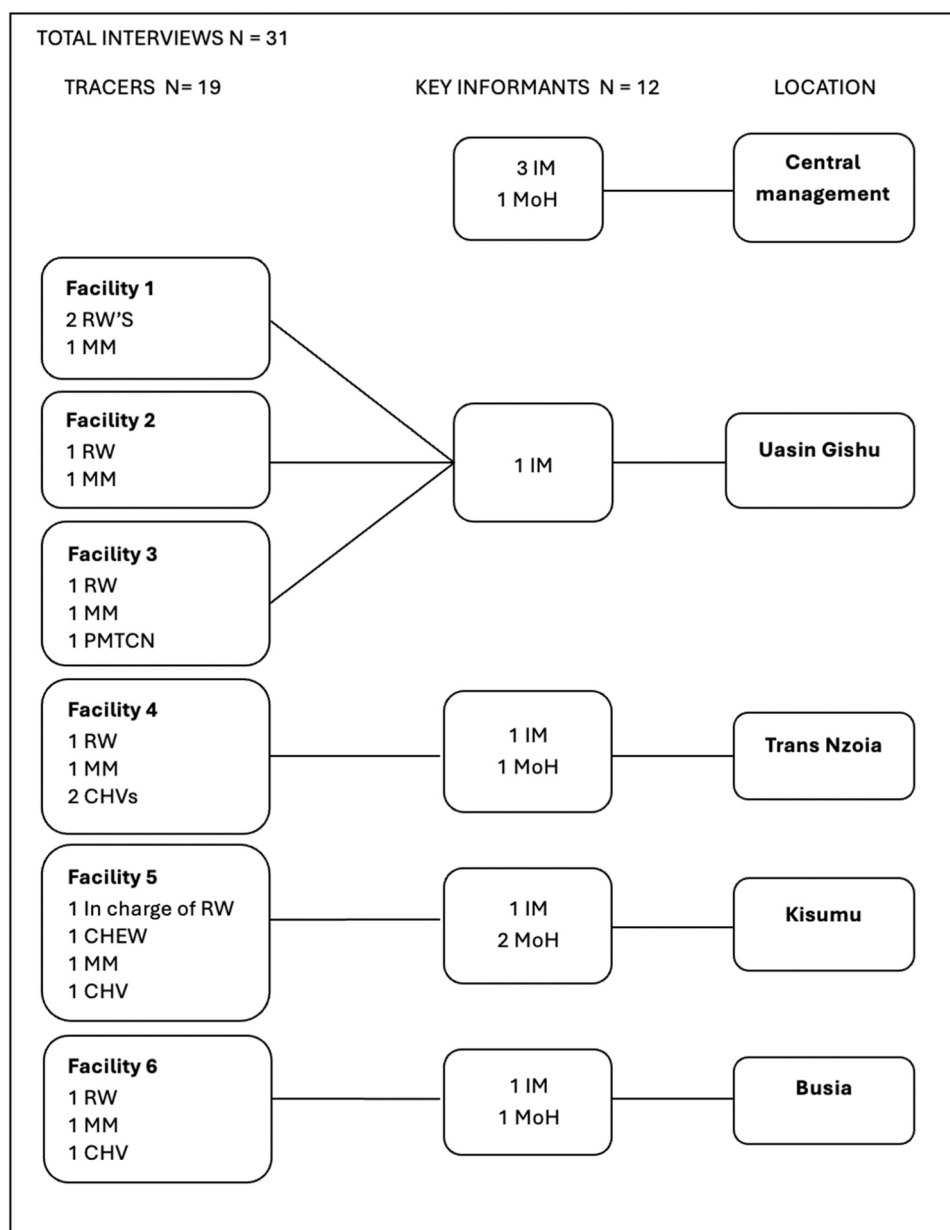


Fig. 1. Overview of semi-structured interviews with tracers and key informants. CHEW = community health extension worker, CHV = community health volunteer, IM = implementing partner, MM = mentor mothers, MOH = ministry of health, PMTCTN= PMTCT nurse, RW= retention worker.

Collaborative Work, Innovation work, Evaluative Work, and one global theme: Repair Work: optimizing what you can with what you have (Table 1).

Data was co-analyzed independently by the first and second author, SS, who deliberated on their findings, which were shared and discussed with two senior social scientists, MS and AK, adding breadth to the final analysis. We used Table 1 to offer a structure for the analysis we present in our results, illustrated in a thematic network (Fig. 2).

2.5. Reflexivity and ethics

The first author and interviewer, a mother and cis woman of Latin American origin with intermediate knowledge of Swahili, is a social scientist and qualitative researcher with many years of experience in sexual and reproductive health and rights. Mindful of her position, KDA approached this research humbly, presenting herself to participants as a PhD student curious to learn and collaborate in exploring ways of

strengthening PMTCT care provision. Throughout the research, positionality was addressed through self-reflexivity, note-taking (Denzin and Lincoln, 2005; Pillow, 2003) and discussions within the research team about methodology and findings. Informal conversations, observations, document reviews and interviews were triangulated to understand the implementation of defaulter tracing comprehensively and to build rapport with staff at the participating facilities. Half of the respondents were known to the first author prior to the interviews, who did her best not to disturb routine care during her observations and interviews. Member checking through sharing preliminary analysis results was done with a random sample of 10 % due to practical constraints, and findings presented and discussed in a workshop with the implementing partner and representatives from MoH.

All procedures were performed in compliance with relevant laws and institutional guidelines and privacy rights of human subjects have been observed. The research was approved by the Institutional Research and Ethics Committee at Moi University, School of Medicine, Eldoret, Kenya

Table 1
Thematic network of basic and organizing themes.

Basic themes	Organizing themes	Global theme
– Demonstrating compassion and understanding through language and actions – Acknowledging that everyone is unique and responding to that uniqueness – Exercising patience – Knowledge-transfer from tracers to clients – Providing clients with a language to express themselves and communicate in discretion with tracers – Maintaining confidentiality through professionalism and integrity – Tracing of clients from caring – Creating rapport with clients by making yourself known and familiarizing yourself with their realities – Giving clients time to accept living with HIV – Using social skills – Using own money – Using private time – Sharing own food – Being motivated to trace by peer experience – Accompanying clients to clinic – Finding income generating activities for clients – Tracers give their private phone numbers – Sharing own personal stories and own experience of living with HIV to motivate and empower clients – Shifting tasks around to manage scarcity and optimizing client care – Lacking resources (training, airtime, funds for transport) – Changing SOPs to optimize client care engagement – Operationalization of policy as a team and according to available resources – Engaging clients in care is a team effort customized to individual client's needs – Creating youth friendly services – Initiating targeted support groups – Developing community interventions – Exploring income generating activities – Assisted disclosure – WhatsApp group to discuss individual cases beyond facility level – Mentor mothers to trace – Ownership created through facility specific data monitoring – Interpretation of indicators and forms is not consistent	1. Interpersonal work: tracing through skills, counselling, and in-the-moment judgment 2. Resourceful work: capitalizing on personal experience, drive, funds, and time to trace clients 3. Collaborative work: managing facility resource constraints response 4. Innovation work: tailoring innovations to client needs 5. Evaluative work: tracing efforts through data capture	Repair work: optimizing what you can with what you have

Table 1 (continued)

Basic themes	Organizing themes	Global theme
– Mentor mother data capture may cause reporting fatigue and constitute a missed opportunity for evaluation – No standard measurement of data because data is not captured similarly across all sites		

(FAN;IREC 1292), and the Regional Ethics Review Board, Stockholm, Sweden (2018/742–31/1).

