Data Privacy Breaches: A Governance or a Human Behavior Problem in HIV Index testing?

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Abstract

Background: HIV index testing represents a critical strategy for identifying undiagnosed people with HIV through contact tracing of sexual partners and family members of known people living with HIV. However, privacy and confidentiality breaches during index testing pose significant barriers to HIV care engagement and public health outcomes. Research demonstrates that confidentiality violations prevent individuals from seeking timely HIV care, disclosing their status, and adhering to treatment protocols, ultimately undermining HIV prevention and control efforts. While evidence shows that maintaining privacy during service delivery significantly improves index case testing uptake, the underlying causes of privacy breaches remain unclear, with potential origins in both inadequate governance frameworks and problematic human behaviours among healthcare providers.

Objective: This study examines the question whether data breaches are a data governance issue or a human behavior issue in relation to HIV index testing among women living with HIV in Kisumu County, Kenya.

Methodology: This study employed a participatory action research design to examine privacy breaches in HIV index testing, establishing a Project Implementation Committee (PIC) comprising young women with lived experience in HIV services who were trained in qualitative research methods, ethical considerations, and confidentiality protocols. Data collection involved eight focus group discussions alongside 48 in-depth interviews with purposively selected adolescents and young women living with HIV. Thematic analysis was conducted to identify patterns related to governance failures versus human behavioral factors.

Findings: The findings highlight the significance of maintaining privacy and confidentiality in management of HIV including utilization of sexual and reproductive health services by young women. Despite the HIV index testing strategy being hailed for its ability to enhance testing and enrolment to ART, its implementation is riddled with significant gaps among them privacy breaches which result or amplify stigma, and discrimination. The participants underscored the benefit it accords them but had reservations on its implementation particularly failure to adhere to the consent procedures by the healthcare workers. Participants emphasized the need to train implementers on policies, particularly those involved in administering health services, to prevent situations where women encounter social and structural barriers—such as fear of rejection, financial constraints, and legal obstacles resulting from privacy breaches—that limit their ability to fully access and benefit from SRH services.

Implications: The study underscores the need for training of the health care workers on the tenets for the introduction and implementation of a policy to ensure that the reforms achieve their intended purpose. Understanding the inherent intersection of policy and human behavior ensures that reforms implemented improves health outcomes and empowers the targeted beneficiaries especially women living with HIV to exercise their reproductive rights fully.

Key Words: Data Breach, Governance, Human Behavior, Index testing

1. INTRODUCTION

1.1 Background and Context

HIV remains a critical global health issue, particularly in sub-Saharan Africa (SSA), where the epidemic has disproportionately affected women (Ramjee & Daniels, 2013; Brown et al., 2011). The region bears the highest burden of the HIV epidemic globally, with women and girls significantly more vulnerable to the disease. In Kenya, approximately 1.4 million people live with HIV, and more than one million children have been orphaned by the epidemic (Kimanga et al., 2014; UNAIDS, 2023). Women and girls account for a significant portion of this population, reflecting the deep-seated gender inequalities that heighten their risk of infection and hinder access to healthcare services (Ogolla et al., 2023; Amornkul et al., 2009; UNAIDS, 2023).

HIV index testing, also known as Assisted Partner Notification (APN), has emerged as a cornerstone public health strategy for identifying undiagnosed HIV infections and enhancing linkage to care (Ministry of Health, National AIDS & STI Control Program (2022). The approach involves offering HIV testing to the sexual partners and biological children of people diagnosed with HIV, with the goal of identifying undiagnosed cases early, reducing onward transmission, and ensuring timely initiation of treatment (McGowan et al., 2024; Dalal et al., 2017; Wamuti et al., 2015). According to WHO guidelines (2019), index testing contributes significantly to the first and second "95" targets of the UNAIDS 95-95-95 strategy, ensuring that 95% of people living with HIV know their status and that 95% of those diagnosed are on treatment.

