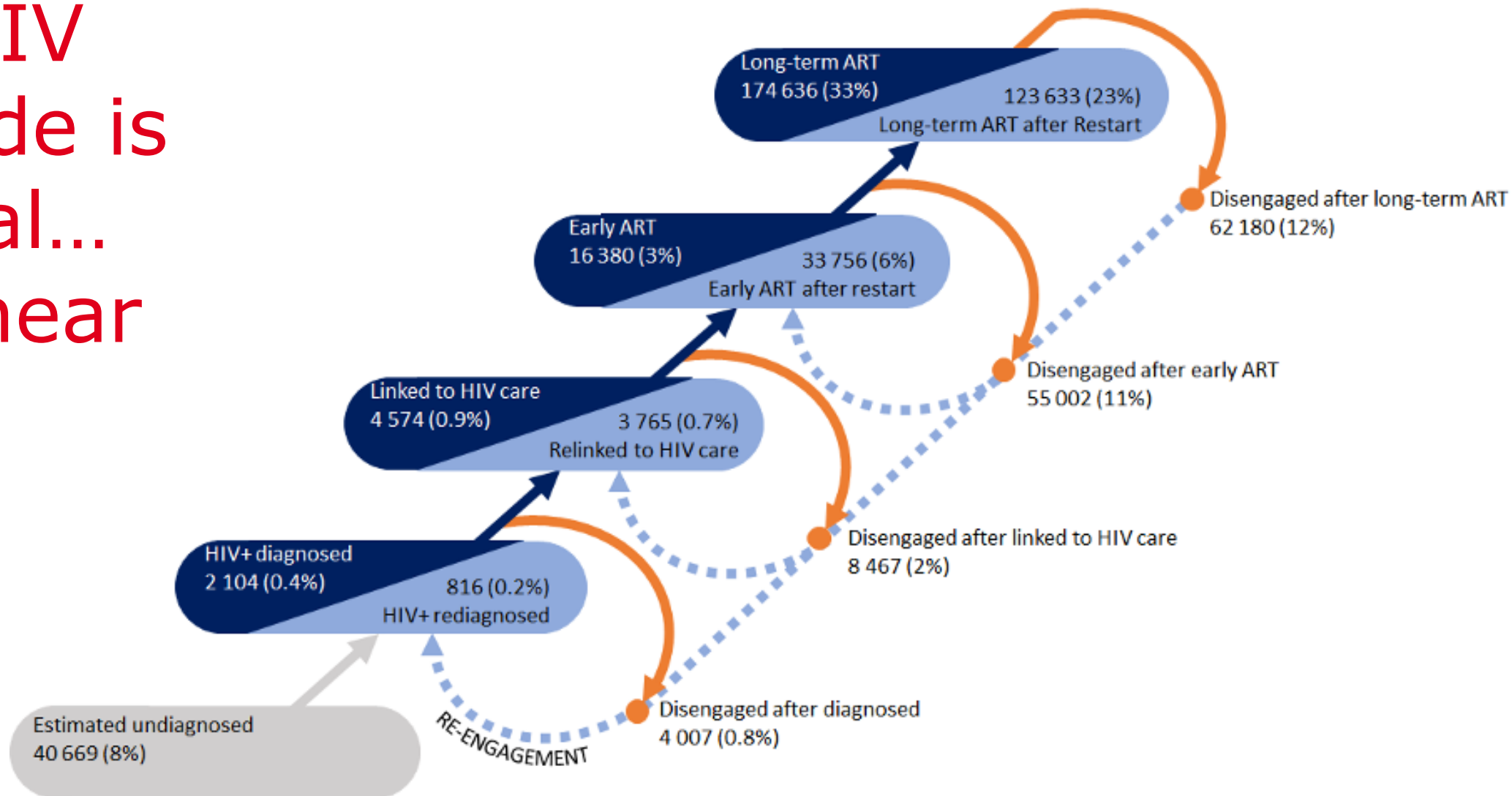


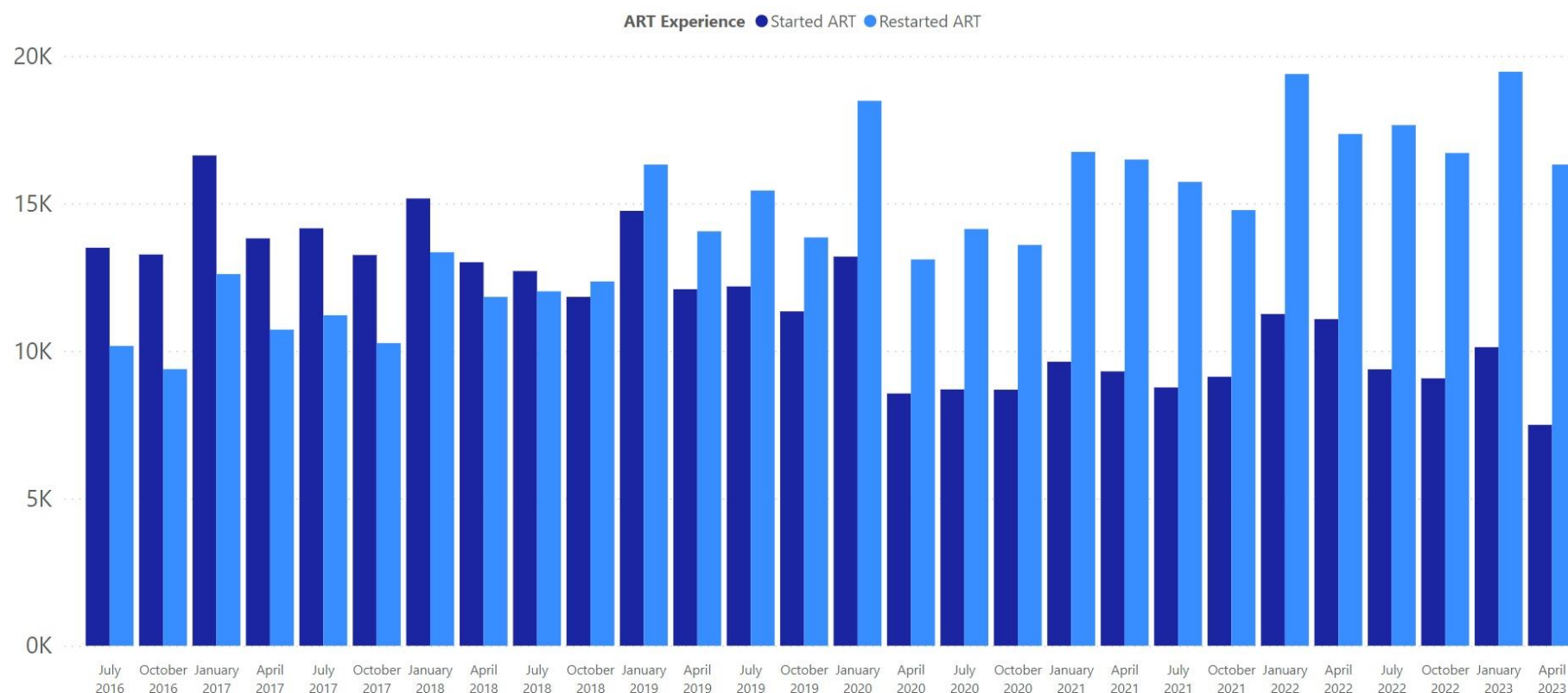
# Re-engagement in HIV treatment services