3. RESULTS

Our analysis revealed that the six participating facilities had varied structural setups and systems in place for tracing, each representing unique cases. Our results provide a brief overview of the facility specific tracing practices (Table 2), before presenting similarities in the ‘everyday work involved in keeping systems going’ (Vernooij et al., 2022) that cut across all participating facilities. We then proceed with interrogating each “repair work” theme that we identified during the analysis, using illustrating quotes.

3.1. Facility-specific tracing practices

While defaulter tracing policy and guidelines were similar across the six facilities, implementation after the integration of PMTCT services into MCH varied based on available resources and facility setups (see Table 2). Facilities integrated at different times and paces between 2015 and 2017, and the use of mentor mother defaulter tracing logbooks, capturing tracing incidents cross-sectionally, only started in 2016. Using their diaries for identification, mentor mothers at three facilities reported calling the same day a mother missed her visit. The remaining three facilities called the following day.

Most facilities used outreach teams from regular CCC to perform home tracing. Facility 1 experimentally started home tracing by mentor mothers only two months prior to the interviews, no home tracing was performed before this. Facilities also differed in whether CHVs or retention workers were the first choice to perform home tracing.

3.2. ‘Everyday work involved in keeping systems going’

According to the respondents, women traced had diverse and intersecting identities. They were predominantly younger, recently diagnosed, living in serodiscordant relationships, or single mothers. Most were of low socio-economic status, had limited education, and faced unstable family circumstances. Married women often depended on their husbands or in-laws, some moved between family members, while others dealt with mental illness, substance abuse, and a few held strong religious beliefs or believed in witchcraft. Many women had no help with childcare, making clinic visits difficult.

Respondents noted that women often defaulted after the child stopped breastfeeding, completed the vaccination schedule, following the child’s first negative HIV test, or upon transfer to CCC. A significant challenge in tracing was incorrect contact information provided by women due to status denial or fear of stigma. According to tracers, the long walks to the clinic, waiting for hours without food, encountering stressed and unempathetic staff, led to defaulting despite subsequent tracing efforts. Respondents emphasized that especially clients who were accustomed to food support from previous HIV care programs were dissatisfied to return home without food for their families.

Below are repair work strategies utilized by tracers to retain women in care, illustrated in Fig. 2.

Table 2

Facility specific tracing practices and definitions.

	Outreach program	Missed visit	Defaulter	LTFU	N call attempts when client miss clinic (when/who)	Home visits (when/who)	Funding for front-line workers
Facility 1	None-existent since integration in 2015.	< 7 days missed appointment > 7 days "no show"	> 1 month	> 3 months	MMs call the same day (4 attempts/7 days)	Non-existent since 2015MMs experimentally home trace > 7 days since May 2017.	MMs given stipend, phones & airtime. Airtime not always available for extended periods, and some phones inactive. Sometimes use own fundsWhen MM trace physically they are given transport and lunch. No access to a vehicle
Facility 2	Outreach from CCC	< 7 days	> 1 month	> 3 months	MMs call same day (4–10 attempts /week) and send SMS	RWs > 7 daysMay visit 3–4 times before the patient return	MMs given stipend, a phone & airtime. Airtime not always available, once it was lost for 1 month. Since MoH took over provision is unstable. Sometimes use own fundsRWs paid, given airtime & transport monthly. No access to a vehicle
Facility 3	Outreach from CCC	< 1 month> 7 days missed opportunity	Inconsistent> 1 month> 3 months	N/A	MMs call the next day (3 attempts/ consequently for3 days). Sometimes nurse calls, outreach will also try to callIf a woman says she will come the next day, and she does not show up you call and then home trace	RW > 4 days up to a monthSometimes MMs, PMTCN and social worker go together	MMs given stipend, a phone & airtime. Sometimes the airtime is not enough, and they use own fundsRWs paid, given funds for public transport or a motorbikeSocial worker has access to a vehicle (ambulance)
Facility 4	Outreach from CCC in liaison with CHVs from 4 different health programs	< 7 days	> 7 days	> 3 months	MMs call the next day (up to 5 attempts/7 days)	CHVs > 7 days. Sometimes RWs go if there is no CHV in the area and RW have airtime. It may take additional 7 days to initiate tracing for RWs, but 2 for CHVs	MMs given a stipend, phone and airtime. Airtime not always available. Once it was lost for 1 month. Sometimes use own fundsCHVs under AMPATH use own funds (transport, phone, materials). Sometimes given transport and airtime. In-kinds from clients they trace.RWs paid, given funds for transport or a motorbike, but not always provided. Social worker has access to a vehicle
Facility 5	Joint outreach program for CCC and maternal and child health	< 7 days	> 1 month	> 3 months	MMs call same day (2–3 attempts/7 days)	CHVs or CHEW > 7 days but may delay up to a week or longer due to workload. CHVs only trace within their own unitMMs experimentally visit women with mental issues or notorious defaulters	MMs given stipend, a phone and airtime. Use own funds for home tracing and sometimes for callsCHEW and CHVs use own funds (transport, phone, materials). Some CHV's are given a 2000 KSH stipend since MoH took over. In-kinds from clients they traceRWs paid, have access to a vehicle.
Facility 6	Joint outreach program for CCC and maternal and child health	< 7 days	Inconsistent > 7 days> 3 months	> 3 months	MMs call the next day (3 attempts/consequently for 3 days).	RWs trace as default when there is funds, > 7 days, and prioritise vulnerable casesIf no funds or workload is high CHVs will trace, 2 weeks a month. May visit 4–5 times before the client returns	MMs given a stipend, phone & airtime. Sometimes use own fundsCHVs use own funds (transport, phone, materials). In-kinds from clients they traceRWs paid, given funds for public transport & airtime, but not always available. No access to a vehicle. Sometimes use own funds

AMPATH = Academic Model Providing Access to Healthcare, CCC= comprehensive care clinics (for HIV care), CHEW = Community health extension worker, CHV = community health volunteer, KSH = Kenyan shillings, LTFU = Lost to Follow up, MM = mentor mothers, MoH = Ministry of Health, RW= retention worker

3.2.1. Interpersonal work

Interpersonal work was essential for successful tracing. Tracers described how women would prefer familiar faces and encountering an unknown person at their door could feel intrusive and raise concerns of breached confidentiality. As such, many tracers believed that mentor

mothers were better equipped for home tracing – even though this was not part of their job description. Mentor mothers were only responsible for stigma reduction and adherence counselling at the MCH clinics. To get around this, retention workers tried to establish familiarity with clients before tracing them, such as through visiting support group or

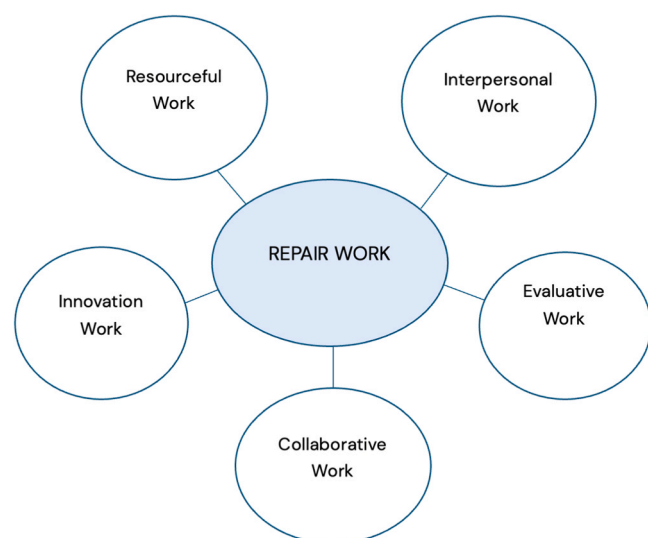


Fig. 2. Thematic network illustrating the ‘repair work’ strategies employed by tracers implementing PMTCT defaulter tracing policy at the six participating health facilities.

collecting clients’ locator information. CHVs utilized their continuous community presence and primarily traced within their communities (Facilities 4–6), where their volunteer roles in PMTCT, water, sanitation, hygiene and family planning were well-known.

