

**MEASURES OF RETENTION IN HIV CARE:
A STUDY WITHIN A REVIEW (SWAR)**

**MEASURES OF RETENTION IN HIV CARE:
A STUDY WITHIN A REVIEW (SWAR)**

BY NADIA REHMAN, BDS

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements
for the Degree Master of Science

McMaster University

©Copyright by Nadia Rehman, June 2022

McMaster University MASTER OF SCIENCE (2022) Hamilton, Ontario

(Health Research Methodology- Clinical Epidemiology Specialization)

TITLE: Measures of Retention in HIV care: A Study Within a Systematic Review (SWAR)

AUTHOR: Nadia Rehman, BDS (Khyber College of Dentistry, Peshawar, Pakistan)

SUPERVISOR: Dr. Lawrence Mbuagbaw

NUMBER OF PAGES: xi, 105

LAY ABSTRACT

Globally, there are more than 37.7 million people living with HIV (PLHIV). Retention in human immunodeficiency virus (HIV) care is a common and modifiable determinant of increased adherence to antiretroviral therapy (ART), better health outcomes, and a better quality of life.

There is no consensus in the literature on measures of retention in HIV care. This makes it very difficult to compare different studies and jurisdictions. This thesis review summarizes the definitions of retention used in randomized controlled trials (RCTs) and identifies the various components used to measure retention, which can be used as a reference for researchers to identify the gaps in the current definitions for HIV retention measures and identify preferred measures with the goal of reaching a standard consensus definition of retention in HIV care.

ABSTRACT

Introduction

Retention in HIV care is critical for PLHIV. However, retention in HIV care is not measured uniformly across studies. The aim of this study within a review (SWAR) is to describe the diversity in definitions used for retention in HIV care in randomized controlled trials.

Methods

We conducted a SWAR, drawing data from an overview of systematic reviews on interventions to improve the HIV care cascade. A comprehensive and exhaustive search was conducted of the following databases: PubMed, Excerpta Medica data BASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Web of Science, and the Cochrane Library. We identified randomized controlled trials (RCTs) of interventions to improve retention in care for people living with HIV (PLHIV). First, from the included studies in systematic reviews and second using targeted searches for RCTs. Only English language systematic reviews were included, but RCTs in any language were eligible. Data were screened and extracted in duplicate using pre-set criteria, with arbitration as needed. We identified distinct components from the definitions used to measure retention. The components were further categorized based on the similarities between them. We described the components narratively and presented the definitions in tables.

Results

We identified 8001 records, after a duplication check, 4147 unique titles and abstracts were examined for relevancy, leaving 744 articles. Full-text screening of the articles resulted in 50 articles that measured retention and provided 59 definitions for retention in care. Of the included studies, 11(22%) were conducted in low-income countries, 12(24%) were conducted in lower-

middle-income and upper-middle-income countries, and 13(26%) were conducted in high-income countries. We identified ten different components used to define retention. These components are follow-up times (83%), administrative records (8%), clinical visits (61%), gap scores (8%), group-level measures (17%), lab records (15%), pharmacy-based measures (29%), scheduled visits (27%) and visit counts (17%). The most frequently used components are follow-up times (n=49), and the easiest to measure are retention data derived from administrative records (n=5). We put the components into categories based on the similarities between them.

Conclusion

We identified existing definitions of retention in HIV care and the commonly used components in the definitions. This compilation of the definitions and identification of the components may provide a framework for developing the standard globally agreed-upon definition of retention in HIV care.

ACKNOWLEDGMENTS

This thesis would not be possible to complete without the support of so many amazing people, whom I am grateful to have on my side.

First and foremost, I would like to express my sincere gratitude to my supervisor Dr. Lawrence Mbuagbaw, without whom I would not have been able to complete this research. His vision, sincerity, and motivation are incomparable, and he has gone above and beyond as a supervisor. Dr. Mbuagbaw's insight and knowledge of the subject matter steered me through this research to the extent that I applied to the Ph.D. program, knowing that I can accomplish all my academic goals and achievements and beyond with his support. His support is not limited to only educational guidance, he has helped me gain confidence and soft skills. I want to pass special thanks to Dr. Mbuagbaw for always going the extra mile to help me.

I further want to thank my supervisory committee members, Dr. Pascal Djiadeu and Dr. Aaron Jones, for their invaluable support and professional guidance. Their insightful comments, kindness, and commitment helped me overcome the obstacles of my research.

I could not have completed this research and thesis without the help of all the beautiful co-authors I have had the privilege of collaborating with. I am very grateful for their contribution and commitment to the project.

I am grateful to all my dear friends and colleagues in the Health Research Methodology program and the Department of Health Research Methods, Evidence, and Impact, whose support was always there in these isolated, unprecedented times of the Covid -19 pandemic. Though the lack of in-person classes, my connection with new people was limited, the wonderful people I had by

my side throughout these two years always guided me through any difficulty. I am grateful to you all for being there and supporting me.

And my most enormous thanks go to my family, especially my husband, Yasir Rehman for always encouraging me and looking after the family. I am grateful for his support under challenging situations and by trying to help by completing the unfinished tasks around the house and not overburdening me.

TABLE OF CONTENTS

LAY ABSTRACT.....	III
ABSTRACT.....	IV
ACKNOWLEDGMENTS.....	VI
TABLE OF CONTENTS.....	VIII
LIST OF FIGURES.....	IX
LIST OF TABLES.....	IX
LIST OF All APPENDIXES	IX
LIST OF ABBREVIATIONS AND SYMBOLS	X
DECLARATION OF ACADEMIC INTEREST.....	XI

CHAPTER 1: LITERATURE REVIEW

1.0 INTRODUCTION.....	2
1.1 HIV: THE GLOBAL EPIDEMIC	2
1.1.1 HIV Treatment.....	2
1.2 HIV CARE CONTINUUM.....	3
1.2.1 What Is the HIV Care Continuum.....	3
1.2.2 Sustainable Development Goals (SDGs).....	4
1.2.3 HIV Care Cascade.....	5
1.2.4 Progress Towards UNAIDS 95- 95-95 Fast-Track Targets.....	6
1.3 RETENTION.....	7
1.3.1 Conceptual Definition of Retention in HIV Care.....	7
1.3.2 Significance of Retention.....	7
1.3.3 Significance of Retention in Care Towards Positive Outcomes.....	8
1.3.4 Progress Towards Achieving Optimal Retention in Care.....	9
1.3.5 Factors Affecting Retention in Care	9
1.4 SIGNIFICANCE OF PROPER ESTIMATES OF RETENTION IN CARE.....	11
1.4.1 Measures of Retention.....	11
1.4.2 Study Designs Used to Measure Retention in Care.....	11
1.5 CONCLUSION AND NEXT STEPS	12

CHAPTER 2: RESEARCH OBJECTIVES AND METHODS

2.0 INTRODUCTION.....	14
2.0.1 Challenges in Retention Measures.....	14
2.1 RESEARCH OBJECTIVES.....	14
2.2 METHODS.....	15
2.2.1 Study Design.....	15
2.2.2 Methodology.....	16
2.3 Statistics Analysis.....	20

CHAPTER 3: RESULTS

3.1 LITERATURE SEARCH RESULTS	22
3.1.1 Description of Excluded studies.....	24
3.1.2 Description of Included Studies.....	24
3.2 Definitions of Retention in care	27
3.2.1 Description of the Components of the Definitions.....	28
3.2.2 Limitations and Benefits of the components of the Definitions.....	31
3.2.2.1 Follow-up time.....	31
3.2.2.2 Type of visit.....	32
3.2.2.3 Type of Count	36
3.2.2.4 Scheduled visits	37
3.2.2.5 Group-level definitions.....	38
3.2.2.6 Ambiguous measures.....	39
3.2.3 OTHER MEASURES TO DEFINE RETENTION	40

CHAPTER 4: DISCUSSION AND FUTURE DIRECTIONS

4.0 DISCUSSION	44
4.1 STEPS TOWARDS A FUTURE DEFINITION	46
4.2 STRENGTHS	47
4.3 LIMITATIONS	47
4.4 CONCLUSION	48
REFERENCES	49

LIST OF FIGURES

Figure 1: HIV continuum of care.....	3
Figure 2: HIV care cascade to identify and fill gaps in the program, Global 2019.....	6
Figure 3: Factors affecting retention in HIV care.....	11
Figure 4: Prisma flow chart	23
Figure 5: Retention in care definitions by year of publication	27
Figure 6: Components of definitions of retention in HIV care	29
Figure 7: Categories of definitions in retention in HIV care by components.....	31

LIST OF TABLES

Table 1: Study and participant characteristics of included RCTs.....	26
Table 2: Pros and cons and recommendations of components of the definitions	40

LIST OF APPENDIXES

Appendix 1: Full Literature Search Strategy.....	75
Appendix 2: Full-text Screening Form.....	86
Appendix 3: Data Abstraction Forms.....	86
Appendix 4: Definitions of retention in HIV care in RCTs.....	90

LIST OF ABBREVIATIONS AND SYMBOLS

Abbreviation	Definition
SWAR	Study within a review
HIV	Human Immune Deficiency Virus
UNAIDS	United Nations Programme on HIV and AIDS
WHO	World Health Organization
ACB	African, Caribbean, and Black populations
PLHIV	People living with HIV
AIDS	Acquired Immunodeficiency Syndrome
SDG	Sustainable Development Goals
FTT	Fast track targets
ART	Antiretroviral therapy
RCT	Randomized controlled trials
MSM	Men who have sex with men
PWID	People who inject drugs
HRSA	Human Resources and Services Administration
EHR	Electronic Health Record

DECLARATION OF ACADEMIC ACHIEVEMENT

Dr. Lawrence Mbuagbaw conceptualized the original idea for this research. I developed the research question and methodology of the project under his guidance. The search strategy was developed in collaboration with a librarian from the Health Sciences Library at McMaster University. Michael Wu, Cristian Garcia, Alvin Leenus, Hussein El-Kechen, Manika Bhandari, Babalwa Zani, Anisa Hajizadeh, Annie Wang, Rita Morassut, Jessica Bartoszko, Gohar Zakaryan, Oluwatoni Makanjuola, Diya Jhuti, and Vaibhav Arora conducted the title and abstract screening, full-text screening, and data extraction. I wrote the first draft of this thesis and created the tables and figures, with subsequent feedback and suggestion from Dr. Lawrence Mbuagbaw and my committee members, Dr. Pascal Djiadeu and Dr. Aaron Jones. All individuals mentioned above will be included as co-authors in the published manuscript(s) resulting from this work.

I, Nadia Rehman, declare this thesis to be my work. To the best of my knowledge, the content of this document does not infringe on anyone's copyright.

CHAPTER 1:

LITERATURE REVIEW

1.0 INTRODUCTION

In this chapter, I will summarize the role of retention in HIV care on the long-term health outcomes of PLHIV across the globe; the social and economic determinants of retention in HIV care; current literature on the relationship between retention in care and desired health outcomes; the challenges in attaining adequate retention and the gaps in measuring retention due to the lack of a standard definition of retention in HIV care.

1.1 HIV: THE GLOBAL EPIDEMIC

Globally, over 37.7 million people are living with HIV, with 1.5 million new infections acquired worldwide in 2020.^{2,3} So far, there is no cure for HIV, and if left untreated, it can lead to Acquired Immune Deficiency Syndrome (AIDS), and eventually premature death.⁴

1.1.1 HIV Treatment The first case of AIDS was reported in the medical literature in 1981, with no effective treatment until 1987, when the first successful antiretroviral (ART) was approved.^{1,2} Since then there has been major progress with the advent of highly effective combination antiretroviral therapy (ART).^{3,4}

According to earlier guidelines ARTs were prescribed to symptomatic patients with CD4 counts ≤ 200 cells/ μ L.⁵ Over the decades, numerous guidelines have evolved on the optimal time to initiate ART.⁶ In 2008, World Health Organization (WHO) recommended a test and treat approach to prescribe and initiate ART soon after receiving the HIV diagnosis regardless of the WHO clinical stage or CD4 count⁷.

These progressive evidence-based changes in HIV treatment have improved health outcomes dramatically, with a significant reduction in the number of AIDS-related deaths by 64% since the peak in 2004.⁸ Given advances in ART, PLHIV are benefitting from more potent medication with fewer side effects, and as a result they are living with better quality, and are more easily able to maintain virologic suppression.⁹⁻¹¹ However, these benefits are contingent upon engagement in HIV care.¹²

1.2 HIV CARE CONTINUUM

1.2.1 What Is the HIV Care Continuum?

The HIV care continuum encompasses a spectrum of patient care, starting from HIV testing and diagnosis, linkage to care, adherence to ART, and ultimately retention in care.¹³ Figure 1 represents the various stages in the HIV care continuum

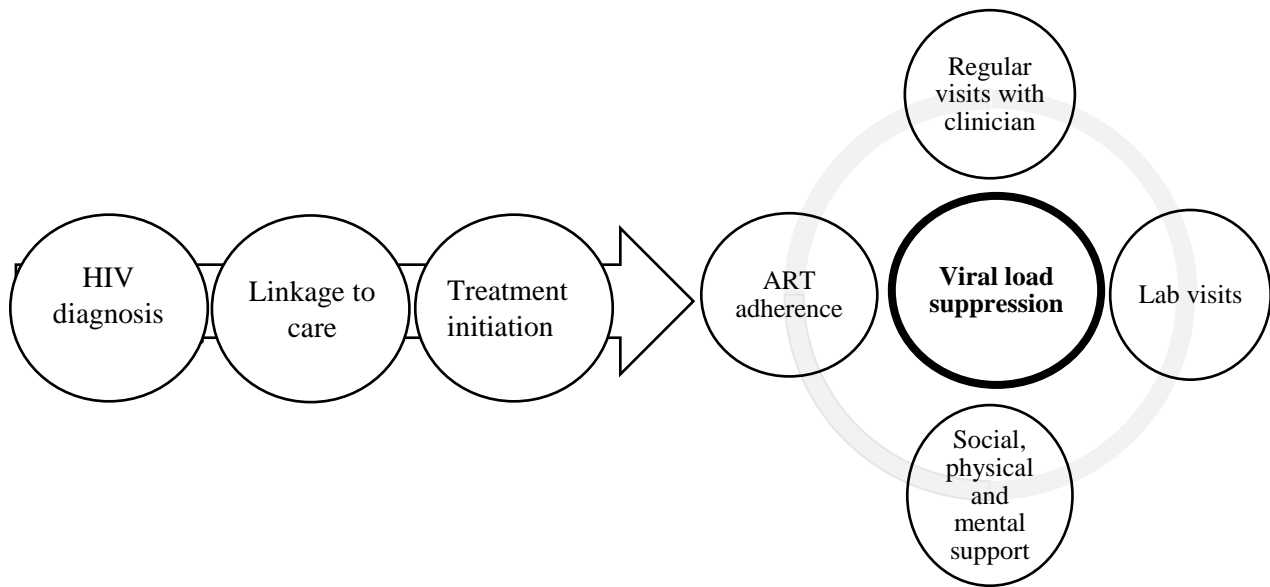


Figure 1: HIV Continuum of Care

1.2.2 Sustainable Development Goals (SDGs)

Engagement in successive stages of the HIV care continuum is pivotal to attaining the 2030 Sustainable Development Goals (SDGs) set by the Joint United Nations Programme on HIV/AIDS in 2020.¹⁴ According to the SDGs, by 2025, PLHIV should meet the Fast-Track Targets (FTTs). The targets set are that by 2025, 95% of PLHIV will be aware of their HIV status, 95% of those with HIV positive status will be receiving ART, and 95% of PLHIV on treatment will be virally suppressed.¹⁵

1.2.3 HIV Care Cascade

HIV care cascade is a framework that outlines the stages that people will go through to quantitatively evaluate progress towards the goals set by the United Nations of meeting the Fast-track targets. PLHIV move through a series of sequential events, with each event contingent on having achieved the preceding target until the desired viral suppression is attained and the positive outcome of reduced HIV incidence, morbidity, and mortality in the population is reached.¹³

The cascade presents a visual image of the HIV care continuum. The HIV care cascade is presented as vertical bar graph which represent number or percentages of people at different stages of the HIV care cascade. Going from left to right, the first bar shows the total percentage of PLHIV, the second bar represents the percentage number of PLHIV aware of their diagnosis, followed by the third bar with the percentage of PLHIV on ART. And the right-most bar represents the percentage of PLHIV who have reached the desired viral suppression load. The difference in the height of the columns gives a visual presentation of the gaps at each subsequent stage of the HIV care continuum.¹⁶ Examining the care cascade helps to identify gaps at every stage of the HIV care continuum. It is useful in monitoring the performance of healthy systems and tailoring programs to the needs of PLHIV to reach the desired goals and outcomes at the population level.^{13,14} The HIV care cascade also provides the opportunity to examine patterns and trends in HIV care utilization over time.¹⁷

1.2.4 Progress Towards UNAIDS 95-95-95 Fast-Track Targets

To date, achievements are far behind the UNAIDS 95-95-95 set goals.¹⁸ As presented in Figure 2, globally, in 2020, 81 % of PLHIV were aware of their HIV positive diagnosis, amongst them, 73% were receiving ART, of which 66% were virologically suppressed.¹⁹The bar graph of the HIV care cascade for 2019 is presented in figure 2.

