

Pathways to Impact in Digital Health: Studies in Malawi and Kenya

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Abstract

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Health inequities remain a persistent challenge, disproportionately affecting communities in low- and middle-income countries. In response, digital health is widely promoted as a way to expand access and improve quality of care. However, many initiatives fall short of their intended impact when technological solutions are misaligned with the realities of healthcare delivery.

This dissertation examines digital health interventions within health systems in Malawi and Kenya through three studies conducted in collaboration with global health partners and in-country stakeholders. The first study examines how the security and privacy of electronic medical records are experienced and managed in Malawi's HIV health system, highlighting the roles of governance, institutional capacity, and frontline practices in shaping data protection. The second study presents a contraceptive decision-support app for adolescent girls and young women in Kenyan pharmacies, demonstrating how intermediated interactions can enable person-centered care. The third study explores chatbot-based support for contraceptive decision-making in Kenyan pharmacies and proposes design guidelines for mediating stakeholder needs.

This dissertation argues that impactful digital health can be enabled by contextually grounded design and an understanding of the processes that support health system goals. It contributes human-centered design of digital health, sociotechnical insights into how technologies interact with care ecosystems, and design guidelines for future technologies that can strengthen healthcare delivery and contribute to advancing health equity and improving health outcomes.

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Glossary

ADOLESCENT GIRLS AND YOUNG WOMEN (AGYW): A population group of females aged 15–24 years.

ANTIRETROVIRAL THERAPY (ART): Medication used to treat HIV (human immunodeficiency virus).

DEPOT MEDROXYPROGESTERONE ACETATE (DMPA): An injectable contraceptive given in the arm or buttock every 3 months. It is also known as depo.

DIFFERENTIATED SERVICE DELIVERY (DSD): A client-centered healthcare approach that adapts services to meet the needs of individual clients. DSD models are usually community-based and commonly used for ART delivery.

EMERGENCY CONTRACEPTION (EC): Methods of contraception that can be used to prevent pregnancy after sexual intercourse. According to the World Health Organization, these are recommended for use within 5 days but are more effective the sooner they are used after the act of intercourse. Methods of EC are the copper-bearing intrauterine devices (IUDs) and the emergency contraceptive pills.

EMERGENCY CONTRACEPTIVE PILLS: These are taken to prevent pregnancy after unprotected sexual intercourse or contraceptive failure. These are also known as the e-pill.

ELECTRONIC MEDICAL RECORD (EMR): An electronic record of health-related information on a client.

LOW- AND MIDDLE-INCOME COUNTRY (LMIC): Countries with economies classified as low-income and middle-income by the World Bank.

NURSE-LED COMMUNITY ART PROGRAM (NCAP): A service delivery model at Lighthouse Trust, Malawi's public HIV care program, that provides ART to stable clients in the community.

OPEN DATA KIT (ODK): A suite of tools that allows organizations to build forms, collect data on mobile devices or the web, and analyze it.

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Dedication

*To my family,
for cheering me on every step of the way.*

Chapter 1

Introduction

Global health inequity is a pressing challenge in healthcare, often disproportionately affecting populations in low- and middle-income countries (LMICs). For instance, in 2023, sub-Saharan Africa accounted for 70% of global maternal deaths and a woman in the region was 400 times more likely to die in childbirth than a woman in Australia and New Zealand [185]. Such disparities are driven by a range of factors, including socioeconomic inequalities, poor infrastructure, and the lack of healthcare workforce [6, 149]. These structural challenges constrain the ability of health systems to deliver timely and high-quality care, particularly in resource-constrained settings.

In response to these constraints, there is growing consensus within the global health community that digital and information and communication technologies can help contribute to improved health and well-being [184]. The use of such technologies in healthcare, broadly referred to as digital health, has shown promise for expanding access to services and improving the quality of care delivery [128]. The widespread availability of mobile devices has expanded the reach of digitally supported care through mobile health (mHealth), enabling services such as remote data collection, quick communication between clients and providers, and access to health information outside traditional facilities [36, 92, 95]. Recently, artificial intelligence (AI) applications have been introduced to support frontline health workers in diagnosis and care delivery, as well as to provide individuals seeking care with tailored health information and decision-support [103, 288].

Despite this promise, many digital health interventions fall short of their intended impact. Numerous digital health initiatives in LMICs remain confined to small-scale pilot deployments and fail to scale or sustain beyond the initial implementation period due to limited evaluation mechanisms, fragmented governance, and insufficient integration into routine health system operations [87, 114, 116, 60]. A key reason for these shortcomings is the misalignment between

technological solutions and the realities and needs of health systems. These misalignments are particularly problematic because they can result in technologies that do not align with local care practices or address priority health needs, limiting their ability to meaningfully improve health outcomes or be sustained within routine service delivery.

Addressing these misalignments requires moving beyond a view of digital health as standalone technologies and instead examining them as interventions embedded within the complex and resource-constrained environments in which healthcare is delivered. Scholars in Human-Computer Interaction (HCI), Computer-Supported Collaborative Work (CSCW), and Information and Communication Technologies for Development (ICTD) have long emphasized the importance of grounding technological systems in the understanding of how people work and live within groups, organizations, and communities [29, 4]. Without such an understanding, technologies risk becoming unusable, ineffective, or disruptive to existing practices. The importance of understanding the broader ecosystem is also recognized by the World Health Organization (WHO) [184]:

“To realize their potential, digital health initiatives must be part of the wider health needs and the digital health ecosystem and guided by a robust strategy that integrates leadership, financial, organizational, human and technological resources...”

Adopting this systems-wide perspective requires careful attention to the specific challenges and conditions of local healthcare contexts, as well as the selection of interventions that align with the needs, priorities, and capacities of local health systems [85, 128]. This work also relies on close collaboration with global health scholars and stakeholders who have deep contextual knowledge of the environments in which technologies are deployed. Such partnerships are essential in all stages of digital health innovation, from design and development to implementation and scale-up, to ensure that technologies remain aligned with local needs and operational realities [128].

Building on these perspectives, this dissertation foregrounds the sociocultural contexts and institutional realities of health systems in LMICs to examine digital health interventions within real-world care environments. In doing so, it seeks to understand how technologies interact

with existing practices, infrastructures, and stakeholder dynamics to positively shape healthcare delivery and ultimately, advance health equity globally.

1.1 Thesis Statement

Health systems in LMICs operate within complex and resource-constrained environments characterized by workforce shortages, fragmented infrastructure, and limited access to care. Digital health should not be understood as isolated technological solutions, but as part of broader systems and processes that determine whether and how technologies can contribute to meaningful and sustained improvements in care delivery. This perspective motivates this dissertation, which advances the following thesis:

Impactful digital health can be enabled by contextually grounded design and an understanding of the processes that support health system goals.

To support this thesis, I examine three digital health interventions in Malawi and Kenya that span different stages of maturity, including the design of a new application and the evaluation of an existing system to strengthen its operation. Across these cases, this dissertation shows that designing effective digital health systems requires both careful attention to local healthcare contexts and a clear understanding of the governance structures, workflows, and human infrastructure that promote the effective use of technologies that can contribute to better health outcomes.

More broadly, my dissertation is motivated by the goal to advance health equity globally. For digital health to meaningfully support equitable care delivery, technology research must be closely connected to the health systems and communities it aims to serve. I therefore embed my research within global health initiatives and partner with in-country researchers and global health scholars to ensure that technologies are aligned with health needs, institutional priorities, and systems-level goals.

1.2 Outline and Contributions

This dissertation contributes human-centered design and development of digital health, sociotechnical insights into how technologies interact with care ecosystems, and design guidelines of future technologies. These contributions are intended to support the broader system of actors and processes working toward preferred futures of care and positive health outcomes.

Chapter 2 provides related work from global health, HCI, CSCW, and ICTD to identify structural challenges facing LMIC health systems, diverse care delivery models, and prior applications of digital health. This chapter establishes the social, institutional, and technological landscape within which the dissertation's contributions are situated.

Chapter 3 examines data security and privacy within Malawi's registered public trust that contributes to the national response to Human Immunodeficiency Virus (HIV) and acquired immunodeficiency syndrome (AIDS). The research was conducted as part of an initiative to expand mobile phone-based electronic medical records (EMRs) into community-based care. Through two qualitative studies engaging with stakeholders across various levels of the health system, this chapter presents how different stakeholders interpret and practice data protection. This chapter contributes a multi-level understanding of how data governance, institutional capacity, and frontline practices safeguard or compromise sensitive client data, highlighting the conditions under which digital systems can formalize and sustain best practices.

Chapter 4 presents a novel mHealth app for contraceptive decision-support for adolescent girls and young women (AGYW; aged 15–24 years) in the pharmacy setting in Kenya. It describes the iterative app development process grounded in human-centered design and findings from co-design workshops to evaluate an initial app prototype. This chapter contributes design insights into integrating mHealth into existing human infrastructures, emphasizing the role of pharmacists in accommodating heterogeneous AGYW needs and demonstrating how mHealth can support person-centered care in sensitive health contexts in community settings.

Chapter 5 presents research building on the work from Chapter 4 to understand how chatbots can augment app-supported contraceptive decision-making for AGYW in the pharmacy setting

in Kenya. Using speculative design and low-fidelity prototypes as design probes in co-design workshops, this chapter examines possible and preferable futures of chatbot-supported care. It contributes chatbot design guidelines and insights into how client-facing decision-support tools can surface and mediate tensions between clients and providers, redistribute authority, and introduce new risks within care ecosystems.

Chapter 6 synthesizes insights across research projects to articulate the broader contributions of embedded HCI research to global health. I describe how I have positioned myself and my research within global health initiatives and the broader insights that emerged from conducting HCI research in global health. I summarize the key contributions and work products that arise from this style of research and how they can support global health efforts.

Chapter 7 summarizes my contributions and future directions for HCI researchers working in global health.

Chapter 2

Related Work

In this chapter, I review related work to situate my research within existing scholarship. I primarily draw on global health literature to contextualize healthcare ecosystems in LMICs, and literature from HCI, CSCW, and ICTD to provide background on digital health. Project-specific related work is discussed in the respective chapters.

2.1 Healthcare Ecosystem of LMICs

This section describes the contexts of health systems in LMICs that pose challenges to access and quality of care, as well as common care models that are observed in LMICs.

2.1.1 Challenges to Healthcare

LMICs face a range of structural, social, and economic challenges that shape healthcare access and services. Many individuals encounter systemic barriers to accessing care in a timely manner, including inadequate infrastructure that contributes to delays in seeking, reaching, and receiving care [149]. Financial limitations compound these challenges, as many individuals struggle to afford transportation to healthcare facilities [45]. As a result, individuals must often navigate trade-offs between cost, accessibility, and perceived quality when deciding where and how to seek care [103, 166, 154, 270]. In many cases, this leaves them with no viable option but to attend understaffed and overcrowded facilities, where they must endure long waiting times, or abandon care altogether [103, 3].

At the same time, social and cultural norms and power dynamics shape how individuals engage with care once it is accessed. Gender power relations affect access to and utilization of

care. For instance, limited access to and control over resources, as well as constrained decision-making autonomy, can restrict women's ability to access maternal health services [155]. In many LMICs, high rates of maternal mortality and morbidity are also tied to gendered expectations, including pressure to have children early on and stigma associated with childlessness, which can increase risks to women's health [246]. Such stigma can influence many decisions throughout the healthcare journey, from where individuals seek care to whether they return for follow-up services [90, 225, 247, 126, 212].

Power asymmetries between clients and frontline health workers further shape health decision-making. In some cases, despite trusting providers, clients may be denied services due to providers' personal beliefs, moral positions, or financial motivations. For example, even in contexts without legal restrictions, providers might refuse contraceptive services to unmarried adolescents due to disapproval of premarital sexual activity [22, 218]. In many LMICs, limited health literacy and strong deference to medical authority further constrain client autonomy. Clients often follow provider recommendations without fully understanding the advice and may avoid asking clarifying questions out of fear of undermining professional authority [165].

The quality of care is further constrained by limitations in infrastructure, workforce capacity, and governance. Ministries of Health (MoH) face persistent difficulty with hiring, training, and retaining experienced specialists due to competition with the private sector and non-governmental organizations (NGOs), both domestically and abroad, a phenomenon known as the brain drain [6], and the financial commitment associated with developing specialist skills [204]. While health workforce shortages are a global phenomenon, they are experienced more acutely in LMICs. For example, the United States had approximately 26 medical doctors per 10,000 people in 2022, while Kenya had only 2.6 per 10,000 people in 2024 [181]. Workforce shortages, spanning both specialist and general healthcare providers, place additional strain on already overburdened systems [6]. Providers working in understaffed environments are more likely to suffer from work-related stress and burnout [264], contributing to high turnover [156] and diminished motivation and performance [62]. The lack of specialist staff makes the management of complex cases more difficult and can lead to overcrowding of healthcare centers [204]. These challenges are compounded

by inadequate client records and limited access to essential equipment, which hinder efforts to improve service quality [174, 204]. Finally, gaps in governance, policy dissemination, and clinical guidelines impede the consistent adoption and implementation of improved care practices [174].

2.1.2 Care Delivery Models

Healthcare services are traditionally delivered through a facility-based care model, in which clients are expected to travel to static sites of care to receive services. Simultaneously, services can be offered through community-based care models in settings where people live and congregate, extending services beyond formal facilities [57]. For instance, differentiated service delivery (DSD) models are led by healthcare providers or recipients of care and conducted with peer supporters from the community to promote treatment adherence and offer social support [140]. This model is commonly used for delivering HIV services in LMICs and designed to be client-centered to reduce the burden on both clinic staff in comparison to standard facility-based models.

In many settings, community health workers serve as the first point of contact connecting community members to the health system, increasing coverage of basic health services in hard-to-reach areas and playing essential roles in addressing the global health worker shortage [180, 8, 103]. In LMICs, commercial retail settings such as pharmacies also play an important role in accessing essential medicines and services, helping communities overcome geographic barriers to care [129]. These retailers often offer greater convenience to consumers and their perceived confidentiality and non-judgmental environments can encourage clients, particularly those who fear facing stigma from providers, to seek services there [80, 81]. However, retail settings face downsides; they may provide medicines with limited history-taking or counseling, stock poor-quality medicines, and pharmacy workers often lack formal medical training [269, 152].

2.2 Digital Health in LMICs

Digital health broadly refers to applications of digital technologies used in healthcare that aim to improve the access to healthcare and the quality of healthcare delivery [128]. A prominent example

of digital health in facility-based care is EMR systems, which compile client health information gathered during clients' interactions with providers and improve data management, data quality and clinical productivity [258, 34, 109].

The growing availability and use of mobile devices has significantly advanced the digital landscape, enabling mHealth, the use of mobile wireless technologies for public health [36]. In LMICs, where infrastructure and workforce constraints often limit access to facility-based care, mHealth has helped extend the reach of healthcare services, enabling client-provider communication via short messaging services and health education for individuals seeking care [92, 266, 203]. Mobile devices have also offered benefits to frontline health workers, allowing them to collect data beyond static care sites [191, 56, 186], monitor treatment adherence remotely and in real-time [51, 92], and conduct follow-up care outside clinical settings [68]. Open Data Kit (ODK), an open-source suite widely adopted in LMICs, is an example of an mHealth application that has supported large-scale data collection, storage, and transfer in resource-constrained health systems since 2010 [95].

While the benefits of digital health are broad, technologies can complicate client-provider dynamics by reinforcing existing hierarchies. For instance, clients perceive computers at the point-of-care as physical and symbolic barriers to engaging with providers, elevating providers' authority while reducing opportunities for dialogue [39, 231, 50]. To address such challenges, researchers have proposed conceptual framings that position technologies as shared infrastructures capable of supporting collaborative interaction rather than reinforcing hierarchy [117, 216, 99, 39]. These relational dynamics underscore that digital health intersects with existing authority structures, trust relationships, and social norms that shape how care is experienced and negotiated.

More recently, there has been a growth in AI applications to address some challenges in LMIC-based healthcare. AI has been used to overcome limitations in medical education capacities and to improve the quantity and quality of medical care [46]. For instance, AI-powered clinical decision-support systems augment provider decision-making by generating client-specific recommendations and supporting diagnostic reasoning [271]. In community settings, mHealth-based AI tools offer low-cost and scalable support for diagnosis and screening for community health workers [103].

Despite enthusiasm around AI's potential, HCI for Development (HCI4D) scholars have taken a cautious approach towards developing and implementing AI applications in LMICs. Researchers emphasize the importance of understanding local needs, perceptions, and sociocultural dynamics before integrating AI into existing care systems [179, 177, 137, 104, 76]. This body of work underscores that technological innovation alone is insufficient; meaningful impact requires careful attention to how digital tools intersect with human relationships, institutional capacity, and broader care infrastructures.

Chapter 3

Secure Digital Systems for HIV Care in Malawi

Digital systems in clinical contexts have shown promise in optimizing the management of client health and data, facilitating client-provider and provider-provider communication, and improving treatment and care outcomes [114]. In many LMICs where HIV prevalence is high, EMRs are critical for monitoring and evaluating care and outcomes across the HIV care cascade, which include testing, diagnosis, and antiretroviral therapy (ART) [24, 258, 278, 34]. However, realizing this potential depends on ensuring the security and privacy of sensitive client data that EMRs manage. If confidentiality is compromised, clients can face social stigma and discrimination. As a result, strengthening data security is a critical consideration for making digital health systems safe, trustworthy, and ultimately effective in improving health outcomes.

This chapter presents research that was conducted through an invitation from a global health researcher partnering with a public HIV care program in Malawi. This research was motivated by a need to understand how Malawi's health system can support efficient and streamlined ART services as part of an effort to extend EMR use to reach broader services. In collaboration with local researchers, I led qualitative, field-based research to understand how to improve the security of an open-source mobile medical record system. I developed study protocols and conducted interviews and focus group discussions with stakeholders in the HIV health system, namely ART clients, nurses, data clerks, IT officers, and data decision makers. Recognizing that these stakeholder groups have distinct roles, interests, and experiences with EMRs, my team and I formulated separate research questions tailored to each group. Through focus groups with ART clients, I examined the following research question: **How do ART clients perceive privacy, data protection, and processes for data collection and use?** Through interviews with data stakeholders, referring to nurses, data clerks, IT officers, and data decision makers, I examined

the following research question: **How do data stakeholders perceive the security of EMR systems and what changes do they wish to see to strengthen data protection?**

This work contributes a sociotechnical account of data security in a public HIV care program, demonstrating how security and privacy are experienced, interpreted, and enacted by different stakeholders within the health system. By engaging both ART clients and data stakeholders, this research reveals how perceptions of risk and trust vary across roles, and how these differences shape the security of EMR systems in a sensitive, low-resource context. Rather than treating data security as a purely technical concern, this research highlights the relational and organizational factors that influence how digital health systems can be used safely and effectively at scale. These insights inform implementation considerations for strengthening digital health infrastructures in resource-constrained settings, particularly where health data and stigma intersect.

In this chapter, I first provide an overview of the public HIV care program in Malawi and related work on security and privacy, client perspectives towards data collection, and governance of EMRs. Next, I describe the qualitative research methodology and present the study findings. I synthesize insights from the various stakeholder groups to examine where perspectives intersect and diverge, and how these insights inform recommendations for building more robust and secure digital health systems. The results of this work were published in *Proceedings of the 2024 CHI Conference on Human Factors in Computing Systems* [186] and *Proceedings of the ACM on Human-Computer Interaction* [187]. I also published a related paper in *PLOS One* [189], but that is beyond the scope of this dissertation.

3.1 Background & Related Work

This work was conducted in Lilongwe, the capital city of Malawi, a country in Southern Africa with over 50% of the population living in poverty in 2019 [33]. As of 2017, Malawi had over 1,000,000 people living with HIV (PLHIV) (9.6% of people aged 15–49) [260]. This work was done in partnership with Lighthouse Trust (hereafter referred to as Lighthouse), a registered public trust and a WHO recognized center of excellence whose role is to support the Malawi MoH in their national HIV response. Lighthouse provides services spanning integrated HIV prevention,

testing, treatment, and care in partnership with the MoH.

Lighthouse facilities, which are static sites of care, employ Malawi's real-time point-of-care EMR system, launched in 2010, to ensure that ART services comply with HIV guidelines and to ease client- and clinic-level monitoring and evaluation. These EMRs are accessed using desktop computers stationed at the facilities, at the reception desk, vital signs station, laboratory, examination rooms, and pharmacy, to enter and access EMRs, as shown in Figure 3.1 (left).

Lighthouse also implements a Nurse-led Community ART Program (NCAP), a DSD model to provide ART to 4000 stable Lighthouse clients in the community. NCAP clients are registered at facilities and can access ART services at one of 120 community-based distribution points within Lilongwe, including churches, schools, outdoor areas, and client homes. NCAP nurses capture program data on an offline tablet-based application, as shown in Figure 3.1 (middle), that operates in rural environments with low connectivity. Due to restrictions in connectivity and automatic data synchronization, tablet data must be manually back-entered into the EMRs at the facility computers, which act as access points to the EMR system. While tablet-based data collection expands care to community settings, it is error-prone and inefficient, risking data exposure or data loss and compromising effective NCAP and Lighthouse program management.

Across care settings, clients bring paper-based health passport booklets to appointments, as shown in Figure 3.1 (right). Each ART client is issued an ART barcode that is attached to the health passport. The barcode is scanned at facility computers and entered manually in NCAP tablets to confirm client identity and to facilitate longitudinal data capture. The health passport is used to check in the client for the appointment and for the provider to manually record information relevant to the client's health.

In direct response to NCAP nurse needs [115] and global calls for evidence on DSD outcomes [290, 140], Lighthouse is testing a new offline-first tablet-based app to expand the reach of EMRs to NCAP settings to facilitate efficient data collection and make client history available to providers. This innovation would remove the duplicative process of manually back-entering the tablet data to the EMRs in Lighthouse facilities.

This new app requires a wide variety of stakeholder support and an understanding of diverse

stakeholders' concerns and perceptions towards the data collection cascade, including the security and privacy of health data. As clients already provide their data at Lighthouse in either facilities or NCAP settings, it is important to ascertain their perspectives on electronic data collection to inform improvements for data collection, privacy protections, or data storage procedures. For buy-in and scale-up support, it is essential to understand feasibility, acceptability and usability of electronic and mobile data collection from providers, data clerks, IT officers, and data decision makers from within Lighthouse and the MoH.



Figure 3.1: Three data collection and management tools used at Lighthouse. Left: Computer used as an EMR access point at a reception desk at a Lighthouse facility. Middle: Tablet used by nurses during an appointment for NCAP. Right: Health passport booklets that ART clients bring to appointments.

3.1.1 Security and Privacy in LMICs

Researchers argue that security and privacy notions from the West and high-income countries (HICs) cannot be fully applied, unchanged and uninformed, to address the needs of people in LMICs [11, 242, 265, 221, 105, 15]. Preferences, expectations, and notions of security and privacy can be contextual, driven by culture, socioeconomic backgrounds, gender, and digital literacy [168], and centers local perceptions to inform threats, knowledge gaps, and influences to strengthen local security practices [265]. There is nevertheless a universal desire for safeguarding and protecting privacy [221, 11, 242]. For instance, Cobb et al. [48] present a threat modeling for ODK [95], a data collection tool used in LMICs, and identifies data confidentiality, integrity, and availability

as possible security and privacy goals of stakeholders. These principles, commonly referred to as the ‘CIA triad’ in computer security literature, are understood and desired globally [40, 199, 35, 105, 242, 38, 215]. While the goals of security and privacy are shared globally, implementing effective security remains challenging. Many of the difficulties in establishing and sustaining security measures in LMICs mirror those faced in HICs, including the need to balance security with usability and system functionality. [21, 277, 69, 106, 192, 240].

Standard best practices emphasize a combination of technical safeguards, such as encryption and access control [120, 200, 291, 40, 11], and behavioral measures, including training and education to raise awareness of security threats [199, 198, 38]. Across contexts, this sociotechnical approach is considered a strong response to privacy threats [159, 198, 12, 274, 73, 240] and has been promoted in healthcare contexts globally [40, 198, 197], where protecting privacy is essential to technology-mediated healthcare work. While there is a significant amount of literature exploring privacy threats, defenses, and practices in collaborative healthcare work in HICs [40, 193, 159, 26], this has not been examined in depth in LMICs, especially from the perspective of people managing healthcare programs and of those receiving healthcare.

3.1.2 Client Perspectives towards Digital Health Data Collection

In HICs, where technologies for health data collection are commonly used at the point-of-care, clients’ perceptions towards electronic data collection have been extensively studied. Clients want to know who accesses their data and desire control over the sharing of data [228, 31, 118, 157]. While clients are willing to contribute their data to inform public health decision-making [276, 123], concerns about data privacy can contribute to their hesitancy [289, 61]. These concerns arise from the lack of awareness of data sharing mechanisms, which is caused by clients’ unfamiliarity with the technical processes for electronic data sharing [63]. To address such issues, researchers emphasize the importance of building trust between clients and the health system through clear, transparent, and comprehensible policies around data sharing and privacy [61, 63]. Client trust is critical for protecting client privacy and for creating buy-in from clients to participate in data sharing [276, 102]. However, data collection devices such as computers can pose physical and

communicative barriers to client-provider engagement by raising perceptions of provider authority and medical expertise [39, 231, 50].

While the understanding of clients' perspectives towards digital data collection in clinical settings remains underexplored in LMICs, there is an abundance of research from the 2010s that examines how individuals perceive the use of data collection tools for health surveys in LMICs [42, 41, 234, 148]. Device familiarity impacts survey respondents' device acceptability and their willingness to answer survey questions [41, 263, 121, 150]. For instance, a study in Angola in 2011 found that the lack of introduction to personal digital assistants used for surveys contributed to respondents' apprehension to answer HIV-related questions and disclose sexual behaviors to interviewers [41]. However, in Sri Lanka in 2014, where respondents were familiar with handheld devices because of the wide availability of mobile phones, survey devices were conducive to attracting interest to the survey itself [121]. Data confidentiality was an important factor that impacted survey respondents' willingness to share health information. Computers were perceived to be more secure than paper for recording and storing personal data because limited digital literacy restricted access to data and because paper was more prone to misplacement or damage [41, 150]. More broadly, security and privacy views can derive from individuals' experiences with technologies, their health, and varying sensitivities around their health conditions [139, 31]. Especially in the context of sensitive or stigmatized topics such as HIV, respondents' acceptability of technology for health data collection is critical for obtaining accurate information [41].

3.1.3 Governance of EMR Systems in LMICs

Many EMR system implementations in LMICs are unsuccessful due to weak healthcare infrastructure [240]. While the reasons for failure are typically assumed to be the high cost of set-up and maintenance and technical pitfalls [13, 72], the challenges of adoption and implementation are rarely related to technology itself, but rather the lack of regulation and guidance [10, 240, 116, 60]. In fact, many LMICs have not yet been successful with developing, implementing, and enforcing comprehensive legal frameworks and governance for EMR systems [27, 164].

Despite challenges, there are examples in African countries that successfully implemented

EMRs at scale. These successes, which strengthened health systems, were done by aligning digital health efforts with national priorities [160]. For example, in Rwanda, a collaboration between the MoH and Partners In Health, an international public health organization, led to the co-development of an open source EMR system known as OpenMRS [144]. This partnership played a key role in the MoH's implementation of a nationwide comprehensive EMR system that ensured that parallel systems were not created [160]. OpenMRS has been implemented in over 62 countries [268], with countries joining the community to receive mentorship for learning and developing the software for local contexts [158]. While these cases demonstrate the value of partnerships, digital health interventions often fail to achieve their intended impact when partners' strategies or priorities diverge from one another or from those of the implementing country [163]. To effectively navigate collaboration, digital health initiatives should align with countries' needs, priorities, and policies [163, 160], use standardized project management protocols [217, 5], and close gaps between the objectives of management systems and structures and their execution [96]. Implementation should be approached holistically, taking into account the functionality, organization, and technical infrastructure needed to sustain innovation [74].

3.2 Interviews & Focus Group Discussions

3.2.1 Study Setting

Lighthouse is the largest public provider of ART services, covering urban, peri-urban, and rural populations throughout the Lilongwe district. Lighthouse is widely recognized for its innovations and efforts to improve the quality of care over two decades of HIV-related service delivery [67, 205]. In urban Lilongwe, Lighthouse runs two large flagship facilities. Lighthouse also supports care at nine peri-urban satellite sites in Lilongwe district. Across sites, Lighthouse implements the same training, policy, and practices, including use of the Malawi MoH's real-time, point-of-care EMR system.

Clients from Lighthouse facilities may be referred to NCAP if they meet the following criteria: (1) at least 18 years of age; (2) clinically stable; (3) on ART for at least 6 months; and (4) member of

a peer support group. All NCAP clients previously received services at Lighthouse facilities. NCAP operates in the community during routinely scheduled peer support meetings held in churches, community centers, schools, or other gathering places according to the peer group preference. NCAP clients meet with a community nurse who visits that location with an established peer support group every three to six months.