In Kenya, index testing was integrated into national HIV testing services (HTS) guidelines in 2018 as part of efforts to improve partner notification and early diagnosis. The program's success depends on trust, confidentiality, and voluntary participation—principles that are enshrined in both WHO's Consolidated guidelines on differentiated HIV testing services (WHO, 2024) and Kenya's Data Protection Act (2019). These principles—privacy, confidentiality, and informed consent—are fundamental to ensuring that individuals can safely access testing and care without fear of stigma, discrimination, or violence (Banda, 2025).

However, the growing digitalization of health systems and the expansion of partner notification strategies have introduced new data privacy and confidentiality risks. Reports from Kenya and other SSA countries indicate that breaches of confidentiality during index testing—such as unauthorized disclosure of HIV status, poorly secured patient records, and informal partner tracing have led to social harms, including partner violence, stigma, and community discrimination (Mugisha et al., 2023; Sharma et al., 2024; Oljira et al., 2024). Globally, similar challenges have been observed in digital health platforms and public health interventions, where weaknesses in data protection and governance frameworks have exposed sensitive health information (Tavakoli et al., 2024). The tension between the public health benefits of partner notification and the ethical imperative to safeguard privacy underscores the need for a balanced, rights-based approach to HIV testing and data governance.

This context frames the present study's focus on how breaches of confidentiality during HIV index testing affect trust, service uptake, and women's access to sexual and reproductive health (SRH) services in Kenya—particularly in high-prevalence regions such as Kisumu County.

1.2 Problem Statement

Confidentiality breaches during HIV index testing represent a significant impediment to the effectiveness of HIV prevention and care efforts. Such breaches deter individuals from accessing vital testing and treatment services, undermine trust in healthcare providers, and exacerbate the stigma associated with HIV infection (Mustefa Adem Hussen et al., 2024; Mugisha et al., 2023).

Despite Kenya's progress in developing data protection legislation and ethical guidelines for HIV services, evidence suggests continued violations of privacy and consent during the implementation of index testing (Mugisha et al., 2023). Women, in particular, remain disproportionately affected, facing heightened risks of intimate partner violence, social exclusion, and economic hardship following involuntary disclosure of their HIV status (Sharma et al., 2024; Alhassan et al., 2022).

The central dilemma is whether these confidentiality breaches stem primarily from weak governance systems such as gaps in data protection infrastructure, limited policy enforcement, and inadequate institutional oversight or from individual healthcare provider behaviours, including ethical lapses, insufficient training, and cultural biases (Alhassani, Windle & Konstantinidis, 2024)**.** The persistence of such breaches suggests that both systemic and behavioral factors may be at play, yet their relative influence remains unclear.

This ambiguity complicates the design of effective interventions and accountability mechanisms for protecting patient confidentiality in HIV index testing. Understanding whether the problem is rooted in governance failures or provider behaviours or both is therefore critical to developing sustainable, rights-based solutions that enhance the safety, trust, and effectiveness of index testing programs in Kenya.

1.3 Objectives

- To investigate the underlying drivers of privacy breaches during HIV index testing among women living with HIV.
- To distinguish between governance-related and behaviours-related causes of confidentiality breaches.
- To identify actionable and contextually appropriate interventions aimed at strengthening confidentiality and data protection within HIV service delivery.

2. Literature Review

2.1 Overview of HIV Index Testing

HIV index testing is a systematic approach that involves offering HIV testing services specifically to the sexual partners and biological children of individuals who have been diagnosed with HIV. The primary objective of this strategy is to identify undiagnosed HIV cases and ensure timely linkage to appropriate care and treatment services (McGowan et al., 2024; WHO, 2024). Globally, HIV index testing has been integrated into various national HIV programmes, demonstrating diverse levels of effectiveness largely influenced by differences in healthcare infrastructure, resource availability, and sociocultural dynamics within different regions . In the Kenyan context, index testing forms a fundamental component of the national HIV response framework. The Kenya Ministry of Health (MoH) has developed and implemented protocols that prioritise voluntary participation, confidentiality, and ethical considerations to optimise uptake and effectiveness (Ministry of Health, National AIDS & STI Control Program (2022). Despite these structured efforts, the strategy continues to face persistent ethical challenges. These include concerns related to coercion, involuntary disclosure of HIV status, and breaches of confidentiality, which have been documented in prior empirical studies (Banda, 2025). Such issues not only undermine the effectiveness of index testing but also pose significant risks to the rights and well-being of those involved, necessitating ongoing vigilance and enhancement of safeguards within programme implementation. These efforts align with Sustainable Development Goal 3.3, which seeks to end the AIDS epidemic by 2030 through strengthened prevention, testing, and treatment initiatives (United Nations, 2015).

