HUMAN IMMUNODEFICIENCY VIRUS PRE-EXPOSURE PROPHYLAXIS ADHERENCE, RETENTION AND ASSOCIATED FACTORS AMONG USERS AT KITGUM GENERAL HOSPITAL, NORTHERN UGANDA

BY

AKANYO JOYCE

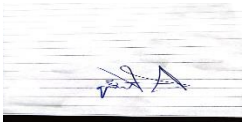
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A DISSERTATION SUBMITTED TO THE DIRECTORATE OF RESEARCH AND GRADUATE TRAINING IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF PUBLIC HEALTH OF GULU UNIVERSITY

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DECLARATION

I, **JOYCE AKANYO**, hereby affirm that to the best of my knowledge, this is my original work and has never been submitted to a university or other higher education institution for an award of any academic qualification. I also acknowledged the authors of the secondary information used.

Signature:  Date: 8/10/2026

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APPROVALS

We acknowledge that the student developed this protocol and dissertation under our supervision, and is now ready for examination

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ABBREVIATIONS

CDC	Centers for Disease Control
DBS	Dried Blood Spot
GUREC	Gulu University Research Ethics Committee
HIV	Human Immunodeficiency Virus
HR	Hazard Ratio
IDI	In-Depth Interview
MSM	Men who have sex with Men
PEP	Post Exposure Prophylaxis
PrEP	Pre-Exposure Prophylaxis
PWID	People Who Inject Drugs
SEM	Social Ecological Model
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDs
WHO	World Health Organisation

OPERATIONAL DEFINITIONS

1. Retention in PrEP: consistent use of a PrEP method for ≥ 3 months
2. PrEP initiation; the first prescription of PrEP for eligible and confirmed HIV-negative individuals.
3. PrEP Refill: Receiving an additional PrEP supply that is every 3 months (oral PrEP)
4. PrEP Drop-out; missing refills for ≥ 3 months without any reason (lost to follow up or discontinued)
5. An emancipated minor is an individual below the age of 18 years who is legally recognized as an adult and is free from parental or guardian control and able to make decisions for themselves including medical decisions

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TABLE OF CONTENTS

DECLARATION i
APPROVALS ii
ACKNOWLEDGEMENTS iii
ABBREVIATIONS iv
OPERATIONAL DEFINITIONS v
ABSTRACT ix
CHAPTER ONE: INTRODUCTION 1
Background 1
STATEMENT OF THE PROBLEM 3
STUDY OBJECTIVES 4
1.3.1. General objective 4
1.3.2. Specific objectives 4
Research questions 4
CONCEPTUAL FRAMEWORK 5
1.6. THEORETICAL FRAMEWORK 6
1.7. JUSTIFICATION OF STUDY 7
CHAPTER TWO: LITERATURE REVIEW 8
2.0. Introduction 8
2.1. Introduction to PrEP use 8
2.2. PrEP retention rates 9
2.3. Factors Associated with Dropout from PrEP Use (Quantitative Findings) 11
2.4. Barriers and Facilitators to PrEP Adherence and Retention (Qualitative) 13
2.5. Literature summary and conclusion 19
CHAPTER THREE: STUDY METHODS 21
3.0 Introduction 21
3.1. Study Design 21
3.2. Study setting 21
3.3. Population 22
3.3.1. Target population 22
3.3.2. Study Population 22
3.4. Eligibility criteria (Quantitative) 22
3.4.1. Inclusion criteria 22
3.4.2. Exclusion criteria 22
3.5. Eligibility criteria (Qualitative) 22
3.5.1. Inclusion criteria 22

3.5.2. Exclusion criteria 22
3.6. Sampling technique 23
3.7. Sample size 23
3.7.1. Sample size for the quantitative phase of the study 23
3.7.2. Sample size for the qualitative part of the study 24
3.8. Data Collection and Tools 25
3.8.1. Data collection tools 25
3.8.2. Data collection procedure 25
3.8.2.2. Qualitative data collection procedure 26
3.9. Data management 26
3.9.1. Data Entry 26
3.9.2. Data storage 26
3.9.3. Data Quality control and assurance 27
3.10. Data Analysis 28
3.10.1. Quantitative data analysis 28
3.10.2. Qualitative data analysis 29
3.11. Ethical considerations 30
3.12. Dissemination plan 31
CHAPTER 4: RESULTS 33
4.1.0 SECTION A: QUANTITATIVE FINDINGS 33
4.1.1. Demographic characteristics of participants (objective 2) 33
4.1.2. Programmatic and Clinical Characteristics 34
4.1.3. Objective 1: To measure the retention rates among PrEP users at Kitgum General Hospital.35
Table 1. Life-table estimates of PrEP retention and dropout over six months (N=1,102). 35
4.1.4. Objective 2; To determine the factors Associated with drop out from PrEP use at Kitgum General Hospital 36
Table 2. Bivariate and multivariable Cox proportional-hazards regression for factors associated with PrEP dropout 37
4.2. SECTION B: QUALITATIVE FINDINGS 38
4.2.1. Facilitators of PrEP Adherence and Retention 38
Table 4. Summary table for the facilitators of PrEP adherence and retention 38
4.2.2 Barriers to PrEP Adherence and Retention 51
4.3. Conclusion 64
CHAPTER 5: DISCUSSION 65
5.1. Introduction 65
5.2. DISCUSSION OF KEY FINDINGS 65

5.2.1. SECTION A: Quantitative findings 65
5.2.1.1. Retention rates (Objective 1) 65
5.2.1.2. Factors associated with drop out from PrEP use 66
5.2.2. SECTION B: QUALITATIVE FINDINGS 70
5.2.2.1. Barriers and facilitators to PrEP adherence and retention 70
5.2.2.2. Facilitators of PrEP Adherence and Retention 70
5.2.2.3. Barriers to PrEP Adherence and Retention 77
5.3. Study Limitations and Mitigation Strategies 88
5.4. RECOMMENDATIONS 89
5.5. CONCLUSION 91
REFERENCES 92
APPENDIX 1: INFORMED CONSENT FORM 106
APPENDIX 2: DATA ABSTRACTION GUIDE FOR THE QUANTITATIVE 116
APPENDIX 3: INTERVIEW GUIDE FOR THE QUALITATIVE STUDY ON BARRIERS AND FACILITATORS TO PREP ADHERENCE AND RETENTION (Version 2.0) 122
APPENDIX 5: MEASURES FOR THE PREVENTION AND CONTROL OF RISK OF SPREAD OF COVID-19 DURING THE IMPLEMENTATION OF RESEARCH 136
APPENDIX 6: STUDY WORKPLAN 138
APPENDIX 7: BUDGET 140

ABSTRACT

Introduction: Pre-exposure prophylaxis (PrEP) prevents HIV infection when taken consistently by individuals at high risk but adherence and long-term retention remain a major challenge, in resource-limited settings like Northern Uganda where retention rates remain suboptimal, jeopardizing the effectiveness of this prevention strategy.

Objectives: To determine PrEP retention rates, identify factors associated with dropout from PrEP use, and explore barriers and facilitators to adherence and retention among PrEP users at Kitgum General Hospital

Methods: A mixed-methods study was used, combining retrospective cohort design and qualitative in-depth interviews. Quantitative data were extracted from medical records to assess retention rates at 1, 3, and 6 months and to identify factors associated with drop out and analysed using survival analysis. Qualitative interviews explored personal experiences, barriers, and facilitators influencing adherence and retention and analyzed thematically.

Results: A total of 1,102 PrEP user records were reviewed, with a mean age of 28.1± 8.6 years; mostly males (n = 610, 55.3%), and 78.8% resided in urban areas. PrEP retention declined from 81.2% (n=895) at 1 month to 45.0% (n=496) at 3 months and 24.2% (n=267) at 6 months. Factors independently associated with dropout included younger age (aHR = 0.98, 95% CI: 0.98–0.99, p < 0.001), primary education (aHR = 0.74, 95% CI: 0.62–0.89, p = 0.001), longer distance to the facility (aHR = 1.01, 95% CI: 1.00–1.01, p = 0.017), facility-based entry (aHR = 2.55, 95% CI: 2.18–2.97, p < 0.001), and priority population status (aHR = 1.26, 95% CI: 1.06–1.51, p = 0.010).. Key barriers to adherence and retention included stigma, fear of disclosure, side effects, misconceptions, pill burden and treatment fatigue, low perceived risk and service gaps, while facilitators included awareness, motivation to protect self and partner, negative HIV test results, acceptability and availability of PrEP, integration, adherence strategies, peer support, and positive healthcare experiences.

Conclusion:

Overall, PrEP retention at Kitgum General Hospital was low, highlighting the need to address stigma, structural barriers, and improve community support and service integration

Keywords: PrEP, adherence, retention, dropout, barriers and facilitators, Uganda, Kitgum General Hospital,

CHAPTER ONE: INTRODUCTION

Background

Pre-exposure prophylaxis (PrEP) refers to the use of antiretroviral medications by HIV-negative individuals to reduce their risk of acquiring HIV, particularly among those who are at high risk of exposure through sexual contact or injection drug use (CDC, 2024). The effectiveness of PrEP relies on consistent adherence, achieved only through retention in care to maintain protective drug levels. Therefore, discontinuation or inconsistent use significantly reduces the effectiveness and increases vulnerability to HIV infection. The World Health Organization (WHO) in 2015, recommended the use of oral PrEP, followed by Dapivirine Vaginal Ring in 2021, and Long-acting Cabotegravir PrEP in 2022, for those at Substantial risk for HIV infection (WHO, 2022). In sub-Saharan Africa including Uganda where the HIV epidemic is most severe, PrEP delivery is scaling up, but challenges remain in sustaining retention over time (UNAIDS, 2023).Globally, approximately 3.5 million individuals had initiated PrEP by the end of 2023, with average retention rates of about 61% at six months and 44% at 12 months (UNAIDS, 2024). In Sub-Saharan Africa, previous studies in South Africa and Kenya reported retention rates as low as 30% at 12 months after PrEP initiation (Corneli et al., 2022; Kinuthia, Pintye, Abuna, Mugwanya, Fondo, et al., 2020). In Uganda, by the end of 2022, PrEP uptake was at 60% among those eligible, with only 20% continuation rates among those initiated (PrEP Technical Guidelines, Uganda 2022).

In Kitgum District, by the end of 2021, the retention rate was at 50% at six months and 20% at 12 months (Kitgum District Annual HIV Report, 2022). However, this is still far from the approximated UNAIDS target of 21.2 million people at substantial risk globally, including 1.2 million in Uganda, to be initiated on PrEP by 2025, with an annual continuation rate of at least 75% among those initiated, as part of the global effort to reduce new HIV infections to less than 370,000 globally and 18,000 in Uganda (UAC, 2024; UNAIDS, 2024).

The Centers for Disease Control (CDC) guidelines recommend follow-up every three months for oral PrEP users (CDC, 2021). In Uganda, follow-up is recommended one month after initiation, two months after the second visit, and every three months thereafter (PrEP Technical Guidelines, Uganda 2022). These visits allow healthcare providers to assess ongoing HIV risk and PrEP suitability while providing adherence support, risk-reduction, and behavioural counselling (Lankowski et al., 2019).

Achieving sustained PrEP use remains challenging due to limited knowledge of its benefits, low perceived HIV risk, and concerns about side effects (Lunkuse et al., 2022; Muwonge et al., 2020; Beesham et al., 2022). Structural barriers, including long distances to health facilities, transportation costs, and drug stockouts, further disrupt PrEP use (Mayer et al., 2019). Inadequate counselling and follow-up also reduce user engagement and support (Camlin et al., 2022; Lanham et al., 2021), while stigma and discrimination discourage continued PrEP use (Chautrakarn et al., 2022; Stangl et al., 2019).

Social support from family, friends, and healthcare providers promotes PrEP adherence by providing encouragement and reducing stigma (Elopre et al., 2022). Differentiated service delivery, including community-based distribution and mobile clinics, improves access and retention (Doblecki-Lewis et al., 2024; Medina-Marino, 2021; Rousseau et al., 2021). Peer-led interventions also strengthen adherence and retention through shared experiences and community support (McGowan et al., 2022; Wairimu et al., 2023). Regular communication with healthcare providers further builds confidence in PrEP and supports long-term adherence and retention (Edwards et al., 2022; Wagner et al., 2023).

This study, therefore, sought to determine retention rates and associated factors, barriers, and facilitators to PrEP adherence and retention among PrEP users at Kitgum General Hospital.

STATEMENT OF THE PROBLEM

Uganda continues to face a significant burden of new HIV infections, with about 38,000 new HIV infections in 2023, with Kitgum District contributing 109 of the cases (UAC, 2024). This surge is partly attributed to poor risk recognition, low adherence, and retention in PrEP programs, which are essential in reducing new infections among individuals at substantial risk.

At Kitgum General Hospital, there has been an observed trend of drop-out of PrEP use during subsequent visits following PrEP initiation. Furthermore, some of the clients do not adhere to PrEP use as prescribed, while others discontinue using PrEP without formally dropping out. Non-adherence may lead to an increase in new infections and rising primary drug resistance, which could potentially reverse the substantial gains made in the fight against HIV in Uganda and the world at large.

Most studies on PrEP use in Uganda have primarily examined adherence within specific sub-populations, such as pregnant women and female sex workers, without adequately addressing retention or the broader PrEP-using populations (Atukunda et al., 2022; Kayesu et al., 2022; Nakiganda et al., 2022; Nalukwago et al., 2021). This narrow focus limits the generalizability of findings and overlooks other users' diverse needs and experiences, thereby contributing to ongoing challenges of low adherence and poor retention. Moreover, previous research has often employed cross-sectional quantitative designs, which do not capture the dynamic nature of PrEP use or provide insights into reasons for discontinuation or dropout. As a result, understanding context-specific barriers and facilitators remains limited. Longitudinal studies are therefore essential to track sustained use over time and to identify critical points for targeted interventions (Ntabadde et al., 2024).

STUDY OBJECTIVES

1.3.1. General objective

To determine the retention rate, the factors associated with dropout from PrEP use and the barriers and facilitators to adherence and Retention among PrEP users at Kitgum General Hospital.

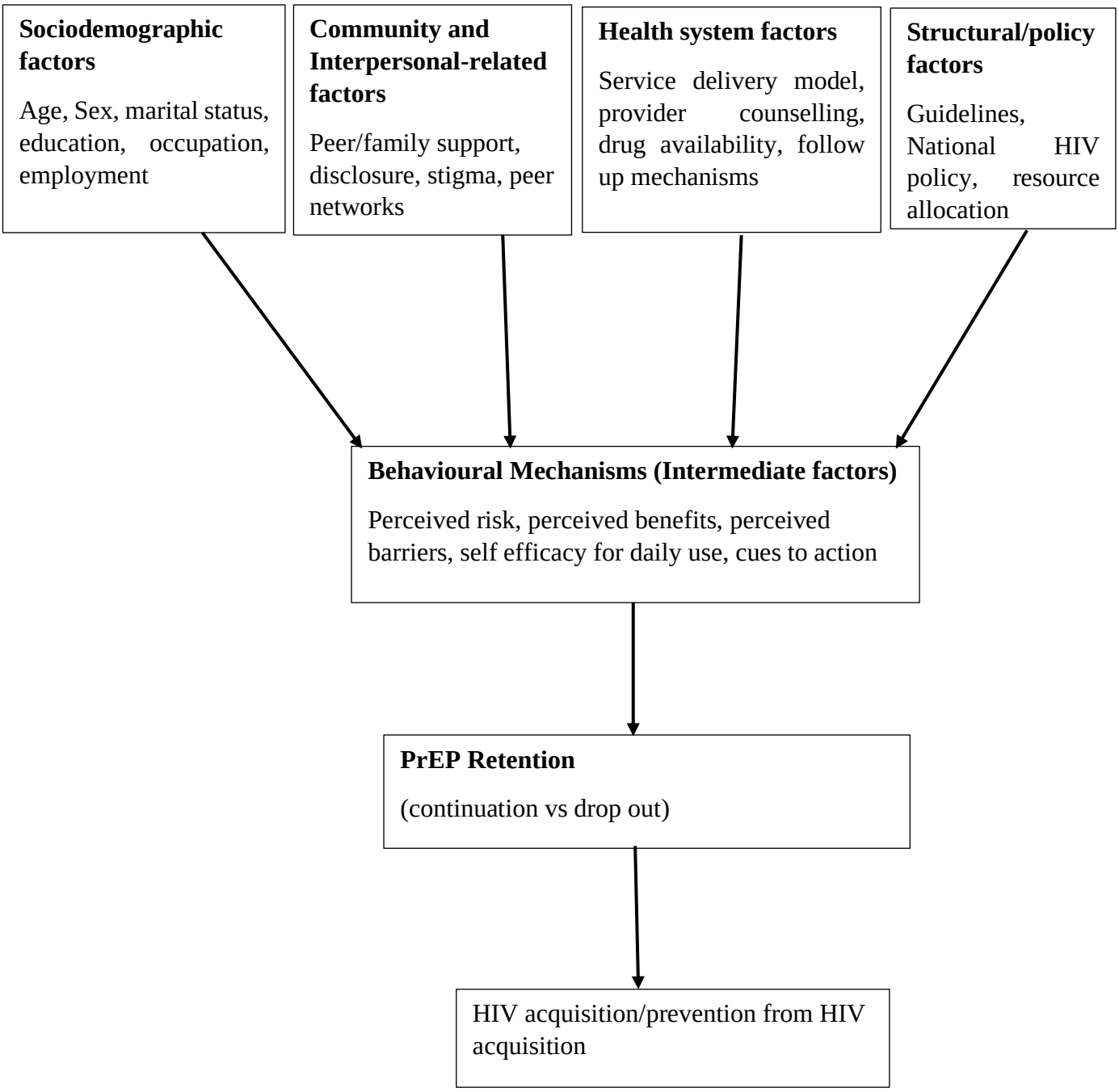
1.3.2. Specific objectives

1. To measure the retention rates among PrEP users at Kitgum General Hospital
2. To determine the factors associated with dropout from PrEP use among users at Kitgum General Hospital
3. To explore the barriers and facilitators to PrEP adherence and retention among PrEP users at Kitgum General Hospital

Research questions

1. What is the retention rate among PrEP users at Kitgum General?
2. What factors are associated with dropout from PrEP use among users at Kitgum General Hospital?
3. What are the barriers and facilitators to PrEP adherence and retention among PrEP users at Kitgum General Hospital?

CONCEPTUAL FRAMEWORK



1.6. THEORETICAL FRAMEWORK

This study was guided by the Social Ecological Model (SEM) to examine factors associated with dropout from PrEP use and the barriers and facilitators to adherence and retention among PrEP users at Kitgum General Hospital. The SEM recognized that health behaviours could be shaped by interacting factors at individual, interpersonal, community, organizational, and policy/structural levels. Therefore, these ecological levels were considered to interact in shaping PrEP adherence and retention, potentially resulting in either continued engagement in care or dropout.

At the individual level, factors such as age, sex, education, knowledge of PrEP, perceived HIV risk, side effects, pill burden, and forgetfulness were considered potential influences on adherence and continued PrEP use. Adequate knowledge, perceived HIV risk, and motivation to prevent HIV were considered potential facilitators of retention, while side effects, low perceived risk, and pill fatigue were considered potential contributors to dropout.

At the interpersonal level, relationships with partners, family members, and peers were considered potential influences on PrEP use. Social and peer support could facilitate adherence and retention, whereas stigma, fear of disclosure, and lack of partner or family support could contribute to dropout.

At the community level, social norms, misconceptions, and stigma surrounding HIV and PrEP were considered potential barriers to continued PrEP use, while community awareness, acceptance of PrEP, and supportive peer networks could facilitate retention.

At the organizational/health-system level, factors such as PrEP entry point, availability of PrEP, healthcare-worker attitudes, quality of counselling, waiting time, confidentiality, service integration, and accessibility were considered potential influences on retention. Supportive and accessible services could facilitate continued engagement, whereas poor service experiences and access challenges could contribute to dropout.

At the policy and structural level, national PrEP policies, availability of commodities and funding, differentiated service-delivery approaches, distance to health facilities, transport costs, and financial constraints were considered potential influences on continued access to PrEP services.

1.7. JUSTIFICATION OF STUDY

Pre-exposure prophylaxis (PrEP) is an effective biomedical intervention for HIV prevention when used consistently and correctly (CDC, 2024). In Uganda, where HIV prevalence remains high, particularly among women and vulnerable populations, effective PrEP implementation is critical to reducing new HIV infections (UNAIDS, 2024; UAC, 2024). However, its effectiveness depends on adherence and retention in care, which remain challenging, including at Kitgum General Hospital

This study aimed to determine the retention rates, associated factors, barriers, and facilitators to PrEP adherence and retention among users at Kitgum General Hospital, thus contributing to addressing the challenges of low adherence and high dropout rates at Kitgum General Hospital which significantly reduces the effectiveness of PrEP, increasing an individual's vulnerability to HIV but also accelerating the development of primary drug resistance.

This study generated evidence on PrEP dropout, adherence, and retention at Kitgum General Hospital. By identifying factors associated with dropout and barriers and facilitators to sustained PrEP use, the findings may inform client-centered interventions to improve PrEP services. The findings may also support the Ministry of Health and implementing partners in strengthening PrEP guidelines, service integration, and resource allocation, while helping healthcare providers improve counselling and follow-up. Furthermore, the study contributes to evidence on PrEP implementation and efforts to strengthen HIV prevention. ultimately enhancing the health and resilience of individuals and communities, thus supporting global efforts to combat the HIV epidemic.

CHAPTER TWO: LITERATURE REVIEW

2.0. Introduction

This chapter reviews the literature on PrEP retention, factors associated with drop-out from PrEP use, barriers and facilitators to PrEP adherence and Retention. The literature search was restricted to online sources: Google Scholar, PubMed, Cochrane Database Systematic Reviews, MEDLINE (Medical Literature On-Line), and HINARI. The scope of the literature review was confined to published works in English and works on PrEP use and retention. The time scope was restricted to published works from 2014 to 2024.

2.1. Introduction to PrEP use

Despite global efforts to reduce HIV transmission, sub-Saharan Africa continues to bear a substantial HIV burden. In Uganda, HIV prevalence was approximately 5.1% in 2023, with a higher prevalence among women (6.6%) than men (3.6%), and approximately 38,000 new HIV infections were reported (UNAIDS, 2024; UAC, 2024). These figures show the need to strengthen HIV prevention and address barriers to accessing prevention services, particularly among populations at substantial risk. Expanding access to pre-exposure prophylaxis (PrEP) remains an important strategy for preventing new HIV infections.

WHO defines substantial HIV risk as an HIV incidence of approximately ≥3 per 100 person-years (WHO, 2022). Populations at substantial risk include key populations, such as sex workers, men who have sex with men, transgender people, people who inject drugs, and people in prisons (UNAIDS, 2019). Priority populations include adolescent girls and young women, serodiscordant couples, mobile populations, pregnant and breastfeeding women, and others with increased HIV exposure, including recurrent PEP users and individuals with frequent STIs or multiple sexual partners (PrEP Technical Guidelines; UNAIDS, 2024).

The World Health Organization (WHO) recommends PrEP for individuals at substantial risk of HIV infection as part of combination prevention, alongside strategies such as condom use, harm reduction, and regular HIV testing (WHO, 2022). PrEP involves the use of antiretroviral drugs by HIV-negative individuals to prevent HIV acquisition, with consistent oral PrEP use reducing sexual HIV acquisition by over 90% (CDC, 2024). Alternative options include the dapivirine vaginal ring, which is used for 28 days and reduced HIV acquisition among women by approximately 30–35% in clinical trials, with greater protection observed with higher

adherence consistently (Baeten, Palanee-Phillips, et al., 2016; Nel et al., 2016). Long-acting injectable cabotegravir, administered every two months, provides another effective option and was more effective than daily oral tenofovir/emtricitabine in clinical trials, offering an important alternative for individuals who may experience challenges with daily pill-taking (Landovitz et al., 2021; Scarsi and Swindells, 2021)

WHO recommends differentiated service delivery models to improve the accessibility and responsiveness of PrEP services for individuals at substantial HIV risk (WHO, 2022). Globally, PrEP is delivered through diverse settings, including health facilities, pharmacies, STI clinics, and community-based organizations (Irungu and Baeten, 2020). In Uganda, recommended models include integration of PrEP into family planning, antenatal, postnatal, STI, youth-friendly, and outpatient services, as well as community approaches such as peer-led hotspot interventions, drop-in centres, and community drug distribution points. These models aim to bring safe and effective PrEP services closer to clients and address their specific needs (PrEP Technical Guidelines, Uganda 2022).

2.2. PrEP retention rates

Globally, PrEP uptake has grown with over 560,000 initiations by 2019, yet retention remains low, below 50% by the 12th month of use (UNAIDS, 2020; Haberer et al., 2022). In sub-Saharan Africa, countries like South Africa and Kenya report strong initiation, especially among key populations, but retention drops to about 50% at six months and below 30% at 12 months (Khadka et al., 2023; Kinuthia, Pintye, Abuna, Mugwanya, Lagat, et al., 2020). Uganda recorded 30,000 PrEP initiations by 2021, rising to 60% initiation by 2022, but with only 20% retention (Uganda PrEP Guidelines, 2022).

Retention in PrEP care remains challenging, with substantial dropout occurring within 6–12 months after initiation. A systematic review among female sex workers (FSWs) in low- and middle-income countries reported 76% retention at 6 months, with higher retention in facility-based than community-based models (83% vs. 66%), while retention generally declined from over 80% shortly after initiation to about half by 12 months (Mpirirwe et al., 2024; Mubezi et al., 2023). Similarly, studies among FSWs in Rwanda and Uganda reported 12-month retention of approximately 53% and 50–60%, respectively (Kawuma et al., 2025; Mubezi et al., 2023). Lower retention was reported in Cameroon, where continuation among FSWs and men who have sex with men declined from 37% at 3 months to 28% at 6 months and 19% at 12 months,

highlighting substantial variation in PrEP retention across populations and settings (Ndenkeh et al., 2022).

By contrast, certain pilot and research settings have achieved higher retention. Controlled trials and demonstration projects often show better continuation and adherence than a routine program. Some demonstration projects managed to retain the majority of participants through 12 months, likely due to enhanced support and follow-up (Baeten, Heffron, et al., 2016; McCormack et al., 2016; Mujugira et al., 2022). Overall, real-world PrEP programs consistently report lower retention than those in clinical trials, underlining the implementation gap.

Adolescents and young adults appear particularly prone to early PrEP discontinuation. Studies among Adolescent Girls and Young Women (AGYW) in Africa have found that a substantial proportion never return for their first refill, and most stop PrEP within 6 months of initiation (Kinuthia, Pintye, Abuna, Mugwanya, Lagat, et al., 2020; Mugwanya et al., 2019; Pintye et al., 2021). Global evidence similarly points to adherence challenges in youth, with adolescents and young adults found to meet only about 64% of study-defined adherence thresholds during follow-up (Allison et al., 2022). By contrast, older adults in some cohorts have shown somewhat higher persistence. Retention outcomes indicate that early dropout is common, many users stop within the first few months, and maintaining long-term PrEP use is difficult for over half of initiators in typical programmatic conditions.