3.2.2 Study Design

To investigate diverse stakeholders' views on data security and privacy at Lighthouse to expand the understanding of gaps and opportunities in addressing client data protections, two qualitative studies were conducted between September–October 2022:

1. Focus group discussions (FGDs) with Lighthouse ART clients who were enrolled in Lighthouse facilities or NCAP. Eight FGDs were conducted: four with clients who received facility-based care (two at each flagship facility) and four with clients who received care through NCAP. Eight FGDs were determined to be sufficient to reach theoretical saturation of key themes [97].
2. Key informant interviews (KIIs) with data stakeholders in Lighthouse and the MoH who collected or managed routine ART data from EMRs or who informed EMR data policy or practice. Data stakeholders are NCAP nurses, data clerks and IT officers, and data decision makers.

3.2.3 Participant Recruitment

In total, four stakeholder groups were formed and recruited, as described below.

1. **ART Clients:** ART clients were enrolled in the Lighthouse facilities or NCAP. All clients in this study were eligible for NCAP, but either chose to remain in facility-based care or opted into NCAP. NCAP clients were stable ART clients who were also registered at facilities, but mainly accessed ART services at community-based distribution points near

their homes. NCAP clients were familiar with computer-based data collection at the facilities and tablet-based data collection in NCAP.

2. **NCAP Nurses:** NCAP nurses were responsible for providing care to stable clients on ART at NCAP settings outside of facilities. They used paper and a tablet-based app for data collection and documentation. After nurses completed appointments at the NCAP settings, they transported the tablets and paper records back to the main Lighthouse facility.
3. **Data Clerks and IT Officers:** Data clerks exported NCAP tablet data as CSV files, printed the files, and then manually re-entered the data into the facility's EMR system. IT officers were most knowledgeable about the technical protections and technology practices at Lighthouse and monitor the data flow, transfer, and quality.
4. **Data Decision Makers:** Data decision makers include Lighthouse program managers who were well-versed in client data protections, data collection training, facility- and NCAP-based data collection, data verification, and processes to ensure quality data aggregation across settings. Also included were MoH members who were knowledgeable about the management and usage of individual-level and aggregate HIV-related data at the national level.

Eligible PLHIV on ART from the Lighthouse facilities and NCAP were identified at clients' routine care settings. Purposeful sampling [253] was used at two flagship facilities and four NCAP care locations to enroll 63 ART clients in eight FGDs. Lighthouse staff providing care for both models screened clients for study eligibility: (1) age 18 and above; (2) at least a primary education; (3) written voluntary consent to FGD participation; and (4) permission to audio record the discussion. FGDs were conducted at the location of participants' routine care model, either the facility or NCAP site. ART client participants were compensated with 10310.00 Malawian Kwacha (approximately 10 USD) for their participation.

In a private location, each eligible ART client individually underwent an informed consent process. Appropriate information and explanation of the study goals and objectives were also

provided in a consent form written in an accessible language level for improved comprehension. The process of obtaining informed consent was prepared by the local staff in Malawi, taking into account the average literacy levels of their clients. The consent form highlighted two key points: (1) the voluntary nature of participation in the study, emphasizing that it is entirely up to the individuals to decide whether or not to take part and (2) ensuring that their decision to participate or not will not have any negative impact on the ART care. The local study staff provided detailed information about the study procedure, including the use of audio recording. The risks and potential benefits of study participation were discussed and questions answered. After signing the consent form, clients were still able to refuse to answer questions or withdraw from the study.

To gain an understanding of data security practices, concerns, and use of EMRs, 14 data stakeholders who required or reviewed data as part of their ART-related work were recruited, namely NCAP nurses, data clerks and IT officers, and data decision makers. The sample was considered feasible and appropriate for this exploratory study and is in line with a recent review of qualitative studies that noted that interviews with 9–17 people were sufficient for thematic saturation [97]. While most participants were not information technology experts, the goal of recruitment was to gather experts with different areas of data-related expertise to capture diverse security- and privacy-related perspectives and experiences of representative roles within Lighthouse and the MoH. Thus, participants were intentionally recruited through purposive sampling [253] with the support of the Malawian study team who were deeply embedded in the Lighthouse’s health system and understood the various roles within it. Eligible data stakeholders were recruited from Lighthouse and the MoH and collected, used, synthesized, managed, or aggregated routine ART data from EMRs or informed EMR data policy or practice.

3.2.4 Data Sources and Collection Process

FGDs with ART Clients

A total of eight FGDs were conducted: four in facilities and four in NCAP settings. Each FGD was composed of seven to nine participants and was facilitated by a Malawian qualitative researcher

with support from a notetaker. All FGDs were conducted in Chichewa, the main language used in Malawi.

Each FGD began with a short introduction by the facilitator, including the background, purpose, and objectives of the study, and a review of confidentiality and consent guidelines. Participants were then asked an ice-breaker question about their preferences for care settings to allow them to gain comfort in speaking. Next, participants were asked about the flow of their appointment visits, what information they shared with providers, and how providers used the devices for data collection tools in their routine care setting (i.e., computers at facilities, tablets at NCAP settings) during appointments. Participants were also asked to compare the devices used in their routine care setting to other tools they saw being used at Lighthouse, such as paper records (e.g., *“In thinking about how your providers record your information in a computer or on paper, which do you prefer and why?”*). Participants were asked about their comfort with their health information being collected with devices, how they made sense of how the devices were used (e.g., *“How do you know that the provider is entering your data into the tablets if you cannot see what they are doing?”*), and how they thought devices affect care (e.g., *“How do you think the tablets affect the way your providers guide your care?”*).

The next set of questions aimed to understand participants’ mental models of data flow and management. Participants were asked about data storage and transfer (e.g., *“How do you think your health information moves from the computer that the provider uses to other people at Lighthouse?”*). To understand participants’ perceptions towards access to personal health information, participants were further asked to identify entities with whom they would and would not want their data shared with, explain views on data sharing with the MoH and authorized entities (e.g., *“What do you think the MoH does with the data?”*), and share concerns about sensitive information being seen by individuals outside of the health system (e.g., *“How would you feel if your health information is accessed by your family or your neighbors?”*). After participants were informed of a Malawian policy that required local data hosting for local partner digital health implementations, they were asked about their views on the country’s efforts to protect their data.

Lastly, participants were given time to share feedback for Lighthouse and to ask questions

about data security and privacy and data management which were not addressed during the session. Each FGD lasted approximately one hour.

KIIs with Data Stakeholders

Three separate interview guides were developed, making a distinction between the questions asked to each of the three data stakeholder groups, given differences in groups' interactions with the EMR system and client data. Modifications based on the stakeholder group allowed for interviews tailored to a participant's area of expertise and role within the health system. Feedback on the interview guides from Lighthouse's study team were incorporated to improve question clarity, content, and contextualization.

All interviews were conducted in English, an official language of Malawi, and audio recorded with participants' consent. In all interviews, participants were asked about their perceptions towards electronic data collection and paper-based data collection to compare the security of these data collection approaches. All interviews ended by inquiring about other concerns or opinions around security and privacy that were not addressed during the interviews and recommendations for improving the security of client data. Interviews lasted approximately 45 minutes. Details on tailored interview guides for each stakeholder group are described below.

NCAP Nurses: Interviews with NCAP nurses were focused on understanding tablet usage during data collection in NCAP settings, daily security- and privacy-related practices during data collection, and attitudes towards device and data management. Participants were asked about concerns related to electronic data collection and management, security protocols they followed while using tablets (e.g., *"Can your colleagues use the same tablet as the one you use?"*), understanding of data flow (e.g., *"How does the data you collect in NCAP get transferred to the EMR?"*), and perceptions towards data sharing (e.g., *"What concerns do you have with how or with whom the data is shared?"*).

Data Clerks and IT Officers: Interviews with the data clerks and IT officers focused on understanding how security was executed during the data review and management process and Lighthouse's technical security measures. Participants were asked about how they defined

the security of EMRs, security measures and potential threats in electronic data collection and management (e.g., “*Who has access to what data?*”), and proper usage of tablets (e.g., “*How can nurses and clinicians use the tablet to ensure that the data is kept safe?*”).

Data Decision Makers: Interviews with data decision makers were aimed to gather participants’ perceptions towards device and data management, data pipeline supervision, and aggregation of data to inform data-related policy or practice decision-making. These participants were asked about concerns around data collection in facilities and NCAP, concerns around data storage and data transfer (e.g., “*What are your concerns with data transfer from Lighthouse to MoH?*”), data usage at the national level, perceptions towards policies for client data protections, and recommendations for enhancing security at the facility and NCAP sites (e.g., “*What do you wish Lighthouse would do to ensure the confidentiality of clients and electronic data?*”, “*What policy or practice would make you feel more comfortable with the new NCAP app?*”).

3.2.5 Data Analysis

FGDs were translated and transcribed into English by a local qualitative researcher. Audio recordings of KIIs were transcribed into English for analysis. For each dataset, a mixture of deductive and inductive thematic analysis [28] was used to code all transcripts. Initially, I developed a codebook while conducting a detailed reading of all transcripts and returned to the transcripts to apply the codes. A secondary researcher reviewed the code application and disagreements were resolved through discussion. The secondary researcher did not add new codes but helped refine the language and meaning in the initial codes. As a researcher with more than a decade working at and with Lighthouse, the secondary researcher also provided a larger view of the environment and history of the responses, helping add nuance and trustworthiness to the codes and their refinements. Similar codes were grouped into higher-level themes, reflecting those suggested a priori from the study guide (deductive) and from reviewing participants’ contributions (inductive). The themes and their alignment with quotes was discussed at three separate meetings with the Lighthouse study team, fine tuning the themes and illustrative quotes until all believed that the findings and discussion points reflected the diverse perspectives of clients.

3.2.6 Ethical Considerations

This study was approved by the University of Washington Institutional Review Board (STUDY00013936) and the National Health Sciences Research Committee of Malawi (2968). All participants provided written informed consent. I worked closely with the in-country team on all aspects of the study design, refining of the study procedure, implementation, and interpretation of the findings. This included working closely and on-site with a local qualitative interviewer to refine the study protocols. The local interviewer is a seasoned qualitative researcher who is part of the Lighthouse team and is well acquainted with the community, the clients, the sensitivities, and the clinic setting.

3.3 Findings: ART Clients

63 ART clients (51 females, 12 males) from Lighthouse’s two urban facilities and four NCAP settings participated in FGDs. The median age was 47 (IQR 41–56), 81% were female, 51% received care from NCAP, and 49% from facilities. In this section, participants are identified using the format P#-[site of care], where P# denotes the participant number and the site of care indicates where they received services, as shown in Table 3.1.

Table 3.1: Participant characteristics of ART clients at Lighthouse Trust by site of care.

Site of Care	Participants (n; % female)	Median Age
Facility1	8; 6 females (75%)	40
Facility2	7; 5 females (71%)	41
Facility3	8; 6 females (75%)	34
Facility4	8; 5 females (63%)	56
NCAP1	8; 6 females (75%)	54.5
NCAP2	7; 7 females (100%)	48
NCAP3	8; 7 females (88%)	50
NCAP4	9; 9 females (100%)	45

3.3.1 Selective Disclosure of HIV Status

Disclosure of positive HIV status is a complex challenge and experience faced by PLHIV. When explaining their discomfort with their data being accessed by individuals outside of the health system, clients referred to their fears of unintended disclosure of positive HIV status. Clients were concerned about having their positive HIV status known publicly, as there were “[people] who diminish our respect, they say bad things” (P4-NCAP2).

To avoid having their status wrongfully exposed, some ART clients engaged in selective disclosure, in which they carefully considered which individuals to disclose their status to and what to disclose. Disclosing to trusted individuals empowered clients to establish a support system that encouraged them to adhere to treatment. Participants said that their friends or family helped them take their medication and get medication refills from Lighthouse and provided transportation money for appointments. While some emphasized the importance of disclosing their status to their families, especially their children, to garner support, others chose not to disclose to their families because they could face discrimination:

“In a family where people love each other, it is not difficult...But there are some cases where it is hard to disclose. For [PLHIV], we consider ourselves to be from one family and whenever we hear that one of our friends is not fine, then we need to rush and help, so that when others come, we have already rendered a helping hand.” — P9-NCAP4

This quote also speaks to how the concerns of wrongful status exposure were minimal when sharing their status to other PLHIV. In NCAP, clients relied on group leader clients for assistance when one was sick or for retrieving medication, forms of medical support that could only be provided when sensitive information was shared in their trusted circle. Rather than hiding their HIV status, disclosure to other PLHIV was viewed as a critical experience that can foster hope for a healthy future, for others and for themselves:

“I was comfortable disclosing to everyone because if I am to keep it to myself, I would have died by now. Because when you disclose to someone about your status, they tend to

share with you some other ideas. You also motivate others who come and ask how you managed to open-up, in that case you are helping other people...But when I open-up and shared about my status, I noted that some of them became comfortable and asked me how I take care of myself so that they can do the same.” — P3-Facility4

However, because of the consequences of unintended disclosure, clients expressed an obligation to protect fellow PLHIV from discrimination and stigma. One client shared how they encouraged another PLHIV to join Lighthouse’s NCAP without revealing that they had accidentally come to know of this person’s positive HIV status:

“I escorted my neighbor to maternity. She gave me the health passport and I happened to be playing with it in my hands. She didn’t tell me that she is positive and on ART, but she saw me with her health passport. I just gave it back...She later opened-up [about her HIV status] when we got home...I told her that I am going to the clinic to get my medication since I am on treatment. That is when she asked me that you are on medication, she said that she is on treatment. She is also one of the NCAP members. I had maintained confidentiality at the time and didn’t tell anyone.” — P5-NCAP2

While clients were cautious of who to disclose their HIV status to, there were unavoidable risks of unintended disclosure, including in their decision to seek care at Lighthouse, which is a widely-known provider of ART services: “[The cleaners and guards at Lighthouse] are talkative... When you are passing by, they will say ‘don’t admire her hips, she was at Lighthouse’” (P7-Facility1). The ever-present risk of inadvertent and unwelcomed disclosure permeated ART decision-making among clients, from choosing where to start care to adhering to treatment.

3.3.2 Trust in the Health System to Protect Data

Clients agreed that publicly exposing personally identifiable information (PII), including name, phone number, and address, would not only be a violation of one’s rights, but would have severe consequences for their well-being and mental health. They expected the health system to protect

their sensitive information with the utmost care and expressed clear views about who should and should not have access to their data. Clients were comfortable with their information being shared with healthcare providers, trusted family members, the MoH, program supervisors and coordinators, district health officers, NGOs, and international partners including donors.

At the same time, clients demonstrated a nuanced understanding of data access within Lighthouse. They emphasized that access should be limited to individuals whose roles involve collecting or managing client information. Beyond assigning access based on job responsibilities, clients noted that individuals requesting access should have a specific purpose for accessing the data.

Trust in National Efforts

After learning about the MoH policy requiring local data hosting for implementing partners' digital health systems, many clients responded positively: *"It is good, it is giving us a picture that [the MoH protects] the Malawians and that everyone has the right regarding their health. In addition to that, we are protected"* (P6-Facility2). They viewed the policy as an important measure for protection. At the same time, some participants expressed uncertainty about the policy's implications, particularly regarding how health data might still be shared internationally. Their questions suggested confusion about the distinction between de-identified aggregate data and client-level data containing PII. For example, several clients recognized that sustaining Malawi's HIV response depended on continued international support and funding. As a result, they expressed concern that restrictions on data sharing might inadvertently affect the country's ability to maintain HIV programs and support ART clients' health: *"We hear that the drugs that are helping us are from the outside countries, so how do they keep the information confidential so that those outside Malawi wouldn't know?"* (P2-NCAP1).

Other participants demonstrated a clearer understanding of how data could be shared responsibly. They emphasized that research and media reporting should communicate broader health challenges without exposing individual identities, noting that such efforts should *"make known the issue that the people are facing and not the person"* (P6-NCAP4).

Trust in Lighthouse

Clients also trusted Lighthouse staff to execute their day-to-day work in a manner that respected and protected clients' privacy. Lighthouse was described as a caring organization that brought comfort to clients, helping to reinforce clients' trust that Lighthouse staff took precautions to protect client records. Their trust in Lighthouse as a whole stemmed from their observations that the staff properly handled their data, including paper records. Clients' trust in Lighthouse was strongly shaped by their interactions with healthcare providers. Participants widely believed that providers had good intentions and upheld professional responsibilities to protect client privacy. Several clients emphasized that they had never experienced or heard of providers disclosing clients' HIV status, which reinforced their confidence in the system:

“This is the headquarters and I noticed that our records are kept safe. They have never given me a wrong file. They always give one their right file. This means our files are well protected and no one can know about another person.” — P7-Facility4

At the same time, this trust sometimes shaped interactions in ways that limited clients' willingness to ask questions. Providers were viewed as authority figures with specialized knowledge, particularly regarding the digital devices used for data collection. Because of this perceived expertise, some clients hesitated to question providers during appointments, worrying that doing so might appear disrespectful or signal a lack of trust. As a result, the power dynamics embedded in provider-client relationships occasionally constrained opportunities for clients to seek clarification about how their data was collected or used, and how their health was being managed: *“If we are to ask them questions and show that we are being suspicious then the provider is also a human being and might tell us to go to someone [else] since we don't trust them” (P6-Facility2).*

3.3.3 Perceptions towards Data Collection and Management

Perceived Purposes of Data Collection Devices

ART clients had a partial understanding of the purposes and benefits of the computers used at facilities, tablets used at NCAP, and health passports. ART clients recognized that the computers and tablets carried clients' health information, such as when the client tested positive for HIV, the type of medication administered, appointment dates, and lab results that indicated viral load. Clients thought that data in the computers and tablets aided providers with accomplishing important tasks for care, including calculating adherence to medication, monitoring appointment compliance, and reminding providers to take blood samples. They assumed that providers could access client history with the devices, like a *“bank where one can get the bank statement [to] show you your account activities”* (P5-NCAP2) and helped providers follow the right procedures and provide the right care, such as prescribing new medications. Outside of appointments, clients believed that the devices were helpful for calculating the number of drugs to bring to NCAP visits and transferring data to other providers.

While clients had a nearly accurate understanding of the capabilities of computers and tablets used in care, these were at best, educated guesses. Clients explained that providers did not directly communicate how devices were used, leaving some to wonder how the devices were actually purposed for their care, during and after appointments: *“what we know is that the provider documents for us, whether they write what we told them or not, we don't know”* (P8-NCAP3).

Comparing Digital to Paper-Based Data Collection

Participants felt that paper records created a greater workload for providers than computers or tablets, particularly for entering and searching for data. Searching client information with devices was thought to take minimal effort because clients assumed that all of the important information was stored in them:

“We registered during the first visit. When I reported for the second time, they just asked

about my phone number and searched it on their tablet and they were able to find all the information, which shows that it is easy. If it was paper-based, then [my information] could have been lost.” — P7-NCAP1

Clients agreed that digital devices protected data better than paper records. Health passports were easier to access while computer-based documentation was not accessible to everyone because not all knew how to operate such devices. Clients recognized the value of password protection and viewed restricted password access as an advantage of computer- or tablet-based data collection over paper records. The most serious concern with paper records was their susceptibility to damage. Digital data, on the other hand, was viewed as more permanent and less vulnerable, partly because there were multiple access points in the facilities and protection mechanisms. However, the most notable benefit of paper-based records, specifically health passports, was that clients maintained access to and control over their health information, although some written clinical notes could be difficult to interpret, leaving clients to wonder about their diagnosis and next steps for health management:

“It is our right to access the information. There are others who do not have time to ask the providers about their viral load and that information is kept in the health passport. We can also see the information that has been documented in the health passport... One can lose the health passport, but when you report to the facility, they check and find your [client] ID. This shows that these two approaches are good. Health passports keep the information for themselves, and the other information is kept at the facility in the computers.” — P8-Facility3

Making Sense of Data Flow

Through personal experiences, clients made sense of the data flow in the continuum of care. During facility appointments, clients visited multiple stations to meet different staff and discuss various information. In this process, they observed that their information was linked across the computers at different stations and could be accessed by entering client ID. As a result, information

was presumed to be shared among staff to maintain a consistent understanding of the client's health and to prevent critical information from being overlooked during appointments.

Clients also recognized that data collected through NCAP was transferred back to the Lighthouse facilities' computers and records. Some clients described how facility staff could retrieve their information when they arrived for care. Clients viewed this transfer of data as important for continuity of care, noting that their information would still be available even when they visited the facility outside of NCAP service days: *"One time when I reported to the facility, I would just go and mention my name and the computer would be able to show all the information"* (P8-NCAP3). Notably, while only a couple of clients were able to articulate how they thought data transferring occurred, these participants alluded to the similarity between tablets and personal mobile phones, saying that the way in which data transferred from the tablet to the computer was like *"the way we do with our phones, by forwarding the information... like a message"* (P6-NCAP4).

3.4 Findings: Data Stakeholders

14 data stakeholders participated in the KIIs: three NCAP nurses, five data clerks and IT officers, and six data decision makers. NCAP nurses are referred to as nurse-#, data clerks and IT officers as tech-#, and data decision makers as data-#. Most, but not all participants were male. Demographic details of data stakeholders are described in Table 3.2.

3.4.1 Multi-Level Dedication to Best Practices in Security and Privacy

Participants had a shared understanding that they collectively and individually had a responsibility to protect client data. Trust was placed in multiple actors of the HIV health system and drove forward the collaborative and collective efforts to protect client data. Aside from the group-level commitment to implement best practices in security and privacy, individuals carried out additional tasks in their day-to-day work to ensure that client data was protected.

Table 3.2: Participant characteristics of data stakeholders at Lighthouse Trust.

P#	Affiliation	Position	Years of Experience
nurse-1	Lighthouse	NCAP Nurse	>5
nurse-2	Lighthouse	NCAP Nurse	>10
nurse-3	Lighthouse	NCAP Nurse	>5
tech-1	Lighthouse	Data Clerk/IT Officer	>10
tech-2	Lighthouse	Data Clerk/IT Officer	>5
tech-3	Lighthouse	Data Clerk/IT Officer	>10
tech-4	Lighthouse	Data Manager	>5
tech-5	Lighthouse	Data Clerk/IT Officer	>15
data-1	Lighthouse	Health Informatics Advisor	>20
data-2	Lighthouse	Program Manager	>20
data-3	Dept. of HIV & AIDS (MoH)	MoH Key Personnel	>25
data-4	Dept. of HIV & AIDS (MoH)	MoH Key Personnel	>25
data-5	Dept. of HIV & AIDS (MoH)	MoH Key Personnel	>25
data-6	Dept. of HIV & AIDS (MoH)	MoH Key Personnel	>25

Collective Commitment to Protect Data Privacy

Participants presented group-level commitment to protect data throughout their collection, management, and use. The MoH and its partners, including Lighthouse, played a critical role in the data pipeline, for example, in the process of approving data sharing, and were expected to understand the sensitivity of HIV data. Lighthouse staff viewed the IT team as central to maintaining the data security at Lighthouse. Knowing that digital systems were managed and maintained by the IT team increased participants' confidence in the security of the systems themselves. Several participants linked their trust in data collection and management devices to their greater trust in Lighthouse's servers and technical infrastructure which were overseen by the same IT personnel which had exclusive knowledge of the technology: "*nobody can go in and access the server, unless the IT guys*" (tech-1).

Such trust in group efforts extended to individual staff at Lighthouse who collected and managed client data, including NCAP nurses and data clerks. Data collection and management processes across facilities and NCAP settings were considered secure because those handling client

data were trained and required to sign confidentiality agreements, signaling their commitment to protecting client information. Stakeholders also believed that individuals responsible for managing sensitive data had a clear purpose and defined role within the HIV data pipeline, which contributed to their confidence that client data was handled responsibly.

Individual-Level Practices to Enhance Security

Commitment to data protection extended beyond trust and was reflected in the execution of individual-level practices to uphold security and privacy. Participants described incorporating precautionary practices into their day-to-day work to maintain data security, such as replacing client identification numbers with randomly generated numbers, positioning tablets away from other clients, and retrieving printed documents from printers as quickly as possible. Such practices reflected an understanding that safeguarding sensitive data required consistent vigilance by individuals managing data. At the same time, some participants expressed uncertainty about whether these precautions were being consistently followed:

“For myself, with the tablet I’m using...I check on auto-delete after syncing [the tablet data] with the server. So the moment I’m at the facility, [the tablet data] has synced to the server, the data is gone in the tablet. There’s nothing else I can access in the tablet...The raw data is synced and is deleted [from the tablet]. That’s what I do, but for other individuals, I cannot say, I’m not sure.” — nurse-1

3.4.2 Threats to Data Protection

While acknowledging that trust was central to client data protections, participants also recognized that an overreliance on trust could lead to a lack of caution, and consequently, security mishaps.

Threats at Facilities

To ensure that any individual attempting to access the EMR system was authorized, the system required individuals to enter correct login credentials, namely username and password. The

requirement of passwords was commonly viewed as a sufficient security mechanism because password knowledge was assumed to be exclusive. However, participants reflected on hypothetical situations that illustrated the consequences of overreliance on passwords. For example, an authorized individual could leave their work station and forget to log out, allowing unauthorized individuals to access the EMRs. Additionally, while access to the EMRs was restricted to authorized users who were connected to Lighthouse's local network, unauthorized individuals could easily access, enter, and download sensitive and confidential client data. Rather than relying solely on the technical security mechanisms for data protection, stakeholders stated the importance of recognizing that "*security is only coming in terms of the individual user*," (tech-2) and that each individual was responsible for ensuring data security and privacy.

Participants identified the lack of regulation and regular inspection of data access privileges. Data decision makers recognized that there were no proper policies on how to govern server rooms and the lack of security audits for IT centers. Participants also recognized the possibility of security breaches when staff transitioned out of Lighthouse: "*people we employ, they don't always stay with the same company or partner, and so as people transition, information gets potentially shared*" (data-3).

Paper records were still used for a few, discrete client-level data collection activities at Lighthouse facilities and NCAP settings. However, errors such as forgetting to lock a paper file cabinet and misplacing paper files posed a risk to client data privacy. Even if paper records were properly stored, the security measures for paper records were much weaker than those for EMRs because local file cabinets could be easily broken into. Concerns around the improper disposal of paper records further motivated stakeholders to want to shift away from the use of paper: "*clearly managing paper records requires a whole set of other measures to protect, to make sure that that paper is shredded and destroyed properly and it doesn't find its way back somewhere it shouldn't be*" (data-3).

Threats at NCAP Settings

While no tablet had been lost or stolen in Lighthouse programs, one of the most common concerns raised was the consequences of tablet theft or loss while the device was being transported back to the facility after NCAP appointments. Because the current tablet-based app cannot automatically sync its data to the EMRs at the facility, data was solely stored on the tablet until the device was returned to the facility. If the tablet were to be lost in transportation, then all of the captured data would be lost, complicating the continuation of client care and preparation for the next visit, and would require nurses to revisit all NCAP clients.

Participants also feared the possibility that someone with technical expertise could hack into a lost or stolen tablet to gain access to client data, which was possible given the weak security measures of the tablet. A data manager noted that the main challenge in device-based data collection at NCAP settings was that lack of full control and monitoring of devices outside of facilities: “*we have control over how data is being collected at the facility. But in the community, we don’t know what’s happening*” (tech-4). This lack of oversight raised concerns that NCAP tablets carries risks for both client privacy and organizational accountability:

“People can use it for anything that they want. So, if you lose the tablet, you can also lose data in the process...those people will have also the data for other people, I mean for let’s say, for the patients. And that won’t be good for the program itself or the organization.”

— nurse-2

Participants were also concerned about improper use of the tablets by authorized individuals, including downloading irrelevant apps that could introduce risks into the set-up and bringing tablets home to use them as personal devices. The root of this concern was in policy weakness:

“As it is now, I think the policies are not really enforced and...some of them I think are not clearly outlined...to the [tablet] users...As long as [the tablet is] working, they are not really looking at the security part.” — tech-3

Threats at the National Level

Implementing partners and NGOs funded by international donors that were tasked with providing HIV services in partnership with the MoH could risk client data privacy by not following MoH recommendations. Implementing partners that lacked transparency around data management raised concerns for the MoH, particularly because highly sensitive, client-level data could potentially be stored outside Malawi in ways that conflicted with MoH expectations. The concern surrounding implementing partners' data management has advanced the agenda to establish policies that restrict data hosting to Malawi within the MoH. Furthermore, implementing partners and external research teams complicated security management because “*different projects are doing their things in different ways*” (tech-3) and failed to update security mechanisms, such as changing passwords frequently and using encryption. To ensure that all parties involved guaranteed the protection of client data, the MoH was motivated to improve monitoring of implementing partners' data sharing and management processes:

“There are implementing partners that abide by the Ministry’s recommendations. They make databases. We know where their database is stored. And then we have other partners that... have a database but we don’t know where their database is stored. Some transfer that information to the U.S., you have no idea. So, it varies according to which partner is storing that data.” — data-4

The lack of clearly documented data sharing protocols exacerbated data management concerns. Participants recognized that there was no central place to look for updated protocols and policies, giving room for confusion on best practices for data sharing. Negligent practices around data sharing were attributed to the lack of oversight and enforcement:

“In the West and in the North, there are severe consequences for sharing, inadvertently or negligently, somebody’s data and that raises people’s fears of course, and they pay more attention. And here [in Malawi], it’s like a gentleman’s mistake and nobody cares.” — data-3

3.4.3 Opportunities for Multi-Level Policies for Device and Data Management

Lighthouse-Level Opportunities

Participants proposed various considerations to enhance security of data collection devices and processes, including monitoring of tablets, regulating data access, and enforcing best practices in day-to-day work. They strongly advocated for mobile device management, which is the remote management of Lighthouse devices. If tablets were lost or stolen, device data could be wiped or locked to prevent adversaries from accessing client data. To prevent improper use of tablets, stakeholders wanted to limit the functionality of tablets so that they would only be used for data collection and monitor tablet use. While technology-driven supervision could boost security, the protection of client data also heavily relied on the users and ensuring that they returned the tablets to locked cabinets in Lighthouse facilities. Moreover, there should be a “*clear chain of custody*” for every device used within and outside of facilities (data-3).