“Okay, for me like I had told you earlier that when I go to a homestead, I look at so many things. I look at the hygiene and everything. So, they might not have any bad feeling for me because when I go there, they don’t know the specific reason for why I am there” (Community Health Extension Worker, Facility 5)

Tracers described how they built rapport during home visits by situationally adapting their language and approach to gain the client’s confidence and trust. Some tracers living with HIV stated that disclosing their own HIV status could be a useful strategy. If others were present, they would use in-the-moment judgement and could pose as a social visitor. Clients could also signal tracers to stay away through body language, pulling them aside and requesting a later visit. Tracers sometimes provided their private phone numbers and asked clients to give them a ‘missed call’ during a time convenient for them.

“If I find the first contact is a relative or a neighbor, then I will introduce myself to be a church member or a friend or a school mate so that I make sure I don’t alert. Because if... You know stigma is still there. So, if I make a mistake of saying something suspicious then I will never reach that person. I will never attain what I wanted.” (Retention Worker Facility 2)

As a retention strategy, some tracers described how they would give their clients priority treatment upon return to the clinic, such as letting them skip the queue. Mentor mothers also offered lengthy counselling to help women navigate challenges to attending their visits, often in liaison with a social worker. Allowing clients time to accept their HIV status was mentioned by respondents to be key in preventing tracing in the first place. They emphasized how many women enrolled in PMTCT needed time to adjust and more extensive counselling, which was often unfeasible due to understaffing and crowded facilities.

“I think the best thing that should be done is the time taken to take this mother through the counselling session at initial stage... I think it is because of the workload. People are really busy, we want to finish the queue but I think if we just have time at the initial stage then the rate of retention will be high.” (Retention Worker, Facility 4)

Another aspect of tracing, requiring interpersonal work was safety concerns during home tracing, which often involved entering unsafe

slum areas without debriefing or safety measures. In-the-moment judgment was critical in hostile situations and several tracers reported being chased with a panga (machete) by clients or their husbands. One CHV even reported facing disdain when visiting households of wealthy clients.

“At times you go to the field, you meet somebody who is chasing you with a panga [machete]...it is risky, it is trauma. You pass through things that even you yourself, you cannot sleep after.” (Retention Worker 1, Facility 1)

3.2.2. Resourceful work

Our analysis further revealed how understaffing, the volunteer nature of the work, low salaries, and MoH staff strikes, necessitated tracers to be resourceful. Many tracers were living with HIV and poor single mothers with young children themselves, struggling to pay school fees as the sole providers for their households. While respondents noted this had led both mentor mothers and CHVs colleagues to quit their jobs, many tracers said they continued their work with pride despite the struggles they faced, such as having to use their own funds to cover transport costs and phone calls during tracing. Some CHVs even made ends meet through in-kind appreciations from clients they traced, such as chickens or vegetables, illustrated by this quote from a CHV describing how a woman reacted to her home visit:

“Fruits, veggies. Sister, don’t go, let me give you something. Oh, let me give you eggs, hen, you go and eat. Hey, you really care for us.” (CHV 1, Facility 4)

Tracers expressed frustration about not having anything tangible from the program to support poor women during home visits, such as soap, sugar or flour. In response, tracers showed resourcefulness by using their own funds to offer immediate support to women they traced. This involved sharing their food, providing lunch, generating income by buying their products, covering transport back to the clinic or sourcing discounts from friends on products they would share or use during home tracing of women in care:

“So sometimes you go to like sacrifice yourself and say, if she had cleaned clothes for me, I would have paid her these 300 (Ksh) and sometimes you have to intervene. I do it as a passion, so I sometimes source food from other people to give to women I trace.” (CHV 2, Facility 4)

Tracers’ engagement or motivation often came from personal stories of living with HIV, which drove them to go the ‘extra mile’. All but one respondent described sharing their private phone numbers with women they traced. Some felt that empowering other women in need put their own struggles in perspective, instilling gratitude for what they had, but it was the ability to help their peers and make a difference that fueled their work.

“Yeah, because at the end of the day, these are our people. They are our sisters and our brothers. They are our children. So, when I don’t go, and she fails the regiment, who is going to be blamed? It is me who interacts with her every now and then. So, we just volunteer and go.” (Mentor Mother, Facility 5)

Another source of frustration was tracing women with incorrect locator information in vain. In rural areas, discreetly teaming up with local chiefs helped identify women who lived in the area. However, tracers noted that, this option was not feasible in the slums, where some believed that CHVs familiar with the communities were better suited for tracing women.

3.2.3. Collaborative work

Tracing involved collaboration among several actors, each playing a role in returning clients to clinics. Despite differences in facility structures and setups, tracers across nearly all facilities (Facility 1, 3–6) would task-shift and share resources to ensure clients returned.

Occasionally systems would fail entirely, halting tracing efforts until funds were restored which could be anything from a few weeks to two months (Facility 1 & 4). But, when funds or working hours were limited, retention workers or mentor mothers with airtime or phones could share these with other colleagues to ensure tracing continued despite program funding shortages.

"I can share with the mentor mothers; I can share with the staff at the clinic." (Retention Worker, Facility 2)

The difficult circumstances faced by many clients and reluctance to attend clinics often required tracers to make multiple visits to persuade them to return. This involved customizing their approach to each client's needs. If a CHV could not convince a woman to return, they would get help from more experienced colleagues such as retention outreach workers, a community health nurse, or mentor mothers who had established better relationships with the client. Sometimes, tracing involved a multidisciplinary group effort with various colleagues collectively visiting the client's home.

"We went as a whole team. Social worker was there, nutritionist was there, pharmacist was there, all cadres. We were all there to see where the loophole is." (Mentor Mother, Facility 5)

In complex cases where clients were bedridden or children severely neglected, social workers who had access to vehicles could be contacted to assist with transport to the hospital. However, this type of support did not exist at all facilities:

"There is nothing I could do. I begged the driver if we could carry her, we called the office, I was told no, that is not your responsibility. Your responsibility is to tell the family members and the neighbors if they can bring her to the hospital." (Retention Worker 1, Facility 1)

3.2.4. Innovative work

It also became clear that tracers used innovative strategies to tailor care to the challenges faced by the women they traced, such as initiating income-generating activities already part of other programs at MCH, such as the family planning initiative, or by setting up *chamas* within women's communities. The latter is also referred to as merry-go-rounds where women's groups co-invest and pool savings to give individual women a financial boost to start small-scale businesses:

"The income ensures that they have a garden that they can plant kale, onions, tomatoes. Some also have poultry keeping, some have animal keeping. It is something that they do occasionally. So, whenever somebody has something, they get money, they empower one person. It is working because we have one of the staffs, a health worker, who is going round the groups to sensitize that." (Mentor Mother, Facility 5)