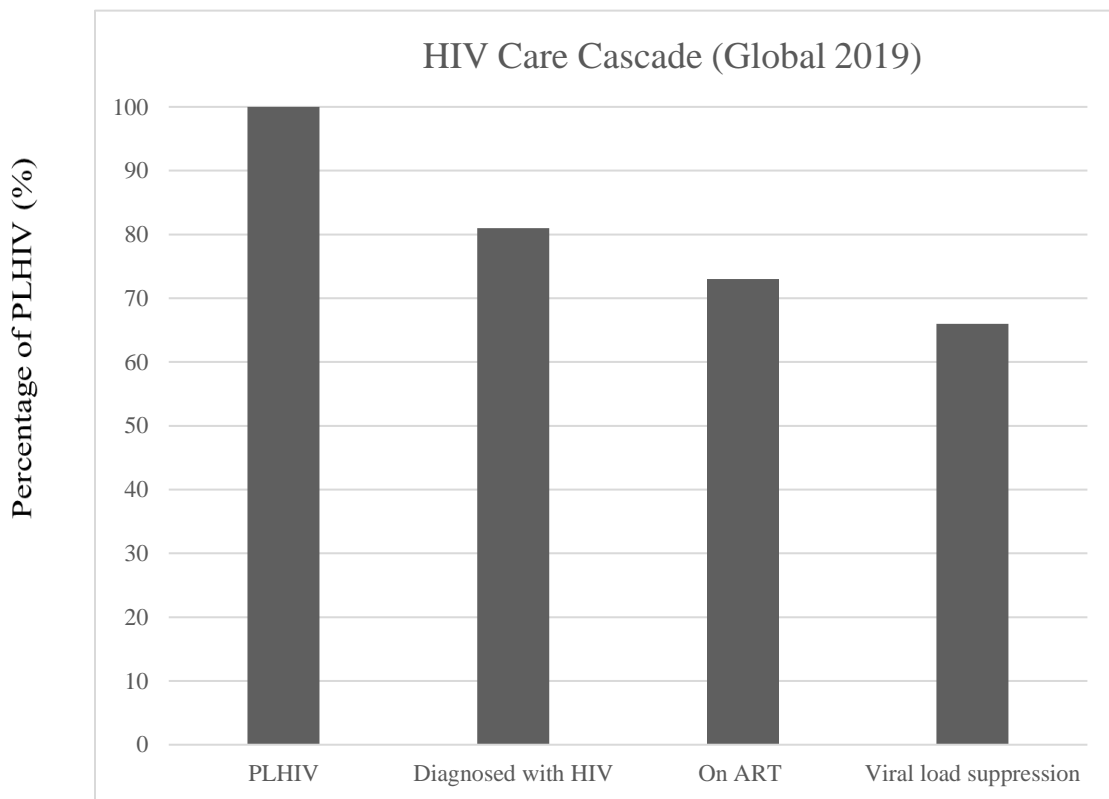


Figure 2: HIV care cascade to identify and fill gaps in the program, Global 2019

There are discrepancies between populations geographically and by socioeconomic status towards achievements of set the targets. The comparison of milestones in the HIV care cascade on national treatment cascades on UNAIDS 90-90-90 across 196 countries reported that only 32/196 countries reported results with full cascades and 12/196 countries with partial cascades. None of the countries had reached the set targets. There was a wide discrepancy in the range of virally suppressed individuals varying from 68% achieved in Switzerland to only 7% in China.²⁰

1.3 RETENTION

Retention in the HIV care cascade is crucial for achieving the SDGs,¹⁴ and it begins as early as the diagnosis of HIV.²¹ Retention in care implies receiving continuous and uninterrupted medical care at regular intervals from initiation to death or discharge of the patient.²²⁻²⁵

1.3.1 Conceptual Definition of Retention in HIV Care

Conceptually retention is defined as:

“Retention (in care) is a client’s continued engagement in health services and captures the whole ‘continuum of HIV care’: from enrollment to discharge/death of the client.”²⁵

1.3.2 Significance of Retention

Retention in care is a critical element for optimal clinical outcomes at the individual and public level and improving cost effectiveness.²² Research has shown that retention in care

results in high levels of adherence and success with ART which leads to viral load suppression.²⁶ As adequate retention in care offers the opportunity to monitor response to HIV therapy, this helps to identify medication toxicities and ART resistant strains that may result in treatment failure. It also permits timely switches to a second regimen of ART medications if indicated.²⁶

1.3.3 Significance of Retention in Care Towards Positive Outcomes

Patients with poor retention in care are more likely to have symptomatic disease. Patients with only one health care provider visit per year tend to have lower CD4 cell counts²⁷ and unmonitored suboptimal viral load suppression, resulting in late presentation of comorbid health conditions and opportunistic infection. This further translates to increased mortality and morbidity.²²

In addition, optimum retention in care opens opportunities for implementing preventive health care and health behavior change interventions that may eliminate the risk of transmission and reduce the population burden of HIV.²⁸

Generally, there are higher healthcare cost associated with lower retention in care at the individual level due to loss or reduction of income and at the public health level due to increased emergency room visits and hospitalization.²⁶ Patients accessing HIV care regularly benefit from timely access to ancillary and social services, treatment for substance use, psychiatric diseases, diabetes, heart disease, hepatitis C, and prophylaxis against opportunistic infections.^{25,29}

1.3.4 Progress Towards Achieving Optimal Retention in Care

Despite the evidence supporting the benefits of retention at individual and population levels, retention in the HIV care cascade remains an ongoing challenge. Twelve-month average retention has been reported to range from 64 to 94% in high-income countries but can fall below 60 % in low-income and resource-limited populations over 60 months.⁹ Almost 25% of patients enrolled in the large US, and Canada-based cohort of people living with HIV were not fully retained in care after eight years of follow-up.³⁰ The most common attrition rates occur in the first year after being newly diagnosed with HIV.^{17, 13}

1.3.5 Factors Affecting Retention in Care

Improved access to low-cost care have reduced the financial barriers to quality care even in low- or middle-income countries, despite this progress, PLHIV often encounter multiple challenges in accessing and staying connected in the available health-care²⁵

The disparities in access of HIV care are due to various individual and socio-economical factors, including but not limited to clinical factors, social support, stigma, mental health, addiction and substance abuse^{9, 31, 32} Structural inequities such as poor access to transportation, poverty, and work/child care responsibilities contribute to lower rates of retention in HIV care.^{30, 33, 34} Lower rates of retention in care is linked with specific demographic attributes such as younger age, female sex, race, ethnicity, and belonging to a key populations such as men who have sex with men (MSM), African, Caribbean, Black populations (ACB), prisoners, injection drug users (IDU), youth, transgenders (TG), migrants' populations, refugees, people with precarious migration status, and indigenous

people^{27,35,36} A longitudinal cohort study conducted in British Columbia, where there is universal ART and high-quality free care available provided evidence that although 85% of individuals on ART in British Columbia were virally suppressed, this proportion ranged between 60% and 93% across different subgroups.²⁸ Though multiple studies had identified the factors it remains unclear why these disparities continue to persist despite the global efforts.^{9, 29, 31, 34} However Figure 3 presents the factors related to low retention in PLHIV.

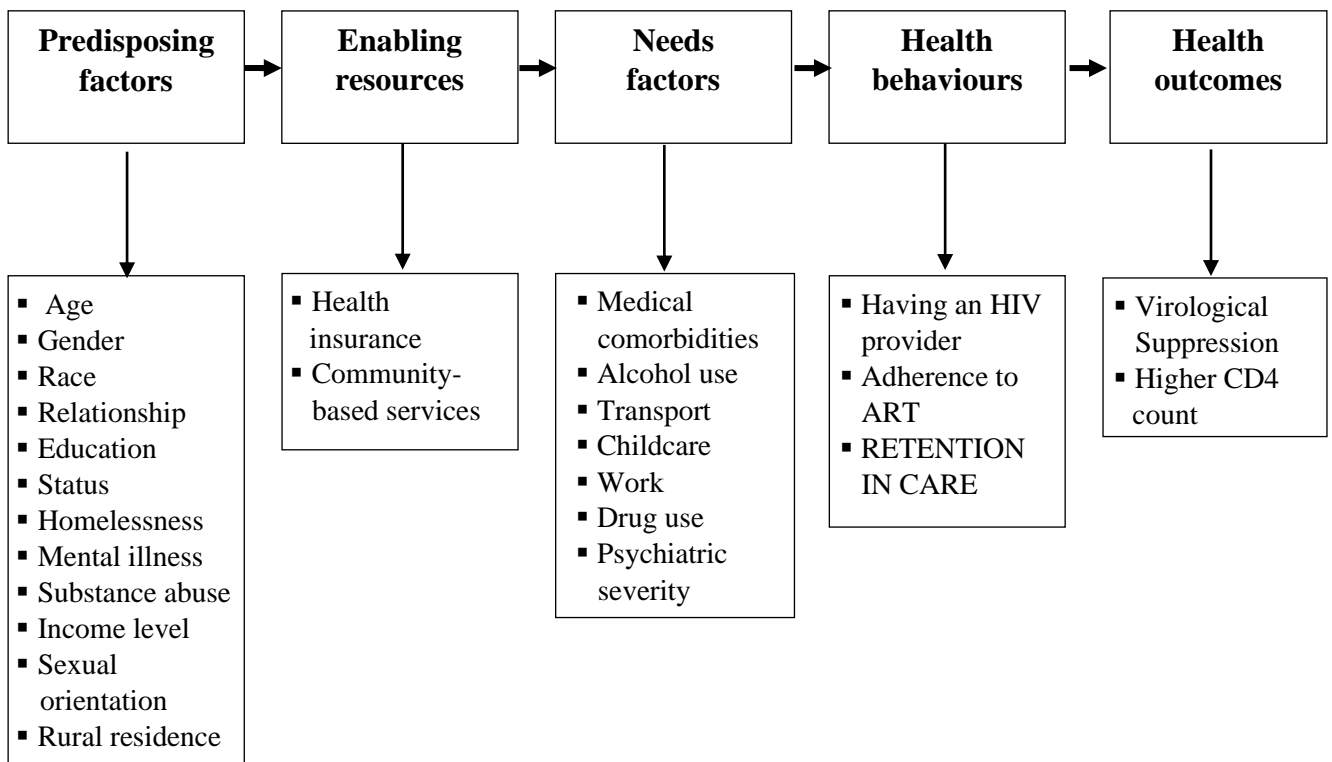


Figure 3: Factors Affecting Retention in HIV Care

1.4 SIGNIFICANCE OF PROPER ESTIMATES OF RETENTION IN CARE

The disproportionate rates of retention in care amongst different populations suggests that meeting the FTTs will not only depend on the availability of quality care.³⁷ There is a need to devise a comprehensive strategy to address the existing gaps in retention in care so that better data is available to make policies and programs to improve management strategies, decentralization, and social support^{9, 22, 27}

1.4.1 Research in the Field of Retention in Care

There had been a lack of research on retention in HIV care, but the number of studies have increased since 2011.³³ Researchers, and clinical practitioners have used different approaches to measure retention, e.g., gaps in care, visit adherence, composite measures, surveillance, medical records and administrative databases.³⁸⁻⁴⁰

1.4.2 Study Designs Used to Measure Retention in Care

Retention has been mostly measured from cross-sectional or longitudinal studies. Cross-sectional studies are more straightforward and economical for large populations. However, there are the limitations that participants may exit and return at varying stages and can increase the bias by being counted twice or not being counted at all within the time frame of data collection. Longitudinal studies provide an advantage over cross-sectional studies by tracking patients continuously and allowing relatively fewer points of patients' attrition to the study.⁴⁰

1.5 CONCLUSION AND NEXT STEPS

HIV is a worldwide major public health issue. The health outcomes of the PLHIV have dramatically improved due to the availability of low-cost highly potent combination ART and quality care. For ART to be efficient to reach the desired health outcomes, PLHIV must be retained in HIV care over their life span. Retention is a metric for the day-to-day delivery of health care at the front lines. Therefore, it is necessary to have a proper estimate of the magnitude of retention.

CHAPTER 2:

RESEARCH OBJECTIVES AND METHODS

2.0 INTRODUCTION

2.0.1 Challenges in Retention Measures

One major challenge for the researchers in measuring retention is that a standard consensus definition of retention in HIV does not exist. Previous studies have highlighted the heterogeneity and lack of standardization in retention measures.^{26, 29, 33, 34, 40,41,42,43}

The need for standardization and consensus definition of retention is necessary:²⁵

1. To compare and combine studies
2. To compare jurisdictions
3. To compare programmes

Despite the clinical and programmatic importance of retention in care in the HIV care continuum and acknowledgement of the lack of consensus and standard definition, reaching an agreed upon and consistent definition has been difficult. As measuring retention is complex given its longitudinal nature including multiple visits scheduled at varying time intervals and over an indefinite period.^{39, 43,44}

2.1 RESEARCH OBJECTIVES

The objective of this SWAR is to describe the definitions of retention used in published randomized controlled trials (RCTs). This work will allow researchers to compare the different definitions and to weigh the pros and cons and the potential applications of the

definitions. Further examining the definitions may provide a framework for developing a standard definition for retention in HIV care.

2.2 METHODS

2.2.1 Study Design

This is a methodological study, performed as a part of a published overview of systemic reviews on strategies to improve treatment initiation, adherence to ART, and retention in care for PLHIV. The methodology is covered in detail in the published overview,^{44, 45} but described in brief here.

Study within a review (SWAR)

The SWAR design aims to identify and explore areas of uncertainty within a review. The SWAR design was established by The Hub for Trials Methodology Research in Northern Ireland, which is funded by the UK Medical Research Council. A SWAR can be used in several ways, to resolve uncertainties about the methodologies of the systematic review or to answer other research questions arising due to gaps in the literature found during the conduct of the systematic review.⁴⁶ In our published overview of reviews, we found a gap in the literature, i.e., heterogeneity in measures of retention in HIV care.⁴⁵

2.2.2 Methodology

This is a review of definitions used in randomized controlled trials for PLHIV. This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.⁴⁷

Stage 1: Eligibility Criteria

Inclusion Criteria

We aimed to collect definitions of retention in HIV in published RCTs.

Studies were included in the review if they met the following inclusion criteria:

- The participants were people diagnosed with HIV of all age groups and locations.
- We included studies which described and measured retention in HIV care i.e any published articles containing text that defines or attempts to define retention in care.
- Randomized controlled trials (RCTs) that prospectively evaluated both a treatment group and a control group.
- Full-text articles available in English.

Exclusion Criteria

Studies were excluded if they were conference abstracts since they would lack sufficient details on the definitions of retention.

Stage 2: Search Strategy

An exhaustive and comprehensive search strategy was developed in consultation with a librarian specializing in health databases, collaboratively with the authors to search and select relevant articles for the previously published overview of reviews.⁴⁴ The following databases were searched systematically for the overview of systematic reviews from 1995 until 13 November 2018: PubMed EMBASE (Excerpta Medica Database), CINAHL (Cumulative Index to Nursing and Allied Health Literature), PsycINFO, Web of Science, and the Cochrane Library. For retrieving any additional reviews, the websites of World Health Organization (WHO), United Nations Programme on HIV and AIDS (UNAIDS), National Institute for Health and Care Excellence, and the systematic review database housed at the OHTN: Synthesised HIV/AIDS Research Evidence (<http://www.hivevidence.ca/frmSearch.aspx>) were also searched. The search strategy is available as Appendix 1.

The bibliographies of included reviews were searched manually to capture potentially relevant RCTs⁴⁵.

The search strategy was updated by replacing the search term “systematic reviews” to “randomized controlled trials” with the most recent updated done in August 2021.

Stage 3: Selection of Sources of Evidence

The articles retrieved from the search results were collated in the Endnote reference manager.⁴⁸ After removing duplicates, screening of the title and abstract was done independently in pairs by at least two reviewers (NR, MU, CG, AL, HL, MB) using Distiller SR software (Evidence Partners, Ottawa, Canada)⁴⁹. Studies that met the pre-determined inclusion criteria were selected.

We retrieved complete articles when they were judged potentially pertinent to the aims of this review. Full text screening was done independently by the pair of reviewers (NR, MU, CG, AL, HL, MB). Studies that measured and defined retention in HIV care as an outcome were selected. Inclusion criteria are provided in Appendix 2.

Stage 4: Extracting Data from The Selected Studies

The eligible studies were then retained for final analysis. We developed, and pilot tested a data extraction form in Distiller SR prior to the beginning of data extraction. Data were extracted on relevant background variables, including first author, year of the study, trial details, design, country, target populations including MSM, ACB, prisoners, IDU, youth, TG, migrants' populations, refugees, people with precarious migration status, and indigenous people^{27,35}, type of intervention, setting of HIV care delivery, study outcomes, detailed definitions of retention and any supporting citations. A full list of the data extracted is available in Appendices 3.

We measured inter-rater agreement between the reviewers using the kappa (k) statistic. Values of 0 to 0.20 represent slight agreement, 0.21 to 0.40 represent fair agreement, 0.41

to 0.60 represent moderate agreement, 0.61 to 0.80 represent substantial agreement, and >0.80 represents almost perfect agreement.⁵⁰

We manually searched all eligible publications for definitions of retention in HIV care. We extracted text that defined retention in HIV care in explicit terms or indirectly. When a definition was identified, the text was extracted verbatim. Some articles defined retention in more than one way so we included all definitions identified, so the number of definitions may be different from the number of total studies.

Additionally, we also examined whether the authors provided a rationale for the definitions used, including any supporting citations. We resolved any discrepancy by discussion or arbitration with an expert (LM).

Stage 6: Data Synthesis

After the primary data extraction, to explore the heterogeneity among the definitions and to facilitate the comparison of the definitions, we identified the distinct components used to define retention. The components refer to the different methods used to measure retention including any visit, clinical, immunological criteria and time periods. The components were identified by reviewing the definitions. There was no pre-defined list of components, and we kept expanding the list based on new components we identified. One reviewer (NR) established the components, and they were verified by another (CG). Any disagreement was resolved by consensus or arbitration by a third author (LM).

The number and frequency of definitions using that component was calculated. The salient feature of each unique component in their specific categories were described narratively

Further, the components with similarities between them were put in categories together.

The definitions are presented in tables.

The Risk of Bias Assessment

The risk of bias was not conducted as it was not pertinent to our research question.

2.3 Statistics Analysis

We used descriptive statistics, including frequencies and percentages, to describe the target population, country income level (upper, upper-middle, lower-middle, and low) ⁵¹, and type of intervention. We generated summary statistics (frequency %) of the definitions by counting the number of definitions containing the specific component.

CHAPTER 3:
RESULTS

3.1 LITERATURE SEARCH RESULTS

The search strategy developed for the Overview of reviews⁴⁵ identified a total of 2420 systematic reviews from the electronic data bases, and 76 from other sources. After removing duplicates (n=915), 1505 systematic reviews for title and abstract screening. We retrieved 66 potential eligible articles. A total number of 14 RCTs which measured retention were identified by hand searching the bibliographies of the selected reviews on HIV care cascade.

Our updated search strategy resulted in a total of 3886 RCTs, after removing duplicates, 2859 unique titles and abstracts were retrieved for screening, out of which 1832 were considered ineligible and excluded. A total of 483 articles were available for full text screening.

A total of 302 studies reported on HIV care cascade and 50 articles measured retention in HIV care. Details of the screening process and study selection are illustrated in the study flow diagram (Figure 4). The independent full-text review by the reviewers had moderate agreement (Cohen's kappa = 0.58).