## Welcome and overview

The HIV cascade is cyclical... not linear



# Increasingly, those initiating ART are not treatment-naïve



In the Western Cape province of South Africa, among those starting ART now, 2/3<sup>rd</sup>s have previously been on ART

1

For returning patients,  
the *first return visit*  
experience is critical

Welcoming, supportive and  
empathetic

Clear facility visit flow focused on a  
positive patient experience

2

*Not all patients* late for  
scheduled appointments  
are re-engaging patients

Defined period

3

All re-engaging patients  
*DO NOT* have the same  
service delivery needs

Easier access to treatment

Psychosocial support

Clinical management

Always  
be kind

No  
judgement  
zone

**Differentiation is critical → move  
away from a one-size-fits-all  
approach to returning patients**

# Session co-chairs and presenters

## Session co-chairs



**Baker  
Bakashaba**  
AIC, Uganda



**Peter  
Ehrenkranz**  
BMGF, USA

## Session presenters



**Khumbo  
Phiri  
Nyirenda**  
PIH, Malawi



**Chipo  
Mutyambizi**  
Anova Health  
Institute  
South Africa



**Chiedza  
Mupanguri**  
MoHCC,  
Zimbabwe

»How can we support people to re-engaged in care?

»How can we reduce treatment interruptions?

»And how can we minimize the frequency and duration of these interruptions?

# Session overview

## Welcome and overview of re-engagement

- Baker Bakashaba, AIC, Uganda
- Peter Ehrenkranz, BMGF, USA

## Meeting people where they are: Importance of flexible support to facilitate quality re-engagement

- Khumbo Phiri Nyirenda, Partners in Hope, Malawi

## How late is too late? Definitions of interruptions and the impact on supportive interventions

- Chipso Mutyambizi, Anova Health Institute, South Africa

## How Zimbabwe built a differentiated approach to support differentiated needs at re-engagement

- Chiedza Mupanguri, MoHCC, Zimbabwe

## Wrap-up and closing

- Session co-chairs

# Meeting people where they are

The importance of flexible  
support to facilitate  
quality re-engagement

# Partners in Hope (PIH)

- Local Malawi NGO
- USAID-PEPFAR Partner supporting 123 facilities in nine districts
  - Supporting >200,000 clients on ART
- For-pay clinical and surgical unit, free HIV clinic
- Regional lab for the country

## Highlights

- 15+ years of collaboration
- >20 clinical trials (n=7) and implementation / social science studies (n=13)
- >80 publications (qualitative and quantitative)
- Research contributes to national policy and global HIV guidelines



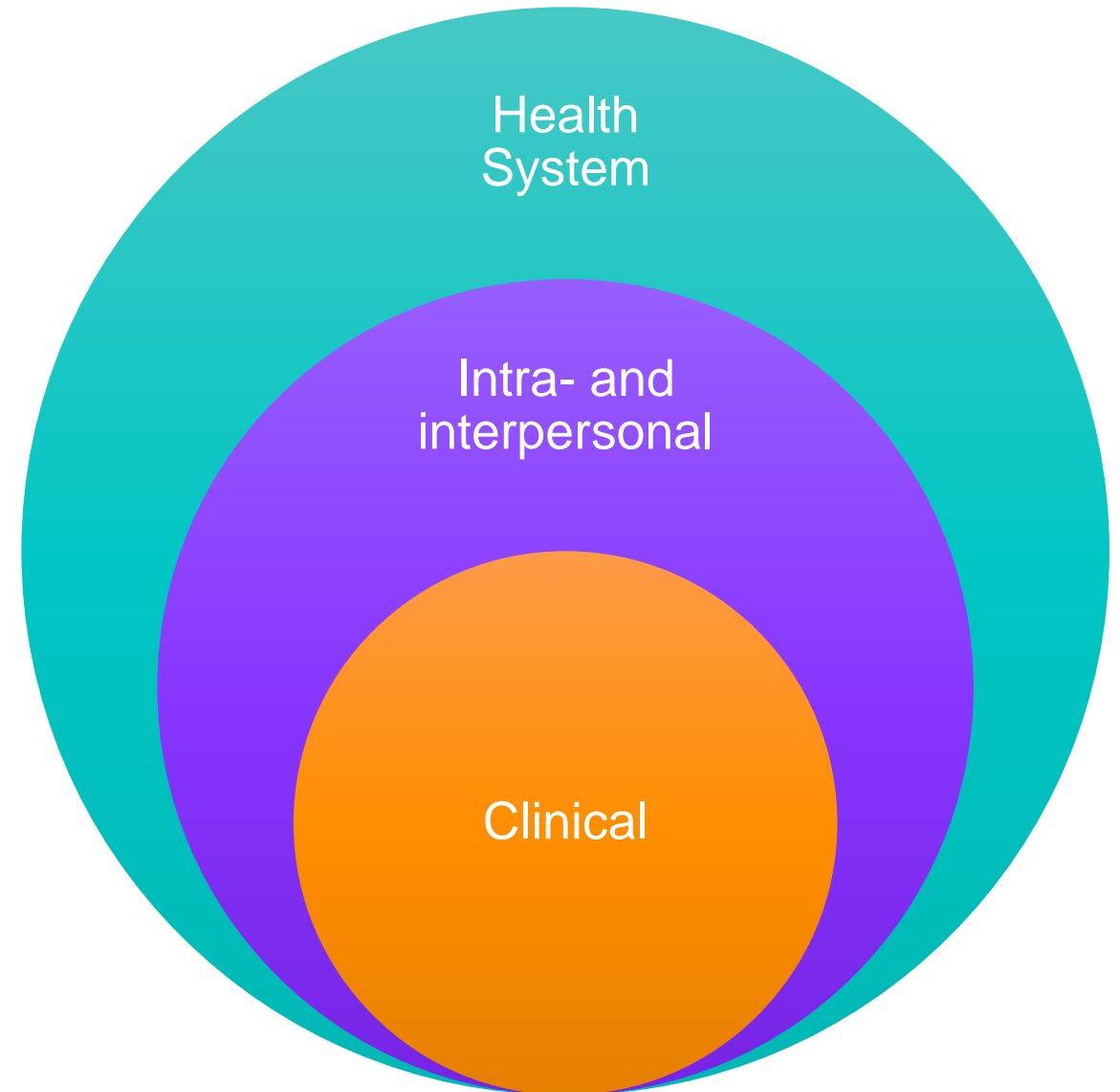
Partners In Hope, Lilongwe, Malawi

# What is disengagement?

- An interruption in treatment (ITT)
- Different definitions
  - Days late, days since last visit, etc.
- In Malawi:
  - 60 or more days late for a scheduled appointment (MOH definition)
  - Loss to follow-up (28+ days late) (PEPFAR/PIH definition), flagged 7-days after the missed appointment

# Why do people disengage?

- Healthcare attendance burden
  - Inflexibility of ART care schedules (mobility, unplanned travel, frequency of visits and cost), provider attitudes
- Intra and inter-personal drivers
  - Sex, age, education level and socioeconomic status, stigma and disclosure, religious and cultural beliefs, relationship status
- Clinical reasons
  - Side effects, pill burden, disease stage, other comorbidities





# Research in focus: treatment disengagement

Open access

Protocol

## BMJ Open Identifying efficient linkage strategies for men (IDEaL): a study protocol for an individually randomised control trial