2.2 Conceptualizing Data Privacy and Confidentiality

Data privacy is broadly defined as the protection of personal and sensitive information from unauthorized access, use, or disclosure. It ensures that individuals' data are handled in a manner that respects their rights to control personal information (Banda, 2025; Liginlal, Sim & Khansa, 2009). Confidentiality, closely related but distinct, refers to the ethical and legal obligations of healthcare providers and institutions to safeguard information entrusted to them by patients, preventing unauthorized sharing or exposure (Banda, 2025; Turkstani et al., 2025). Within the context of HIV services, these concepts are critical due to the highly sensitive nature of HIV-related information and the potential consequences of breaches, including stigma, discrimination, and social harm. Data governance encompasses the comprehensive framework of policies, standards, and operational practices designed to uphold data privacy and confidentiality especially as health systems increasingly digitize (Ahmed et al., 2025). This includes mechanisms for data security, access controls, accountability, and compliance monitoring. In Kenya, the legal landscape supporting data privacy and confidentiality in HIV services is anchored by key legislation, notably the Data Protection Act (2019) and the HIV & AIDS Prevention and Control Act (2022). These laws establish binding mandates for confidentiality, specify penalties for violations, and provide guidance on ethical conduct for healthcare providers and institutions managing HIV-related data (Data Protection Act, 2019; HIV & AIDS Prevention and Control Act, 2022).. Together, these conceptual and legal frameworks form the foundation for protecting sensitive information within HIV index testing programmes.

2.3 Governance Perspective

From a governance standpoint, breaches of confidentiality in HIV index testing are frequently attributed to systemic weaknesses within organisational and institutional frameworks. Research indicates that gaps in policy enforcement, insufficient institutional oversight, and the absence of clear, standardised data-handling protocols significantly contribute to vulnerabilities in maintaining confidentiality (Conduah, Ofoe & Siaw-Marfo, 2025). Moreover, the increasing reliance on digital health information systems introduces additional risks, as these platforms may harbour security vulnerabilities that can be exploited, leading to unauthorised access or data leaks (Ogbodo et al., 2025; Isibor, 2024; Jawad, 2024). The World Health Organization's Digital Health Ethics Framework and the Organisation for Economic Co-operation and Development's (OECD) Principles on Data Governance emphasise the necessity of robust governance structures that incorporate transparency, accountability, and comprehensive security measures to protect health data effectively (World Health Organization, 2021; OECD, 2019). In Kenya, research reveals that the Office of the Data Protection Commissioner and health facilities frequently lack resources to fully implement the Data Protection Act's requirements such as designated data protection officers and systematic audits (Lawyers Hub, 2022). Globally, similar vulnerabilities have been observed; for instance, the 2019 Singapore HIV Registry data leak exposed the personal information of more than 14,000 individuals, highlighting the worldwide risks associated with inadequate data safeguards (Ministry of Health Singapore, 2019). These governance deficiencies create an environment where confidentiality breaches are more likely to occur, undermining the integrity of HIV index testing programmes.

2.4 Human Behavior Perspective

The human behaviour perspective centres on the role of individual healthcare providers and staff in maintaining or compromising confidentiality during HIV index testing. Literature highlights that the attitudes, ethical awareness, and level of training among health workers are critical determinants of confidentiality practices (Alhassani, Windle & Konstantinidis, 2024; Njuguna et al., 2019). Stigma and discrimination directed towards people living with HIV (PLHIV) can lead to moral disengagement—whereby healthcare providers rationalise or justify breaches of confidentiality, either consciously or unconsciously (Fauk et al., 2024: Mokgatle & Madiba, 2023). The Theory of Planned Behaviour (Ajzen, 2011) provides a valuable framework for understanding how health workers' attitudes, perceived social norms, and perceived behavioural control influence their intentions and actual behaviours regarding confidentiality. Similarly, Moral Disengagement theory (Bandura, 2011) explains mechanisms through which individuals may disengage from ethical standards, thereby increasing the likelihood of unethical conduct such as unauthorised disclosure of sensitive information. These behavioural insights underscore the importance of addressing individual-level factors through targeted training, awareness-raising, and fostering an organisational culture that prioritises ethical conduct and respect for patient privacy.