Participants also suggested role-based access control, a mechanism of restricting EMR access based on individuals’ job responsibilities, to grant data access only to staff relevant to collecting and analyzing client data: “*if you’re just a mere vitals clerk, you shouldn’t be able to see information about consultations or prescriptions that are done in the system*” (tech-5). Participants also mentioned reinforcing an existing protocol for changing access levels with additional improvements; before granting an individual with access to the EMR system, data clerks and IT officers should not only consult with one another, but also correctly answer security questions to provide evidence that they are authorized to grant new access privileges.

In addition to frequently updating passwords, participants suggested other critical actions to ensure that day-to-day work practices were more secure. These included orientations for handling client data, training on device use, provision of protocols for device and data use, and enforcement of punitive processes. These recommendations highlight the importance of developing clear expectations for individuals working with client data. One data decision maker recommended developing protocols for technical staff that aligned with security and privacy practices in HICs. This participant recognized that national efforts would need to be strengthened in order to influence

practices at Lighthouse:

“Developing protocols that clearly outline...expectations of IT and [data clerks] as far as the electronic data capture is concerned. So the government may bring in a policy but the [health information systems] partner or HIV department, who are responsible for the HIV program, should work on creating these protocols on how data should be managed. Then people who are working should go through the protocols. After they go through the protocols, they sign an agreement...So people would have that sense of responsibility that the data that I’m working on is confidential data.” — data-1

National-Level Opportunities

Stakeholders emphasized the need for centralized data governance, with the MoH positioned at the center of decision-making and oversight. Participants described a case in which an abrupt termination of services led by an implementing partner disrupted the support of an EMR system in its early stages. This incident led the MoH to quickly address a leadership gap, illustrating the importance of the MoH being at the center of identifying, managing, and sustaining activities to strengthen data systems. This central positioning of the MoH can also help resolve the lack of unification in project implementation and management by different partners. Establishing clear standards for implementing partners would help ensure that everyone would be subjected to the same standards. Stakeholders also suggested reviewing data collection practices to ensure that only the data that is necessary for care is collected, removing collection of data that is not meaningful for client services. To ensure that client data use aligns with the MoH’s standards, there should be an agreement between the MoH and its partners:

“I think the government and also Lighthouse should have a data agreement on how this data is going to be used. And it’s not supposed to be used outside the stipulated agreements that the government had set up with Lighthouse or these partners. I think it just needs to have that proper agreement and policies on how data is supposed to be used.” — data-6

In terms of data sharing, if a research team or an organization requested a facility to share client data, there should be a clear procedure for determining whether or not the data should be shared. While there were procedures in principle for data sharing with these groups, the lack of clarity reflected a gap in policy, necessitating the development of a document clearly outlining protocols: *“a structure, a document, a standard or a protocol where they look at the requests to say, ‘does it meet this standard in terms of data security?’”* (data-5).

However, outlining policies and protocols can ensure security improvements only to a certain extent. Individuals and organizations should continuously enforce policy implementation in practice. Stakeholders emphasized that regular reminders and supervision would sensitize individuals about the issues at hand, urging them to execute best practice. Stakeholders also encouraged the continuous review of security protocols, including security audits of the IT department by external organizations to create opportunities for future improvements.

3.5 Discussion

This section synthesizes insights from FGDs and KIIs to understand how privacy expectations, security practices, and institutional structures shape the security of digital systems in Malawi’s HIV health system. First, I examine how ART clients conceptualize privacy and disclosure when living with HIV. I then analyze how data stakeholders operationalize security and privacy practices within the health system and how these practices align with best practices that have been recognized in other contexts. Building on these insights, I discuss implications for designing robust digital health systems and conclude with reflections on the structural strengths and future opportunities within Malawi’s HIV data ecosystem.

3.5.1 Privacy, Disclosure, and Trust in HIV Care

ART clients’ views of privacy were shaped less by technical concerns about digital systems and more by the social consequences of HIV disclosure. Privacy decisions were therefore closely tied to how clients navigated disclosure and how they trusted health system actors to protect sensitive

information. Rather than focusing on technological safeguards, clients framed privacy through the social dynamics of stigma, confidentiality, and trust.

Disclosure

ART clients expressed a strong desire to control who could access information about their HIV status, reflecting broader concerns about managing disclosure. Clients described fears of social rejection or discrimination that followed inadvertent disclosure of positive HIV status. As a result, PLHIV practiced selective disclosure as a strategy to minimize the risks associated with revealing their status. At the same time, clients expected actors within the health system to uphold confidentiality and responsibly manage the sensitive information entrusted to them. Despite these expectations, clients recognized that some risks of unintended disclosure were unavoidable, such as being seen visiting Lighthouse facilities. The ever-present risk of inadvertent and unwelcomed disclosure permeates ART decision-making among clients, from choosing where to start care to adhering to treatment.

Importantly, disclosure was not universally perceived as risky. ART clients were less concerned about the privacy risks of disclosing within the HIV community. Rather, disclosure to other PLHIV was a mechanism for gaining emotional and medical support. Within this community, trust was reinforced by shared norms around confidentiality and mutual protection of one another's status [110, 30]. By upholding these norms, PLHIV empowered each other to take control of their disclosure processes.

Clients' Trust in the Health System

Although prior work identifies privacy concerns as a barrier to data sharing for clients [289, 61], ART clients in this study expressed interest in contributing their data for public health purposes. Many participants wanted their data to demonstrate the success of Malawi's HIV response and gather global support for Malawi's ART activities. They believed that aggregated data collected through the health system helped international donors evaluate the effectiveness of Malawi's HIV programs and sustain funding for treatment efforts. This willingness stemmed from their trust in

national privacy protection efforts and positive interactions with healthcare providers. As clients' closest point of contact within the health system, providers played a critical role in maintaining this trust. Providers' practices not only shaped how data was collected and managed, but also influenced whether clients felt confident that their privacy expectations were respected within digitally supported care environments.

3.5.2 Operationalizing Security and Privacy in Practice

Clients' willingness to share sensitive data depended on their confidence that the health system would protect their confidentiality. This underscores the importance of examining how data stakeholders interpret and practice privacy protections. I will discuss how stakeholders' practices and aspirations aligned with established best practices in healthcare security and privacy. At the same time, these findings reveal the organizational and infrastructural conditions needed to sustain these protections.

Data stakeholders presented similar understandings of security, privacy, and threats to those observed in other contexts employing digital health data collection tools. For instance, physical theft of a data collection device and unauthorized access to data on a device was identified by data stakeholders in other contexts as a threat to data security and privacy [48]. Among the three goals of the CIA triad - confidentiality, integrity, and availability - data stakeholders in this study most strongly emphasized confidentiality, reflecting the sensitivity of HIV-related information and the severe consequences that may arise from unintended disclosure. As such, they aimed to adhere to common technical protections such as passwords, mobile device management, and user restrictions, while recognizing the importance of individual responsibility in upholding security standards.

Data stakeholders also demonstrated a nuanced understanding that different types of data required different levels of protection. Client-level data was considered significantly more sensitive than aggregated program data, similar to what has been recognized in other contexts [159]. With this nuanced understanding, data stakeholders supported the implementation and reinforcement of role-based access control in the EMR system, which would grant or deny EMR access based

on users' job responsibilities. Such mechanisms allow security practices to function within collaborative care environments rather than relying on rigid, all-or-nothing access restrictions.

In addition to technical safeguards, NCAP nurses and data clerks engaged in invisible work, which refers to informal tasks that occur in the background [245, 243], to protect data privacy through their day-to-day practices. NCAP nurses and data clerks quickly retrieved printed data, digitally obscured PII when sharing data, positioned tablets away from other people's eyes, and checked to see that the data in the tablets were deleted after saving the data elsewhere. These practices were not formally required but were incorporated into routine work as precautionary measures. Similar forms of invisible work have been documented in healthcare settings globally, where healthcare workers take additional steps beyond formal procedures to ensure that privacy protections are respected [159, 26, 193, 244, 267].

These practices reinforce that protecting sensitive health information depends not only on technological safeguards but also on the vigilance and judgment of individuals interacting with digital systems [40, 198, 197, 125, 44]. By incorporating additional protective behaviors into their everyday routines, healthcare workers sustained privacy protections in environments where formal protocols alone were insufficient or unclear. At the same time, the reliance on such invisible work highlights the importance of strengthening institutional supports that can more consistently reinforce these practices across the health system.

3.5.3 Designing Robust Digital Health Systems

Clients' privacy expectations and data stakeholders' operational security practices highlight both the strengths and remaining gaps in current digital health infrastructures. In Malawi and other LMICs, health systems face challenges with privacy regulation and mechanisms for redress. The existing state of health systems and the large population of PLHIV in LMICs call for continued interventions that can improve protocols, policies, training, and supervision. This agenda is further motivated by the nascent digital infrastructure of many LMICs that provides an early opportunity for data security interventions that can be built into health systems, as opposed to being retrofitted. With these considerations in mind and building on study insights, I present recommendations for

building robust and secure digital health systems in LMICs.

Standardizing Protocols

Data stakeholders emphasized the importance of governance structures for sustaining privacy protections. Strong governance has been identified by the WHO as a critical component of successful digital health [183, 184]. In line with this perspective, data stakeholders proposed positioning the MoH at the center of project oversight and data management to enforce consistent standards across implementing partners. Not only is the establishment of centralized management a practical step towards enforcing national goals to partners, but also an indication of efforts to establish interoperability at administrative and technical levels. Standardizing procedures and coordinating at a national level is critical for the successful application of technologies that can protect data [217] and has been acknowledged as a foundational driver of digital health adoption [5].

Data stakeholders also proposed written guidelines for device usage and standardized procedures for data sharing and transfer, recommendations which align with global guidelines for protecting HIV information [259]. Such policies would shift some privacy practices from invisible, individual efforts to visible, collective responsibilities. Overall, data stakeholders' push towards implementing new policies reflects the recognition that the incorporation of technologies into healthcare necessitates the reconfiguration of work practices and responsibilities [248].

Aligning with Global Standards

Digital systems should be designed to meet established global security standards, even when clients themselves may not explicitly demand such protections. In this study, clients expressed limited concern about technical security mechanisms, reflecting an expectation that the health system and its governance structures would ensure the safety of their data. Clients' trust in the health system urges a call to action to ensure that technical security is competently built, assessed, strengthened, and sustained by professionals. Global standards such as the Principles for Digital Development [2], which identify core tenets of addressing security and privacy, and the Health

Data Governance Principles [1], which outline standards for the usage of data within and across health systems, promote learning from well-established policies and regulations, and outline limitations on data access. Aligning digital health initiatives with such principles can help ensure that security protections remain strong as digital systems expand.

Communicating Data Collection and Sharing Purposes

Clients should be informed about how their data is collected and used through accessible, non-technical language. Lighthouse ART clients wanted support with translating health information from their health passports into accessible language, suggesting that providing access to data is insufficient if clients cannot interpret data [292, 171, 84, 211]. Health information should be presented to clients in a language that allows clients to understand how their data relate to their care and daily health management [195]. Data collection devices can support these efforts when used as a “*common information space*” [216] that enables providers and clients to review information together rather than serving only as tools for one-directional documentation [99, 39].

Clear explanations are also needed to distinguish between different types of data and their uses. While some clients understood the difference between aggregate data and client-level data, this distinction was not obvious to all, calling for clarification on the categories of data, how different data is used, the risks associated with each, and data protection strategies [102]. In the FGDs, clients were informed about Malawi’s in-country policy on data hosting which opened up discussion. Such explanations of privacy protection policies and efforts in a comprehensible language are essential to build client trust in the health system [61, 63].

Building on Clients’ Prior Experiences with Technologies

ART clients generally accepted the use of computers and tablets in clinical encounters and demonstrated a partial understanding of how such tools could support care delivery. These findings highlight the progression of familiarity with digital technologies in healthcare in LMICs from the 2010s, when handheld devices used for health documentation and surveying were viewed with suspicion and confusion [88, 41]. Clients’ prior exposure to digital tools in healthcare settings

likely contributed to the smooth integration of tablet-based data collection in NCAP. The expansion of tablet-based care in NCAP likely stemmed from clients' prior, positive exposures to computer-based data collection at the facilities, allowing tablet adoption to be accomplished without creating friction or opposition from clients. With several years of practicing tablet-based data collection and recent efforts to optimize the process, Lighthouse provides an example of successful integration of mobile devices in healthcare, contrary to many mHealth projects in LMICs that do not go beyond pilots due to the lack of follow-ups and rigorous evaluations [87, 114].

These insights point to an important consideration for integrating new technologies into care. Prior work has identified the importance of assessing the digital maturity of an environment, which includes identifying the level of technology that an environment is prepared for, considering the sustainability of technology usage, and setting realistic expectations for technology use [66]. In addition to digital maturity, clients' familiarity with technology should also be considered to ensure that new technologies are accepted by the people whose care they affect. After implementation, health systems must also support ongoing efforts to help clients understand how these technologies benefit care [121]. Attention to client familiarity is especially important for EMR-related devices. Although these devices are typically provider-facing, the consequences of misuse can directly affect clients' well-being.

3.5.4 Collaboration as a Foundation for Strengthening Data Security

The findings also reveal structural features of Malawi's HIV data ecosystem that shape the success of digital health systems. I present my own analysis of Malawi's HIV health system, highlighting data stakeholders' actions and aspirations that indicate an optimistic future for strengthened digital systems.

A central constraint, not unique to Malawi but common across many LMICs, lies in workforce capacity. Many LMICs face difficulty with hiring, training, and retaining experienced data privacy technicians due to competition with the private and NGO sector, both domestically and abroad [6]. Yet, expertise at both the clinic and MoH levels is critical for identifying, anticipating, and addressing evolving threats to data security. These gaps exist alongside broader constraints,

including weak policy dissemination and limited supervision capacity [6, 27, 164]. Together, these factors hinder the consistent implementation and enforcement of security practices, even when appropriate policies are in place. As digital health and its challenges continue to evolve, global donors and stakeholders will need to prioritize funding and human resources to meet emerging and persistent needs.

Beyond workforce capacity, governance coordination across multiple organizations presents an additional challenge. In Malawi's HIV health system, implementing partners play a significant role in data collection and program operations, making coordinated oversight essential for maintaining consistent data management standards. Data stakeholders therefore emphasized the need for stronger national-level governance structures to standardize protocols for data collection, storage, sharing, and transfer across implementing partners.

Despite these challenges, existing patterns of collaboration between stakeholders point to important opportunities for strengthening data security. Participants described a strong, shared commitment to protecting client data across multiple levels of the health system, an important condition for managing privacy in collaborative environments such as healthcare [159]. However, while trust supported organizational collaboration and commitment to data protection, stakeholders also emphasized that clearer policies and procedures were needed to improve the co-management of data. Strengthening data security therefore requires coordination between national institutions and frontline care environments to ensure that policies are not only developed, but can also be put into practice. The partnership between Lighthouse and the MoH illustrates how such alignment can be achieved. Their close collaboration reflects a shared vision of protecting client data and improving the quality of HIV care, and exemplifies how coordinated institutional relationships can support integrated health system strengthening [160, 235, 23]. At the same time, ensuring that policies do not hinder healthcare workers' workflows and everyday practices is critical for overall privacy compliance [159]. Accordingly, findings from this research can inform the joint effort between Lighthouse and the MoH to develop the new tablet-based app for NCAP by ensuring that the intervention responds to on-the-ground workflow challenges while remaining aligned with MoH expectations. This partnership therefore offers a promising foundation for

developing governance approaches that are both effective and contextually appropriate.

Taken together, these insights suggest that strengthening data security in Malawi's HIV health system will depend not only on new technical infrastructure, but also on continued investments in human capacity, governance, and institutional partnerships, echoing an argument that has been raised in global health and ICTD [74, 160, 254, 284]. While challenges remain, the collaborative structures present within Malawi's HIV program provide a strong foundation for developing secure and sustainable digital health systems.

3.5.5 Limitations and Future Work

While this study has a sufficient sample size of participants to reach data saturation, the findings of this study are not generalizable to all clients and data stakeholders at Lighthouse. The recommendations for building strong digital health systems in LMICs may not necessarily be applicable to all health systems in LMICs, given different levels of maturity with digital health integration. Lastly, these findings can be used to support additional data security training for Lighthouse, providing guidance for improved practices stemming directly from these lessons learned.

3.6 Conclusion

EMRs support coordinated care delivery, improve monitoring of treatment programs, and enable data-driven health system decision-making, playing a critical role in strengthening health systems globally. However, as digital infrastructures evolve and expand, it becomes increasingly important to ensure that systems for collecting, storing, and sharing sensitive health data are secure and aligned with the needs and expectations of those who rely on them.

This research expands the understanding of how diverse beneficiaries perceive the privacy, confidentiality, and security of EMR systems in Malawi's HIV health system. By examining perspectives across multiple stakeholders, including ART clients, nurses, IT officers, data clerks, and data decision makers, this research highlights how privacy is experienced and shaped not

only by technical safeguards but also by institutional practices, governance structures, day-to-day work practices, and partnerships. These insights informed recommendations for strengthening digital health systems, which build on the shared commitment among stakeholders to protect client confidentiality while identifying practical pathways for strengthening privacy protections within existing structures.

More broadly, this research demonstrates the value of examining digital health security and privacy as sociotechnical concerns. In LMICs, research on digital health security and privacy has been limited, particularly from perspectives that span clients, healthcare providers, technical staff, and decision makers. Understanding how different actors experience and manage sensitive data helps reveal the individual, organizational, and national efforts required for digital technologies to benefit diverse beneficiaries. Centering these perspectives can help ensure that digital technologies are designed, governed, and sustained in ways that protect clients while supporting the realities of care delivery.

Chapter 4

Contraceptive Decision-Support App in Pharmacies in Kenya

Many adolescent girls and young women (AGYW; aged 15–24 years) in Kenya encounter community- and health systems-level stigma related to sexual and reproductive health (SRH), which poses significant barriers to accessing relevant services [247]. Although the pharmacy setting is key source of contraceptive services for Kenyan AGYW, contraceptive counseling in these settings struggles to align with the values and preferences of AGYW [82, 83, 80]. These gaps highlight the need for innovative, community-based approaches that better support AGYW's engagement with contraceptive care.

This chapter presents a novel tablet-based app that provides person-centered contraceptive decision-support tailored to AGYW seeking contraceptive services in the pharmacy setting in Kenya. I joined this mHealth initiative at the invitation of a clinical reproductive health expert with extensive experience in Kenya. I worked with a team of experts in human-centered design and clinical reproductive health in Kenya and the U.S. and led a team of five undergraduate software engineers in app development. Through co-design workshops with AGYW and pharmacy workers in Kenya including rapid app prototype updates, my team and I developed an understanding of app integration into a multi-stakeholder, sensitive pharmacy environment. The broader goal of this research is to empower vulnerable AGYW to make informed contraceptive choices and contribute to improved reproductive health outcomes.

The research in this chapter addresses the following research question: **How can a contraceptive decision-support app for AGYW successfully integrate into the pharmacy setting?** To guide this work, I draw on the model of intermediation from ICTD literature. Intermediation is a multi-user cooperative effort in which digitally adept individuals (i.e., intermediaries) support individuals who are typically non-literate, lack technology-operation

skills, and/or have financial constraints to use technology and access information [222, 194]. Such interactions are commonly observed in LMICs, where economic, access, literacy, and infrastructure barriers shape how people engage with technologies, to enable technology use and information access. Applying the intermediation model, I conceptualize pharmacies as intermediated environments in which pharmacists play critical roles in supporting AGYW with varying levels of digital literacy, SRH knowledge, and language proficiency. My research highlights how a decision-support app can be embedded within an existing care structure to extend its benefits to a wide range of AGYW. More broadly, this work contributes insights into how mHealth can be effectively integrated into complex, resource-constrained care ecosystems.

In this chapter, I first describe the contraceptive care context in Kenya and review related work on contraceptive decision-support and intermediation. I then detail the design and development of the tablet-based app, along with the qualitative research methodology and study findings. Finally, I synthesize insights from this research to articulate considerations for integrating decision-support technologies into care settings, highlighting how differential roles among pharmacists can support diverse client needs while navigating social norms, power dynamics, and resource constraints. The results of this research were published in *Proceedings of the 2025 CHI Conference on Human Factors in Computing Systems* [188].

4.1 Background & Related Work

As of 2019, nearly 50% of pregnancies among AGYW aged 15–19 years in LMICs were unintended and 55% of these ended in abortions, often unsafe in LMICs [247]. In sub-Saharan Africa, adolescents face multiple barriers to contraceptive care, including stigma around female sexual activity and pregnancy, negative attitudes of health workers, and social pressure to have a child [247, 167]. Despite recognition of AGYW needs for contraceptive services, conventional health facilities struggle to reach AGYW because their services are costly, time-consuming, or providers resist serving adolescents [236, 64].

As a result, pharmacies are key access points for contraception for AGYW in sub-Saharan Africa [80, 81, 207]. Half of AGYW aged 15–19 years using modern contraceptive methods obtain

their method from commercial drug sellers or informal providers [207]. In Kenya, many AGYW prefer pharmacies for receiving contraceptive services because of their convenience, privacy, speed of service, and perception of less judgmental providers [80, 81, 93]. However, pharmacies have limited availability of contraceptive methods [80], pharmacists lack medical training [83], and counseling can be sporadic and inaccurate [82]. As such, contraceptive counseling in the pharmacy setting struggles to align with AGYW's values and preferences. Tense dynamics between AGYW and pharmacists also pose a barrier for AGYW to ask sensitive questions and get the information and services they need [77, 188].

4.1.1 Person-Centered Contraceptive Decision-Support

Person-centered care is “*care that’s guided and informed by patients’ goals, preferences, and values*” [70]. Person-centeredness has been emphasized in various aspects of care, including client-provider communication [186, 135] and shared decision-making by clients and providers [89, 117]. In the contraceptive context, person-centered care is reflected in preference-sensitive decision-making, where method choice is shaped by factors such as perceived safety, effectiveness, and potential side effects [141, 145]. This emphasis arises in part from misalignments between client preferences and provider priorities [275]. For instance, a study in Australia found that clinicians valued higher efficacy of methods more than women, while women were more accepting of lower efficacy rates if methods offered preferable bleeding patterns, lower cost, and less frequent administration [275].

The focus on preference-sensitive decision-making has informed the design and development of digital contraceptive decision-support tools. My Birth Control is a web-based tool in the U.S. used before counseling to improve women’s experiences of contraceptive counseling and to support choosing contraceptive methods that fit needs and preferences [53]. This tool features educational models and surveys for users to indicate method characteristics preferences and was effective for increasing women’s knowledge of methods, reducing decision conflict, encouraging providers to acknowledge clients’ preferences and values, and making clients feel confident in their method preferences [98, 54]. My Birth Control’s person-centered approach inspired the decision-support

app presented in this chapter. There are several digital tools targeting adolescents and young adults. Health-E You is an mHealth app that provides contraception decision-support for English- and Spanish-speaking adolescents with tailored method recommendations based on user interests and information is shared with a provider before an in-person visit [250]. Miller et al. [151] developed a clinical decision-support questionnaire which utilizes client-entered responses to create tailored service recommendations, such as treatment for sexually transmitted infections (STIs), appointments at teen clinics, and offering emergency contraception (EC).

However, to date, person-centered contraceptive decision-support tools have not yet been developed or rigorously studied in LMICs. Contraceptive decision-support tools in these settings often focus on increasing contraceptive uptake, for example through short messaging services [18]. Although some of these mHealth interventions tailor message content based on user characteristics such as marital status, maternal history, and pregnancy and postpartum timing [92, 261, 147], they remain limited in their ability to support truly person-centered decision-making. In particular, they rely on predefined categories rather than adapting to individuals' nuanced needs, values, and preferences. One explanation for the lack of person-centered contraceptive decision-support tools in LMICs is the lack of data on contraceptive preferences and priorities of women in these contexts. There is even less data on adolescents' priorities in decision-making processes. Although there are some digital interventions aimed to provide SRH guidance for adolescents in LMICs [210, 153, 272, 169, 170], they fall short of considering adolescents' limited access to and familiarity with mobile devices [188, 142]. Moreover, approaches to support person-centered decision-making in community-based settings, such as pharmacies where many adolescents in LMICs access contraception, are limited [80, 81, 207]. Making person-centered contraceptive counseling available in pharmacy settings could significantly support informed and free contraceptive choice [14].

4.1.2 Intermediation in LMICs

In LMICs, where access to technology or digital literacy is limited, human relations or “human infrastructure” plays a critical role in overcoming technology and information access and use constraints and influencing information penetration [111, 212]. Human infrastructure enables

the practice of intermediation, in which a digitally skilled user, or “intermediary,” enables information-seeking and use for a “beneficiary-user” in accessing and using information that would otherwise be inaccessible due to limited literacy, technical skills, or financial constraints [222]. Intermediated interactions are not uniform; they are shaped by the availability of technology, existing power relationships, levels of technical literacy, and the backgrounds and motivations of intermediaries [194, 209, 201, 202]. A key strength of intermediation lies in its flexibility. Intermediaries can adapt to users’ needs in real time, accommodating unexpected questions, behaviors, and contextual constraints that rigid technological systems may not anticipate [126]. In practice, intermediaries often take on additional responsibilities beyond their primary roles. For example, in Tanzania, mobile money agents, whose primary role was to facilitate financial transactions, also supported feature phone users in navigating a newly introduced mobile app [208]. In India, mobile shop workers assisted the dissemination of health education videos in addition to their routine business activities [266].

Regardless of the tasks they support, intermediaries often contribute more than their digital literacy. Intermediaries play a critical role in facilitating the flow and uptake of information. In Digital Green in India, locally hired and trained village staff mediated video screenings on targeted agricultural information to farmers, where this human mediation helped make content active and prompted better engagement from farmers [78]. Building on this model, Projecting Health adapted a similar approach to deliver community-based video education for new and expectant mothers, where community health workers facilitated both dissemination and discussion of topics such as birth preparedness, breastfeeding, and family planning [126]. In Bangladesh, small businesses such as pharmacies and grocery shops similarly acted as intermediaries, bridging information gaps by connecting low-income populations to affordable healthcare services [209]. Across these examples, intermediaries do more than enable access to technology; they actively support the dissemination, interpretation, and uptake of information, encouraging meaningful engagement with services and resources [213].

4.2 App Design and Development

In collaboration with a team of experts in human-centered design and clinical reproductive health in Kenya and the U.S., I designed and developed a contraceptive decision-support app tailored to AGYW seeking contraceptive services in the pharmacy setting. The app was named the Mara Divas app, in which “Mara” means “my own” in Dholuo, the local language of Kisumu County, Kenya, where this research took place. The design and development of the app was grounded in human-centered design, as shown in Figure 4.1.