Other innovative techniques to bring women back to care included topic-specific support groups, such as those for women with alcoholism, serodiscordant couples, youth, women with high viral loads, or pairing newly diagnosed individuals with known positives for peer support. Some groups became permanent structures, while others were ad hoc for immediate needs. In Uasin Gishu County, multidisciplinary WhatsApp groups with facility focal persons were created to discuss complex cases and defaulters. At Facility 3, where many women came from slum areas and faced challenges such as alcohol or substance use disorders and engaged in transactional sex, care was brought directly to the communities as an experiment. Mentor mothers also volunteered to send daily SMS reminders to clients with high viral loads:

"Most of those women are HIV positive. They don't come to the clinic; they are not enrolled in care. They give birth to the babies, they don't care. The babies are not immunized, the babies are HIV infected. So, we took services to them and after that, you enroll them." (PMTCT Nurse, Facility 3)

Facilities 1 and 5 both used mentor mothers for home visits. At

Facility 5, mentor mothers decided to home trace vulnerable women with cognitive impairments or mental illness, as they had better rapport and knowledge from their interactions at the clinic. At Facility 1, five mentor mothers rotated to search for defaulting women from the clinic five days a week:

"We haven't had airtime for two months so that is why the number of lost to follow ups went high... the quality improvement team sat down and discussed. They realized that most clients were not there and so they decided to look for funds so that these clients can be traced physically... We rotate like if someone went today, a different person will go tomorrow." (Mentor Mother, Facility 1)

In addition, a management-level respondent from NASCOP mentioned that counties and implementing partners should not limit innovation to the policy. Instead, the defaulter tracing policy document should be seen as a minimum package to implement based on available funding and local capacities. NASCOP embraced PMTCT innovations if they worked, but to make it policy was a process.

3.2.5. Evaluative work

Evaluation of tracing efforts was conducted using the Strengthening Outcomes by Analyzing Results (SOAR) framework, standardized indicators, data quality audits, and analysis of data in electronic health information systems (DHIS) as required by the Ministry of Health (MoH). AMPATH also performed internal evaluations using their own systems and programs.

Tracers, CHVs, mentor mothers, and retention workers alike, described how evaluation of their tracing efforts was appreciated, but there were various challenges. They observed how clients were at higher risk of defaulting when transitioning from PMTCT to CCC, and the lack of a formal protocol for this process. Respondents agreed on the need for structural support during this transition and to wean clients off PMTCT care as CCC care was perceived as less holistic, with longer lines and separate management of mother and child.

"They might default after being transferred from the PMTCT, they should be prepared actually. I don't know how they do it, but they should be prepared psychologically that now they are going to the CCC, it is like now we are going to the world out there." (Retention Worker, Facility 4)

Evaluation systems for defaulter tracing relied on manual data capture by mentor mothers with logbooks lacking longitudinal tracking for individual women, making data transfer to CCCs problematic. Consequently, tracing of women in CCCs was attempted when they had already transferred to other facilities or were lost to follow-up during their time in PMTCT care. Handwritten data could be out-of-date, difficult to access, and prone to misinterpretations, contrary to CCCs which used electronic data capture.

"The fact that they are not able to follow them up well is that the systems in the CCCs are not the same systems as in PMTCT. So, it is not like the way we can go to the computer and like search for high viral load, look for no-show in the computer, you will not find them in the PMTCT." (CHV 2, Facility 4)

Respondents highlighted how frequent changes in funding, programs and interventions disrupted the link between implementation and evaluation, as well as increased women's risk of defaulting. Structural changes confused clients, while tracers faced challenges such as inconsistent remuneration and frequent introduction of new tools, leading to varied interpretation of indicators and data.

"Another program come with its own interventions, AMPATH has its own interventions, the government itself has its own interventions, so they get mixed up." (Retention Worker, Facility 6)

Despite these challenges, respondents noted how facility-specific performance evaluations gave tracers ownership, but also frustration when data was underutilized due to poor quality or lack of managerial

efforts. Respondents further complained that limited evaluation, coupled with transition of PMTCT ownership to county governments, hindered consistent remuneration of volunteers and mentor mothers, and constrained scaling innovations and effective task-shifting within and beyond the program.

“So, what has been worked on now is like having a scheme of service for mentor mothers and community health volunteers and the reason for this is even to give like a mandate for the counties to be obliged to employ them.” (Key Informant, NASCOP, MoH)

4. Discussion

We set out to explore the early implementation of the Kenyan defaulter tracing policy for PMTCT across six health facilities in Western Kenya. Our findings revealed variability in policy implementation, influenced by the integration of PMTCT services into MCH and the unique resources and contexts of each facility. Persistent challenges described by tracers as well as PMTCT managers included understaffing, inadequate remuneration, resource limitations, women providing incorrect locator information, frequent programmatic changes, and insufficient evaluation of the policy in practice. Successful tracing and re-engagement of women in care thus heavily depended on the tracers' ingenuity, including their use of interpersonal skills, private and facility resources, collaboration among colleagues, and the creation of innovative solutions such as ad hoc support groups, income-generating activities, and multidisciplinary teamwork. Tracers demonstrated adaptability and delivered differentiated, person-centered care by making real-time decisions, while balancing their own lives as caregivers living in poverty. Mentor mothers, who played a critical role in tracing, sometimes engaged in home visits voluntarily or experimentally, beyond standard procedures. We interpreted these strategies as locally tailored practices and forms of 'repair work', used to sustain healthcare delivery for PMTCT through defaulter tracing.

4.1. Repair of a system or systems of repair?

We found that tracing included intricate relations and transactions between cadres of tracers, the women they traced, and the organizations that engaged them in tracing. When the formal systems failed in provision of adequate resources, PMTCT tracing was achieved through constant repair work by economically disadvantaged tracers shouldering the burden of service delivery within their own communities to ensure continuity of care. This brings us to discuss the difference between repair of a system and systems of repair, how it unfolded in our study, and its relevance for the initial creation of the PMTCT tracing policy.

The repair of a system refers to efforts to fix or improve existing structures to function as intended (Livingston, 2012). In contrast, systems of repair involve the creation of parallel, often informal, practices that operate within or alongside the formal health system to address its deficiencies (Livingston, 2012). As observed in our study, tracers can be engaged in both types of repairs. They work to repair the system by filling gaps left by inadequate resources and support, while simultaneously building systems of repair through innovative and collaborative strategies. This dual role highlights the adaptability and creativity required of tracers (as well as other healthcare staff) but also points to the systemic inadequacies that necessitate such repair work in the first place.

To maximize available resources, a respondent from NASCOP highlighted the institution's openness to innovations from implementing partners, noting that formalizing innovations into policy is a gradual process. Several interventions that were later adopted into Kenyan PMTCT defaulter tracing policies (Ministry of Health Kenya, National AIDS and STI Control Council, 2014, 2012) are examples of how innovative forms of repair work have evolved into institutionalized systems

of care. For example, the World Health Organization (WHO) introduced task shifting in 2007 as an innovative solution to address health workforce shortages in HIV care by expanding the roles of lay cadres (World Health Organization, 2008). mHealth technology similarly emerged as an innovative solution to bridge service delivery gaps in HIV care (Goldstein et al., 2023 Jul). Trials conducted in Kenya (Dicarlo et al., 2018; Fayorsey et al., 2019a; Larson et al., 2018; Njoroge et al., 2017; Odeny et al., 2018; Wanga et al., 2019) and across sub-Saharan Africa (Braun et al., 2013; Puchalski Ritchie et al., 2019; Fassinou et al., 2024; Rapaport et al., 2023; Schmitz et al., 2019) to enhance PMTCT policies involving mHealth, mentor mothers and CHVs further demonstrate how repair work and innovations evolve, highlighting the impermanent nature of health systems.