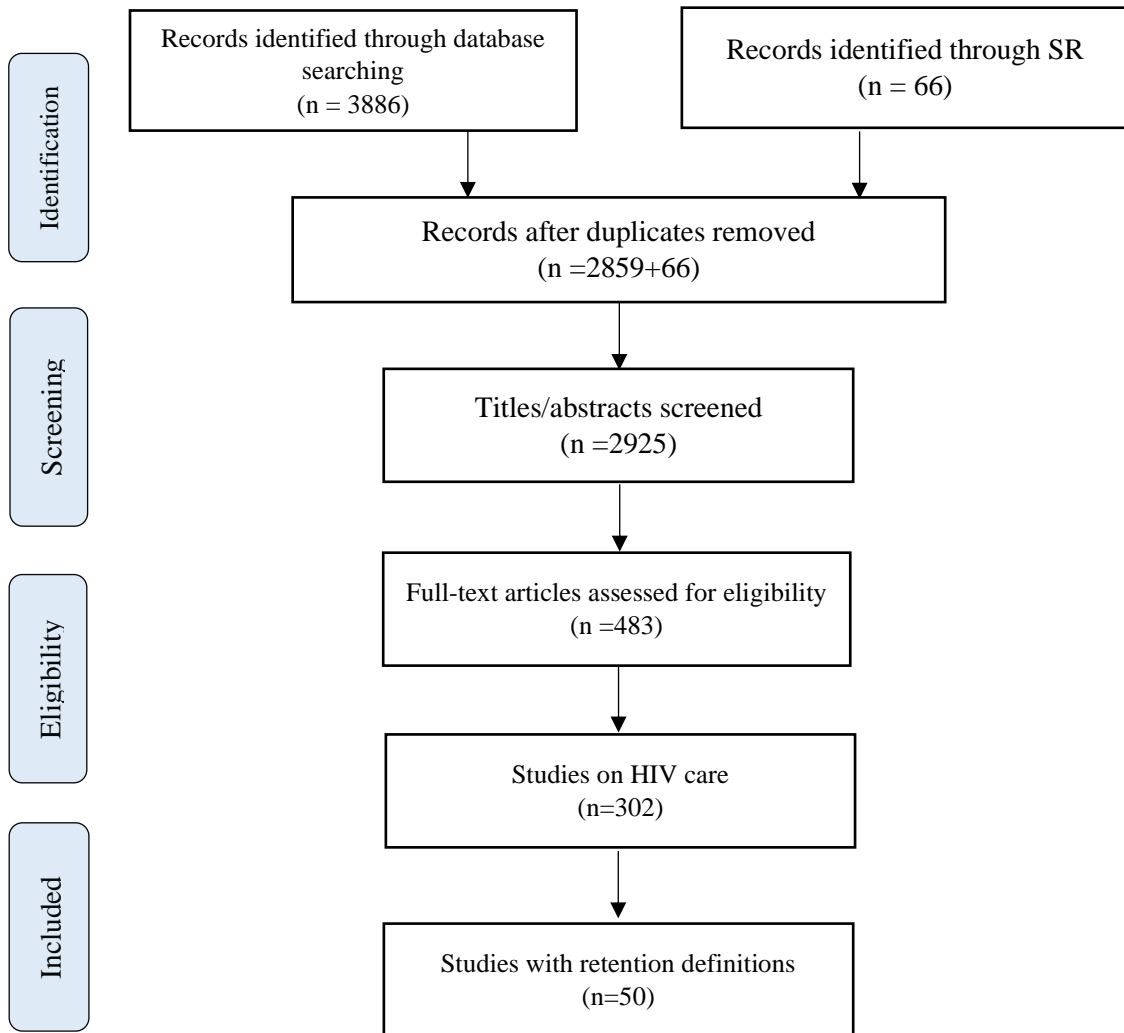


Fig. 4. The PRISMA-*ScR* flow diagram detailing the database searches, the number of abstracts screened, and the full texts retrieved.

3.1.1 Description of Excluded studies

A total of 1193 articles were excluded based on various reasons. The reasons for excluding the articles are given in Appendix 4.

3.1.2 Description of Included Studies

The 50 included randomized controlled trials were published between 2007-2021. Eleven (22%) studies were conducted in the low-income countries^{37, 52-61}, 12(24%) studies were conducted in the low-middle income countries⁶²⁻⁷³, 12(24%) were conducted in the upper middle⁷⁴⁻⁸⁵,13(26%) in the high-income countries⁸⁶⁻⁹⁷ and 2(4%) were conducted in countries with different income levels on the World Bank List of Economics.^{51, 98, 99} The median sample size was 437 (interquartile range [IQR], 205-1237). The median age for the participants across all RCTs was 35 years. Females accounted for 62% of all trial participants.

Of the 50 included studies, 28 (56 %) were conducted in the general population.^{52, 56, 58, 63-65, 68, 77, 81, 85-87, 92-94, 96-98, 100-106} The key population in which most of the studies were conducted in this SWAR is comprised of African Caribbean or Black (ACB) which accounted for 21(42%) of the total studies.^{57, 59, 67, 74, 88, 89, 104, 107-120} There are only eight RCTs conducted on other key populations which includes IUD, , prisoners,^{32, 90} youth,^{59,}

^{107, 110, 120} MSM,⁹⁷ TG, migrants' populations, refugees, people with precarious migration status, and indigenous people.

With regards to the interventions used in the trials, the interventions were organised into various categories described in the previously published overview.⁴⁵ These categories are behavioral and educational, digital, mixed, economic, health system, medication modification, peer or community-based, pharmacy-based, or task shifting. The most common interventions used in the retention studies were behavior and education interventions used in 11 trials (22%) and the least common interventions used are economic interventions used in three trials. (6%). The study and baseline participant characteristics are presented in Tables 1.

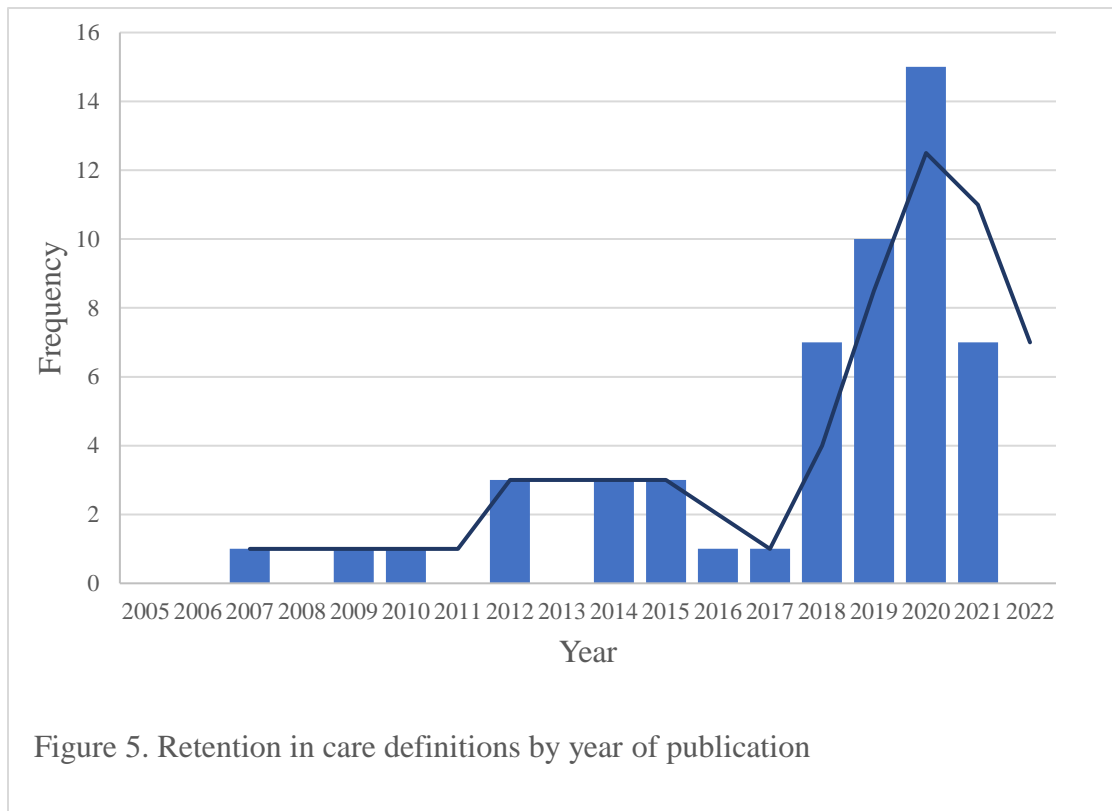
Table 1. Study and participant characteristics of included randomized controlled trials

Characteristics	Statistics
Year: median (quartile 1; quartile 3)	2016 (2014;2017)
Sample size: median (quartile 1; quartile 3)	437.5 (205.2-1237.5)
Study duration: median (quartile 1; quartile 3)	12 (18;29)
Age: median (quartile 1; quartile 3)	35 (27.95;40.1)
Female: median (quartile 1; quartile 3)	62 (38;72)
General population: n (%)	28 (56)
Key populations	
African, Caribbean, or Black people (ACB)	21 (42)
Men who have sex with Men	1 (2)
Intravenous drug users (IDU)	1 (2)
Prisoners	2 (4)
Youth	4 (8)
Country income level: n (%)	
Low-income countries	11 (22)
Low middle countries	12 (24)
Upper middle countries	12 (24)
High income countries	13 (26)
Mixed*	2 (4)
Intervention types: n (%)	
Behavioural and education	11 (22)
Digital	9 (18)
Mixed	7 (14)
Economic	3 (6)
Health system	5 (10)
Peer or community based	6 (12)
Pharmacy based	4 (8)
Task-shifting	5 (10)

*Two or more countries includes at different income levels on the World Bank List of Economics.⁵¹

3.2 Definitions of retention in care

There has been a steep increase in the number of RCTs measuring and defining retention in HIV care since 2017 (figure 5). The 50 studies included, provided 59 distinct definitions of retention in HIV care. Out of these, seven studies (11%) defined retention in more than one way.^{73, 75, 76, 108, 118, 121, 122} The term retention was most used for defining retention in 52% of the trials.^{57, 64, 66, 68, 72-77, 83, 85, 87, 91, 95-98, 101, 103, 105, 108-114, 120, 122} Other terms used were retained in care, missed appointments, continuity of care, adherence to care, exiting care, follow-up visits and appointment adherence.^{52, 55, 58, 59, 62, 67, 81, 86, 88-90, 92-94, 99, 108, 110, 111, 115, 123-127}. The table of the definitions is provided in Appendix 5.



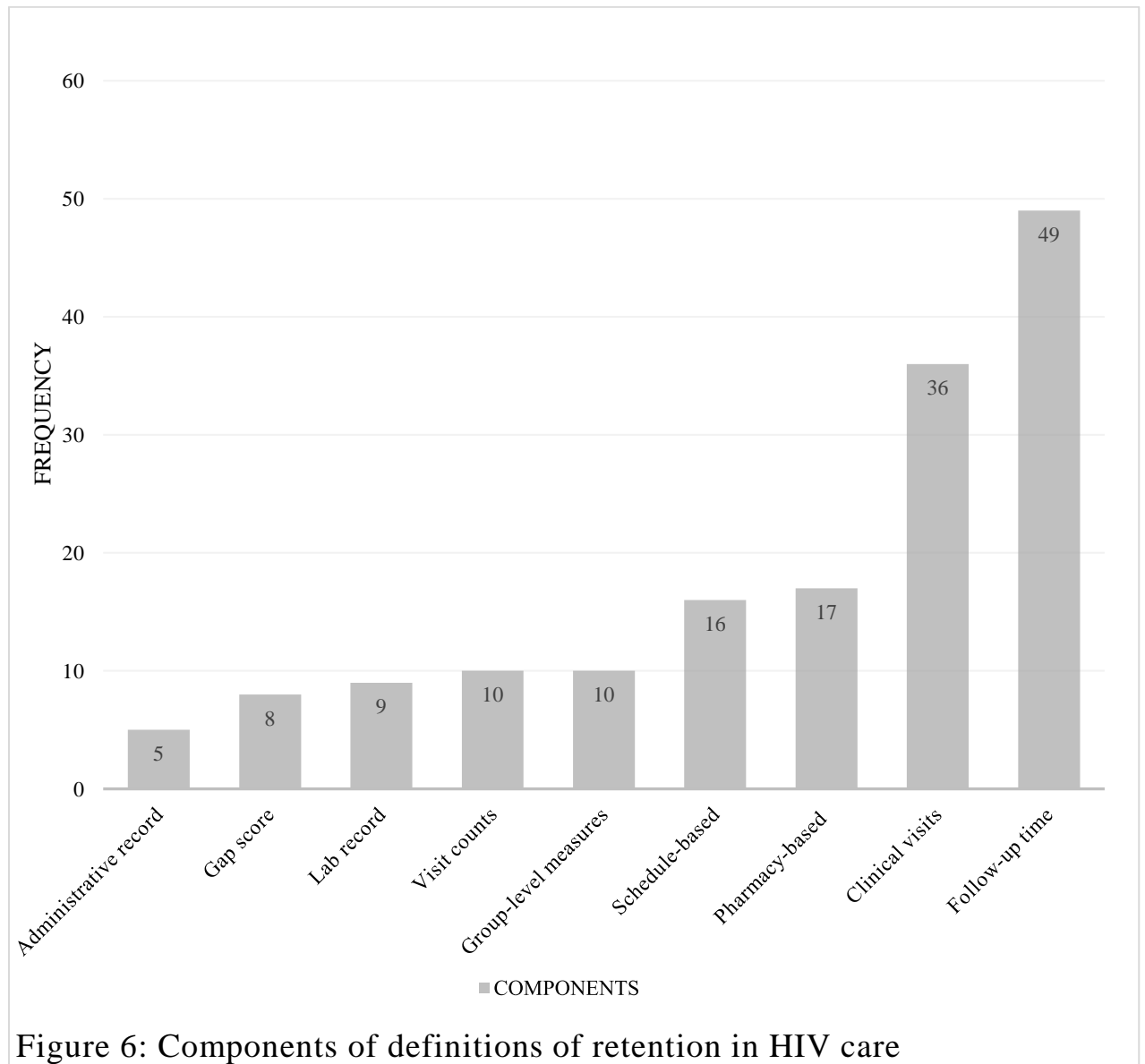
A total of 35 studies (70%) developed their own definitions without a rationale for the choice of the definition^{52-54, 56, 64, 66, 69, 70, 73, 75, 76, 85, 86, 89, 90, 94-96, 101, 104, 105, 108, 110, 113, 114, 119, 122, 123, 128-130} and three studies (6%)^{58, 87, 91} provided definitions cited from other articles along with a literature reference^{21, 128, 131-134} to support their definition. In total, 11(22%) of the definitions^{54, 62, 67, 88, 111, 125, 135} explicitly mentioned the names of the organisations, checklists and databases that informed their definitions of retention. Out of the total, 3(5%) did not provided a clearly defined measure of retention.^{68, 92, 93}

Some definitions have been developed at the national and international level. WHO (2011) criteria used in its report on retention in HIV care of measuring retention as retained in care at 6 months¹³⁶ was used in one study.⁵⁹The US national standards is completion of two or more HIV primary care appointments per year was also used once out of the studies given.¹⁰⁷The WHO threshold for virological failure at 6 months is viral load ≤ 1000 copies/ml.¹³⁷

3.2.1 Description of the Components of the Definitions

The definitions are classified into nine components, these components are visit counts, scheduled visits, pharmacy, lab visits, group-level, gap score, clinical visits, administrative records, and follow-up time (0-3 months, 3-6 months, 6-12 months, and 18+ months). The components are kept broad, to make them distinct from each other and identify any differences. The component most commonly used in the definitions is follow-up times used

49 times (83%), and the components used least frequently is administrative record used 5 times (8%). Figure 6 presents a bar graph of the components of the definitions.



We further categorized the definitions into six categories based on the similarities between the components. The category follow-up times comprise all the components recognized in the definitions which measure the follow-up times i.e., 0-3 months, 3-6 months, 6-12 months, and 12+months follow-up times. Type of visit category contains any time of visits considered towards patient's retention including clinic, pharmacy, laboratory, and any record of visit from the administrative record. The count of visit contains the components by the definitions have kept a record of the visit count i.e., either by counting the kept or missed visits or a gap-score. Scheduled visits category describes whether the appointment used as a retention measure was scheduled or not. The category unclear measures remain ambiguous and vague. Group-level definitions comprise definitions of measures defining retention as a group. Figure 7 represents the different categories of the definitions grouped according to the similar components.