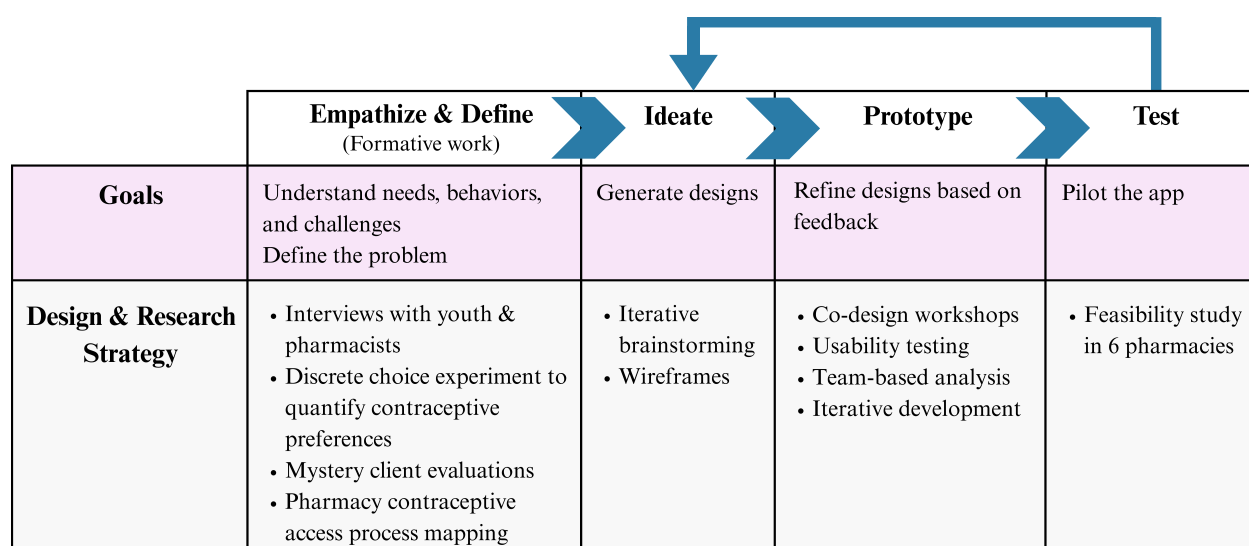
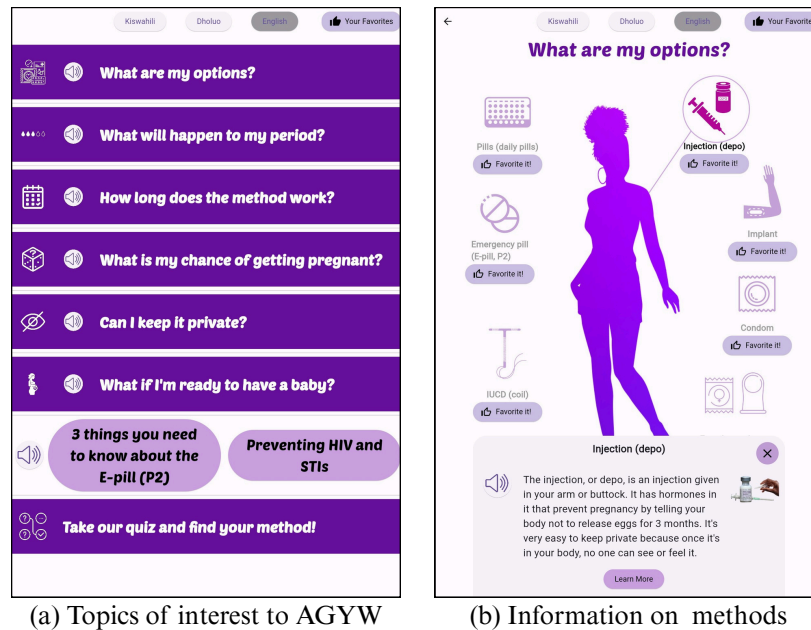


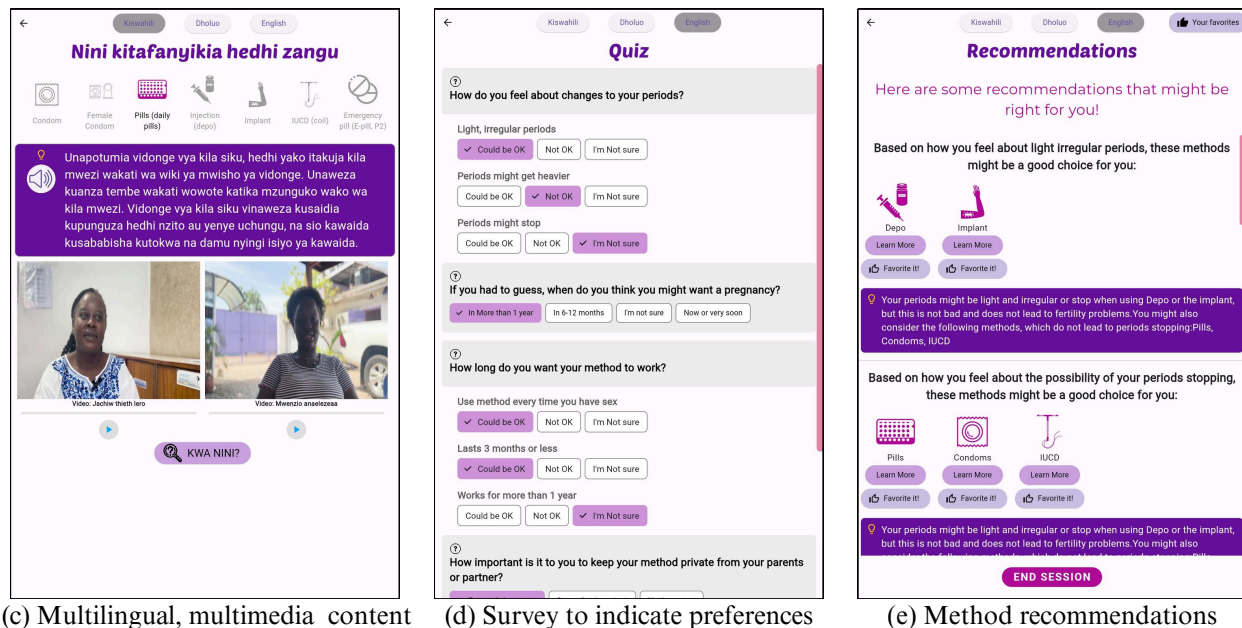
Figure 4.1: Human-centered design process that grounded the Mara Divas app design and development.

The Mara Divas app is designed to be used in a private counseling room in the pharmacy setting, where a tablet with the app installed and a pair of headphones are provided. The intended users of the app are AGYW seeking contraceptive services in the pharmacy setting. As such, the term “user” hereafter refers to AGYW using the app. When AGYW approach the pharmacist, they would be taken to a private counseling room to use the app for 5–20 minutes. Lastly, the pharmacist would communicate directly with the AGYW about their choice and provide either the desired method or a referral.



(a) Topics of interest to AGYW

(b) Information on methods



(c) Multilingual, multimedia content

(d) Survey to indicate preferences

(e) Method recommendations

Figure 4.2: Mara Divas app configuration. (a) Main screen with questions and topics that are of most interest and importance to AGYW. (b) Short explanations of each contraceptive method and where it is administered on a female body. (c) Information presented with text, audio, and videos. (d) Survey where users can indicate preferences for method characteristics. (e) Recommendations for contraceptive methods based on survey results.

The content of the app was carefully crafted by a clinical reproductive health expert who has extensive research experience in Kenya. The content was based on insights from formative work conducted by members of the broader research team, as described in “Empathize & Define” of Figure 4.1. Formative work included an exploration of factors that influence contraceptive preferences and decision-making for AGYW in Kisumu, the relative importance of contraceptive method and service delivery characteristics, and the quality of contraceptive care in pharmacies in western Kenya [77, 94, 90]. Considering that AGYW have low levels of knowledge regarding side effects of contraception and hold strong beliefs about contraceptive harms [90, 173, 229], the app is not intended to recommend the “right” contraceptive method. Rather, the motivation for the app is to provide information on various contraceptive options regarding topics that are important to AGYW, including bleeding patterns, privacy of contraceptive use, and influence on future fertility [91, 90] and demystify side effects. The app is inspired by the person-centeredness of My Birth Control, a U.S.-based decision support tool that assists women with contraceptive method selection [53, 98, 54].

The app’s main screen presents sections with topics that are of most interest to AGYW, as shown in Figure 4.2(a). Each section leads the user to a screen with topic-specific information for seven contraceptive methods, namely the male condom, female condom, daily contraceptive pills, implant, injection (depo), intrauterine contraceptive devices (IUCDs), and emergency contraceptive pills (e-pill), as shown in Figure 4.2(b) and Figure 4.2(c). For each method, a screen that briefly summarized information about that method was presented. Users can also “favorite” methods that they like and want to return to for review.

Once all sections are visited, users complete a survey to indicate preferences for method characteristics, as shown in Figure 4.2(d). The survey is composed of five multiple choice questions. Although five questions are limited in understanding the users’ contraceptive preferences, the number of questions were restricted because AGYW dislike lengthy questioning [82]. Based on survey responses, the app recommends contraceptive methods, as shown in Figure 4.2(e). For example, if the user indicated that it was extremely important to keep their method private, the recommendation would state, “*Based on how important it is to you to keep your method private, the*

following methods might be a good choice for you.” and present methods that align with the user’s preference around privacy.

The Mara Divas app was prepared in Dholuo, Kiswahili, and English, which are languages spoken in Kisumu County, Kenya. A language toggle tool is available on all screens so that users can engage with content in their preferred language. To reach AGYW with limited language literacy, audio and brief video components were included, as shown in Figure 4.2(c). Text content was accompanied by a spoken version of the text which was recorded by study staff, indicated by an audio button next to the text. Two types of videos were presented: four videos where providers share their expertise on contraceptive topics, and three videos where AGYW share their experiences with using contraceptives. These videos were narrated by service providers and AGYW actors in Kisumu. Videos were between one to three minutes long.

An Android app was built using the Flutter ¹ 3.19.5 platform that supports Android 5.0 and all subsequent versions. The app targets Samsung Galaxy Tab A8 tablets with a 10.5-inch display. Tablets were chosen because the pharmacy setting provides a large enough space for private table usage and the contents on a tablet would be easier to interact with than on a phone. Android devices were selected because of their low cost and AGYW’s familiarity with Android. Flutter was selected as an app development framework because it is a mature mobile app platform and provides a professional app appearance.

4.3 Co-Design Workshops

4.3.1 Study Setting

This study took place in Kisumu County which is located in western Kenya. Its largest population center is the city of Kisumu, which is the third largest city in Kenya. Luo is the primary ethnic group of Kisumu County where Dholuo, Kiswahili (the national language), and English are spoken. According to the 2022 Demographic and Health Survey, the median age at first birth in Kisumu County was 19 years, 9.2% of AGYW aged 15–19 years had ever experienced a live birth and

¹<https://flutter.dev/>

11.1% had ever experienced pregnancy in Kisumu County [176]. Public health clinics offer most contraceptive methods for free or for a small fee. Pharmacies usually offer condoms, emergency contraceptive pills, depot medroxyprogesterone acetate (injectables, also known as “depo”), and combined oral contraceptive pills. Some pharmacies also place contraceptive implants on site, but most refer clients to nearby clinics for implants or intrauterine devices (IUDs).

4.3.2 Study Design

Four co-design workshops were conducted in April–May 2024 to allow for app prototype iterations between workshops: three with AGYW aged 15–24 years with pharmacy-based contraceptive care experience and one with pharmacy workers.² One workshop of 12 AGYW aged 15-17 years, two workshops with 10 and 11 AGYW aged 18-24 years, and one workshop of 10 pharmacy workers were conducted.³ The goal of the co-design workshops was to gather app stakeholders with varied preferences to understand how to integrate the Mara Divas app into the pharmacy setting, gather app feedback, and ideate new designs or content. AGYW were included in the workshops because they were the intended users of the app. Pharmacy workers were also included because they were key stakeholders in the pharmacy setting where the app would be introduced; understanding pharmacy workers’ perceptions of and openness to the app was essential for informing how such an intervention would integrate into situated practices of pharmacy-based care.

Workshops were conducted using a combination of Dholuo, Kiswahili, and English. Data was collected through pre-workshop questionnaires, artifacts (i.e., arranged sticky notes written by participants or facilitators), observation notes in English, and audio recordings. Workshops were led by four facilitators, with expertise in human-centered design, clinical reproductive health, and study execution with AGYW. All facilitators were Kenyan and spoke Kiswahili and English, and two were local to Kisumu County and also spoke Dholuo. All facilitators were involved in the creation and revision of the study design. Workshops lasted between 9AM and 5PM, including

²“Pharmacist” and “pharmacy worker” are used interchangeably.

³All except one participant in the younger age group workshop was aged 15-17 years. AGYW workshops are presented as having two distinct age groups.

one 90-minute lunch break and two 30-minute tea breaks in between workshop activities. Small revisions to the app were made in response to feedback in between workshops and after completion of all workshops.

4.3.3 Participant Recruitment

AGYW participants were recruited using community-based strategies to optimize the diversity of perspectives and experiences in the three AGYW workshops by age, education, contraceptive experience, and experience with mobile apps. Purposive sampling [253] was used to recruit AGYW from peer mobilizers in the community and in-person in the pharmacy settings. Snowball sampling [196] was also used, by which study staff asked interested participants to recommend peers for inclusion. Female study staff who spoke Dholuo, Kiswahili, and English provided an introduction to the study and potential participants who met the inclusion criteria were assessed for their availability for workshop dates. AGYW under 18 years of age and not emancipated minors were encouraged to speak to a trusted adult about participating in the study. Eligible AGYW met the following criteria: (1) cisgender female; (2) age 15–24 years; (3) has accessed pharmacy-based contraception in the last three months; (4) not currently pregnant; (5) speaks Dholuo, Kiswahili, and/or English; (6) feels comfortable reading Dholuo, Kiswahili, and/or English; and (7) willing to sign informed consent. This work targeted AGYW aged 15–24 years because this age group was representative of a population that would most likely benefit from the app. Most AGYW under the age of 15 are not sexually active, as only 8% of Kenyan AGYW aged 15–24 years experienced first sexual intercourse before the age of 15 [262]. Additionally, by working with slightly older AGYW, the risks to a vulnerable population were minimized.

Pharmacy worker participants were recruited from pharmacies in Kisumu and peri-urban areas to balance the gender and age of pharmacy workers. Eligible pharmacy workers met the following criteria: (1) at least 18 years of age; (2) currently working in a pharmacy providing condoms, EC, combined oral contraceptive pills, and depot medroxyprogesterone acetate (hormonal contraceptive injection); (3) currently working in a pharmacy that has a counseling room/private space; (4) speaks Kiswahili and/or English; (5) feels comfortable reading Dholuo, Kiswahili, and/or

English; and (6) willing to sign informed consent.

In total, 33 AGYW and 10 pharmacy workers were recruited. The sample size was determined through the review of relevant literature in the health domain using similar methods [100, 281, 90] and guidelines in qualitative research [226]. AGYW participants and pharmacy worker participants were compensated with 1000 KSH and 2000 KSH (approximately 8 USD and 15 USD), respectively, for their participation. The compensation was determined based on the judgment of the Kenyan ethics review board of what was appropriate and not coercive.

4.3.4 Data Sources and Collection Process

Data from workshop activities was collected using workshop artifacts, written observation notes, and audio recordings. The primary data sources were artifacts and written observation notes in English, which were produced for all workshop activities, as the workshops were centered around activities that involved creating visual representations of ideas and concepts. Large group interviews were audio recorded as a secondary source of data to retain individual participant quotations and perspectives. When participants were engaged in small-group activities or speaking one-on-one with a facilitator, it was impractical to rely on audio recordings, so written note-taking was used. Audio recordings were translated and transcribed into English after the workshops by Kenyan workshop facilitators.

Each workshop began with informed consent procedures, followed by a pre-workshop questionnaire administered individually on a tablet by study staff. For AGYW, the questionnaire collected the following data: (1) demographic information; (2) mobile phone and app use; (3) relationships and sexual history; and (4) reproductive history and contraceptive experience and desires. For pharmacy workers, the following data was collected: (1) demographic information and (2) confidence in advising AGYW on contraception using a 5-point Likert scale (1: being not at all confident, 5: being extremely confident).

Participants re-grouped to review the background and objectives of the study, and confidentiality and consent guidelines. During activities, participants were encouraged to share their thoughts aloud and/or write them on sticky notes. Facilitators proceeded to conduct activities

where participants engaged in discussion and produced artifacts and facilitators took field notes. Below, workshop activities are described in the order they were conducted.

Journey Mapping

Facilitators led participants to create a journey map to visualize the entire flow of a pharmacy visit experience. The activity was focused on understanding “pain points” or moments that created discomfort, embarrassment, or inconvenience, and moments where there was the potential for delight. Journey mapping lasted between one to two hours.

For AGYW workshops, different methods of journey mapping were applied. In some workshops, participants used sticky notes to write their actions, thoughts, and goals that they have before, during, and after pharmacy visits, as depicted in Figure 4.3. In other workshops, participants conducted an interactive role play depicting a pharmacy visit, in which one participant acted as the pharmacist, another acted as an AGYW, and observing participants commented on their experiences, as shown in Figure 4.4 (left). The purpose was to understand counseling from AGYW’s perspective.

In the pharmacy worker workshop, one participant acted as a pharmacist and one member of the study team acted as an AGYW to role play a contraceptive counseling scenario, as shown in Figure 4.4 (right). The purpose was to understand how a pharmacy worker would conduct counseling. After role play, participants discussed how their experiences differed or aligned with what was presented.

Free App Engagement

Facilitators introduced the Mara Divas app to participants, explaining its objective and the workshop’s goal to gather app feedback. Each participant was given a tablet and headphones. Participants were given unstructured time to engage with the app to gain familiarity. Workshop facilitators answered questions and documented real-time observations and feedback. Free app engagement was conducted in both AGYW workshops and the pharmacy worker workshop. This activity lasted approximately 20 minutes.



Figure 4.3: AGYW journey mapping activity in which AGYW and workshop facilitators wrote actions, thoughts, goals, and emotions before a pharmacy visit on sticky notes.

Usability Testing

In AGYW workshops, participants individually conducted a series of tasks on the app. The purpose was to test how easy the app was used by AGYW to inform changes for future design iterations. A total of 12 tasks were prepared. Each participant was given three tasks to complete (e.g., watch a video in Dholuo of a peer talking about how to keep family planning methods private) and a facilitator observed and took notes as the participant attempted the tasks. Usability testing was only conducted in the AGYW workshop because AGYW were the target users of the app. This

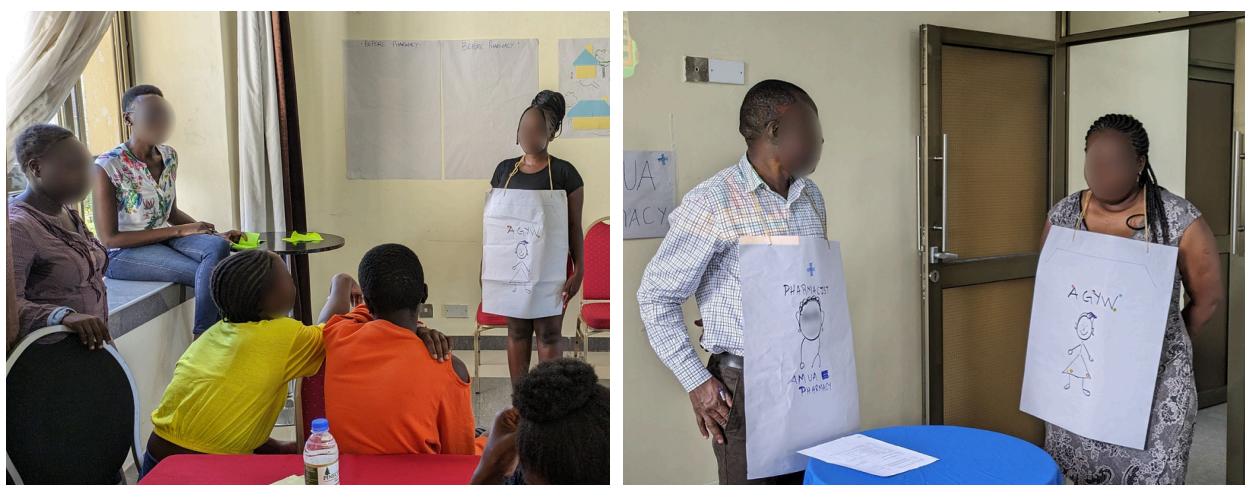


Figure 4.4: Role play conducted during the journey mapping activity in AGYW and pharmacy worker workshops. Left: AGYW role play led by a workshop facilitator to understand counseling from AGYW's perspective. Right: Pharmacy worker role play in which a participant and facilitator acted out a contraceptive counseling scenario.

activity lasted approximately one hour.

Facilitated App Engagement

As a group, participants discussed specific aspects or sections of the app. Participants were asked to discuss whether and how their opinions on contraception changed after engaging with the app, whether the content was helpful for addressing AGYW concerns, and how the app could influence their decision-making. In the pharmacy worker workshop, participants also discussed whether and how the app's content differed from their training or experience. All participants also discussed the language toggle tool, audio, and video and compared their experiences and preferences with reading, listening, and watching. This activity lasted approximately one hour.

App Feedback

In a group, facilitators elicited structured positive feedback, criticisms, questions, and ideas regarding the app. The "I Like, I Wish, What If" method [71] was used because it allowed

participants who do not have much experience with giving constructive critique in engaging in participatory ideation. Facilitators probed feedback on the app's content, language toggle tool, audio, and video. Participants and/or facilitators documented the feedback on sticky notes. App feedback was conducted in both AGYW workshops and the pharmacy worker workshop. This activity lasted approximately one hour.

Group Interview

Facilitators conducted a semi-structured group interview to discuss how participants' experiences in the pharmacy would change after exploring the app. Participants discussed their concerns with app usage in the pharmacy setting, the pharmacist's role in supporting AGYW with and after using the app, how to combine counseling with app engagement, the app's usefulness to the pharmacy workers, and how contraceptive access can be made easier for AGYW. The group interview was conducted in both AGYW workshops and the pharmacy worker workshop. This activity lasted approximately one to two hours.

4.3.5 Data Analysis

The data was analyzed by a research team composed of researchers and study staff from Kenyan and U.S. institutions, with expertise in human-centered design, computer science/HCI, and clinical reproductive health with experience researching adolescent SRH in Kenya. The team included all workshop facilitators. All but one research team member was female; the one male member was a human-centered design expert with experience planning, facilitating, and analyzing data from the workshops.

Data from the workshops was analyzed using two processes in tandem: a collaborative analysis by the larger research team, and in-depth thematic analysis by myself. Team-based collaborative analysis took place in real-time immediately after each workshop and at weekly team meetings that continued after workshop completion. In meetings held immediately after and between workshops, the team discussed observations from each workshop and compared emerging patterns across workshops. The main goal of these discussions was to identify app prototype updates to be

prepared for the next workshop, drawing on insights from free app engagement, usability testing, facilitated app engagement, and app feedback. After all workshops were complete, the larger team conducted analytic virtual meetings to consolidate data sources and begin to interpret the data holistically. The team recollected and discussed workshop interactions, observations, and feedback from participants that was particularly insightful, emerged frequently, or was surprising, and cataloged the iterative changes to the app. The Kenyan team members contributed additional expertise in the local context and languages, which enriched and contextualized the data.

Concurrent with the collaborative process, I qualitatively analyzed multimedia data (i.e., artifacts, written notes) with a specific focus on AGYW interactions with the Mara Divas app and perceptions towards the role of the pharmacist with the app. I independently reviewed multimedia data from journey mapping, with a focus on key actions and emotions that AGYW and pharmacists expressed, and created an initial matrix of concepts highlighting AGYW concerns, desires, and decision-making processes when accessing contraception in the pharmacy setting. These concepts contextualized participant responses generated from app-specific workshop activities (i.e., free and facilitated app engagement, app feedback, group interview), which were coded using a mixture of deductive (guided by the intermediation model) and inductive approaches. Using thematic analysis [28], the codes were consolidated into an initial set of themes and iteratively refined. Themes were then discussed between the first and last author to build consensus and develop cross-cutting insights across the workshops. After identifying themes, I reviewed the audible audio recordings to select representative participant quotations that speak to the themes and concepts and transcribed and translated them in English with support from the Kenyan study staff.

4.3.6 Ethical Considerations

Kenya Medical Research Institute (KEMRI) Scientific Ethics Research Unit (KEMRI/SERU/CMR/4917) and the University of Washington Human Subjects Division (00020507) granted ethical approval for this study, as well as a waiver for parental permission for minors. This study was also approved by the Kenya National Commission for Science, Technology, and Innovation (NACOSTI, research

permit P/24/33897). Written informed consent (age 18 years or older) or assent (age 15–17 years) was obtained from all participants.

Although minors were involved in this study, parental permission for study involvement was waived with approval from the ethics review boards. This decision was made through reflection on the reality that parental involvement in sensitive sexual and reproductive health research among adolescents may be harmful for adolescent research participants. To prepare to address conflicts arising from parents who have concerns about their child’s participation in the study, minors were encouraged to consult with a trusted adult prior to giving their assent. Participants were given a contact number so that parents may call to learn more or to arrange to talk with the study team.

4.4 Findings

33 AGYW and 10 pharmacy workers (6 female) participated in the co-design workshops. AGYW ranged in age from 15–24 years and the median age was 19 (IQR 17–21). Pharmacy workers ranged in age from 32–48 years and the median age was 33.5 (IQR 32–40).

Table 4.1 details participant characteristics for the three AGYW workshops. I refer to “older AGYW” as those aged 18–24 years (i.e., workshops AGYW-1 and AGYW-3) and “younger AGYW” as those aged 15–17 years (i.e., workshop AGYW-2). Younger AGYW, as expected, had overall lower levels of education than older AGYW. While all older AGYW owned a personal mobile phone, less than half of younger AGYW owned a personal mobile phone. Smartphone access was more common among older AGYW. Among all 33 AGYW, the most common contraceptive method that was used was condoms (n=25), followed by emergency contraceptive pills (n=13) and implants (n=13). Table 4.2 describes the demographics of 10 pharmacy worker participants and indicates that their confidence levels in advising AGYW were high.

In this section, I first provide a brief summary of app feedback and how they impacted decisions for iterative app development. Then, I elaborate on findings pertaining to understanding how the Mara Divas app could integrate into the pharmacy setting. Participant quotes are attributed by workshop ID, as shown in Table 4.1 and Table 4.2.

Table 4.1: Participant characteristics of AGYW for app co-design workshops.

Characteristic	Workshop ID		
	AGYW-1	AGYW-2	AGYW-3
Total Participants, n	10	12	11
Median Age (IQR)	20.5 (19.25–21.75)	17 (15.75–17)	21 (19–23)
Education Level, n			
Primary school, not complete	0	1	0
Primary school, complete	1	3	1
Secondary school, not complete	1	7	1
Secondary school, complete	3	1	7
Post-secondary school	5	0	2
Mobile Phone Use, n			
Has access to a mobile phone	10	5	11
Owns a personal mobile phone	10	4	11
Has access to a smartphone	9	2	6

4.4.1 App Feedback

While app feedback was not the primary focus of the research presented in this chapter, I first summarize feedback from AGYW and pharmacists. Participants generally responded positively to the app, and their feedback prompted the team to make changes that better aligned the app with AGYW preferences. I also describe feedback that was discussed but did not lead to design changes.

Positive Validation of App Design

Overall, participants reacted positively to the app, noting its strengths in addressing questions in a systematic way that covered topics of importance and interest to AGYW. Participants appreciated the videos featuring providers, saying they added credibility to the app's information. AGYW also praised the peer videos and felt encouraged when hearing peers talk confidently about their contraceptive experiences.

Table 4.2: Participant characteristics of pharmacy workers for app co-design workshops.

Characteristic	Workshop ID Pharmacy-1
Total Participants, n	10 (6 female)
Median Age (IQR)	33.5 (32–40)
Licensure, n	
Pharmacy owner	1
Pharmacy technician	8
Years Working in Pharmacy, n	
5 or more years	9
1–2 years	1
Median Confidence Score in Advising AGYW (IQR)	
On family planning options	5 (4–5)
On how to use family planning methods	5 (4–5)
On family planning side effects	5 (4.25–5)

Changes Made

Aside from a substantial change to the app’s color scheme, which was revised to bright purple and pink based on feedback from AGYW, most changes concerned the presentation of information. One notable change was in the framing of the app. Pharmacists and AGYW said that “family planning” was not relatable for AGYW who were not preparing to raise a family, but rather were prioritizing pregnancy prevention: *“What is family planning, by the way? You are planning a family. This is a 16-year-old person who does not have a family. What are they planning? ‘I want to prevent pregnancy’”* (Pharmacy-1). To make the app’s framing more appropriate for AGYW’s needs and desires, the phrase “family planning” was replaced with “pregnancy prevention” throughout the app. These findings also echo insights from prior work reflecting AGYW’s perceived dissonance between “family planning” and “pregnancy prevention” [90].

Signifiers on the app were updated to be more recognizable (e.g., larger buttons, text that prompts actions). Younger AGYW had difficulty interpreting icons representing contraceptive methods although they were complemented with text-based labels (e.g., “IUCD (coil)”). Icons were complemented with real-life images of contraceptive methods so that AGYW of varying literacy

levels could comprehend the content.

Usability testing revealed that AGYW had difficulty finding information relevant to preventing HIV and STIs and important things to know about emergency contraceptive pills. Instead of linking this information from other screens which required navigation through multiple screens, a button on the main screen was added to link AGYW directly to important information. This change also reflected pharmacists' emphasis on the importance of educating AGYW about preventing HIV and STIs.

Changes Not Made

In all workshops, participants suggested making the Mara Divas app publicly available so that more individuals could access it. However, the team's intention was to restrict the app's availability to the pharmacy setting, with the main reason being AGYW's lack of smartphone access, as evident in the demographics of younger AGYW participants (Table 4.1). Some AGYW had access to a mobile device but shared it with family members, meaning the app may not be used privately and could risk exposing them to harm if family members discover their use. Placement of the app in a pharmacy's private counseling room ensures privacy. Importantly, the app and its effectiveness needs to be studied and refined to make it usable, understandable, and beneficial for AGYW before making it widely available.

Participants from all workshops expressed that the app should include information on male contraceptives and/or aim to educate male peers. However, inclusion of this content fell outside of the scope of the motivation for this app, namely focusing on supporting AGYW (not young boys or men) in contraceptive education and decision-making.

Older AGYW also suggested adding all languages spoken in Kenya to the app. Aside from the lack of time to translate all content in all languages, the app was restricted to three languages because most AGYW in Kisumu County would likely only be comfortable with Dholuo, Kiswahili, and/or English.