Kathryn Dovel <sup>1,2</sup> Kelvin Balakasi,<sup>2</sup> Julie Hubbard,<sup>1</sup> Khumbo Phiri,<sup>2</sup> Brooke E Nichols <sup>3,4,5</sup> Thomas J Coates,<sup>1,6</sup> Michal Kulich,<sup>7</sup> Elijah Chikuse,<sup>2</sup> Sam Phiri,<sup>2</sup> Lawrence C Long,<sup>3,8</sup> Risa M Hoffman,<sup>1</sup> Augustine T Choko<sup>9,10</sup>

AIDS and Behavior (2022) 26:674–685  
<https://doi.org/10.1007/s10461-021-03427-1>

ORIGINAL PAPER

## How HIV Clients Find Their Way Back to the ART Clinic: A Qualitative Study of Disengagement and Re-engagement with HIV Care in Malawi

Stephanie Chamberlin<sup>1</sup>  · Misheck Mphande<sup>2</sup> · Khumbo Phiri<sup>2</sup> · Pericles Kalande<sup>2</sup> · Kathryn Dovel<sup>2,3</sup>

PLOS ONE

STUDY PROTOCOL

Engaging men through HIV self-testing with differentiated care to improve ART initiation and viral suppression among men in Malawi (ENGAGE): A study protocol for a randomized control trial

# Why do they re-engage?

**Objective:** To understand why individuals miss appointments and how they re-engage in HIV care

**Design:**

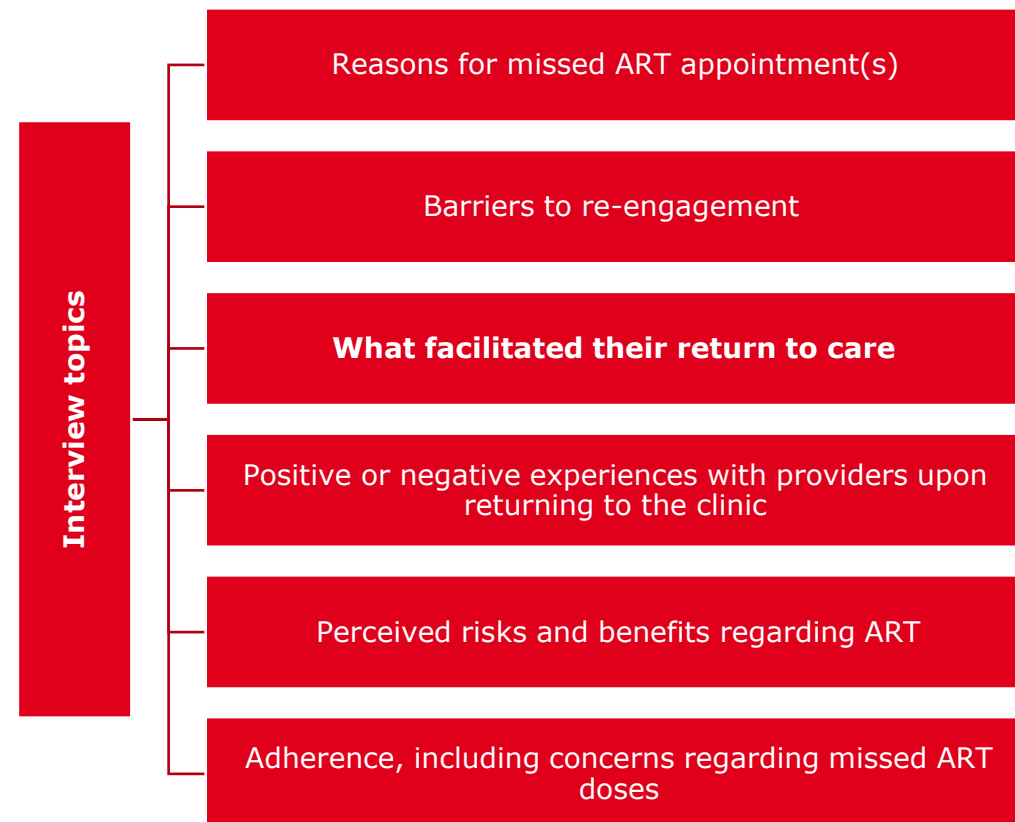
- Qualitative in-depth interviews with 44 participants (21 men; 23 women)

**Eligible participants:**

- ≥15 years of age, had initiated ART for the first time in the last 12-months, >14 days late for an ART appointment in the same 12-month period, returned to HIV care within 60 days after a late ART appointment; were non-pregnant/non-breastfeeding.

**Analysis**

- Conducted in Chichewa, transcribed & translated in English, coded in Atlas.ti, analyzed using framework analysis





# Why do they re-engage?

- Concern for family is a common motivation, particularly for wage earners
- Fear of personal illness and desire to preserve health
- Disclosure to a friend, relative, or community member creates a support network encouraging reengagement

*"If I am sick, I would not be able to care for my family."*

-52-year-old, married man

**Concern for family**

**Active outreach from healthcare workers**

*"So when the [Community Health Worker] discovered that I am not coming, they came and picked me up to say 'You should start taking medicine again.'" 40-year-old, married man*

*"I thought maybe I could die anytime."*

- 47 year-old, unmarried woman

**Fear of illness**

**Social support + encouragement**

*"My relative said that I should go back [to the clinic] because my life depends on the drugs."*

-32-year-old, married woman

# Experiences at return to care: IDEaL and ENGAGE trials

## Design

2 unblinded individually randomized control trials

## Interventions

- Standard of care (ENGAGE)
- Male-specific counseling + facility navigation (IDEaL)
- Male-specific counseling + home-based ART (re)initiation 1-month (IDEaL)
- Male-specific counseling + home-based ART (re)initiation 3-months (ENGAGE)
- Stepped intensity interventions including ongoing male mentorship (IDEaL)