Impermanence and ever evolving innovations are central themes in repair and maintenance studies (Vernooij et al., 2022; Corwin and Gidwani, 2021). Tracers in our study extended mHealth technology and task shifting through use of WhatsApp groups, multi-stakeholder tracing, and initiation of targeted support groups to address client-specific challenges. Such innovations, and the use of in-kinds to ensure successful tracing and return of clients, not only reflect tracers' deep understanding of their local context and the social realities of the communities they serve (Olaniran et al., 2017). Moreover, it highlights the dynamic interactions among human actors, geographic locations, and material technologies in maintaining health systems' continuity (Corwin and Gidwani, 2021). Previous studies on the role of mentor mothers in eliminating mother-to-child transmission (Helova et al., 2021; Ligami, 2023), and the recent policy change to standardize home tracing by mentor mothers (Ministry of Health, National AIDS and STI Control Council, 2023), also reflect ad hoc innovations evolving into systems of repair. This shift appears natural, given that outreach teams were based at CCC, while PMTCT services transitioned to MCH where mentor mothers now oversee counselling and adherence.

That tracers enacted the policy through kinship, repair and based on care needs beyond their own, resulting in differentiated and person-centered care, aligns with Tronto's definition of care (Tronto, 1993). The 'logic of care' (Mol, 2008) employed by tracers, characterized by tinkering, adaptability, and ingenuity, further embodies 'care as repair work'. While tracers went above and beyond, their repair work had limits such as when tracing ceased for weeks due to lack of funds or were challenged by systemic changes when county governments assumed increased responsibility for PMTCT services. This calls attention to power interplays and how the political organization of care governs actions within a health system (Janzen, 1978). Our respondents' calls for integrating tracers into formal service schemes additionally accentuates the question of what is deemed socially legitimate in organization of health systems and who determines this legitimacy.

4.2. Care as repair, but who is responsible?

Repair and maintenance studies emphasize the need to recognize people involved in keeping systems going (Corwin and Gidwani, 2021). Scholars of care ethics, particularly in the context of repair, raise critical questions about responsibility and who bears the burden of addressing systemic gaps (Tronto, 1993; Robinson, 2008).

Our findings reveal that much of this burden falls on tracers (CHVs, mentor mothers and retention outreach workers alike), who assume responsibilities beyond their formal roles, often using personal resources to ensure continuity of care. Despite their efforts, some of our respondents indicated they would cease their work due to poor remuneration; similar to how a study from South Africa found that lack of compensation for tracing led to low motivation (Etoori et al., 2020). The inadequate remuneration of mentor mothers (Rotheram-Borus et al., 2014) and CHVs (Olaniran et al., 2017) has also been reported to jeopardize the feasibility and sustainability of their work. Others have criticized that the majority of unpaid HIV care labor falls disproportionately on women (Newman et al., 2011).

Situations such as the ones described above reflect broader systemic issues where the responsibility for repair and care is implicitly shifted from the state to individual workers. Rather than relying on institutional support and accountability, this system relies on the goodwill and resourcefulness of front-line workers. This raises ethical concerns about the sustainability and equitable distribution of responsibility within health systems. We must ask which power relations are sustained by these norms for care provision (Robinson, 2008), and who will escape their responsibility (Tronto, 1993) while benefiting “*without doing their own work of maintenance and repair*” (Corwin and Gidwani, 2021).

Research shows that continuous training, effective coordination, management, and proper working conditions are essential for successful tracing by lay cadres (Vogt et al., 2015; Lunsford et al., 2015). Stakeholders involved in PMTCT tracing in our study, have addressed some of these concerns through reports, policies and research. AMPATH acknowledges the lack of program evaluation and the challenges in harmonizing dual information systems (Berlacher et al., 2021). PEPFAR has criticized the insufficient national funding for lay cadres, inadequate resources, poor management and monitoring, and ineffective data systems, including their utilization (PEPFAR, 2020). Recent NASCOP guidelines also emphasized the need to review and enhance the tools used for tracing (Ministry of Health, National AIDS and STI Control Council, 2023). Yet, little has changed in practice (AMPATH, personal communication, May 20, 2024) despite the new national guidelines on person-centered care, and even though our data were collected before this policy change.

4.3. Implications for policy and practice

We find that our study holds several implications for policy and practice. First, our findings that front-line tracers deviate from policy and SOPs to ensure care delivery demonstrate a remarkable capacity for ingenuity, empathy and devotion, even utilizing private resources to address challenges in low-resource settings where health workforce and fiscal shortages are common. Some of these innovations, such as using mentor mothers to home trace, have since been scaled to national policy. Further evaluation is needed to assess the potential scalability of other innovations from our study for inclusion in national PMTCT guidelines.

Second, the reliance on tracers' resourcefulness and the informal systems of repair they create raise both ethical and practical concerns regarding sustainability. In highly donor-dependent countries that are slowly transitioning towards independence post colonialism, national and international stakeholders hold a joint responsibility to launch sustainable policies that demonstrate financial and operational ownership from the outset through implementation. In balancing global trends and donor demands, national policymakers and program managers should assess health systems preparedness to avoid setting unrealistic standards and ensure that policies are locally contextualized, equitably implemented and realistic (Maaløe et al., 2021).

Third, although our study highlights concerns about recognition and remuneration, recent policy documents indicate a shift. Donors (PEPFAR, 2020), international agencies (Joint United Nations Programme on HIV/AIDS, 2024) and governments (Ministry of Health, National AIDS and STI Control Council, 2023) are now pushing to integrate CHVs and mentor mothers into formal public schemes of service. These calls, emerging twelve years after the initial tracing policy was launched underscore the protracted nature of systemic change. The ingenuity of front-line tracers, as seen in our study, further illustrates a PMTCT tracing system that is far from broken. Rather it illustrates PMTCT tracing as an ongoing process reliant on 'repair work', pending the recognition and ownership by stakeholders who have the power to adequately evaluate and remunerate the work of those who keep systems going.

Repair work should extend 'caring for others' by filling the apparent gaps in international and national health budgets (Vernooij et al., 2022), and by formally acknowledging the work that keeps systems going in

policy planning and health systems structures. For PMTCT programs to be fair, equitable and sustainable, it is essential to scrutinize budget expenditures and allocations, including salary levels, to redistribute institutional resources and funds towards front-line workers, such as tracers. We concur Ballard et al. (2023), essential health services should not rely on volunteers.

Finally, no study is without limitations. While our study provides an in-depth account of the improvisations and daily practices of front-line tracers, it may not be representative of contexts within Kenya and Sub-Saharan Africa with less resources and different structural setups. However, the focus on PMTCT defaulter tracing as enacted under an implementing partner in Kenya is likely similar to other low-resource settings with comparable contexts. Experiences shared by participants in this study represent one aspect of the implementation process and further research is needed to understand how policy implementation unfolded at different levels and by other actors in the health system. While this study was implemented prior to the recent policy shift towards person-centered HIV care, our findings shows that tracers were already practicing this before the change. To our knowledge, this study is the first to explore how the Kenyan defaulter tracing policy is implemented in routine practice, drawing on perspectives of providers and managers across different levels of the PMTCT system. Our exploration of PMTCT defaulter tracing policy in practice provides a nuanced understanding of the challenges to implementing policy in low-resource settings, the gap between policy and practice, and how tracers adapt by developing solutions for continuity of care.