4.4.2 Key Moments in Face-to-Face Counseling

Through role play and discussions, participants discussed the realities of AGYW-pharmacist interactions that give context to challenges in pharmacy-based counseling.

Misaligned Interests between AGYW and Pharmacists

The role play in the pharmacy worker workshop, which depicted a hypothetical counseling session, offered insight into instances of misalignment between pharmacists' personal beliefs, interests, and priorities and those of AGYW, as shown in the key moments below:

1. The pharmacist asks AGYW whether her religion allows her to use contraceptives.
2. The pharmacist asks AGYW about her boyfriend, insists that she brings her boyfriend to her next visit, and asks for her boyfriend's contact information. AGYW says she does not want her boyfriend involved, but the pharmacist insists.
3. The pharmacist is concerned about the AGYW's potential exposure to HIV and STIs and risk of dropping out of school. AGYW says she is not concerned about HIV and STIs, only about getting pregnant.

In each of these key moments, there is misalignment between what the AGYW wants and what the pharmacist prioritizes. AGYW participants expressed that such types of misalignment caused anxiety and fear in voicing their needs. To avoid confrontation and uncomfortable interactions, AGYW rehearsed how to talk to the pharmacist before visits and considered visiting a pharmacy where the AGYW was not known to the pharmacist. These fears also stemmed from AGYW's prior negative experiences with pharmacists, such as being scolded by the pharmacist for not knowing anything about contraceptives, being told that they were too young for sex, and being asked who their sexual partners were.

Not all pharmacists shared the same beliefs, indicating the possibility of inconsistent practices. The variability of pharmacists' attitudes seemed to contribute to AGYW's anxiety and uncertainty

about whether they would encounter a judgmental or friendly pharmacist. For instance, the young age of AGYW presented a challenge for some pharmacists, but not all, to provide contraceptive services. Pharmacists were concerned about being seen as a business that gave AGYW “*a ticket to promiscuous-ity*” and being known as the “*clinic that offers these services that makes our girls behave this way*” (Pharmacy-1). However, not all pharmacists thought the client’s age affected their decision to provide contraceptive services: “*At the end of the day you end up giving what you will be giving. You end up exposing her to these questions, the methods. Whether she’s 15 or 24, whether she’s below 18... So is [age] really important?*” (Pharmacy-1).

Challenges in Counseling

In response to the 20 minute role play, observing pharmacy worker participants said that most AGYW were unwilling to be counseled for that long. AGYW typically avoided lengthy interactions with pharmacists because they worried about the pharmacist’s demeanor towards AGYW, being seen by someone they know at the pharmacy, and the pharmacist not maintaining confidentiality. Many AGYW presented themselves as having all necessary knowledge, were clear about what they wanted from the pharmacist, and did not desire counseling. There were also AGYW who sent others to request emergency contraceptive pills on their behalf, resulting in challenges with counseling AGYW who required the service: “*Some will even send boda boda [motorcycle or bicycle taxi] guys, they will send their younger siblings... the end users will not come, they will send someone else. So even to counsel them, it is not easy*” (Pharmacy-1). Other times, while they were able to approach the pharmacists, AGYW pretended to obtain contraceptives for someone else or hide their identities by wearing a face covering. These deliberate choices that AGYW made presented challenges for pharmacy workers to counsel AGYW.

4.4.3 Differences between Older AGYW and Younger AGYW

Older AGYW and younger AGYW presented different levels of language, digital, and health literacy, impacting how they perceived the app and interacted with it.

Language Literacy

While the lower education levels of younger AGYW were not unexpected, this impacted their comfort with engaging in text-based app content. For instance, younger AGYW were overall less comfortable than older AGYW in comprehending English and relied on the app's Kiswahili content. Some younger AGYW preferred to only engage with audio and video, saying that audio helped them quickly understand the content and provided benefits for non-literate individuals. For example, one younger AGYW participant said that the audio reminded them of listening to a teacher, which encouraged them to pay attention to the content more keenly than reading it.

Digital Literacy

Older AGYW used the tablets very comfortably, likely because of their prior experiences with smartphones, and did not require assistance. On the other hand, younger AGYW were not familiar with touchscreen devices and were seen tapping parts of the screen that were irrelevant to the app's functionality. As a result, facilitators assisted younger AGYW with app use, such as with launching the app (i.e., tapping the app icon to open the app) and finding the volume adjustment buttons on the side of the tablet. Younger AGYW took an experimental approach to app use, as opposed to their interactions being informed by prior experiences with technology: "*At first, I was just choosing randomly and I found [the audio]. Now I know how to find it*" (AGYW-2).

Health Literacy

Older AGYW suggested that they were more familiar with the app's information than were younger AGYW. Older AGYW had prior experiences independently searching for contraceptive information and were mostly familiar with the contraceptive methods on the app. The app was helpful for confirming or augmenting prior knowledge with additional information, such as the administration of contraceptive methods. Some older AGYW were interested in obtaining in-depth information on specific contraceptive methods, such as injectables, as opposed to general contraceptive information that was on the app. Moreover, older AGYW expressed that the app

provided them with the “*reassurance that all will be well*” (AGYW-1) because it laid out all potential concerns and the app’s content resonated with what they had experienced before (AGYW-3). For example, one older AGYW participant said that the app’s information minimized their fear of side effects of injectables and gave them a better sense of the right method for them (AGYW-1). Videos also contributed to feelings of reassurance; provider-based videos provided additional information that boosted their confidence in decision-making and peer videos helped AGYW feel less isolated.

In contrast, for younger AGYW, the information presented in the app was entirely new to them. For instance, one younger AGYW participant said that they learned from the app that only condoms could prevent HIV and STIs. Younger AGYW’s behaviors during the workshops also suggested their unfamiliarity with the app’s information. They were writing notes on the app’s content, discussing among themselves about the content, and asking follow-up questions to the workshop facilitators about the side effects and the length of method effectiveness. Younger AGYW expressed that the app would allow them to gain knowledge on contraception and feel more confident in expressing their needs to the pharmacist.

4.4.4 Desired Roles of the Pharmacist

Pharmacists and AGYW agreed that pharmacists played a critical role in facilitating contraceptive decision-making, even with the app. Participants discussed the various roles and responsibilities of pharmacists in an app-supported pharmacy setting.

Create a Safe Space

Overall, pharmacists agreed on the importance of creating a safe space to allow AGYW to openly share their needs and concerns. Creating a safe space required the pharmacist to place their personal beliefs aside and to support AGYW in their decision-making as opposed to forcing a choice. AGYW expressed that they wanted to be treated with respect and trust that pharmacists would maintain confidentiality, suggesting counseling training to make AGYW feel more comfortable approaching the pharmacy setting. Most importantly, “*counseling and questioning are different*”

and pharmacists should provide person-centered guidance as opposed to lengthy interrogation that AGYW dislike and fear (Pharmacy-1).

Accommodate a Broad Range of Needs

Older AGYW thought that the applicability of the app differed depending on the literacy levels of AGYW. They suggested that in-person counseling would be more valuable for AGYW with limited literacy, whereas the app would be more useful for those with some prior knowledge of contraception: *“The ones who will use this app, they are aware. So the ones who do not understand it need more consultation”* (AGYW-1).

In contrast, younger AGYW did not question whether they were an appropriate audience for the app. Although they anticipated potential challenges using it due to limited digital literacy, they expected pharmacists to assist them when needed. Pharmacists similarly expressed willingness to support AGYW, particularly those less familiar with technology. Together, these perspectives suggest that both AGYW and pharmacists viewed pharmacists as mediators who could help accommodate varying levels of language, digital, and health literacy during app-supported decision-making.

Address Questions After App Use

While the app introduced key information, AGYW expected pharmacists to confirm what they learned from the app and provide further explanations, reflecting their trust in pharmacists' expertise and guidance. Pharmacists similarly recognized that the app could prompt new questions that required additional counseling. This was in fact true, as younger AGYW asked follow-up questions about the side effects and the length of method effectiveness, suggesting that the app helped them structure new questions. Pharmacists noted that AGYW might encounter unfamiliar concepts in the app, such as hormones or bodily changes, which would require clarification during the consultation:

“The service provider will be in a position to explain further... the terms [that AGYW do

not understand]...‘What are hormones and what do they do in our body, why will there be changes, and if I stop using them will there be other changes?’” — Pharmacy-1

These possible interactions highlight the importance of pharmacists supporting AGYW’s understanding of contraceptive information. As the app expands access to information, it also surfaces the need for pharmacists to interpret, contextualize, and respond to a wide range of questions. Accordingly, pharmacists emphasized that effectively fulfilling this role requires comprehensive knowledge and training: “[pharmacists] need to be trained on the services and especially the methods, the side effects, the do’s and the don’ts” (Pharmacy-1).

Guide Method Choice

The desire for the pharmacist to supportively “*affirm your choice*” (AGYW-1) and provide guidance on appropriate methods was more strongly expressed by older AGYW than younger AGYW. Younger AGYW were more focused on thinking about how the pharmacist could support information provision as opposed to guidance on method choice.

In discussing the benefits of making the app widely available, older AGYW suggested that they perceived different purposes in using the app and engaging in counseling with the pharmacist. These AGYW suggested that, if the app were available for use outside of the pharmacy setting, they could identify a method beforehand and use counseling to request in-depth information about their preferred method or immediately request the method. These older AGYW explained that they could approach the pharmacist with less anxiety because the app would answer most of their questions prior to the pharmacy visit:

“I feel like when you go to the hospital or pharmacy it’s all about seeing the doctor...and tell him or her what’s really happening or what I want. So I think the app should just be on the Play Store so that you can just have the information at hand. You can go and tell the doctor you want this and this.” — AGYW-1

4.5 Discussion

Overall, the app received positive feedback from participants. Videos, especially those featuring peers, were popular among AGYW, confirming the strengths of video-based health education as established in prior literature in ICTD and HCI4D [126, 78, 219, 20]. Co-design allowed the team to amplify AGYW's experiences with contraception in pharmacies and incorporate their voices into iterations of the app [219, 220, 75].

In this section, I discuss insights into how the Mara Divas app can successfully integrate into the pharmacy setting to support person-centered contraceptive care, drawing on the intermediation model. This section elaborates on: (1) the role of intermediation in the pharmacy setting; (2) potential differential impact of the Mara Divas app on subgroups of AGYW; and (3) broader considerations for technological interventions in LMIC healthcare settings.

4.5.1 Intermediation in the Pharmacy Setting

The pharmacy setting provides both the physical and human infrastructure necessary to support app access and information comprehension [222, 194]. From a physical standpoint, pharmacies can offer private consultation rooms and a tablet with the app, eliminating the need for AGYW to own or access personal mobile devices. From a human infrastructure perspective, pharmacists play a critical role in facilitating contraceptive education and supporting decision-making. Consistent with prior work on intermediated interactions in LMICs [208, 209, 266], the introduction of the Mara Divas app also implies an expansion of pharmacists' roles. Beyond their primary responsibility of providing services, pharmacists may take on additional tasks such as assisting with app use, clarifying information, and guiding clients through the decision-making process. With this understanding of intermediation, in the next section, I elaborate on how the Mara Divas app shifts the role of human infrastructure in the pharmacy setting and how pharmacists play a critical role in app-supported contraceptive decision-making.

Differential Roles of the Pharmacist

One of the main takeaways from this work was the differences between older AGYW and younger AGYW, in terms of language, digital, and health literacy levels. These insights highlight the limitations of relying on app content alone to accommodate the diverse needs of AGYW seeking contraceptive counseling. While the app can provide structured information and prompt new questions, it cannot fully address the wide range of knowledge levels, concerns, and decision-making behaviors that AGYW might bring to the pharmacy. Instead, the pharmacist plays a central role in interpreting and extending the information presented in the app, adapting their support to each client's needs, reflecting a key strength of intermediated interactions [223, 59]. These roles, however, will look different depending on the AGYW that the pharmacist assists.

For older AGYW with basic contraceptive knowledge, the app was not only viewed as an information provision tool, but also as a decision-support tool that provided reassurance. Some older AGYW were more interested in obtaining in-depth information on specific methods of interest, suggesting that they already had an idea of which method was right for them. For this group, the pharmacist will likely be relied upon to discuss topics of interest, acting as a “*last-mile connector*” [222] who provides guidance on making informed choices and facilitates the last steps in decision-support.

On the other hand, for younger AGYW who are less technically experienced and less informed about contraception, pharmacists may need to play a more active role. To support successful technology use, pharmacists may need to practice “*proximate enabling*” [222] by helping AGYW with using the app. For AGYW with nascent contraceptive knowledge, the app helped build foundational knowledge and structure new questions that can guide them towards making informed choices. For this subgroup, the pharmacist will need to practice “*proximate translation*” [222] to explain app information in an understandable language and bridge younger AGYW's knowledge gap to build a foundation for making informed choices.

In this way, the app helped reveal where additional decision-support guidance will be required, whether through assisting with technology use, translating complex health information, or

providing method-specific counseling. These findings suggest that the effectiveness of app-supported contraceptive counseling depends not only on the quality of the digital tool but also on the capacity of pharmacists to serve as knowledgeable and responsive intermediaries. For instance, counseling younger AGYW may require broad SRH knowledge, as younger clients often ask wide-ranging questions that extend beyond contraception. By contrast, consultations with older AGYW may be shorter and focused on validating an already-selected method, requiring the pharmacist to have in-depth, method-specific knowledge, particularly when older AGYW request additional details that are not addressed by the app. This highlights the importance of pharmacist training to support clinical knowledge and communication skills for engaging a wide range of AGYW to enable a successful mHealth intervention, and more broadly, person-centered care.

4.5.2 Extending Impact to a Hard-to-Reach Population

Intermediation shapes who ultimately benefits from the Mara Divas app. While intermediated interactions via the pharmacist can enable person-centered care to reach diverse AGYW, it is important to reflect on how the design choices of the app, including its interface design and where the app is situated, shape which populations are reached and which are excluded. Especially in LMICs, where education levels vary and access to resources is limited, it is important to consider not only who is reached by interventions but also those who fall just outside their reach. This reflection has been voiced in the ICTD community as new technologies have become increasingly popular. Specifically, despite the strong presence of feature phone owners in LMICs [237, 175, 19, 49], smartphone users became a primary interest for ICTD projects as they became technologically easy-to-reach due to growth in smartphone penetration in LMICs [55] and the perception that smartphones are innovative, convenient, and desirable. However, some ICTD researchers advocate for the continued support of feature phone users [208, 284, 285].

Extending this reflection to the present work, I examine how intervention design decisions may differentially impact older AGYW, who are technologically easier-to-reach and younger AGYW, who are harder-to-reach. Older AGYW's familiarity with technology and contraceptive information led them to perceive the app as less relevant for individuals with lower language

literacy or SRH knowledge. They also expressed a desire for additional features and for the app to be made publicly available for smartphone users to access prior to visiting a pharmacy. However, prioritizing the needs of technologically easier-to-reach populations risks reinforcing existing inequities. If the app were primarily designed around the preferences of older AGYW, younger AGYW, who have less access to decision-support resources, may have fewer opportunities to access and benefit from contraceptive information. In response, the Mara Divas app is intentionally designed to extend its impact to harder-to-reach AGYW, particularly those with limited education, technological experience, and SRH knowledge. The pharmacy setting provides a space where technology can be made accessible, while pharmacists act as intermediaries who help bridge gaps in understanding and access. For these harder-to-reach users, the benefits of digital technologies may only be realized through such intermediated interactions [223]. More broadly, these insights suggest that the impact of digital health interventions is not uniform across a single population, but varies across subpopulations with different needs, resources, and constraints.

4.5.3 Implications for Complex Healthcare Settings in LMICs

This work contributes to HCI scholarship to advance the understanding of how technologies can be designed for and embedded within sensitive domains, including health [186, 187, 202, 201]. In this section, I describe three considerations that emerge when integrating technologies into an existing care ecosystem, where human infrastructure, community beliefs, and care practices impact individuals' experiences with health.

Aligning Health Messaging

While alignment in health messaging between decision-support tools and human service providers is critical, it remains challenging to achieve in practice. Pharmacy worker participants suggested that their personal beliefs influenced decisions about service provision, sometimes leading to the discouragement of AGYW from using contraception. In contrast, the app delivers information designed to support AGYW in achieving their pregnancy prevention goals, following evidence-based recommendations. This potential divergence between pharmacists' views and the app's

content risks exposing AGYW to conflicting messages. Standardized health messaging is critical for ensuring accurate and consistent information dissemination and supporting behavior change [9, 162]. However, achieving such standardization in LMICs is difficult due to limited funding, overburdened health workers, and weak accountability mechanisms [6]. These challenges are further amplified in commercial pharmacy settings, where profit incentives and limited monitoring and enforcement reduce adherence to standardized guidance [282, 152]. Additionally, the sensitive and contested nature of contraception further complicates the establishment and acceptance of standardized messaging.

Strengthening Human Relationships

Client-provider relations can impact clients' willingness to seek healthcare services and their reception of technologies in healthcare [186]. In this study context, AGYW were anxious about approaching pharmacies because sometimes their incentives, goals, and priorities did not align with those of pharmacists. Strained AGYW-pharmacist relationships could consequently dissuade AGYW from approaching the pharmacy setting to use the app. This concern demonstrates the limitations of technology alone to make an impact. While relationship-building was not intended to be a focus of the Mara Divas app, it may be necessitated as part of a broader goal to improve person-centered contraceptive resources and contribute to improved health outcomes. To realize the potential significance of intermediated interactions in the pharmacy setting, pharmacists will need to improve their relationships with AGYW, a critical foundation of intermediated interactions [223], by building their competencies and attitudes to promote an AGYW-friendly environment [37].

Accounting for Spatial Constraints

The physical infrastructure of healthcare settings in LMICs is an important consideration of where technologies are placed and how they are used in practice. Retail settings often lack waiting areas and private counseling rooms [52], limiting opportunities for confidential interactions. If the Mara Divas app were used at the pharmacy counter, where activities are highly visible and open, AGYW could be exposed to other pharmacy clients, potentially compromising their privacy. To

mitigate this risk, the app is intended to be used only in pharmacies with private counseling rooms, providing a safer space for discussing sensitive reproductive health topics. These considerations highlight how physical infrastructure can influence the feasibility and safety of digital health interventions. Designing technologies for healthcare settings in LMICs therefore requires careful attention to spatial constraints and privacy risks, as overlooking these factors may unintentionally expose clients to harm.

4.5.4 Limitations and Future Work

Following this work, members of the broader research team carried out a feasibility study across six pharmacies with 100 AGYW in Kisumu County, Kenya between July–September 2024. The goal of the feasibility study was to evaluate the feasibility, acceptability, and appropriateness of the app in the pharmacy setting from the perspectives of AGYW and pharmacy workers at study sites.

The research presented in this chapter was carried out in a single county in Kenya and its findings are not generalizable to the whole of Kenya. However, findings from this study will be useful for informing the next phase of research, which is to refine the app with consideration for uses in rural areas and other regions of Kenya. Members of the research team plan a hybrid effectiveness implementation trial to concurrently examine both clinical effectiveness and implementation outcomes in the intermediated pharmacy setting. This research will include ongoing refinement of the app and strategies for integrating it into the pharmacy setting, as well as a cluster-randomized trial to examine clinical outcomes.

At this stage of the research process, it is appropriate to optimize situating the app into the pharmacy setting where AGYW already seek contraceptive services. After the value and utility of the app in the pharmacy setting is studied and validated, there may be opportunities to extend the benefits of this app beyond the pharmacy setting. This process, though, will entail its own strategy and design changes to the app to ensure the app's success as part of a wider contraception awareness agenda. Peer mobilizers, who were leveraged to recruit AGYW participants for the co-design workshops, could play an important role in helping peers prepare for pharmacy visits.

For example, peer mobilizers with smartphones could assist AGYW without smartphone access in using the app before visiting the pharmacy setting. This process would entail training peer mobilizers to facilitate app usage, including smartphone usage. Future work could also involve the expansion of the population of interest for male peers by presenting male contraceptive methods in the app and expanding app usage to young men. Enabling wider availability of the app so that it can be used outside of the pharmacy setting could provide opportunities for AGYW and their male peers to use the app together and collaboratively learn about contraception.

4.6 Conclusion

AGYW in Kenya and more broadly in sub-Saharan Africa lack contraceptive decision-support resources that are tailored to this population's needs, values, and preferences. To contribute to the empowerment of an underserved population and improve SRH outcomes, I supported the development of the Mara Divas app, a tablet-based app that provides person-centered contraceptive education and decision-support for AGYW in the pharmacy setting in Kenya. Through co-design workshops with AGYW and pharmacy workers, this research examined both the usability of the app and the ways in which it could be integrated into existing pharmacy-based contraceptive care.

This research suggests that the Mara Divas app will have a differential impact on AGYW depending on their age, education, technology experience, and contraceptive knowledge. Pharmacists play a critical role in interpreting app content, addressing client questions, and adapting their counseling practices to meet diverse client needs. These dynamics also shape who is able to meaningfully engage with and benefit from the technology. By examining who is reached and who remains excluded, this work emphasizes the importance of intermediation in extending the benefits of digital tools to harder-to-reach populations.

More broadly, this work contributes insights on the importance of and various roles of human infrastructure to positively shape digitally supported futures of care. While well-designed technologies can provide clients with important health information, they are limited in their ability to support decision-making on their own. This is especially relevant in LMICs, where uneven access to technology, education, and literacy can shape who is able to use and benefit from digital

tools. Human infrastructure should therefore be understood as a central part of technology design and implementation, rather than as a separate layer of support. When technologies are designed to work with intermediaries, such as pharmacists, they can extend access to a wider range of clients. In this way, human infrastructure helps translate the potential of technologies into more meaningful forms of care.

Chapter 5

Chatbot Designs for Contraceptive Decision-Support in Pharmacies in Kenya

This chapter builds on research presented in Chapter 4 to explore how chatbots can augment the Mara Divas app to facilitate person-centered decision-support for AGYW seeking contraceptive services in the pharmacy setting in Kenya. The work presented in Chapter 4 revealed that although the Mara Divas app was well-received and had potential to help AGYW develop contraceptive understanding, static app content was unable to address the breadth of questions raised by AGYW. AGYW were reluctant to bring these questions to counseling with the pharmacist due to fears of judgment, bias, and limited privacy or time, compounded by variability in pharmacy workers training [188, 77, 83]. These insights reveal a service gap between app-based decision support and in-person pharmacy counseling in supporting person-centered contraceptive care, motivating the research presented in this chapter.

This work aims to understand how chatbots can bridge this service gap by augmenting the Mara Divas app. Chatbots offer a strong advantage with its ability to support open-ended dialogue, offering a safe channel to ask questions that would otherwise be difficult to discuss openly [210, 214, 58, 272, 206, 169]. The envisioned chatbot would be embedded within the pharmacy setting and used after the Mara Divas app. This work addresses the following research question: **How can chatbots be designed to support AGYW's contraceptive decision-making in ways that are responsive to the realities of the pharmacy setting in Kenya?**

Given known concerns about accuracy, privacy, and bias in chatbot responses [172, 136, 273, 214, 169], which can have particularly harmful consequences in health [172], I applied speculative design to explore preferable and possible futures of chatbot-supported decision-making in the pharmacy setting, as opposed to developing a functional chatbot. Speculative design was well-

suited for a sensitive health context involving a diverse AGYW group with wide variations in digital and health literacy. I developed low-fidelity chatbot prototypes, which were used as design probes in co-design workshops in Kisumu County, Kenya, with AGYW and pharmacy workers.

This work contributes concrete design guidelines for contraceptive chatbots for AGYW that are grounded in potential use cases. I describe how chatbots could navigate the provision of medically accurate information where community-wide beliefs are perpetuated by pharmacists, and when and how chatbots could balance AGYW needs with pharmacist expectations. I also reflect on how chatbots could be designed to inclusively support diverse AGYW and the strengths of situating client-facing decision-support tools within a broader care ecosystem. More broadly, this work contributes to the growing body of research examining chatbot use for health information-seeking in LMICs. Insights from this work can be applied to chatbots in other sensitive health contexts and are intended to provide guidance to chatbot designers and HCI researchers on identifying tension points and design principles for sensitive health domains.

In this chapter, I first recall key insights from Chapter 4 that motivate this work and describe related literature on AI for person-centered decision-making and chatbots for health information-seeking in LMICs. I then describe the speculative chatbot prototypes which were presented at co-design workshops to understand possible and preferable futures of chatbot-supported contraceptive decision-support. I synthesize insights from the workshops to articulate concrete design guidelines for chatbots operating in a sensitive, multi-stakeholder pharmacy setting. The results of this work are being prepared for publication.

5.1 Background & Related Work

While the Mara Divas app demonstrated potential to support contraceptive decision-making, engagement with static app content followed by in-person counseling with a pharmacist was insufficient to address the informational needs of a diverse group of AGYW. Interactions with the app encouraged some AGYW to formulate new questions they had not been previously considered. These questions varied across age groups. Younger AGYW (aged 15–17) often raised general inquiries about contraception, reflecting limited prior exposure to the topics presented in the

app. In contrast, older AGYW (aged 18–24) wanted to ask more personalized questions about method suitability, suggesting that they already had foundational knowledge and were seeking tailored guidance. Ideally, pharmacists would address these questions during counseling. However, pharmacists' ability to provide comprehensive and accurate responses is highly variable and often constrained by limited medical training [77]. Additionally, many AGYW reported that they were reluctant to approach pharmacists due to fear of judgment. These challenges point to opportunities for chatbots to complement app-supported, pharmacy-based contraceptive care by offering AGYW additional avenues to ask sensitive questions and receive tailored information.

5.1.1 AI for Person-Centered Decision-Making

AI is increasingly being applied to healthcare to augment clinical decision-making, expand access to care, and address systemic gaps in health systems. To date, many AI applications remain provider-facing, and dominant perspectives on AI in healthcare are from the Global North [178, 238]. In LMICs, the use of AI is often motivated by persistent gaps in healthcare access and quality [178]. As a result, much of the existing work on AI for health has focused on supporting community health workers, exploring how AI systems can be effectively integrated into care delivery and support frontline work [179, 238]. AI applications in LMICs necessitate distinct considerations related to varying levels of digital and AI literacy. Compared to HICs, users in LMICs may have less familiarity with AI systems [238], which can influence how these tools are interpreted and used. In some cases, this may lead to greater levels of trust or overreliance on AI-generated recommendations [7].

While AI has shown potential for improving clinical efficiency globally, many applications undermine person-centered care by sidelining clients' values and preferences [117], feeding data into an algorithm that generates recommendations for providers [101, 25]. With the recognition that clients' background, context, and thoughts are critical for making informed decisions [117, 101, 210, 214], HCI researchers have explored how AI can contribute to person-centered decision-making. For instance, Kim et al. [117] emphasize clients as active decision-makers and frame AI as a “*shared technology*” that mediates client-provider interactions. Such framing highlights the

importance of clients becoming more informed and proactive in decision-making, rather than focusing solely on the technical capabilities of AI systems [130].

Pre-consultation chatbots are an example of client-facing AI that aims to facilitate shared decision-making by the client and provider. Compared to traditional questionnaires, large language model (LLM)-based chatbots can provide more engaging, open-ended interactions [134, 133, 122, 287, 249, 119], helping clients reflect on their concerns and prepare for consultations [133, 32]. Providers also view these chatbots as a partner in the care team that facilitates client-provider communication [230, 224]. These chatbots also provide an opportunity to emphasize best practices in client-provider communication by designing them to balance precision and clarity with the compassion and empathy expected of medical professionals [133]. A previous study also found that when clients perceive chatbots as extensions of a healthcare provider's persona, they share the same level of self-disclosure with the provider as they do with the chatbot, indicating that chatbots can positively shape future client-provider communications [132].

Across contexts, researchers have emphasized the need to ensure that AI systems do not undermine providers' judgment in decision-making by positioning these technologies as complements to, not replacements of, medical professionals [214]. This work considers how AI impacts pharmacists' roles in contraceptive decision-making by recognizing them as key stakeholders whose perspectives impact how decision-support tools operate within the practices of pharmacy-based care. At the same time, this work reflects on how chatbot-enabled decision-support can balance meeting the needs of AGYW while considering the expectations of pharmacists.

5.1.2 Chatbots for Health Information-Seeking

Recent advancements in LLMs have made it increasingly possible for people to receive quick, tailored guidance on health-related questions through conversational chatbots, including for topics such as mental health [239, 279, 132, 108], weight management [43], and vaccinations [112]. Chatbots can encourage self-disclosure [132] and reduce stigma around certain health conditions [131]. However, concerns about accuracy, privacy, and bias remain especially

consequential in health contexts [172, 136, 273, 214, 169]. Researchers therefore argue that chatbots should serve as complementary sources of support that do not replace human professionals [210, 214].

In LMICs, where access to care and health information is often limited, chatbots are a promising tool to aid health efforts by serving as the first point of contact for addressing health-related inquiries and extending access to healthcare beyond conventional health facilities [273, 288, 86, 210, 112]. Chatbots have been used for health information-seeking on a wide range of topics that may be difficult to discuss openly with doctors or community members [210, 288]. In these contexts, researchers emphasize the need for context-aware and culturally appropriate chatbots [58, 113, 169], while recognizing challenges in balancing medical accuracy with respect for cultural beliefs [58]. Access and privacy are also important, as shared use of mobile devices, which are common in LMICs, can shape when, where, and how people can privately engage with chatbots [112].