2.5 The Governance–Behavior Interface

Evidence from the literature suggests that governance and human behaviour are deeply interrelated rather than mutually exclusive factors influencing confidentiality outcomes in HIV index testing. Governance frameworks establish the normative environment, accountability structures, and operational protocols that shape individual behaviours within healthcare settings (Alhassani, Windle & Konstantinidis, 2024). Conversely, the behaviours of healthcare providers and staff can either reinforce governance effectiveness by adhering to established standards or undermine it through non-compliance and ethical lapses (Zadeh & Haggerty, 2023). This bidirectional relationship highlights the need for integrated approaches that simultaneously strengthen governance mechanisms and address behavioural determinants. Despite this recognition, significant gaps remain in the literature, particularly with regard to Kenya-specific contexts and the experiences of women living with HIV. Women may face distinct privacy risks and social consequences from confidentiality breaches, necessitating gender-sensitive analyses and interventions (Imam & Manimekalai, 2025). Focusing on women living with HIV the current study situates confidentiality breaches within a gendered framework, exploring how structural and behavioural drivers converge to affect women's health-seeking behaviour in index testing programmes. Against this backdrop, this study examines how governance structures and individual provider behaviours interact to shape confidentiality outcomes in HIV index testing in Kisumu County, Kenya.

3. Methods

3.1 Study Design and Setting

The study adopted a Participatory Action Research (PAR) design to capture women's voices, promote dialogue between communities and health providers, and ensure the research was contextually relevant and action oriented. Kisumu County, with one of Kenya's highest HIV prevalence rates (16.3%, compared to the national average of 4.9%) (Simba, 2023; Sing'oei et al., 2024), provided an ideal context for examining confidentiality challenges in HIV index testing. The study focused on women living with HIV (WLHIV), who are disproportionately affected by the epidemic and experience unique privacy and disclosure risks, aligning with the study's emphasis on gender-sensitive analyses.

A total of 116 participants (24 IDIs, 11 FGDs (88 participants) and 4 KIIs) were involved in the study, including diverse groups of HIV-positive women and girls aged 16-34 years. The FGDs were classified by age and sexual orientation giving 4 main categories of groupings 1) Adolescents aged 16 – 19 2) Young women aged 20-24 3) Middle-aged women aged 25-34 and 4) LGBTQ. KII participants were drawn from national and county health management team, healthcare worker, member of civil society, and a policymaker. These participants were selected purposively through partner organizations in Kisumu that are involved in HIV programs. The data collection process was supported by 12 community researchers who were women living with HIV. These researchers were trained on research methodology, ethics, data collection techniques, and the legal and policy framework concerning privacy and confidentiality in HIV testing. The study protocol was reviewed and approved by the AMREF Ethical and Scientific and Review Committee. In adherence to the ethical considerations, informed consent was sought from all the participants who participated in the study.

Sessions were conducted in English, Kiswahili, or Dholuo, and audio-recorded with informed consent. Additional measures to ensure privacy included conducting sessions in private settings, de-identifying transcripts, and safeguarding digital recordings. The use of community researchers also enhanced cultural appropriateness and increased participants' willingness to share sensitive experiences.

Data were transcribed, translated into English where necessary, and analyzed using thematic analysis. A coding matrix was developed based on the study's conceptual framework, focusing on governance-related and behavior-related drivers of confidentiality breaches. Codes were grouped into broader themes. Reflexive analysis was applied to link participants' narratives with institutional practices, highlighting how governance and behavior converge to affect women's access to HIV and SRH services. Attention was paid to gendered dimensions of confidentiality breaches and the potential psychosocial consequences for WLHIV, ensuring that findings were both analytically rigorous and actionable for policy and practice.