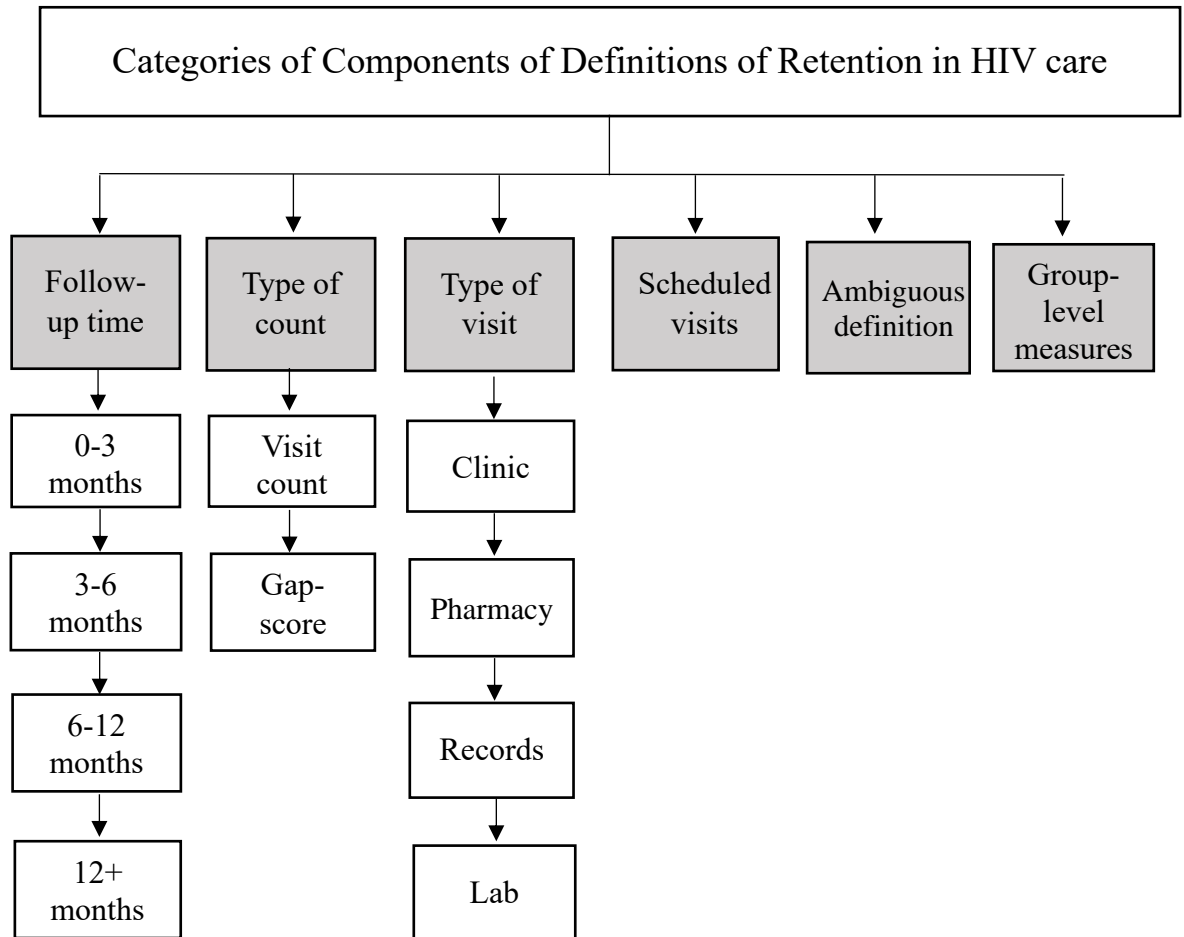


Figure 7: Categories of definitions of retention in HIV care by components

3.2.2 Limitations and Benefits of the Components of the Definitions

The limitations, benefits and potential applications of the various components used in the existing definitions must be discussed before framing a standard consensus definition of retention in care. Below we have tried to describe the components of the definitions in each category.

3.2.2.1 FOLLOW UP TIME

Follow-up time was used 47 times , the current definitions have focused on duration of follow-up at certain intervals from 0-3months^{110, 122, 129}, 3-6months^{24, 63, 88, 93, 96, 97, 100, 102, 103, 119, 122}, 6-12 months^{32, 52, 73, 74, 85, 87-89, 94, 98, 99, 102, 104, 108, 109, 119, 120, 122, 138} and 12 + months^{55, 58, 66, 73, 75, 82, 97, 123} with 6-12 months follow-up the being the most common duration of follow-up time.

BENEFITS

In clinical practice, the follow-up times should be based on the needs of the individual patients, a shorter follow-up time for patients who need more medical attention and patients with better health can have longer periods of time in between their regular visits.¹³⁹

Retention is an ongoing and dynamic and thus looking at short periods (even 1 year) may not reflect the nature of retention as a longitudinal entity.^{140,29}

LIMITATION

Follow up times vary according to the patients need, with patients with poor health needing more frequent visits. But the patients might be attending fewer visits then required but still considered as retained in care, based on the visits they attended.

3.2.2.2 TYPE OF VISIT

CLINIC RETENTION

Clinic retention was used in 36 definitions.^{55-57, 59, 60, 64-66, 68, 80, 82, 83, 87-91, 93, 96, 103, 106, 110, 115, 118-120, 122, 125, 141}

The retention in care must involve periodic visits with a HIV care physician or nurse practitioner, who can prescribe ART and assess the adherence to ART and overall health outcomes.³⁸ Benefit Engagement in clinical care to the clinic makes longitudinal tracking of PLHIV convenient, and allows comparison between clinics or individual providers.²⁴

Limitations

Definitions which account for retention based on adherence to a particular clinic do not include longitudinal retention in care. The patients who move locations without notifying the HIV care clinics in which they were receiving care are falsely considered as lost to care.
13, 22

Another limitation of the clinic visit is these visits are meant for prescription and management of therapy, while HIV management is a team-based effort, and social services, nurses and pharmacists are all integral part of the team.^{26, 29}

PHARMACY BASED RETENTION MEASURE

The eighteen studies which defined retention from the perspective of ART adherence, focussed on pharmacy refill.^{54, 56, 73-75, 98, 110, 118, 122, 123, 127, 142}

Benefits

Definitions of retention in care based on prescription refill ensures that the patients are receiving their ART medication regularly.²⁶

Limitations

Retention based on prescription refill do not encompass the overall retention in care, including health outcomes assessment, blood monitoring of immune status, access to treatment and HIV related social and medical support.¹⁴³

Furthermore, retention in these measures based on ART adherence, are directly related on availability of ART especially in low-resource settings. Moreover, even if the ART is picked up, this does not ensures that the patients are actually taking their medication as prescribed.²⁵

ADMINISTRATIVE RECORD BASED RETENTION MEASURE

Five definitions recorded retention status from the electronic or documented administrative record.^{80, 114, 115, 125, 144}

Benefits

At the clinic, research and program level it is a convenient method to track retention, and identify the patients' need at individual level and make comparisons with clinics and programs.²⁴

Limitations

Patient who moved locations without informing the clinics are marked as lost to follow in resource-limited settings and countries, though they may be retained in care in a new location. ^{34, 145}In high-income countries, where electronic health records (HER) are used administrative record is linked between the clinics, patients record can be easily retrieved and this issue is resolved. ¹⁴⁶

LABORATORY RECORD-BASED RETENTION MEASURES

Nine definitions used clinical biomarkers HIV-1 RNA or CD4 tests as proxies for outpatient clinic visits either attaining the virological success undetected viral load (<50 copies/ml) or a threshold of virological suppression ranged from with an undetectable HIV RNA (defined as < 50 copies/mL) to (<1000 copies per mL). ^{65, 67, 81, 82, 86, 116, 118, 124}The

Benefits

HIV biomarkers are directly related to the treatment effect of the HIV care, so are very accurate depiction of patients' health status. ³⁵

Limitations

HIV biomarkers are directly related to the health outcomes in the PLHIV, but they cannot replace the patients' HIV care visits. As previous research has provided evidence that patients with low CD4 and increase viral load at entry are more prone to attrition in care leading to increased mortality rate. ¹²⁸ Some patients who are not regularly attending their

HIV care visits might be needing more frequent emergency department visits, where biomarkers are obtained more often, if the retention measure is based on a laboratory record, these laboratory results might misrepresent an engagement in specialized HIV clinical care retained in care³⁹

In low-income and in some middle-income countries, routine monitoring of patients on ART using viral load testing is not always possible or regularly conducted especially when out of pocket payments are required. Laboratory tests are also limited by structural factors including laboratory capacity, specimen transportation, provider-patient, and clinic transfers, which make can impede meeting repeat testing goals.¹⁴⁷

Moreover, the lab records might not be linked with the patient record in the clinics, so the patients' record may have incomplete data on viral loads. The sensitivity of the assays can also vary, in determining whether a person has an undetectable viral load.¹⁴⁸

3.2.2.3 TYPE OF COUNT

VISIT COUNTS

Thirteen definitions focussed on retention as a simple count whether the patient attended or did not attend the visit.^{57, 73, 87, 94, 96, 101, 103, 107, 149} . The missed and kept visits both measure the opposite information, but both of them are useful in keeping the visits counts, though kept visits count are more feasible in administrative settings.¹⁵⁰

Benefits

The benefits to using absolute visit count is the ease of measurement for the clinicians and administration. There is less computational and programming burden to use these measures as a day-to-day measure, as they only require capturing of the number of visits missed or kept. The no show patients can be easily followed by generating a list of missed appointments.^{38, 39, 29}

Limitations

The major drawback from visit counts is establishing which appointments are considered kept and missed, keeping under consideration the appointments which got cancelled or rescheduled appointments. Moreover, the cause of missed appointment must be kept into account, as good and worsening health conditions both might perpetuate missed visits. Appointments count due to other socio-economical factors, cannot be assessed with these measures, as patient retention is not assessed over time.^{26, 29} As its not a longitudinal measures, dichotomous counts can not assess health outcomes over a longer duration of time.¹⁵⁰ Other appointments which should be focussed on this regard are the sick call or urgent care visits.^{26, 29}

GAP-SCORE

Gap-score is used as a measure in eight studies.^{26, 58, 75, 85, 89, 91, 120, 122, 151}

Gap-score refers to having at least one visit within a predetermined time period e.g. 3 months, 6 months, 9 months or 12 months.²⁴

Benefits

Establishing visits in a given period of time ensures that the patient does not have significant gap in receipt of care for a certain duration of time. Thus, gap score is an efficient measure in establishing continuous retention.²⁸

This approach allows the appointments to be closely or widely spaced depending on the individual needs.³⁹

Limitations

Though gap-score seems a desirable measure, but it has the challenges of computational assessment, as its difficult to assess the retention based on the patients who have more often gaps in care. ²⁵

3.2.2.4 SCHEDULED VISITS

Sixteen definitions have used scheduled visits as a component in their definitions.^{52, 54, 58, 60, 64, 66, 68, 75, 96, 101, 104, 109, 110, 122, 149}

These definitions have conceptualized retention in care based on visits scheduled at regularly defined intervals.^{26, 55, 152}

Benefits

These measures require less complex data capture and manipulation in the recording of the measure.²⁹

Limitations

PLHIV need different kind of visits due to their diverse and multifactorial needs. Major inconsistencies exist in the type of appointments which contribute towards patient's retention in care. PLHIV have various health and psychosocial issues and seek various kinds of interactions including appointment with primary care physician, HIV nurse specialist, HIV pharmacist, laboratory services or subspecialty phlebotomy, public health clinics for STI testing, social support, and psychological/mental support appointments. ^{26,}

29

3.2.2.5 GROUP-LEVEL DEFINITIONS

10 definitions^{56, 58, 59, 66, 73, 74, 125, 149, 153, 154} have measured retention rate of the patients in the clinic or program instead of individually for each patient.

Benefits

These measures are useful in comparing retention amongst clinics, countries and cascades by comparing the proportions of the PLHIV who have attained retention in care.

Limitations

Yet again, retention of individual patients is affected by individual factors, and it is very important to measure the rate individually.⁹

Moreover, there is a lot of variability in the numerators and denominators used to calculate the proportion of patients who are retained.²¹

3.2.2.6 AMBIGUOUS MEASURES

Three definitions were vague and did not provide much information about the measures they used.^{68, 92, 93} These measures defined retention as suboptimal time to follow-up, unambiguous visits times and undefined appointment adherence rates.

3.2.3 OTHER MEASURES TO DEFINE RETENTION

COMPOSITE DEFINITION

Three definitions^{60, 113, 121} provided an overall impact of the patient's status and prognosis in an individual, considering the severity of symptoms and clinical outcomes. But they are difficult to measure in outpatient clinics, and emergency visits. These definitions are more sophisticated measures and more feasible to be used in a trial.^{38, 39}

POST PARTUM RETENTION IN HIV POSITIVE WOMEN

Out of the total, seven studies^{47, 54, 57, 63, 105, 106, and 109}(11%) defined differently for expecting women/postpartum mothers and infants.

Pregnancy is not associated with disease progression in HIV positive women, but many women are lost to HIV care postpartum due to the increased emotional and physical distress.¹⁵⁵ This may result in viral rebound and poorer outcomes for both the mother and infant. Additionally, treatment interruptions can lead to the development of drug resistance and increase rates of vertical transmission in the setting of breast feeding.,¹⁵⁵⁻¹⁵⁷ and more advanced disease has been associated with infant morbidity and mortality.¹⁵⁶

Table 3: Pros and cons and recommendations of components of the definitions

COMPONENTS	PROS	CONS	RECOMMENDATIONS
Follow up time	<ul style="list-style-type: none"> ▪ Can be individualized based on patients needs. 	<ul style="list-style-type: none"> ▪ Limited in standardization. 	<ul style="list-style-type: none"> ▪ Needs a minimum standard for all patients for easy comparison but should be individualized based on patients needs.
Clinical visits	<ul style="list-style-type: none"> ▪ Easy to track patients. ▪ Allows comparison between patients and clinics. 	<ul style="list-style-type: none"> ▪ Difficult to account for patients who moved location ▪ Does not include overall HIV management. 	<ul style="list-style-type: none"> ▪ More elaboration on what kind of visits should be considered for patients to be retained in care.
Adherence to ART	<ul style="list-style-type: none"> ▪ Ensures the adherence to ART therapy. 	<ul style="list-style-type: none"> ▪ Cannot encompass the patient overall health care and outcomes 	<ul style="list-style-type: none"> ▪ It is important to ensure that patients are receiving HIV care visits along with ART therapy.
Administrative records	<ul style="list-style-type: none"> ▪ Convenient to track overall health. ▪ Patients' records are easily available 	<ul style="list-style-type: none"> ▪ Patients becomes lost to follow up if moved location without notice. 	<ul style="list-style-type: none"> ▪ Electronic data bases should be ensured globally so that patients record is easily accessible without restriction of time and location.
Laboratory records	<ul style="list-style-type: none"> ▪ Accurate depictions of health status 	<ul style="list-style-type: none"> ▪ Patients still need HIV care visit ▪ Inaccurate depiction of health if patients go more often to emergency ▪ Resource demanding ▪ Variable with test sensitivity. 	<ul style="list-style-type: none"> ▪ Viral load assays and CD4 counts should be ensured at a standard time and data should be available along with patients' health record.
Visit counts	<ul style="list-style-type: none"> ▪ Computationally convenient ▪ Less administrative burden 	<ul style="list-style-type: none"> ▪ Can show falsified results due to missed, cancel and emergency visits. 	<ul style="list-style-type: none"> ▪ Clarification should be ensured in which visits should count towards patients' retention in care.

	<ul style="list-style-type: none"> ▪ Easy patients follow up 		
Gap score	<ul style="list-style-type: none"> ▪ Can ensure patients is making regular visits according to their needs 	<ul style="list-style-type: none"> ▪ Difficult computationally ▪ Patients may attend less visits than needed and still considered as retained in care. 	<ul style="list-style-type: none"> ▪ Needs to ensure that patients are retained to care according to their needs.
Scheduled visits	<ul style="list-style-type: none"> ▪ Easy to account and keep track of Patients' retention 	<ul style="list-style-type: none"> ▪ Lots of visit types come under scheduled visit 	<ul style="list-style-type: none"> ▪ Standardization on which visits should be considered for retention
Group-level	<ul style="list-style-type: none"> ▪ Comparison amongst clinics and 	<ul style="list-style-type: none"> ▪ Lacks the individual retention 	<ul style="list-style-type: none"> ▪ More clarification on numerators and denominators

CHAPTER 4:

DISCUSSION

4:0 DISCUSSION

This review is the first to summarize the definitions of retention in HIV care. We identified 59 definitions in 50 published eligible studies. Both within and across studies, there is no consistency evident amongst the different definitions, in terms of referencing, terminology used, time intervals, duration of follow-up, along with endpoints. This review highlights where agreement is needed including i) the time of follow -up visits ii) what kind of visits to measure for retention iii) how to keep track of visits iv) unclarity in the information v) type of count of visits v) terminology of the definitions.

We identified ten components that are used across the studies to define retention. We further categorized the components into six categories based on the similar characteristics, to find which components need to be standardized. The components used to present the methods of measuring retention are kept broad, so some of the components of the retention definitions sound similar, for example clinic visit, administrative record and scheduled visits. We left those components come under the same terminology as used in the studies on purpose, for example clinic visit and scheduled visit both might mean a scheduled visit with an HIV care provider, but it needs further clarification both in terminology and description. It may not be perfectly obvious what the difference between them is, and further it is unclear whether all authors have used these terms in the same context. Because of this ambiguity between the definitions, we chose to present more detailed components.

The need for a standard measure of retention has been always a focus of researchers in the field of HIV care cascade.^{26, 29, 33, 34, 40,41,42,43,150} Previous studies have been conducted to compare multiple measures of retention including missed and kept visits, gap scores, visit constancy and appointment adherence, and HRSA(Human Resources and Services Administration)and determined all the measures were predictive of viral suppression.^{39, 43, 150, 158} These studies and definitions provide evidence that retention measures significantly affect the health outcomes, but none of the studies was able to prefer any measure over the others. The need for standardization is still a gap for comparison of retention data across studies and countries.⁴⁰

Mcclarty et al., 2021 conducted a HIV care cascade cross-sectional study to estimate the local needs to improve service coverage within Manitoba, due to lack of standard definitions available data was not recorded for in time point measurement of estimates. They developed lenient to moderate definitions with consensus with HIV care providers and experts in the field to measure retention data as available from the record. These efforts again highlights the need of standard definition.¹⁷

4.1 STEPS TOWARDS A STANDARD DEFINITION (FUTURE IMPLICATIONS)

Retention in care is predictive of health outcomes in PLHIV.^{33, 159} Its assessment requires a need to at least develop a minimum set of criteria. A standard and consensus definition is needed to ascertain the outcomes which gauge the needs from the individualistic perspective, along with the specific context and objectives of the researcher and clinician. The development of the standard globally agreed-upon definition should be through an iterative review process with feedback from the HIV programs experts across the globe with definitions and the components presented to providers and researchers. The definitions should be reviewed after the provided feedback on whether the definitions reflect clinical realities and their experience in providing care, until a consensus can be reached on final definition for retention in care.¹⁷ A final consideration towards a standard definition, emphasizes on clarity and standardization of the terminologies and measures must be taken. The focus should be on the standardization of the components more frequently used in the definitions provided in this review.

A standard definition should fulfill the criteria of being flexible and easy to use in different setting and circumstance, keeping in mind the diversity of infrastructure across settings and countries.¹⁴⁰ The resources to measure retention should be readily available at the point of care.²⁴ Moreover, the final agreed upon measure must be sensitive to capture patient ‘retention behavior’s as regular users, sporadic users, and nonengagers and providing them with needed interventions and supports based on the standard measure.²⁶

As a further step to improve data accuracy, timeliness, availability of patient record, and decrease data duplication or loss, emphasises should be placed on electronic health record (EHR), so that the record for any kind of appointment is easily linked to the patients record and loss of patients due to patients transfers to other clinics is minimized.¹⁴⁶

4.2 STRENGTHS

The strength of this review is embedded within the novelty of summarising the range of retention definitions available in RCTs. We included definitions from RCTs within the overview of studies⁴⁵ and supplemented these with the definitions from updated search by replacing the search term systematic review to RCT. The review was conducted with a strong systematic review methodology to minimize opinion bias and subjectivity.