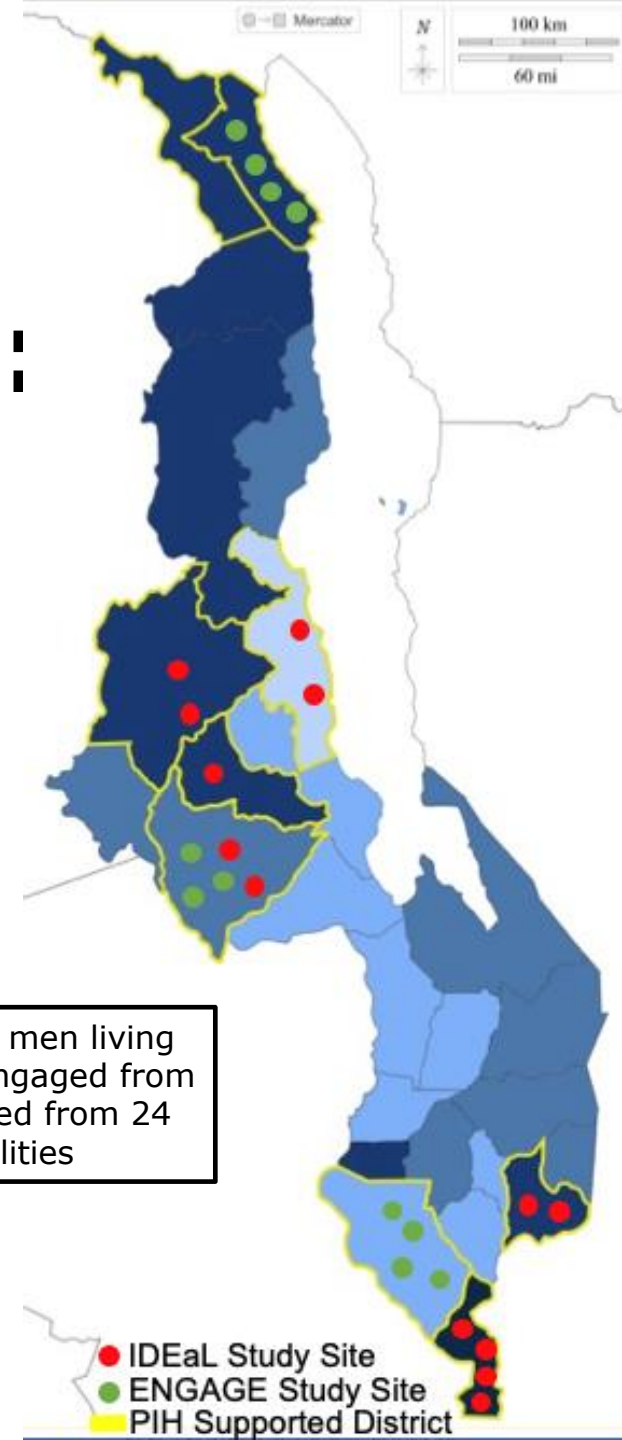
## Qualitative work

- Male clients – in depth interviews with 36 men
- Healthcare workers – focus group discussions with 20 providers

## Population

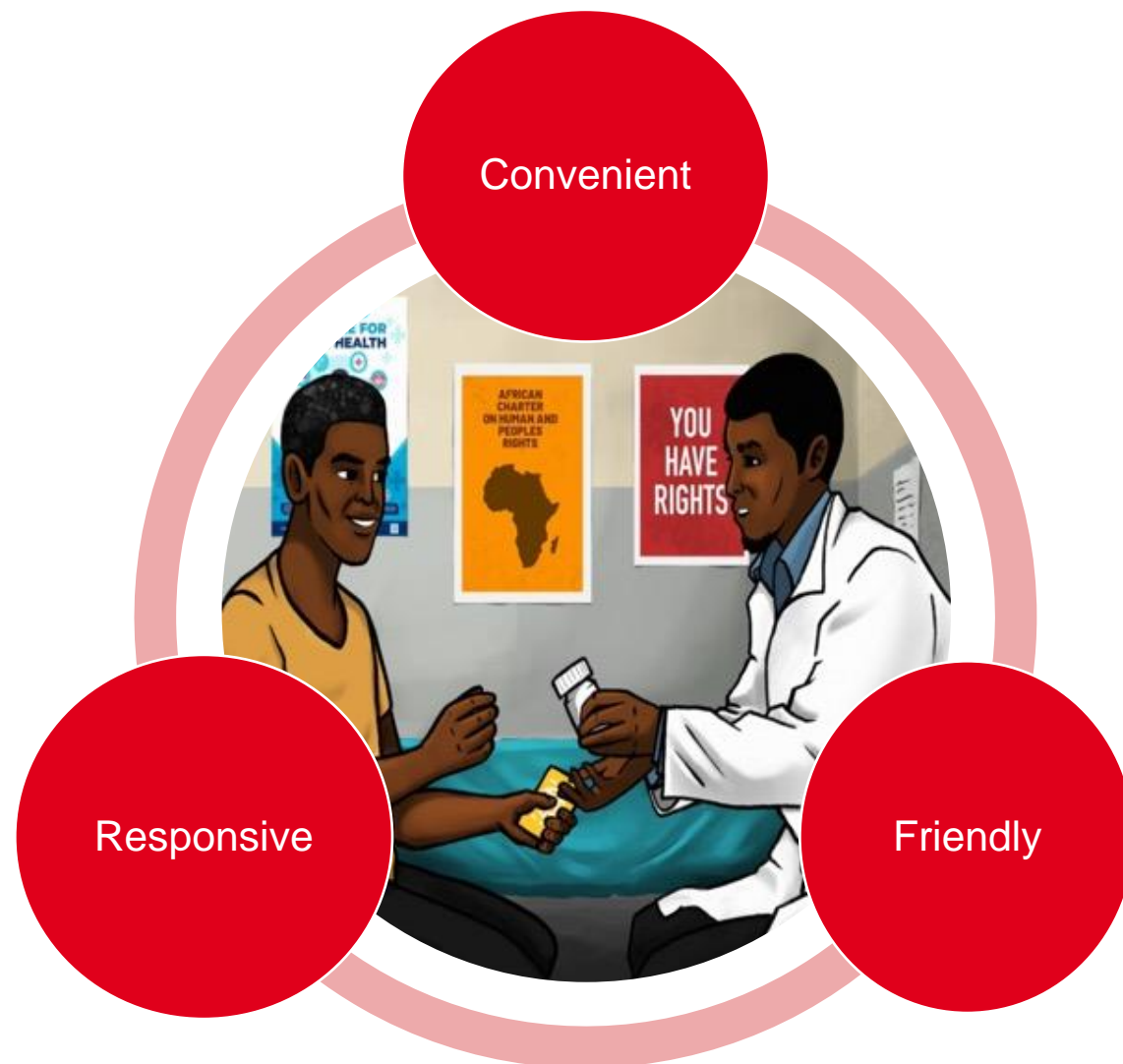
- Male, Living with HIV, not currently on treatment (ART naïve,  $\geq 28$  days late for any ART appointment),  $\geq 15$  years old, living within facility catchment area

Combined 1,303 men living with HIV but disengaged from care were enrolled from 24 health facilities



# Experiences at return to care: *Person-centered care*

- Convenient
  - Outside-facility services, minimal time
- Friendly
  - Welcoming, positive interactions
- Responsive
  - Choice, peer support, tailored counseling



# Experiences supporting return to care

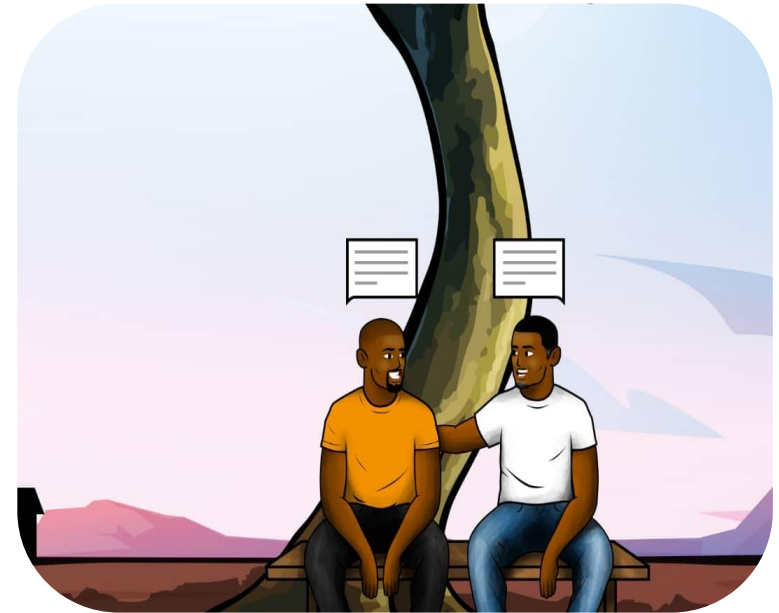
## 1. Positive interactions with HCWs

The way we interacted was so open, he was open about everything he said and he was never angry.