While still underexplored, there has been growing research on chatbots for information-seeking on SRH in LMICs. For example, Kaur and Singh [113] examined how postpartum women in India use ChatGPT for family planning information within broader support-seeking networks. However, only a few SRH chatbots are tailored to adolescents and young adults in LMICs [153]. A WhatsApp-based chatbot provided menstrual health education for Pakistani college women [232]. AdolescentBot is a text-based chatbot that allowed adolescents in Bangladesh to ask questions about SRH [210]. Snehai in India promoted SRH conversations among adolescents and young adults through multimodality, entertainment features, and a familiar female persona [272]. Nthabi delivers SRH information to young women in Lesotho and provides contraceptive information through a local midwife persona and multiple-choice menu of clinical topics [169, 170].

These SRH chatbots, however, assume access to personal mobile devices that can be privately used, sufficient digital literacy, and prior use of social media platforms, which may not be common for adolescents in many LMICs [142]. Moreover, most chatbots in LMICs are standalone tools, independent of other health resources and not directly tied to service provision. This work contributes a reflection on positioning an SRH chatbot within a broader ecosystem of decision-making resources, focusing on the Kenyan pharmacy context where many AGYW seek

contraceptive services.

5.2 Speculative Chatbot Prototypes

This work examines how chatbots can be designed to support person-centered contraceptive decision-making. Chatbots were chosen because they can support open-ended interaction and have been perceived to offer a safe, private channel for questions [214]. In this work, a chatbot is envisioned as an extension of the Mara Divas app, meaning that it would be used by AGYW seeking contraceptive services in the pharmacy setting after app use.

Given the sensitivity of contraception and the risks of deploying a functional chatbot, it is important to understand the acceptance and feasibility of a chatbot before committing to technical development. As such, this work applies speculative design to evoke reflections on possible and preferable futures with chatbot-supported contraceptive decision-making. Speculative design has been used in HCI and CSCW, including in LMICs, to explore how technologies can balance the needs of various stakeholders [124], plan possible AI futures in high-stakes healthcare scenarios [280], and provoke discussions about appropriate digital interventions [284]. In this work, this approach was valuable because it suspended concerns about technical feasibility or performance [117], allowing for an exploration into how stakeholders responded to the idea of chatbots even when they were unfamiliar with the technology [238, 179, 283].

This work draws on the understanding of speculative design by Tharp and Tharp [251], which states that the practice is presented as “*near- or far-term ‘what-if’ artifacts and scenarios that seek popular reflection and debate about the extent to which the sociomaterial or sociotechnical futures and alternatives it presents are desirable or not.*” Three speculative chatbot prototypes with different modalities were designed to represent potential chatbot interactions: text chatbot, options chatbot, and avatar chatbot. Guided by insights from the research presented in Chapter 4, I designed low-fidelity chatbot prototypes that were anticipated to resonate with AGYW and reflected the types of support AGYW might value and find preferable. While non-functional, the prototypes showcased scripted fictional conversations between an AGYW and a chatbot. Each prototype focused on a conversation about a contraceptive method and depicted AGYW’s questions, concerns, and

decision-making needs (e.g., “*I am concerned about my fertility with using the injection,*” “*How well does the E-pill work?*”). To ensure clinical accuracy in the chatbot’s responses, all dialogues were developed with a clinical reproductive health expert with extensive experience in Kenya. To examine how interaction style shapes user preferences, each prototype employed a distinct chatbot response tone.

The focus was not on evaluating the prospect of chatbots working in different languages, but on eliciting reactions to the visual design, conversational tone, and interaction patterns of each chatbot prototype. During the co-design workshops, participants were asked to assume that the chatbot could function in whatever languages they preferred, and that it was not necessary for them to follow the dialogue line-by-line. This allowed participants to concentrate on the overall experience of the chatbot rather than its language capabilities.

5.2.1 Text Chatbot

The text chatbot prototype, shown in Figure 5.1, resembled applications like ChatGPT ¹, where a user types a question or response into a text box to receive a text-based response. This modality reflects the most common and generic form of chatbot interaction, one that AGYW who have prior experiences with chatbots may be accustomed to. In this prototype, the chatbot directly addressed AGYW questions and maintained a systematic response pattern by ending each message with the prompt, “*Do you have other questions?*” This prototype was designed to convey a direct tone, emulating the professionalism that AGYW wanted from pharmacists [188], allowing an exploration of preferences between a straightforward response and more human-like or conversational approach.

5.2.2 Options Chatbot

The options chatbot prototype depicted an AGYW user guiding the conversation by selecting from a set of predefined topics. Given low language proficiency levels of some AGYW [188], this

¹<https://chatgpt.com/>

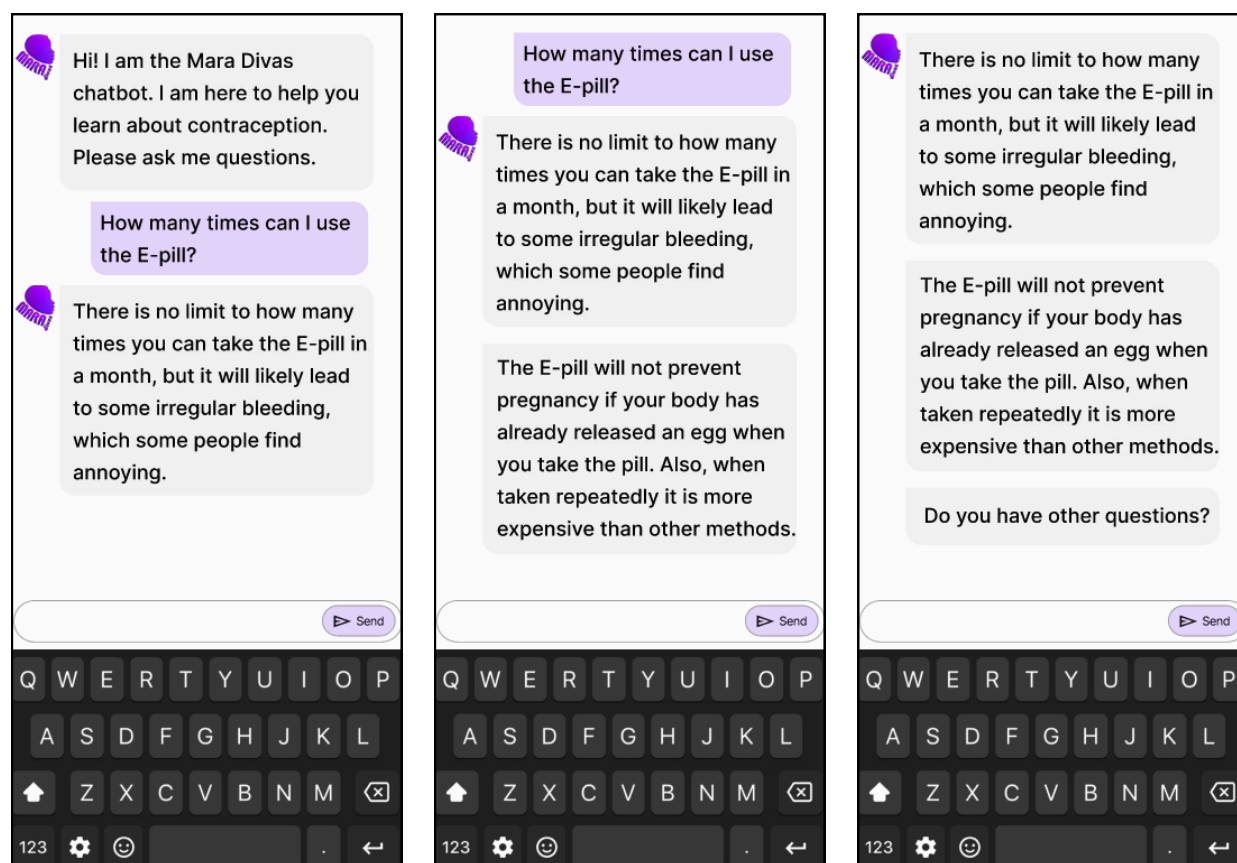


Figure 5.1: Text chatbot prototype depicting a conversation in which an AGYW user engages in text-based exchanges with a chatbot.

prototype was intended to address the burden of generating questions independently. The options chatbot was designed to examine a more structured and scaffolded interaction modality. While in the other prototypes, the AGYW was responsible for articulating their questions, this prototype shows an example in which the AGYW could still engage with a chatbot without directly asking questions.

Figure 5.2 presents an example of how this chatbot would be used. When the chatbot asked “Do you have any concerns about the injection?”, the AGYW chose from options such as fertility, bleeding, or privacy. Once an option was selected, the chatbot provided a text-based response. At the end of the interaction, the chatbot invited the AGYW to type remaining questions. Through

this prototype, I aimed to understand whether AGYW, particularly those who may be unsure about what concerns are relevant or how to articulate their questions, would prefer a guided conversational flow over more open-ended formats.

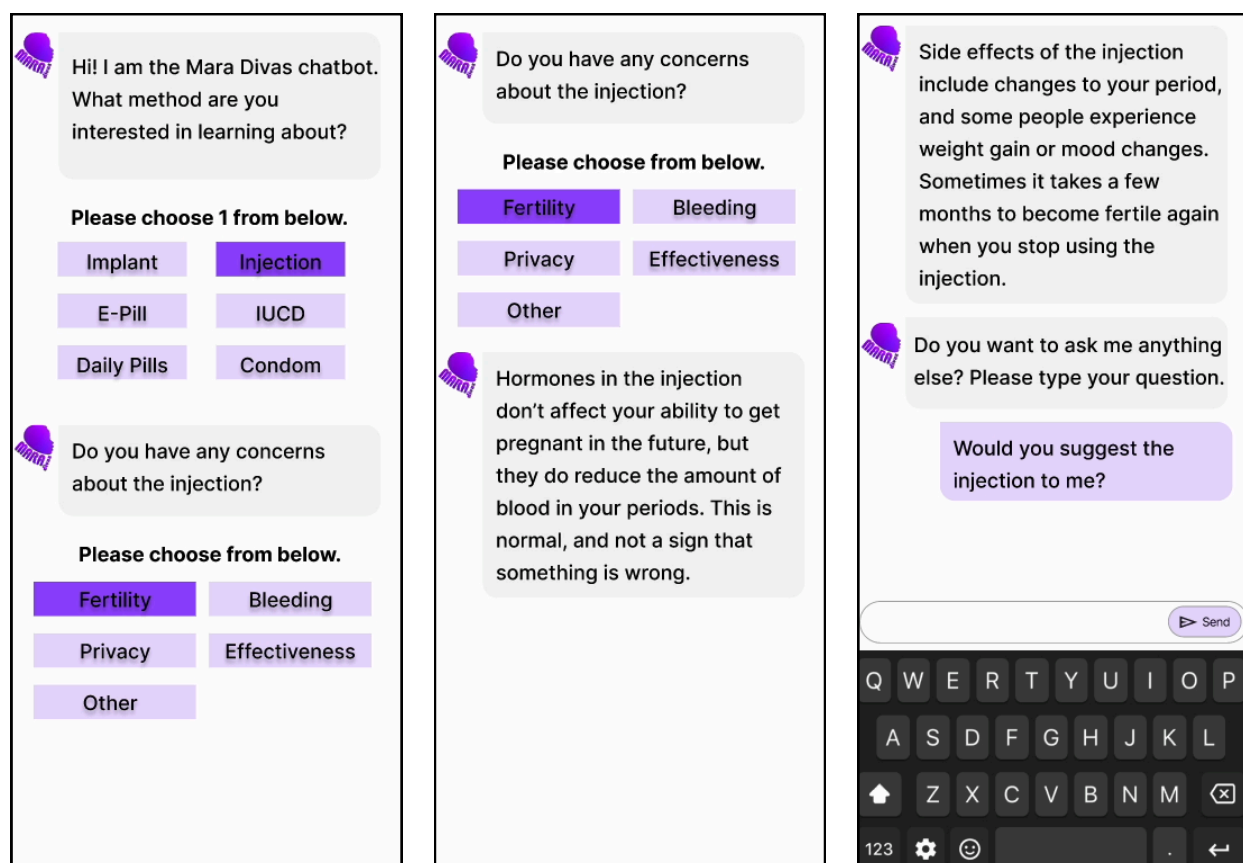


Figure 5.2: Options chatbot prototype depicting a conversation in which an AGYW user guides the conversation direction by selecting from a list of pre-defined options. At the end, the AGYW has the option to type any remaining questions.

5.2.3 Avatar Chatbot

Co-design of the Mara Divas app revealed that AGYW responded positively to multimedia app elements (audio and video), describing them as easier to follow, more engaging than text-heavy content, and allowing quicker comprehension of information. Separately, the team and I knew that

many AGYW in Kenya were accustomed to using Google Voice Search, which allows users to use voice commands to look up information. This familiarity suggested that voice-based interaction would feel intuitive rather than burdensome. These insights informed the decision to design a chatbot prototype that supports speech and audio engagement, a modality that was expected to be especially attractive and accessible for AGYW with lower language literacy.

The avatar chatbot prototype showed an interaction through voice commands and audio responses. On screen, an illustration of a female-presenting character appeared alongside a female-presenting voice with a British accent, serving as the visual and auditory representation of the chatbot. This prototype intentionally adopted an empathetic, human-like tone, using supportive phrases such as *“That’s a good question!”* and *“I understand that concern,”* to differentiate it from the text chatbot, which employed a more direct and succinct response style. The human-like tone of the avatar chatbot was intended to emulate a real-life conversation that AGYW might have or wish to have with a pharmacist, allowing for an exploration of interaction styles and supportive demeanor that AGYW prefer, and more broadly, in contraceptive counseling. An excerpt of the prototype conversation is shown below.

- **Avatar Chatbot:** Do you have questions about the implant?
- **AGYW:** I am concerned about my fertility with using the implant.
- **Avatar Chatbot:** I understand infertility is a big concern for many AGYW. A few days after having the implant removed, your body will return to your normal level of fertility. Does that ease your concerns about fertility?
- **AGYW:** What are the side effects of the implant?
- **Avatar Chatbot:** That’s a good question! Side effects depend on the method and the person. Your periods might be light and irregular or stop when using the implant, but this is not bad and does not lead to fertility problems.

5.3 Co-Design Workshops

5.3.1 Study Setting

This study was conducted in Kisumu County in western Kenya, where the Luo community is the predominant ethnic group. The main languages spoken are Dholuo, Kiswahili (the national language), and English. In 2022, 9.2% of AGYW aged 15-19 in Kisumu County had ever given birth, and 11.1% had ever been pregnant [176]. Most contraceptive methods are available at public health clinics either free of charge or at a minimal cost. Pharmacies typically offer condoms, emergency contraceptive pills, depot medroxyprogesterone acetate (injectables, commonly known as “depo”), and combined oral contraceptive pills. While some pharmacies also provide contraceptive implant insertions, the majority refer clients to nearby clinics for implants or IUDs/IUCDs.

5.3.2 Study Design

Four co-design workshops were conducted in Kisumu County, Kenya in April 2025: three with AGYW aged 15–24 years with pharmacy-based contraceptive care experience and one with pharmacy workers. The goal of the co-design workshops was to understand preferable and possible futures of chatbot-supported contraceptive care in Kenyan pharmacies. AGYW were included in the workshops because they are the intended users of the envisioned chatbot. Pharmacy workers were also included because their perceptions towards and acceptability of chatbots were essential for informing how such a tool could operate within the constraints and situated practices of pharmacy-based care.

Workshops were conducted using a combination of Dholuo, Kiswahili, and English. Data was collected through pre-workshop questionnaires, artifacts (i.e., arranged sticky notes written by participants or facilitators), observation notes in English, and audio recordings. Workshops were led by three female facilitators, including myself and two of whom were involved in design of the Mara Divas app, local to Kisumu County, spoke Dholuo, Kiswahili, and English, and recruited participants. All facilitators were involved in the creation and revision of the study design. Workshops lasted between 9AM and 3PM, including one 90-minute lunch break and one

15-minute tea break in between workshop activities.

5.3.3 Participant Recruitment

Given that the workshop activities involved discussion of AI-related concepts, AGYW who were comfortable with technology were recruited. AGYW participants were recruited using community-based strategies to optimize the diversity of perspectives and experiences in the three AGYW workshops by age, education, and contraceptive experience. Purposive sampling [253] and snowball sampling [196] were used to recruit AGYW from mobilizers in a community program. After mobilizers identified potential AGYW participants, female Kenyan study staff who spoke Dholuo, Kiswahili, and English met with potential participants to assess their eligibility. Some potential AGYW participants were approached directly by the study staff. Eligible AGYW were (1) cisgender female; (2) age 15–24 years; (3) accessed pharmacy-based contraception at least once in the past year; (4) not currently pregnant; (5) speakers of Kiswahili and/or English; (6) comfortable reading Dholuo, Kiswahili, and/or English; and (7) willing to sign informed consent.

Pharmacy workers were also recruited for the workshops, from pharmacies in Kisumu and peri-urban areas, balancing gender and age of participants. Recruitment prioritized pharmacy owners or assistants², with initial participants recruited from those who participated in the feasibility study of the Mara Divas app and were familiar with the broader project. Snowball sampling was also used by requesting introductions by pharmacy workers involved in formative work. Kenyan study staff (same as those who recruited AGYW participants) identified eligible pharmacists who were (1) at least 18 years of age; (2) currently working in a pharmacy providing condoms, EC, combined oral contraceptive pills, and depot medroxyprogesterone acetate; (3) currently working in a pharmacy that has a counseling room/private space; (4) speaks Kiswahili and/or English; (5) feels comfortable reading English and/or Dholuo, Kiswahili, and English; and (6) willing to sign informed consent.

In total, 36 AGYW and 12 pharmacy workers were recruited. The sample size was determined

²Pharmacy owners own the businesses and have medical backgrounds while only a subset of pharmacy assistants have medical backgrounds.

through the review of relevant literature in the health domain using similar methods [100, 281, 90] and guidelines in qualitative research [226]. AGYW participants and pharmacy worker participants were compensated with 1000 KES and 2000 KES (approximately 8 USD and 15 USD), respectively, for their participation. The compensation was determined based on the judgment of the Kenyan ethics review board of what was appropriate and not unduly incentivizing.

5.3.4 Data Sources and Collection Process

Data was collected through the pre-workshop questionnaires, workshop artifacts, written observation notes in English, and audio recordings. The primary data sources were artifacts and written observation notes in English, which were produced for all workshop activities, as the workshops were centered around activities that involved creating visual representations of ideas and concepts. Audio recordings were a secondary data source to retain individual participant quotations and perspectives. Audio recordings were translated and transcribed into English after the workshops by Kenyan workshop facilitators.

Each workshop began with the distribution of consent forms and a group explanation of the study, including confidentiality and consent procedures. Participants then signed the consent forms individually and completed a paper-based pre-workshop questionnaire. For AGYW, the questionnaire collected demographic information and technology familiarity, including mobile app comfort levels using a 5-point Likert scale (1: not at all comfortable, 5: extremely comfortable). For pharmacy workers, it only collected demographic information.

Participants re-grouped to collectively establish workshop norms and expectations and then engaged in workshop activities. During activities, participants were encouraged to share their thoughts aloud and/or write them on sticky notes. Activities were sequenced to mirror the flow of a pharmacy visit, guiding participants to reflect on their experiences from start to finish and discuss how the chatbot could fit into and shape pharmacy visits. Below, workshop activities are described in the order they were conducted.

Journey Mapping: Approaching the Pharmacy

For AGYW workshops, participants discussed their experiences preparing for pharmacy visits, questions they wanted to ask the pharmacist, and how they hoped the pharmacist would support decision-making. For the pharmacy worker workshop, participants reflected on their interactions with AGYW, including how AGYW approached them, commonly asked questions, and ways to provide better contraceptive services to AGYW. Journey mapping lasted approximately 30 minutes.

App Engagement and Discussion

In both AGYW and pharmacy worker workshops, facilitators instructed participants to engage with the Mara Divas app to contextualize the chatbot, which was envisioned as a tool used after the app. This activity was not intended to elicit app feedback, but to help participants imagine how digital decision-support tools might fit into pharmacy-based care.

In AGYW workshops, facilitators first guided participants through one section of the app to ensure they were comfortable using the tablet and app. Participants in both AGYW and pharmacy worker workshops independently engaged with the app for 15 minutes. Afterwards, they discussed how learning about contraception with the app compared to learning from a pharmacist, and what questions AGYW might still have after app use. This activity lasted approximately 45–60 minutes.

Chatbot Prototype Feedback

Participants were introduced to chatbots as technologies that can answer many questions but have limitations compared to human healthcare providers. They were asked about prior exposure to chatbots, ChatGPT, Google Voice Search (which was known to be popular among AGYW), and AI more broadly. Facilitators then asked participants to imagine that AGYW could use a chatbot after the app and before face-to-face counseling. Participants were shown three speculative chatbot prototypes - text chatbot, options chatbot, and avatar chatbot - in that order. Participants were informed that while the chatbot prototypes depicted English dialogues, they should pay attention to the visual design, tone, and interaction patterns of each prototype and assume that

the prototypes could be replicated in other languages. After each prototype, participants shared their initial reactions and critiqued the chatbot's responses and modality using the "I Like, I Wish, What If" method [71]. They also compared the prototypes and reflected on who they would or would not recommend each prototype to. Each prototype discussion lasted 30 minutes, and the full activity lasted roughly 100 minutes.

Chatbot Ideation

Participants referred to the speculative chatbot prototypes to ideate the ideal chatbot. In AGYW workshops, participants discussed what questions AGYW wanted the chatbot to ask them, what questions AGYW wanted to ask the chatbot, and how much personal information they were willing to disclose to the chatbot, as depicted in the artifacts created by participants shown in Figure 5.3 (left). Participants were also encouraged to sketch their ideal chatbot on sticky notes or on a blank poster board, as shown in Figure 5.3 (right). In the pharmacy worker workshop, participants reflected on which topics and questions were appropriate or inappropriate for a chatbot to address, and how the chatbot should interact with AGYW to facilitate person-centered counseling. Chatbot ideation lasted approximately 30–45 minutes.

Journey Mapping: Counseling

Participants discussed how the pharmacist should support AGYW after chatbot use and during in-person counseling. In the AGYW workshops, participants were also asked to compare the advantages and disadvantages of having the chatbot in their pharmacy visit experience. The second journey mapping lasted approximately 30 minutes.

5.3.5 Data Analysis

The data was analyzed by a research team from Kenyan and U.S. institutions with expertise in HCI and clinical reproductive health with experience researching adolescent SRH in Kenya. Analysis proceeded in two stages: inductive coding of multimedia data (i.e., artifacts and observation notes)

by two researchers, followed by collaborative analysis by the larger research team.

Preliminary themes were discussed with the larger research team, including all workshop facilitators, through virtual meetings to allow for in-depth analysis to interpret the data holistically. The goal of these meetings was to develop the themes and identify opportunities and challenges in integrating chatbots into pharmacy-based contraceptive care. Kenyan team members contributed

essential contextual and linguistic expertise, ensuring culturally nuanced and contextually relevant interpretation of the data. Once themes were finalized, I reviewed the English transcripts of audio recordings to select representative participant quotes.

5.3.6 Ethical Considerations

KEMRI Scientific Ethics Research Unit (KEMRI/SERU/CMR/4917) and the University of Washington Human Subjects Division (00020507) granted ethical approval for this study, as well as a waiver for parental permission for minors. This study was also approved by the Kenya NACOSTI (research permit P/24/33897). Written informed consent (age 18 years or older) or assent (age 15-17 years) was obtained from all participants.

Although minors participated, parental permission was formally waived with approval from the ethics review boards. This decision reflected recognition that requiring parental involvement in sensitive SRH research could place adolescents at risk of harm. To mitigate potential concerns, minors were encouraged to consult a trusted adult before providing assent. In addition, participants were provided with a contact number that trusted adults could call to obtain further information or to speak directly with the study team. Given the sensitivity of the topics discussed in the workshops, workshop facilitators included researchers from the same local contexts as the participants and with extensive experience engaging AGYW in conversations about SRH.

5.4 Findings

36 AGYW and 12 pharmacy workers (6 female) participated in the co-design workshops. AGYW ranged in age from 15–24 and the median age was 19.5 (IQR 17–23). Pharmacy workers ranged in age from 22–49 and the median age was 30.5 (IQR: 30–34.5). Table 5.1 and Table 5.2 show the summary of AGYW participants and pharmacy worker participants, respectively, including the number of participants per workshop who had used or heard of chatbots, ChatGPT, and Google Voice Search.

In this section, I first describe the limitations of app-only decision-support, detailing the

types of questions that AGYW had after using the app to reiterate the motivation for this research. Then, I describe the findings specific to the chatbot, detailing positive perceptions, how it impacts pharmacist roles, tensions that can emerge due to chatbots, and feedback on interactional characteristics. Participant quotes are attributed by workshop ID, as shown in Table 5.1 and Table 5.2.

Table 5.1: Participant characteristics of AGYW for chatbot co-design workshops.

Characteristic	Workshop ID		
	AGYW-1	AGYW-2	AGYW-3
Total Participants, n	12	12	12
Median Age (IQR)	23 (20.75–24)	18 (18–22.25)	17 (17–17)
Education Level, n			
Primary school, not complete	0	0	0
Primary school, complete	0	0	0
Secondary school, not complete	2	3	10
Secondary school, complete	5	4	2
Post-secondary school	5	5	0
Mobile Phone Use, n			
Has access to a mobile phone	12	12	11
Has access to a smartphone	12	10	9
Owns a personal mobile phone	12	11	8
Median Score of Comfort with Mobile Phones (IQR)	4 (4–4.25)	4.5 (3.75–5)	4 (3–5)
AI Familiarity, n			
Chatbot	0	1	0
ChatGPT	6	7	8
Google Voice Search	6	4	2

5.4.1 Limitations of App-Only Support

During the co-design workshops, participants were asked to engage with the Mara Divas app to help them imagine how digital tools could support decision-making. AGYW were invited to share any questions they had after using the app. I describe their questions to reaffirm the motivation to explore chatbots and to contextualize the chatbot-related findings that follow.

Table 5.2: Participant characteristics of pharmacy workers for chatbot co-design workshops.

Characteristic	Workshop ID Pharmacy-1
Total Participants, n	12 (6 female)
Median Age (IQR)	30.5 (30–33.5)
Highest Education Level, n	
Bachelor's Degree	8
Diploma	4
Professional Title, n	
Pharmacist	3
Pharmacy owner	5
Pharmacy technician	2
Pharmacy assistant	1
Other (Nurse)	1
Years Working in Pharmacy, n	
5 or more years	4
2–4 years	4
1–2 years	3
Less than 1 year	1
AI Familiarity, n	
Chatbot	0
ChatGPT	12
Google Voice Search	8

The questions AGYW raised fell broadly into three categories: (1) general knowledge gaps; (2) conceptual clarification questions; and (3) individualized, context-specific concerns. General knowledge questions included inquiries about information that was covered in the app but not fully retained: “*Is it possible to get pregnant when you use the implant?*” (AGYW-3), “*Do you take daily pills immediately after sex?*” (AGYW-1), “*Is it true depo can lead to infertility?*” (AGYW-1). These questions suggest that AGYW had difficulty retaining all information on the app, possibly due to the limited time that they were given during the app engagement activity. They also highlight the limitations of static app content in supporting real-time clarification.

Conceptual clarification questions demonstrated that AGYW were synthesizing information from the app and forming new questions beyond what was explicitly addressed. One participant

asked, “*What is the difference between hormonal and non-hormonal family planning?*” (AGYW-1). This question likely arose because, although the app identifies which contraceptive methods are hormonal or non-hormonal, it does not clearly explain the implications of that distinction. Another participant asked, “*Why is that using a male condom, there is a low chance of getting pregnant compared to a female condom? Could it be that female condoms are rare or putting it on is difficult?*” (AGYW-2). This participant’s question engaged directly with app content describing pregnancy-prevention rates and sought deeper explanation and context.

Individualized questions reflected AGYW’s efforts to use the app’s general information to gain more insight into personal situations. For instance, one participant asked, “*Why do I experience certain side effects that are not stated in the app, such as strong headache, weight loss, regular yeast infections?*” (AGYW-2). These tailored concerns illustrate the need for responsive, context-specific guidance that static app content cannot fully accommodate.

These findings indicate that there was a broad range of questions that AGYW had after using the app. However, AGYW felt that they could not ask these questions to the pharmacist for a variety of reasons. The physical layout of a busy pharmacy setting limited opportunities for private conversation, making it difficult to ask sensitive or personal questions. Feelings of shyness and fear of judgment also discouraged open dialogue. Some AGYW perceived pharmacists as prioritizing sales over person-centered counseling. Others worried about interrupting pharmacists during peak hours, feeling that their questions might be seen as disruptive rather than legitimate:

“I feel like I might not be able to ask the pharmacist...When the pharmacist is having many patients, like casualties outside there, then you want to ask him the question, him or her the question. You feel like somehow you are interrupting his or her own business.”