It is important to note how retention is defined. Most studies define “retained” as continuing to follow up at clinics and refill PrEP on schedule, which is attending a 1-month, 3-month, or 6-month visit. This differs from adherence, which refers to taking the pills consistently as prescribed. A person could remain formally in a PrEP program (retained) but not actually take the medication regularly, or conversely, someone could be taking PrEP pills they have on hand but miss clinic visits. Nevertheless, retention and adherence are linked; individuals with poor medication adherence often tend to disengage from programs, whereas those who successfully establish a daily pill routine are more likely to stay on PrEP. A previous study in Cameroon reported that users with good or moderate adherence had significantly lower discontinuation rates than those with poor adherence, indicating that supporting adherence is central to improving retention.In summary, PrEP retention rates in sub-Saharan Africa typically decline sharply within the first 6–12 months, with only half or fewer of initiators remaining on PrEP after one year in many settings. AGYW often have especially low continuation. While there

are success stories of high retention in certain contexts, the overall trend points to a need for strategies to sustain PrEP use over time. The next sections explore factors driving these dropouts and the barriers and facilitators influencing both retention and adherence while applying the Socio-Ecological Model (SEM)

2.3. Factors Associated with Dropout from PrEP Use (Quantitative Findings)

Quantitative studies have identified numerous factors associated with PrEP discontinuation. These factors span individual characteristics, behaviors, and external circumstances. Social-demographic factors are one important category. Younger age has consistently been linked to higher dropout rates. A systematic review showed that among FSWs, older women above 35 were significantly more likely to remain on PrEP; FSWs above age 35 had a markedly lower hazard of discontinuation compared to those aged 18–25 years (Mpirirwe et al., 2024). Similarly, a global meta-analysis reported suboptimal adherence in 62.5% of people aged ≤24, compared to 34% of those over 24 (Zhang et al., 2022)**.** This suggests that younger users tend to stop PrEP sooner, possibly reflecting life-stage challenges such as irregular routines or lower perceived risk (Allison et al., 2022; Lunkuse et al., 2022).

Gender and key population status also plays a role, for example, in Cameroon, female sex workers had higher odds of discontinuing PrEP than MSM, indicating FSWs faced unique retention difficulties (Ndenkeh et al., 2022). This is due to stigma or mobility in sex work, whereas MSM in that context may have had stronger community support (Huang et al., 2022; Kawuma et al., 2024).

Behavioral and risk-related factors may influence PrEP retention. Among female sex workers (FSWs) in Rwanda, inconsistent or non-use of condoms was associated with lower PrEP retention, despite potentially indicating greater HIV exposure (Mubezi et al., 2023). In contrast, hormonal contraceptive use or use of contraceptive methods other than relying solely on condoms was associated with greater 12-month retention. Women who desired future children were also more likely to remain in PrEP care, potentially reflecting greater motivation to remain HIV-negative. These findings suggest that sexual risk behaviours, reproductive intentions, and contraceptive practices may influence continued engagement in PrEP care (Mubezi et al., 2023).

Health, side effects, and service-related factors may contribute to PrEP dropout. In Cameroon, severe adverse effects accounted for only 3% of provider-reported discontinuations, while mild side effects accounted for 14% of client-reported discontinuations. Providers more frequently attributed discontinuation to repeated missed appointments (19%) and drug stockouts or expiration (17%), while clients also reported relocation or mobility (11%) as a reason for stopping PrEP (Ndenkeh et al., 2022). These findings suggest that side effects, missed appointments, medication availability, and mobility may contribute to PrEP dropout across different settings (Ndenkeh et al., 2022; Wanyama et al., 2022)

Psychosocial factors such as mental health and substance use are emerging as critical associated factors as well. Previous studies reported that mental distress, such as depression and anxiety, and younger age were risk factors for dropping out in the initial months of use (Lichtwarck et al., 2023; Mpirirwe et al., 2024; Zia et al., 2023) . Likewise, substance abuse has been linked to lower continuation as FSWs in Uganda noted that heavy alcohol or drug use interfered with daily pill-taking and clinic attendance (Kawuma et al., 2024). Such factors can erode the consistency needed for adherence.

Structural and service-related factors may influence PrEP retention. In Rwanda, female sex workers (FSWs) receiving PrEP from city-centre clinics had significantly lower retention than those attending clinics on the outskirts, indicating that service location may affect continued engagement in care (Mubezi et al., 2023). In Uganda, inconvenient daytime clinic schedules were identified as a barrier to PrEP retention among FSWs (Kawuma et al., 2024). Similarly, long waiting times and inconvenient clinic hours have been associated with poor engagement in PrEP services (O'Malley et al., 2019). These findings show the importance of accessible service locations, flexible clinic schedules, and convenient service delivery in improving PrEP retention.

In summary, younger individuals, those with poor early adherence, and those facing side effects or life disruptions tend to discontinue PrEP at higher rates, while older age and integration of PrEP into one's routine, alongside contraception or strong future health intentions, support greater retention (Mubezi et al., 2023). Programmatic and structural elements like reliable drug supply and flexible clinic access also significantly influence dropout. Understanding these predictors is useful, but to design interventions, we must delve into why users stop or continue PrEP. The next section uses qualitative insights to explore the

barriers and facilitators to PrEP adherence and retention at multiple levels while incorporating SEM constructs.

2.4. Barriers and Facilitators to PrEP Adherence and Retention (Qualitative)

Qualitative studies and mixed-methods research provide rich information on the barriers that affect PrEP adherence and retention and the facilitators that help people stay on PrEP. These factors occur at all levels, and in this section, findings are organized by level of influence, from individual to interpersonal to health system, policy, and structure.

2.4.1. Individual-Level Factors

At the individual level, knowledge, beliefs, and experiences with PrEP may influence adherence and retention. Perceived HIV risk is particularly important, as users may discontinue PrEP when they perceive their risk to have decreased. Studies in Kenya and Uganda found that some users stopped or paused PrEP during periods of sexual inactivity, separation from partners, or after a partner tested HIV-negative (Camlin et al., 2020; Pintye et al., 2021; Whitfield et al., 2018). Similarly, female sex workers (FSWs) who stopped sex work were more likely to discontinue PrEP because of reduced perceived HIV exposure (Kawuma et al., 2024). Conversely, continued perception of HIV risk was reported as a motivation for sustained PrEP use among FSWs in Uganda (Kawuma et al., 2024). These findings suggest that changes in perceived HIV risk may influence decisions to continue or discontinue PrEP.

Perceived benefits and confidence in PrEP effectiveness may influence adherence and continuation. In Kenya, young women reported that consistently testing HIV-negative while using PrEP reinforced their belief in its effectiveness and motivated continued use (Pintye et al., 2021). Conversely, doubts about PrEP effectiveness or limited perception of its benefits may reduce motivation, particularly among individuals who perceive themselves to be at low HIV risk. Evidence suggests that clear information about PrEP effectiveness and positive experiences with PrEP may strengthen perceived benefits and support continued use (Admassu et al., 2024; Camlin et al., 2020; Koss et al., 2021).

Individual-level barriers to PrEP adherence and retention include concerns about side effects, pill burden, and difficulties maintaining daily medication routines. Side effects such as nausea and dizziness may discourage continued use, particularly among adolescent girls and young women (AGYW) (Admassu et al., 2024). In Kenya, some AGYW reported difficulties taking

PrEP daily and used it mainly during periods when they perceived themselves to be at HIV risk (Pintye et al., 2021). Forgetfulness and competing daily activities have also been frequently reported as barriers to adherence (Allen et al., 2020; Muwonge et al., 2020). One study attributed approximately 20% of non-adherence to forgetting and 14% to being too busy (Pintye et al., 2021). These findings indicate that side effects, pill burden, forgetfulness, and competing responsibilities may undermine consistent PrEP use.

Self-efficacy, or confidence in one's ability to manage PrEP use, may influence adherence and retention. Users who have difficulty remembering daily doses or taking PrEP discreetly may experience challenges maintaining consistent use. Conversely, integrating PrEP into an established daily routine may facilitate adherence. For example, individuals already accustomed to taking daily medications, such as hormonal contraceptives or treatment for other conditions, may find it easier to incorporate PrEP into their routines (Mubezi et al., 2023)

Cues to action at the individual level include any triggers or reminders that prompt PrEP use. Personal health goals, like wanting to stay HIV-negative to have a healthy family in the future, can serve as internal cues. Strategies such as phone reminders, linking PrEP use to daily routines, and follow-up calls may help users maintain regular pill-taking and refill visits. In Cameroon, a nurse follow-up call after PrEP initiation was used to address side effects and support adherence (Ndenkeh et al., 2022). Pregnancy may also facilitate PrEP use, as medication-taking is often normalized during this period. Studies in Kenya found that some women could take PrEP discreetly during pregnancy because the pills could be perceived as part of routine prenatal medication, whereas continued use became more difficult postpartum when PrEP use was more conspicuous (Kinuthia, Pintye, Abuna, Mugwanya, Lagat, et al., 2020; Moran et al., 2022). These findings suggest that established routines, reminders, and changing life circumstances may influence continued PrEP use. Other life events that can trigger re-initiation of PrEP include learning about a friend or community member acquiring HIV, which can heighten one's perceived risk again and cue one to resume protection.

2.4.2. Interpersonal Factors

Interpersonal relationships may influence PrEP adherence and retention through partner, family, and peer support or opposition. Among adolescent girls and young women (AGYW), parental and partner disapproval, fear of judgment, and concerns about disclosure have been identified as barriers to PrEP use (Admassu et al., 2024; Moran et al., 2022). Some women

concealed PrEP use because partners associated the medication with HIV infection, mistrust, or infidelity, potentially creating conflict and making continued use difficult (Agot et al., 2022, 2024; Pintye et al., 2021). Gender power imbalances, including controlling or violent relationships, may further restrict women's ability to take PrEP safely or attend clinic visits (Cabral et al., 2018; Thomas et al., 2024). These findings suggest that stigma, disclosure concerns, partner opposition, and unequal relationship dynamics may undermine PrEP adherence and retention.

Conversely, supportive partners, family members, and peers may facilitate PrEP adherence and retention. Encouragement from trusted partners, friends, or relatives has been associated with PrEP initiation and continued use among young women (Pintye et al., 2021; Young et al., 2023). Supportive relationships may reinforce motivation, reduce concerns about PrEP use, and help users maintain adherence. Peer support may also promote continued use by providing opportunities to share experiences, practical adherence strategies, and encouragement

Misinformation and stigma in the social network can be a barrier. Partners or community members might spread myths like "PrEP causes infertility" or "those pills give you bad side effects", which can discourage users. In one qualitative study, it was observed that sharing misinformation discouraged PrEP use among FSWs and healthcare providers, undermining their confidence in the medication (Geldsetzer et al., 2022; Kumar et al., 2025). Addressing interpersonal misinformation through couples counseling or community education could mitigate this barrier.

Interpersonal dynamics also provide cues to action. A concerned friend reminding someone to take their pill or accompanying them to the clinic is a helpful cue. Peer support groups have been noted as facilitators in some programs; for instance, the presence of PrEP peer educators or support groups at drop-in centers helped FSWs in Uganda stay engaged in care (Kawuma et al., 2024). Knowing that one has social support can increase self-efficacy and make individuals feel they have someone to turn to for advice on side effects or adherence strategies. Moreover, several interventions have leveraged interpersonal support like SMS or phone-based counseling that provides not just reminders but psychosocial support, and have shown promise (Haberer et al., 2021). One example is the use of "treatment buddies" or adherence supporters, borrowed from the ART field, to keep PrEP users accountable and encouraged.

2.4.3. Health System and Service Factors

The design and quality of health services delivering PrEP significantly affect user retention and adherence. Judgmental or stigmatizing attitudes from healthcare providers have been reported as barriers among adolescent girls and young women (AGYW), particularly when PrEP use is associated with assumptions about sexual behaviour (Admassu et al., 2024; Lanham et al., 2021). Similarly, discrimination within healthcare settings may discourage continued engagement among key populations, including sex workers and men who have sex with men (Stangl et al., 2019). Conversely, nonjudgmental, confidential, and youth-friendly services may create a more supportive environment for continued PrEP use (Keuroghlian et al., 2021).

Another barrier is service accessibility and convenience. Many PrEP programs initially required monthly clinic visits for refills, which can be burdensome. Long travel distances, transportation costs, and time away from work impede retention (Mayer et al., 2019; Mwima et al., 2025). A previous study found that geographical distance to clinics and long wait times were notable barriers, in addition to the inconvenient clinic hours or extended queues, discouraging busy clients from coming regularly (Barnabee et al., 2022; Mpirirwe et al., 2024). In Uganda, FSW participants pointed to restrictive clinic schedules that is daytime only as a hindrance, since many sex workers work at night and sleep during the day (Kawuma et al., 2024). If services are not aligned with clients' lifestyles, dropout will increase.

Service integration may influence PrEP access and retention. Stand-alone PrEP clinics may create inconvenience or stigma, particularly among adolescent girls and young women (AGYW) (Admassu et al., 2024). Conversely, integrating PrEP into routine services such as maternal and child health, family planning, and other HIV prevention services may improve accessibility and normalize PrEP use. In Kenya, integration of PrEP into maternal and child health and family planning services supported uptake and early engagement among young women (Bhavaraju et al., 2021; Mugwanya et al., 2019). Similarly, integrated sexual health and HIV prevention services have been identified as facilitators of continued PrEP use among female sex workers (Anand et al., 2023; Butler et al., 2023). These findings suggest that integrated service delivery may reduce service-related barriers and support continued engagement in PrEP care.

The availability and Retention of drug supply are another crucial health system factor. Drug stockouts or interruptions in supply chains directly undermine retention, as clients who come

for a refill and find none available may be forced to stop and possibly lose trust in the program. In Cameroon, a widespread PrEP drug stockout in late 2020 led to a severe drop-off in PrEP continuation (Ndenkeh et al., 2022). Stockouts were one of the most commonly cited reasons for PrEP interruption in that program. Thus, ensuring consistent medication availability through better forecasting, procurement, and distribution is a basic prerequisite for retention.

Health services can also enhance adherence and retention by providing active support interventions. Several facilitators fall in this category:

Peer navigators or counselors can improve retention by deploying peer outreach workers who engage with PrEP users. For FSWs, peer support at drop-in centers was identified as helpful (Kawuma et al., 2024). Drop-in centers are community-based sites often run by NGOs where key populations can receive health services in a friendly environment. FSWs who utilized such centers instead of general hospitals felt more comfortable and supported, aiding continuation.

Follow-up communications: Simple interventions like a nurse's follow-up phone call to check on new users in some programs can address concerns like side effects and questions and reinforce the importance of staying on PrEP (Mugo et al., 2016). Ongoing SMS check-ins or adherence texting services can remind and motivate users.

Differentiated service delivery, like multi-month dispensing that provides 2-3 months of pills at once to reduce visit frequency, fast-track pickup where clients can quickly grab refills without a full clinic visit, or community outreach refills that bring PrEP refills closer to where people live or work, helps to tailor how PrEP is delivered to client needs. The literature suggests that such differentiated models could improve retention (Butler et al., 2023; Doblecki-Lewis et al., 2024; Lavoie et al., 2023; Rousseau et al., 2021).

Counseling and education: Ongoing counseling that reinforces PrEP knowledge, addresses emerging concerns, and supports risk reduction can be a facilitator. For instance, in some programs, counseling is provided at each visit to problem-solve around adherence barriers like forgetting pills and to re-emphasize personal HIV risk, which can sustain motivation.

2.4.4. Policy and Structural Factors

Community and structural stigma may influence PrEP adherence and retention. Among adolescent girls and young women (AGYW), stigma has been identified as a cross-cutting

barrier throughout the PrEP prevention cascade, affecting initiation, adherence, and continued use (Admassu et al., 2024). Misconceptions that associate PrEP with HIV treatment may lead users to fear being perceived as HIV-positive or promiscuous, potentially discouraging continued engagement in PrEP care.

In some African settings, community awareness of PrEP remains low, including Kitgum District, which fuels suspicion and stigma. Indeed, low community awareness about PrEP was cited as a barrier by several studies (Apreku et al., 2025; Lunkuse et al., 2022; Nkosi et al., 2024; Ntabadde et al., 2025). Increasing public knowledge that PrEP is a preventive, empowering tool that could reduce stigma and improve uptake and retention.

Legal and policy frameworks may influence access to and continuation of PrEP, particularly among adolescents and young people. Age-of-consent requirements and policies requiring parental involvement may restrict independent access to PrEP services. For example, PrEP implementation in Cameroon initially targeted individuals aged 21 years and older, limiting access among younger populations who might otherwise have been eligible based on HIV risk (Ndenkeh et al., 2022). Such policy restrictions may create structural barriers to PrEP initiation and continued engagement in care among adolescents and young people.

For key populations like sex workers, MSM, or people who inject drugs, the criminalization of their behaviors is a structural barrier that indirectly affects PrEP retention. FSWs and MSM operating in criminalized or highly stigmatized contexts may avoid regular clinic visits for fear of outing themselves. There have been reports of FSWs being arrested or harassed by police, and being in police custody was explicitly noted as a reason some FSWs discontinued PrEP (Kumar et al., 2025; Mpirirwe et al., 2024). If carrying PrEP pills is misconstrued by law enforcement as evidence of sex work or if crackdowns disrupt outreach programs, retention will suffer. Structural interventions like decriminalization, or at least ensuring safe zones and legal protections for those seeking healthcare, would create a more enabling environment for PrEP adherence.

Economic factors are another structural dimension. Poverty and lack of resources can make prioritizing PrEP difficult. While PrEP medication in many African countries is provided free through donor programs, indirect costs such as transportation to the clinic and time off work can be prohibitive for some. Additionally, unstable housing or migration for economic reasons are common among key populations, leading to treatment interruptions. The high mobility of

sex workers moving between towns or regions for work was identified as a barrier to PrEP continuation in Uganda. Mobile populations may not establish consistent care at one site, and tracking them is challenging. Solutions like a national patient tracking system or allowing one to carry multi-month supplies while traveling might help.

Policies at the health system level, such as how PrEP is rolled out and prioritized, are also important. The Ugandan study concluded that restrictive health facility policies should be addressed to scale up PrEP (Kawuma et al., 2025**).** This could refer to limiting PrEP to certain clinics or only certain hours, a policy decision, or not allowing community-based distribution. A flexible, enabling policy environment that supports community delivery, task-shifting to lay providers, and inclusion of PrEP in all relevant health programs can significantly improve retention. By contrast, a policy environment that treats PrEP as a stand-alone vertical program or imposes unnecessary requirements like frequent mandatory lab tests could hamper retention.

Policy and structural factors may influence the availability, accessibility, and Retention of PrEP services. Supportive national policies, sustainable funding, provider training, and integration of PrEP into existing health services may facilitate consistent service delivery and continued engagement in care. Conversely, inadequate policy support, limited resources, and socioeconomic constraints may hinder PrEP implementation and access (Sidebottom et al., 2018).

2.5. Literature summary and conclusion

Despite increasing PrEP initiation globally and in sub-Saharan Africa, literature consistently shows steep declines in retention, with less than half of users remaining engaged after one year. While these studies highlight overall trends, gaps remain in understanding the unique contextual drivers of PrEP discontinuation, particularly in post-conflict settings like Northern Uganda, where socio-economic, cultural, and health system challenges differ from other regions. Evidence is also limited on the experiences of diverse populations, especially adolescents and young women, and the effectiveness of tailored interventions to sustain retention beyond the first few months. Furthermore, few studies have examined facility-level dynamics in secondary hospitals such as Kitgum General Hospital, leaving a critical gap in localized programmatic insights.

In conclusion, addressing these gaps is essential to maximizing the public health impact of PrEP as a cornerstone of HIV prevention. By generating context-specific evidence on retention rates, associated factors, and barriers and facilitators to adherence, this study will contribute valuable insights to inform policies, strengthen health services, and design targeted interventions that improve Retention of PrEP use in Kitgum and similar settings.

CHAPTER THREE: STUDY METHODS

3.0 Introduction

This chapter describes the methodology used to conduct the study. It includes an overview of the study design, study population, sample size determination, and sampling techniques used to select study participants. This section further highlights the research tools, data management, and ethical considerations.

3.1. Study Design

This study employed a mixed-methods design, with the qualitative component concurrently nested into the quantitative part. The quantitative component was a retrospective cohort study to assess the retention rates and factors associated with drop-out from PrEP use (objectives 1 and 2). The qualitative component used in-depth interviews to explore barriers and facilitators to PrEP adherence and retention (Objective 3). Integration of the two components occurred mainly at the interpretation stage, where qualitative themes were merged with and compared against quantitative findings to explain, support, or provide context for observed patterns in retention and dropout.

3.2. Study setting

This study was conducted at Kitgum General Hospital, Kitgum District. Kitgum District borders the Republic of Southern Sudan to the North, the Karenga District to the East, the Agago District to the South, the Kotido District to the southeast, the Pader District to the southwest, and the Lamwo District to the northwest. Kitgum town is located approximately 108 kilometres (67 miles) northeast of Gulu, the largest city in the sub-region, and lies about 460 kilometres (290 miles) north of Uganda's capital, Kampala. Kitgum district has only one PrEP reporting Site, Kitgum General Hospital, on which this study was based.

Kitgum General Hospital is located within Langolango village, Kitgum Town Parish, Central Division, Kitgum Municipality, Kitgum District, in the Acholi Sub-region of Northern Uganda. The hospital serves as a referral center for several neighbouring districts, including Lamwo, Pader, Agago, Karenga, and Abim, as well as some parts of neighbouring South Sudan. Kitgum General Hospital is strategically positioned to cater to a large population, making it an ideal location for this study. Kitgum General Hospital serves a diverse population from Kitgum and

surrounding districts, providing an appropriate setting for examining PrEP retention and dropout among clients receiving PrEP services in this context.

3.3. Population

3.3.1. Target population

All PrEP users at public health delivery sites in Northern Uganda

3.3.2. Study Population

Clients initiated on PrEP at Kitgum General Hospital between October 2023 to October 2024

3.4. Eligibility criteria (Quantitative)

3.4.1. Inclusion criteria

i. Records of PrEP users with clearly documented HIV-negative baseline test results at initiation at Kitgum General Hospital between October 2023 and October 2024
ii. Records of adolescents 15-17 years who met the criteria of emancipated minors were included in the study.

3.4.2. Exclusion criteria

i. Records with insufficient information to determine PrEP follow-up or dropout status were excluded.

3.5. Eligibility criteria (Qualitative)

3.5.1. Inclusion criteria

i. Individuals who were using PrEP, had used PrEP intermittently or discontinued use of PrEP within the study period
ii. Participants aged 18 years and older.

3.5.2. Exclusion criteria

i. Individuals who were too ill to participate in interviews.

3.6. Sampling technique

For the quantitative phase of the study, systematic sampling was employed to select participants from the Hospital's PrEP records from the list of clients initiated on PrEP from October 2023 to October 2024. Eligible participants were selected using systematic sampling from the facility registers. Following random selection of the first participant, every second eligible client was enrolled until the required sample size was attained.

For the qualitative sample, we used purposive sampling to select participants. The sample included participants who were then using PrEP, had intermittently used PrEP, or had discontinued PrEP use, capturing their demographic characteristics, PrEP use patterns, and behavioral and social factors.

3.7. Sample size

3.7.1. Sample size for the quantitative phase of the study

The sample size for this study was determined using the Kish and Leslie formula, which is given by:

$$n = Z^2 \times p \times (1-p)/ d^2$$

Where:

n = required sample size

Z = Z-score corresponding to the desired confidence level (e.g., 1.96 for 95% confidence)

p = estimated proportion of the population with the characteristic of interest (based on previous studies or pilot data)

d= margin of error or precision (e.g., 0.05 for 5% margin of error)

This formula determined the minimum sample size needed to ensure the study results are statistically significant and generalizable. The sample size calculation considered an anticipated non-response rate, ensuring that the final sample size was sufficient even when some participants do not complete the study.

Assumptions for Calculation

Z = 1.96 (for 95% confidence level)

p = 0.5 (since there is no prior estimate, 50% was used to provide the maximum sample size) (Cochran,1977; Kish, L. John Wiley and Sons, Wiegand, 1968)

d = 0.05 (a margin of error of 5%)

Calculation

$$n = \frac{(1.96)2 \times 0.5 \times (1-0.5)}{(0.05)2}$$

n = 384.16

The sample size **is 384**

Non-response rate of 20% was expected; therefore

n adjusted = 384+ (384×0.20)

= 384+76.8

n adjusted = 460.8

The adjusted sample size was **461** participants

To account for clustering in the sampling design, we inflated the non-response–adjusted size using the design effect (DEFF):

$n = n_{adjusted}$ x DEFF

n = 461 x 2.39

n = 1102 participants

We therefore enrolled **1102** participants who had been on PrEP between October 2023 and October 2024 at KGH.

3.7.2. Sample size for the qualitative part of the study

For the qualitative arm of the study, a purposive sample size of 10 participants was achieved and data saturation attained by the 7th participant, with collected data capturing all major themes relevant to the study objectives.

3.8. Data Collection and Tools

3.8.1. Data collection tools

A custom-made data abstraction tool (shown in Appendix 2) was used to abstract quantitative data from medical records and electronic health systems at Kitgum General Hospital. This tool captured participants' demographic data, HIV risk profile, adherence metrics based on clinical visits, and self-reports.

Qualitative interviews were recorded using a *SONY ICD-PX470* digital audio recorder, and the interviewer's notes were written using ink and paper.

3.8.2. Data collection procedure

3.8.2.1. Quantitative data collection procedure

Participants were retrospectively identified from both PrEP paper-based and electronic HMIS records at Kitgum General Hospital. Trained research assistants used a standardized data abstraction tool to extract relevant demographic, clinical, and follow-up data from patient files, PrEP registers, electronic health records, and pharmacy records. Information on PrEP initiation, follow-up visits, and medication refills was cross-checked across available data sources to ensure completeness and accuracy.

Participants were followed up from the date of enrolment into PrEP (first visit) up to 30 days from the scheduled date of the expected last visit (endpoint). Those who stopped PrEP because of the health provider's recommendation, because they were no longer at risk, and those who turned HIV positive during follow-up were censored on the day they stopped or tested positive for HIV, respectively. Those who did not drop out were followed up for a maximum period of 6 months (administrative censoring).

Dropout was defined as the first occurrence of missing a scheduled PrEP refill for 3 months or more without a documented reason. Participants who subsequently re-initiated PrEP remained classified as having experienced a dropout event at the date of their first qualifying dropout. Re-initiation did not reverse the initial dropout classification, and subsequent episodes of dropout or re-initiation were not counted as additional events because the survival analysis assessed time to first dropout.

3.8.2.2. Qualitative data collection procedure

Qualitative data was collected through in-depth interviews using a semi-structured interview guide. The participants were PrEP users who were then using PrEP, had intermittently used PrEP, or had discontinued using PrEP. The interviews explored personal experiences, challenges, and motivators related to PrEP adherence and retention.

The eligible participants interviewed were identified from client records and contacted by a research assistant who was a registered nurse working at the clinic. Those who consented were then taken to a private room for an in-depth interview conducted by the principal investigator. Before beginning the interview sessions, consent was obtained from the participants so that their voices could be recorded. The research team also took notes during each session. Each interview session was anticipated to last about one hour. After the interview, the participants were thanked and released.

3.9. Data management

3.9.1. Data Entry

Data was entered into dedicated data entry software, and quality checks was performed during data entry. Data cleaning included identifying and correcting duplicate entries, verifying missing data, and resolving inconsistencies by cross-referencing medical records. Validation consisted of logical checks that ensured timeline accuracy, such as treatment start dates and follow-up visits.

3.9.2. Data storage

The quantitative data were stored in a password-protected computer and accessible only to the research team. All qualitative interviews were transcribed and stored on secure, password-protected computers. Transcriptions were anonymized to protect participants' identities. The research team stored hard copies of questionnaires and interviewers' notes in private spaces, with access restricted to authorized research team members. Electronic data were regularly backed up to ensure security and data integrity. All identifiable information was removed from the transcripts to protect participants' privacy, and participants were assigned unique codes or pseudonyms.