5. Conclusion

This qualitative study demonstrates how the PMTCT defaulter tracing policy in Kenya, while well-intentioned, heavily relied on the ingenuity, adaptability, and 'repair work' of tracers for implementation when formal systems failed. Our findings highlight the relevance of maintenance and repair theory in health systems research, illustrating its social nature, real-world functioning, and the improvised actions that keep systems alive. Policymakers, donors, and program managers must both acknowledge and address the heavy burden placed on tracers by providing adequate resources, formal recognition and employment, contractual compensation, and institutional support. Future studies should explore the real-life implementation of defaulter tracing policy for HIV care (and other health policies) in varied settings to identify gaps between policy and practice currently bridged by repair work. We further encourage health systems researchers to explore the potential of repair work for other types of health systems research. Such efforts facilitate moving towards more resilient health systems where policies are sustainable and effectively operationalized – truly responsive to the needs of those they are designed to serve.

CRedit authorship contribution statement

Skovdal Morten: Writing – review & editing, Supervision, Conceptualization. **Kågesten Anna:** Writing – review & editing, Supervision, Conceptualization. **Ekström Anna Mia:** Writing – review & editing, Funding acquisition. **Nordberg Björn:** Writing – review & editing. **Storey Simone:** Writing – review & editing, Formal analysis. **Kaguir Eunie:** Writing – review & editing, Project administration. **Were Edwin:** Writing – review & editing, Funding acquisition. **Dusabe-Richards John:** Writing – review & editing. **Judith Chamorro De Angeles Katrine:** Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization.

Ethical approval

This study was performed according to the principles of the Helsinki Declaration and approved by the Institutional Research and Ethics Committee at Moi University, School of Medicine, Eldoret, Kenya (FAN;

IREC 1292), and the Regional Ethics Review Board, Stockholm, Sweden (2018/742–31/1).

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors used ChatGPT in order to improve the grammar and readability of the manuscript. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

Upon request.

References

- Attride-Stirling, J., 2001. Thematic networks: an analytic tool for qualitative research. *Qual. Res.* 1 (3), 385–405. <https://doi.org/10.1177/146879410100100307>.
- Ballard, M., Abimbola, O., Iberico, M.M., Rogers, A., Thapa, A., Cook, J., et al., 2023. Labour conditions in dual-cadre community health worker programmes: a systematic review. *Lancet Glob. Health* 11 (10), e1598–e1608. [https://doi.org/10.1016/S2214-109X\(23\)00357-1](https://doi.org/10.1016/S2214-109X(23)00357-1).
- Baszanger, I., Dodier, N., 2004. Ethnography: relating the part to the whole. In: Silverman, D. (Ed.), *Qualitative Research - Theory, Method and Practice*, second ed. Sage, London, pp. 9–34.
- Berlacher, M., Mercer, T., Apondi, E.O., Mwangi, W., Were, E., McHenry, M.S., 2021. Integrating prevention of mother-to-child transmission of HIV care into general maternal Child Health Care in Western Kenya. *Int. J. MCH Aids*. 10 (1), 19–28. <https://doi.org/10.21106/ijma.429>.
- Braun, R., Catalani, C., Wimbush, J., Israelski, D., 2013. Community Health Workers and Mobile Technology: A Systematic Review of the Literature. In: Bullen, C. (Ed.), *PLoS One*, 8, e65772. <https://doi.org/10.1371/journal.pone.0065772>. Jun 12.
- Cataldo, F., Seeley, J., Nkhata, M.J., Mupambireyi, Z., Tumwesige, E., Gibb, D.M., 2018. She knows that she will not come back: tracing patients and new thresholds of collective surveillance in PMTCT Option B+. *BMC Health Serv. Res.* 18 (1), 76. <https://doi.org/10.1186/s12913-017-2826-7>.
- Corwin, J.E., Gidwani, V., 2021. Repair work as care: on maintaining the planet in the capitalocene. *Antipode*. <https://doi.org/10.1111/anti.12791>.
- Denzin, N.K., Lincoln, Y.S., 2005. Introduction: the discipline and practice of qualitative research. In: Denzin, N.K., Lincoln, Y.S. (Eds.), *The Sage Handbook of Qualitative Research*, third ed. Sage Publications Ltd, London, pp. 1–32.
- Dicarolo, A., Fayorsey, R., Syengo, M., Chege, D., Sirengo, M., Reidy, W., et al., 2018. Lay health worker experiences administering a multi-level combination intervention to improve PMTCT retention. *BMC Health Serv. Res.* 18 (1), 17. <https://doi.org/10.1186/s12913-017-2825-8>.
- Etoori, D., Wringe, A., Renju, J., Kabudula, C.W., Gomez-Olive, F.X., Reniers, G., 2020. Challenges with tracing patients on antiretroviral therapy who are late for clinic appointments in rural South Africa and recommendations for future practice. *Glob. Health Action* 13 (1), 1755115. <https://doi.org/10.1080/16549716.2020.1755115>.
- Fassinou, L.C., Songwa Nkeunang, D., Delvaux, T., Nagot, N., Kirakoya-Samadoulougou, F., 2024. Adherence to option B + antiretroviral therapy and associated factors in pregnant and breastfeeding women in Sub-Saharan Africa: a systematic review and meta-analysis. *BMC Public Health* 24 (1), 94. <https://doi.org/10.1186/s12889-023-17004-9>.
- Fayorsey, R.N., Wang, C., Chege, D., Reidy, W., Syengo, M., Owino, S.O., et al., 2019a. Effectiveness of a lay counselor-led combination intervention for retention of mothers and infants in HIV care: a randomized trial in Kenya. *J. Acquir. Immune Defic. Syndr.* 80 (1), 56–63. <https://doi.org/10.1097/QAI.0000000000001882>.