— AGYW-2

These findings reaffirm that AGYW had a wide range of informational needs after using the Mara Divas app and felt unable to ask pharmacists directly, motivating the exploration of chatbots. In the remainder of this section, I describe the findings that emerged specifically around chatbots.

5.4.2 Chatbot Offer a Safe Space

Overall, AGYW and pharmacy workers thought that the chatbot could provide a safe space for AGYW to ask questions and discuss sensitive topics. The chatbot can help bridge the questions they have from using the app to making informed choices. They thought that the chatbot could provide opportunities for unbiased, judgment-free interactions that are difficult to have with pharmacists. As a result, participants thought that AGYW would be more confident in their contraceptive knowledge and decisions.

Judgment-Free Space to Ask Questions

AGYW underscored the importance of the chatbot being a judgment-free space for discussing sensitive concerns, something they felt was difficult to find in face-to-face interactions. They described the chatbot as being free from the social scrutiny that they associated with pharmacists or community members. In this way, AGYW thought that their experiences asking questions to a chatbot and to a pharmacist would significantly differ. Because of the low-stigma of engaging with a chatbot, AGYW thought that they could ask any question, which would be difficult to do with just the app and a pharmacist:

“Since when you are using the app and the chatbot, you will be asking your questions. Every single stone will be turned, you will be asking. But when you consider the app and the provider, you will still have some questions. But let me say the provider is held up. It will force you to wait until he is free, when he or she can attend to you.” — AGYW-2

Pharmacy workers also recognized that the chatbot could provide an outlet for questions AGYW might not feel comfortable raising directly to pharmacists. This perspective suggests that pharmacy workers viewed the chatbot as a complementary tool that could reduce barriers felt in face-to-face counseling:

“I think [the chatbot is] a little more private and it will enable the AGYWs to ask some private questions that they are not bold enough to come out and ask [the pharmacy

worker]. So, I think that is one of the benefits, that their most private questions or concerns will be able to be addressed through the chatbot.” — Pharmacy-1

Trust in Unbiased, Comprehensive Information

In contrast to pharmacy workers, who were perceived to prioritize business profits and omit information during counseling, AGYW viewed the chatbot as an unbiased, reliable information source that would help “*bridge that service gap because now I can just be and just get the information that I really need to get*” (AGYW-3). In this way, AGYW thought that the chatbot would provide more information than a pharmacist would. Even pharmacy workers acknowledged that they can be biased in the recommendations they give to their clients and recognized the strengths of the chatbot:

“I believe when they use the chatbot, the information they get will be unbiased. You see most of the time we are human, maybe somebody comes to you and you are very tired. You have dealt with so many people... You will want to push them on a particular kind of family planning which you want. So, I believe through the chatbot, the information they get is unbiased.” — Pharmacy-1

AGYW wanted the chatbot to be honest, for example, about the disadvantages of using contraceptive methods. The chatbot’s honesty would in turn make AGYW feel more informed and reassured. AGYW saw the chatbot as an opportunity to clarify “*myths*” about contraception:

“I don’t know, it’s a rumor or maybe if you go through TikTok, there are some doctors there, they usually say that the disadvantage of P-2 [short for Postinor-2, an emergency contraceptive pill brand in Kenya]...You can find that some ladies can stay three years before they conceive. So, they say that that can be a disadvantage of excessive use of P-2. And I would prefer, chatbot, to just be open and say that because I’m worried about that.” — AGYW-2

Enhanced Confidence and Autonomy

AGYW perceived one of the main benefits of using the chatbot as gaining confidence in their knowledge and in their ability to speak with pharmacists. AGYW described the chatbot as a tool that could transform how prepared they felt for counseling with the pharmacist. The chatbot could help AGYW resist pharmacist pressure and preserve autonomy to make decisions. One AGYW emphasized this sense of strengthened agency, noting that the chatbot could help elevate themselves as knowledgeable clients, shifting the power dynamics between AGYW and the pharmacist:

“After using the chatbot, you have every knowledge that you want on the method that you feel is safe for you. So, even if the provider still tries to change your method, you are the one who knows whatever you discussed with the chatbot. And that is why you’re settled for it.” — AGYW-2

5.4.3 Implications for Pharmacist Roles

The roles that AGYW wanted pharmacy workers to have post-chatbot use varied, depending on the questions AGYW had afterwards and what they wanted from the pharmacy workers. While the chatbot has the benefit of reducing workload for the pharmacy worker, there were concerns about AGYW’s dependency on the chatbot.

Building on AGYW’s Newfound Knowledge

Some AGYW emphasized that pharmacists should be proactive in helping them choose a suitable contraceptive method. AGYW thought that the chatbot would help narrow down their choices and provide a starting point for counseling, such as requesting clarification on information from the chatbot they did not understand and following up on topics the chatbot referred them back to the pharmacist for. For example, one AGYW explained that the app and chatbot could help them decide whether to use the injectable, while the pharmacist could help them finalize a choice among the injectable options available at the pharmacy:

“After reading all [information on the app and chatbot], maybe [the pharmacy worker] can question which one is good for me, the [contraceptive method] for three years or for five years. Then he or she can tell you the difference or the effects of the two between the three years and the five years.” — AGYW-3

Pharmacy workers also recognized that the chatbot could make counseling easier. Rather than counseling under the assumption that AGYW have no contraceptive knowledge, pharmacy workers thought that they could build on the knowledge that AGYW gained from the app and chatbot, and fill in the gaps in knowledge that remained:

“I would start by assessing the information the client has had, that I know is in the chatbot, so that I would assess the level of information she received. So that where I see she doesn’t learn that much I would put more emphasis.” — Pharmacy-1

Minimizing Pharmacist Involvement in Decision-Making

Some AGYW preferred to have brief exchanges with the pharmacy worker after using the chatbot, mainly to confirm prices, available brands, or instructions for contraceptive method use. These participants assumed that the chatbot would help them finalize their contraceptive choice, reducing the need for lengthy counseling with the pharmacist. One AGYW expressed that they hoped the chatbot would even provide the medication names so they could request the method directly from the pharmacist without having their choice questioned.

Pharmacy workers viewed the chatbot as a tool that could help them manage their workload and streamline workflow. For example, the chatbot could create more time for pharmacy workers to attend to other clients in busy pharmacies:

“In a scenario where after getting the client has finished reading through the tablet, that period where she’s supposed to ask you some more questions, she can just talk to the chatbot. And that time you can use it to maybe if you have other clients, you can serve other clients as you come back to them.” — Pharmacy-1

However, not all pharmacists were comfortable with shifting too much counseling responsibility to the chatbot. One participant worried that AGYW might overrely on the chatbot and disengage during counseling, disrupting rapport with the pharmacist and limiting opportunities for tailored guidance. While pharmacy workers appreciated the chatbot's potential to reduce workload and save time, they also wanted to stay connected to AGYW's concerns and maintain their role in person-centered care:

“My concern would be if a client of mine identifies with the app and now, in reaction to this now, she becomes more closed to me and more open to the app. How are you going to address that?...Is there any way that the app is able to kind of collect some of the most asked questions, so that at the end of the day you also come up with some of the answers to most asked questions.” — Pharmacy-1

At the same time, pharmacy workers felt assured that the chatbot would not replace them. They thought that human judgment and professional experience were essential for contraceptive counseling and viewed themselves as a critical factor that impacts AGYW decision-making. They emphasized that the chatbot would have limitations in addressing the full range of AGYW's emotional, contextual, and nuanced questions.

5.4.4 Tensions Introduced by the Chatbot

Participants recognized that chatbots might fail to align with pharmacist guidance, and that there may be issues of confidentiality in its use. Some of these perspectives differed between AGYW and pharmacy workers.

Informational Conflict

One of the main concerns raised by participants was the consequences of informational conflict between the app/chatbot and the pharmacy worker. An example of this conflict is that the Mara Divas app states that emergency contraceptive pills can be taken up to 5 days after unprotected

intercourse, following evidence-based management of EC. However, pharmacy workers advise clients that they cannot take emergency contraceptive pills if over 72 hours have passed since unprotected intercourse, as this is the timeline on many pills' packaging and is what is approved by regulatory agencies. Pharmacy workers emphasized the importance of aligning the information on the app/chatbot to information provided by pharmacy workers:

“Our main point is to make it be strict, so that they can remain compliant. Like for example, if you say P-2, you still have till 5 days, the person will go and relax. Then they will come and tell you, ‘you told me 3 days and I have read the app talks of 5 days and now I am pregnant’...But you know you have to be strict on the client. I told you this is the day you are supposed to come. Why have you come now? You know you can get pregnant. But if you give the client the option of knowing, I can relax for more days, then I believe they’ll start...You’ll end up having so many...cases of pregnancy.” — Pharmacy-1

Informational conflict can also emerge between the app/chatbot and community-wide beliefs. In Kenya, there is widespread concern that contraception can lead to permanent infertility and this concern is most strongly expressed with injectable contraception such as depot medroxyprogesterone acetate (DMPA), also known as “depo” [173]. While the app provides evidence-based guidance suggesting that DMPA does not cause infertility but can delay return to fertility, pharmacy workers often refuse to provide DMPA to AGYW, especially those who are unmarried or have not had a child, leading AGYW to wonder which source to rely on: *“This one for depo, not everyone but most times when I go to the hospital, you find they tend to discourage you, that it can lead to infertility or something. Is that true?”* (AGYW-1).

Despite this informational conflict, the sentiment among AGYW was that the chatbot was more knowledgeable and trustworthy than pharmacy workers. This was related to the perception that while pharmacists might give false or biased information, the chatbot would provide clear, unbiased, and full information.

Informational Boundaries

When asked about what AGYW should or should not ask the chatbot, responses differed between AGYW and pharmacy workers. When pharmacy workers were asked what questions the chatbot should not be allowed to answer in general, participants expressed that the procedures for abortion (e.g., the drugs for abortion, the brand name, how to use it) should not be discussed with a chatbot. They emphasized the importance of limiting the chatbot's scope because the responsibility for providing guidance ultimately lies with the pharmacy worker:

“What I always believe in is information or knowledge is power. And whatever the chatbot is designed to offer is knowledge. So, in this, one way or another, we are empowering these young girls...In terms of professionalism, there's defined roles. Like, in terms of as a nurse or as a clinician, there's stipulated boundaries that you can go even in your profession. So, in terms of providing information, I really think there's certain information that I would not let the adolescents have. In terms of information, the drugs, the prescriptions. So, I think when it comes to now, the details, in terms of offering all the services, how to offer them, I think from that bit, it can be left for the providers themselves.” — Pharmacy-1

On the other hand, AGYW felt that they should be able to ask the chatbot anything without boundaries. Some AGYW thought that they should discuss their concerns with the chatbot as much as possible so that it could address all of their questions. When AGYW were asked about whether they would want abortion-related information from a chatbot, participants expressed that they wanted to learn about abortion-related medications from the chatbot because pharmacy workers can be unapproachable or judgmental:

“Where I come from, like the lady who works in the pharmacy, she is...I don't know if I should say she's scary, rude or a snitch. So, I prefer asking the chatbot or I just move to another pharmacy that is very far from that one. I think that's the only way.” — AGYW-2

Privacy and Utility

AGYW recognized that a major advantage of chatbot-supported decision-making was privacy, that conversations would not be shared with others. Some AGYW were not concerned about privacy and did not mind the pharmacy worker seeing their interactions with the app or chatbot, because they thought the information could facilitate counseling. However, most AGYW wanted their privacy preserved and suggested that the chatbot delete its history:

“But if it’s going to be, like ChatGPT, like it has a backup, every detail that you’re going to talk or everything that you’re going to say, it should be backed up. What if it reveals my name? My data might be disclosed and also my name, and what if the pharmacist has a malicious intent and then she finds out my details later.” — AGYW-2

This perspective was reflected in how some AGYW understood the role of the chatbot in their care. Rather than viewing it as a shared tool between themselves and pharmacists, they saw it as a personal resource for independently exploring contraceptive options and forming preferences prior to consultation:

“The chatbot is there to help me to know more about these methods and choose whichever I feel is suitable for me, so I don’t see if it will help [the pharmacist]. It’s for me like the information is meant to help me, once I’ve gotten the help then I don’t see the need of him knowing whatever I did there. His focus should be on what I have discovered, whatever methods I am okay with after reading everything.” — AGYW-1

On the other hand, pharmacy workers suggested that access to chatbot-AGYW interactions could strengthen person-centered counseling rather than undermine it. Some viewed the chatbot as a way to surface concerns that AGYW might hesitate to share directly, allowing providers to better understand client priorities. Even limited access, such as knowing which contraceptive method an AGYW was leaning toward, could help align counseling with the client’s preferences while preserving autonomy:

“We are not supposed to influence the informed consent of the client, so we are not supposed to choose for the client. It is the client to choose. So, if you go in and bulldoze your suggestion, then you’re just supposed to guide based on whatever the client wants. So, based on that, you will give whatever they have decided because it is the informed choice.” — Pharmacy-1

Challenges with Integrating into a Business Setting

Pharmacy workers expressed concern about the potential impact of chatbots on their business operations. The chatbot would require the use of a private room for AGYW. However, in most pharmacies, these rooms are designated for consultations. The chatbot would occupy space and time that pharmacists would otherwise dedicate to serving other clients:

“This chatbot means some of our clients will be taking more time in our facilities. So, I will be making up for the limited resources in terms of free space. Now balancing that to the ones that we’ve been having. So, there will be additional work all together...So maybe crowding within the facility. Planning that interface. That will be a challenge.” — Pharmacy-1

One pharmacy worker requested consideration for compensation for the pharmacy workers, to incentivize them to allow the app and chatbot in their work setting and to convince AGYW to use these tools.

5.4.5 Chatbot Design Suggestions

Using the speculative chatbot prototypes as design probes, participants ideated on how they wanted the chatbot to look and feel, including its modality and tone, and implications for chatbot use.

Characteristics of Chatbots that Embody an Ideal Pharmacist

Both AGYW and pharmacy worker participants expressed that the chatbot should embody characteristics of a healthcare provider. In discussing the avatar chatbot, pharmacy workers suggested that it should look like a healthcare provider to indicate to AGYW that they can trust medical professionals. For AGYW, the chatbot was an opportunity to engage in ideal interactions for contraceptive care. In general, many AGYW perceived female pharmacists as less approachable than male pharmacists, describing them as more judgmental, less confidential, or prone to adopting a maternal role that discouraged certain contraceptive choices. However, in discussing the avatar chatbot, many AGYW wanted the chatbot to present itself as a female pharmacist with professional characteristics, indicating their interests in the chatbot reflecting pharmacist characteristics and interactions that they desire:

“...an indication that they are hearing, they’re listening...Indicate they are friendly and I also want the response to be simpler and understandable...It looks like professional attire, something like...a lab coat. It will make me feel that whatever information I am getting is from a provider.” — AGYW-1

Some AGYW preferred that the chatbot were portrayed as a robot rather than a person to indicate that it was non-judgmental, impartial, and free from social biases, as shown with sketches made by AGYW in Figure 5.4. Other AGYW preferred a human-like, empathetic tone, such as the one presented by the avatar chatbot because “*you feel at home*” (AGYW-2) and “*you feel heard*” (AGYW-1), contrary to how they perceived pharmacy workers’ tones during consultation. Others preferred a direct tone that went straight to the point, which was portrayed in the text chatbot and options chatbot.

When AGYW were asked what questions they would like chatbots to ask them, they indicated that they wanted the conversations to be tailored to their contraceptive understanding, interests, and concerns. AGYW explained that pharmacy workers rarely asked them questions that checked in with how they were feeling, especially if pharmacy workers were busy attending to other

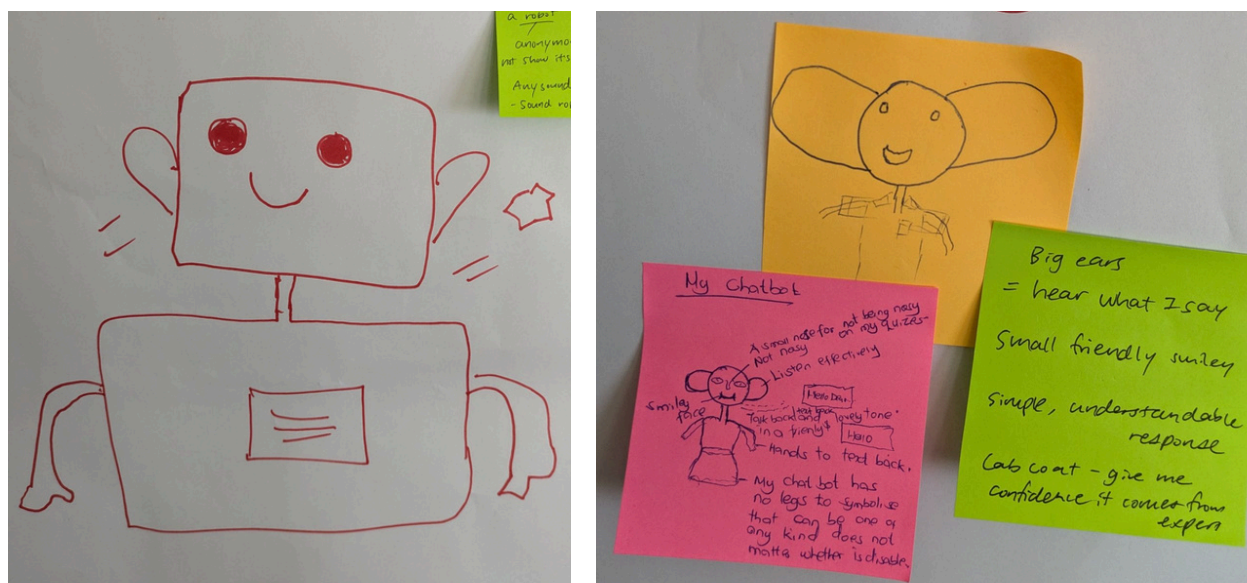


Figure 5.4: Drawings of an ideal chatbot persona created by AGYW participants.

clients. AGYW recognized the value in having the chatbot match the pace of conversations to how they were feeling, which in turn would encourage them to ask more questions: *“It should ask if the patient is satisfied or does she have any other question”* (AGYW-2).

Designing for Different AGYW Groups

Overall, participants thought that the chatbot would be suitable to a wide range of AGYW, especially those who are shy: *“The curiosity is there, but they don’t want to tell others”* (AGYW-3). At the same time, participants noted that the three speculative chatbot prototypes might appeal to different types of AGYW. For each of the three chatbot prototypes, participants were asked who they would recommend the chatbot to and who would benefit from it. Their responses provided insight into how designs of the chatbot could impact what groups of AGYW would be able to access and use the chatbot. The main challenge with the text chatbot, aside from digital familiarity, was structuring and verbalizing thoughts and questions clearly:

“The majority of them I know wouldn’t have the real words to put across...maybe the

redirection by the app can actually put the mind, ‘actually this is what I mean,’ and actually help the app to actually ask the right question and get the appropriate answer or the correct answer...I don’t know if it’s in terms of communication or putting across the question intended. I think there must be a challenge putting it across in terms of words, in statements written.” — Pharmacy-1

The options chatbot was seen as a potential solution to this challenge, as it offered options for conversation directions that AGYW could choose from without requiring them to write out questions. The speed of interaction was also noted as a benefit of the options chatbot, as one pharmacy worker said that AGYW who were in a rush could use this chatbot. One AGYW also expressed that the options chatbot was a preferred option for someone who was anxious about asking questions. However, for AGYW who have the confidence and literacy to express themselves, the text chatbot and avatar chatbot were preferred because they could freely ask any question. AGYW suggested adding autocorrect and sentence-completion features to the text chatbot to help users articulate their questions.

The avatar chatbot was seen as a way to expand accessibility to a broad range of AGYW due to its audio- and speech-based interaction. Participants thought that the avatar chatbot was most suitable for one “*who is confident enough to express themselves, but are not comfortable to express themselves to someone one-on-one*” (AGYW-1). However, participants were concerned about voice-based interactions, as other clients or pharmacists may overhear conversations. To address this concern, AGYW suggested that the chatbot incorporate elements from all three prototypes, allowing users to choose the modality that best suits their needs. One AGYW suggested the combination of text, options, and avatar (audio/speech) taking inspiration from how they used ChatGPT:

“What if all of them are in there? The audio, you talk and it also talks back and then when the second one, where it asks you a question and gives you options to choose. So, you are able to select what you want to use to ask questions.” — AGYW-2

5.5 Discussion

Overall, participants had a positive attitude towards chatbot-supported decision-making in the pharmacy setting. They agreed that chatbots could help bridge the service gap between the app and the pharmacy worker by offering a safe space for AGYW to ask sensitive questions and enhancing their confidence to talk to pharmacists, echoing the benefits of chatbots recognized in prior work [108, 32, 210]. At the same time, the findings reveal two tensions: first, between the forms of support that chatbots and pharmacists can each offer AGYW; and second, between what AGYW want from chatbot interactions and how pharmacists expect those interactions to be bounded.

In this section, I discuss chatbot design choices that can mediate these tensions, by examining how chatbots can navigate community beliefs and balance AGYW needs with pharmacist expectations. I also reflect on the strengths of situating client-facing AI decision-support tools to extend their impact to a diverse group of AGYW. I propose these design considerations to provide guidance to chatbot designers and HCI researchers investigating chatbots for sensitive health contexts.

5.5.1 Navigating Community Beliefs

The findings reaffirm that a variety of beliefs about contraceptive risks, some medically inaccurate, are strongly present at the community level. A widespread belief in Kenya is that injectable contraceptives such as DMPA (depo) could lead to permanent infertility [252, 173], leading some providers and pharmacists to refuse DMPA to unmarried AGYW [257, 77]. However, scientific evidence indicates that DMPA does not cause infertility, though injectable contraceptives are associated with prolonged anovulation among some users, delaying the return to fertility [182]. At the same time, the widely-held belief that DMPA causes infertility stems from a valid concern: while it does not cause permanent infertility, some users experience a prolonged return to ovulation after discontinuation [190].

Building on the work by Kaur and Singh [113] which argues that chatbots should support

“*knowledge building*,” I propose chatbot conversation pathways where medically accurate information can be offered while respecting community beliefs. Rather than dismissing beliefs about infertility, the chatbot could validate AGYW’s concerns, acknowledge that these beliefs are common, and then offer clear information to support informed decision-making. Although AGYW wanted the chatbot to help distinguish “myths” from “facts,” they may not always know which beliefs are inaccurate. The chatbot could therefore invite AGYW to share beliefs they have encountered: “*Many AGYW are worried about the impact of depo on fertility. Have you heard anything similar?*” It could also present frequently asked questions (FAQs) framed as “*Is it true that...?*” with corresponding answers. Rather than simply labeling beliefs as myths or facts, the chatbot could use them as entry points for dialogue, helping AGYW reflect on why these beliefs exist and how they shape decision-making and information-seeking [58, 210].

However, AGYW’s ability to act on evidence-based guidance may still be constrained by pharmacists’ beliefs and practices. Many community beliefs, including the one about DMPA, are propagated by healthcare providers and pharmacists, leaving a gap to inform AGYW on medically accurate information. While pharmacist-level barriers may limit immediate changes in access to certain methods, the chatbot has potential to support incremental, individual-level change by filling in informational gaps and strengthening AGYW’s confidence in making informed choices. Chatbots could act as mediators [32, 108], empowering AGYW to become confident, prepared participants and challenge existing power dynamics between themselves and pharmacists. At the same time, this agency carries trust in the accuracy of chatbot responses, which has been met with concern [172, 136, 273, 214, 169].

5.5.2 Designing to Balance the Needs of AGYW and Pharmacists

AGYW’s strong trust in the chatbot may unintentionally undermine AGYW-pharmacist relationships. Prior research shows that AI-mediated decision-support can shift authority and trust away from human providers [271, 227], especially when AI-generated responses are perceived as more valid or satisfactory than professional input [233]. These risks may be amplified in LMICs, where AI literacy may be lower and overtrust in AI is more pronounced than in western

settings [238, 7]. In this study context, these risks can amplify relational tensions between AGYW and pharmacists. For instance, pharmacists were concerned that AGYW might become closed off during counseling and rely more on the chatbot for decision-support.

These concerns highlight the importance of designing chatbots that complement, rather than compete with, pharmacists. I illustrate three designs that consider how to balance pharmacist perspectives with AGYW priorities: (1) aligning chatbot guidance with pharmacist recommendations; (2) positioning chatbots as a shared technology; and (3) prioritizing AGYW's informational needs. This discussion builds on the dialogue in HCI and CSCW on how to design technologies that balance supporting, leveraging, and extending client-provider communication and interaction [117, 133, 132].

Aligning Chatbot Guidance with Pharmacist Recommendations

While in most cases, chatbots should generally prioritize providing medically accurate information, the findings reveal that certain situations warrant providing information that aligns better with accepted social practices. For example, in Kenya, pharmacy workers typically advise clients that they cannot take emergency contraceptive pills if over 72 hours have passed since unprotected intercourse, as this is the timeline on many pills' packaging and is what is approved by regulatory agencies. However, medical professionals familiar with evidence-based management of EC and many online sources may recommend use up to 5 days after intercourse, with the disclaimer that it is most effective as soon as possible after intercourse. Pharmacy worker participants expressed that the EC timeline presented on the app and chatbot should match pharmacist guidance. In this case, it is appropriate for the chatbot to present information consistent with pharmacist practice. Recommending the health practice that is endorsed by pharmacists and does not conflict with medical consensus can help reinforce uptake [58], minimize confusion, and ensure that the chatbot supports rather than contradicts pharmacists.

Positioning Chatbots as a Shared Technology

I consider opportunities for a chatbot to mediate between AGYW's desires for privacy, autonomy, and information, and pharmacists' expectations around medical responsibility and professional authority. In pharmacy-based care, these tensions surface around who controls information flow, how trust is distributed between human and AI actors, and how medical nuance is communicated in ways that support, rather than undermine, shared decision-making. I examine three ways a chatbot could be positioned as a "*shared technology*" [117] between AGYW and pharmacists to meet both groups' interests.

Supporting Pharmacists' Counseling without Compromising AGYW Privacy. Many AGYW wanted their chatbot conversations to remain hidden from pharmacists because they would use the chatbot to ask questions they hesitated to raise in-person, echoing findings from other health contexts [210, 214, 288]. Pharmacists, however, wanted access to conversation histories to tailor counseling to AGYW preferences. While pharmacist-facing insights are important, the chatbot's primary goal is to support AGYW in articulating their concerns, distinguishing this envisioned chatbot from pre-consultation chatbots that collect information for provider-led counseling [134, 133]. Giving pharmacists access to individual conversations could erode AGYW trust and reduce their willingness to ask candid questions. At the same time, as pharmacists are "*gatekeepers*" [241] who play a critical role in the acceptance and success of interventions [256], the chatbot should offer value to them.

One approach to mitigate this tension is for the chatbot to generate aggregated FAQs that are shared to both pharmacists and AGYW. For pharmacists, FAQs could provide insights into the general interests and knowledge gaps of AGYW, providing resources for the pharmacist to focus counseling efforts on AGYW values [134]. For AGYW, FAQs can be beneficial to share during individual chatbot sessions, helping them to understand the concerns and questions raised by their peers that they might not have recognized themselves. For instance, at the beginning of the chatbot session, the chatbot can present a list of FAQs and instruct AGYW, "*Here are questions that are commonly asked by your peers. Look through this or ask me a different question!*" Showing

FAQs could help reassure AGYW that their peers share similar concerns and questions and that any question is appropriate to ask. Another approach is to give AGYW control over which topics they are comfortable sharing and which they prefer to keep confidential [230]. Here, the chatbot can foster both trust and privacy while ensuring that important information is shared with the pharmacist.

While this work examines the contraceptive pharmacy context, similar tensions between clients' privacy needs and institutional desires for visibility and monitoring arise across multi-stakeholder healthcare contexts [214, 107]. Client-facing AI decision-support tools often sit at the intersection of personal sensemaking and institutional care, where misaligned expectations around data sharing can undermine trust and participation. These tensions are especially pronounced in sensitive health contexts, where clients may disclose stigmatized experiences to a chatbot that they would avoid sharing with community members or providers due to fear of judgment [210]. As such, chatbots should be designed to support selective information sharing, preserving private spaces to articulate questions and concerns while enabling providers to benefit from aggregated insights.

Providing a Model for Pharmacist-AGYW Interaction. AGYW and pharmacy workers both wanted the chatbot to embody characteristics of a healthcare professional, though for different reasons. Lee et al. [132] suggest that clients may perceive chatbots as extensions of a healthcare provider's persona, indicating that chatbots can shape future client-provider communication and relationships. Building on this insight, the chatbot could foreground interactional qualities such as active listening, reassurance, and appropriate deference to professional judgment, reflecting best practices in client-provider communication. These qualities may help AGYW imagine what constructive engagement with pharmacists can look like and feel more willing to voice their concerns during counseling. At the same time, by modeling a trustworthy and supportive healthcare professional, AGYW may feel more willing to open up to the pharmacist [132], reinforcing pharmacists' desired role as credible sources of guidance. However, designing the chatbot to embody ideal qualities could further incentivize overreliance, underscoring the importance of designing interactions that reinforce

the value of in-person counseling. I discuss concrete design considerations for reinforcing these boundaries and supporting pharmacist-chatbot collaboration next.