4. Findings

4.1 Descriptive statistics

From the results the mean age of respondents was 24 years which indicated a relatively young cohort of women living with HIV. Majority of the respondents had attained formal education with 33% having completed secondary education (form 4), 36% have attained college level education and 15% had attained university level education. The education level suggests that the participants could understand confidentiality and privacy concepts crucial for HIV index testing. Additionally, it suggests that they could offer informed perspectives on their experiences with behavioral and governance factors influencing privacy outcomes.

4.2 Thematic analysis

Thematic analysis generated four themes: (a) the role of healthcare workers in the implementation of HIV index testing; (b) barriers to accessing SRH services; (c) impact of index testing on disclosure; and (d) opportunities for integrating SRH and HIV services.

a) Role of healthcare workers on the implementation of HIV Index Testing Programs

The study found that HIV index testing is primarily conducted in healthcare facilities, where the behaviour of the healthcare providers plays a central role in facilitating the process. Participants reported that index testing typically involves counselling sessions both pre and post where newly diagnosed HIV-positive individuals are asked to provide contact information for their sexual partners or drug-injecting partners. In line with the aim of the strategy, the partners identified are then contacted by healthcare providers and encouraged to undergo HIV testing. This process reflects a governance structure designed to promote partner notification however it seems to be largely dependent on the behaviour and discretion of individual providers.

While many participants viewed the process positively, due to its potential to identify undiagnosed HIV cases and link the individuals to care, there were also concerns about the inconsistent implementation and follow-up. Some participants reported that health workers did not trace partners as required which reflects weak enforcement protocols and supervision gaps which is a governance deficiency.

> *"Okay, I will start here. It's very poor. You know, in the hospitals I have gone and I have never been asked about my partner <laughing> like, okay, what they usually ask is whether he is positive or negative. You say negative, but, tracing him so that he can come for the test. They never do that. So it is up to me to take him to the hospital for the test, I confirm then again take him to the facility after three months for more confirmation. But the health facilities never do any contact tracing. So like in three hospitals where I took medicine I have never been asked about something of that sort" (FGD08 participant)*

This quote illustrates how absence of structured follow-up systems and monitoring frameworks (governance issue) interacts with individual provider attitudes and priorities (behavioral issue), resulting in lapses in partner tracing.

On the other hand, participants described trust in the healthcare providers as a result of positive and supportive encounters.

> *".... And when the test was being conducted. I was treated well. They welcome me also. They encourage me when they're doing this counselling. Also, they motivate me to feel, to be free when I want to know my status. And they counselled me on how I can do adherence. Okay. I'm doing adherence good. Okay. They make me to feel free. And they made me to feel free on my disclosure. The first time I was having the stigma and now they do counselling on me, and they make me proud. Now I can, I don't have that stigma at all" (24 yrs. old IDI participant)*

This experience shows that even within weak governance systems, empathetic and well trained providers can uphold confidentiality thus improving patient experience - a huma behaviour factor mitigating systemic weaknesses.

b) Barriers to Accessing SRH Services

The study also identified several barriers to SRH services among women living with HIV, many of which are exacerbated by the index testing process.

Stigma, abuse and discrimination were the most significant barriers reported by participants. Fear of being stigmatized or abandoned discouraged women from disclosing their status or accessing care. These fears are rooted in the societal attitudes and behavioural norms but are intensified by weak institutional mechanisms for privacy protection and redress.

> *"There was a time my mother was throwing words at me, so at that time she forgot, and she shouted that am HIV and the neighbours heard, so I was stigmatized and some they were looking at me badly". (FGD06 participant).*
>
> *"From my partner. Mm-hmm at first. Yeah. Financial support was not there from my partner. Mm-hmm also my parents. They didn't, they, I think they were shocked. They, they, they did not support me financially. So, I was just there by my own doing my own things." (26 yrs. old IDI participant - Kisumu Central)*

These experiences demonstrates that when governance systems fail to protect confidentiality or offer psychosocial support, women face exclusion driven by human behavior – discrimination, gossip and rejection. The result is a breakdown in trust between clients, families and healthcare institutions.

c) Impact of Index Testing on Disclosure

Disclosure emerged as a complex and emotional issue shaped by both policy and human factors. Some women described positive disclosure experiences facilitated by supportive counselling and partner cooperation – evidence that governance efforts that promote safe disclosure can succeed when combined with sensitive provider behavior.