Second, as the main purpose of this review is to extract definitions verbatim from RCTs, but other relevant information (e.g., funding source, country of trial, population of study), were extracted as well, suggested by PRISMA-ScR, to elaborate which definitions are more effective under which circumstances.

4.3 LIMITATIONS

Our review does have some limitations, which need to be considered. The overview of systematic reviews only included English language systematic reviews. This may have

introduced some publication bias. However, the updated searches included systematic reviews in all languages.

Another limitation of our review is that based on our findings, we cannot recommend a standard definition of retention. The purpose of our review was to summarize of definitions of retention in HIV care used in RCTs and what are pros and cons of the different definitions. This work is a step towards future research seeking HIV stake holders' views on a standard definition Our review provided a summary of the definitions and reviewed the components, to support their usage, moreover, this work does not provide whether specific definitions were related with better retention outcomes than others. This was limited due to the diversity of definitions which precluded synthesis.

4.5 CONCLUSION

This is the first comprehensive systematic review of the definitions used for retention measures in HIV care.

This review provides a compilation of existing definitions of retention in HIV care in the randomized controlled trials. In summary, we report very little consensus regarding definitions of retention in HIV care in the research literature. We report and compare definitions of retention so researchers can weigh their definitions with the body of definitions, with the ultimate aim of motivating the research community to establish a clear and unambiguous definition. This work will provide resource for researchers to recommend a definition of retention. Future research is needed to seek practitioners' views

on the most unambiguous, explicit definition of retention. This is only a first step in research towards a standard definition of retention.

REFERENCES

1. Bor R, Miller R, Goldman E. HIV/AIDS and the family: A review of research in the first decade. *Journal of Family Therapy*. 1993;15(2):187-204.
2. Epidemiology of HIV/AIDS-United States, 1981-2005. *MMWR Morb Mortal Wkly Rep*. Jun 2 2006;55(21):589-92.
3. World Health Organization.(2013). *Consolidated Guidelines On The Use Of Antiretroviral Drugs For Treating And Preventing Hiv Infection:Recommendations For A Public Health Approach*, London: World Health Organization; 2013. p. 271.
4. Laurent C, Ngom Gueye NF, Ndour CT, et al. Long-term benefits of highly active antiretroviral therapy in Senegalese HIV-1-infected adults. *J Acquir Immune Defic Syndr*. Jan 1 2005;38(1):14-7. doi:10.1097/00126334-200501010-00003
5. Gibert CL. Treatment Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents: An Update. *Fed Pract*. 2016;33(Suppl 3):31S-36S.
6. Harlow AF, Bor J, Brennan AT, et al. Impact of Viral Load Monitoring on Retention and Viral Suppression: A Regression Discontinuity Analysis of South Africa's

- National Laboratory Cohort. *American Journal of Epidemiology*. 2020;189(12):1492-1501. doi:10.1093/aje/kwaa140
7. World Health Organization. (2016). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach*. Retrieved from <https://www.who.int/publications/i/item/9789241549684>
 8. World Health Organization. (2021). *HIV/AIDS Progress report 2021*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/hiv-aids>.
 9. Bulsara SM, Wainberg ML, Newton-John TRO. Predictors of Adult Retention in HIV Care: A Systematic Review. *AIDS Behav*. Mar 2018;22(3):752-764. doi:10.1007/s10461-016-1644-y
 10. Patterson S, Cescon A, Samji H, et al. Life expectancy of HIV-positive individuals on combination antiretroviral therapy in Canada. *BMC Infectious Diseases*. 2015/07/17 2015;15(1):274. doi:10.1186/s12879-015-0969-x
 11. Shrestha RK, Gardner L, Marks G, et al. Estimating the cost of increasing retention in care for HIV-infected patients: results of the CDC/HRSA retention in care trial. *J Acquir Immune Defic Syndr*. Mar 1 2015;68(3):345-50. doi:10.1097/QAI.0000000000000462
 12. Bradley H, Hall HI, Wolitski RJ, et al. Vital Signs: HIV diagnosis, care, and treatment among persons living with HIV--United States, 2011. *MMWR Morb Mortal Wkly Rep*. Nov 28 2014;63(47):1113-7.

13. Cheever LW. Engaging HIV-infected patients in care: their lives depend on it. *Clin Infect Dis*. Jun 1 2007;44(11):1500-2. doi:10.1086/517534
14. UNAIDS. (2021). *Getting to Zero: How will we fast-track the AIDS response? discussion paper for consultations on UNAIDS Strategy 2016-2021*. Retrieved from http://www.icad-cisd.com/pdf/UNAIDS/Strategy-Consultations/1-UNAIDS-Discussion-Paper_2016-2021-Strategy-Consultation.
15. UNAIDS. (2015). *Understanding Fast-Track: accelerating action to end the AIDS epidemic by 2030*. https://www.unaids.org/sites/default/files/media_asset/201506_JC2743_Understanding_FastTrack_en.pdf (accessed Feb 25, 2022).
16. World Health Organization. (2018). *HIV strategic information for impact: cascade data use manual: to identify gaps in HIV and health services for programme improvement: user manual*. Retrieved from <https://www.who.int/publications/i/item/9789241514415>
17. McClarty LM, Kasper K, Ireland L, Loeppky C, Blanchard JF, Becker ML. The HIV care cascade in Manitoba, Canada: Methods, measures, and estimates to meet local needs. *Journal of Clinical Epidemiology*. 2021;132:26-33.
18. UNAIDS. 90-90-90: an ambitious treatment target to help end the AIDS epidemic. secondary 90-90-90: an ambitious treatment target to help end the AIDS epidemic. 2014. Available: https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf
19. UNAIDS.(2020). *Special Analysis 90-90-90: Good Progress, but the World is Off-track for Hitting the 2020 Targets*. 2020. Retrieved from

https://www.unaids.org/en/resources/presscentre/featurestories/2020/september/20200921_90-90-90.

20. Levi J, Raymond A, Pozniak A, Vernazza P, Kohler P, Hill A. Can the UNAIDS 90-90-90 target be achieved? A systematic analysis of national HIV treatment cascades. *BMJ Global Health*. 2016;1(2):e000010. doi:10.1136/bmjgh-2015-000010
21. Mugglin C, Wandeler G, Estill J, et al. Retention in care of HIV-infected children from HIV test to start of antiretroviral therapy: systematic review. *PLoS One*. 2013;8(2):e56446. doi:10.1371/journal.pone.0056446
22. Geng EH, Nash D, Kambugu A, et al. Retention in care among HIV-infected patients in resource-limited settings: emerging insights and new directions. *Curr HIV/AIDS Rep*. Nov 2010;7(4):234-44. doi:10.1007/s11904-010-0061-5
23. Messeri PA, Abramson DM, Aidala AA, Lee F, Lee G. The impact of ancillary HIV services on engagement in medical care in New York City. *AIDS Care*. 2002/08/01 2002;14(sup1):15-29. doi:10.1080/09540120220149948
24. Roscoe C, Hachey DM. Retention in HIV Care. *National HIV curriculum*. 2020. <https://www.hiv.uw.edu/go/basic-primary-care/retention-care/core-concept/all>
25. Stricker SM, Fox KA, Baggaley R, et al. Retention in care and adherence to ART are critical elements of HIV care interventions. *AIDS Behav*. Oct 2014;18 Suppl 5:S465-75. doi:10.1007/s10461-013-0598-6
26. Horstmann E, Brown J, Islam F, Buck J, Agins BD. Retaining HIV-infected patients in care: Where are we? Where do we go from here? *Clin Infect Dis*. Mar 1 2010;50(5):752-61. doi:10.1086/649933

27. Giordano TP, Gifford AL, White AC, Jr., et al. Retention in care: a challenge to survival with HIV infection. *Clin Infect Dis*. Jun 1 2007;44(11):1493-9. doi:10.1086/516778
28. Lourenço L, Nohpal A, Shopin D, et al. Non-HIV-related health care utilization, demographic, clinical and laboratory factors associated with time to initial retention in HIV care among HIV-positive individuals linked to HIV care. *HIV Med*. Apr 2016;17(4):269-79. doi:10.1111/hiv.12297
29. Giordano TP. Retention in HIV care: what the clinician needs to know. *Topics in antiviral medicine*. Feb-Mar 2011;19(1):12-16.
30. Rebeiro P, Althoff KN, Buchacz K, et al. Retention among North American HIV-infected persons in clinical care, 2000-2008. *Journal of acquired immune deficiency syndromes (1999)*. 2013;62(3):356-362. doi:10.1097/QAI.0b013e31827f578a
31. Anderson AN, Higgins CM, Haardörfer R, Holstad MM, Nguyen MLT, Waldrop-Valverde D. Disparities in Retention in Care Among Adults Living with HIV/AIDS: A Systematic Review. *AIDS Behav*. Apr 2020;24(4):985-997. doi:10.1007/s10461-019-02679-2
32. Chandra DK, Bazazi AR, Nahaboo Solim MA, Kamarulzaman A, Altice FL, Culbert GJ. Retention in clinical trials after prison release: results from a clinical trial with incarcerated men with HIV and opioid dependence in Malaysia. *HIV Res Clin Pract*. Feb 2019;20(1):12-23. doi:10.1080/15284336.2019.1603433

33. Yehia BR, Fleishman JA, Metlay JP, et al. Comparing different measures of retention in outpatient HIV care. *AIDS*. Jun 1 2012;26(9):1131-9. doi:10.1097/QAD.0b013e3283528afa
34. Geng EH, Odeny TA, Lyamuya R, et al. Retention in Care and Patient-Reported Reasons for Undocumented Transfer or Stopping Care Among HIV-Infected Patients on Antiretroviral Therapy in Eastern Africa: Application of a Sampling-Based Approach. *Clin Infect Dis*. Apr 1 2016;62(7):935-944. doi:10.1093/cid/civ1004
35. Spiegel PB. HIV/AIDS among conflict-affected and displaced populations: dispelling myths and taking action. *Disasters*. Sep 2004;28(3):322-39. doi:10.1111/j.0361-3666.2004.00261.x
36. Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *Lancet Infect Dis*. Mar 2013;13(3):214-22. doi:10.1016/s1473-3099(12)70315-8
37. UNAIDS. (2021). *Fact sheet 2020 - Latest statistics on the status of the AIDS epidemic. Secondary Fact* .Retrieved from <https://www.unaids.org/en/resources/fact-sheet>.
38. Mugavero MJ, Davila JA, Nevin CR, Giordano TP. From access to engagement: measuring retention in outpatient HIV clinical care. *AIDS Patient Care STDS*. Oct 2010;24(10):607-13. doi:10.1089/apc.2010.0086
39. Mugavero MJ, Westfall AO, Zinski A, et al. Measuring retention in HIV care: the elusive gold standard. *J Acquir Immune Defic Syndr*. Dec 15 2012;61(5):574-80. doi:10.1097/QAI.0b013e318273762f

40. Mugglin C, Kläger D, Gueler A, Vanobberghen F, Rice B, Egger M. The HIV care cascade in sub-Saharan Africa: systematic review of published criteria and definitions. *J Int AIDS Soc.* Jul 2021;24(7):e25761. doi:10.1002/jia2.25761
41. Ssekalembe G, Isfandiari MA, Suprianto H. Current Status Towards 90-90-90 UNAIDS Target and Factors Associated with HIV Viral Load Suppression in Kediri City, Indonesia. *HIV AIDS (Auckl).* 2020;12:47-57. doi:10.2147/HIV.S231173
42. Colasanti J, Kelly J, Pennisi E, et al. Continuous Retention and Viral Suppression Provide Further Insights Into the HIV Care Continuum Compared to the Cross-sectional HIV Care Cascade. *Clin Infect Dis.* Mar 1 2016;62(5):648-654. doi:10.1093/cid/civ941
43. Crawford TN, Sanderson WT, Thornton A. A comparison study of methods for measuring retention in HIV medical care. *AIDS Behav.* Nov 2013;17(9):3145-51. doi:10.1007/s10461-013-0559-0
44. Mbuagbaw L, Mertz D, Lawson DO, et al. Strategies to improve adherence to antiretroviral therapy and retention in care for people living with HIV in high-income countries: a protocol for an overview of systematic reviews. *BMJ open.* 2018;8(9):e022982.
45. Mbuagbaw L, Hajizadeh A, Wang A, et al. Overview of systematic reviews on strategies to improve treatment initiation, adherence to antiretroviral therapy and retention in care for people living with HIV: part 1. *BMJ Open.* Sep 23 2020;10(9):e034793. doi:10.1136/bmjopen-2019-034793
46. Education section – Studies within a review (SWAR). *Journal of Evidence Based Medicine.* 2012;5(3)

47. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med.* Aug 18 2009;*151*(4):264-9, w64. doi:10.7326/0003-4819-151-4-200908180-00135
48. Reuters. T. Endnote X7. Philadelphia, PA, USA: Thomson Reuters, 2013.
49. DistillerSR. Version 2.35. Evidence Partners; 2021. Accessed May-June 2021. <https://www.evidencepartners.com>
50. Viera AJ, Garrett JM. Understanding interobserver agreement: the kappa statistic. *Fam med.* 2005;*37*(5):360-363.
51. World bank list of economics. (2017).<https://iccmoot.com/wp-content/uploads/2017/07/World-Bank-List-of-Economies.pdf>.
52. Byonanebye DM, Nabaggala MS, Naggirinya AB, et al. An Interactive Voice Response Software to Improve the Quality of Life of People Living With HIV in Uganda: randomized Controlled Trial. Journal Article; Randomized Controlled Trial; Research Support, Non-U.S. Gov't. *JMIR mhealth and uhealth.* 2021;*9*(2):e22229.
53. Fahey C, Njau P, Katabaro E, et al. Effects of financial incentives for clinic attendance on HIV viral suppression among adults initiating antiretroviral therapy in Tanzania: a three-arm randomized controlled trial. Journal: Conference Abstract. *Journal of the International AIDS Society.* 2020;*23*(SUPPL 4)
54. Fatti G, Ngorima-Mabhena N, Mothibi E, et al. Outcomes of Three- Versus Six-Monthly Dispensing of Antiretroviral Treatment (ART) for Stable HIV Patients in Community ART Refill Groups: A Cluster-Randomized Trial in Zimbabwe. *J Acquir Immune Defic Syndr.* Jun 1 2020;*84*(2):162-172. doi:10.1097/qai.0000000000002333

55. Gosset A, Protopopescu C, Larmarange J, et al. Retention in care trajectories of HIV-positive individuals participating in a universal test-and-treat program in rural South Africa (ANRS 12249 TasP Trial). *Journal of acquired immune deficiency syndromes*. 2019;80(4):375-385.
56. Jani IV, Meggi B, Loquiha O, et al. Effect of point-of-care early infant diagnosis on antiretroviral therapy initiation and retention of patients. *AIDS*. Jul 17 2018;32(11):1453-1463. doi:10.1097/QAD.0000000000001846
57. Kim MH, Ahmed S, Tembo T, et al. VITAL Start: Video-Based Intervention to Inspire Treatment Adherence for Life-Pilot of a Novel Video-Based Approach to HIV Counseling for Pregnant Women Living with HIV. *AIDS Behav*. Nov 2019;23(11):3140-3151. doi:10.1007/s10461-019-02634-1
58. Lubega M, Tumwesigye NM, Kadobera D, et al. Effect of Community Support Agents on Retention of People Living With HIV in Pre-antiretroviral Care: A Randomized Controlled Trial in Eastern Uganda. *J Acquir Immune Defic Syndr*. Oct 1 2015;70(2):e36-43. doi:10.1097/qai.0000000000000723
59. Mavhu W, Willis N, Mufuka J, et al. Effect of a differentiated service delivery model on virological failure in adolescents with HIV in Zimbabwe (Zvandiri): a cluster-randomised controlled trial. *The Lancet Global Health*. 2020;8(2):e264-e275.
60. Sabin LL, Halim N, Hamer DH, et al. Retention in HIV Care Among HIV-Seropositive Pregnant and Postpartum Women in Uganda: Results of a Randomized Controlled Trial. *AIDS Behav*. Nov 2020;24(11):3164-3175. doi:10.1007/s10461-020-02875-5

61. Willis N, Milanzi A, Mawodzeke M, et al. Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: a randomised trial among adolescents living with HIV in rural Zimbabwe. *BMC Public Health*. Jan 28 2019;19(1):117. doi:10.1186/s12889-019-6447-4
62. Dulli L, Ridgeway K, Packer C, et al. A Social Media-Based Support Group for Youth Living With HIV in Nigeria (SMART Connections): randomized Controlled Trial. Journal: Article. *Journal of medical Internet research*. 2020;22(6):e18343-.
63. Fayorsey RN, Wang C, Chege D, et al. Effectiveness of a Lay Counselor-Led Combination Intervention for Retention of Mothers and Infants in HIV Care: a Randomized Trial in Kenya. Journal Article; Randomized Controlled Trial; Research Support, N.I.H., Extramural. *Journal of acquired immune deficiency syndromes (1999)*. 2019;80(1):56-63.
64. Goodrich S, Siika A, Mwangi A, et al. Development, assessment and outcomes of a community-based model of anti-retroviral care in western Kenya through a cluster-randomized control trial. Journal: Article in Press. *Journal of acquired immune deficiency syndromes (1999)*, 87(2),e198.
65. Khan S, Spiegelman D, Walsh F, et al. Early access to antiretroviral therapy versus standard of care among HIV-positive participants in Eswatini in the public health sector: the MaxART stepped-wedge randomized controlled trial. Journal Article; Randomized Controlled Trial; Research Support, N.I.H., Extramural; Research Support, Non-U.S. Gov't. *Journal of the International AIDS Society*. 2020;23(9):e25610.