3.9.3. Data Quality control and assurance

3.9.3.1. Quality control and assurance of quantitative data

Data verification was performed using a double data entry approach to minimise errors and maintain data integrity. This process involved two individuals entering the same data into the system twice and then comparing the entries to identify discrepancies. Any inconsistencies between the two entries were flagged for review and corrected by cross-referencing the original medical records to ensure accuracy and reliability.

Additionally, regular training sessions were conducted for all research assistants to provide knowledge on the study protocol, standardise the data extraction process, familiarise the data collectors with the electronic health systems and patient files, and emphasise the importance of accuracy and consistency. The training also covered handling incomplete or ambiguous data in medical records and the appropriate steps for addressing such challenges to minimize the likelihood of data entry errors and inconsistencies.

To maintain data quality, periodic audits occurred throughout the data collection phase. These audits involved reviewing a random sample of the extracted data to check for completeness, accuracy, and adherence to the data collection protocol. Any issues identified during these audits were addressed promptly, and corrective actions were taken to prevent the recurrence of similar problems. Audits also helped ensure that any missing or incomplete data was identified early and resolved through follow-up checks with the original records, thus ensuring that the data collected was comprehensive and accurate.

Lastly, continuous supervision and feedback mechanisms were implemented to support the data collection team. Regular feedback sessions were held with data collectors to discuss any challenges and provide guidance on improving data accuracy. Supervisors monitored the data entry process closely and provided real-time assistance to ensure that data was captured correctly and efficiently, thus ensuring that the study's data was of the highest possible quality and enabling meaningful analysis and reliable results.

3.9.3.2. Quality control and assurance for qualitative data

Interviewers and facilitators received training on qualitative data collection techniques, including building rapport with participants and probing for deeper insights. Interview guides were pretested to ensure clarity and appropriateness for the study population. After each interview or focus group, debriefing sessions were held to reflect on the data collection process

and ensure that key themes were captured. A random sample of transcriptions was checked for accuracy by comparing them against the original recordings.

Transcriptions were checked for completeness and accuracy. Revisiting the audio recordings and consulting with the interviewer resolved any transcription errors or gaps. Another research team member double-checked some data to ensure the transcription accurately reflected the recorded interviews.

After the qualitative data were analyzed to ensure validity, a subset of participants was asked to review the preliminary findings to confirm whether the themes accurately reflected their experiences. Data from different sources were triangulated to confirm the consistency of findings across various methods. The research team held regular debriefing sessions to discuss the findings and ensured that multiple perspectives were considered when interpreting the data.

3.10. Data Analysis

3.10.1. Quantitative data analysis

The quantitative dataset was exported into STATA 18 (StataCorp, College Station, USA) for cleaning and analysis. The participants' baseline data were summarized using descriptive statistics and presented in tables. If non-parametric, categorical variables were described using frequencies and percentages, and the continuous data were means with standard deviations or medians and interquartile ranges. The Shapiro-Wilk test of Normality and box plots assessed whether the numerical data were typically distributed.

For objective one: The PrEP retention rates at 1, 3, and 6 months were determined through survival analysis using the Kaplan-Meier method. The beginning of observation was the enrollment date into PrEP, and the end of the observation was 6 months after initiation. The event of interest (failure) was dropping out of PrEP use. The Analysis time was in months. Those who turned positive were rightly censored on the day of the positive HIV test. Additionally, log-rank tests were used to compare survival curves (retention rates) between groups.

Dropout was defined as the first occurrence of missing a scheduled PrEP refill for three months or more without a documented reason. Participants who subsequently re-initiated PrEP remained classified as having experienced a dropout event at the date of their first qualifying

dropout. Re-initiation did not reverse the initial dropout classification, and subsequent episodes of dropout or re-initiation were not counted as additional events because the survival analysis assessed time to first dropout.

Objective two's data analysis analyzed the factors associated with drop-out from PrEP using Cox-proportional hazards regression analysis. The proportional hazards assumption was checked using graphical methods and the Proportionality of Hazards test with a p-value threshold 0.05. If the assumption was violated, a model for time-varying covariates was used. At the Bivariate level, factors whose crude hazard ratios had p-values of not more than 0.2 or were highly suspected to have a plausible association with drop-out from PrEP use were selected for multivariable analysis. After multivariable analysis, covariates whose adjusted hazard ratios had a p-value of less than 0.05 were considered statistically significant.

3.10.2. Qualitative data analysis

For the third objective, the barriers and facilitators to PrEP adherence were qualitatively analysed using a thematic analysis. All interviews were transcribed verbatim by trained transcribers and translated into English. The transcribed dataset was then entered into NVivo version 3.1 for coding and analysis, which the investigators conducted: the principal investigator and another investigator with experience in qualitative data analysis.

Before formal analysis began, the investigators familiarized themselves with the data by repeatedly reading the interview transcripts and, where necessary, listening to the audio recordings to capture nuances that might not have been evident in the transcripts. Preliminary notes were made to document initial impressions, recurring ideas, and emerging patterns that warranted further exploration.

The data were initially analyzed using an inductive open-coding approach. Codes were assigned to relevant segments of the transcripts without restricting the analysis to a predetermined coding framework. This approach allowed themes and concepts to emerge directly from participants' experiences and enabled the identification of unexpected barriers and facilitators to PrEP adherence and retention.

Following open coding, related codes were compared and grouped through axial coding to form broader categories and subthemes. After the inductive themes had been developed, the Social

Ecological Model (SEM) was applied deductively as a theory-informed framework for organizing and interpreting the findings. Identified themes were examined across relevant SEM levels, including individual, interpersonal, community, and health-system/structural factors.

The coding structure and relationships among codes, categories, subthemes, and themes were summarized using a code tree and thematic table. The final findings were presented narratively according to the major themes and their relationship to the research question on barriers and facilitators to PrEP adherence and retention. Relevant participant quotations were used to illustrate and support the interpretation of each theme.

The findings were subsequently discussed in relation to existing literature on PrEP adherence and retention, particularly evidence from Uganda and other Sub-Saharan African settings. Areas of convergence and divergence with previous studies were highlighted, and limitations relevant to the qualitative findings and their interpretation were acknowledged

3.11. Ethical considerations

Ethical approval was sought from the Gulu University Research Ethics Committee (GUREC) with approval number GUREC-2024-993. Administrative clearance was obtained from Kitgum district leadership and hospital/institutional leadership.

Informed consent: Participants were given comprehensive information about the study, including its purpose, procedures, potential risks and benefits, voluntary participation, and their right to withdraw without any consequences. This information was provided in a language the participants understood, ensuring clarity. Participants signed a written informed consent form before any data collection.

Privacy and confidentiality: All data collected from participants, including data extraction guides, interview recordings, transcripts, and field notes, were kept confidential and stored securely, with only the research team having access to them. The questionnaire did not capture identifying information to protect participants' identities, and all identifying information was removed from the transcripts. Pseudonyms or codes were used in place of participants' names in all written reports and publications, and care was taken to ensure that participants could not be identified through contextual details.

The interviewer was trained to handle sensitive topics carefully and allowed participants to pause or stop the interview if they felt uncomfortable. Moreover, if any participant experienced distress during the interview, they were provided with information on available support services, such as counselling or peer support groups.

Compensation: Since secondary data were used, quantitative participants were not reimbursed. Only participants in the qualitative component were provided Ugshs. 10,000 as compensation for their time and effort in the study.

3.12. Dissemination plan

The dissemination of findings from this study was structured to ensure that the results reached a broad range of stakeholders, including healthcare providers, policymakers, community leaders, PrEP users, and the academic community. The first step in the dissemination plan involved PrEParing a comprehensive research report and executive summaries tailored to different audiences.

A detailed report was distributed to healthcare providers at Kitgum General Hospital and other regional health facilities, focusing on practical insights that could improve PrEP adherence and retention strategies. For policymakers, a policy brief summarized the key findings and proposed recommendations to improve PrEP programs, such as increasing access through mobile health clinics and addressing community stigma. These documents were shared with the Ministry of Health (MOH) in Uganda and local health officials, encouraging the integration of the study's recommendations into existing national HIV prevention programs.

Additionally, presentations and workshops were organized to engage stakeholders directly. Workshops were held with healthcare workers to provide practical training on improving patient counselling and addressing barriers to PrEP adherence identified in the study. Policymakers and community leaders were invited to discussions where they offered feedback on the proposed recommendations and collaborated on solutions.

For community dissemination, community meetings and radio broadcasts were used to share findings with the general public and PrEP users, particularly in rural areas where formal dissemination platforms were less accessible. These community-based efforts helped reduce stigma, promoted PrEP benefits, and encouraged community-wide support for adherence and retention. For the academic audience, the study was published in peer-reviewed journals and

presented at international conferences, such as the International AIDS Conference, to contribute to the global discourse on HIV prevention and PrEP adherence challenges in low-resource settings.

CHAPTER 4: RESULTS

This chapter presents the study's findings in relation to the stated objectives. Results are organized into two main sections: quantitative and qualitative. The quantitative results summarize the participants' demographic, programmatic, and clinical characteristics. At the same time, the qualitative narratives provide detailed insights into lived experiences, perceptions, and contextual realities that influence PrEP use and related health behaviors. These findings provide a comprehensive picture of PrEP retention and its underlying drivers.

4.1.0 SECTION A: QUANTITATIVE FINDINGS

4.1.1. Demographic characteristics of participants (objective 2)

1102 individual participant records were included in the study. The mean age of participants was 28.1 years (SD: 8.6). More than half were male (n = 610, 55.3%), most resided in urban settings (n = 868, 78.8%), and nearly two-thirds had completed primary or secondary education. The mean distance to the health facility was 8.4 km (SD: 17.0).

Table 1. Socio-Demographic Characteristics of Study Participants

Variable	**Levels**	**Total (N = 1102)**	**% (of Total)**	**Mean (SD)**
Age (years)				28.09 (8.6)
Distance (km)				8.38 (16.96)
Gender	Female	492	44.8	
	Male	610	55.3	
Location	Rural	234	21.2	
	Urban	868	78.8	
Education	None	286	26.0	
	Primary	403	36.5	
	Secondary	315	28.6	
	Tertiary	98	8.9	

Source; primary data

4.1.2. Programmatic and Clinical Characteristics

All were initiated on daily oral PrEP (n = 1102, 100%) and enrolled through community entry points (n = 808, 73.2%), and over one-third reported using fertility awareness for family planning (n = 430, 39.0%). STI assessment was completed for most participants (n = 784, 71.0%), and 13.6% (n = 150) had an STI diagnosis.

Table 2. Programmatic and Clinical Characteristics of Study Participants (N = 1102)

Variable	Levels	Count	%
Family Planning	None	601	54.4
	Fertility awareness	430	39.0
	Condoms	34	3.1
	Injectables	16	1.5
	Implants	12	1.1
	Oral contraceptives	8	0.7
	IUDs	3	0.3
PrEP Options	Oral (Daily)	1102	100%
Entry Point	Community	808	73.2
	Facility	296	26.8
Population Category	Key Populations (KP)	474	42.9
	Priority Populations (PP)	630	57.1
HIV Testing Approach	PITC	672	60.9
	Outreach HTS	260	23.6
	VCT	171	15.5
	HIV self-test	1	0.1
STI assessment	Done	784	71.0
	Not done	320	29.0
STI diagnosis	Yes	150	13.6
STI Syndromes	Vaginal discharge (Yes)	36	3.3
	Genital ulcer disease (Yes)	113	10.2
	LAP (Yes)	114	10.3
	STI diagnosis (Yes)	150	13.6
Hepatitis B/C screening	Yes	21	1.9
GBV reported	Yes	217	19.7
GBV education provided	Yes	610	55.4
Post-GBV Care	Clinical care (Yes)	66	6.0
	LIVES support (Yes)	108	9.8
	Legal support (Yes)	5	0.5
	PEP provided (Yes)	29	2.6
	Psychosocial support (Yes)	217	19.7

Source: Primary data

4.1.3. Objective 1: To measure the retention rates among PrEP users at Kitgum General Hospital.

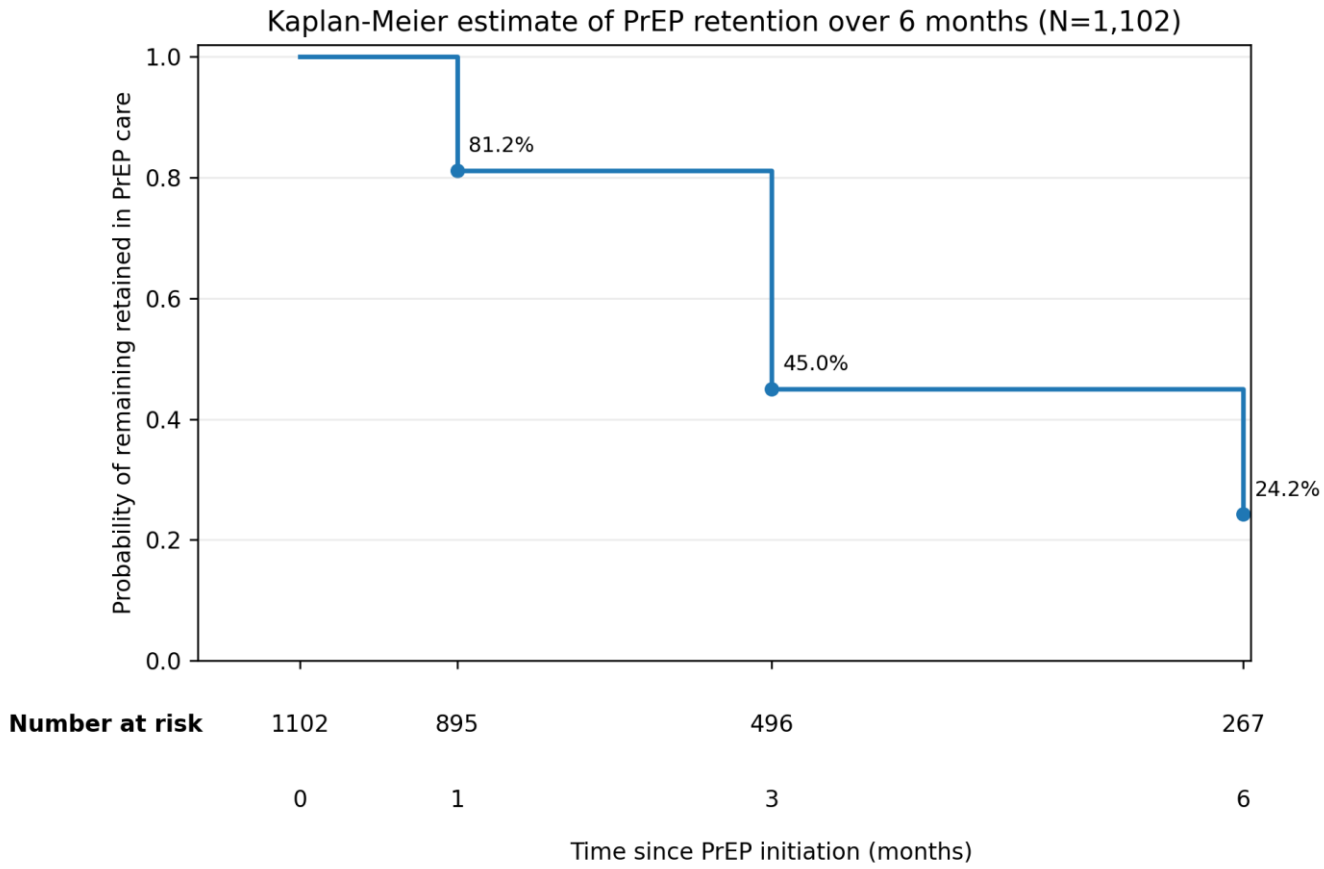
A Kaplan-Meier survival analysis was conducted to assess PrEP retention among the study cohort over 6 months. The total sample size at the initiation of the study was 1102.

Table 1. Life-table estimates of PrEP retention and dropout over six months (N=1,102).

Time	At risk	Dropouts	Censored	Interval retention	Interval dropout	Cumulative retention	Cumulative dropout	SE	95% CI (retention)
0 months	1,102	0	0	1.000	0.000	1.000	0.000	—	—
1 month	1,102	207	0	0.812	0.188	0.812	0.188	0.012	78.9–83.5%
3 months	895	399	0	0.554	0.446	0.450	0.550	0.015	42.1–47.9%
6 months	496	229	267	0.538	0.462	0.242	0.758	0.013	21.7–26.8%

At 1 month, 207 participants had dropped out, giving an interval dropout probability of 18.8% and a cumulative retention probability of 81.2% (95% CI: 78.9–83.5%). Between months 1 and 3, a further 399 participants dropped out. Among the 895 participants entering this interval, the conditional probability of dropout was 44.6%, reducing cumulative retention to 45.0% (95% CI: 42.1–47.9%) at month 3. Between months 3 and 6, 229 of the 496 participants at risk dropped out, corresponding to an interval dropout probability of 46.2%. Cumulative retention therefore declined to 24.2% (95% CI: 21.7–26.8%) at 6 months, while cumulative dropout reached 75.8%. Overall, 835 participants experienced dropout and 267 remained retained at the end of follow-up and were administratively censored.

Figure 1. Kaplan-Meier curve of PrEP retention with numbers at risk at 0, 1, 3 and 6 months.



4.1.4. Objective 2; To determine the factors Associated with drop out from PrEP use at Kitgum General Hospital

After adjustment, age, distance to the health facility, primary education, entry point and population category were independently associated with PrEP dropout. Each additional year of age was associated with a lower hazard of dropout (aHR=0.98, 95% CI: 0.98–0.99; p<0.001). Each additional kilometre of distance was associated with a small increase in dropout hazard (aHR=1.01, 95% CI: 1.00–1.01; p=0.017). Participants with primary education had a lower hazard of dropout than those with no formal education (aHR=0.74, 95% CI: 0.62–0.89; p=0.001).

Participants enrolled through facility entry points had approximately 2.55 times the hazard of dropout compared with those enrolled through community entry points (aHR=2.55, 95% CI: 2.18–2.97; p<0.001). Priority-population participants had a higher hazard of dropout than key-population participants (aHR=1.26, 95% CI: 1.06–1.51; p=0.010).

Table 2. Bivariate and multivariable Cox proportional-hazards regression for factors associated with PrEP dropout

Variable and categories	Dropout at 6 months (n=835)	Retained at 6 months (n=267)	cHR (95% CI)	Crude p-value	aHR (95% CI)	Adjusted p-value
Age (years)						
Per 1-year increase	27.56	29.81	0.99 (0.98–0.99)	0.001	0.98 (0.98–0.99)	<0.001
Gender						
Female	337	155	Reference	—	Reference	—
Male	498	112	1.30 (1.13–1.49)	<0.001	1.31 (0.69–2.49)	0.401
Residence						
Rural	193	41	Reference	—	Reference	—
Urban	642	226	0.81 (0.69–0.95)	0.010	1.17 (0.89–1.54)	0.262
Distance to facility (km)						
Per 1-km increase	9.58	4.65	1.01 (1.01–1.01)	<0.001	1.01 (1.00–1.01)	0.017
Education						
No formal education	222	64	Reference	—	Reference	—
Tertiary	85	13	1.18 (0.92–1.52)	0.194	1.17 (0.91–1.51)	0.214
Primary	277	126	0.72 (0.60–0.86)	<0.001	0.74 (0.62–0.89)	0.001
Secondary	251	64	0.91 (0.76–1.09)	0.326	0.90 (0.75–1.08)	0.263
Family planning						
None	490	111	Reference	—	Reference	—
Fertility awareness	295	133	0.79 (0.68–0.91)	0.001	1.22 (0.64–2.34)	0.545
Other	50	23	0.76 (0.57–1.02)	0.065	1.11 (0.61–2.01)	0.733
Entry point						
Community	559	247	Reference	—	Reference	—
Facility	276	20	2.70 (2.33–3.14)	<0.001	2.55 (2.18–2.97)	<0.001
Population category						
Key population (KP)	314	158	Reference	—	Reference	—
Priority population (PP)	521	109	1.46 (1.27–1.68)	<0.001	1.26 (1.06–1.51)	0.010

STI						
No	717	235	Reference	—	—	—
Yes	118	32	1.11 (0.91–1.35)	0.297	—	—
GBV						
No	680	205	Reference	—	Reference	—
Yes	155	62	0.89 (0.74–1.05)	0.171	1.04 (0.87–1.24)	0.659

Note: cHR = crude hazard ratio; aHR = adjusted hazard ratio; CI = confidence interval; KP = key population; PP = priority population; STI = sexually transmitted infection; GBV = gender-based violence. Reference = reference category

4.2. SECTION B: QUALITATIVE FINDINGS

Barriers and Facilitators to PrEP Adherence and Retention

A total of 10 in-depth qualitative interviews were conducted, with thematic saturation reached by the 7th interview. Emerging themes under facilitators included awareness and knowledge on PrEP, motivation to protect self and partner, social support and peer encouragement, positive healthcare experience and confidence in the healthcare workers, adherence strategies, Negative HIV test results, acceptability and perceived benefits of PrEP, integration with other services, and availability of PrEP.

The barriers to PrEP adherence and retention included stigma, limited PrEP choice, side effect and adverse drug reactions, structural and financial barriers, fear of disclosure, travel, community misconceptions of PrEP, low community knowledge and awareness on PrEP, religious and moral concerns, clinic related barriers, low perceived risk, treatment fatigue and daily pill burden, negative health worker attitudes and forgetfulness.

4.2.1. Facilitators of PrEP Adherence and Retention

Table 4. Summary table for the facilitators of PrEP adherence and retention

Theme	Category	Codes	Example quote
Knowledge and Awareness of PrEP (14)	Exposure via health facilities (5))	Facility sensitization (5)	"I came to hear about PrEP from the Kitgum General Hospital because there was a sensitization and mobilization… they gave

			us knowledge every OPD days." IDI 3
	Community sensitization and mobilization (3)	Community outreaches/peer diffusion (3)	"I first heard from a friend of mine… she explained to me all the details… and told me that I get it from Kitgum General Hospital." IDI 7
	Understanding preventive benefits (4)	Perceived effectiveness (4)	"When I was trained, I kept on giving health education… I knew the benefits of PrEP and how it prevents HIV." IDI 1
	Knowledge empowerment and decision-making (2)	Autonomy, informed choice (2)	"That is why I decided to use PrEP." IDI 1
Motivation to Protect Self and Partner (15)	Perceived HIV risk and fear of infection (10)	Risky contexts and uncertainty (7)	"Even if you're married you may just wake up one day with HIV… to be safe, I decided to use PrEP." IDI 4
		Protection in sero-different (03)	"I am 43 years old… I have a boyfriend who is HIV positive, with two wives."
	Personal agency and self-determination (2)	Self-discipline and self-care (2)	"I just often encourage myself because I know it's for my good." IDI 2
	Protecting partners and loved ones (2)	Preventing transmission to partners; Caring for others (2)	"I also feel like by me taking PrEP, I can protect my other two girlfriends who are still students." IDI 6
	Family history of HIV (1)	Motivation from lived experience (1)	"In our family, we had many HIV positive people… that made me start and continue." IDI 5
Social Support and Peer Encouragement (6)	Partner support and involvement (2)	Reminders and encouragement (2)	"My husband has also supported and encouraged me… he always asks if I have taken my medication IDI 1."
	Family encouragement (1)	Normalization at home (1)	"They actually encouraged me to continue using PrEP to protect myself from getting HIV." IDI 7

	Peer support and shared experiences (2)	Seeing peers succeed (2)	"When I see others taking without problem, I also feel strong." IDI 3
	Social networks and community groups (1)	Informal peer groups (1)	"PrEP peer support groups exist… other people whose return dates are due are reminded to go for their PrEP." IDI 5
Positive Healthcare Experience and Confidence in Providers (13)	Respectful, welcoming care (3)	Friendly and welcoming staff (3)	"Healthcare providers warmly welcome me… call me by my name, I feel valued."(IDI 1) "Whenever I come here, the healthcare providers attend to me very fast… I feel the clinic is conducive and they usually welcome me warmly whenever I come" (IDI 7)
	Effective counseling and ongoing encouragement (3)	Adherence counselling and side-effect support (3)	"The support I have got is PrEP adherence counselling… to follow time, and to come get my medications when I have 3 to 4 tablets left (IDI 2)"
	Trust in expertise and confidentiality (1)	Professionalism and privacy (1)	"They explain well… I believe what the nurse says, so I don't skip." (IDI 2)
	Follow-up and reminders from clinic (3)	Reminder calls from providers (3)	"Providers initially used to give a call… remind you of when to pick up your PrEP… They ask 'How are you nowadays, are you still continuing on PrEP?'" (IDI 3)
	Convenience and accessibility of services (3)	Suitable time/place (3)	"I feel the time and the place where PrEP is offered is very ok to me.(IDI 8)"
Adherence Strategies (12)	Routine-based adherence (4)	Fixed time dosing (4)	"I usually take my PrEP… around 8:00 pm… later it became like senses in my body…"IDI 1
	Reminders and support systems (5)	Tools and people (5)	"I have set an alarm… my child… tells me that mummy, it's already time to take your drugs."IDI 1
	Adapting to lifestyle/context (3)	Flexible timing and settings (3)	"I switched the time to 9 pm… At times I move with it to work and when 9 pm

			gets me there I take it." IDI 2
Acceptability and Perceived Benefits of PrEP (6)	Acceptability and comfort with use (4)	Fading fears and preference (4)	"At the beginning, I was worried… but as I continued… it was the best option." IDI 2
	Perceived health and psychological benefits (2)	Peace of mind; hope (2)	"Now I feel calm, comfortable, no longer worrying about HIV." IDI 1
HIV-Negative Test Results (4)	Reinforcement from negative results (4)	Validation of effectiveness (4)	"Whenever I do an HIV test, it turns out negative… This has made me… continue taking PrEP…" IDI 1
Integration with Other Services (3)	One-stop, bundled services (3)	HIV testing; STI screening; FP; Condoms/lubricant; Emergency pill; Treatment for intercurrent illness (3)	"They first test you for HIV… screen you for STI… I also get my family planning from here." IDI 5
Availability of PrEP at Facility	Reliable supply and zero cost (6)	Stock reliability and free access (6)	"There is no time I came and the drugs were out of stock… we do not pay…" IDI 5

Individual-Level Factors

Knowledge and Understanding of PrEP

Participants described knowledge and understanding of PrEP as important facilitators of adherence and continued use. Awareness of PrEP's ability to prevent HIV increased participants' confidence in the intervention and strengthened their motivation to remain on PrEP. Participants who understood its preventive benefits viewed PrEP as an important means of protecting themselves and their families.

Understanding of PrEP's Preventive Benefits

Participants consistently reported that understanding the preventive benefits of PrEP motivated them to use it regularly. Awareness of its effectiveness provided a sense of security, control, and confidence in protecting themselves against HIV infection. Knowledge acquired through health education and training also enabled some participants to make informed decisions and share information about PrEP with others.

"When I was trained, I kept on giving health education to people in my community, so I knew the benefits of PrEP and how it prevents HIV. That is why I decided to use PrEP." (IDI 02)

Perceived HIV Risk and Motivation for Self-Protection

Participants reported that perceived vulnerability to HIV infection was an important motivation for initiating and continuing PrEP. Fear of acquiring HIV and the desire to remain HIV negative encouraged continued use, particularly among participants who perceived themselves to be at substantial risk because of their relationships, sexual behaviours, occupations, or social environments.

Participants described circumstances including sero-different relationships, multiple sexual partners, alcohol use, unprotected sexual intercourse, and uncertainty about their partners' sexual behaviour as increasing their perceived susceptibility to HIV.