However, others reported disclosure that led to stigma, rejection and financial hardships highlighting the absence of structured protection mechanisms and follow-up support for women after disclosure.

> *"From my partner ......financial support was not there from my partner. .... also, my parents .... they did not support me financially. So, I was just there by my own doing my own things." (26 yrs. old IDI participant - Kisumu Central)*

These negative experiences reveal that the governance framework does not adequately safeguard women against social repercussions of disclosure, leaving them vulnerable to behavioral dynamics such as blame, abandonment, or violence. As a result, many participants indicated that they avoided disclosures altogether as a self-protective behavioral response to perceived institutional and social risks.

d) Opportunities for Integrating SRH and HIV Services

Despite the challenges identified, the participants highlighted opportunities for improving confidentiality through governance reforms and service integration. Many emphasized that integrating SRH services and HIV services would normalize HIV testing and reduce stigma by protecting the reason for one's visit to a facility.

> *"Okay. About integration. It reduces stigma. Cause maybe if I go to one room, nobody will know what I'm going to do there yes. That one I'm sure. Yes, because if I, maybe if I go to an HTS room or, uh, family planning room and at the same time they conduct all these processes, maybe somebody may not know what, the exact thing exactly I'm doing there." (28 yrs. old IDI participant - Nyando)*

> *".... integration of the HIV and sexual reproductive health should be under one roof to avoid the movement of maybe from here you're going to another room and from here you moving to another room. That one makes that confidentiality." (22 yrs. old FGD01 participant)*

Participants also emphasized that policy enforcement and accountability mechanisms were necessary to ensure confidentiality. They called for actions against health workers who disclose client information – an acknowledgment that governance structures must regulate huma behavior through clear policies, sanctions and training.

> *"... And then I think maybe with the issue of that confidentiality I said if it's a must that there is not that soft copy then I think the issue of the…the policy has to maybe include such a thing to be strict of which if maybe you found like you, you're trying to disclose somebody's status to somebody else I think there is an action that has to be taken and then the rest will follow. It's not that you just saying." (22 yrs. old FGD01 participant)*

Overall, these findings demonstrate that privacy outcomes in HIV index testing are influenced by the interaction between governance and human behavior. Weak institutional structures such as inadequate policy enforcement, limited provider supervision, and poor service integration create conditions where individual discretion largely determines confidentiality outcomes. At the same time, healthcare workers' attitudes, empathy, and professionalism either mitigate or exacerbate these systemic weaknesses. Similarly, clients' fear of stigma and their coping strategies such as non-disclosure reflect behavioral adaptations to perceived governance failures.

5. Discussion

This study examined women living with HIV (WLHIV) in Kisumu County regarding HIV index testing and access to sexual and reproductive health (SRH) services, with a particular focus on data privacy breaches. The findings reveal that privacy breaches arise from a combination of governance deficiencies, human behavior factors, and the interaction between the two, directly addressing the research questions regarding the drivers of confidentiality breaches and informing actionable interventions. The study demonstrates that both structural and individual-level factors significantly influence the effectiveness and privacy outcomes of HIV index testing programs, highlighting the need for multi-level interventions. These insights underscore that sustainable protection of privacy in HIV programs requires a balance between strong governance systems and positive behavioral practices at the provider and client level.