66. Kinuthia J, Ronen K, Unger JA, et al. RCT of 2-way vs 1-way sms messaging to improve efficacy of pmtct-art in Kenya. Journal: Conference Abstract. *Topics in antiviral medicine*. 2021;29(1):215-.
67. Labhardt ND, Ringera I, Lejone TI, et al. Effect of Offering Same-Day ART vs Usual Health Facility Referral During Home-Based HIV Testing on Linkage to Care and Viral Suppression Among Adults With HIV in Lesotho: The CASCADE Randomized Clinical Trial. *JAMA*. Mar 20 2018;319(11):1103-1112. doi:10.1001/jama.2018.1818
68. Mbuagbaw L, Thabane L, Ongolo-Zogo P, et al. The Cameroon Mobile Phone SMS (CAMPS) trial: a randomized trial of text messaging versus usual care for adherence to antiretroviral therapy. *PLoS One*. 2012;7(12):e46909. doi:10.1371/journal.pone.0046909
69. Neduzhko O, Postnov O, Sereda Y, et al. Modified Antiretroviral Treatment Access Study (MARTAS): A Randomized Controlled Trial of the Efficacy of a Linkage-to-Care Intervention Among HIV-Positive Patients in Ukraine. *AIDS Behav*. Nov 2020;24(11):3142-3154. doi:10.1007/s10461-020-02873-7
70. Odeny TA, Hughes JP, Bukusi EA, et al. Text messaging for maternal and infant retention in prevention of mother-to-child HIV transmission services: A pragmatic stepped-wedge cluster-randomized trial in Kenya. *PLoS Med*. Oct 2019;16(10):e1002924. doi:10.1371/journal.pmed.1002924
71. Roy M, Bolton-Moore C, Sikazwe I, et al. Participation in adherence clubs and on-time drug pickup among HIV-infected adults in Zambia: A matched-pair cluster randomized trial. *PLoS Med*. Jul 2020;17(7):e1003116. doi:10.1371/journal.pmed.1003116

72. Sarna A, Saraswati LR, Okal J, et al. Cell Phone Counseling Improves Retention of Mothers With HIV Infection in Care and Infant HIV Testing in Kisumu, Kenya: A Randomized Controlled Study. *Glob Health Sci Pract.* Jun 2019;7(2):171-188. doi:10.9745/ghsp-d-18-00241
73. Tukei BB, Fatti G, Tiam A, et al. Community-based multimonth dispensing of ART: a cluster randomised trial in Lesotho. Journal: Conference Abstract. *Topics in antiviral medicine.* 2020;28(1):15-20.
74. Bassett IV, Coleman SM, Giddy J, et al. Sizanani: A Randomized Trial of Health System Navigators to Improve Linkage to HIV and TB Care in South Africa. *J Acquir Immune Defic Syndr.* Oct 1 2016;73(2):154-60. doi:10.1097/qai.0000000000001025
75. Cassidy T, Grimsrud A, Keene C, et al. Twenty-four-month outcomes from a cluster-randomized controlled trial of extending antiretroviral therapy refills in ART adherence clubs. Journal Article; Randomized Controlled Trial; Research Support, Non-U.S. Gov't. *Journal of the International AIDS Society.* 2020;23(12):e25649.
76. Chandra DK, Bazazi AR, Nahaboo Solim MA, Kamarulzaman A, Altice FL, Culbert GJ. Retention in clinical trials after prison release: results from a clinical trial with incarcerated men with HIV and opioid dependence in Malaysia. *Hiv Research & Clinical Practice.* Jan 2 2019;20(1):12-23.
77. Date A, Pals SL, Alexander H, et al. Effect of tuberculosis screening and retention interventions on early antiretroviral therapy mortality in Botswana: A stepped-wedge cluster randomized trial. *BMC Medicine.* 2020;18(1):19.

78. Fox MP, Pascoe S, Huber AN, et al. Adherence clubs and decentralized medication delivery to support patient retention and sustained viral suppression in care: results from a cluster-randomized evaluation of differentiated ART delivery models in South Africa. Comparative Study; Journal Article; Multicenter Study; Observational Study; Randomized Controlled Trial; Research Support, N.I.H., Extramural; Research Support, Non-U.S. Gov't. *PLoS medicine*. 2019;16(7):e1002874.
79. Lebelonyane R, Bachanas P, Abrams W, et al. Fast-track ART initiation in Botswana is associated with high rates of ART initiation, retention in care, and virological suppression. *Journal of the International AIDS Society*. 2018;21(Supplement 6)22nd International AIDS Conference, AIDS 2018. Netherlands.
80. Maskew M, Brennan AT, Fox MP, et al. A clinical algorithm for same-day HIV treatment initiation in settings with high TB symptom prevalence in South Africa: the SLATE II individually randomized clinical trial. Journal Article; Multicenter Study; Pragmatic Clinical Trial; Randomized Controlled Trial; Research Support, Non-U.S. Gov't. *PLoS medicine*. 2020;17(8):e1003226.
81. McLaughlin MM, Franke MF, Muñoz M, et al. Community-Based Accompaniment with Supervised Antiretrovirals for HIV-Positive Adults in Peru: a Cluster-Randomized Trial. Journal Article; Randomized Controlled Trial; Research Support, N.I.H., Extramural. *AIDS and behavior*. 2018;22(1):287-296.
82. Myer L, Phillips TK, Zerbe A, et al. Integration of postpartum healthcare services for HIV-infected women and their infants in South Africa: A randomised controlled trial. *PLoS Med*. Mar 2018;15(3):e1002547. doi:10.1371/journal.pmed.1002547

83. Pascoe SJ, Fox MP, Huber AN, et al. Differentiated HIV care in South Africa: the effect of fast-track treatment initiation counselling on ART initiation and viral suppression as partial results of an impact evaluation on the impact of a package of services to improve HIV treatment adherence. *J Int AIDS Soc.* Nov 2019;22(11):e25409. doi:10.1002/jia2.25409
84. Quame-Amaglo J, Thomas KK, Donnell D, et al. Point-of-care HIV viral load testing combined with task shifting to improve treatment outcomes (STREAM): findings from an open-label, non-inferiority, randomised controlled trial. *The Lancet HIV.* 2020;7(4):e229-e237.
85. Samet JH, Blokhina E, Cheng DM, et al. A strengths-based case management intervention to link HIV-positive people who inject drugs in Russia to HIV care. *AIDS (02699370).* 2019;33(9):1467-1476.
86. El-Sadr WM, Beauchamp G, Hall HI, et al. Durability of the Effect of Financial Incentives on HIV Viral Load Suppression and Continuity in Care: HPTN 065 Study. *J aids-Journal of Acquired Immune Deficiency Syndromes.* Jul 1 2019;81(3):300-303.
87. Gardner LI, Giordano TP, Marks G, et al. Enhanced personal contact with HIV patients improves retention in primary care: a randomized trial in 6 US HIV clinics. *Clin Infect Dis.* Sep 1 2014;59(5):725-34. doi:10.1093/cid/ciu357
88. Gwadz M, Cleland CM, Applegate E, et al. Behavioral intervention improves treatment outcomes among HIV-infected individuals who have delayed, declined, or discontinued antiretroviral therapy: a randomized controlled trial of a novel intervention. *AIDS Behav.* Oct 2015;19(10):1801-17. doi:10.1007/s10461-015-1054-6

89. Konkle-Parker DJ, Amico KR, McKinney VE. Effects of an intervention addressing information, motivation, and behavioral skills on HIV care adherence in a southern clinic cohort. *AIDS Care*. 2014;26(6):674-83. doi:10.1080/09540121.2013.845283
90. MacGowan RJ, Lifshay J, Mizuno Y, Johnson WD, McCormick L, Zack B. Positive Transitions (POST): Evaluation of an HIV Prevention Intervention for HIV-Positive Persons Releasing from Correctional Facilities. *AIDS Behav*. Jun 2015;19(6):1061-9. doi:10.1007/s10461-014-0879-8
91. Naar-King S, Outlaw A, Green-Jones M, Wright K, Parsons JT. Motivational interviewing by peer outreach workers: a pilot randomized clinical trial to retain adolescents and young adults in HIV care. *AIDS Care*. Jul 2009;21(7):868-73. doi:10.1080/09540120802612824
92. Norton BL, Person AK, Castillo C, Pastrana C, Subramanian M, Stout JE. Barriers to using text message appointment reminders in an HIV clinic. *Telemed J E Health*. Jan 2014;20(1):86-9. doi:10.1089/tmj.2012.0275
93. Robbins GK, Lester W, Johnson KL, et al. Efficacy of a clinical decision-support system in an HIV practice: a randomized trial. *Ann Intern Med*. Dec 4 2012;157(11):757-66. doi:10.7326/0003-4819-157-11-201212040-00003
94. Rotheram-Borus MJ, Rice E, Comulada WS, et al. Intervention outcomes among HIV-affected families over 18 months. *AIDS Behav*. Jul 2012;16(5):1265-75. doi:10.1007/s10461-011-0075-z
95. Sherman EM, Niu J, Elrod S, Clauson KA, Alkhateeb F, Eckardt P. Effect of mobile text messages on antiretroviral medication adherence and patient retention in early HIV care:

- an open-label, randomized, single center study in south Florida. *AIDS Research & Therapy*. 2020;17(1):1-8.
96. Wagner GJ, Hoffman R, Linnemayr S, et al. START (Supporting Treatment Adherence Readiness through Training) Improves Both HIV Antiretroviral Adherence and Viral Reduction, and is Cost Effective: results of a Multi-site Randomized Controlled Trial. Journal: Article in Press. *AIDS and behavior*. 2021;
97. Wolitski RJ, Kidder DP, Pals SL, et al. Randomized trial of the effects of housing assistance on the health and risk behaviors of homeless and unstably housed people living with HIV. *AIDS Behav*. Jun 2010;14(3):493-503. doi:10.1007/s10461-009-9643-x
98. Hoffman RM, Moyo C, Balakasi KT, et al. Multimonth dispensing of up to 6 months of antiretroviral therapy in Malawi and Zambia (INTERVAL): a cluster-randomised, non-blinded, non-inferiority trial. Journal Article; Randomized Controlled Trial; Research Support, U.S. Gov't, Non-P.H.S. *The lancet Global health*. 2021;9(5):e628-e638.
99. Rosen S, Maskew M, Larson BA, et al. Simplified clinical algorithm for identifying patients eligible for same-day HIV treatment initiation (SLATE): results from an individually randomized trial in South Africa and Kenya. Journal Article; Multicenter Study; Randomized Controlled Trial; Research Support, Non-U.S. Gov't. *PLoS medicine*. 2019;16(9):e1002912.
100. Fahey C, Njau P, Katabaro E, et al. Effects of financial incentives for clinic attendance on HIV viral suppression among adults initiating antiretroviral therapy in Tanzania: A three-arm randomized controlled trial. *Journal of the International Aids Society*. Jul 2020;23:67-67.

101. Gosset A, Protopopescu C, Larmarange J, et al. Retention in Care Trajectories of HIV-Positive Individuals Participating in a Universal Test-and-Treat Program in Rural South Africa (ANRS 12249 TasP Trial). *J Acquir Immune Defic Syndr*. Apr 1 2019;80(4):375-385. doi:10.1097/qai.0000000000001938
102. Heckman TG, Carlson B. A randomized clinical trial of two telephone-delivered, mental health interventions for HIV-infected persons in rural areas of the United States. *AIDS Behav*. Jan 2007;11(1):5-14. doi:10.1007/s10461-006-9111-9
103. Neduzhko O, Postnov O, Sereda Y, et al. Modified Antiretroviral Treatment Access Study (MARTAS): a Randomized Controlled Trial of the Efficacy of a Linkage-to-Care Intervention Among HIV-Positive Patients in Ukraine. Journal Article; Randomized Controlled Trial. *AIDS and behavior*. 2020;24(11):3142-3154.
104. Pascoe SJS, Fox MP, Huber AN, et al. Differentiated HIV care in South Africa: the effect of fast-track treatment initiation counselling on ART initiation and viral suppression as partial results of an impact evaluation on the impact of a package of services to improve HIV treatment adherence. Journal: Article. *Journal of the International AIDS Society*. 2019;22(11)
105. Sabin LL, Halim N, Simmons EM, et al. Retention in HIV Care Among HIV-Seropositive Pregnant and Postpartum Women in Uganda: Results of a Randomized Controlled Trial. *AIDS and behavior*. 2020;24(11):3164-3175.
106. Sherman EM, Eckardt P, Niu J, Elrod S, Clauson KA, Alkhateeb F. Effect of mobile text messages on antiretroviral medication adherence and patient retention in early HIV care:

An open-label, randomized, single center study in south Florida. *AIDS Research and Therapy*. 2020;17(1):16.

107. Dulli L, Ridgeway K, Packer C, et al. A Social Media-Based Support Group for Youth Living With HIV in Nigeria (SMART Connections): Randomized Controlled Trial. *J Med Internet Res*. Jun 2 2020;22(6):e18343. doi:10.2196/18343
108. Fatti G, Ngorima-Mabhena N, Mothibi E, et al. Outcomes of Three- Versus Six-Monthly Dispensing of Antiretroviral Treatment (ART) for Stable HIV Patients in Community ART Refill Groups: A Cluster-Randomized Trial in Zimbabwe. *Journal of acquired immune deficiency syndromes (1999)*. 2020;84(2):162-172.
109. Fox MP, Pascoe S, Huber AN, et al. Adherence clubs and decentralized medication delivery to support patient retention and sustained viral suppression in care: Results from a cluster-randomized evaluation of differentiated ART delivery models in South Africa. *PLoS Med*. Jul 2019;16(7):e1002874. doi:10.1371/journal.pmed.1002874
110. Graves JC, Elyanu P, Schellack CJ, et al. Impact of a family clinic day intervention on paediatric and adolescent appointment adherence and retention in antiretroviral therapy: A cluster randomized controlled trial in Uganda. *PLoS ONE*. 2018;13(3):e0192068.
111. Khan S, Spiegelman D, Walsh F, et al. Early access to antiretroviral therapy versus standard of care among HIV-positive participants in Eswatini in the public health sector: the MaxART stepped-wedge randomized controlled trial. *Journal of the International AIDS Society*. 2020;23(9):e25610.
112. Lebelonyane. Fast-track ART initiation in Botswana is associated with high rates of ART initiation, retention in care, and virological suppression. 2018:76.

- 113.Maskew M, Brennan AT, Fox MP, et al. A clinical algorithm for same-day HIV treatment initiation in settings with high TB symptom prevalence in South Africa: The SLATE II individually randomized clinical trial. *PLoS Med.* Aug 2020;*17*(8):e1003226. doi:10.1371/journal.pmed.1003226
- 114.Myer L, Phillips TK, Zerbe A, et al. Integration of postpartum healthcare services for HIV-infected women and their infants in South Africa: a randomised controlled trial. Journal Article; Randomized Controlled Trial; Research Support, N.I.H., Extramural; Research Support, U.S. Gov't, Non-P.H.S. *PLoS medicine.* 2018;*15*(3):e1002547.
- 115.Odeny TA, Hughes JP, Bukusi EA, et al. Text messaging for maternal and infant retention in prevention of mother-to-child HIV transmission services: A pragmatic steppedwedge cluster-randomized trial in Kenya. *PLoS Medicine.* 2019;*16*(10):e1002924.
- 116.Rosen S, Maskew M, Larson BA, et al. Simplified clinical algorithm for identifying patients eligible for same-day HIV treatment initiation (SLATE): Results from an individually randomized trial in South Africa and Kenya. *PLoS Med.* Sep 2019;*16*(9):e1002912. doi:10.1371/journal.pmed.1002912
- 117.Roy M, Bolton-Moore C, Sikazwe I, et al. Participation in adherence clubs and on-time drug pickup among HIV-infected adults in Zambia: A matched-pair cluster randomized trial. *PLoS Medicine.* 2020;*17*(7):e1003116.
- 118.Sabin LL, Halim N, Hamer DH, et al. Retention in HIV Care Among HIV-Seropositive Pregnant and Postpartum Women in Uganda: results of a Randomized Controlled Trial. Journal Article; Randomized Controlled Trial. *AIDS and behavior.* 2020;*24*(11):3164-3175.

- 119.Sarna A, Saraswati LR, Okal J, et al. Cell Phone Counseling Improves Retention of Mothers With HIV Infection in Care and Infant HIV Testing in Kisumu, Kenya: a Randomized Controlled Study. *Journal Article; Randomized Controlled Trial; Research Support, U.S. Gov't, Non-P.H.S. Global health, science and practice.* 2019;7(2):171-188.
- 120.Willis N, Milanzi A, Mawodzeke M, et al. Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: a randomised trial among adolescents living with HIV in rural Zimbabwe. *BMC Public Health.* 2019;19(1):117-117.
- 121.Khan S, Spiegelman D, Walsh F, et al. Early access to antiretroviral therapy versus standard of care among HIV-positive participants in Eswatini in the public health sector: the MaxART stepped-wedge randomized controlled trial. *J Int AIDS Soc.* Sep 2020;23(9):e25610. doi:10.1002/jia2.25610
- 122.Labhardt ND, Ringera I, Lejone TI, et al. Effect of offering same-day ART vs usual health facility referral during home-based HIV testing on linkage to care and viral suppression among adults with HIV in Lesotho: The CASCADE randomized clinical trial. *JAMA - Journal of the American Medical Association.* 2018;319(11):1103-1112.
- 123.Drain PK, Dorward J, Violette LR, et al. Point-of-care HIV viral load testing combined with task shifting to improve treatment outcomes (STREAM): findings from an open-label, non-inferiority, randomised controlled trial. *The Lancet HIV.* 2020;7(4):e229-e237.
- 124.Fahey CA, Njau PF, Katabaro E, et al. Financial incentives to promote retention in care and viral suppression in adults with HIV initiating antiretroviral therapy in Tanzania: a

- three-arm randomised controlled trial. *The Lancet HIV*. 2020;7(11):e762-e771. doi:10.1016/s2352-3018(20)30230-7
125. Fayorsey RN, Wang C, Chege D, et al. Effectiveness of a Lay Counselor-Led Combination Intervention for Retention of Mothers and Infants in HIV Care: A Randomized Trial in Kenya. *J Acquir Immune Defic Syndr*. Jan 1 2019;80(1):56-63. doi:10.1097/qai.0000000000001882
126. Jani IV, Siteo NE, Alfai ER, et al. Effect of point-of-care CD4 cell count tests on retention of patients and rates of antiretroviral therapy initiation in primary health clinics: an observational cohort study. *The Lancet*. 2011/10/29/ 2011;378(9802):1572-1579. doi:[https://doi.org/10.1016/S0140-6736\(11\)61052-0](https://doi.org/10.1016/S0140-6736(11)61052-0)
127. Roy M, Glidden DV, Geng E, et al. Participation in adherence clubs and on-time drug pickup among HIV-infected adults in Zambia: A matched-pair cluster randomized trial. *PLoS Medicine*. 2020;17(7):e1003116.
128. Fox MP, Rosen S. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007-2009: systematic review. *Trop Med Int Health*. Jun 2010;15 Suppl 1(s1):1-15. doi:10.1111/j.1365-3156.2010.02508.x
129. Kim MH, Ahmed S, Tembo T, et al. VITAL Start: Video-Based Intervention to Inspire Treatment Adherence for Life-Pilot of a Novel Video-Based Approach to HIV Counseling for Pregnant Women Living with HIV. *AIDS and behavior*. 2019;23(11):3140-3151.
130. McLaughlin MM, Franke MF, Munoz M, et al. Community-Based Accompaniment with Supervised Antiretrovirals for HIV-Positive Adults in Peru: A Cluster-Randomized Trial. *AIDS Behav*. Jan 2018;22(1):287-296. doi:10.1007/s10461-017-1680-2

131. Burke BL, Arkowitz H, Menchola M. The efficacy of motivational interviewing: a meta-analysis of controlled clinical trials. *Journal of consulting and clinical psychology*. 2003;71(5):843.
132. Mugavero MJ, Lin H-Y, Allison JJ, et al. Failure to establish HIV care: characterizing the "no show" phenomenon. *Clinical Infectious Diseases*. 2007;45(1):127-130.
133. Schöni-Affolter F, Keiser O, Mwangi A, et al. Estimating loss to follow-up in HIV-infected patients on antiretroviral therapy: the effect of the competing risk of death in Zambia and Switzerland. *PloS one*. 2011;6(12):e27919.
134. Tobias CR, Fox JE, Walter AW, Lemay CA, Abel SN. Retention of people living with HIV/AIDS in oral health care. *Public Health Reports*. 2012;127(2_suppl):45-54.
135. Auld AF, Agizew T, Mathoma A, et al. Effect of tuberculosis screening and retention interventions on early antiretroviral therapy mortality in Botswana: a stepped-wedge cluster randomized trial. *BMC Medicine*. 2020/02/11 2020;18(1):19. doi:10.1186/s12916-019-1489-0
136. World Health Organization. (2012). *Retention in HIV programmes: defining the challenges and identifying solutions*. Meeting report (13–15 September 2011, Geneva, Switzerland). 2012. Retrieved from https://www.who.int/hiv/pub/meetingreports/retention_programmes/en/ (accessed June 2, 2022).
137. World Health Organization. (2013). *WHO guidelines on the use of CD4, viral load and EID tests for initiation and monitoring of ART*, The 2013 Consolidated ARV Guidelines. Retrieved from <https://www.who.int/hiv/amds/102>.