*"I'm a drunkard so, I am at risk of getting HIV … because the area where we are, there are fine girls … when time gets late and you try to jazz one, she agrees and then you move with her to that respective place where you go and give yourselves pleasure."(*IDI 03*)*

Others described uncertainty about their partners as an important reason for protecting themselves:

"Even if you're married you may just wake up one day with HIV… to be safe, I decided to use PrEP."(IDI 10)

*"The kind of women we fall in love with… you can't trust them, so I protect myself."(*IDI 03*)*

Participants in sero-different relationships or those with multiple sexual partners considered PrEP an important independent HIV-prevention strategy, particularly when condom use could not be negotiated or their partners' behaviours could not be controlled.

*"I am 43 years old… I have a boyfriend who is HIV positive, with two wives."(*IDI 01*)*

"Because my partner refused to use a condom, I saw PrEP as the only way to be safe."(IDI 06)

*"I wanted to be faithful but I could not guarantee that my partner is faithful, so I decided to protect myself."(*IDI 04*)*

For some participants, information about possible HIV exposure within their sexual networks further strengthened their motivation to use PrEP.

"I was actively having sexual intercourse with all the 5 partners but later I started hearing rumors that one was HIV positive and was on ART so it made me decide to use PrEP." (IDI 10)

Fear of acquiring HIV also reinforced adherence among some participants:

"I really don't forget because I am so afraid, yet at times I realise that my drugs get finished before the appointment date, it's like at times I used to take double dose of the medication, but I am taking it well now."(IDI 01)

Personal Agency and Self-Motivation

Participants associated continued PrEP use with personal responsibility, self-discipline, and a desire to remain healthy. Adherence was therefore not always dependent on external encouragement. Some participants viewed taking PrEP consistently as an individual responsibility and an expression of self-care.

"I just often encourage myself because I know it's for my good." (IDI 10)

"I want to keep healthy and not get HIV because I love myself."(IDI 07)

Participants also expressed motivation to protect their sexual partners and other people close to them. PrEP was therefore perceived not only as a means of self-protection but also as a way of protecting others.

"I also feel like by me taking PrEP, I can protect my other two girlfriends who are still students." (IDI 06)

Family Experience of HIV as Motivation for Prevention

Previous experiences of HIV within participants' families strengthened their motivation to remain HIV negative. Participants who had witnessed relatives living with or dying from HIV viewed PrEP as an opportunity to prevent similar experiences in their own lives.

"In our family, we had many HIV positive people… that made me start and continue." (IDI 05)

Personal Adherence Strategies and Daily Routines

Participants developed individual strategies for incorporating PrEP into their daily lives. Establishing regular routines, taking medication at specific times, using reminder tools, and adjusting medication schedules to fit daily activities helped participants maintain adherence.

Routine-Based Adherence and Consistent Timing

Taking PrEP at a consistent time was described as an important strategy for avoiding missed doses. For some participants, bedtime provided a predictable opportunity to take their medication. With continued use, medication-taking gradually became habitual.

*"I usually take my PrEP when I am already going to bed around 8:00 pm in the night." (*IDI 08)

*"When I had just started taking my PrEP, I used to forget because I was not yet used to but later it became like senses in my body such that when it is time for taking my drugs, I just remember... when I stay out of home beyond 8:30 pm, even if it's late, I take my drugs immediately I return home."(*IDI 02*)*

These experiences showed that establishing consistent routines enabled participants to integrate PrEP into everyday activities and strengthened their confidence in maintaining adherence.

Use of Personal Reminder Tools

Participants used alarms, phones, watches, and notebooks as practical reminders for taking PrEP and remembering clinic appointments.

*"The dates they give me, I always make them my write it in my notebook… my watch and phone remind me."(*IDI 04*)*

*"I always put an alarm around 10 pm or 11 pm... when it rings I just know that it is time to take my PrEP."(*IDI 05*)*

These reminder strategies reduced forgetfulness and helped make medication-taking part of participants' normal daily routines.

Adaptation of Medication Routines to Daily Life

Participants also adjusted medication schedules to accommodate work, religious activities, and other daily responsibilities. Flexibility enabled them to continue taking PrEP despite changes in their circumstances.

*"I had started moving with my drugs to church, but I found it difficult to swallow…. consulted a healthcare provider from here, then I switched the time to 9 pm in the night and now I'm safe and have no problems. At times I move with it to work and when 9 pm gets me there I take it, at times when I realise that there are few minutes left like 10 minutes, I rush home."(*IDI 01*)*

Adapting medication schedules to personal circumstances enabled participants to balance PrEP use with work, faith, and other everyday responsibilities.

Acceptability and Perceived Benefits of PrEP

Participants described increasing acceptance of PrEP after gaining experience with the medication. Initial fears about side effects or using PrEP diminished when participants experienced no major problems and received reassurance. PrEP subsequently became associated with protection, confidence, and greater control over HIV prevention.

*"At the beginning, I was worried that using the drug would affect me, but as I continued using it, I did not get any problems and it was the best option."(*IDI 04*)*

*"My only problem was fear of starting to take this medication... and fear of coming to the health facility but now I am comfortably taking my PrEP." (*IDI 01*)*

*"I realized it keeps me safe… now I feel okay using it."(*IDI 04*)*

Some participants also considered PrEP more acceptable than condoms.

*"I was comfortable with it more than using condoms." (*IDI 04*)*

Continued experience with PrEP therefore increased confidence in its safety and strengthened participants' willingness to continue using it.

Perceived Psychological Benefits of PrEP

In addition to protection against HIV, participants described psychological benefits associated with PrEP use. Feeling protected reduced anxiety, fear, and stress related to possible HIV exposure and gave participants greater peace of mind.

*"I'm assured of my health and then my protection is guaranteed because PrEP is there to protect."(*IDI 03*)*

"It reduced my stress, I don't fear anymore even if my partner refuses condoms."(IDI 02)

"It has changed my life, it has given me hope... Because of PrEP, I now feel calm and comfortable... I am ok now and no longer worried of getting HIV because all my hope is on PrEP." (IDI 02)

The psychological reassurance associated with PrEP strengthened participants' motivation to adhere and remain engaged in PrEP care.

HIV-Negative Test Results as Reinforcement for Continued PrEP Use

Repeated HIV-negative test results provided reassurance that strengthened participants' motivation to continue using PrEP. For some participants, remaining HIV negative reinforced their belief in the effectiveness of PrEP.

"I just love my life very much... Ever since I started taking this drug, whenever, I do an HIV test, it turns out negative, this has really motivated me because I can testify that PrEP really works well... This has made me to decide to continue taking PrEP because it is really protecting me from getting HIV" (IDI 02)

Negative HIV test results therefore served as positive reinforcement for continued adherence and engagement in PrEP care.

Interpersonal-Level Factors

Partner, Family, and Peer Support

Social support from partners, family members, friends, and peers was an important facilitator of adherence and continued PrEP use. Supportive relationships provided emotional reassurance, encouragement, practical assistance, and reminders. Open communication about PrEP also helped reduce misconceptions and strengthened acceptance of PrEP use.

Partner Support and Involvement

Partners were important sources of motivation for continued PrEP use. Participants described how explaining the purpose of PrEP to their partners helped address concerns and encouraged partner support.

"When I just told my partner that I am using PrEP, he had a lot of questions but when I explained to him, he agreed and started supporting me to use PrEP."(IDI 05)

Some partners actively supported adherence by reminding participants to take their medication.

"My husband has also supported and encouraged me, when he is around, he always asks if I have taken my medication."(IDI 01)

Partner involvement therefore provided both emotional encouragement and practical support for adherence.

Family Encouragement and Acceptance

Family members also played an important role in encouraging participants to continue using PrEP. Participants who disclosed their PrEP use to family members described receiving reassurance, guidance, and practical support.

"I have friends, family members who support me including my mother and sisters. They actually encouraged me to continue using PrEP to protect myself from getting HIV."(IDI 07)

Although some family members initially misunderstood PrEP use, education and discussion sometimes changed these perceptions and resulted in greater acceptance.

"Then my father heard about it, he told me I should immediately leave my husband but my brother told him that 'daddy, very many people right now are living with HIV and are on ART... it would really be very good for my sister to take PrEP."(IDI 02)

Family understanding and acceptance therefore strengthened continued PrEP use and reduced potential stigma within households.

Family members also provided direct adherence reminders:

"First of all, I told my husband that 'I take my drugs every day at 8:30 pm, in case I have forgotten, please help and remind me.' Secondly, I have set an alarm for 8:30 pm on my phone... Then, I have a child of mine... when it clocks 8:25 pm, he runs to me and tells me that mummy, it's already time to take your drugs."(IDI 02)

Peer Support and Shared Experiences

Peers provided encouragement, shared experiences, and informal reminders that supported continued PrEP use. Observing other people using PrEP successfully increased confidence and helped normalize PrEP use.

"I encouraged my friend who is also at risk to start using PrEP, and now we remind each other."(IDI 06)

"Yes, we often help our friends with advice so that they continue taking their drugs."(IDI 08)

These peer relationships acted as informal support and accountability systems, helping participants remain adherent when their individual motivation fluctuated.

Community-Level Factors

Community Sensitization, Mobilization, and Social Support Networks

Community-level activities increased awareness of PrEP and connected potential users with prevention services. Participants identified community sensitization, outreach programmes, word-of-mouth communication, peers, and community health workers as important sources of information about PrEP.

"A friend of mine who had come to watch film…and talked to me about PrEP that it helps to prevent HIV…I had gone to the club and found a group of health workers who were providing HIV testing and they encouraged us about PrEP."(IDI 06)

"I first heard from a friend of mine… she explained to me all the details, I needed to know and told me that I get it from Kitgum General Hospital."(IDI 07)

"The facility team had gone to the community and they were educating people…that there is a new HIV prevention drug called PrEP… I came to the facility and I was offered PrEP and upto now I am still using PrEP."(IDI 10)

Community sensitization and mobilization expanded access to PrEP information beyond health facilities and encouraged initiation and continued use.

Community and Peer Support Networks

Broader community networks and peer-support groups provided spaces where PrEP users could discuss experiences, challenges, and adherence. These groups provided encouragement and helped participants remember clinic return dates.

"PrEP peer support groups exist but people gather in their safe places to share their experiences about PrEP with their friends who are also using PrEP… other people whose return dates are due are reminded to go for their PrEP."(IDI 05)

Community-based support fostered solidarity among PrEP users and helped connect facility-based services with participants' everyday social environments.

Health-System-Level Factors

Health-Facility Education and PrEP Awareness

Health facilities were important sources of PrEP information. Participants described health education, mobilization activities, outpatient visits, and interactions with healthcare workers as opportunities to learn about PrEP. These interactions increased awareness, built confidence in PrEP services, and facilitated initiation and continued use.

"I came to hear about PrEP from the Kitgum General Hospital because there was a sensitization and mobilization… they gave us knowledge every OPD days."(IDI 03)

"There was a time I came to the facility for general check up… healthcare providers talked to me about PrEP because I didn't know."(IDI 08)

Health-facility education therefore provided participants with information that strengthened their motivation to adhere to and continue using PrEP.

Positive Healthcare Experiences and Confidence in Healthcare Workers

Positive interactions with healthcare workers encouraged participants to remain engaged with PrEP services. Respectful treatment, effective counselling, confidence in healthcare workers, and confidentiality strengthened relationships between participants and providers and encouraged return for PrEP refills.

Respectful and Welcoming Healthcare Provider Interactions

Participants described respectful and welcoming treatment from healthcare workers as an important facilitator of continued engagement. Being treated with dignity and kindness made participants feel valued and comfortable when accessing services.

"Healthcare providers warmly welcome me… call me by my name, I feel valued."(IDI 02)

"The way I was welcomed, then told about PrEP, gave me courage. Right now, my heart is calm and I have no problems."(IDI 01)

Effective Counselling and Continued Encouragement

Participants valued counselling that explained PrEP, addressed side effects, and reinforced the importance of adherence. Continued encouragement during refill visits provided reassurance and motivation.

"The counselor told me how to handle side effects and that helped me continue."(IDI 02)

"The healthcare providers encourage me every time I go for refills, and this motivates me to continue."(IDI 10)

"The support I have got is PrEP adherence counselling, encouraging me to continue taking my medications, to follow time, and to come get my medications when I have 3 to 4 tablets left." (IDI 01)

Regular communication and counselling strengthened participants' confidence and encouraged continued PrEP use.

Trust in Healthcare Provider Expertise and Confidentiality

Participants expressed confidence in healthcare workers' knowledge and professionalism. Clear communication and credible information increased participants' willingness to follow healthcare advice.

"They explain well… I believe what the nurse says, so I don't skip." (IDI 04)

"The healthcare providers assured me that it would help me greatly to reduce my chances of getting HIV from my husband and that if I use it well." (IDI 08)

Confidence that healthcare workers would maintain confidentiality also enabled participants to discuss personal concerns, side effects, and other challenges without fear of judgement.

Integration of PrEP with Other Health Services

Participants described receiving PrEP alongside other services, including HIV testing, STI screening, family planning, counselling, condoms, and other health services. Integration made accessing PrEP more convenient and helped normalize its use.

"They first test you for HIV, they screen you for STI before being given the drugs especially during the time when PrEP Ring was being provided." (IDI 05)

"I am often tested for HIV everytime I come. I also get my family planning from here." (IDI 09)

"They also offered condoms, lubricant and emergency pill for me to give to my girls after sex." (IDI 06)

Integration of PrEP with other healthcare services reduced the need to seek services separately and facilitated continued engagement with PrEP care.

Policy/Structural-Level Factors

Accessibility and Convenience of PrEP Services

The organization and accessibility of PrEP services influenced participants' ability to remain engaged in care. Participants appreciated service locations and schedules that accommodated their needs and made it easier to attend appointments and obtain medication refills.

"I feel the time and the place where PrEP is offered is very ok to me." (IDI 09)

Convenient service arrangements therefore reduced structural barriers to continued PrEP use.

Reliable Availability and Affordability of PrEP

Reliable availability of PrEP at the health facility was an important facilitator of continued use. Participants reported being able to obtain their medication without experiencing stock-outs.

"There is no time I came and the drugs were out of stock, it has not been there." (IDI 05)

The provision of PrEP without direct user fees at a government health facility also reduced financial barriers to continued access.

"This facility being a government facility, we do not pay so I have not experienced any financial challenges…no one asks for money." (IDI 05)

Reliable medication supply and the absence of direct costs therefore supported continued access to PrEP and reduced structural barriers to retention in care.

4.2.2 Barriers to PrEP Adherence and Retention

Table 5. Summary table for barriers to PrEP adherence and retention

Theme	Sub-theme	Category	Codes	Example quote
Stigma (15)		Social judgment and internalized stigma (4)	Labeled promiscuous/unfaithful (4)	"They will start saying that I am not trusted... they can easily say I am a prostitute." IDI 4
	Community Misconceptions on PrEP (11)	HIV-related mislabeling and misunderstanding (7)	PrEP confused with ART/has HIV virus (7)	"Many people say that PrEP is ART… others say the drug has already HIV virus which one day will wake up in their bodies." IDI 10 "People in the community think that those who swallow pills every day are HIV positive." IDI 3

		Moral and cultural misconceptions (2)	Promotes immorality (2)	"Even religious beliefs also discourage PrEP because it sounds like promoting immorality." IDI 3
		Biomedical misinformation and health-related myths (2)	Causes infertility/cancer/others (2)	"When the injectable PrEP was brought… some people kept saying we are being injected with the active virus kept in the fridge." IDI 5
Side Effects and Adverse Drug Reactions (7)		Initial adjustment challenges (5)	Transient side effects (5)	"When I had just started… I used to get very strong headache… those side effects… took almost 11 months to disappear." IDI 1
		Severe or persistent reactions (2)	Discontinuation due to intolerability (2)	"I made up my mind to stop… I can't stay the whole day with feelings of wanting to vomit." IDI 9
Structural and Financial Barriers (8)		Transportation and geographical barriers (3)	Long travel and rainy season (3)	"Sometimes I get thoughts that now I don't even have transport… when my bicycle breaks down, I have to get a Bodaboda and pay." IDI 1
		Financial constraints and opportunity costs (5)	Transport fares and time away from business/work (5)	"Getting the time to move from the business point to come to the hospital is very hard… but when I reach they do not ask for any money." IDI 4
Fear of Disclosure (5)		Partner mistrust and accusations (3)	Accused of infidelity (3)	"I was afraid that if he realizes I was using PrEP Ring, he would think that I am cheating on him." IDI 4

		Selective or concealed disclosure (2)	Self-protection strategies (2)	"Difficult to tell people about PrEP use, only my close friend knows." IDI 5
Clinic-Related Barriers (3)		Limited human-resource capacity and workload pressure (1)	Few staff (1)	"Sometimes only one provider is available… ends up giving surface information without going into details." IDI 5
		Inconsistent drug supply and short dispensing intervals (1)	1-month refills instead of 3 (1)	"Sometimes… the drugs are few... they give us for one month instead of 3 months." IDI 5
		Staff rotation and Retention gaps (1)	Inexperienced new staff; weak rapport (1)	"When they bring a new provider… we the clients can easily turn to be their mentors on PrEP." IDI 5
Travel-Related Interruptions		Mobility and absence (6)	Away from home; overstays; unexpected trips/burials (6)	"I travelled somewhere far… I had left my medicine home… I missed taking my drugs for 2 days." IDI 2
Low Community Knowledge and Awareness (5)		General low awareness (5)	Confusing PrEP with PEP (5)	"People do not have the knowledge… many people mistaken PrEP for PEP." IDI 5
Limited PrEP Choice (2)		Modality constraints (2)	lack of preferred option (2)	"I stopped using PrEP due to absence of injectable PrEP… we were told it would not be available due to funding challenges." IDI 9
Religious and Moral Concerns (2)		Norms and doctrine (2)	Moral opposition (2)	"Even religious beliefs also discourage PrEP because it sounds like promoting immorality." IDI 3

Low Perceived Risk (4)		Reduced risk perception (4)	Inappropriate risk perception (4)	"Also currently, I do not have a serious sexual partner… so I do not feel at risk of getting HIV." IDI 9
Treatment Fatigue and Daily Pill Burden (5)		Pill-taking burden (5)	Tired of daily swallowing (5)	"Things that need swallowing at times makes one tired… let me first rest for 2–3 days then continue." IDI 3
Negative Health Worker Attitudes (1)		Harsh communication (1)	Tough tone and poor client relations (1)	"The healthcare provider was very tough and did not know how to speak to her clients well." IDI 4
Forgetfulness and Formulation Issues (4)		Memory lapses and pill size (4)	Forgetting doses (4)	"Let me tell you oral is so hectic because you can easily forget." IDI 3

Individual-Level Factors

Side Effects and Adverse Drug Reactions

Side effects and adverse drug reactions emerged as important barriers influencing PrEP adherence and retention. Participants described experiencing various physical discomforts, particularly during the initial stages of PrEP use, which discouraged some from continuing the medication. Although many participants reported that these effects were temporary and subsided over time, others found them distressing enough to interrupt or completely discontinue PrEP use. The most commonly reported symptoms included nausea, headaches, dizziness, diarrhea, abdominal fullness, and skin rashes. These experiences revealed how drug tolerability shaped participants' overall perception of PrEP and their long-term commitment to its use.

a). Initial Adjustment Challenges and Transient Side Effects

Several participants described experiencing mild to moderate side effects when they first started taking PrEP. These early reactions, though uncomfortable, were often tolerated with

continued use and reassurance from healthcare providers. Over time, participants noted that their bodies adapted to the medication, allowing them to continue without major complications.

"When I had just started taking PrEP, even if I had eaten a very small amount of food, I used to feel too full... I also used to get a lot of nausea... I used to get very strong headache... So those side effects like headache, nausea, abdominal fullness are currently not there, it took almost 11 months for those side effects to disappear." (IDI 02)

"When I had just started, I had diarrhea for about 2 days... I also had headache and increased appetite." (IDI 06)

"My experience with PrEP was not very good because at first when I had just started swallowing, I used to get dizzy making me feel weak." (IDI 07)

b). Severe or Persistent Reactions Leading to Discontinuation

For some participants, the side effects were more persistent or severe, resulting in discomfort, anxiety, and in a few cases, discontinuation. Skin reactions, prolonged nausea, and vomiting were the most commonly mentioned concerns that undermined trust in the medication. Despite clinical evaluations that revealed no major complications, participants associated these symptoms with PrEP and felt compelled to stop taking it.

"After those side effects disappearing is when I started getting the body itchiness and rashes all over my body. I came and they did a lot of investigations, but they did not get anything wrong." (IDI 02)

"I therefore made up my mind to stop using it because I can't stay the whole day with just feelings of wanting to vomit, and worse if you want to vomit, the vomit refuses even to come." (IDI 09)

These narratives illustrate how discomfort and uncertainty around drug side effects affected participants' willingness to persist with PrEP.

c). Treatment Fatigue and Daily Pill Burden

Participants expressed difficulty maintaining daily pill-taking, describing it as exhausting despite their willingness.

"Not so many problems only that it is difficult to take drugs everyday... I just take this drug for protection against HIV although I do not feel comfortable with taking drugs, but I just take it like that."

"You know things that need swallowing at times makes one tired when it becomes a routine. So one can easily start to think that 'I have been taking these drugs for everyday, let me first rest for 2-3 days then continue"

d). Forgetfulness

Some participants reported forgetfulness as a barrier to PrEP adherence and retention

"When I had just started using the drug, I felt like stopping because the pill size was too big"

"Let me tell you oral is so hectic because you can easily forget"

Travel

Some participants reported that travel cause disruption to their PrEP adherence and continuation

"I have missed taking PrEP like twice… I picked a few pills but overstayed… making me miss my pills for 3 days" (IDI 10)

"There were times I could forget... or when I travel and take longer, I end up missing my drugs" (IDI 06)

Interpersonal-Level Factors

Fear of Disclosure

Disclosure of PrEP use was a sensitive and complex issue for many participants. Fear of negative partner reactions, accusations of infidelity, and concerns about judgment from family and community members discouraged open discussion about PrEP. This reluctance to disclose created secrecy and limited opportunities for adherence support. Participants described navigating these fears by concealing their PrEP use or confiding only in a few trusted individuals.

Two related subthemes emerged: fear of partner mistrust and accusations of infidelity and selective or concealed disclosure for self-protection.

a). Fear of Partner Mistrust and Accusations of Infidelity

Participants expressed anxiety about revealing their PrEP use to intimate partners, fearing that such disclosure might be interpreted as evidence of unfaithfulness or hidden sexual relationships. This was especially common among women, who reported concerns that partners might misinterpret PrEP as a sign of infidelity.

"Yes, I had the thoughts because of my husband because I was afraid that in case he ever realizes that I was using PrEP Ring, he would think that I am cheating on him." (IDI 04)

b). Selective or Concealed Disclosure for Self-Protection

Because of anticipated stigma and misunderstanding, several participants chose to disclose their PrEP use only to trusted individuals such as close friends or relatives, while others kept it completely private. Limited disclosure served as a self-protective strategy against gossip, family conflict, and social scrutiny.

"No one knows about it apart from myself." (IDI 10)

"Difficult to tell people about PrEP use, only my close friend knows." (IDI 01)

While this strategy helped participants maintain privacy, it also reduced social support for adherence, such as reminders or encouragement. The resulting isolation increased the risk of inconsistent pill-taking and missed refills, particularly when participants were away from home or when medication intake conflicted with family routines.

Community-Level Factors

Stigma

Stigma, both perceived and experienced was identified as a major barrier to PrEP adherence and retention. Participants described fear of judgment, gossip, and misperceptions from peers and community members who often confused PrEP with antiretroviral therapy (ART) for HIV-positive individuals. This misunderstanding created emotional distress, secrecy, and reluctance to take PrEP openly, leading to inconsistent use and, in some cases, discontinuation.

Two interconnected categories emerged under this theme that is fear of HIV-related mislabeling and misunderstanding, and social judgment and internalized stigma. Additionally, one major subtheme emerged under this category that is community misconception

a) Fear of HIV-Related Mislabeling and Misunderstanding

Many participants expressed anxiety about being mistaken for someone living with HIV because PrEP pills resemble ART medication. The limited community awareness about PrEP's preventive purpose reinforced these misconceptions and made users feel vulnerable to ridicule or suspicion.

"They will say that I am taking ART because they do not understand it very well and they have not used it." (IDI 07)

Such misunderstanding discouraged open use, as participants feared that being seen taking daily pills would invite gossip or stigma.

b). Social Judgment and Internalized Stigma

Beyond fear of being labeled HIV-positive, participants also experienced moral judgment from others who associated PrEP use with promiscuity or infidelity. Women reported being viewed as untrustworthy or sexually immoral, while men faced suspicion of being "carriers." These social reactions generated embarrassment and self-consciousness that affected adherence behavior and sustained use.

"They will start saying that I am not trusted... they can easily say I am a prostitute." **(**IDI 04**)**

"Some people say I could be a carrier… because how can he survive in all this scenario?" (IDI 03)

"Some of my friends... kept on talking behind my back." (IDI 05)

This stigmatizing environment fostered silence and isolation. Participants often avoided disclosing their PrEP use even to close friends or relatives, resulting in limited social support. Some internalized these judgments, developing self-stigma that further reduced their willingness to attend clinic visits or refill their prescriptions.

Community Misconceptions on PrEP

Community misconceptions emerged as a major barrier to PrEP uptake, adherence, and retention. Participants reported that many people in their communities lacked accurate information about PrEP's preventive purpose and instead associated it with HIV treatment or other unfounded beliefs. These misconceptions generated fear, stigma, and moral judgment, discouraging individuals from initiating or continuing PrEP use.

Three interrelated subthemes were identified: confusion between PrEP and ART, moral and cultural misconceptions, and biomedical misinformation and health-related myths.

a). Confusion Between PrEP and ART

A common misunderstanding in the community was that PrEP was the same as antiretroviral therapy (ART) used for treating HIV. Participants explained that many people assumed those who took PrEP were already HIV positive, which reinforced stigma and deterred potential users from starting or disclosing their PrEP use.

"They say PrEP is ART for HIV treatment... some say it is a form of family planning the government is using to regulate the population." (IDI 06)

"Many people say that PrEP is ART, that's the first thing that comes to their mind... others say that the drug has already HIV virus which has been killed but for those taking it, one day the virus will wake up in their bodies and they will realize it much later that they have been infected." (IDI 05)

These misconceptions blurred the line between HIV prevention and treatment, fueling social gossip and mistrust toward PrEP users. As a result, many feared being mislabeled as HIV-positive and preferred to remain silent about their PrEP use to avoid discrimination.

b). Moral and Cultural Misconceptions

Beyond confusion with ART, PrEP use was also viewed through a moral and cultural lens. Participants shared that some community members associated PrEP use with promiscuity or sex work, particularly among women. This moral framing portrayed PrEP as a drug for people perceived as sexually irresponsible, creating an environment of judgment and shame.

"Even religious beliefs also discourage PrEP because it sounds like promoting immorality." (IDI 03)

"Some people say that PrEP is for prostitutes... others say it has HIV virus inside." (IDI 05)

Certain religious and cultural norms further discouraged PrEP use by suggesting that it promoted immorality or undermined traditional sexual values.

c). Biomedical Misinformation and Health-Related Myths

Participants also described widespread biomedical misinformation about PrEP. Many community members believed that PrEP contained the HIV virus or caused severe health complications such as infertility, cancer, or cervical damage. Misconceptions intensified whenever new PrEP delivery methods such as rings or injectables were introduced.