–Client, 37yrs, Central region

My clients main concern is being shouted at after missing their appointments. But when they see the friendliness that we approached them with, they are less worried going back [to the facility].

– Lay cadre, 28yrs, Southern region



# Experiences supporting return to care

## 2. Motivating counseling on how ART contributes to goals

We chat about business and my farming. He says I can still be leader in my community despite my HIV status. I ask him how to face my issues. Yes, we are indeed friends.

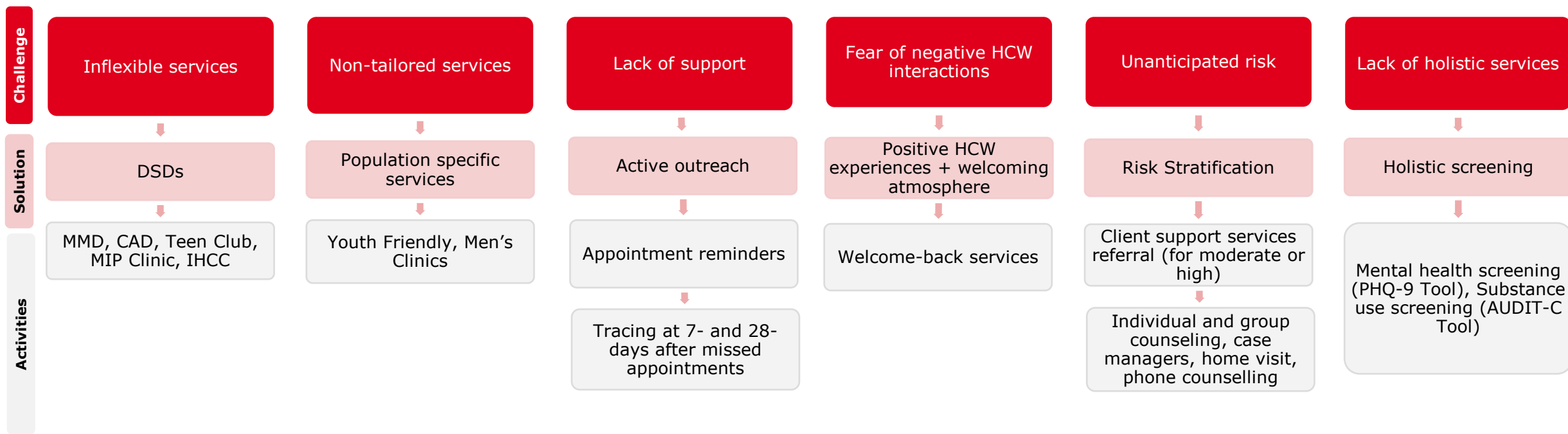
– Client, 37yrs, Central region

My client always travels to Mozambique, but for a very good reason: to make sure that there is food on his table. This means I need to support him, despite his travels, to make ARVs a priority.

–Lay Cadre, 37yrs, Southern region



# Looking forward, what is Partners in Hope doing?





# ACKNOWLEDGEMENTS

---

## Funders:

Bill and Melinda Gates Foundation  
(INV-001423)

NIH (R01MH122308)

U.S. Agency for International  
Development (USAID) and the  
President's Emergency Plan for  
AIDS Relief (PEPFAR) (AID-OAA-A-  
15-00070)

University of California Los Angeles  
(UCLA) CFAR (AI028697)

---

## Acknowledge:

PIH Facility staff

Client and HCW participants



Kathryn Dovel, PhD, MPH



Augustine Choko, PhD



Kelvin Balakasi, MSc



Isabella Robson, MSc



Misheck Mphande, MSc



Tom Coates, PhD



Morna Cornell, PhD



McDaphton Bellos



Julie Cronjaeger, MSc



Marguerite Thorp, MD



Rose Nyirenda



Stephanie Chamberlin, PhD



Sam Phiri, MSc, PhD



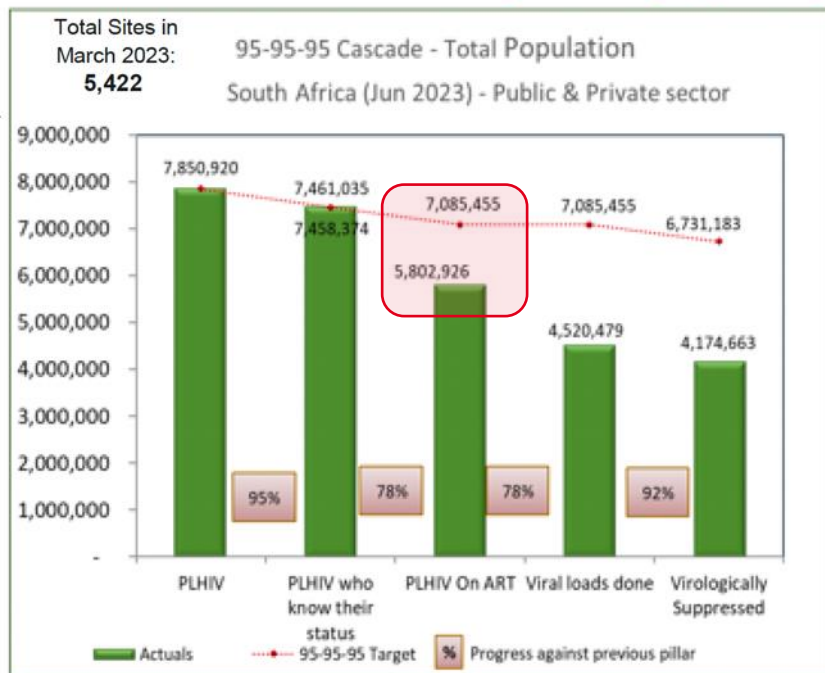
# How late is too late? Definitions of interruptions and the impact on supportive interventions



# In South Africa, large gap between the first and second 95

## 95-95-95 Cascade – 2<sup>nd</sup> 95 Remains the Biggest Challenge

- PLHIV unaware : 400k out of 7,9M (95% are aware)
- PLHIV not on ART: 2M out of 7,9M (74% are on ART)
- PLHIV with VL ≥ 1,000: 3,8M out of 7,9M (53% are virally suppressed)