- 138.Maskew M, Vezi L, Brennan AT, et al. A clinical algorithm for same-day HIV treatment initiation in settings with high TB symptom prevalence in South Africa: The SLATE II individually randomized clinical trial. *PLoS Medicine*. 2020;17(8):e1003226.
- 139.Berheto TM, Haile DB, Mohammed S. Predictors of Loss to follow-up in Patients Living with HIV/AIDS after Initiation of Antiretroviral Therapy. *N Am J Med Sci*. 2014;6(9):453-459. doi:10.4103/1947-2714.141636
- 140.Abebe Moges N, Olubukola A, Micheal O, Berhane Y. HIV patients retention and attrition in care and their determinants in Ethiopia: a systematic review and meta-analysis. *BMC Infect Dis*. Jun 22 2020;20(1):439. doi:10.1186/s12879-020-05168-3
- 141.Samet JH, Blokhina E, Cheng DM, et al. A strengths-based case management intervention to link HIV-positive people who inject drugs in Russia to HIV care. *AIDS*. Jul 15 2019;33(9):1467-1476. doi:10.1097/QAD.0000000000002230
- 142.Fahey CA, Bradshaw PT, Padian NS, et al. Financial incentives to promote retention in care and viral suppression in adults with HIV initiating antiretroviral therapy in Tanzania: a three-arm randomised controlled trial. *The Lancet HIV*. 2020;7(11):e762-e771.
- 143.Hall HI, Gray KM, Tang T, Li J, Shouse L, Mermin J. Retention in care of adults and adolescents living with HIV in 13 US areas. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2012;60(1):77-82.
- 144.El-Sadr WM, Donnell D, Beauchamp G, et al. Financial Incentives for Linkage to Care and Viral Suppression Among HIV-Positive Patients: A Randomized Clinical Trial (HPTN 065). *JAMA Intern Med*. Aug 1 2017;177(8):1083-1092. doi:10.1001/jamainternmed.2017.2158

145. Bengtson AM, Colvin C, Kirwa K, Cornell M, Lurie MN. Estimating retention in HIV care accounting for clinic transfers using electronic medical records: evidence from a large antiretroviral treatment programme in the Western Cape, South Africa. *Trop Med Int Health*. Aug 2020;25(8):936-943. doi:10.1111/tmi.13412
146. Menachemi N, Collum TH. Benefits and drawbacks of electronic health record systems. *Risk Manag Healthc Policy*. 2011;4:47-55. doi:10.2147/RMHP.S12985
147. Fox, M. P., Bor, J., Brennan, A. T., Macleod, W. B., Maskew, M., Stevens, W. S., & Carmona, S.. (2018). Estimating retention in HIV care accounting for patient transfers: A national laboratory cohort study in South Africa. *PLOS Medicine*, 15(6), e1002589. <https://doi.org/10.1371/journal.pmed.1002589>.
148. World Health Organization. (2018). *HIV Strategic information for impact; To identify gaps in HIV and health services for programme improvement*. Retrieved from <https://www.who.int/publications/i/item/cascade-data-use-manual-to-identify-gaps-in-hiv-and-health-services-for-programme-improvement>.
149. Auld AF, Agizew T, Mathoma A, et al. Effect of tuberculosis screening and retention interventions on early antiretroviral therapy mortality in Botswana: a stepped-wedge cluster randomized trial. *BMC Med*. Feb 11 2020;18(1):19. doi:10.1186/s12916-019-1489-0
150. Batey DS, Kay ES, Westfall AO, et al. Are missed- and kept-visit measures capturing different aspects of retention in HIV primary care? *AIDS Care*. 2020/01/02 2020;32(1):98-103. doi:10.1080/09540121.2019.1659918

- 151.El-Sadr WM, Beauchamp G, Hall HI, et al. Brief Report: Durability of the Effect of Financial Incentives on HIV Viral Load Suppression and Continuity in Care: HPTN 065 Study. *J Acquir Immune Defic Syndr*. Jul 1 2019;*81*(3):300-303. doi:10.1097/qai.0000000000001927
- 152.Batey DS, Kay ES, Westfall AO, et al. Are missed- and kept-visit measures capturing different aspects of retention in HIV primary care? *AIDS Care*. 2019;*32*:103 - 98.
- 153.Odeny TA, Hughes JP, Bukusi EA, et al. Text messaging for retention in PMTCT: A stepped-wedge cluster-randomized trial. *Topics in Antiviral Medicine*. 2018;*26*(Supplement 1):365s. 25th Conference on Retroviruses and Opportunistic Infections, CROI 2018. United States.
- 154.Sherman EM, Niu J, Elrod S, Clauson KA, Alkhateeb F, Eckardt P. Effect of mobile text messages on antiretroviral medication adherence and patient retention in early HIV care: an open-label, randomized, single center study in south Florida. *AIDS Res Ther*. May 13 2020;*17*(1):16. doi:10.1186/s12981-020-00275-2
- 155.Sha BE, Tierney C, Cohn SE, et al. Postpartum viral load rebound in HIV-1-infected women treated with highly active antiretroviral therapy: AIDS Clinical Trials Group Protocol A5150. *HIV Clin Trials*. Jan-Feb 2011;*12*(1):9-23. doi:10.1310/hct1201-9
- 156.Adams JW, Brady KA, Michael YL, Yehia BR, Momplaisir FM. Postpartum Engagement in HIV Care: An Important Predictor of Long-term Retention in Care and Viral Suppression. *Clin Infect Dis*. Dec 15 2015;*61*(12):1880-7. doi:10.1093/cid/civ678
- 157.Onen NF, Nurutdinova D, Sungkanuparph S, Gase D, Mondy K, Overton ET. Effect of postpartum HIV treatment discontinuation on long-term maternal outcome. *J Int Assoc*

Physicians AIDS Care (Chic). Sep-Oct 2008;7(5):245-51.
doi:10.1177/1545109708325466

158. Yehia BR, Fleishman JA, Metlay JP, et al. Comparing different measures of retention in outpatient HIV care. *AIDS*. 2012;26:1131–1139.

159. Rachlis B, Burchell AN, Gardner S, et al. Social determinants of health and retention in HIV care in a clinical cohort in Ontario, Canada. *AIDS Care*. Jul 2017;29(7):828-837.
doi:10.1080/09540121.2016.1271389

160. Dulli L, Ridgeway K, Packer C, et al. A Social Media-Based Support Group for Youth Living with HIV in Nigeria (SMART Connections): Randomized Controlled Trial. *Journal of Medical Internet Research*. 2020;22(6):e18343.

Appendix 1

Full Literature Search Strategy

Database: CINAHL via EBSCOhost Research Database

- S1 (MH "Randomized controlled trials")
- S2 (MH "Patient Compliance+") OR (MH "Treatment Refusal") OR (MH "Medication Compliance")
- S3 (MH "Research Subject Retention")
- S4 (MH "Research Dropouts") OR (MH "Patient Dropouts")
- S5 (MH "After Care")
- S6 adhere* OR nonadhere* OR complian* OR uncomplian* OR retention OR dropout OR lost to follow-up OR attrition OR treatment refusal OR persistence OR non-persistence OR initiat* OR start* OR uptake
- S7 S2 OR S3 OR S4 OR S5 OR S6
- S8 (MH "Human Immunodeficiency Virus+")
- S9 (MH "HIV-Infected Patients+") OR (MH "HIV Infections+")
- S10 HIV OR human immun* deficiency virus
- S11 S8 OR S9 OR S10

S12 (MH "Antiretroviral Therapy, Highly Active")

S13 antiretroviral therapy OR antiretrovirals OR antiretroviral treatment OR anti-HIV agents OR anti-retroviral agents OR Highly Active Antiretroviral Therapy OR HAART

S14 S12 OR S13

S15 S1 AND S7 AND S11 AND S14

Database: Cochrane Central Register of Controlled Trials (CENTRAL)

Search Strategy:

adhere* OR nonadhere* OR complian* OR uncomplian* OR retention OR dropout OR lost to follow-up OR attrition OR treatment refusal OR persistence OR non-persistence OR initiat* OR start* OR uptake in All Text AND HIV OR human immun* adj2 deficiency virus in All Text AND antiretroviral therapy OR antiretrovirals OR antiretroviral treatment OR anti-HIV agents OR anti-retroviral agents OR Highly Active Antiretroviral Therapy OR ART OR HAART in All Text

Database: Embase

Search Strategy:

- 1 randomized controlled trial.mp. or "exp randomized controlled trial"/
- 2 (complian* or uncomplian*).mp. or exp "medication compliance"/
- 3 retention.mp.
- 4 dropout.mp. or exp "patient dropout"/
- 5 (los* adj2 to follow up).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

6 attrition.mp.

7 (adhere* or nonadhere*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

8 treatment refus*.mp. or exp "treatment refusal"/

9 persistence.mp.

10 initiat*.mp.

11 start*.mp.

12 uptake.mp.

13 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12

14 (HIV or human immune-deficiency virus or human immuno-deficiency virus).mp.

15 exp "human immunodeficiency virus"/ or exp "human immunodeficiency virus infection"/ or exp "human immunodeficiency virus infected patient"/

16 14 or 15

17 antiretroviral therapy.mp. or exp "antiretroviral therapy"/

18 antiretrovirals.mp.

19 antiretroviral treatment.mp.

20 exp "antiretrovirus agent"/

21 highly active antiretroviral therapy.mp. or exp "highly active antiretroviral therapy"/

22 (ART or HAART).mp.

23 17 or 18 or 19 or 20 or 21 or 22

24 1 and 13 and 16 and 23

25 limit 24 to yr="2018 -Current"

Database: PsycINFO via Ovid

Search Strategy:

-
- 1 randomized controlled trials.mp. or exp randomized controlled trials/
 - 2 exp "compliance"/ or exp "treatment compliance"/
 - 3 (complian* or uncomplian*).mp.
 - 4 dropout.mp. or exp "treatment dropout"/
 - 5 retention.mp.
 - 6 attrition.mp. or exp "experimental attrition"/
 - 7 (los* adj2 to follow up).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
 - 8 adhere*.mp.
 - 9 treatment refus*.mp. or exp "treatment refusal"/
 - 10 persistence.mp.
 - 11 initiate.mp.
 - 12 start*.mp.
 - 13 uptake.mp.
 - 14 nonadherence.mp.
 - 15 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14

16 HIV.mp. or exp "HIV"/

17 (human immunodeficiency virus or human immune-deficiency virus or human immuno-deficiency virus).mp.

18 16 or 17

19 exp "drug therapy"/

20 (antiretroviral or antiretroviral therapy or antiretroviral treatment or ART or HAART).mp.

21 19 or 20

22 1 and 15 and 18 and

23 limit 22 to yr="1995 -Current"

Database: PubMed

Search Strategy:

(randomized controlled trial) AND (adhere* OR nonadhere* OR complian* OR uncomplian* OR retention OR dropout OR lost to follow-up OR attrition OR treatment refusal OR persistence OR non-persistence OR initiat* OR start* OR uptake) AND (HIV OR human immune-deficiency virus OR human immuno-deficiency virus) AND (antiretroviral therapy OR antiretrovirals OR antiretroviral treatment OR Highly Active

Antiretroviral Therapy OR ART OR HAART OR anti-HIV agents OR anti-retroviral agents) Filters:

MeSH headings [mh], captured via ‘All Fields’ search:

patient dropouts / patient compliance (patient adherence/nonadherence) / treatment adherence and

compliance (therapeutic adherence/compliance) / medication adherence (nonadherence,

compliance/noncompliance) /lost to follow-up

HIV / anti-HIV agents / anti-retroviral agents / antiretroviral therapy, highly active (HAART)

randomized "randomized controlled trial"[Publication Type] OR "randomized controlled trial controlled trials as topic"[MeSH Terms] OR "randomized controlled trial"[All Fields] OR "randomised controlled trial"[All Fields]

retention "retention (psychology)"[MeSH Terms] OR ("retention"[All Fields] AND "(psychology)"[All Fields]) OR "retention (psychology)"[All Fields] OR "retention"[All Fields]

lost to follow-up "lost to follow-up"[MeSH Terms] OR ("lost"[All Fields] AND "follow-up"[All Fields]) OR "lost to follow-up"[All Fields] OR

("lost"[All Fields] AND "follow"[All Fields] AND "up"[All Fields])
OR "lost to follow up"[All Fields]

attrition "tooth attrition"[MeSH Terms] OR ("tooth"[All Fields] AND "attrition"[All Fields]) OR "tooth attrition"[All Fields] OR "attrition"[All Fields]

treatment refusal "treatment refusal"[MeSH Terms] OR ("treatment"[All Fields] AND "refusal"[All Fields]) OR "treatment refusal"[All Fields]

HIV "hiv"[MeSH Terms] OR "hiv"[All Fields]

human "humans"[MeSH Terms] OR "humans"[All Fields] OR "human"[All Fields]

immune-deficiency "immunologic deficiency syndromes"[MeSH Terms] OR ("immunologic"[All Fields] AND "deficiency"[All Fields] AND "syndromes"[All Fields]) OR "immunologic deficiency syndromes"[All Fields] OR ("immune"[All Fields] AND "deficiency"[All Fields]) OR "immune deficiency"[All Fields]

virus "viruses"[MeSH Terms] OR "viruses"[All Fields] OR "virus"[All Fields]

immuno-deficiency "immunologic deficiency syndromes"[MeSH Terms] OR ("immunologic"[All Fields] AND "deficiency"[All Fields] AND "syndromes"[All Fields]) OR "immunologic deficiency syndromes"[All Fields] OR ("immuno"[All Fields] AND "deficiency"[All Fields]) OR "immuno deficiency"[All Fields]

therapy "therapy"[Subheading] OR "therapy"[All Fields] OR
"therapeutics"[MeSH Terms] OR "therapeutics"[All Fields]

treatment "therapy"[Subheading] OR "therapy"[All Fields] OR "treatment"[All
Fields] OR "therapeutics"[MeSH Terms] OR "therapeutics"[All
Fields]

Highly Active "antiretroviral therapy, highly active"[MeSH Terms] OR
Antiretroviral ("antiretroviral"[All Fields] AND "therapy"[All Fields] AND
Therapy "highly"[All Fields] AND "active"[All Fields]) OR "highly active
antiretroviral therapy"[All Fields] OR ("highly"[All Fields] AND
"active"[All Fields] AND "antiretroviral"[All Fields] AND
"therapy"[All Fields])

ART "art"[MeSH Terms] OR "art"[All Fields]

HAART "antiretroviral therapy, highly active"[MeSH Terms] OR
("antiretroviral"[All Fields] AND "therapy"[All Fields] AND
"highly"[All Fields] AND "active"[All Fields]) OR "highly active
antiretroviral therapy"[All Fields] OR "haart"[All Fields]

anti-HIV agents "anti-hiv agents"[Pharmacological Action] OR "anti-hiv
agents"[MeSH Terms] OR ("anti-hiv"[All Fields] AND "agents"[All
Fields]) OR "anti-hiv agents"[All Fields] OR ("anti"[All Fields]
AND "hiv"[All Fields] AND "agents"[All Fields]) OR "anti hiv
agents"[All Fields]

anti-retroviral agents "anti-retroviral agents"[Pharmacological Action] OR "anti-retroviral agents"[MeSH Terms] OR ("anti-retroviral"[All Fields] AND "agents"[All Fields]) OR "anti-retroviral agents"[All Fields] OR ("anti"[All Fields] AND "retroviral"[All Fields] AND "agents"[All Fields]) OR "anti retroviral agents"[All Fields]

Database: Web of Science

Search Strategy:

- #1 TS=(randomized controlled trials)
- #2 TS=(adhere* OR nonadhere* OR complian* OR uncomplian* OR retention OR dropout OR los* follow-up OR attrition OR treatment refusal OR persistence OR non-persistence OR initiat* OR start* OR uptake)
- #3 TS=(HIV OR human immun* deficiency virus)

#4 TS=(antiretroviral therapy OR antiretrovirals OR antiretroviral treatment OR anti-HIV agents OR anti-retroviral agents OR ART OR Highly Active Antiretroviral Therapy OR HAART)

#5 #4 AND #3 AND #2 AND #1

Appendix 2: Full-Text Screening form

1. Is the study design a randomized controlled trial?

If no, EXCLUDE.