5.1 Role of Healthcare Workers and Human Behavior in Privacy Outcomes

Healthcare providers were found to play a central role in HIV index testing, including pre- and post-test counselling, partner notification, and follow-up care (Sharma et al., 2024). Participants frequently reported that supportive interactions with healthcare providers reduced stigma, encouraged openness, and improved adherence to antiretroviral therapy (ART), reflecting human behavior factors such as empathy, professional diligence, and interpersonal skills (Alhassani, Windle & Konstantinidis, 2024). These behaviours positively influenced privacy outcomes by fostering trust and making participants feel safe to disclose sensitive information about their HIV status and sexual partners (Banda, 2025). This aligns with evidence that empathetic provider conduct promotes confidentiality and adherence in HIV care settings (Alhassani, Windle & Konstantinidis, 2024).

However, significant gaps were also noted. Many women reported inconsistent counselling quality, inadequate follow-up, and minimal partner tracing. In some cases, participants indicated that they had to personally ensure that their partners underwent testing, which exposes systemic vulnerabilities in the HIV index testing program. These findings suggest that privacy breaches are not purely the result of individual actions; they occur when governance structures, such as clear protocols for partner tracing and follow-up, are weak or poorly enforced, and when human behaviour such as lapses in provider diligence fails to fill these gaps (Ahmed et al., 2025; Zadeh & Haggerty, 2023). As a result, the combination of weak institutional accountability and discretionary provider behaviour increases the risk of inadvertent disclosures and loss of client trust.

The mixed experiences with confidentiality reported by participants further illustrate the critical role of human behaviour. While some participants expressed high levels of trust in their providers, others were concerned that breaches of confidentiality could occur, particularly during disclosure or partner notification. These findings are consistent with prior research showing that provider behaviour both intentional and unintentional directly influences confidentiality outcomes in HIV care (Banda, 2025; Alhassani, Windle & Konstantinidis, 2024; Tees, 2021). This indicates that effective strategies to protect privacy must address both the human and structural dimensions of service delivery.

5.2 Barriers to Accessing SRH Services

The study also highlighted numerous barriers that limit access to SRH services among WLHIV, many of which are exacerbated by the processes inherent in HIV index testing. Stigma, discrimination, and social rejection emerged as critical human behaviour-related barriers. Fear of negative reactions from partners, families, and the broader community discouraged participation in index testing and inhibited access to SRH services (Ninsiima, Chiumia, & Ndejjo, 2021). Participants described experiences of emotional distress, social isolation, and, in some cases, financial hardship following disclosure, illustrating the profound impact of interpersonal and societal behaviours on privacy and health outcomes. These findings show that enduring social norms that stigmatize HIV may shape both provider and client actions within health systems.

At the structural level, participants highlighted governance-related barriers, including financial constraints, distance to health facilities, and the requirement to access multiple service points for HIV and SRH care. Such factors increase the risk of privacy breaches by making it more difficult for women to access services discreetly, while also adding logistical burdens that reduce service uptake (Jimu et al., 2025; Timyan et al., 2018). These findings underscore that access to care is mediated not only by social behaviours and attitudes but also by institutional design and policy enforcement, emphasizing the importance of addressing both domains. Improving governance mechanisms such as integrated service delivery and streamlined facility layout could therefore mitigate stigma while enhancing confidentiality.

5.3 Impact of Index Testing on Disclosure

Disclosure of HIV status is a pivotal component of HIV index testing but remains fraught with challenges. Positive experiences with disclosure often led to supportive behaviours from partners and families, open communication about health and treatment, and adherence to ART. These experiences reflect the human behavior dimension, in which interpersonal dynamics and social support networks facilitate safe disclosure and improved health outcomes (Alhassani, Windle & Konstantinidis, 2024). Thus, social trust and emotional safety are considering key enablers for successful partner notification.

Conversely, negative experiences with disclosure were profound. Participants reported experiences of stigma, discrimination, rejection, and social or financial consequences, which in turn discouraged participation in index testing or further SRH engagement. Some women adopted non-disclosure strategies as protective measures to avoid these outcomes, illustrating adaptive human behaviour in response to social risks. However, these behaviours interact with governance deficiencies, such as inadequate enforcement of confidentiality protocols and weak oversight of provider practices, which exacerbate the risk of breaches and perpetuate cycles of undiagnosed HIV cases (Conduah, Ofoe & Siaw-Marfo, 2025). These dynamics reveal that governance failures amplify the social risks of disclosure, while behavioural responses to stigma further weaken the efficacy of testing and partner notification programs.