2 million people living with HIV not on ART

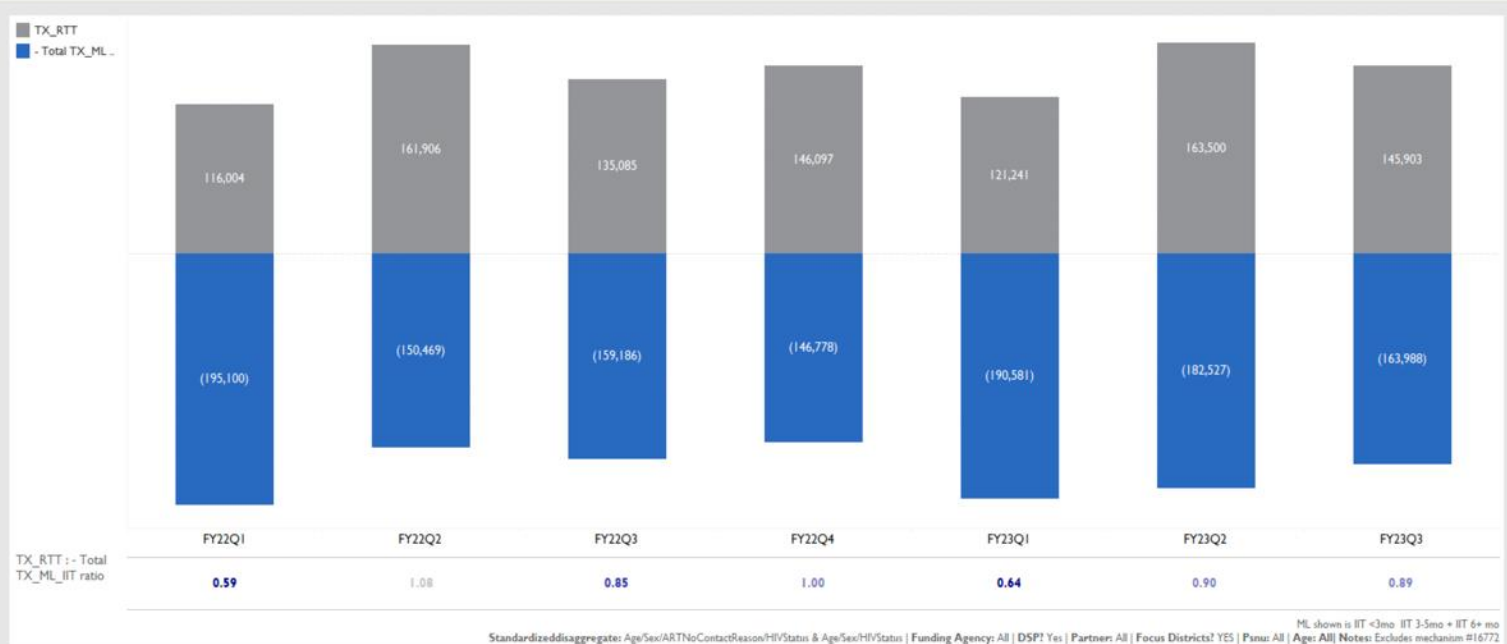
To achieve 95-95-95 targets, South Africa must increase the number of:

- Total Clients on ART by 1,249,851,
- Adult Females on ART by 573,925,
- Adult Males on ART by 605,468,
- Children (<15) on ART by 70,457.

# Lots of returns & lots of “missed scheduled appointments”

## PEPFAR Data from South Africa

Despite Improvement In Return To Care (RTT), It Remains Insufficient For Growth



- **TX\_RTT**: Number of ART patients with no clinical contact (or ARV drug pick-up) for greater than 28 days since their last expected contact who restarted ARVs within the reporting period
- **TX\_ML**: Number of ART patients (who were on ART at the beginning of the quarterly reporting period) and then had no clinical contact since their last expected contact

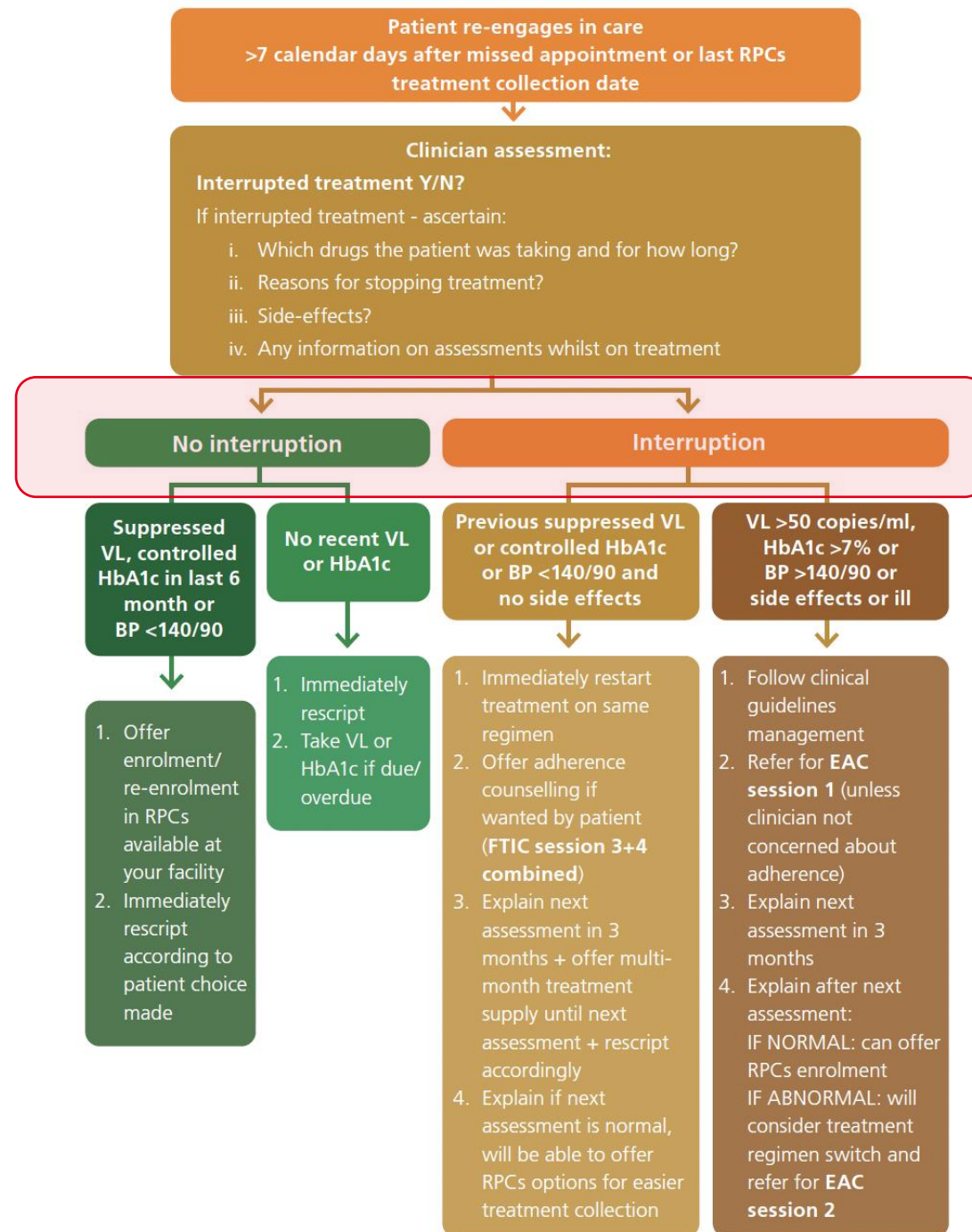


***“I lost my clinic card but knew my return date for my ARVs. A nurse in the consultation room called me a “defaulter”, shouting at me while the door was open. Some of the patients and clinical staff were moving around and they could hear what was going on. She also chased me and said “I don’t have time for defaulters, there are serious people that seek my help”. As she said this she was standing up and telling me to sit outside while she helps serious people first and I was going to be last. I was so sad, felt humiliated and disrespected because I made every effort to visit the clinic early so that I could return to work to provide food at home” — Gompo Clinic (Buffalo City), interview in March 2023***



# South Africa's 2020 re-engagement algorithm

**SOP9 – Differentiated between those unwell and who DID and DID NOT interrupt treatment**



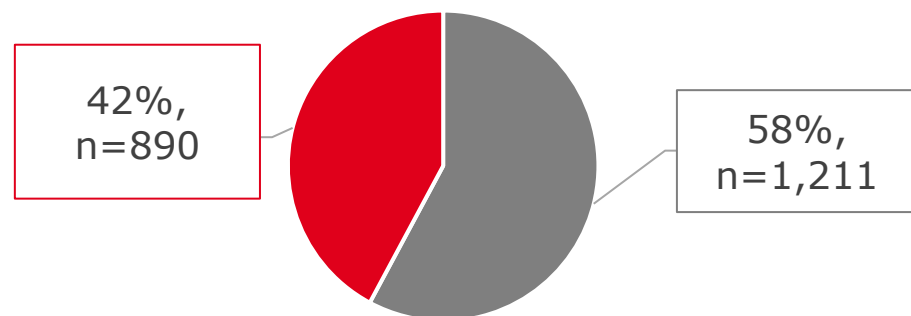
# Are these interruptions? And how long are they? Of those returning, who requires clinical support?