If yes, go to next question.

2. Is the article about includes people diagnosed with HIV of any age?

If no, EXCLUDE.

If yes, go to next question.

3. If the study measures any of the HIV care cascade outcomes: engagement, initiation, retention to care, and adherence to ART?

If no, EXCLUDE.

If yes, INCLUDE

Appendix 3: Data Abstraction Forms

Study Characteristics

Ref ID	
Author	
Year	
Country	

Country Income level	
High-income countries	
Upper middle-income countries	
Low-middle income countries	
Low-income countries	
Study design	
Trial duration	

Patient Characteristics

General population	
Gender	
Average Age	
Special populations	
Prisoners	
ACB (African, Caribbean, or Black) people	

Youth	
Men who have sex with men (MSM)	
People who inject drugs (PWID)	
Transgender individuals	
Sex workers	
Immigrants	
Indigenous people	

Intervention Characteristics

Brief name of intervention	
Describe any rationale, theory, or goal of the elements essential to the intervention.	
What? Describe the materials and procedures used.	
How provided the intervention -> Clinicians (nurses, doctors, other professional health staff)	

Intervention types	
Behavioural and education interventions	
Digital intervention	
Mixed intervention	
Economical intervention	
Health system intervention	
Peer or community-based intervention	
Pharmacy based intervention	
Task-shifting intervention	
When and how much the intervention was delivered?	

Retention

Outcome measured	
Outcome definitions	
Outcome definitions	

Outcome definitions	
Is the definition of the outcome cited	
References	
Time points	
Additional notes on the outcome	

Appendix 4: Reasons for Studies Exclusion

Reasons	N
Full text articles excluded, with reasons	545
Not a systematic review of interventions	278
Did not report care cascade outcomes	162
Did not included RCTs	143
Participants were not PLHIV	59
Conference abstract	6

Appendix 5:

Table 2. Definitions of retention in HIV care in randomized controlled trials(n=59)

No.	Author, & year	Retention definition
1.	Gosset et al., 2019 ⁵⁵	<p>The study outcome was a time-varying binary variable “retention in trial care” (RIC) status, describing whether a patient remained or not in trial care during the 18-month study period. A patient was considered to have exited trial care if she/he was 3 months late for his/her last appointment at the clinic, if she/he transferred out, or if she/he died.</p> <p>RIC status in the trial clinics was assessed for each patient every month from 4 to 18 months after his/her baseline visit (RIC status was therefore not defined during the first 4 months of follow-up). A patient lost to follow-up (LTFU) at a given month could re-enter trial care if she/he revisited a trial clinic later.</p>
2.	Lubega et al., 2015 ⁵⁸	<p>The primary outcome measure was the proportion(participants)of newly detected and enrolled PLHIV in both arms who had attended their scheduled quarterly pre-ARV care visits at their nearest HC for at least 6 out of the anticipated 8 visits over a period of 24</p>

months since enrollment vs those who had missed their scheduled pre-ARV appointment for 3 or more of the anticipated 8 visits [categorized as either retained or not retained in pre-ARV care.

3. Chandra et al., 2019(a)⁷⁶ “Sustained retention” was measured as a dichotomous variable, defined as having completed all 12 monthly follow-ups.
4. Chandra et al., 2019(b)⁷ Retention was measured as a continuous variable, using each of the 12 monthly follow-up visits as repeated measures.
6
5. Kim et al., 2019⁵⁷ Short-term retention (retention at 1-month) in ART clinic was defined as retained if there was a visit between 14-61 days after their ART start date.
6. Graves et al., 2018¹¹⁰ Adherence to appointment schedule of pediatric and adolescent patients. Patients were classified as adherent to the appointment schedule if they returned to the clinic for their most recent appointment in a number of days that was equal to or less than the number of ARV pills prescribed at their last appointment.
7. Labhardt et al., 2018(a)⁶ Median time between visits and number of visits attended according to the study protocol (monthly for usual care and 1.5, 3, 6, 9, and 12 months for same day). If a participant attended a visit within 7 days of their expected visit schedule (i.e., monthly for
7

usual care and 1.5, 3,6, and 9 months for same day), he/she was considered to have attended the visit according to the protocol.

8. Labhardt et al.,2018(b)⁶
⁷ Prespecified secondary endpoints assessed among patients who remained in care at the 12-month follow-up were changes in CD4 cell count, hemoglobin level, bodyweight, and occurrence of a new clinical WHO stage 3 or 4 events.
9. Labhardt et al.,2018(c)⁶
⁷ 1-year retention in care that was defined as either the patient or his/her treatment buddy going to the health facility to get a drug refill during the 11 through 14 months after enrollment. It is part of Lesotho care protocol for patients to send a friend or relative to pick-up their drugs if they cannot attend personally.
10. Naar-King et al., 2009⁹¹ A primary care visit was defined as care received from a doctor, nurse practitioner, or physician’s assistant who could monitor CD4 and viral load counts and prescribe HIV medications. A minimum of quarterly HIV primary care appointments is recommended for YLH. A gap was defined as no appointments in a three-month period (quarter).
11. Willis et al., 2019¹²⁰ 3 monthly clinic visit for 12 months.
12. Fahey et al., 2020⁵³ The primary outcome was retention in care with viral suppression (<1000 copies per mL, the WHO threshold for virological failure) at 6 months after starting ART. This outcome definition is

consistent with global treatment as prevention strategies, including the UNAID Fast-Track targets. Participants who could not be found after exhaustive tracing efforts were classified as not retained in care. (i.e., the PEPFAR definition of loss to follow-up from facility-based care. Following PEPFAR guidelines, individuals considered not retained in ART care include those who died, disengaged from care or otherwise stopped ART, or had no evidence of facility-based care for 28 days or more after a missed appointment.

13. McLaughlin et al., 2018¹³⁰ The primary outcome was retention with HIV viral load suppression. Individuals who died became lost to follow-up or defaulted from treatment were not considered retained. (<400copies/mL).
14. Wolitski et al., 2009⁹⁷ Retention to follow-up assessments 6- and 18-month follow-up.
15. Heckman et al., 2006¹⁰² Patients were followed-up at post-intervention, 4-month follow-up, and 8-month follow-up.
16. Pascoe et al., 2019¹⁰⁴ Twelve-month retention was defined as being listed as retained in TIER.Net defined as not transferred, become lost-to-follow-up (failure to attend the clinic within 90 days of a scheduled ART

visit), or died at 12 months. A patient could be retained without initiating ART. We considered those without a viral load as not suppressed and those who transferred as not retained.

17. Gwadz et al., 2015⁸⁸ Based on national guidelines, we assessed whether the participant attended at least one HIV primary care visit in the previous 6 months from the T3 MRF.
18. Tukei et al., 2020(a)⁷³ The primary outcome was retention in ART care defined as the proportion of participants remaining in care 12 months after study enrollment. The primary outcome of retention in ART care considered both death and loss to follow-up (LTFU) as attrition.
19. Tukei et al., 2020(b)⁷³ The proportion of participants retained in the study model of care (study arm) after 12 months, is defined as participants alive and continuously receiving ART at 3- or 6-monthly intervals in the same study arm as at enrollment in the study. This secondary outcome of retention in the study arm considered all participants who died, were LTFU, who transferred out to other facilities, and those transitioning off the arm due to needing more frequent dispensing of ART for clinical reasons as losses to the arm. Participants who missed a pick-up date for their ART medication for more than 90 days after the last missed appointment and who were not known to have transferred out to another facility or service or died were considered LTFU.

20. Sabin et al., A composite outcome “full retention,” defined as meeting three
2020(a)¹¹⁸ criteria: (1) attended all scheduled visits over the intervention period, pre-and post-delivery (within one month of scheduled appointment); (2) collected ART medications at each visit; and (3) delivered at the study hospital. We also measured the components of the composite measure separately and by major time periods: attendance at all scheduled visits in the pre-delivery period, attendance at all scheduled visits in the post-delivery periods, and delivery at the study hospital.
21. Sabin et al., “Visit retention,” reflected the degree to which visits were
2020(b)¹¹⁸ completed, was measured by the proportion of all scheduled visits which were attended (for the full intervention period and again for pre-and post-delivery periods separately), and “postpartum retention,” which measured retention at 3 months postpartum, defined by participants missing ≤ 1 monthly clinic visits among the 3 possible post-delivery monthly visits.
22. Khan et al., The combined endpoint was defined as the date when either non-
2020(a)⁶⁵ retention in care or elevated viral load (VL) occurred, and survival time was the minimum of the times from enrolment to any events qualifying for non-retention or elevated VL. The operational definitions of the primary endpoints, retention, and viral

suppression were established according to the definitions outlined by the Eswatini Ministry of Health Integrated HIV Management Guidelines 2015.

23. Khan et al., 2020(b)⁶⁵ a. Participant is classified as retained in HIV care if they are a) alive and b) have not stopped treatment, whereby either:
- a). [End of the Study periods]- [Last Visit date] <90 days: or
 - b). [Next appointment date]- [End of the study period]> (within 30 days).

Time to non-retention was the last date at which the first of the above defining events occurred.

24. Maskew et al., 2020⁸⁰ Initiation of ART within 1 month (28 days) and retention on ART 8 months after study enrollment (composite outcome). Seven days is WHO's definition of "rapid" initiation. Retention is measured as having an observed clinic visit in either the patient's paper record or the site's electronic patient register between 5 and 8 months after study enrollment. Eight months was selected to allow up to 1 month to initiate ART, 6 months of follow-up after treatment initiation, and up to 1 month to return for the 6-month routine clinic visit. Patients with no evidence of a clinic visit or laboratory test between 5 and 8 months after study enrollment were assumed lost to follow-up.

25. Graves et al., 2018¹¹⁰ Individual-level primary outcomes included 1) the retention in care of pediatric and adolescent patients, and. Patients were classified as retained in care if they attended any ART clinic appointment at least once over the last 3 months of the study period, from 1 January 2015 to 31 March 2015. Any patients who transferred out to another facility were excluded.
26. MacGowan et al., 2015⁹⁰ Receipt of healthcare at an HIV clinic at baseline and the 3-month assessment.
27. Rotheram-Borus et al., 2012⁹⁴ The number of medical visits during the past year.
28. Sherman et al., 2020¹⁵⁴ Retention in care was calculated as the number of participants in care at the clinic at the time of the follow-up visit divided by the total number of patients enrolled in the treatment arm.
29. Gardner et al., 2014⁸⁷ The primary outcomes were a binary visit constancy measure (at least 1 kept visit with an HIV primary care provider in 3 consecutive 4-month intervals), and a visit adherence measure (number of kept appointments in 12 months divided by the total number of scheduled appointments, excluding cancellation).

30. Neduzhko et al., 2020⁶⁹ Retention is defined as at least one additional HIV clinical visit within 6 months after linkage to HIV care (yes/no).
31. Wagner et al., 2021⁹⁶ Participants were determined to be “in care” if they had attended their most recent scheduled routine care visit or had been seen by their provider in the past 6 months; this binary variable representing HIV care retention
32. El-Sadr et al., 2017¹⁴⁴ Continuity in care was defined as the proportion having evidence of a clinical visit (i.e., a CD4+ cell count or viral load test data in the Surveillance Database) in 4 of the prior 5 quarters.
33. Rosen et al., 2019⁹⁹ We defined patient as “retained” if the patient initiated within 28 days(ref) of enrollment and a clinic visit was made or a viral load test observed between 5 and 8 months after enrollment, allowing a broad window for irregular visit schedules.
34. Fatti et al., 2020(a)¹⁰⁸ Participants not arriving for the scheduled 12-month visit were considered retained if collecting ART within 90 days after the appointment date. For the secondary outcome of retention in the study arm, participants were considered not retained if transitioning off the study arm for any reason including death, LTFU, transfer to another clinic, or required increased ART dispensing frequency. VS was defined as VL,1000 copies/ml.

35. Fatti et al., 2020(b)¹⁰⁸ Retention in ART care was defined as 1-participant attrition, where attrition was defined as either death (all-cause) or loss to follow-up (LTFU). Participants were considered not retained if transitioning off the study arm for any reason including death, LTFU, transfer to another clinic, or required increased ART dispensing frequencies was defined as VL,1000 copies/ml.
36. Fatti et al., 2020(c)¹⁰⁸ The proportion of participants remaining in ART care 12 months after enrollment by intention-to-treat (ITT). LTFU was defined in all arms as no ART collection for .90 days after the last missed scheduled ART collection date. Participants not arriving for the scheduled 12-month visit were considered retained if collecting ART within 90 days after the appointment date.
37. Robbins et al., 2012⁹³ 6-month suboptimal follow-up (no arrived appointment for >6 months).
38. Mavhu et al.,2020⁵⁹ The proportion of participants who were not retained in-clinic services stratified according to the WHO definition of retention in HIV care
39. Auld et al., 2020¹⁴⁹ The key HIV care retention indicator used for monitoring purposes was the rate of loss to follow-up (LTFU) per 100 person-years. LTFU was defined as being > 60 days late for a scheduled appointment, per Botswana guidelines.

40. Dulli et al., 2020¹⁶⁰ If a participant failed to return after a scheduled visit for more than 28 days, the date of the missed visit was the date of loss to care recorded, unless death or transfer of service was documented before the missed visit. For a small number of patients, their first missed scheduled visit was scheduled on or within 28 days before study enrollment. If the participant missed this first scheduled visit by more than 28 days, he or she was assigned a retention time of 0, consistent with the President’s Emergency Plan for AIDS Relief (PEPFAR) indicator definitions.
41. Konkle-Parker et al., 2014⁸⁹ Adherence to care, or visit constancy, while on study defined as at least one kept HIV medical visit in each third of the year following baseline assessment.
42. Mbuagbaw et al., 2012⁶⁸ Participants who came for scheduled clinic visits.
43. Norton et al., 2014⁹² Appointment attendance rates.
44. Samet et al., 2019⁸⁵ One or more visits to HIV medical care in two consecutive 6-month periods) within 12 months of enrollment.
45. Goodrich et al., 2021⁶⁴ Participant seen within 3 months of their last scheduled clinic visit or Co-op meeting).

46. Byonaneby e et al., 2021⁵² Attending appointments within 3 working days of the scheduled visit. Appointment keeping at 12 months.
47. Sarna et al., 2019⁷² Retention in care was assessed at 3-time points: at delivery, 6 weeks postpartum, and 14 weeks postpartum. Participants who delivered at the health facility where they received PMTCT services, or at another health facility, or for whom there was information of a home delivery and pregnancy outcome were considered retained. at delivery. Participants who completed their 6-week PNC visit or had their baby tested for HIV (PCR test) or had the baby immunized at 6 weeks were considered retained at 6 weeks postpartum. Participants who had their baby immunized at 14 weeks were considered retained at 14 weeks postpartum.
48. Myer et al., 2018⁸² The primary trial outcome was a composite endpoint of women's retention in ART care and VS (VL < 50 copies/ml based on VL testing at trial measurement visit) at 12 months postpartum. Retention in care at 12 months postpartum was measured using routinely collected medical records and defined as evidence of an HIV-related clinical contact from the period 9–18 months postpartum. Data used to define a clinical contact came from routinely

collected records of ARV dispensing, HIV-related laboratory testing, and clinical care visits.

49. Fayorsey et al., 2019⁶³ The primary outcome, mother-infant attrition, was defined as the proportion of mother-infant pairs not retained in the clinic at 6 months postpartum because of mother or infant death or loss to follow-up (LTFU). LTFU was defined as no documented clinic attendance at 6 months postpartum in the 3 months prior to or after the 6-month scheduled visit. Maternal clinic attendance was measured through attendance at an ANC or HIV care visit, and infant attendance through attendance at HEI visit, as documented in medical records and registers. We calculated retention among mother-infant pairs at 6 months postpartum to compare outcomes with other reports in the literature. We defined retention as the complement to attrition (percent attrition + percent retention = 100%).²³ Women reported to have transferred to another HF were verified through a phone call, and these subjects were classified as retained in outcome measures
50. Odeny et al., 2019¹¹⁵ The proportion of women retained in postpartum care—is defined as a documented return for at least one visit at the PMTCT, postnatal, or general HIV care clinic within 8 weeks after delivery.
51. Janie et al., 2018¹²⁶ The proportion of HIV-positive infants who initiated antiretroviral therapy that was retained in care at 90 days of follow-up. Patients

were considered retained in care at 90 days if they had visited the health facility within the previous 30days.

52. Kinuthia et al., 2021⁶⁶ On-time clinic visit attendance during follow-up to 12 and 24 months postpartum was defined as the proportion of scheduled clinic visits attended on time.
53. Roy et al., 2020⁷¹ Time to first late drug pickup: “Twelve-month cumulative incidence of first missed drug pickup.” Late drug pickup defined as >7 days late.
54. Basset et al., 2016⁷⁴ Linkage to and initial retention in care at 12 months, defined as the proportion of patients with less than 60 consecutive days without ART at any point during follow-up.
55. Hoffman et al., 2021 The primary outcome was retention in care at 12 months, defined as the proportion of patients with less than 60 consecutive days without ART at any point during follow-up.
56. Cassidy et al., 2020⁷⁵ “Retention in care” at 24 months was defined as any ART collection (AC or clinic visit) at 24 months or within three months thereafter. If the last documented AC or clinic attendance was 12 months or more after the participant’s first study visit, they were considered retained in care at 12 months.
57. Cassidy et al., 2020⁷⁵ Retention in AC care” was defined as attending the scheduled AC 24-month visit. AC patients who missed an AC visit by more than

five days but were allowed to return to the AC were not considered retained.

- Drain et al., Retained in care was defined as collecting ART at the study clinic or a community pick-up point between 44 weeks and 56 weeks after enrolment.
58. 2021¹²³
59. Fox et al., Retention in care at 12-months after eligibility for ACs (Adherence Clubs) or Decentralized Medication Delivery (DMD) is defined as 100%–% attrition, with attrition as the sum of reported deaths, loss to follow-up, and transfers. Loss to follow-up was defined based on clinic definitions—failure to attend the clinic within 90 days of a scheduled appointment).
- 2019⁷⁸