- Fernández-Luis, S., Fuente-Soro, L., Augusto, O., Bernardo, E., Nhamposha, T., Maculuvu, S., et al., 2019. Reengagement of HIV-infected children lost to follow-up after active mobile phone tracing in a rural area of Mozambique. *J. Trop. Pediatr.* 65, 240–248. <https://doi.org/10.1093/tropej/fmy041>.
- Finocchiaro-Kessler, S., Brown, M., Maloba, M., Nazir, N., Wexler, C., Goggin, K., et al., 2021. A pilot study to evaluate the impact of the HIV infant tracking system (HITSys 2.0) on priority Prevention of Mother-to-Child Transmission (PMTCT) outcomes. *AIDS Behav.* 25 (8), 2419–2429. <https://doi.org/10.1007/s10461-021-03204-0>.
- Goldstein, D., Salvatore, M., Ferris, R., Phelps, B.R., Minior, T., 2023 Jul. Integrating global HIV services with primary health care: a key step in sustainable HIV epidemic control. *Lancet Glob. Health* 11 (7), e1120–e1124. [https://doi.org/10.1016/S2214-109X\(23\)00156-0](https://doi.org/10.1016/S2214-109X(23)00156-0).
- Graham, S., Thrift, N., 2007. Out of order: understanding repair and maintenance. *Theory Cult. Soc.* 24 (3), 1–25. <https://doi.org/10.1177/0263276407075954>.
- Health Policy Plus, 2022. Trends in Public Sector Investments in HIV in Kenya. USAID. (https://pdf.usaid.gov/pdf_docs/PA002RZV.pdf).
- Helova, A., Onono, M., Abuogi, L.L., Hampanda, K., Owuor, K., Odwar, T., et al., 2021. Experiences, perceptions and potential impact of community-based mentor mothers supporting pregnant and postpartum women with HIV in Kenya: a mixed-methods study. *J. Int. AIDS Soc.* 24 (11), e25843. <https://doi.org/10.1002/jia2.25843>.
- Henke, C.R., 2000. The mechanics of workplace order: toward a sociology of repair. *Berkeley J. Socio* 44, 55–81. (<https://www.jstor.org/stable/41035546>).
- Jackson, S.J., 2013. Rethinking repair. In: Tarleton, G., Pablo, J.B., Kirsten, A.F. (Eds.), *Media Technologies: Essays on Communication, Materiality and Society*. MIT Press, pp. 221–239.
- Jaffré, Y., Suh, S., 2016. Where the lay and the technical meet: using an anthropology of interfaces to explain persistent reproductive health disparities in West Africa. *Soc. Sci. Med.* 156, 175–183. <https://doi.org/10.1016/j.socscimed.2016.03.036>.
- Janzen, J.M., 1978. The comparative study of medical systems as changing social systems. *Soc. Sci. Med. B* 12 (2B), 121–133. [https://doi.org/10.1016/0160-7987\(78\)90020-0](https://doi.org/10.1016/0160-7987(78)90020-0).
- Joint United Nations Programme on HIV/AIDS. UNAIDS DATA 2023 [Internet]. Geneva: UNAIDS; 2023 [cited 2024 Aug 8]. Available from: https://www.unaids.org/sites/default/files/media_asset/data-book-2023_en.pdf.
- Joint United Nations Programme on HIV/AIDS, 2023. The path that ends AIDS: UNAIDS Global AIDS Update 2023. UNAIDS, Geneva. (<http://www.wipo.int/amc/en/mediation/rules>).
- Joint United Nations Programme on HIV/AIDS, 2024. The urgency of now: AIDS at a Crossroads. UNAIDS, Geneva. (https://www.unaids.org/sites/default/files/media_asset/2024-unaids-global-aids-update_en.pdf).
- Kanyuuru, L., Kabue, M., Ashengo, T.A., Ruparelia, C., Mokaya, E., Malonza, I., 2015. RED for PMTCT: An adaptation of immunization's Reaching Every District approach increases coverage, access, and utilization of PMTCT care in Bondo District, Kenya. *Int. J. Gynaecol. Obstet.* 130 (2), S68–S73. <https://doi.org/10.1016/j.ijgo.2015.04.002>.
- Larson, B.A., Bii, M., Tsikhutsu, I., Halim, N., Wolfman, V., Coakley, P., et al., 2018. The enhanced mentor mother Program (EMMA) for the prevention of mother-to-child transmission of HIV in Kenya: study protocol for a cluster randomized controlled trial. *Trials* 19 (1), 594. <https://doi.org/10.1186/s13063-018-2975-y>.
- Larson, B.A., Tsikhutsu, I., Bii, M., Halim, N., Agaba, P., Sugut, W., et al., 2023. The effects of revised peer-counselor support on the PMTCT cascade of care: results from a cluster-randomized trial in Kenya (the EMMA study). *BMC Infect. Dis.* 23 (1), 257. <https://doi.org/10.1186/s12879-023-08246-4>.
- Ligami, C., 2023. Mentor mothers stopping vertical transmission in Kenya. *Lancet HIV* 10 (7), e430–e431. [https://doi.org/10.1016/S2352-3018\(23\)00148-0](https://doi.org/10.1016/S2352-3018(23)00148-0).
- Livingston, J., 2012. *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic*. 1st ed. Improvising Medicine. Duke University Press, Durham, NC.
- Lumivero. NVivo (Version 14) [Internet]. 2023 [cited 2024 Aug 7]. Available from: (www.lumivero.com).
- Lunsford, S.S., Fatta, K., Stover, K.E., Shrestha, R., 2015. Supporting close-to-community providers through a community health system approach: case examples from Ethiopia and Tanzania. *Hum. Resour. Health* 13 (1), 12. <https://doi.org/10.1186/s12960-015-0006-6>.
- Maaloe, N., Ørtved, A.M.R., Sørensen, J.B., Sequeira Dmello, B., van den Akker, T., Kujabi, M.L., et al., 2021. The injustice of unfit clinical practice guidelines in low-resource realities. *Lancet Glob. Health* 9 (6), e875–e879. [https://doi.org/10.1016/S2214-109X\(21\)00059-0](https://doi.org/10.1016/S2214-109X(21)00059-0).
- Marcos, Y., Phelps, B.R., Bachman, G., 2012. Community strategies that improve care and retention along the prevention of mother-to-child transmission of HIV cascade: a review. *J. Int. AIDS Soc.* 15 (2), 17394. <https://doi.org/10.7448/IAS.15.4.17394>.
- Ministry of Health Kenya, National AIDS and STI Control Council, 2012. Guidelines for Prevention of Mother to Child Transmission (PMTCT) of HIV / Aids in Kenya. MoH Kenya, NASCOP, Nairobi. (<http://guidelines.health.go.ke/#/category/27/64/meta>).
- Ministry of Health Kenya, National AIDS and STI Control Council, 2014. Guidelines on Use of Antiretroviral Drugs for Treating and Preventing HIV Infection. MoH Kenya,