"Many people say that PrEP is ART, that's the first thing that comes to their mind..others say that the drug has already HIV virus which has been killed but for those taking, it one day the virus will wake up in their bodies and they will realize it much later that they have been infected… so they really do not understand and that's what they say….then on PrEP Ring, when it just came, people talked a lot of things. some said it causes cancer, some said it causes infertility or will damage the cervix, but anyone who had interest in it and was counselled by the provider, they actually used it well without any problems. Then when the injectable PrEP was brought, some people in the community kept on saying that we are being injected with the active virus which was kept in the fridge directly in our bodies, that atleast the one we used to swallow had a dead virus, so with time these virus will infect us and that we shall actually become HIV positive." (IDI 05)

Despite these misconceptions, some participants observed that community acceptance improved with effective counseling and sensitization by healthcare providers.

"Community embraced PrEP, they're looking at it as a cure." (IDI 03)

Health-System-Level Factors

Clinic-Related Barriers

Clinic-level and system constraints undermined adherence and retention among PrEP users. Participants described structural like inefficiencies long waiting times, drug stock-outs, limited staffing, and frequent staff rotation that shaped their service experience. These challenges reflected broader health-system weaknesses that directly affected the quality, Retention, and reliability of PrEP delivery.

Three related subthemes emerged: limited human-resource capacity and workload pressure, inconsistent drug supply and short dispensing intervals, and staff rotation and Retention gaps.

a). Limited Human-Resource Capacity and Workload Pressure

Participants emphasized that inadequate staffing stretched providers and reduced service efficiency. Often, a single clinician handled multiple tasks HIV testing, counseling, dispensing, and data entry resulting in long queues and rushed consultations.

"There is shortage of providers in the unit because sometimes I come when only one provider is available, the same provider is the one offering HIV testing, counselling, dispensing the drugs and other things, so when people are many it becomes hard for them and they also forget to provide other services or reschedule you to come another time. Even at times when they are counselling or providing health education this provider ends up giving surface information without going into details." (IDI 05)

b). Inconsistent Drug Supply and Short Dispensing Intervals

Frequent stock-outs and limited supplies disrupted Retention of care. Participants described instances where drugs were insufficient to cover the full three-month period, forcing facilities to ration and provide only one-month supplies.

"Sometimes when we come to the facility, I get when the drugs are few... they give us for one month instead of 3 months." (IDI 05)

c). Staff Rotation and Retention Gaps

Frequent transfer or rotation of providers also disrupted the consistency and quality of PrEP services. Participants reported that new staff were sometimes unfamiliar with the program and lacked practical experience, forcing clients to spend time re-explaining their histories.

"When they bring a new provider, we the clients can easily turn to be their mentors on PrEP because they can only be knowing the basic knowledge without the knowledge of our experiences and other details unlike the older or previous healthcare provider so those providers take time to learn and they are forced to sit down and read more about PrEP." (IDI 05)

Such transitions weakened provider-client trust and Retention of care. Clients preferred stable relationships with experienced providers who understood their adherence challenges and offered consistent guidance.

Negative Health Worker Attitudes

Harsh communication styles from providers discouraged return visits.

"The healthcare provider was very tough and did not know how to speak to her clients well."

Policy/Structural-Level Factors

Structural and Financial Barriers

Participants described several systemic and socioeconomic challenges that hindered consistent access to PrEP services. Despite acknowledging PrEP's protective benefits, many users faced obstacles related to distance, transportation costs, and financial hardship. These barriers not only made it difficult to attend refill appointments regularly but also contributed to occasional treatment interruptions and, in some cases, discontinuation.

Two interrelated subthemes were identified: transportation and geographical barriers and financial constraints and opportunity costs.

a). Transportation and Geographical Barriers

Distance to health facilities was a major challenge for many participants, particularly those living in remote or rural areas. Traveling long distances often by bicycle or motorcycle to reach the clinic was physically demanding and costly. Poor road conditions and weather disruptions, especially during the rainy season, further compounded these challenges. Participants explained that these difficulties sometimes led to missed appointments or delayed refills, despite their determination to continue using PrEP.

"Sometimes I get thoughts that 'now I don't even have transport means to go to the health facility' but I still struggle and get. Sometimes when my bicycle breaks down, I have to get a Bodaboda and pay." (IDI 02)

"I have faced challenges with transport especially during the rainy season... sometimes I miss my appointments." (IDI 06)

These reveals how structural barriers such as long distances and unreliable transportation created persistent access gaps. Even highly motivated individuals found it difficult to maintain regular attendance when faced with logistical challenges beyond their control.

b). **Financial Constraints and Opportunity Costs**

Financial limitations were another major barrier affecting adherence and retention. Although PrEP medication and clinical services were provided free of charge, participants still incurred indirect costs such as transport fares and time lost from income-generating activities. For many, these hidden costs posed ongoing difficulties that tested their commitment to stay on PrEP.

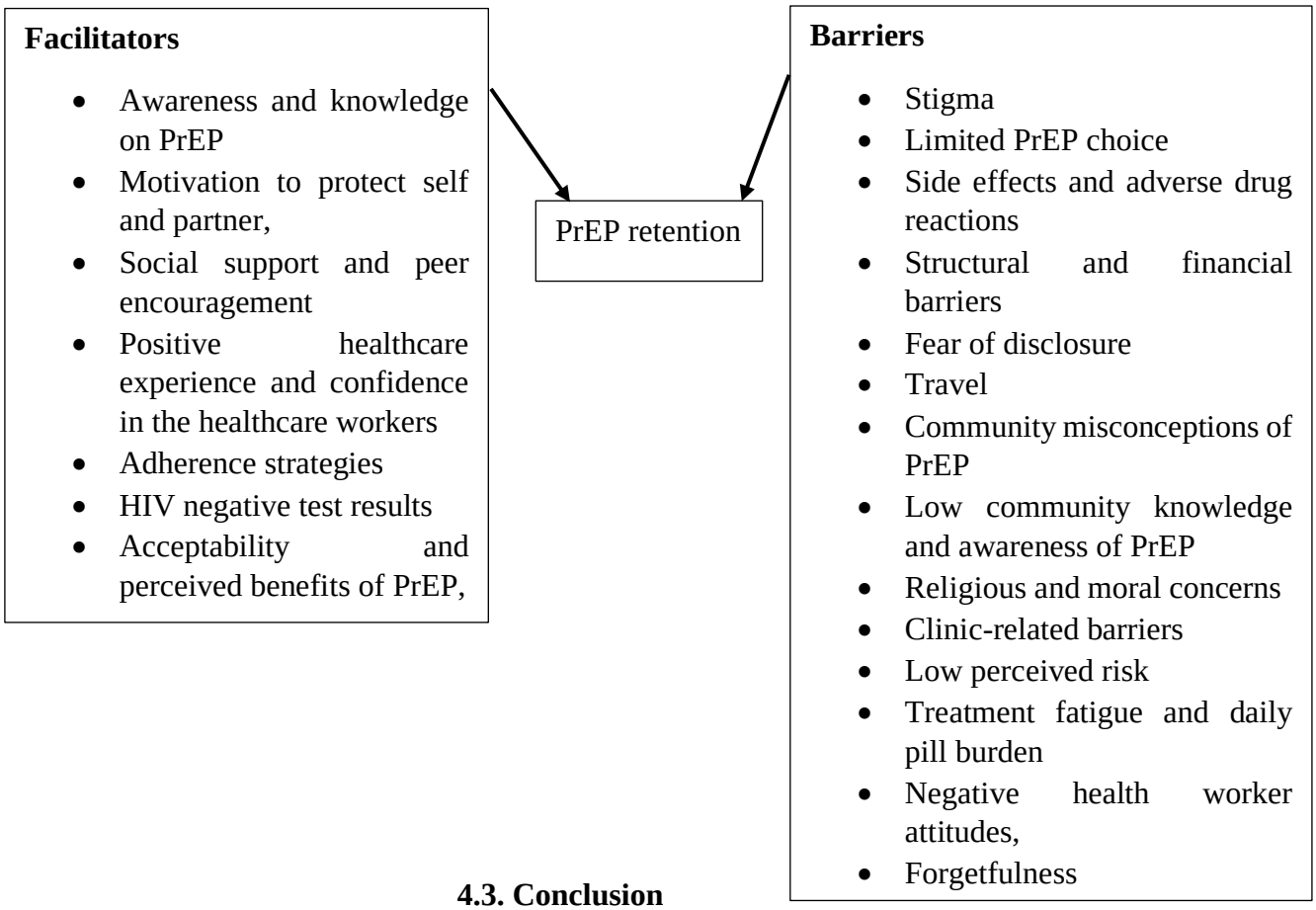
"Money, being human like any other may not be there but I struggle to look for because I need the drugs." (IDI 01)

"I have mainly experienced transport challenges but also getting the time to move from the business point to come to the hospital is also very hard but when I reach they do not ask for any money." (IDI 04)

"Sometimes there can be transport challenges but because I want good health, I struggle and manage to come and get the drug." (IDI 08)

These statements reflect participants' resilience and determination to prioritize their health despite financial strain. However, the repeated struggle to secure transport and time away from work imposed a heavy burden, which, over time, eroded consistency in attending appointments and collecting refills.

Fig 2 showing a summary of qualitative themes



4.3. Conclusion

Quantitative results indicate that the study population was predominantly young, urban, and male. Retention in PrEP programs was markedly low, with most participants disengaging within the follow-up period. However, clinical services such as STI screening were relatively well integrated. The limited uptake of modern contraceptive methods and the high burden of GBV point to unmet needs that may impact PrEP Retention.

Qualitative findings emphasize that PrEP retention is not solely a programmatic or clinical issue but is deeply influenced by social relationships, gender power dynamics, and perceptions of health interventions. While facilities and communities are key in raising awareness, barriers undermine consistent PrEP use.

CHAPTER 5: DISCUSSION

5.1. Introduction

This mixed-methods study aimed at determining how well clients remained engaged in a PrEP program over time and why they did so or did not. Specifically, we sought to measure retention rates at key intervals quantitatively, that is, 1, 3 and 6 months after PrEP initiation, as well as associated factors, and qualitatively explore barriers and facilitators influencing PrEP adherence and continued use.

The study was grounded in the Social Ecological Model (SEM), whose frameworks were used to interpret individual beliefs and multi-level contextual factors affecting PrEP use. By integrating quantitative outcomes with insights from in-depth interviews, the research objectives focused on identifying patterns in PrEP retention and generating a comprehensive understanding of the challenges and supports shaping PrEP use in this setting.

5.2. DISCUSSION OF KEY FINDINGS

5.2.1. SECTION A: Quantitative findings

5.2.1.1. Retention rates (Objective 1)

PrEP retention at Kitgum General Hospital declined significantly over the six-month follow-up period, The Kaplan–Meier analysis showed that retention decreased from 81.2% (95% CI: 78.9–83.5%) at 1 month to 45.0% (95% CI: 42.1–47.9%) at 3 months and 24.2% (95% CI: 21.7–26.8%) at 6 months Although the study did not extend to 12 months, the finding that only 24.2% of participants remained retained by six months suggests a steep decline in retention. If this declining pattern persisted beyond six months, retention at 12 months could potentially be lower than the national 12-month retention rate of 20% reported in 2022 (Uganda PrEP Technical Guidelines).

This pattern is also consistent with other real-world PrEP programs within sub-Saharan Africa, as countries like South Africa and Kenya report strong initiation, especially among key populations, but retention drops to about 50% at six months and below 30% at 12 months (Khadka et al., 2023; Kinuthia, Pintye, Abuna, Mugwanya, Lagat, et al., 2020). Another large implementation project in Cameroon focused on Female Sex Workers (FSW) and men who have sex with men (MSM) reported PrEP continuation rates of only 37% at 3 months, 28% at 6 months, and 19% at 12 months (Ndenkeh et al., 2022).

This sharp early drop-off suggests that the first 1–3 months are the most critical period for PrEP persistence. Our qualitative findings revealed several reasons for this early attrition. Some participants struggled with side effects or practical issues soon after starting PrEP: *"When I felt side effects like dizziness, I stopped for some time."* Others experienced pill fatigue and daily adherence burden and reported that *"It is difficult to take drugs every day,"* one user admitted, highlighting how quickly the routine of a daily pill can become exhausting.

After the initial drop, our retention curve stabilized somewhat, gradually declining between 3 and 6 months. This suggests that those who overcome the early hurdles may find a sustainable routine. However, these low retention rates mean that the majority of those who start PrEP do not persist long enough to benefit from its protective effects fully. This finding shows that translating PrEP's high efficacy into real-world effectiveness requires keeping people engaged on PrEP over time. Our results echo widespread concerns that PrEP persistence is suboptimal globally; thus, programs must focus not only on PrEP initiation but also on supporting continued use.

In many cases, PrEP use may be *"episodic"* or cyclic, that is, some users stop and later restart when they feel at risk again, with nearly half of those who stop PrEP eventually reinitiating it within a year (Shipp et al., 2024). Our qualitative narrative suggested that some participants paused and resumed PrEP based on life circumstances; *"I used my PrEP intermittently depending on my risk. For example when I had my last baby, I had first stopped taking PrEP because I was alone but later when I got a partner and realized that he was having other women at the same time as me, I resumed taking my PrEP"*. This emphasizes the importance of maintaining contact with clients who discontinue, so they can be encouraged to re-engage with PrEP when their risk rebounds**.** Most importantly, strengthening retention, especially in that vulnerable first 3-month window, is critical. Interventions like enhanced early counseling for side effect management, follow-up check-ins or reminders, and support groups or peer navigation during the initial weeks could help new users build adherence habits before pill fatigue or setbacks lead them to give up.

5.2.1.2. Factors associated with drop out from PrEP use (Objective 2)

Age

Age was independently associated with PrEP dropout. Each additional year of age was associated with approximately a 1.6% reduction in the hazard of dropout **(**aHR = 0.98, 95%

CI: 0.98–0.99, p < 0.001**)**, indicating that younger participants were more likely to discontinue PrEP than older participants.

This finding is consistent with that of a systematic review in Sub-Saharan which showed that younger individuals have more difficulty maintaining adherence to PrEP (Mpirirwe et al., 2024). Similarly, a global meta-analysis reported suboptimal adherence in 62.5% of people aged ≤24, compared to 34% of those over 24 (Zhang et al., 2022).

Younger users may face greater challenges with daily pill routines due to lifestyle factors, lower risk perception, or less experience managing medications. Our qualitative data suggest that maturity and life situation play a role in commitment to PrEP. As one participant observed, *"Young girls in school may not take it seriously, but for us who are older and married, we know the risk."* Older individuals, especially those in marriages or with children, often viewed HIV risk with greater seriousness and were more disciplined in prevention efforts.

Another noted that life experience and education helped her persist: *"Because I studied, I can understand why taking PrEP is important, even when others discourage me."* This resonates with the idea that older age and higher health literacy confer a sense of responsibility and risk awareness that can improve adherence and continuation. Conversely, younger people may feel invulnerable or find the daily pill disruptive to their routines. Interventions targeting youth such as youth-friendly clinic services or peer support networks are thus needed to improve PrEP persistence in that demographic.

Education level

Participants with primary education had a 26% lower hazard of dropout than participants with no formal education **(**aHR = 0.74, 95% CI: 0.62–0.89, p = 0.001) suggesting that basic literacy and knowledge enhance one's ability to follow through with PrEP. This likely reflects higher health literacy meaning that educated individuals may better grasp the benefits of PrEP, adhere to instructions, and navigate healthcare systems.

Our results shows this intuitive notion that education appears to facilitate PrEP continuation, possibly by improving comprehension of PrEP's importance and the ability to integrate health advice. As one of our participants put it, her schooling helped her navigate negative opinions: *"I can understand why taking PrEP is important, even when others discourage me."* It's worth noting that in our cohort, tertiary-educated individuals were relatively few (9%) and their retention was not significantly different, however, the trend that some formal education

correlates with better adherence is plausible and aligns with broader public health experience that literacy eases the adoption of health interventions. This suggests that additional counseling support may be needed for those with little or no education, using clear, simplified messaging or visual aids to ensure comprehension of PrEP and adherence strategies.

Distance

Increasing distance from the health facility was independently associated with PrEP dropout. Each additional kilometre was associated with approximately a 0.8% increase in the hazard of dropout **(**aHR = 1.01, 95% CI: 1.00–1.01, p = 0.017). Although the effect per kilometre was small, its cumulative effect may become important for clients living substantially farther from the facility. Greater distance can increase transport costs, travel time and the opportunity costs associated with attending scheduled refill appointments. This finding is consistent with evidence demonstrating that geographical accessibility influences continued engagement with HIV prevention services (Mayer et al., 2019; Mwima et al., 2025). A participant living in a far sub-county candidly explained, *"Sometimes I fail to go [for refills] because the facility is far and transport money is hard to get."* Travel cost and time are significant barriers as unemployed participants in particular struggled with transport, as highlighted in both our data and other studies (Mayer et al., 2019; Mwima et al., 2025).

Our qualitative narratives reinforced that distance matters. several participants said if PrEP were available nearer to their homes they *"would not miss"* doses or appointments so often. In light of this, the non-significance of "urban vs rural" in the adjusted model simply indicates it is not *urbanicity per se*, but physical distance and related infrastructure barriers that affect retention. This suggests that bringing PrEP closer to where people live via community pick-up points, decentralizing to peripheral clinics, or mobile services could substantially improve continuation, especially for rural populations.

Point of entry

Participants enrolled through a facility entry point had approximately 2.55 times the hazard of dropout compared with those enrolled through community entry points (aHR = 2.55, 95% CI: 2.18–2.97, p < 0.001).This finding suggests that community-based initiation may facilitate continued engagement in PrEP care. Community delivery may reduce transport costs, travel time and other barriers associated with facility attendance. It may also increase access among

populations who experience stigma or inconvenience when seeking facility-based services. The finding is consistent with differentiated PrEP delivery approaches that aim to bring prevention services closer to populations who need them (Barnabee et al., 2022; Edwards et al., 2022; Mudzingwa et al., 2024).

This quantitative data contrasts with the qualitative data which shed light that many participants prefer the health facility setting compared to community when it came to obtaining PrEP. They described the facility as a source of trust, privacy, and support. For example, one said, *"What I like most is getting my drugs from the health facility here because people will not easily suspect anything."* At the clinic, the providers offered PrEP in a different clinic from ART thus patients felt confidentiality would be maintained. Others appreciated that clinics offered additional services and professional counseling, *"That day when I came to the hospital, I had doubts but the health workers explained and I started [PrEP],"* one participant recalled, highlighting how facility counselors allayed her fears. In contrast, someone starting in a community setting might get a basic briefing but perhaps not the same depth of counseling or sense of security; they may also lack a routine schedule for follow-up unless actively tracked. It will be important for programs to find a balance between leveraging on community platforms for outreach and initiation, while bolstering them with adequate counseling and follow-up or quickly linking clients to health facilities for ongoing support.

Population Category

Population category was also independently associated with dropout. Priority populations had a 26% higher hazard of dropout compared with key populations (aHR = 1.26, 95% CI: 1.06–1.51, p = 0.010). The greater retention among key populations may reflect stronger perceived HIV risk, greater exposure to targeted HIV-prevention programmes, peer networks, and community-based PrEP delivery. Participants who perceived themselves to be at substantial HIV risk frequently described this risk as a motivation for continued PrEP use. For example, one participant explained*, "I was actively having sexual intercourse with all the 5 partners… so I decided to use PrEP to protect myself."* (IDI 10).

This finding suggests that programmes designed for key populations may contain useful retention mechanisms that could be adapted for other PrEP users. Peer navigation, targeted risk counselling, community outreach, and differentiated service delivery may be particularly valuable for priority populations whose perceived risk or connection to HIV-prevention

programmes may be weaker. However, population category encompasses heterogeneous groups, and the observed association should not be interpreted as indicating that all individuals within either category experience the same barriers or facilitators.

5.2.2. SECTION B: QUALITATIVE FINDINGS

5.2.2.1. Barriers and facilitators to PrEP adherence and retention (objective 3)

We used qualitative indepth interviews to to explore why participants either struggled with or succeeded in maintaining PrEP use, beyond the demographic predictors. The facilitators of PrEP adherence and retention included knowledge and awareness of PrEP, motivation to protect one's self and partner, support and peer engagement, positive healthcare experience and confidence in healthcare providers, adherence strategies, HIV negative test results, acceptability and perceived benefits of PrEP, integration with other services and availability of PrEP at the facility. The barriers to PrEP adherence and retention included stigma, limited PrEP choice, side effect and adverse drug reactions, structural and financial barriers, fear of disclosure, travel, community misconceptions of PrEP, low community knowledge and awareness on PrEP, religious and moral concerns, clinic related barriers, low perceived risk, treatment fatigue and daily pill burden, negative health worker attitudes and forgetfulness.

5.2.2.2. Facilitators of PrEP Adherence and Retention

Individual level Facilitators

Knowledge and awareness of PrEP use

Knowledge and awareness of PrEP were foundational facilitators. Participants consistently reported that understanding how PrEP works and its benefits motivated them to start and stick with it. Many learned about PrEP through health facility sensitizations, community meetings, or friends, and this initial awareness was crucial. One participant shared; *"I first heard about PrEP from healthcare providers in the hospital…they gave us knowledge every OPD day."* With correct information, people could make an informed decision and were empowered to.

In our case, because many participants did receive education up front, it became a positive driver since they saw PrEP as a legitimate prevention method, not a mysterious pill. Awareness was described as giving participants a sense of control and confidence, knowing that *"PrEP*

protects you from HIV if you take it well" was a motivating belief. Essentially, knowledge normalized PrEP for them. This finding reveals that ongoing community education and counseling are critical when people know what PrEP is and isn't, they are more likely to embrace and adhere to it. Some users who oftened served as peer educators, spread awareness to friends and partners. This peer information-sharing can create a virtuous cycle supporting retention. It is worth noting that knowledge alone isn't always sufficient but a necessary first step. As evidenced in other research studies, clients who lack understanding of PrEP's purpose or doubt its efficacy are far more likely to discontinue use (Ntabadde et al., 2025). Therefore, maintaining high levels of knowledge through regular counseling refreshers, support groups, and public sensitization facilitates sustained PrEP use.

Motivation to protect onself and one's partner

Another facilitator was motivation to protect oneself and one's partner. Many participants continued PrEP because they keenly recognized their personal risk of HIV and were determined to remain HIV-negative. This was especially pronounced for those in high-risk situations like sero-different relationships, multiple concurrent partners, or those engaged in transactional sex. One 43-year-old woman explained her situation *"I have a boyfriend who is HIV positive with two wives."* This inherent risk propelled her to stay on PrEP as a safeguard. Another participant recounted, *"I got into a relationship with an HIV-infected person… after finishing PEP, I found that PrEP was the most convenient thing for me."* Here, the fear of infection and realization that PrEP offered reliable protection if adhered to was a major incentive to persist. Other participants also cited risky behaviors or environments such as a young man with multiple girlfriends, including sex workers, or an individual who, due to alcohol use, often had unplanned sexual encounters and they viewed PrEP as a vital shield: *"I'm a drunkard…there are fine girls; when time gets late… she agrees and then… we give ourselves pleasure"* this man took PrEP because he knew those encounters were high risk and he wanted to be safe afterwards. Such testimonies show that high perceived risk can drive high adherence. Indeed, quantitative analyses elsewhere have found that users who perceive themselves at substantial risk are more likely to continue PrEP (Mugwanya et al., 2019; Nkosi et al., 2024). Our participant [serodifferent] echoed this: *"Because my partner refused to use a condom, I saw PrEP as the only way to be safe."*

The desire to protect one's partner also surfacedas a few individuals particularly those with multiple partners felt that by staying HIV-negative themselves via PrEP, they were indirectly

protecting their partners as well; *"I also feel like by me taking PrEP, I can protect my other two girlfriends who are still students."* This sense of responsibility and altruism reinforced their commitment. Some had witnessed HIV in their families and were determined not to go through the same experience, using that as fuel to adhere. Essentially, PrEP gave them agency over their HIV risk, and that agency was highly valued. As one person put it, *"I want to keep healthy and not get HIV because I love myself."* This intrinsic motivation of loving oneself enough to consistently take a preventive medicine is perhaps the most profound facilitator and was clearly present in many narratives therefore programs can tap into a user's own drive to continue PrEP.

Adherence strategies and Routines

Participants developed various adherence strategies and routines, which served as personal facilitators to taking PrEP consistently. Many recognized that incorporating PrEP into a daily habit was key to success, and they devised methods to achieve this. One common strategy was linking pill-taking to a specific time or routine, often bedtime. *"I usually take my PrEP when I am already going to bed around 8:00 pm,"* said one user, noting that doing it at the same time each day made it easier not to forget. Others adjusted their schedules around daily activities or obligations; for example, a participant who was busy in the evenings decided to set an alarm for 9 pm and would *"move with [the pill] to work, and if 9 pm gets me there I take it."* and some kept a dedicated notebook or calendar for their PrEP schedule.

Enlisting family members was another tactic; *"I told my husband, if I have forgotten, please help and remind me,"* and even her child would tell her when it's 8:25 pm that it's pill time. Over time, these strategies helped integrate PrEP into daily life to the point that it became *"like senses in my body – when it is time… I just remember."* This indicates the formation of a habit loop where the body/brain gets accustomed to a routine. Establishing such routines is well-known to aid adherence for daily medications. Behavior change science suggests that tying a new behavior (taking a pill) to an existing cue (an alarm, a mealtime, bedtime,) improves consistency. Our participants' experiences are a practical demonstration of this principle.

HIV Negative Test results

Several participants cited the reassurance of their HIV-negative test results at follow-up visits as a motivator to continue PrEP. This facilitator is somewhat unique to prevention; unlike

treatment, where the reward is improved health or undetectable viral load, for PrEP users the reward is remaining HIV-negative over time. In our study, those who diligently took PrEP and then saw on testing that they stayed negative felt validated. *"Ever since I started taking this drug, whenever I do an HIV test, it turns out negative, this has really motivated me because I can testify that PrEP really works,"* one user said. Knowing the medication was fulfilling its purpose of keeping them HIV-free reinforced their commitment, *"This has made me decide to continue taking PrEP because it is really protecting me."* Essentially, each negative test result served as positive feedback, strengthening the individual's resolve.

This phenomenon has been noted anecdotally in other qualitative research for instance, PrEP users often report reduced anxiety and a sense of relief from knowing they are staying uninfected, which encourages ongoing use (Willie et al., 2021). Programmatically, this suggests that frequent HIV testing as required in PrEP programs can be harnessed as a positive experience, counselors can explicitly congratulate clients on staying negative and link that outcome to their good adherence. Celebrating these milestones could reinforce behavior, much like weight-loss programs celebrate each few pounds lost to keep participants motivated.

Acceptability and perceived benefits of PrEP

Another facilitator was the acceptability and perceived benefits of PrEP after using it for some time. Many participants described how initial fears or rumors about PrEP were dispelled once they personally experienced it. Early on, some were worried about side effects or long-term harm, but those who did not encounter serious issues grew comfortable with PrEP. *"At the beginning, I was worried that using the drug would affect me, but as I continued, I did not get any problems and it was the best option,"* said one woman. Others compared PrEP favorably to condoms or abstinence *"I was comfortable with it more than using condoms,"* one participant noted, highlighting that PrEP did not interfere with the moment of sex or pleasure, thus being a more acceptable prevention strategy for her.

Additionally, participants widely reported psychological benefits from PrEP. They frequently mentioned that PrEP made them feel *"calm," "comfortable," "not worried anymore"* about HIV. One powerful quote was, *"It has changed my life, it has given me hope... I now feel calm and no longer worried of getting HIV because all my hope is on PrEP."* This peace of mind is a significant benefit that users valued, and it became a reason to continue they enjoyed the reduced anxiety and sense of security that came with being on PrEP. This suggests that if users

can be supported to push through early adaptation, they may find PrEP highly acceptable in the long run. The perceived benefits both physical (protection) and mental (stress relief) thus serve as strong facilitators. To leverage this, interventions might encourage new users to talk to long-term adherent users (peer champions) who can attest to these benefits; hearing from a peer could reinforce a new user's commitment to reach that point of comfort.