The findings highlight the dual influence of human behavior and governance in shaping privacy outcomes: even when women engage in protective behaviours, the absence of robust governance structures limits the effectiveness of privacy safeguards, indicating the necessity of interventions that address both levels simultaneously. Strengthening governance alone cannot succeed without transforming provider and community attitudes toward confidentiality and stigma.

5.4 Opportunities for Integrating SRH and HIV Services

Participants highlighted integration of SRH and HIV services as a key opportunity to enhance privacy and access. Integrated services were perceived to reduce stigma by normalizing HIV testing as part of routine healthcare and minimizing the visibility of HIV-specific service utilization (Shahmanesh et al., 2024: Gómez-Ramírez et al., 2021; Drake et al., 2021; Narasimhan et al., 2019). Such interventions are primarily governance-driven, involving the strategic organization of health services to optimize privacy, efficiency, and accessibility. Integration also represents a governance reform that can indirectly shape positive behavioral norms by reframing HIV testing as a standard component of primary care (Palanee-Phillips, 2023).

However, participants emphasized that integration alone is insufficient without well-trained and conscientious providers who uphold confidentiality and provide supportive care (Dzinamarira et al., 2025). This underscores the role of human behavior in safeguarding privacy. The findings demonstrate that successful integration requires an interaction of governance and human behavior: institutional arrangements and service design provide the framework for privacy, while provider practices and attitudes determine its practical implementation. This privacy culture within health institutions which takes into consideration the interplay between governance and human behavior must be cultivated through both policy and practice.

5.5 Limitations

This study has several limitations. First, the qualitative approach and purposive sampling limit the extent to which the findings can be generalized outside Kisumu County. Second, self-reported experiences may be influenced by recall bias or social desirability bias, potentially under- or over-estimating privacy breaches or disclosure experiences. Third, the study focused exclusively on women, excluding the perspectives of men and other key populations, which could provide a more comprehensive understanding of privacy challenges. Future research should explore interventions targeting both governance and human behaviour factors across diverse populations and settings, and evaluate the effectiveness of integrated SRH-HIV service models in enhancing privacy outcomes.

6. Conclusion

This study demonstrates that privacy and confidentiality breaches in HIV index testing stem from both governance gaps and human behavioral factors among healthcare providers. While index testing is vital for early HIV detection and linkage to care, breaches particularly non-adherence to consent protocols, undermine its effectiveness and exacerbate stigma and discrimination. Strengthening governance frameworks alone is insufficient; targeted training and sensitization of healthcare workers are essential to ensure ethical, client-centered service delivery. By addressing both structural and behavioral challenges, interventions can enhance trust in HIV services, improve utilization of sexual and reproductive health services, and empower women living with HIV to exercise their reproductive rights fully. Ultimately, integrating robust policy with ethical practice ensures that HIV index testing achieves its intended public health impact.

Policy and Practice Implications

The findings suggest several actionable measures for reducing privacy breaches in HIV index testing:

1. Governance-focused interventions: Strengthen enforcement of privacy policies, standardize partner tracing protocols, implement routine monitoring, and establish accountability mechanisms. Clear governance structures ensure consistent practices across facilities, reduce variability, and provide a framework for provider behavior.
2. Behavior-focused interventions: Train healthcare providers on confidentiality principles, supportive counselling, ethical disclosure, and non-judgmental patient care. Such interventions address provider behavior, enhancing adherence to protocols and mitigating privacy breaches.

Acknowledgement: We would like to express our sincere gratitude to all individuals and organizations who contributed to the completion of this research. Special thanks go to PIC members for their invaluable support and guidance throughout the study. We also appreciate the funding provided by Privacy International that made this work possible. Lastly, we thank the participants for their willingness to share their experiences, which enriched the findings of this research.

Funding: This research was supported by Privacy International which provided financial assistance for the study. The funders had no role in the design of the study, data collection and analysis, decision to publish, or preparation of the manuscript. We are grateful for their support, which made this work possible.

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