**Heterogeneity among people re-engaging in antiretroviral therapy highlights the need for a differentiated approach: results from a cohort study in Johannesburg, South Africa**

- Understand the profile of people with returning after missing a scheduled appointment re-engaging and duration until their delayed visit
- July-November 2022, n=9 primary healthcare sites in Johannesburg
- Clinicians completed “re-engagement clinical assessment forms” for those who missed their appointment by >2 weeks,
- Collected information about the consultation, days since appointment, reasons for interruption, clinical details and management plan details on regimen and viral load were extracted from clinic folders, self-report on whether an interruption took place or not

# Many people *delay* visits, interruptions are short

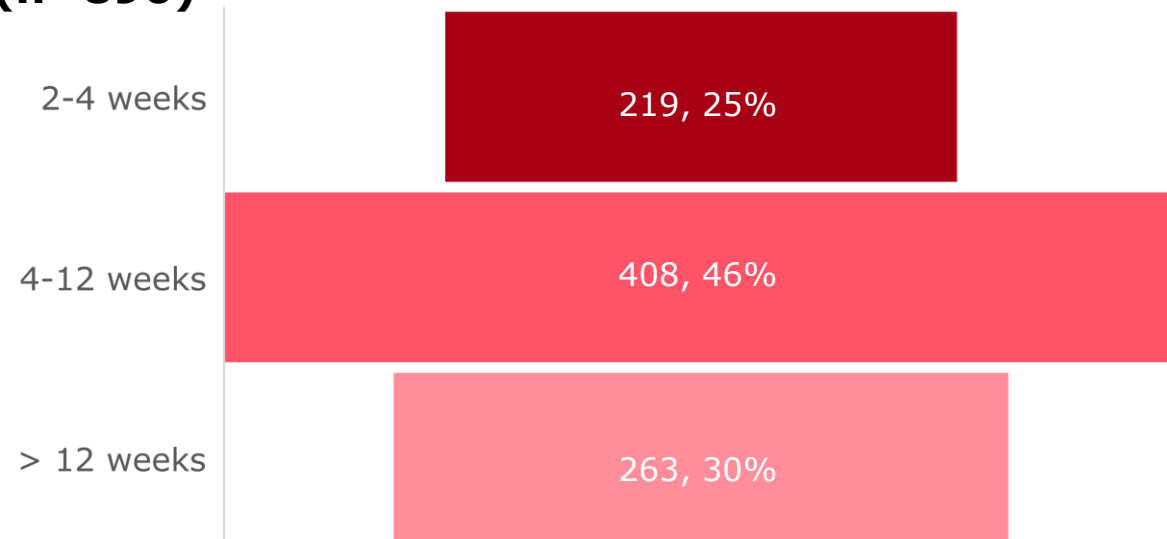
Time to visit after missing scheduled ART appointment (n=2,111)



- < 2 weeks late (Missed appointment, but not re-engaging)
- ≥ 2 weeks late (re-engaging in care)

More than half of people who had missed their appointment returned within two weeks.

Time to visit among people who return more than two weeks late after missing scheduled appointment (n=890)



Among those returning after two weeks days, **less than a third** returned after **three months**.

# Those returning have not necessarily interrupted and many don't need clinical support

Of those returning more than 2 weeks after a scheduled appointment (n=890)

- 39% (n=387) self-reported no treatment interruption.

**Takeaway: Not all people with a missed appointment have interrupted**

- 71% (n=503/708) of those with a pre-interruption viral load (VL) result had a VL <50 copies/ml

**Takeaway: Majority of those re-engaging have previously been suppressed**

- Clinicians identified clinical concerns (including a high VL) in 13% (97/720)

**Takeaway: Few with clinical concerns**

1

For returning patients,  
the *first return visit*  
experience is critical

Welcoming, supportive and  
empathetic

Clear facility visit flow focused on a  
positive patient experience

2

*Not all patients* late for  
scheduled appointments  
are re-engaging patients

28 days

3

All re-engaging patients  
*DO NOT* have the same  
service delivery needs

Easier access to treatment

Psychosocial support

Clinical management

Always  
be kind

No  
judgement  
zone

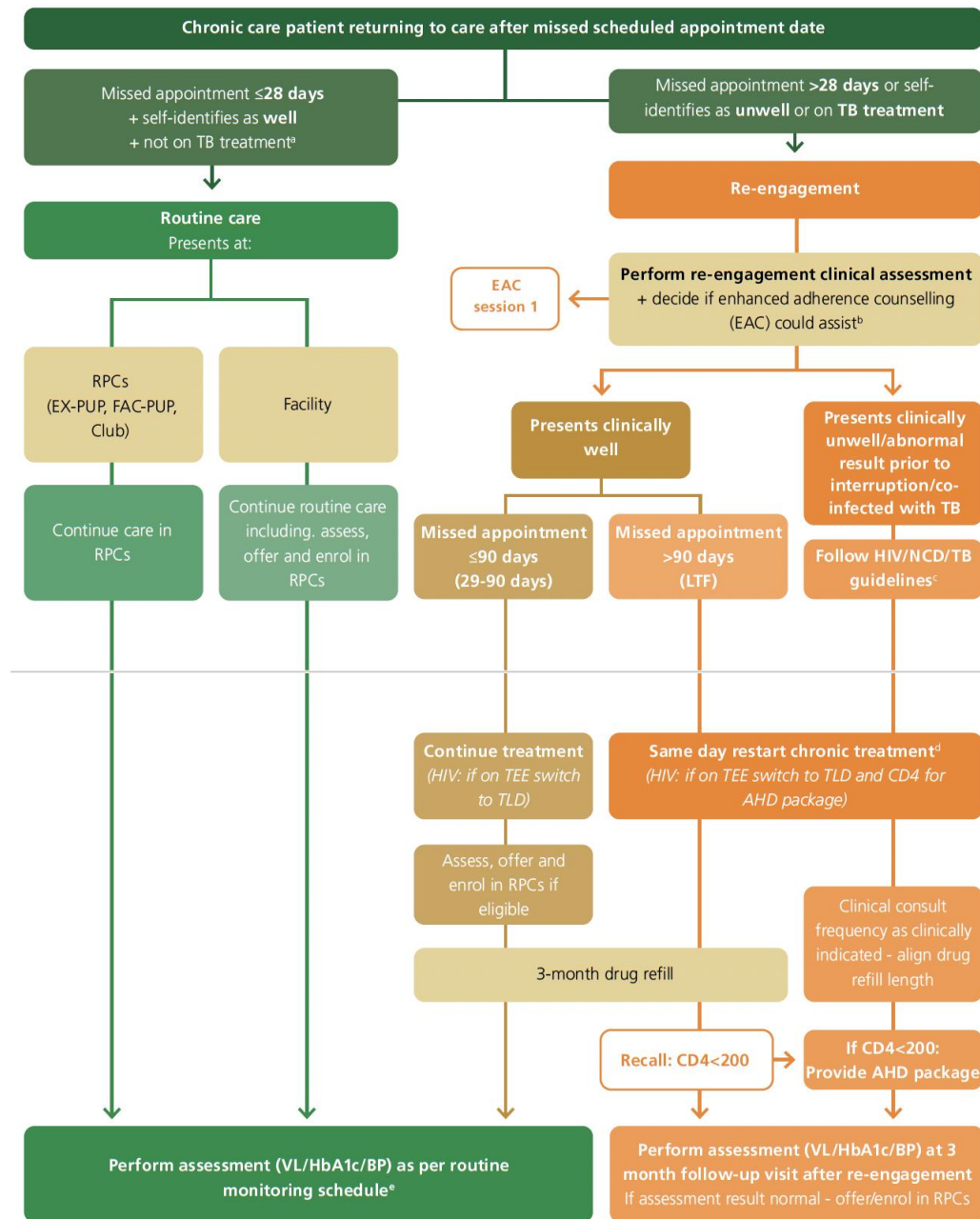
**Differentiation is critical → move  
away from a one-size-fits-all  
approach to returning patients**