Interpersonal level facilitators

Social support and peer encouragement

Social support and peer encouragement emerged as one of the facilitators that helped participants overcome challenges. Those who had support from friends, partners, or family were far more likely to continue using PrEP. For some, disclosure and transparency with a partner built trust and enlistment of the partner's help. One married woman described, *"When I told my partner that I am using PrEP, he had a lot of questions, but when I explained to him, he agreed and started supporting me."* Her husband would remind her to take the pill and encourage her to keep at it.

Another participant noted, *"First of all, I told my husband that 'I take my drugs everyday at 8:30pm, incase I have forgotten, please help and remind me'. Secondly, I have set an alarm for 8:30pm on my phone... Then, I have a child of mine... when it clocks 8:25pm, he runs to me and tells me that mummy, its already time to take your drugs."* This kind of active involvement by a partner not only provides practical adherence reminders but also reduces the fear and stigma around taking PrEP since the partner is on board. Family members also played a role one participant said her mother and sisters encouraged her to continue PrEP for her own protection. Peer support was especially prominent participants formed informal networks or buddy systems where *"we remind each other"* about refills and share experiences. *"I encouraged my friend who is also at risk to start using PrEP, and now we remind each other,"* said one young woman, illustrating a peer-driven adherence strategy. In some areas, peer support groups existed where people using PrEP would gather in safe spaces to chat, though these were informally organized.

Simply knowing others who were successfully taking PrEP helped normalize it *"When I see others taking [it] without problem, I also feel strong,"* one person remarked. This finding is in line with broader evidence that social support improves medication adherence. In HIV

treatment literature, support groups and treatment buddies are a proven intervention, similarly for PrEP, having a peer or community that positively reinforces PrEP use can buffer individuals against stigma or forgetfulness (Kiguba et al., 2022; McGowan et al., 2022) . Studies among MSM in the US have shown that peer norms and support can facilitate PrEP persistence (Chamberlin et al., 2023; Dijkstra et al., 2021; Shangani et al., 2017).

In Kenya, focus groups revealed that peer educators and friends could help counteract stigma and misinformation, thereby supporting continued use (Adeagbo et al., 2022). Our findings strongly concur that is PrEP should not be a solitary journey. When individuals received encouragement whether a friend saying "Keep it up, you're doing the right thing" or a sibling reminding them to take a pill they felt accountable and motivated. Conversely, those who hid their PrEP use from everyone had to rely solely on internal motivation, which could be more challenging. The implication is that fostering supportive environments through couples counseling, community support groups, or peer outreach can significantly enhance retention.

Health system/organizational level

Positive experience and confidence in healthcare providers

Another key facilitator identified was having a positive healthcare experience and confidence in healthcare workers. Participants who felt welcomed, respected, and well-counseled by providers reported greater ease in continuing PrEP. Many praised the clinic staff for their friendly and nonjudgmental attitude; *"Healthcare providers warmly welcome me… call me by my name, I feel valued."* Being treated with dignity made clients comfortable returning for follow-ups.

Additionally, thorough adherence counseling and management of concerns by providers built trust. *"The counselor told me how to handle side effects and that helped me continue,"* This kind of ongoing encouragement at each visit reinforced the importance of staying on PrEP and helped users overcome doubts. Feeling "cared for" by the health system gave them a sense of security: *"There is no day that I came here and [was] delayed… I am usually helped immediately,"* said one user, highlighting good customer service.

These testimonials align with research showing that trust in one's provider and a good patient–provider relationship improves adherence (Chipidza et al., 2015). When clients trust that their provider has their best interests at heart and will support them, they are more likely to follow medical advice and stick with treatment. A study among PrEP users in the found that *trust in the provider increased adherence* measured by concordance of self-report and drug levels (Beauchamp et al., 2023). Likewise, providers' ability to communicate respectfully and tailor services to client needs supports adherence, that is a positive clinic environment and supportive healthcare workers act as significant facilitators**.** This suggests that training healthcare providers in PrEP counseling, emphasizing empathy and confidentiality, and ensuring adequate time for client questions is vital. Health services that are youth-friendly, stigma-free, and client-centered effectively become an adherence intervention in themselves.

Integration of PrEP with other health services

Integration of PrEP delivery with other health services facilitated retention by making PrEP collection convenient and relatively stigma-free. Participants appreciated when PrEP was offered as part of a package of services, rather than requiring a separate trip. For example, at the clients could get their PrEP refills alongside routine HIV testing, STI check-ups, or family planning services. One participant noted, *"They first test you for HIV, they screen you for STI before being given the drugs…"* indicating a comprehensive approach each visit. Another participant mentioned receiving other prevention tools concomitantly *"They also offered condoms, lubricant and emergency pill for me to give to my girls after sex."* This suggests that PrEP was embedded in a context of broader prevention, which may reinforce its use. Participants explicitly said this one-stop-shop aspect was convenient as they could address multiple needs together. From a health systems perspective, combining services can reduce the number of visits, stigma, travel burden the exact reason for the visit. Previous studies supported the value of such integration and concluded that it is cost-effective due to leveraging existing staff and infrastructure (Anand et al., 2023; Butler et al., 2023; Wagner et al., 2023)

Structural level facilitators

Availability of PrEP

Logistical factors like availability of PrEP at the facility (reliable supply) and free access were noted facilitators. Participants were relieved that *"there is no time I came and the drugs were*

out of stock" and that in this government program *"we do not pay, no one asks for money."* Although these seem basic, they are crucial conditions for retention. Any stock-out could force a break in adherence and potentially lead to dropout, and any user fees could deter clients from returning. The participants' appreciation of this highlights that removing financial and supply barriers is a fundamental facilitator thus ensuring uninterrupted medication supply and providing PrEP at no or minimal cost.

5.2.2.3. Barriers to PrEP Adherence and Retention

Here we consider the barriers that impeded some participants from adhering to PrEP or led others to discontinue. Many of these barriers are essentially the inverse of the facilitators while others are structural or individual challenges that need to be addressed to improve retention.

Individual level barriers

Limited choices of PrEP

Another barrier noted was the limited choice of PrEP methods during the study. At the time, oral PrEP was essentially the most widely available method with a few accessing the PrEP vaginal ring and injectable PrEP through the MOSAIC -CATALYST implementation science project offering PrEP choice. Some participants expressed a strong preference for other forms and became frustrated that they could not access them. One participant flatly said, *"I stopped using PrEP due to absence of injectable PrEP… we were told [it] would not be available due to funding challenges."* This indicates that she might have continued if the injectable had been offered, but since it wasn't, she discontinued oral PrEP. Similarly, a few participants tried the Dapivirine vaginal ring and one of them found it highly acceptable, stating *"Even that PrEP ring, I never felt any pain or something disturbing me. I was comfortable with it."*. The lack of a method that fits one's lifestyle or preference is a known barrier in the sense that one size does not fit all.

Some people struggle with daily pills but might do well with a bi-monthly injection; others might prefer a topical method like a ring if they don't want systemic medication. The importance of user preference is acknowledged in the HIV prevention field, which is why new modalities are being introduced. One participant said, *"Oral is so hectic because you can easily forget, especially when you're high,"* implying that a method not requiring daily remembrance

like an injection would be better for him. The implications are significant as additional PrEP options become more widely available, we may retain more people by matching them to their preferred method. From a program standpoint, this barrier suggests advocating for and rolling out these options. In the meantime, where only oral PrEP is available, it's crucial to set as managing those expectations and perhaps offering interim adherence support could prevent folks from giving up entirely while waiting for new methods. Overall, expanding PrEP choice is likely to be a game-changer for retention as individuals can switch to a method that suits them rather than quitting prevention altogether.

Side effects and adverse drug reactions

Side effects and adverse drug reactions proved to be a considerable barrier, especially early in PrEP use. Many participants recounted unpleasant side effects after starting PrEP, which in some cases persisted for weeks or months. These included gastrointestinal issues (nausea, vomiting, diarrhea, feeling abnormally full), headaches, dizziness, increased appetite, and skin problems (itchiness, rashes). For some, the side effects were transient and manageable; for others, they seriously disrupted daily life. One participant described a combination of effects: *"When I had just started taking PrEP, even if I had eaten very small amount of food, I used to feel too full… I also used to get a lot of nausea… a very strong headache."* She noted those particular side effects eventually went away after about 11 months which is a very long adjustment period to endure.

However, she then experienced a new issue, *"after those side effects disappeared is when I started getting body itchiness and rashes all over."* Extensive investigations were done to rule out other causes, but it appeared to be a PrEP-related reaction. Another participant had *"diarrhea for about 2 days… and headache and increased appetite"* initially. These kinds of side effects are documented with oral PrEP (TDF/FTC), particularly in the first few weeks often termed the "start-up syndrome." (Glidden et al., 2016). Trials have shown mild gastrointestinal side effects in a subset of users, usually resolving in a month or so. However**,** for some individuals, side effects can be severe or persist, leading them to discontinue. One participant's story was stark: *"My experience with PrEP was not very good because at first I used to get dizzy making me feel weak. I therefore made up my mind to stop using it because I can't stay the whole day with feelings of wanting to vomit, and worse, the vomit refuses to come."* This person's daily quality of life was so affected that she abandoned PrEP, a clear-cut case of side effects undermining retention.

Also, a global meta-analysis noted real-world discontinuations often mention real or perceived side effects as a cause (Zhang et al., 2022). Managing this barrier requires a two-pronged approach that is anticipatory guidance and mitigation. Anticipatory guidance means counseling new users about possible side effects so if they occur, users aren't alarmed and know they are usually temporary. Mitigation means giving tips to cope and possibly medical management. Our data showed some participants did receive which helped them continue but others might not have had sufficient support or patience to weather the side effects. Additionally, as newer PrEP drugs become available, some of these issues might be alleviated for future users. Nonetheless, for oral PrEP programs, side effects remain a significant barrier and a reason some otherwise willing individuals drop out.

Low perceived HIV risk

Low perceived HIV risk at certain times led some participants to lower their guard and become non-adherent or to discontinue PrEP. This is somewhat paradoxical, as high perceived risk was a facilitator; however, risk perception can fluctuate. Several interviewees described periods where they thought they were "safe" such as when they did not have a current sexual partner or were in a lull in their sexual activity and thus didn't feel a need to continue daily PrEP. One said, *"Also currently, I do not have a serious sexual partner… so I do not feel at risk of getting HIV."* Such individuals might stop taking PrEP during those times. Another admitted, *"Sometimes you think you are safe and [you] reduce taking it."* This highlights an interesting pattern of *seasonal or intermittent use* of PrEP depending on one's risk perception. While in theory, adjusting PrEP use to actual periods of risk is rational (why take it if truly abstinent?), the concern is that risk perception can be imperfect and risk can rapidly change. One participant noted that some peers who *"refused [PrEP] because they did not believe in the benefits… ended up contracting HIV"* an example of underestimating risk. Moreover, even those on PrEP may prematurely judge they are no longer at risk when they still might be for example trusting a new partner without knowing their status).

Other similar studies also cited low perceived risk as a reason for stopping PrEP (Agaku et al., 2022; Agwang et al., 2023; Shipp et al., 2024) . This barrier is tricky because some degree of risk assessment should guide PrEP use, it's not intended to be lifelong if someone's risk truly drops to zero. The problem is premature discontinuation or oscillation that may leave gaps in protection. In our study, one participant even said, *"I don't take PrEP consistently because I go with [the] program,"* suggesting he starts and stops according to own sense of need. The

implication is that *we need better counseling around understanding HIV risk and making informed choices about when to continue or pause PrEP*. Rather than blanket telling everyone to stay on it indefinitely, providers could employ decision counseling such that if someone genuinely enters a low-risk phase, maybe a planned pause could be okay but ensuring they restart promptly when risk returns but that requires trust and accurate self-assessment.

On the other hand, if someone's risk fluctuates unpredictably, they might be better staying on PrEP continuously. Educating users on how to evaluate their situations and emphasizing that risk is often not fully known for example a partner's fidelity or status might not be as assumed is important. This barrier intersects with the need for possibly more flexible dosing strategies like event-driven PrEP for those with infrequent exposures, though that currently is recommended only for Men. The key is to avoid "inappropriate" discontinuations that is stopping while still at considerable risk. Strengthening risk perception without inducing excessive fear is a delicate balance.

Treatment fatigue and pill burden

Treatment fatigue and the burden of daily pill-taking were commonly cited barriers, even among those who tried their best to adhere. We discussed on pill fatigue earlier as something that facilitators like routines attempted to overcome, but it is clear that many participants found the daily regimen psychologically tiring over time. One noted, *"You know, things that need swallowing every day make one tired when it becomes a routine."* Another expressed that *"I do not feel comfortable with taking drugs [daily], but I just take it like that,"* implying that even though he was continuing, it was burdensome. *"Not so many problems only that it is difficult to take drugs everyday... I just take this drug for protection against HIV although I do not feel comfortable with taking drugs, but I just take it like that."*This sense of fatigue can lead to intentional breaks: *"One can easily start to think, 'I have been taking these drugs every day, let me first rest for 2-3 days then continue,'"* as one participant described.

Of course, "resting" from PrEP undermines its efficacy, but to the person, it feels like a relief from a relentless routine. In a few cases, the pill itself (size, taste) was a minor issue someone mentioned the pill was "too big" and that initially made them consider stopping because swallowing a large pill daily was uncomfortable. Pill fatigue is a well-known phenomenon in chronic therapy and it's well documented in ART and in PrEP trials (Holtz et al., 2019). Our

findings resonate with the global meta-analysis which found that about 17% of discontinuations were due to pill burden (Zhang et al., 2022)**.**

Even among those who acknowledge PrEP's benefits, the grind of daily adherence can wear them down. This is a major reason why long-acting PrEP options are eagerly anticipated to alleviate the burden of daily dosing. On-demand PrEP and long acting injectable provides an option for people who don't want daily medication although event driven PrEP is only recommended for men leaving women without options. Programs should advocate for availability of other options like Dapavirine Ring and Long Acting injectable PrEP in all healthcare settings but until those are available, we must find ways to support users through pill fatigue such as adherence clubs or peer groups where people encourage each other, or digital reminders/apps that make adherence more engaging. Rotating the messaging in counseling to keep it fresh might also help to avoid it becoming a droning reminder.

Forgetfulness

Finally, a simple but significant barrier was forgetfulness, especially before routines were established. Several participants admitted there were times you can forget. One participant said; *"Let me tell you oral is so hectic because you can easily forget"*. Another stated that *"There were times I could forget... or when I travel and take longer, I end up missing my drugs".* Forgetting once in a while might not immediately cause discontinuation, but it can reduce effectiveness and, if frequent, can discourage the person. For those who hadn't built an adherence habit or lacked external reminders, forgetfulness was a major hurdle. This barrier is quite generic but important; it shows why many of the facilitators focus on combating forgetfulness.

Interpersonal level barriers

Fear of disclosure

Fear of disclosure and resultant relationship conflict were significant barriers for many, particularly women in relationships. Several female participants chose not to tell their husbands or boyfriends about PrEP. They feared that disclosure would be misinterpreted as infidelity or lack of trust. *"He did not know,"* one woman said flatly, stating she kept it secret. Another confided, *"I was afraid that if my husband ever realized I was using the PrEP ring, he would*

think I am cheating on him." Even without violence, women anticipated relationship strife, accusations, or being compelled to stop PrEP if their partner found out.

Some resorted to deception or partial truth: one participant mentioned her husband actually thought her PrEP pills were ART (antiretrovirals) that *he* was taking [husband- HIV positive] and left him to assume she too was on ART for HIV. Disclosure difficulties are widely reported in PrEP studies among women (Beesham et al., 2022; Shipp et al., 2024). Addressing this barrier is tricky. It involves couples counseling or engaging partners in understanding PrEP's benefits. In some serodiscordant couples, PrEP has been successfully used with both partners' knowledge, but in more casual or mistrustful relationships, disclosure may be dangerous (Baeten, Heffron, et al., 2016; Cabral et al., 2018; Thomas et al., 2024). For those who truly cannot disclose safely, providers might help strategize on adherence without disclosure like using discreet packaging, timing doses when partner isn't around. But ultimately, the fear of disclosure will remain a retention barrier as long as societal norms and gender power imbalances persist. Building broader acceptance is a long-term goal that goes hand in hand with destigmatizing PrEP.

Community level barriers

Stigma related to PrEP use

The most pervasive barrier that emerged was stigma both experienced and feared. Despite educational efforts, PrEP-related stigma in the community was high and had a direct negative impact on retention. Participants recounted that people around them often misunderstood PrEP and consequently stigmatized those who used it. A common issue was PrEP being mistaken for HIV treatment (ART**)**. Because the PrEP pills and bottles resemble antiretrovirals, community members would assume anyone taking daily pills is HIV-positive. *"People in the community think that those who swallow pills every day are HIV positive,"* one participant lamented. Others reported being called "a prostitute" or accused of promiscuity for using PrEP. One young woman said, *"They will start saying that I am not trusted... they can easily say I am a prostitute."* This echoes findings from previous studies where, where researchers identified product stigma and behavior stigma as major barriers for young women, the fear of being seen with pills or having to explain why one is taking a preventive drug for HIV can be debilitating (Admassu et al., 2024; Atukunda et al., 2022).

Being labeled as HIV-positive or promiscuous not only affects one's social standing but can lead to serious consequences like relationship conflict or even violence. Another participant mentioned friends talking behind her back, which caused her distress**.** Stigma breeds silence and dropout as clients may not take pills openly or regularly, skip doses to avoid being seen, or stop attending clinics for refills thus addressing stigma is paramount. It requires community education to correct misconceptions by making it clear PrEP is for HIV-negative people to stay negative, and is not an indicator of one's behavior or status, social marketing could help reframe PrEP as a responsible, even empowering choice rather than something shameful and finally engaging key influencers to speak positively about PrEP can slowly chip away at stigma.

Community misconceptions and low awareness on PrEP

Community misconceptions and low awareness on PrEP were identified as barriers closely related to stigma. Our participants reported hearing an array of myths and false beliefs about PrEP circulating in the community. These misconceptions included claims that PrEP is actually a government ploy to secretly spread HIV or control the population, *"They say PrEP is ART for HIV treatment... some say it is a form of family planning the government is using to regulate the population".* Another participant recounted community members;

"Many people say that PrEP is ART, that's the first thing that comes to their mind..others say that the drug has already HIV virus which has been killed but for those taking, it one day the virus will wake up in their bodies and they will realize it much later that they have been infected… so they really do not understand and that's what they say….then on PrEP Ring, when it just came, people talked a lot of things. some said it causes cancer, some said it causes infertility or will damage the cervix, but anyone who had interest in it and was counselled by the provider, they actually used it well without any problems. Then when the injectable PrEP was brought, some people in the community kept on saying that we are being injected with the active virus which was kept in the fridge directly in our bodies, that atleast the one we used to swallow had a dead virus, so with time these virus will infect us and that we shall actually become HIV positive." Such rumors are extreme but were taken seriously by some, deterring them from using PrEP or making them quit out of fear.

Another participant recalled community members saying, *"PrEP only covers up the virus, making it difficult to detect even when you already have the virus… then one day the virus will finally be detected and you will no longer respond to treatment."* This is scientifically false but was a narrative out there essentially warning that PrEP could turn you into an asymptomatic

carrier whose HIV will become untreatable. These misconceptions likely stem from low general knowledge and a mistrust of new health interventions. Regardless of origin, misinformation directly undermines PrEP uptake and retention.

If someone hears that the ring might cause infertility, they may remove it prematurely. If they believe taking PrEP will actually give them HIV later, they will understandably be afraid to take it. Our data show that participants who *had not used PrEP* were especially prone to believing these misconceptions, but even users were not immune to their influence if they weren't well counseled. This barrier highlights a crucial need for community-wide education campaigns.

If only PrEP users are informed but the broader community isn't, the environment remains hostile and filled with falsehoods, which can eventually sway even the users. Our participants repeatedly pointed out that people "do not understand [PrEP] very well and have not used it," hence their wild speculations. So, increasing community understanding through media, community leaders, testimonials from satisfied PrEP users would reduce this barrier. Until that happens at scale, misconceptions will continue to scare off potential and current PrEP users. This barrier is a subset of stigma, but specifically about misinformation. It reminds us that providing accurate information beyond just the individual level creating a supportive, well-informed community is necessary for sustained retention.

Religious and Moral Concerns

In certain cases, religious or moral beliefs in the community acted as barriers. A few participants noted that some religious leaders or community figures discouraged PrEP use on moral grounds, claiming that *"it sounds like promoting immorality."* The notion here is that providing an HIV prevention pill might encourage premarital or extramarital sex, similar to how some oppose contraception. If a participant is part of a faith community that holds this view, they may feel guilty or face pressure not to use PrEP.

This barrier is somewhat related to stigma, but originates from moralistic judgment rather than misinformation. It was not the most frequently cited issue, but it did emerge and is consistent with known challenges in some settings, where moral opposition frames PrEP as enabling "bad behavior." In Kenya, qualitative study revealed that some health providers themselves had moral reservations (Camlin et al., 2022). Overcoming this requires engagement with those moral gatekeepers and educating religious leaders about the public health benefits of PrEP and

perhaps likening it to other health tools that protect the community. Without that, a person deeply involved in a conservative community might quit PrEP to align with those norms.

Health system/organizational level barriers

Clinic related barriers

Clinic-related barriers pertaining to health system issues also deterred some participants. We discussed how a positive clinic experience is a facilitator; conversely, any shortcomings in service delivery became barriers. Participants mentioned issues like long waiting times, partly due to staffing shortages. If a client comes and waits hours to be seen, they may be less inclined to return regularly. If they perceive the clinic as disorganized or overburdened, they might lose confidence. One participant pointed out that sometimes a single provider was multitasking, so either clients waited long or got rushed counseling which could be frustrating for someone who made the trip.

Another clinic-related barrier was rotation of trained staff. Participants noticed that when a new provider replaced the familiar one, the new person often had only basic PrEP knowledge and was not as well-versed in the nuances or the clients' experiences. *"When they bring a new provider, we the clients can easily turn to be their mentors on PrEP because they can only be knowing the basic knowledge without the knowledge of our experiences and other details unlike the older or previous healthcare provider so those providers take time to learn and they are forced to sit down and read more about PrEP".* This could temporarily reduce the quality of support, and clients might not get answers to specific questions or concerns, possibly impacting their satisfaction and adherence.

Drug stock management was another clinic barrier as mentioned, occasional low stock led to giving shorter refills for 1 month rather than the usual 3 months. This effectively increased the frequency of clinic visits needed, which is a barrier especially for those with transport or time constraints. While fortunately outright stock-outs (running out completely) did not occur as per participants, even these adjustments created inconvenience.

Lastly, fear of being seen at the PrEP clinic by others in the waiting area was a subtle barrier for some. One said she prefers the facility because *"people will not easily suspect anything"* implying some lingering worry about being identified. If a clinic lacks privacy or a client encounters someone they know, it could discourage attendance thus, continuous quality

improvement at service delivery points is needed: adequate staffing, training, logistic support, and creating a welcoming atmosphere all directly feed into retention.

Negative attitude of healthcare providers

In a few instances, participants encountered negative attitudes or communication from healthcare workers, which became a barrier. While most praised the staff, one participant's experience was different: *"The healthcare provider was very tough and did not know how to speak to her clients well."* A harsh or scolding tone can alienate clients. If a provider responded to a missed dose with anger, or was judgmental about the client's lifestyle, the client might avoid follow-up to escape that negativity.

This is the contrast of the facilitator we discussed ealier as it shows that not all staff interactions were perfect and that even one poor interaction can jeopardize retention. If that participant felt disrespected or uncomfortable, she might not come back. Research has shown that providers who demonstrate respect and empathy foster better adherence whereas those who moralize or dismiss patient concerns push patients away (Camlin et al., 2022; Geldsetzer et al., 2022; Keuroghlian et al., 2021; Nagai et al., 2023). In the PrEP context, some providers may harbor biases and inadvertently convey disapproval. Addressing this barrier means continuous training and supervision to ensure all providers maintain a client-centered, nonjudgmental approach. Mystery client surveys or patient feedback could help identify any problematic behaviors to be corrected.

Structural level barriers

Structural and financial barriers

Various structural and financial barriers hampered consistent PrEP use, echoing the theme of access discussed earlier. A primary issue was the cost and availability of transportation to the health facility. Many participants live in low-resource settings where transport fares can be burdensome, or they rely on bicycles/foot travel. As one explained, *"Sometimes I get thoughts that 'now I don't even have transport means to go to the health facility,' but I still struggle."* If her bicycle broke down, she had to pay for a motorcycle taxi (boda boda), which was not always affordable. During rainy seasons, travel became even harder and some missed

appointments. These accounts mirror a widespread barrier in healthcare related distance and travel cost. Another structural barrier was time and competing livelihood needs, some participants, especially those running businesses or doing daily wage work, found it hard to carve out time to go to the clinic. One mentioned, *"getting the time to move from the business point to come to the hospital is very hard."* If clinic hours overlap with work hours, people might choose income over a refill visit, leading to interruptions.

Structural barriers extend to clinic factors as well, participants observed that sometimes only one provider was handling all PrEP clients, causing long wait times or rushed service. *"When people are many it becomes hard for them and they also forget to provide other services or reschedule you,"* a participant noted. At times, staff turnover meant new providers weren't well-versed in PrEP, which could diminish the quality of counseling until they caught up. Additionally, a few participants noted that on occasion the clinic rationed PrEP that is gave 1 month supply instead of 3, if stock was low, meaning the client had to return sooner, effectively increasing their transport burden.

All these structural issues erode adherence by making it inconvenient or impossible to maintain consistent refills. The literature on retention in HIV prevention and treatment consistently points to such barriers: inconvenient clinic hours, long waits, and travel costs are major causes of drop-out (Admassu et al., 2024; Beesham et al., 2022; Mpirirwe et al., 2024). To address these, programs might implement differentiated service delivery, such as multi-month dispensing, outreach refill points, extended clinic hours or fast-track refills for working clients, and transport vouchers or mobile clinics for remote communities. Without tackling these structural issues, even the most motivated clients might default simply due to life's logistics.

Travel

Participants who had to travel away from home whether for work, family visits, or other reasons often found this disrupted their PrEP use. Travel is related to structural barriers but deserves mention because it was explicitly cited. For instance, one participant shared *"There was a time I traveled somewhere far away... I ended up staying 2 additional days on top of the 4 days [of pills I had carried] and I had left my medicine home... so I missed my drugs for 2 days."* This scenario highlight how being away from one's routine environment can lead to missed doses or even running out of pills. Travel can also make adherence physically awkward as one

participant used to carry drugs to church but felt uncomfortable taking them there. This barrier indicates that mobility and migration pose challenges to continuous PrEP coverage.

If someone is highly mobile, they may not be able to attend the same clinic or adhere to daily dosing on the road. The current HMIS tool for PrEP does not track PrEP refills from other care points thus providers can not acertain whether these clients are refilled or not especially for those who decide to obtain refills from other points of care. Solutions might include providing larger pill quantities for those who expect to travel, informing them of nearest clinics or pharmacies in other areas where they could get a refill, or using technology such as phone reminders even when away, telemedicine check-ins. There is also need to improve on the current HMIS tools to be able to track refills from other points of care ,

5.3. Study Limitations and Mitigation Strategies

This retrospective cohort study relied heavily on routine health records, which were sometimes incomplete, particularly regarding reasons for dropout and income status. Poor documentation and limitations in the Health Management Information System (HMIS) tools contributed to these gaps.To address this limitation, we employed a mixed-methods approach, supplementing quantitative data with in-depth qualitative interviews. These narratives provided valuable context for understanding why participants discontinued Pre-Exposure Prophylaxis (PrEP), thereby strengthening the interpretation of associations observed in the quantitative analysis.

