

APPENDIX 5: SUB-STUDY 3- KEY INFORMANT INTERVIEW GUIDE FOR PARENTS AND CARETAKERS (English Version)

Study Title: Retention in Intensive Adherence Counselling as a Pathway to Viral Suppression among Virally Non-Suppressed Adolescents and Young People Living with HIV in East-Central Uganda: A Sequential Explanatory Mixed-Methods Study

Introduction

Thank you for taking the time to participate in this interview.

My name isand I am part of a research team from Makerere University conducting a study on retention in Intensive Adherence Counselling (IAC) among adolescents and young people living with HIV.

Your child or the adolescent under your care was enrolled into Intensive Adherence Counselling after receiving a viral load result indicating that the virus was not suppressed. Intensive Adherence Counselling is intended to help adolescents improve adherence to antiretroviral therapy (ART), remain engaged in HIV care, and ultimately achieve viral suppression. As a parent or caretaker, you play an important role in supporting adolescents throughout the IAC process. We would therefore like to understand your experiences in supporting your child to attend and complete IAC sessions, the challenges encountered, the factors that facilitated retention, and your views on how IAC contributes to viral suppression.

The information you provide will help us understand why some adolescents successfully complete IAC and achieve viral suppression while others do not. Findings from this study will be used to improve HIV services for adolescents and young people in Uganda. The interview will take approximately 45–60 minutes. With your permission, the interview will be audio-recorded to ensure that your responses are accurately captured. All information you provide will remain confidential and will only be used for research purposes. Your participation is voluntary, and you are free to decline answering any question or withdraw from the interview at any time without any consequences.

Do you have any questions?

Are you willing to participate in this interview?

Participant Signature: _____

Interviewer Signature: _____

Date: _____

Interview Guide

Domain	• Main Questions	Probes (COM-B)
Opening Questions	• Could you briefly tell me about the adolescent or young person under your care (age, schooling, duration on ART)? • What was your reaction when you learned that his/her viral load was not suppressed? • What did you understand about the purpose of Intensive Adherence Counselling (IAC)?	✓ Understanding of viral suppression. ✓ Initial emotional response. ✓ Knowledge about IAC. ✓ Expectations after referral to IAC.
Introduction to IAC Experience	• Please describe your experience after your child was enrolled into IAC. • How were you involved during the IAC process? • How easy or difficult was it for your child to attend all scheduled IAC sessions?	✓ Number of sessions attended. ✓ Caregiver participation. ✓ Communication with health workers. ✓ Perceived usefulness of IAC.
Psychological Capability	• Thinking about the adolescent under your care, what personal factors affected his/her ability to remain in IAC until completion?	Explore: ✓ Understanding of HIV and viral suppression. ✓ Knowledge of IAC. ✓ Memory and forgetfulness. ✓ Decision-making ability. ✓ Planning skills. ✓ Self-management. ✓ Treatment literacy. ✓ Understanding appointment schedules.

Physical Capability	• Were there any physical or health-related conditions that affected your child's attendance and completion of IAC?	✓ Illness. ✓ ART side effects. ✓ Fatigue. ✓ Disability. ✓ Mental health concerns. ✓ Physical wellbeing during IAC.
Social Opportunity	• How did family members, friends, school staff and other people influence your child's attendance and completion of IAC?	✓ Family support. ✓ Caregiver supervision ✓ Peer influence. ✓ School support. ✓ Partner support (older youth) ✓ Disclosure status. ✓ HIV stigma. ✓ Social discrimination. ✓ Community acceptance.
Reflective Motivation	• What motivated your child to continue attending IAC sessions? • What do you think encouraged him/her to complete IAC?	✓ Reflect on: ✓ Self-confidence. ✓ Hope for viral suppression. ✓ Treatment beliefs. ✓ Future aspirations. ✓ Educational goals. ✓ Career ambitions. ✓ Family responsibilities. ✓ Perceived benefits of completing IAC.
Automatic Motivation	• Did emotions influence your child's participation in IAC? Please explain.	✓ Reflect on: ✓ Anxiety. ✓ Fear. ✓ Depression. ✓ Shame. ✓ Frustration. ✓ Treatment fatigue. ✓ Embarrassment. ✓ Hope. ✓ Trust in health workers. ✓ Trust in ART.

Physical Opportunity	Thinking about the health facility and your community, what factors made it easier or more difficult for your child to remain in IAC?	✓ Distance. ✓ Transport costs. ✓ Clinic waiting time ✓ Appointment scheduling. ✓ Availability of counsellors. ✓ Privacy during counselling. ✓ Clinic environment. ✓ Youth-friendly services. ✓ Availability of ART. ✓ Community follow-up.
Retention in IAC and Viral Suppression	- In your opinion, how did attending and completing IAC influence your child's adherence to ART? - How do you think completing IAC contributed to viral suppression? - Why do you think some adolescents complete IAC while others discontinue?	✓ Changes in adherence behaviour. ✓ Improved understanding of treatment. ✓ Behaviour change. ✓ Family support. ✓ Counselling effectiveness. ✓ Persistent barriers. ✓ Reasons for missed appointments. ✓ Link between retention and viral suppression.
Facilitators of Retention in IAC	- What helped your child remain engaged in IAC until completion? - Which support systems were most helpful?	✓ Family support. ✓ Counsellors. ✓ Peer supporters. ✓ Community health workers. ✓ School support. ✓ Appointment reminders ✓ Telephone follow-up. ✓ Support groups. ✓ Community-based services.
Recommendations	- What can health facilities do to improve retention of adolescents in IAC? - What can parents, families and communities do to support adolescents to complete IAC and achieve viral suppression?	✓ Consider strategies such as: ✓ Family-centred counselling. ✓ Peer support programmes. ✓ Community follow-up. ✓ Telephone/SMS reminders. ✓ WhatsApp support groups. ✓ Home visits. ✓ Youth-friendly clinics.

	• What additional services would you recommend?	✓ Flexible clinic appointments. ✓ Community-based IAC models.
Conclusion	• Is there anything else you would like to add regarding your experiences supporting an adolescent through Intensive Adherence Counselling? • Do you have any additional suggestions for improving retention in IAC and viral suppression among adolescents and young people living with HIV?	✓ Thank the participant for their valuable contribution and explain how the findings will be used to strengthen adolescent HIV care services.