- NASCOP, Nairobi. (http://guidelines.health.go.ke:8000/media/Rapid_Advice_Booklet_2014_July_v5.pdf).
- Ministry of Health Kenya, National AIDS and STI Control Council, 2016. Guidelines on Use of Antiretroviral Drugs for Treating and Preventing HIV Infection in Kenya 2016 Edition. MoH Kenya, NASCOP, Nairobi [cited 2024 Aug 8]. Available from: <https://www.prepwatch.org/wp-content/uploads/2016/08/Guidelines-on-ARV-for-Treating-Preventing-HIV-Infections-in-Kenya.pdf>.
- Ministry of Health, National AIDS & STI Control Council. The Kenya Plan to End AIDS in Children by 2027. 2023.
- Mol, A., 2008. *The Logic of Care: Health and the Problem of Patient*. Routledge, Milton Park, Abingdon, Oxon; New York, NY.
- Murray, M.C.M., O'Shaughnessy, S., Smillie, K., Van Borek, N., Graham, R., Maan, E.J., et al., 2015. Health care providers' perspectives on a weekly text-messaging intervention to engage HIV-positive persons in care (WeTel BC1). *AIDS Behav.* 19 (10), 1875–1887. <https://doi.org/10.1007/s10461-015-1151-6>.
- National AIDS Control Council, 2021b. National AIDS Control Council Strategic Plan 2021/2022 - 2026/2027. NASCOP, Nairobi. (<https://nsdcc.go.ke/download/national-aids-control-council-strategic-plan-2021-2022-2026-2027/>).
- National AIDS Control Council, 2021a. The National AIDS Control Council Strategic Plan 2021/2022 - 2026/2027. NACC, Nairobi. (<https://hivpreventioncoalition.unaids.org/en/resources/kenya-national-aids-control-council-strategic-plan-20212022-20262027>).
- Newman, C.J., Fogarty, L., Makoe, L.N., Reavely, E., 2011. Occupational segregation, gender essentialism and male primacy as major barriers to equity in HIV/AIDS caregiving: findings from Lesotho. *Int. J. Equity Health* 10 (1), 1–13. <https://doi.org/10.1186/1475-9276-10-24>.
- Njoroge, M., Zurovac, D., Ogara, E.A.A., Chuma, J., Kirigia, D., 2017. Assessing the feasibility of eHealth and mHealth: a systematic review and analysis of initiatives implemented in Kenya. *BMC Res. Notes* 10 (1), 90. <https://doi.org/10.1186/s13104-017-2416-0>.
- Nordberg, B., van der Kop, M.L., Mwangi, W., Mwangi, J., Kaguiri, E., Chamorro de Angeles, K.J., et al., 2023. The effect of an interactive weekly text-messaging intervention on retention in prevention of mother-to-child transmission of HIV care: a randomised controlled trial (WeTel PMTCT). *Sci. Rep.* 13 (1), 9389. <https://doi.org/10.1038/s41598-023-35817-x>.
- Odeny, T.A., Hughes, J.P., Bukusi, E.A., Akama, E., Geng, E.H., Holmes, K.K., et al., 2019. Text messaging for maternal and infant retention in prevention of mother-to-child HIV transmission services: a pragmatic steppedwedge cluster-randomized trial in Kenya. *PLoS Med.* 16 (10), e1002924. <https://doi.org/10.1371/journal.pmed.1002924>.
- Odeny, T.A., Onono, M., Owuor, K., Helova, A., Wanga, I., Bukusi, E.A., et al., 2018. Maximizing adherence and retention for women living with HIV and their infants in Kenya (MOTIVATE! study): study protocol for a randomized controlled trial. *Jan 29 Trials* 19 (1), 77. <https://doi.org/10.1186/s13063-018-2464-3>.
- Odiambo, F., Onyango, R., Mulwa, E., Aluda, M., Otieno, L., Bukusi, E.A., et al., 2024. Evaluation of person-centered interventions to eliminate perinatal HIV transmission in Kisumu County, Kenya: a repeated cross-sectional study using aggregated registry data. *PLoS Med.* 21 (8), e1004441. <https://doi.org/10.1371/journal.pmed.1004441>.
- Olaniran, A., Smith, H., Unkels, R., Bar-Zeev, S., van den Broek, N., 2017. Who is a community health worker? – A systematic review of definitions. *Glob. Health Action* 10 (1). <https://doi.org/10.1080/16549716.2017.1272223>.
- PEPFAR, 2016. Kenya Country Operational Plan COP 2016 Strategic Direction Summary. PEPFAR. (<https://www.state.gov/wp-content/uploads/2019/08/Kenya-13.pdf>).
- PEPFAR, 2020. Country Operational Plan (COP/ROP) 2020 Strategic Direction Summary. PEPFAR. (<https://www.state.gov/wp-content/uploads/2020/08/Kenya-COP20-SDS-Final.pdf>).
- Peters, D.H., Adam, T., Alonge, O., Agyepong, I.A., Tran, N., 2013. Implementation research: what it is and how to do it. *BMJ* 347, f6735. <https://doi.org/10.1136/bmj.f6735>.
- Pillow, W.S., 2003. Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *Int. J. Qual. Stud. Educ.* 16 (2), 175–196. <https://doi.org/10.1080/0951839032000060635>.
- Puchalski Ritchie, L.M., Van Lettow, M., Pham, B., Straus, S.E., Hosseinipour, M.C., Rosenberg, N.E., et al., 2019. What interventions are effective in improving uptake and retention of HIV-positive pregnant and breastfeeding women and their infants in prevention of mother to child transmission care programmes in low-income and middle-income countries? A systematic review and meta-analysis. *BMJ Open* 9 (7), e024907. <https://doi.org/10.1136/bmjopen-2018-024907>.
- Rachlis, B., Ochieng, D., Geng, E., Rotich, E., Ochieng, V., Maritim, B., et al., 2015. Implementation and operational research: evaluating outcomes of patients lost to follow-up in a large comprehensive care treatment program in western Kenya. *J. Acquir Immune Defic. Syndr.* 68 (4), e46–e55. <https://doi.org/10.1097/QAI.0000000000000492>.
- Rapaport, S.F., Peer, A.D., Viswasam, N., Hahn, E., Ryan, S., Turpin, G., et al., 2023. Implementing hiv prevention in sub-saharan africa: a systematic review of interventions targeting systems, communities, and individuals. *AIDS Behav.* 27 (1), 150. <https://doi.org/10.1007/s10461-022-03751-0>.
- Robinson, F., 2008. The importance of care in the theory and practice of human security. *J. Int. Political Theory* 4 (2), 167–188. <https://doi.org/10.3366/E1755088208000207>.
- Rotheram-Borus, M.J., Richter, L.M., Van Heerden, A., Van Rooyen, H., Tomlinson, M., Harwood, J.M., et al., 2014. A cluster randomized controlled trial evaluating the efficacy of peer mentors to support south African women living with HIV and their infants. *PLoS One* 9 (1), e84867. <https://doi.org/10.1371/journal.pone.0084867>.
- Schmitz, K., Basera, T.J., Egbujie, B., Mistri, P., Naidoo, N., Mapanga, W., et al., 2019. Impact of lay health worker programmes on the health outcomes of mother-child pairs of HIV exposed children in Africa: a scoping review. *Jan 31 PLoS One* 14 (1), e0211439. <https://doi.org/10.1371/journal.pone.0211439>.
- Sellers, C.J., Lee, H., Chasela, C., Kayira, D., Soko, A., Mofolo, I., et al., 2015. Reducing lost to follow-up in a large clinical trial of prevention of mother-to-child transmission of HIV: the breastfeeding, antiretrovirals and nutrition study experience. *Clinical Trials* 12 (2), 156–165. <https://doi.org/10.1177/174077451456203>.
- Suchman, L., 1987. *Plans and Situated Actions: The Problem of Human-Machine Communication*. Cambridge University Press, Cambridge.
- Thomson, K.A., Cheti, E.O., Reid, T., 2011. Implementation and outcomes of an active defaulter tracing system for HIV, prevention of mother to child transmission of HIV (PMTCT), and TB patients in Kibera, Nairobi, Kenya. *Trans. R. Soc. Trop. Med. Hyg.* 105 (6), 320–326. <https://doi.org/10.1016/j.trstmh.2011.02.011>.
- Tong, A., Sainsbury, P., Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int. J. Qual. Health Care* 19 (6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>.
- Tronto, J.C., 1993. *Moral Boundaries: A Political Argument for an Ethics of Care*. Routledge, London.
- Vernooij, E., Koker, F., Street, A., 2022. Responsibility, repair and care in Sierra Leone's health system. *Soc. Sci. Med.* 300, 114260. <https://doi.org/10.1016/j.socscimed.2021.114260>.
- Vogt, F., Ferreyra, C., Bernasconi, A., Ncube, L., Taziwa, F., Marange, W., et al., 2015. Tracing defaulters in HIV prevention of mother-to-child transmission programmes through community health workers: Results from a rural setting in Zimbabwe. *J. Int. AIDS Soc.* 18 (1), 20022. <https://doi.org/10.7448/IAS.18.1.20022>.
- Wanga, I., Helova, A., Abuogi, L.L., Bukusi, E.A., Nalwa, W., Akama, E., et al., 2019. Acceptability of community-based mentor mothers to support HIV-positive pregnant women on antiretroviral treatment in western Kenya: a qualitative study. *BMC Pregnancy Childbirth* 19 (1), 288. <https://doi.org/10.1186/s12884-019-2419-z>.
- Wendland, C.L., 2010. *Heart for the Work: Journeys through an African Medical School*. Chicago, Press, London.
- World Health Organization, 2008. *Task Shifting Global Recommendations and Guidelines HIV/AIDS*. WHO, Geneva. (https://apps.who.int/iris/bitstream/handle/10665/43821/9789241596312_eng.pdf).