Inconsistencies between paper-based and electronic data tools posed a risk of bias and reduced data reliability. To mitigate this, we utilized standardized data abstraction tools derived from the Ministry of Health's PrEP program HMIS tools, complete with clear operational definitions. Duplicate reviews of a subset of records yielded over 97% inter-rater agreement. Discrepancies were resolved through consensus, cross-referencing multiple data sources, and engaging trained research assistants familiar with both electronic and paper-based data tools.

Data on retention (PrEP refills) at 12 months was not available due to the seizing of funds from USAID, a major funder for the PrEP program in Uganda. This funding disruption led to changes in reporting tools and updates, resulting in incomplete data. Consequently, we conducted a 6-month survival analysis

Data heterogeneity, resulting from varying recording practices among providers, was addressed through triangulation. We compared qualitative themes with quantitative patterns to identify consistency,thereby validating the results.

The study population was heterogeneous, reflecting differences in the characteristics of PrEP users at Kitgum General Hospital. Multivariable Cox regression was used to adjust for measured differences between participants when assessing factors associated with dropout.

The study was conducted at a single health facility, Kitgum General Hospital, using systematic sampling, which may limit the generalizability of the findings to other settings with different populations and PrEP service-delivery models. However, the large sample of 1,102 PrEP users and the use of both quantitative and qualitative methods strengthened the study by providing a comprehensive understanding of PrEP retention and dropout within the study setting.

Some clients classified as having dropped out may have transferred to another facility, temporarily discontinued PrEP because of reduced HIV risk, or later restarted PrEP without this being captured in the available records. Therefore, dropout may not necessarily represent permanent discontinuation. This was addressed by clearly defining dropout and interpreting the findings cautiously, particularly in view of the episodic nature of PrEP use

The qualitative component was susceptible to recall and social desirability bias because participants were required to describe their previous experiences with PrEP and healthcare services. This was minimized through confidential individual interviews, use of open-ended questions and probes, and assurance that participants' responses would not affect the services they received.

5.4. RECOMMENDATIONS

The Ministry of Health should prioritize the integration of PrEP services into all healthcare levels and mandate reporting at all health facilities. This will help ensure that PrEP is accessible and consistently provided across the country. Additionally, the Ministry should improve existing Health Management Information Systems (HMIS) to enhance monitoring and evaluation, and ensure a reliable supply chain for PrEP medications.

Strengthen retention support for younger PrEP users. Kitgum General Hospital and the District Health Office should provide youth-friendly PrEP services, including peer support, adherence counselling, appointment reminders, and flexible refill arrangements

Decentralize PrEP services closer to clients. Given the association between increasing distance and dropout, PrEP refills should be expanded through community outreach points, lower-level health facilities, mobile clinics, and other differentiated service-delivery approaches to reduce transport costs and travel time.

Strengthen community-based PrEP delivery while maintaining linkage to facility care. Since community entry was associated with substantially lower odds of dropout, community-based PrEP initiation and refill services should be strengthened. Clients initiated in the community should have clear referral and follow-up mechanisms for clinical assessment, counselling, management of side effects, and other facility-based services.

Provide intensified education and counselling for clients with limited formal education. Healthcare providers should use simple language, visual aids, repeated counselling, and teach-back approaches to improve understanding of PrEP benefits, adherence, side effects, and follow-up requirements, particularly among clients with no formal education.

Strengthen follow-up after PrEP initiation through outreach while incorporating active linkage to longitudinal PrEP care through appointment scheduling, telephone/SMS reminders, peer navigation, and follow-up of missed appointments.

Integrate PrEP with the broader sexual and reproductive health services; strengthening comprehensive counselling that addresses GBV, disclosure, relationships, HIV risk, and available support services alongside routine PrEP care.

Address the barriers identified by PrEP users. Healthcare providers should strengthen early counselling and management of side effects, maintain confidentiality, address PrEP-related stigma and misconceptions through community sensitization, and provide flexible refill options for mobile clients.

Strengthen routine monitoring of PrEP retention and dropout. Kitgum General Hospital should routinely track clients who miss scheduled PrEP visits, identify groups with high dropout,

document reasons for discontinuation, and facilitate easy re-entry for clients who wish to restart PrEP when their HIV risk changes.

Conduct further research on PrEP dropout. Prospective studies should examine whether interventions such as community refills, peer navigation, youth-friendly services, and integrated GBV/SRH services improve PrEP retention.

5.5. CONCLUSION

This study revealed critical gaps in Pre-Exposure Prophylaxis (PrEP) retention and adherence, with significant drop-offs over time especially the first three months after initiation. Disparities among different client sub-groups were also evident. Key findings highlighted that younger individuals, uneducated persons, non-users of family planning, those enrolled from facility were more likely to discontinue PrEP use.

The qualitative findings showed that PrEP adherence and retention are influenced by interacting individual, interpersonal, community, health-system, and structural factors. While knowledge of PrEP, perceived HIV risk, partner and peer support, supportive healthcare providers, counselling, and accessible services facilitated continued use, side effects, stigma and misconceptions, fear of disclosure, transport and financial constraints, travel, and health-system challenges hindered continued engagement in PrEP care.

Addressing PrEP dropout therefore requires differentiated and client-centred service delivery that brings PrEP closer to clients, strengthens support for younger users, improves follow-up after initiation, and integrates PrEP other sexual and reproductive health services. Strengthening provider counselling, community engagement, and mechanisms for re-engaging clients who discontinue PrEP will contribute to improved retention and maximize the effectiveness of PrEP in preventing new HIV infections among populations at risk.

Putting the above recommendations into action will help stakeholders achieve better results from PrEP programs and make progress toward the ultimate goal of preventing HIV; protecting those at risk and reducing new infections in the community.

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APPENDIX 1: INFORMED CONSENT FORM

INFORMED CONSENT DOCUMENT (QUALITATIVE, version 2.0)

Title of the study: HIV Pre-Exposure Prophylaxis Adherence and Retention among Users at Kitgum General Hospital

Investigator(s): Akanyo Joyce

Institution(s): Gulu University, Faculty of Health Science, Department of Public Health

Introduction:

You are invited to participate in a research study on HIV Pre-Exposure Prophylaxis (PrEP) adherence and retention among users at Kitgum General Hospital led by Akanyo Joyce (Principal Investigator). This informed consent explains the study to you. After the study has been explained, any questions you may have will be answered. When you decide to participate in the study, you will be asked to sign a consent form, which you will be given a copy to keep. This study is being sponsored by the Principal Investigator.

Purpose:

The study seeks to determine retention rates, factors associated with dropout from PrEP use and barriers and facilitators to PrEP adherence and retention among users at Kitgum General Hospital. Specifically, in objective three of the study, we aim to explore the experiences and insights through in-depth interviews with individuals who are currently using, have intermittently used PrEP or have discontinued using PrEP for HIV prevention to aid in understanding the factors that help individuals at substantial risk for HIV to continue with PrEP and those that make it challenging to continue using PrEP.

Procedures

If you agree to participate in this study, you will be asked to do an in-depth interview. The interview will last approximately 30 to 60 minutes. It will cover topics such as your personal experience with PrEP, any challenges you have faced while using PrEP, factors that help or motivate you to continue using PrEP, support you receive from family, peers, or healthcare providers, and your views on how PrEP services can be improved. The interview will be audio-

recorded to ensure accuracy in capturing your views. You may request that the recording be stopped at any time and choose not to answer specific questions if you are uncomfortable.

Tape/Audio Recording

During the interview, your voice will be recorded with a digital voice recorder for accuracy during translation, and transcription for coding and theme analysis. Voice recordings will be stored on a password protected computer. You will be offered to receive a copy of the audio-recording. Your voice recording will not be shared among anyone outside of study team and will not be used for any other activity besides this study. All audio recordings will be destroyed after 3 years.

Who will participate in the study?

You have been chosen to participate in this study because you are currently using PrEP, have intermittently used PrEP or have discontinued using PrEP. This in-depth interview will last approximately 30-60 minutes, and 20-30 participants are anticipated to participate in this study.

Risks/discomforts

There is no foreseeable risk of harm or discomfort that will arise from your participation in this study. However, the time spent during the interview will be inconvenient. Additionally, some questions may address sensitive topics, such as your personal experiences with PrEP, sexual health, or stigma. If you feel uncomfortable answering questions, you can choose not to respond. You may also stop the interview at any point without any consequences. If you experience emotional discomfort during the interview, we will offer you referral services to counselling or support as necessary.

Benefits

Participating in this study will contribute valuable insights that will enhance our understanding of PrEP adherence and retention challenges and facilitators in this community. While there may be no direct benefit to you, your input can help improve PrEP services, making them more accessible and user-friendly for individuals seeking to prevent HIV. The findings from this study may inform strategies to strengthen adherence support, reduce barriers, and improve overall service delivery. Additionally, you will receive feedback on the study's findings and

progress, ensuring transparency and engagement throughout the research process. Any new information that may affect you or other participants, including incidental findings, will be communicated promptly to ensure their well-being and informed decision-making regarding PrEP use.

Confidentiality

Your identity will not be revealed to anyone; we shall only use codes to identify participants. Information obtained will only be accessible to the research team. Soft copies of the data will be protected by password, and hard copy files will be kept under lock and key. Confidential information will only be accessed by the principal investigator.

Alternatives

You do not have to participate in this study if you are uninterested. You will not lose any benefit if you do not participate.

Cost

There will not be any additional costs incurred from participating in this study. However, you will be provided with ugx.5,000 as time compensation.

Questions

If you have any questions related to the study as a research participant, you can contact the principal investigator, Akanyo Joyce, by telephone at 0772008380/0752999602 or via email at akanyojoyce@gmail.com

Statement of voluntariness

Participation in the research study is voluntary, and you may join at your own free will. You have a right to withdraw from the study without penalty.

If you have any issues about your rights and participation in the study, please get in touch with the Chairperson, Gulu University Research Ethics Committee, Dr Julaina A. Obika Tel: No., 0772964491; email: j.obika@gu.ac.ug; or the Uganda National Council for Science and Technology, on plot 6 Kimera road, Ntinda, Kampala on Tel 0414705500.

Statement of consent

..... has described to me what is going to be done, the risks, the benefits involved and my rights as a participant in this study. I understand that my decision to participate in this study will not affect me in any way. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Statement of Consent to be Audiotaped

I understand that audio recordings will be taken during the study. *(For the statement below, please choose YES or NO and* ***insert your name and initials*** *in the relevant space)*

- I agree to be audio recorded **Yes** ☐
  No ☐

- I agree to be photographed **Yes** ☐
  No ☐

Name of Participant (please print)	Signature/thumbprint	Date
Name of witness (please print)	Signature/thumbprint	Date

Name of researcher Obtaining Consent	Signature	Date

KARATAC ME NONGO YEYO/TWERO (QUALITATIVE, version 2.0)

Kweda Ikum: Tic maber ki yat me konyo gengo nongo kwidi two jonyo (PrEP) ki mede ki tic kede bene ikin jo madong gitye katic ki yat man in ot yat madit me Kitgum. (HIV Pre-Exposure Prophylaxis Adherence and Retention among Users at Kitgum General Hospital)

Lakwed madit (Lukweda): Akanyo Joyce

Gang Kwan: Gulu University, Faculty of Health Science, Department of Public Health

Wiyewiye madongo:

Watye kalegi me bedo tye I kweda ikum tic maber ki yat me konyo gengo nongo kwidi two jonyo (PrEP) ki mede ki tic kede bene ikin jo madong gitye katic ki yat man in ot yat madit me Kitgum (Kitgum General Hospital) ma Akanyo Joyce aye tye katelo ne (Lakweda madit). Karatac me nongo yeyo man tito boti ngec matut ikum kweda man. Inge nongo ngec ikum kweda man, lapeny moo keken ma itye kweda wabigamone. Kace imoko tami me bedo ikeda man, wabilegi ni iket cingi I karatac man, ma kibi miini mukene me agwokka. Kweda man lakweda madit aye tye ka culo pire.

Tyen lok me timo Kweda man:

Kweda man tye pi nongo ngec ikum dano adii magitye ka mede ki tic ki yat PrEP, tyen lok ma omiiyo dano juku tic ki yat PrEP, ki bene peki onyo lok ma oweko dano mede ki tic ki yat ki maber ikin jo magitye katic ki yat PrEP man I ot yat madit kany (Kitgum General Hospital). Tutwale, I dul me kweda me adek, watye ka miito nongo ngec matut ikum neno ki kit ma inongo tic ki yat PrEP man oteri kede ki I lapeny matut ma wabipenyo kede jo magitye katic ki yat PrEP ikumkareni, dano magin obedo ka kalo kin tic ki yat PrEP mamegi onyo jo madongo ogikko tic ki yat man me konyo gengo nongo kwidi two jonyo ni. Man bikonyo miiyo ngec matut ikum jami ma twero konyo dano ma kakare kere itgin me nongo kwidi two jonyo me mede ki tic ki yat PrEP maber, peki ma jo man nongo magengo gin ka mede ki tic ki yat PrEP

Lok mamite me aluba pi kweda man:

Kace in iye me bedo ikweda man, wabilegi me bedo pi lapeny matut ma wabipenyi. Lapeny man romo rii pi wang cawa maromo dakika pyera adek mioo kede I pyera abicel (30-60 minutes). Lapeny man obibedo ikum ngec onyo neno ni ikum PrEP, peki ma inongo katic ki PrEP, tyen lok ma oweko itye ka mede ki tic ki PrEP, cwak onyo jingo cwiny ma in inongo ki bot jo ma I paco mamegi, luremi, onyo daktari, ki tam mamegi ikum yoo ma gitwero tic kede me medo malo rwom me kony magimiiyo me PrEP. Wabimako dwani ikare me lapeny man me nenoni wagwokko maber tam mamegi kit ma in imiyo kede. Itwero jukuwa pe me mede ki mako dwani cawa moo keken ki bene kwero gamo lapeny moo keken ma pe itye agonya me gamo nee.

Mako dwan

Ikare me lapeny man, dwani kibi mako ne ki lamak dwan pi miiyo ngec me atir ikare me tic ki ngec man. Dwani ma kimakoni kibi gwokkone I computa me dano mukene petwero tic kwede. Dwani man pe kibi miiyone ki ngat moo keken ma pe I kweda man ki bene pe kibi tic kede pi gin moo mapat ki kweda man. Dwani man makimakoni kibi kwanyo ne I inge mwaka adek.

Nga ma obibedo I kweda man?

Wan wayeri me bedo I kweda man pieni itye katic ki PrEP kumkareni, ibedo ka kalo kin tic ki yat PrEP mamegi onyo ijuku dong tic ki yat PrEP. Lapeny man obitero cawa maromo dakika pyera adak mioo ikine dakika pyera abicel. Wabyeko ni dano maromo pyera aryo mioo I pyera adek bibedo pi lapeny man

Ayela/peko matwero bino

Wapee ka byeko kit peko onyo ayela moo keken matwero bino pi bedo ni ikeda man. Peko onyo ayela ma twero bino aye balo cawani I kare me lapeny man. Wabipenyi bene lapeny mogo ikumi macalo kit ma ibedo katic kede ki yat PrEP, lok kum kwoo ni me butu, onyo cimmo tok. Ka pe itye agonya me gamo lapeny moo keken, pe bene itwero gamo ne. Itwero juku gamo lapeny I cawa moo keken labongo ayela moo keken. Ka pe itye ka winyo agonya onyo cwinyi otuu matek ikare ma lapeny man, mabicwali ka nongo kony me nywako tam kit ma mite kede.

Ber pa bedo ikweda man

Kibedo I kweda man, ibikonyo miiyo ngec onyo nenoni matwero konyo wan niang peki ki jami mukene maweko dano makare kare itgi me nongo kwidi two jonyo twero mede ki tic ki yat konyo gengo nongo kwidi two jonyo maber I kabedo man. Kono do magoba moo ma atiir atiir pe ibinongo ne, ngec ma ibimiiyone obikonyo I medo malo rwom me kony me PrEP weko obed maber pi jo mamiito kony man. Ngec man bikonyo dano mede ki tic ki PrEP, dwoko piny peki mapatpat ma medo malo rwom me kony me PrEP. Wabimede ki kube kede ikare me kweda man ki bene wabiyaro kamaleng ngec moo keken ma wabinongone I kweda man. Ngec moo keken manyen mamako kum in or dano mukene matye ikweda man macalo ngec mukene maonongo pe wabyeko, wabi miiyi ingeyo cutcut pi yot kumi onyo konyo moko tami maber me tic ki yat PrEP.

Gwoko Mung

Lok onyo ngec moo keken matwero nyutu nga ma in ibedo pe gibi yarone kamaleng. Wabitic ki numa macegocego me konyo ngeyo in. Lok komi moo keken matye I computa onyo wiyamo wabigwokkone ki numa ma wan keken aye wangeyo ki bene lok komi moo keken matye I karatac wabigwokkone kama watwero pungo ne ki kopulu. Pi lok komi mukene ma pire tek, wabiweko ladit me kweda man keken aye bigwokkone.

Yoo Mukene

Me miite ni ibed ikweda man kace cwinyi pe miito. Yero pe me bedo ikweda man pe ki acara moo keken matwero bino ikumi.

Lok kum Cente (Cost)

Cente moo keken mapat ma ibinongone pi bedo I kweda man peke, kono do wabimiini cente elfu abic pi cwalo cawani.

Lapeny

Kace itye ki lapeny moo keken malupe ki kweda man onyo bedo ni ikweda man, itwero kube ki lakweda madit, Akanyo Joyce I numa 0772008380/0752999602 onyo itwero cwalo email I akanyojoyce@gmail.com

Lok ma nyutu bedo agonyani ikweda man

Bedo ikweda man tye imiitini ki bene itye agonya me donyo iye labongo dic. Itye ki twero me aaoo ki iye cawa moo keken labongo pwod moo keken.

Ka itye ki lok moo keken ikum twero ni ki bedo ikweda man, itwero kube ki won kom maloyo kweda I Gulu University (Gulu University Research Ethics Committee), Dr. Julaina A. Obika Tel: No., 0772964491; email: j.obika@gu.ac.ug ; onyo Uganda National Council for Science and Technology, I plot 6 Kimera road, Ntinda, Kampala on Tel 0414705500.

Lok ma nyutu yeyo ni pi bedo ikweda man

..... otito ita ngo ma obitime , ayela, magoba matye, ki twero na macalo ngat ma oyee bedo tye ikweda man. Aniang maber ni tama me bedo tye ikweda man pe ki kit peko moo onyo acara moo keken ikuma. Itic ki ngec man, ngec moo keken ma twero nyutu nga ma an abedo kibi kanoneo. Atye ki ngec ni atwero aaoo ki kweda man cawa moo keken. Atye ki ngec ni keto cinga I karatac man, pe kwanyo twero na moo keken ento nyutu aniang maber lok kum kweda man ma aye bedo iyeni. Karatac mukene ma aketo cinga iye, kibi miiyone

Lok ma nyutu yeyo ni pi mako dwani

Aniang maber ni dwana kibi mako ne pi kweda man. (Pi lok ma piny eni, yer eyoo onyo kuu kidong I ket nyingi ki nukta me acaki nyingi ducu I kama mitte)

- Ayee ni ki mak dwana **Yes** ☐
  No ☐

- Ayee ni ki mak cal mamega **Yes** ☐
  No ☐

_____ _____ _____

Nyinga (please print) Signature/thumbprint Nino Dwe

Nying lacaden (please print)	Signature/thumbprint	Nino Dwe
Nying lamii karatac man	Signature	Nino Dwe

APPENDIX 2: DATA ABSTRACTION GUIDE FOR THE QUANTITATIVE; (version 2.0)

Section A: Socio-demographic information

Start date on PrEP:

1. Age:

2. Sex: □ Male □ Female

3. Client category: □National □Refugee □Foriegner

4. Client location: □ Urban □ Peri-urban □ Rural

5. Entry point: □ Facility □ Community

6. If facility, entry point name: □ Outpatient □ Youth Friendly Corner □ Antenatal □ STI clinic □ TB clinic □ Young Child Clinic □ Maternity □ Nutrition Unit □ Post Natal Unit □ Family Planning □ Others, specify……

7. If Community, name: □ Outreach □ Homebased □ Workplace □ Hotspot □ Drop-In-Center □ Others, specify

Section B: Eligibility assessment information

8. Population Category:

□ Fisher Folk □ Uniformed force □ Persons in Prison and other closed setting □Migrant workers □ Discordant Couple □ Adolescent girls and Young Women □ Non-injecting drug users □Injecting drug users □ Pregnant woman □ Breastfeeding woman □ Long distance truck drivers □ Boda-Boda □ others, Specify……

9. Baseline HIV test: □ Negative □ Positive

10. Creatinine Clearance: □ Normal □ Abnormal

11. Hepatitis B: □ Negative □ Positive

12. Sexually transmitted disease (STI): □ No signs and symptoms □ Urethral Discharge □ Abnormal Vaginal Discharge □ Lower Abdominal Pain □ Genital Ulcer □Others, Specify…….

13. Sexually transmitted disease (STI) treatment offered: □Yes □ No

14. PrEP option: □ Daily oral □ Event Driven Oral □ Ring □ Injectable □ Others, Specify……

Section C: PrEP adherence and retention

Follow-Up Visit 1

15. Date of appointment:

16. Date of Visit:

17. PrEP option: □Daily oral □Event Driven Oral □Ring □ Injectable □Others, Specify……

18. Side Effects: □ Urinary Tract Infection □ Discomfort in the vagina □ Changes in vaginal wetness or odour □ Increased vulva itching □ Injection site reaction □ Headache □ Diarrhea □ Tiredness □Generalised body weakness □ Vomiting □ Fractures

19. Adverse Drug Reactions: □ None □ Present

20. Adherence:

A] Daily Oral PrEP: □ < 2 pills □ 2-4 pills □ > 5 pills

B] Event-driven oral PrEP: □ 4 or more pills per event □ Below 4 pills per event

C] Ring: □ In situ for 28 days □ Not in situ

D] Injectable: □ 7 days before or after the previous injection □ Greater than 7 days after the previous injection

21. HIV restest Results: : □ Negative □ Positive

22. Sexually Transmitted Disease: □ No signs and symptoms □ Urethral Discharge □ Abnormal Vaginal Discharge □ Lower Abdominal Pain □ Genital Ulcer □Others, Specify…….

23. STI treatment offered: □ Yes □ No

24. STI treatment side effects: □ None □ Present

25. If female, Pregnancy status: □ Pregnant □ Not Pregnant

26. Breastfeeding status: □ Breastfeeding □ Not Breastfeeding

27. Family planning status: □ Using family planning □ Not using family planning

28. If using family planning, which method: □ Condoms □ Oral contraceptives □ Injectables □ Implants □Diaphragm □ Intrauterine device □ Fertility awareness method □ Vasectomy/tubal ligation □Not applicable □ None

29. Tuberculosis (TB) status: □ No signs □ Presumptive TB □ Diagnosed with TB disease □Currently on treatment □ Completed TB treatment

30. Gender Based Violence (GBV) screening: □ No signs □ Emotional or psychological harm □Physical harm □ Inappropriate touch □ Sexual violence

31. If any, post GBV services: □ Psychosocial support □ PEP Clinical care □ Legal Support □Others, specify…..

32. Client status on PrEP: □ Active □ Reinitiated □ Stopped □ Lost □ Transferred out □Died

33. Reason for stopping: □ No longer at risk □Seroconverted □ Side effects □ Stock out □ Not willing to continue

Follow-Up Visit 2

34. Date of appointment:

35. Date of Visit:

36. PrEP option: □Daily oral □Event Driven Oral □Ring □ Injectable □Others, Specify……

37. Side Effects: □ Urinary Tract Infection □ Discomfort in the vagina □ Changes in vaginal wetness or odour □ Increased vulva itching □ Injection site reaction □ Headache □ Diarrhea □ Tiredness □Generalised body weakness □ Vomiting □ Fractures

38. Adverse Drug Reactions: □ None □ Present

39. Adherence:

A] Daily Oral PrEP: □ < 2 pills □ 2-4 pills □ > 5 pills

B] Event-driven oral PrEP: □ 4 or more pills per event □ Below 4 pills per event

C] Ring: □ In situ for 28 days □ Not in situ

D] Injectable: □ 7 days before or after the previous injection □ Greater than 7 days after the previous injection

40. HIV restest Results: : □ Negative □ Positive

41. Sexually Transmitted Disease: □ No signs and symptoms □ Urethral Discharge □ Abnormal Vaginal Discharge □ Lower Abdominal Pain □ Genital Ulcer □Others, Specify…….

42. STI treatment offered: □ Yes □ No

43. STI treatment side effects: □ None □ Present

44. If female, Pregnancy status: □ Pregnant □ Not Pregnant

45. Breastfeeding status: □ Breastfeeding □ Not Breastfeeding

46. Family planning status: □ Using family planning □ Not using family planning

47. If using family planning, which method: □ Condoms □ Oral contraceptives □ Injectables □ Implants □Diaphragm □ Intrauterine device □ Fertility awareness method □ Vasectomy/tubal ligation □Not applicable □ None

48. Tuberculosis (TB) status: □ No signs □ Presumptive TB □ Diagnosed with TB disease □Currently on treatment □ Completed TB treatment

49. Gender Based Violence (GBV) screening: □ No signs □ Emotional or psychological harm □Physical harm □ Inappropriate touch □ Sexual violence

50. If any, post GBV services: □ Psychosocial support □ PEP Clinical care □ Legal Support □Others, specify…..

51. Client status on PrEP: □ Active □ Reinitiated □ Stopped □ Lost □ Transferred out □Died

52. Reason for stopping: □ No longer at risk □Seroconverted □ Side effects □ Stock out □ Not willing to continue

Follow-Up Visit 3

53. Date of appointment:

54. Date of Visit:

55. PrEP option: □Daily oral □Event Driven Oral □Ring □ Injectable □Others, Specify……

56. Side Effects: □ Urinary Tract Infection □ Discomfort in the vagina □ Changes in vaginal wetness or odour □ Increased vulva itching □ Injection site reaction □ Headache □ Diarrhea □ Tiredness □Generalised body weakness □ Vomiting □ Fractures

57. Adverse Drug Reactions: □ None □ Present

58. Adherence:

A] Daily Oral PrEP: □ < 2 pills □ 2-4 pills □ > 5 pills

B] Event-driven oral PrEP: □ 4 or more pills per event □ Below 4 pills per event

C] Ring: □ In situ for 28 days □ Not in situ

D] Injectable: □ 7 days before or after the previous injection □ Greater than 7 days after the previous injection

59. HIV restest Results: : □ Negative □ Positive

60. Sexually Transmitted Disease: □ No signs and symptoms □ Urethral Discharge □ Abnormal Vaginal Discharge □ Lower Abdominal Pain □ Genital Ulcer □Others, Specify…….