Managing Overtrust and Medical Nuances. AGYW’s strong trust in a chatbot means that any inaccuracies generated by the chatbot could carry disproportionate influence, underscoring the need for strong guardrails. Building on CSCW work arguing that chatbots should support nuanced, context-aware conversations rather than rely solely on censorship [108], I examine opportunities and challenges of communicating contraceptive nuance.

One nuance is that embodied experiences may not align with standardized medical information. An AGYW participant expressed that they experienced side effects that were not listed in the app and wanted to know whether this was concerning. If a chatbot contradicted this experience by saying that such side effects are not possible, it could amplify confusion or worry. Instead, the chatbot could validate the concern and refer them to a pharmacist: *“Most people experience X side effects. While not many people experience the side effects you have, it is important to pay attention to how you feel and talk to a professional about it.”*

Another nuance involves communicating uncertain medical evidence without overstating causality. Chatbots may struggle to answer questions such as, *“Does DMPA cause depression?”* Clinically, this is a complex question: evidence suggests that DMPA may be associated with mood changes for some people, but the evidence does not support a causal relationship [47]. Yet, a simple online search often yields definitive statements that it causes depression. Grappling with the difference between “is associated with” and “causes” requires careful, context-sensitive communication, which a chatbot may not be able to deliver consistently or that individuals may not interpret as intended. This underscores the importance of designing responses that acknowledge uncertainty and individual variation while avoiding misleading absolutes.

In both cases, it is important for the chatbot to act as a partner in the care team [224, 117, 230], referring AGYW to pharmacists for medically nuanced or individualized concerns rather than attempting to resolve them independently. These boundaries reinforce the pharmacist’s role as the clinical authority while positioning the chatbot as a supportive tool rather than a replacement

for professional judgment. At the same time, the chatbot can still support AGYW's information-seeking and agency by helping them articulate their concerns, recognize when a question requires professional attention, and enter consultations with greater confidence and clarity.

Prioritizing AGYW's Information Needs

Pharmacy workers opposed the chatbot engaging in conversation about certain topics, such as abortion, emphasizing that they should be discussed with a pharmacist. In contrast, AGYW expressed interest in receiving all information from the chatbot. Their preference stemmed from concerns about being judged by pharmacists and receiving biased guidance. This divergence in preferences for informational boundaries highlights the stigma surrounding contraceptive inquiries even in the pharmacy setting, as well as a tension between professional norms that prioritize control and AGYW's need for access to information on stigmatized topics. For AGYW, the chatbot represented a safer and more private entry point for seeking information that they might otherwise avoid altogether.

Rather than offering specific drug names or instructions, which could introduce safety risks, the chatbot could share general information about medication or procedural processes and, most importantly, connect AGYW to supportive and credible sources of care. For example, the chatbot could provide a trusted hotline number or referral contact, ensuring that AGYW have access to accurate guidance while still upholding safety, and the need for professional medical oversight. However, if community members perceived the chatbot as endorsing abortion, it could provoke backlash or create reputational and interpersonal risks for pharmacy workers. This suggests that designers must attend to how the chatbot may be interpreted in the social contexts where it is used.

5.5.3 Reaching a Wide Range of AGYW

The feedback on the speculative chatbot prototypes highlights important considerations about who chatbots can support and who they may inadvertently exclude. Building on questions posed by HCI and CSCW researchers on reaching a wide audience in disseminating sensitive health

information [256, 113], I examine a central question: *how can a chatbot be designed to extend impact to a wide range of AGYW?*

Offering a Range of Engagement Modalities

AGYW are a diverse group, for whom a one-size-fits-all approach risks excluding those with differing needs or capabilities [256]. For instance, AGYW in their early 20s demonstrate higher levels of digital and language literacy, and greater contraceptive knowledge than teenagers; these differences shape their preferences for technology modalities and information-seeking behaviors [188]. The findings from this work reiterate this diversity: the three chatbot prototypes were viewed as suitable for different subgroups of AGYW, depending on their digital literacy, health literacy, language proficiency, and confidence in self-expression. Participants' interests in the options chatbot as something that can be used by those who struggle to formulate questions echo prior work on chatbot modalities [210]. By contrast, the text and avatar chatbots may suit AGYW with the confidence and language comprehension skills to articulate their thoughts. The avatar chatbot could also expand accessibility by removing the need for reading and writing. Recognizing the need for diverse choices, AGYW suggested a flexible approach: offering multiple modalities and allowing users to choose based on their needs and comfort.

Ensuring accessibility across modalities also depends on language support, highlighting the need to scale natural language processing to meet the linguistic needs of Kenyan AGYW. Specifically, the chatbot needs to accommodate Kiswahili, English, and Dholuo and support mixed language use. Kenyan youth also use “Sheng,” a slang blending English, Kiswahili, and regional languages, which is a critical part of their everyday lives and youth identity [79]. Chatbot designers must account for language and modality choices not only at the broader country- or cultural-level, but also in ways that address the specific needs of adolescents.

Strengths of Situating Chatbots in an Existing Care Ecosystem

Even with successful technical development, a chatbot cannot be a suitable fit for an entire group of AGYW because of varying levels of education, literacy, and confidence in self-expression.

This variability underscores the importance of situating chatbots within a broader ecosystem of decision-support resources to ensure that AGYW have sufficient support. I elaborate on the design choices of the envisioned chatbot that will shape its reachability and potential impact.

Adolescents in LMICs, including in Kenya, often lack consistent access to personal devices and internet connectivity and have varying digital literacy levels [142, 188]. Unlike other SRH chatbots for adolescents and young people in LMICs that require digital experience and mobile phone ownership [210, 272, 169, 170, 232], the envisioned chatbot would be accessed via a tablet provided in the pharmacy setting, ensuring that AGYW can use the technology without owning personal smartphones. The chatbot would be used after the Mara Divas app, which delivers core information on contraceptive methods, serving as a complementary platform to address emerging questions. This is particularly relevant as AGYW had a broad range of questions post-app use. Moreover, by placing the chatbot in the pharmacy setting where AGYW already come to receive contraceptive services, the intervention meets AGYW where they are, integrating digital support into an existing care pathway rather than requiring them to seek information through a separate system. Embedding the chatbot in the pharmacy setting also enables handoffs to human professionals, supporting shared decision-making directly after chatbot use. Questions that surface during chatbot interactions can be addressed through in-person counseling, helping AGYW contextualize information and navigate next steps [255].

More broadly, designing client-facing AI decision-support tools as components within a broader care ecosystem leverages the technical and human infrastructure that can accommodate diverse client needs and profiles [188]. In sensitive health contexts, where trust, stigma, and power asymmetries shape information-seeking behaviors [58], situating such tools alongside human providers and existing resources can support more nuanced and tailored care [188]. The presence of a provider during the final stages of decision-making can help mitigate risks associated with overreliance on AI-mediated guidance, particularly when questions require clinical judgment or interpersonal reassurance. This perspective shifts the design objective from optimizing AI systems in isolation toward enabling flexible handoffs and shared decision-making by clients, healthcare providers, and AI. As AI-enabled decision-support tools become more prevalent in healthcare,

ensuring alignment within the surrounding care ecosystem will be as critical as technical accuracy, performance, or usability.

5.5.4 Limitations and Future Work

This study was conducted in a single county in Kenya, and its findings may not be generalizable to the entire country. However, the insights gained from this work will be valuable for guiding the next phase of research, which aims to refine the Mara Divas app, including exploring opportunities for AI, integration into pharmacy workflows, and use in rural areas and other regions of Kenya.

A major limitation in implementing chatbots in the Kenyan context is that common chatbots are primarily trained on English-based data, leading to potentially inferior performance in non-English languages [138, 65, 273]. Although efforts are growing to expand datasets in Dholuo and Kiswahili [17, 127] and develop chatbots in Kiswahili [161], supporting low-resource languages and multilingual performance remains a challenge.

Broader challenges remain in integrating the chatbot into constrained retail settings. Many commercial healthcare outlets in LMICs lack waiting areas and private counseling spaces [52], raising important questions about how technologies can be integrated into these contexts [188]. As mentioned in the findings, in already crowded pharmacies, the use of a chatbot would require additional time and space, which could reduce the number of clients that pharmacy workers are able to serve, affecting their businesses. Addressing these realities will require consideration of incentives for pharmacy workers to adopt and promote the chatbot. Potential approaches may include training on SRH service provision, financial incentives, or the provision of airtime. However, there are ethical challenges with incentivizing healthcare providers. Financial incentives could undermine intrinsic motivation, prompting providers to focus narrowly on incentivized services [286], potentially disrupting person-centered care and client-provider relationships [146]. This risk is particularly concerning in the context of AGYW, who are a vulnerable group given their age and gender, and who may be more sensitive to coercion. Ensuring that incentive structures do not compromise trust and autonomy will therefore be essential in future work.

5.6 Conclusion

This work explores how chatbots could be designed to support person-centered contraceptive care for AGYW and considers the implications of introducing chatbots into the pharmacy setting in Kenya. Through co-design workshops centered around speculative chatbot prototypes, this work identifies possible and preferable futures of chatbot-supported contraceptive counseling. The findings suggest that chatbots can provide AGYW with a private and safe space to ask sensitive questions and explore sensitive topics. At the same time, they reveal important considerations for how chatbots must balance the informational needs and autonomy of AGYW with pharmacists' professional responsibilities and expectations within the pharmacy setting.

This work also demonstrates the value of situating chatbots within a broader ecosystem of contraceptive decision-support resources. Rather than functioning as standalone decision-making tools, chatbots should be designed with consideration for how they integrate into existing decision-support resources such as the app and the pharmacist to enable handoffs to support person-centered care. This positioning allows the chatbot to accommodate the diverse needs, preferences, and levels of knowledge among AGYW while maintaining the important role of pharmacists in contraceptive counseling.

More broadly, this work contributes concrete design guidelines for chatbots in sensitive health contexts. While chatbots can help individuals navigate personal and stigmatized health concerns, their design must carefully account for the relational dynamics and institutional expectations present in service delivery environments. By identifying key tension points and proposing design considerations for chatbot-mediated contraceptive care, this work provides guidance for chatbot designers and HCI researchers working in sensitive health domains. In doing so, it encourages the HCI community to move beyond designing technologies in isolation and instead consider how chatbots can be thoughtfully integrated into existing care ecosystems to support diverse users and stakeholders.

Chapter 6

Future Directions: Applications of HCI to Global Health

This chapter synthesizes insights from the previous chapters to describe the broader contributions of HCI research embedded within global health initiatives. I begin by reflecting on how I have positioned myself in global health projects. I then take a holistic view across my research projects to identify sociotechnical insights that emerged and how they inform future directions for designing technologies, and more broadly, for future HCI research in global health. In particular, these insights speak to a key component of my thesis statement: developing an understanding of processes that support health system goals. Finally, I summarize the key contributions and work products that HCI research can contribute to global health.

6.1 Self-Positioning within Global Health

My involvement in the research presented in previous chapters was initiated through invitations from global health scholars who had long-standing partnerships with in-country researchers and organizations. By embedding myself within these established collaborations, I ensured that technology design and development was informed by sociocultural contexts, institutional realities, and health needs from the outset, rather than retrofitted after deployment. This research approach is aligned with what Toyama [254] recommends for ICTD, which is that “*technology projects should seek to amplify the impact of existing institutions that are already contributing successfully to development goals.*”

In Kenya, I contributed to the development of a novel contraceptive decision-support app for AGYW in the pharmacy setting. This was a collaborative effort, in which I led a team of five undergraduate software engineers in iterative app development while working closely with experts who had deep understandings of Kenyan AGYW’s contraceptive needs and pharmacy challenges.

My role in this team extended beyond coordinating app development and involved actively mediating between technical feasibility, research objectives, and contextual constraints. I served as a bridge across engineering, design, and health domains, communicating technical limitations while translating stakeholder insights into concrete app requirements. This collaborative structure was intentional. It prevented the engineering process from operating independently of the health goals of the project. For example, app interface designs were shaped by the wide variation in the digital literacy and language proficiency levels of AGYW. These constraints were not afterthoughts, but rather structured choices from the beginning.

I also pursued research examining how new technological possibilities could respond to needs that emerged during the deployment and study of earlier digital health interventions. While studying the decision-support app, it became clear that static app content and pharmacist counseling alone could not fully address the wide range of questions and informational needs expressed by AGYW. These observations motivated follow-on research exploring how chatbots might complement existing decision-support resources in the pharmacy setting. Importantly, this research direction did not emerge from abstract technological curiosity but from empirical insights generated through an early study of the decision-support app and discussions with collaborators working in adolescent reproductive health. The chatbot prototypes were developed with a clinical reproductive health expert and informed through discussions with Kenyan researchers who shared insights into AGYW's technological practices and communication preferences. Rather than introducing entirely new technological interventions in isolation, my research iteratively built on prior systems and observations, ensuring that new technological explorations remain grounded in the realities of care environments and the priorities of global health.

Similarly, my work in Malawi built on an existing digital health system. Building on the prior success of Malawi's HIV care program in rolling out mobile and electronic data collection, my research served as formative work for optimizing mobile app-based data collection in community settings. By embedding myself within this ongoing national digital initiative, I contributed an understanding of how technical considerations, care workflows, and security and privacy practices intersect when evaluating and refining digital health tools. This approach ensured that future

efforts to strengthen data security could build on stakeholders' needs, concerns, and practices around current digital tools, and remain aligned with the institutional goals of Malawi's HIV health system.

My experiences highlight how positioning HCI research within global health partnerships shapes not only how technologies are developed, but also what kinds of insights the work can generate. The following sections synthesize key insights from conducting embedded HCI research within global health initiatives and outline future directions for HCI research.

6.2 Formalizing and Sustaining Best Practices in Care

A key component of my research has been engagement with various stakeholders of the health system. This approach was critical to understanding how different stakeholders perceive and engage with various technologies in healthcare, and to define directions for designing technologies that are grounded in lived realities. Table 6.1 summarizes the processes that digital health can enable to support various stakeholders of a health system. The table highlights how digital technologies can shape multiple dimensions of care delivery, spanning individual interactions, clinical workflows, and system-level coordination.

Table 6.1: Summary of stakeholder groups and the processes enabled by digital health to support their roles and interests in care delivery.

Stakeholder Group	Processes Enabled by Technology
Clients	• Increased access to health information • Greater autonomy in decision-making
Healthcare Providers	• Tailored counseling efforts • Streamlined clinical workflows
Data Clerks	• Improved data organization and monitoring • Enhanced reporting capabilities
Health System Decision Makers	• System-wide visibility into service delivery

Importantly, the processes enabled by these technologies reflect implicit assumptions about how care, data management, and governance should operate. For example, they presume that

clients should have access to information that supports informed health and care decisions, providers should be equipped to deliver tailored care, and decision makers should be able to use data to monitor programs, allocate resources, and improve service delivery. In this sense, processes enabled by technology can be understood as expressions of best practice that are codified into workflows, interfaces, and system structures.

However, while technologies can help formalize best practices, they cannot independently ensure their consistent implementation. Rather, the effectiveness of technology in supporting best practices depends on the individual, organizational, and institutional conditions within which it operates. For example, in Chapter 3, I argue that protecting sensitive health data depends not only on technical safeguards but also on governance structures, workforce capacity, group commitment, and individual execution of responsible data collection, management, and use. Failures to ensure secure digital systems can compromise client privacy and trust, which may deter individuals from seeking care or fully engaging with services, ultimately leading to poorer health outcomes for ART clients.

Similarly, in Chapter 4, I demonstrate the limitations of the contraceptive decision-support app alone to drive immediate changes in care practices. While the app promotes evidence-based and person-centered care, pharmacists play a critical intermediary role in translating information into service provision and retain the authority and discretion to determine whether and how these practices are implemented. Person-centered care in contraceptive services requires not only access to information, but also supportive counseling interactions and high-quality services that empower individuals to make informed choices aligned with their needs and preferences [77, 16]. Without consistent execution of these practices within AGYW-pharmacist interactions, the potential of decision-support tools to improve health outcomes could be limited.

These cases illustrate how the actions or inactions of one actor can generate downstream consequences across the care ecosystem, often affecting those with less power, particularly clients. In LMICs, these breakdowns can occur due to structural and behavioral constraints, including training variability [6, 77], diminished motivation and performance [62], commercial incentives that prioritize profit maximization [282, 152], and systematic barriers to the adoption of new and

improved standards [174].

6.2.1 Implications for Future Research: Building a Strong Infrastructure

HCI research has consistently advocated for ensuring that technologies align with local needs and contexts [85, 58]. While alignment is critical and well-designed technologies can move care closer to best practices, future work must also account for the complementary human and institutional infrastructures that enable technology to support best practices in care. Wyche [284] challenges the *status quo* in design and argues that “*mobile phones may not impact health and education in LMICs if favorable contextual factors concerning community and infrastructure are not present.*” This insight provides a starting point for HCI research to assess whether there is an infrastructure that can support technology. Among these infrastructures, human infrastructure is especially important: in LMICs, it has been shown to shape experiences with technology and people’s ability to benefit from it [223]. Extending this point, Toyama [254] argues that “*direct investments in building human capacity must be made*” for technology to realize its full potential in supporting social and institutional change. These arguments suggest that HCI research should not only evaluate whether technologies are contextually appropriate but also examine and identify the human and institutional capacities required for technologies to be meaningfully adopted and sustained to contribute to improved care.

Future research should examine how and whether technologies can fit into existing capacity, including human relationships, organizational structures, and national priorities. At the same time, it should consider what gaps technologies reveal, where additional support is needed, and how existing infrastructures can be strengthened to build preferable futures of care. HCI is well-positioned to support this effort by placing a particular emphasis on human relationships in discussions of technology and examining how care is experienced from multiple perspectives and across different levels of a health system. The following sections examine the insights that emerge from placing human relationships at the center of digital health research.

6.3 Mediating Tensions in Multi-Stakeholder Environments

Digital health is often designed to support the goals of a specific user group. For example, clinical decision-support systems are intended to optimize clinical workflows and inform clinicians' decisions about care. However, as shown throughout this dissertation, technologies often affect a wider network of actors whose work and responsibilities intersect with these tools. For example, in Chapters 4 and 5, I discuss how AGYW-facing decision-support tools can shift pharmacist responsibilities. As in the case of my work in Kenya, empowering one group can change existing roles, expectations, and incentives among other stakeholders of care delivery. Technologies that fail to account for these intersecting interests risk amplifying friction in care environments or undermining existing responsibilities.

A central dynamic observed across my research is the tension between clients and providers, particularly around authority and voice within care interactions. In the study contexts of my dissertation and in other LMICs, clients are reluctant to question providers' authority, even when they have concerns or unmet informational needs [165]. My work in Chapter 3 revealed that ART clients thought that providers' use of data collection tools at the point-of-care reinforced their professional status or expertise, making it more difficult for clients to ask questions without disrupting established hierarchies. Such dynamics due to point-of-care devices have been similarly observed in other contexts [39, 231, 50]. In Chapter 5, I identify how AGYW's prioritization of privacy, validation, and freedom from judgment can come into tension with pharmacists' desire to maintain professional control and oversight, a dynamic commonly observed in other multi-stakeholder healthcare environments [214, 107]. These examples show how digital interventions designed to empower one stakeholder group may also unsettle existing arrangements of authority, visibility, and responsibility for others.

Importantly, rather than creating friction, technologies often make pre-existing tensions between stakeholders more visible and amplify them. In particular, client-facing tools can intensify the tension between clients and providers by redistributing control over access to information. Such tools can empower clients to become more active, prepared participants in decision-making

and challenge existing power dynamics with providers [32]. Taken together, my dissertation suggests that tensions between stakeholders are central to how technologies are designed and function in practice.

6.3.1 Implications for Future Research: Designing for Shared Value

Technologies do not merely expose tensions between stakeholders; they also intervene in them. Whether technology mediates stakeholder tensions or creates conflict depends on how deliberately potential shifts are anticipated and accounted for early on in technology design. One key direction for future HCI research is to design for shared value across stakeholders, which means creating technologies that help stakeholders coordinate across different roles, priorities, and authority. HCI can examine how technologies mediate tensions and define human-human and human-technology interactions in ways that support collaboration and accountability. Future research should consider how the prioritization of stakeholder needs shift as care progresses and as the goals of an intervention change. For example, in Chapter 3, I demonstrate the importance of recognizing differences in the sensitivity of data and therefore differences in the levels of protection required, while maintaining a core commitment to protecting clients' privacy. Similarly, in Chapter 5, I present how chatbot design priorities shift depending on the stage of care: whether the goal is to create a safe space for asking sensitive questions or to provide locally accepted guidance.

Designing for shared value also means identifying how technology facilitates communication, especially between clients and providers [132, 230, 224]. Well-designed and well-situated technologies can support handoffs between technologies and providers to practice shared decision-making by all actors and create spaces for constructive dialogue between clients and providers [216, 99, 39, 132]. Designing for effective handoffs requires clarifying what decisions technologies can support, what decisions they should not make, and where human or institutional judgment must remain central. By intentionally designing for these mediated dynamics, future research can develop digital health that strengthens coordination among stakeholders.

6.4 Expanding the Benefits of Technology to the Hardest-to-Reach

Tensions emerged not only between stakeholder groups, but also within them. Differences in digital literacy, health knowledge, language proficiency, and access to resources mean that technologies may privilege some subpopulations over others. In Chapter 4, I discuss trade-offs of designing technologies around the preferences and feedback of technologically experienced users, noting how this choice inadvertently marginalizes harder-to-reach individuals with fewer informational or digital resources. More broadly, designing for those who are technologically easiest-to-reach can narrow the scope of impact and reproduce existing inequities. Especially as mobile devices become more available and mHealth expands, a fundamental question needs to be asked: *who is being reached and impacted by technology and who remains peripheral or excluded?*

This question has been repeatedly raised in ICTD scholarship, where technological advances often shift attention toward populations that are more technologically accessible. For example, despite the continued prevalence of feature phone ownership across LMICs [237, 175, 19, 49], increasing smartphone penetration has led many interventions to prioritize smartphone users, who are perceived as easier-to-reach and more aligned with innovation narratives. Such shifts risk reinforcing existing inequalities by directing resources toward those already better positioned to benefit from digital tools.

More broadly, these patterns suggest that inclusion and exclusion are actively produced through technology design decisions. Choices about target users, platforms, features, and interaction models shape who can meaningfully engage with a system and who cannot. In this sense, designing for “ease of deployment” or “rapid adoption” often implicitly prioritizes populations with greater resources, literacy, or familiarity with technology, while rendering others less visible in the design process. This can be particularly salient in global health contexts, where individuals’ ability to benefit from digital interventions is shaped not only by device access, but also by social norms, privacy concerns, language, and trust in institutions. Importantly, exclusion is not always intentional. It can emerge as a byproduct shaped by how technologies interact with diverse user capabilities and existing support structures.

6.4.1 Implications for Future Research: Designing for Inclusion

HCI research plays an important role in critically interrogating who technologies welcome into care systems and who they leave behind. Researchers should consider exclusion from the outset rather than as an afterthought. Exclusion can arise from technological factors such as device access, connectivity, and digital literacy and also emerge from sociocultural dynamics, including literacy, stigma, power relations, and trust in institutions. Given these factors that shape access to and engagement with technology, HCI researchers should consider not only the technological dimensions of inclusion, but also how the surrounding care environment can enable more people to benefit from technology and therefore better health. For example, in Chapters 4 and 5, I argue that situating client-facing decision-support tools within a wider care ecosystem can expand impact across a diverse AGYW population. The pharmacy setting offers an intermediated environment where technology is accessible and where pharmacists can accommodate a wide range of decision-making needs that technology alone may not be able to address. Future research should not only identify variations in user capacities, preferences, and constraints, but also consider how technologies can interact with existing support structures to support inclusion and extend impact.

At the same time, researchers should clarify what “inclusion” means in a given context in order to define the scope of an intervention and assess the trade-offs of design choices early on. In Chapter 4, I describe the deliberate decision to focus the contraceptive decision-support app on AGYW seeking services in pharmacy settings, rather than expanding to other populations or making the app publicly available. While such choices may limit reach, they can also enable more contextually appropriate interventions. A harm reduction perspective [143] helps frame this trade-off: while not comprehensive, offering accessible and context-sensitive support can still provide meaningful benefits by meeting AGYW in their existing circumstances and reducing the risk of unintended pregnancy [77]. More broadly, this highlights that designing for inclusion is not solely about maximizing reach, but about making deliberate and context-sensitive trade-offs that balance accessibility, safety, and relevance.

6.5 Contributions of HCI Research to Global Health

In this chapter, I described my positioning within global health initiatives, insights that emerged from embedded HCI research, and future research considerations. In this section, I summarize the key contributions and work products that arise from this style of HCI research and how they support global health efforts. These contributions illustrate how HCI research can support global health initiatives not only by building digital tools, but also by generating the insights needed to integrate those tools responsibly within complex healthcare systems.

First, embedded HCI research supports **human-centered design of digital health**. HCI plays a critical role in bridging engineering and global health by translating complex, context-specific insights, such as social norms, power dynamics, and care workflows, into concrete design requirements and development decisions. HCI methods help ensure that technologies are not developed in isolation, but are grounded in the lived realities of the people and institutions they aim to support. For example, in my research, speculative design was useful for interrogating the near future and identifying preferable futures, while co-design supported the ideation of possible prototypes and grounding design choices in stakeholder input.

Second, HCI research generates **sociotechnical insights into how digital technologies interact with complex care ecosystems**. By studying technologies in real-world multi-stakeholder care environments, HCI research reveals how digital technologies reshape coordination, authority, and accountability. Across the studies presented in this dissertation, technologies were shown to formalize best practices, surface tensions between stakeholders, and redistribute voice and responsibility within care interactions. These insights can help global health researchers anticipate how digital interventions may influence existing practices and relationships within health systems.

Third, HCI research produces **design guidelines for future technologies**. Design guidelines go beyond optimizing aesthetics or usability; they articulate how people, institutions, and technologies can work together to enable preferred futures of care. In this dissertation, these guidelines include recommendations for secure digital systems to manage client data, potential

pharmacist roles in enabling person-centered care in an app-supported care setting, and chatbot design considerations for facilitating safe, context-sensitive, and person-centered care. By synthesizing insights about sociocultural contexts, care workflows, technology infrastructure, and human infrastructure, effective design guidelines can move digital health efforts beyond isolated technological solutions toward systems that are more likely to be adopted, sustained, and effective in practice.

Chapter 7

Conclusion

This dissertation examines how digital health can effectively support healthcare delivery in LMICs, with the ultimate goal to contribute to better healthcare outcomes. My research demonstrates that the success of digital health depends not only on technical performance but also on how it interacts with existing care systems, institutional practices, and stakeholder dynamics. Through three digital health studies in Malawi and Kenya, this dissertation argues that impactful digital health can be enabled by contextually grounded design and an understanding of the processes that support health systems goals.

In Malawi, I partnered with a public HIV care program to examine how the security of EMR systems is experienced and managed by diverse stakeholders. This work revealed how privacy protections are not solely determined by technical safeguards but are implemented through everyday practices, governance, and coordination across stakeholders within the health system. By analyzing how security practices are operationalized across individual, organizational, and national levels, I identified opportunities for strengthening digital infrastructures through improvements in governance, workforce capacity, and policy coordination. These findings highlight the importance of understanding how institutional structures and human practices collectively support the secure digitization of sensitive health data.

Building on this systems-wide perspective, I led iterative design and development of a contraceptive decision-support mobile app for AGYW in the pharmacy setting in Kenya. Through collaboration with experts in clinical reproductive health and human-centered design in Kenya and the U.S., I explored how such an app could be integrated into the pharmacy to support person-centered care. This work highlights how the app can be integrated into existing care infrastructures and extend impact to a diverse group of AGYW through intermediated interactions

by the pharmacist.

However, the study also identified limitations in relying solely on static app content and pharmacists' counseling capacity to address the wide range of contraceptive questions asked by AGYW. I conducted follow-on research examining how chatbots can augment the app and explored possible and preferable futures of chatbot-supported contraceptive decision-making. This work highlights that while chatbots can offer AGYW a private and non-judgmental space to ask sensitive questions, they can also surface tensions between the roles of chatbots and pharmacists in care delivery, as well as between AGYW's needs and pharmacists' priorities. In response, I developed design guidelines illustrating how chatbots can be positioned within contraceptive counseling workflows, including when and how chatbots should engage with AGYW and how interactions should transition back to pharmacists.

Taken together, this dissertation illustrates the importance of examining digital health within existing care ecosystems by foregrounding social, cultural, and technical contexts. By examining digital health across multiple stakeholders and various stages of technology project maturity, this dissertation demonstrates how HCI research can meaningfully contribute to global health. Specifically, it shows how HCI can support the human-centered design of digital health, generate sociotechnical insights on how digital systems interact with complex care ecosystems, and produce actionable design guidelines that enables technologies to be adopted, sustained, and effective in practice. Ultimately, this dissertation highlights the importance of approaching digital health through a critical, systems-oriented lens that prioritizes alignment with health system goals and the realities of care delivery. Sustained attention to the institutional, social, and infrastructural conditions of care can enable technologies to create meaningful and lasting impact, contributing to equitable healthcare.

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