61. STI treatment offered: □ Yes □ No

62. STI treatment side effects: □ None □ Present

63. If female, Pregnancy status: □ Pregnant □ Not Pregnant

64. Breastfeeding status: □ Breastfeeding □ Not Breastfeeding

65. Family planning status: □ Using family planning □ Not using family planning

66. If using family planning, which method: □ Condoms □ Oral contraceptives □ Injectables □ Implants □Diaphragm □ Intrauterine device □ Fertility awareness method □ Vasectomy/tubal ligation □Not applicable □ None

67. Tuberculosis (TB) status: □ No signs □ Presumptive TB □ Diagnosed with TB disease □Currently on treatment □ Completed TB treatment

68. Gender Based Violence (GBV) screening: □ No signs □ Emotional or psychological harm □Physical harm □ Inappropriate touch □ Sexual violence

69. If any, post GBV services: □ Psychosocial support □ PEP Clinical care □ Legal Support □Others, specify…..

70. Client status on PrEP: □ Active □ Reinitiated □ Stopped □ Lost □ Transferred out □Died

71. Reason for stopping: □ No longer at risk □Seroconverted □ Side effects □ Stock out □ Not willing to continue

APPENDIX 3: INTERVIEW GUIDE FOR THE QUALITATIVE STUDY ON BARRIERS AND FACILITATORS TO PREP ADHERENCE AND RETENTION (Version 2.0)

Introduction

Hello, my name is (Interviewer's Name), and I am working on a study that seeks to understand the experiences of individuals using PrEP for HIV prevention. Thank you for agreeing to participate in this interview. Your input will help us improve PrEP services and support users like yourself better.

This interview aims to learn about your experiences with PrEP, including any challenges you have faced and what has helped you continue using it. The interview will take 30 to 60 minutes, and everything you share will be confidential. Feel free to skip any questions that make you uncomfortable, and you are welcome to stop the interview at any time.

As a reminder, participation is voluntary; you can withdraw anytime. Is it okay to begin?

Section A: General Background on PrEP Use

1. **Can you tell me a little about yourself and how you first learned about PrEP?**

Probe: Who introduced you to PrEP? (A healthcare provider, friend, peer, community health worker, etc.)

Probe: What was your initial reaction to the idea of using PrEP?

2. **Why did you decide to start using PrEP?**

Probe: Did you feel at risk for HIV at the time? If so, what made you feel this way?

Probe: Were there any specific events or circumstances that influenced your decision?

Section B: PrEP Adherence and Challenges

3. **Can you describe what it has been like for you to take PrEP regularly?**

Probe: How do you incorporate taking PrEP into your daily routine?

Probe: Have you faced any difficulties in taking PrEP as prescribed?

4. **Have you ever missed taking your PrEP doses? If yes, what caused you to miss doses?**

Probe: Was it due to forgetfulness, side effects, or external factors?

Probe: How often do you miss doses, if at all?

5. **What are the main challenges you have faced while using PrEP?**

Probe: Are there any physical challenges, such as side effects?

Probe: Have there been logistical challenges, like transportation to the clinic or drug availability?

Probe: Have you faced stigma from your community, family, or friends because you are on PrEP?

Section C: Support Systems and Facilitators of PrEP Adherence and Retention

6. **What has helped you continue taking PrEP despite any challenges you may have faced?**

Probe: Have you received support from family, friends, or your partner?

Probe: Have healthcare providers played a role in supporting your adherence and Retention?

7. **How has your relationship with healthcare providers affected your PrEP use?**

Probe: Do you feel your healthcare providers offer enough support and information?

Probe: What could they do differently to help you stay adherent?

8. **Have you participated in any community or peer-led support programs for PrEP users?**

Probe: If yes, what was your experience like? How did these programs help you?

Probe: If not, would you be interested in such support groups or peer programs?

9. **Do you know others who are using PrEP?**

Probe: How do you support or motivate each other?

Probe: Have you ever shared your experiences with other PrEP users?

Section D: Perceptions and Impact of Stigma

10. **Have you experienced any stigma because of your use of PrEP?**

Probe: How has this stigma affected your willingness to continue using PrEP?

Probe: Are there particular individuals or groups from whom you experience stigma?

11. **How do you handle or overcome stigma related to PrEP use?**

Probe: Do you have support from your family, friends, or community that helps you deal with stigma?

Probe: What could help reduce stigma related to PrEP use in your community?

Section E: Experiences with Healthcare Services

12. **How would you describe your experience with healthcare services related to PrEP?**

Probe: How easy or difficult is accessing PrEP medication from the clinic?

Probe: Are there any issues with waiting times, medication stockouts, or poor treatment from healthcare workers?

13. **Have you ever faced any barriers when trying to refill your PrEP prescription?**

Probe: Have there been times when the clinic was out of PrEP medication?

Probe: Do transportation costs or distance affect your ability to get PrEP refills?

14. **Do you feel healthcare workers understand and address your needs as a PrEP user?**

Probe: Are there any areas where you think the healthcare system could improve to support PrEP users like yourself better?

Section F: Impact of PrEP on Daily Life and Relationships

15. **How has using PrEP affected your daily life?**

Probe: Has PrEP made you feel safer or more confident in your relationships?

Probe: Have you experienced any changes in your social or sexual relationships since starting PrEP?

16. **How has PrEP affected your views on HIV prevention and your health?**

Probe: Do you feel more in control of your health since starting PrEP?

Probe: Has PrEP changed your thoughts on HIV risk or prevention?

Section G: Recommendations for Improvement

17. **What would make it easier for you to continue using PrEP?**

Probe: Are there any changes that could be made at the clinic or in your community to improve your PrEP experience?

18. **What advice would you give someone just starting PrEP or considering it?**

Probe: What should they expect, and what tips would you give them for staying consistent with PrEP use?

19. **Is there anything else you want to share about your experiences with PrEP that we have not covered?**

Closing Remarks

Thank you so much for your time and for sharing your experiences. Your insights are precious and will help us understand how to support PrEP users better. If you have any questions or concerns later on, feel free to contact us.

Please remember that everything you have shared will remain confidential and be used to improve PrEP services in the community.

INTERVIEW GUIDE FOR THE QUALITATIVE STUDY ON BARRIERS AND FACILITATORS TO PREP ADHERENCE AND RETENTION IN ACHOLI (version 2.0)

Introduction

Apwoyo ba, an nyinga (Nying lamii lapeny), atye ka tic I kweda me konyo niang neno onyo ngec pa dano ma gitye ka tic ki yat PrEP me gengo nongo kwidi two jonyo. Apwoyi matek me yee bedo pi lapeny man. Ngec mameginii obikonyo wa ka yubu kit me miyo kony me PrEP ki medo malo rwom me kony me wa miyo ki jo magitiyo ki yat PrEP macalo in.

Lapeny man tye me miiniwa ngec ki dong neno I ikum kit ma tic ki yat PrEP tye ka teri kede, mao tye iye peko ma in inongo ki ginango ma tye ka konyi ka me mede ki tic ki yat PrEP mamegi. Lapeny man obitero dakika maromo pyera adek mioo I pyera abicel (dakika 30-60), ki lok weng mawabinywako kedinii weng wabigwokone I mung. Timber I bed agonya me kwero gamo lapeny moo keken ma in ongongo pe orwate onyo pe itye agonya me gamone, ki bene itwero juko lapeny man cawa moo keken. Atye ka poyowii ni, bedo nii I lapeny man tye I miti ni, itwero aa cawa moo keken. Watwero yapone?

Section A: General Background on PrEP Use

1. **Tit it an/nywak kweda manok kit ma in ingeyo kede lok kum yat PrEP?**

Probe: Nga ma omiini ngec ikum yat PrEP? (Dakta, laremi, ngat ma tye ka tic ki yat PrEP, lumii ngec ikin gang ikum PrEP)

Probe: Ngo ma in itimo cutcut ma in iwinyo lok man me tic ki yat PrEP ni?

2. **Ngo ma oweko in imoko tami me tic ki yat PrEP?**

Probe: Ingongo calo kakare kere it in me nongo kwidi two jonyo I kare enoni? Kace obedo kameno, ngo ma oweko ibedo kanongo ni kakare kere it in?

Probe: Tika obedo gin moo mutime onyo kare moo me iwok ki iye ma okonyi ka moko tami?

Section B: PrEP Adherence and Challenges

3. **Nywak kweda kong kit ma inongo mwonyo yat PrEP jwii tye ka teri kwede?**

Probe: In imwonyo yat mamegi nining ikin tic majwii in itimogini?

Probe: Inongo ayela moo keken I kit me mwonyo yat PrEP mamegi kit ma dakta ocoyo kede?

4. **Tye nino moo ma in ikeng mwonyo yat PrEP mamegi? Kace otimme, ngo maoweko ikeng?**

Probe: Ikeng piyeni wii owilawila, kece inongo ayela moo onyo adwogi marac me tic ki yat PrEP onyo obedo gin moo mapat?

Probe: Tyen adii ma in ikeng yat, kace otimme?

5. **Peki mene ma in itye ka nongone pi tic ki yat PrEP?**

Probe: Itye ka nongo peko onyo adwogi moo marac pi tic ki yat PrEP?

Probe: Tika inongo peki mogo macalo peko me gin wot, onyo pee pa yat in ot yat?

Probe: Tika inongo peko mogo macalo cimo tok ki bot dano ma in kin gang, dano me pacowu, onyo luremi pieni itye ka tic ki yat PrEP?

Section C: Support Systems and Facilitators of PrEP Adherence

6. **Ngo matye kakonyo in me mede ka tic ki yat PrEP ikin peki maitye ka nenone ni weng?**

Probe: Inongo kony onyo cuku cwiny ki bot jo ma gang, luremi, onyo lapalcwinyi?

Probe: Tika lutic me ot yat okonyi ka mede ki tic ki yat PrEP?

7. **Tika wat ni ki daktari ma gimiyo kony me yat PrEP oloko kit me tic ki yat PrEP mamegi?**

Probe: Inongo calo dakta/lutic me ot yat kitye ma miini kony onyo ngec muromo?

Probe: Tye gin moo ma in itamoni gitwero timone mapat me konyi mede ki tic ki yat PrEP?

8. **Tika I bedo I yup/kacoke moo keken me PrEP I kin gang onyo ma daktari kin gang oyubbu pi jo matiyo ki yat PrEP?**

Probe: Kace otimme, yub meno obedo nining? Yub meno okonyi nining?

Probe: Kace pe otimme, tika itye ki miti me bedo I lakodi yub magi?

9. **Tika ingeyo jo mukene magitye ka tic ki yat PrEP?**

Probe: Ka ingeyo, wutye kakonye I kinwu onyo cuku cwinywu ikinwu kekenwu nining?

Probe: Tika I nywako kedgi neno ni ikum PrEP?

Section D: Perceptions and Impact of Stigma

10. Tika inongo peko moo me cimmo tok pi tic ki yat PrEP?s

Probe: Cimmo tok man loko miiti ni me mede ki tic ki yat PrEP nining?

Probe: Tika tye ngat moo or dul moo ma gubedo ka cimmo toki?

11. In itero lok me cimmo tok malupe ki tic ki nyat PrEP nining?

Probe: Itye ki cwak ki bot jo me I paco mamegi, luremi, onyo dano ma I ikin gang ma gi konyo in I peko me cimo tok?

Probe: Itamo ni yoo mene ma gitwero tic kede me juku onyo dwoko cimmo tok malupe ki tic ki yat PrEP in paci ma in iaa ki iye?

Section E: Experiences with Healthcare Services

12. 1In iwaco ni ngo ikum kit ma ibedo kanongo kede kony me PrEP?

Probe: Tika obedo yot onyo tek it in me nongo kony me yat PrEP ki I ot yat kany?

Probe: Tika inongo peko macalo irii pi cawa mapol I ot yat, peke pa yat, onyo dakta oteri/oloko kedi marac.

13. 1Tika ibedo ki peko moo keken ma itye ka teme me bino ka gamo yat PrEP mamegi?

Probe: Calo gwok kare ma yat PrEP peke?

Probe: Peko me wel giwot onyo boo pa piny odwoko keroni piny me bino ka gamo yat PrEP?

14. Itamoni lutic me ot yat/daktari giniang dok bene gicobo mitini macalo ngat ma tye ka tic ki yat PrEP?

Probe: Itamo ni tye kamogo I kit me miyo kony magitwero yubune me medo malo rwom me kony ma ki miyo ki dano magitiyo ki PrEP macalo ini?

Section F: Impact of PrEP on Daily Life and Relationships

15. Tic ki yat PrEP oloko kwoni majwii nining?

Probe: Tika tic ki yat PrEP okwanyo lworo onyo oweko itye ki tek cwiny in winye mamegi ki lapalcwinyi onyo won ot mamegi?

Probe: Tika inongo alokaloka moo keken in kit me kwoo ni majwii ikin gang onyo ikit ma ibedo kede ki lapal cwinyi oyabbe ikare me icako tic ki yat PrEP naka tin?

16. **Tika tic ki yat PrEP oloko neno ni ikum gengo nongo kwidi two jonyo onyo yot kum mamegi?**

Probe: Tika inongo calo itye ki kwero me gwoko yot kumi kekeni oyabe I kare ma in I cako tic ki yat PrEP naka tin?

Probe: Tika tic ki yat PrEP oloko nenoni I kum kero me nongo kwidi two jonyo onyo gengo nongo kwidi two jonyo?

Section G: Recommendations for Improvement

17. **Ngo ma obiweko bedo yot ki in me mede ki tic ki yat PrEP?**

Probe: Tye alokaloka ma in itamo ni ki romo timone i ot yat kany onyo I kin gang me konyi nongo kony marwate malupe ki PrEP?

18. **Tam ango maitwero miyo kin gat moo keken matye ki mitti onyo tye ka yabbu tic ki yat PrEP?**

Probe: Ngo maomyera gin gungee, tam maitwero miinigin me mede ka tic ki yat PrEP?

19. **Tye gin moo mapat ma imito nywako ki wan malupe ki ngeci onyo neno ni ikum yat PrEP mapee waloko iye?**

Closing Remarks

Apwoyo matek pi cawani me imiiniwa ki dong ngeci onyo tami ma in I nywako ki wan. Ngec ki tami man ber tutwal and pire tek botwa me konyo medo malo rwom me kony ma gimiiyo ki dano ma gitye ka tic ki yat PrEP. Ka itye ki lapeny onyo lok moo keken I kare ma lacen, bed agonya me kube kedwa.

Wii opoo ni lok moo keken ma wanywako tini, wabigwokone imung ki dong kibitic kede me medo rwom kony me PrEP in kin paciwa.

APPENDIX 4: COMMUNITY ENGAGEMENT PLAN

Study Title: HIV Pre-Exposure Prophylaxis (PrEP) Adherence and Retention Among Users at Kitgum General Hospital

Principle Investigator: Akanyo Joyce

Supervised by Dr Awor Silvia and Dr Laker Florence

Rationale of the study

Despite global and national efforts to promote PrEP as an effective HIV prevention strategy, adherence and retention remain low, particularly in resource-limited settings like Kitgum District. The study seeked to determine the retention rate, identify factors associated with PrEP discontinuation, and explored barriers and facilitators to adherence and retention. Community engagement is critical to addressing misconceptions, ensuring stakeholder participation, and fostering a supportive environment for PrEP users.

General objective and specific objectives to be achieved

General objective: To determine the retention rate, the factors associated with dropout from PrEP use and the barriers and facilitators to adherence and retention among PrEP users at Kitgum General Hospital

Specific objectives:

1. To measure the retention rates among PrEP users at Kitgum General Hospital (Quantitative)
2. To explore the factors associated with dropout from PrEP use among users at Kitgum General Hospital (Quantitative)
3. To explore the barriers and facilitators to PrEP adherence and retention among PrEP users at Kitgum General Hospital (Qualitative)

The objectives of the community engagement were to;

1. To sensitize the community and the stakeholders about the nature of the research and obtain real-time feedback.

2. Provide clarity on the respective roles and responsibilities of the stakeholders involved in the study before, during and after the study.
3. Address key ethical concerns of the research. These included the benefits of the study to the affected community so that the community appreciates the value of the research, the consenting processes before the research and the rights of the participants.
4. To strengthen community buy-in, enhance PrEP awareness, and address stigma-related barriers.

The key community stakeholders to be involved

The following stakeholders were engaged throughout the study period:

Stakeholder	**Role**
Participants (PrEP users)	To share experience and provide insights on barriers and facilitators to adherence and retention
Local government officials (LCs and District Health Officers)	To facilitate mobilization, administrative clearance and governance support
Healthcare facility administrators	To provide administrative clearances and support the engagement of healthcare providers
Healthcare providers at Kitgum General Hospital	To assist in recruitment, sensitization of PrEP users, PrEP adherence counselling
PrEP Peers (Community Extension Workers)	To support community mobilization and health education on PrEP
Religious and cultural leaders	To address PrEP-related stigma and promote acceptance
Civil society organizations (CSOs) and other implementing working in HIV prevention	To strengthen advocacy and awareness campaigns

We maintained constant engagement of stakeholders throughout the duration of the research,

The research team responsible for managing community engagement activities

Research Team	**Technical abilities**	**Tasks/lead roles**

Principal Investigator	Research coordination, community health, expertise in HIV prevention, including PrEP	Lead the research team, oversee community engagement, and ensure ethical compliance.
Research Assistants	Data collection, stakeholder engagement	Conduct field visits, facilitate community meetings, and record feedback.
Community Extension Workers (PrEP Peers)	Community mobilization, health education	Sensitize communities on PrEP use and retention.
District Health Officer Representative	Public health policy, HIV prevention	Liaise with local authorities and coordinate healthcare provider training.

Approaches, activities and mode of implementation

The approach to community engagement involved formative consultations, existing community structures and community events as follows;

Formative Consultations: We were conducted formative consultations to gain a comprehensive understanding of the study area's geographical landscape, socio-cultural dynamics, power structures, and community perceptions regarding PrEP use. This involved field visits to Kitgum General Hospital and surrounding communities to assess local healthcare access, livelihood patterns, and potential barriers to PrEP adherence and retention. Additionally, we engaged with district health offices to understand governance structures and visit health facilities to gather demographic data on the populations relevant to this study.

Community Stakeholders' Partnerships: Gaining community entry required effective engagement of the community structure and stakeholders as follows;

S/N	Stakeholders	Roles/Involvement
1	Local government (LC 1, DHO)	Supported mobilization, provide approvals, and integrate study findings into local health programs.
2	Kitgum General Hospital staff	Assisted in participant recruitment, PrEP adherence counselling
3	Community Extension workers (PrEP Peers)	Conducted outreach and health education on PrEP benefits and adherence.
4	CSOs and HIV advocacy groups	Provided technical support and community engagement materials.
5	Religious and cultural leaders	Addressed stigma and promote PrEP uptake within communities.

Community engagement activities included meetings, workshops, seminars, and outreach programs, will be conducted to raise awareness about the study and gather real-time feedback from stakeholders. The research team, in collaboration with healthcare providers and district health officials, facilitated these discussions to ensure active participation from the community. Key topics included community concerns regarding PrEP adherence and retention, challenges faced by PrEP users, and potential solutions to improve service delivery. Participants shared their experiences, ask questions, and provide insights to enhance the study's relevance and impact.

Communication strategy for the engagement

Communication between the research team and the stakeholders were conducted throughout the study.

Before conducting consultative meetings, we contacted local leaders, including the LC 1, Community extension workers (PrEP peers), and the District Health Officer and requested meetings and schedule appointments. This was done through phone calls or official letters. During these meetings, we introduced the study, discuss its objectives, and document key insights through note-taking and audio recordings for later review. The feedback obtained was used to refine and enhance the research process.

For workshops and seminars, we notified the LC 1, PrEP Peers, and DHO in advance, requesting their support in mobilizing participants. Workshops were held in centrally located

venues to ensure accessibility, and discussions were conducted in a language familiar to the participants. All sessions were documented to capture valuable insights that can inform and improve the study implementation. We maintained open communication with stakeholders through WhatsApp groups, phone calls, and periodic in-person meetings.

As part of the engagement process, we disseminated study findings by producing and distributing informational leaflets, policy briefs and PowerPoint presentations during workshops. These materials summarized key results, highlight challenges encountered, outline mitigation strategies, and provide recommendations for improving PrEP adherence and retention in the community.

Plan on mitigation of risks and conflicts

Low participant engagement: given that multiple studies may have been conducted in the area, there was a possibility of research fatigue, leading to participant apathy. Low engagement was also due to the fear of wasting time because of the long time taken during the in-depth interviews. To address this, the research team collaborated with local leaders and the PrEP peers to raise awareness about the study's relevance, emphasizing its potential benefits in improving PrEP use, including PrEP adherence and retention, and its relevance to community health.

Misperceptions about the study: some community members and stakeholders misunderstood the study's purpose, potentially leading to skepticism or resistance. To mitigate this, we leveraged testimonials of PrEP users and conducted targeted sensitization sessions, providing clear and accurate information about the study's goals and expected outcomes. Engaging trusted and influential local figures, such as the PrEP peers and other community leaders, also helped foster acceptance.

Confidentiality concerns and stigma: participants feared being identified as PrEP users, leading to reluctance to participate. The research team emphasized strict confidentiality measures, including anonymous data collection and private interview settings, to ensure participant trust and willingness to engage.

Evaluation plan

Evaluation of community engagement was conducted at different stages of the research to ensure effectiveness and continuous improvement. Data was collected through field notes, meeting minutes, stakeholder discussions, and direct observations during community interactions. All feedback were carefully analyzed and integrated to strengthen the research process and enhance community participation.

1. Pre-study evaluation: assessed baseline community knowledge, attitudes toward PrEP use, and stakeholder PrEParedness for the study.
2. Ongoing evaluation: monitored stakeholder and community engagement activities, track participation levels, and document feedback to identify areas for improvement.
3. Post-study evaluation: analyzed stakeholder meeting reports, engagement documentation, and participant feedback to assess the overall impact of the community engagement efforts and inform future interventions

APPENDIX 5: MEASURES FOR THE PREVENTION AND CONTROL OF RISK OF SPREAD OF COVID-19 DURING THE IMPLEMENTATION OF RESEARCH

Study Title: HIV Pre-Exposure Prophylaxis (PrEP) Adherence and Retention Among Users at Kitgum General Hospital

Principal Investigator: Akanyo Joyce

Supervised by: Dr. Awor Silvia, Dr. Laker Florence

Introduction:

The novel Coronavirus is transmitted from human to human through droplets and direct or close personal contact with an infected individual. Novel Coronavirus signs of infection include respiratory symptoms, fever, cough, shortness of breath, and breathing difficulties. In more severe cases, the infection can cause pneumonia, severe acute respiratory syndrome, kidney failure, and even death.

Implementation of the prevention and control measures

In implementing the research activities, the investigators were committed to ensuring the safety of the research team, participants, and communities where the study was conducted. The study team complied with the Standard Operating Procedures issued by the Ministry of Health and presidential directives to mitigate the risk of infection of COVID-19 and effectively respond to any COVID-19 case during the study.

Procedures to be followed during the implementation of the research

A. Before data collection and training

1. Health guidance: There was sensitization and awareness to equip the research team and participants with knowledge of signs and symptoms of COVID-19, preventive measures such as hand hygiene before placing and removing the mask, and storage of the mask social distancing.
2. Wearing face coverings**:** All researchers, research assistants, and any other individuals engaged in research activities that require interaction with fellow researchers, research participants, or community members wore a face mask that thoroughly covered their

mouth and nose in the situations required by the Health Ministry guidance. The study provided face masks for individuals who did not have them.

3. Physical Distancing: There was a reasonable social distance during the training, meetings, community outreach
4. Good hygiene: All team members washed their hands or use hand sanitisers regularly. Hand-washing equipment were supplied and made available at all times. All surfaces and equipment shall be sanitized frequently.

B. During data collection

1. Personal Protective Equipment (PPE): All research assistants involved in tracing respondents and in in-person interviews and research participants used properly fitted face mask. Researchers and research participants washed their hands with soap and water or use hand sanitizer before the interview. Handshakes and hugging were prohibited.
2. Consent Process: The researchers observed reasonable social distancing when obtaining consent upon the participant's arrival. Researchers and research participants washed their hands with soap and water or use hand sanitizer before the interview. As the informed consent form indicates, participants were sensitized on COVID-19 and presented with preventive measures.
3. Equipment sanitization: Devices used to record or capture data, namely tape recorders, were sanitized regularly.

C. During Dissemination/Community engagement

1. Community Engagement: Researchers and research participants wore masks, washed their hands with soap and water or use hand sanitizer before the event.
2. Equipment sanitization: Shared devices used during community engagements were sanitized regularly.

These preventive measures were continuously reviewed based on new information and guidelines communicated by the Ministry of Health.

APPENDIX 6: STUDY WORKPLAN

Activity	Start Date	End Date	Duration	Description
Proposal Development	25-Sep-2024	09-Oct-2024	2 weeks	Develop the research proposal, finalize objectives, and refine the methodology.
Ethical Approval Process	16-Nov-2024	28-Feb-2025	14 weeks	Submit the proposal to Gulu University and Uganda National Council for Science and Technology ethical review boards.
Development of Study Tools	24-Feb-2025	28-Feb-2025	1 week	Finalize questionnaires, interview guides, and consent forms for data collection.
Recruitment and Training of Research Assistants	03-Mar-2025	09-Mar-2025	1 week	Recruit and train research assistants on study protocols, ethical guidelines, and data collection techniques.
Pre-testing of Data Collection Tools	10-Mar-2025	13-Mar-2025	4 days	Pre-test the questionnaires and interview guides in a small pilot study to ensure reliability and validity.
Data Collection (Quantitative and Qualitative)	15-Mar-2025	12-Apr-2025	4 weeks	Conduct both quantitative surveys and qualitative in-depth interviews with PrEP users at Kitgum hospital.

Data Entry and Cleaning	14-Apr-2025	26-Apr-2025	2 weeks	Input survey data into software and transcribe interview data for analysis
Data Analysis (Quantitative)	28-Apr-2025	03-May-2025	1 week	Analyze quantitative data using statistical methods to determine retention rates and associated factors.
Data Analysis (Qualitative)	05-May-2025	10-May-2025	1 week	Conduct a thematic analysis of interview transcripts to identify barriers and facilitators to PrEP adherence.
Report Writing and Dissemination	12-May-2025	31-May-2025	3 weeks	Compile the study findings into a final report and PrEPare presentations for stakeholders.
Dissemination of Findings	02-Jun-2025	15-Jun-2025	2 weeks	Present findings Kitgum hospitals, the Ministry of Health, and other stakeholders

APPENDIX 7: BUDGET

Item	Unit Cost (UGX)	Quantity	Total Cost (UGX)	Comments
Personnel	500,000	4	2,000,000	Payment for training and data collection
Principal Investigator (PI)	1,000,000	1	1,000,000	Coordination, supervision, and report writing.
Training and Pretesting				
Training Materials	50,000	1	50,000	Printing and stationery for training sessions.
Pretesting of Tools	100,000	1	100,000	Travel and allowances for pretesting in a similar population
Data Collection				
Transportation for Data Collection	100,000	20 days	2,000,000	Transport for research assistants to data collection sites
Reimbursement for Participants (Qualitative)	10,000	25	250,000	Compensation for time spent by qualitative interviewees.
Data Management				

Data Entry Clerks	250,000	2	500,000	Payment for data entry and cleaning.
Data Analyst	1,500,000	1	1,500,000	Analyze quantitative and qualitative data
Transcriptionist	300,000	1	300,000	Transcribe qualitative interviews.
Ethical and Administrative Costs				
Ethical Approval Fees	500,000	1	500,000	Fees for ethical approval from Gulu University Research Ethics Committee.
Administrative Clearances	200,000	1	200,000	Obtaining permissions from local authorities and hospital administrations.
Dissemination of Findings				
Printing and Binding of Reports	50,000	20	1,000,000	Printing final reports for dissemination.
Stakeholder Workshop	2,000,000	1	2,000,000	Workshop for presenting findings to stakeholders.

Contingencies	1,000,000		1,000,000	Miscellaneous expenses and unforeseen costs.
Total Budget			11,000,000	