# Updated SOP in 2023

## CRITERIA FOR RE-ENGAGEMENT

Any chronic care patient who returns to the facility either of their own accord or after tracing, self-identifying as unwell or co-infected with TB or more than **28 calendar days** after their scheduled appointment date including a missed Repeat Prescription Collection strategies (RPCs) scheduled appointment.

## ANNEXURE VII: RE-ENGAGEMENT ALGORITHM



- Training for the SOP on reengagement was integrated with training for the new ART and adherence guidelines and is currently taking place
- Lack of good monitoring systems to determine if implementation is taking place or not
- Plans underway to evaluate the implementation and outcomes of re-engagement algorithm in 2024



# Lessons learned

- Majority of those returning have had a short treatment interruption
  - Many are less than 3 months late with a short or no interruption (sourcing ART elsewhere)
- The definition of re-engagement matters → it influences where you focus efforts
- Re-engagement pathways should not be one-size-fits all
- Staff attitudes at re-engagement remain a problem → but there are also opportunities with people who are welcoming and non-judgmental

# How Zimbabwe built a differentiated approach to support differentiated needs at re-engagement

Dr Chiedza Mupanguri, MOHCC, Zimbabwe  
Re-engagement in HIV treatment services, ICASA 2023



# Zimbabwe's updated Operational and Service Delivery Manual

- Ministry of Health and Child Care (MOHCC) updated its HIV Prevention, Testing and Treatment guidelines in 2022 in line with updated WHO guidelines – the **“what to do”**,
- To accompany this, update the *Operational and Service Delivery Manual* - **“how to do it”** with the aim of increasing retention at all steps of the cascade
  - For doctors, clinical officers, nurses, counsellors, pharmacists, health information officers, health promotion officers, community health workers and community-based organisations (CBOs)



## OPERATIONAL AND SERVICE DELIVERY MANUAL

**FOR THE PREVENTION,  
CARE AND TREATMENT  
OF HIV IN ZIMBABWE**

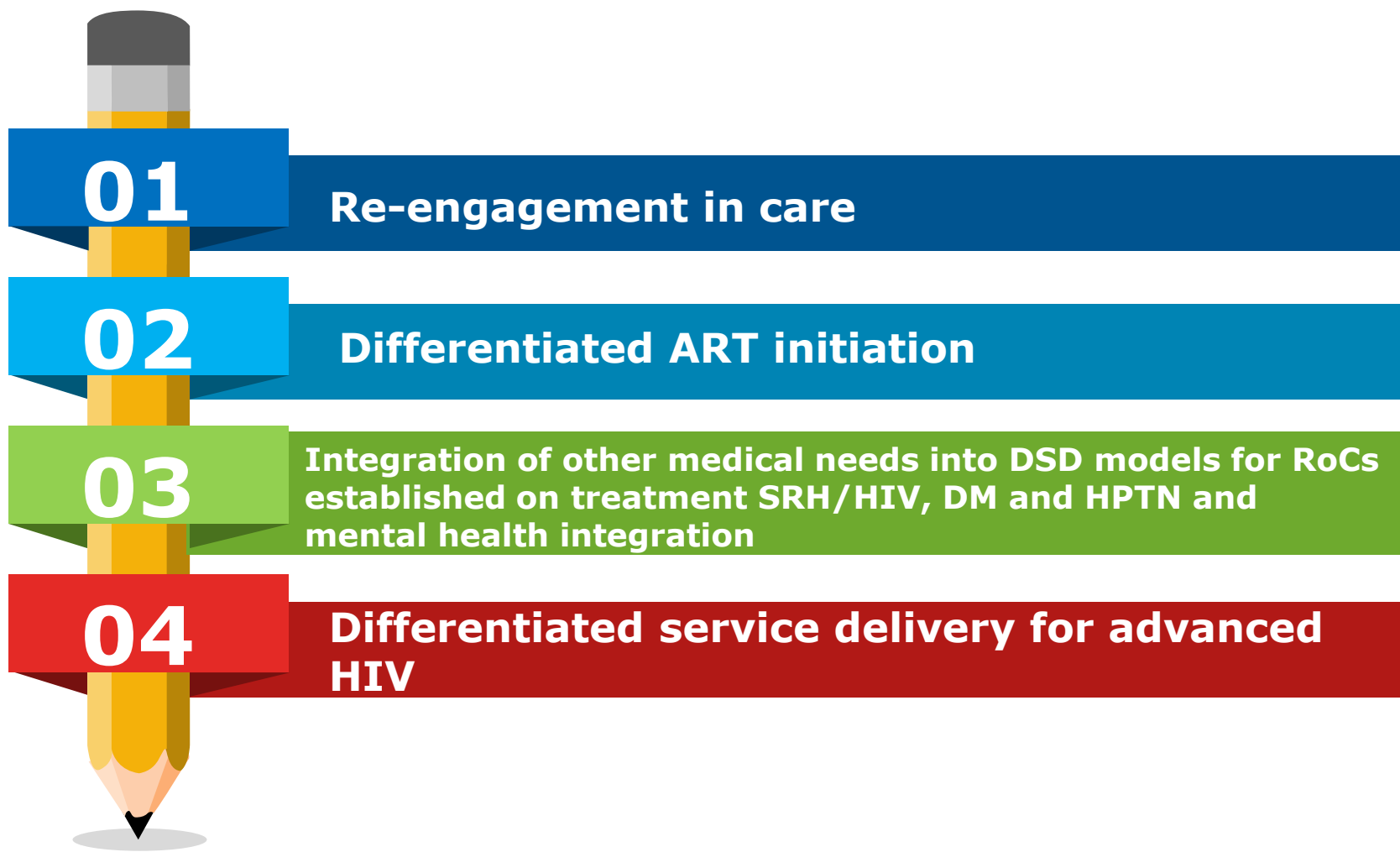
**2022 EDITION**



**AIDS & TB Programme**

**Ministry of Health and Child Care, Zimbabwe**

# What's in OSDM on HIV care and treatment?





## Re-engagement in care

### Definition of re-engagement

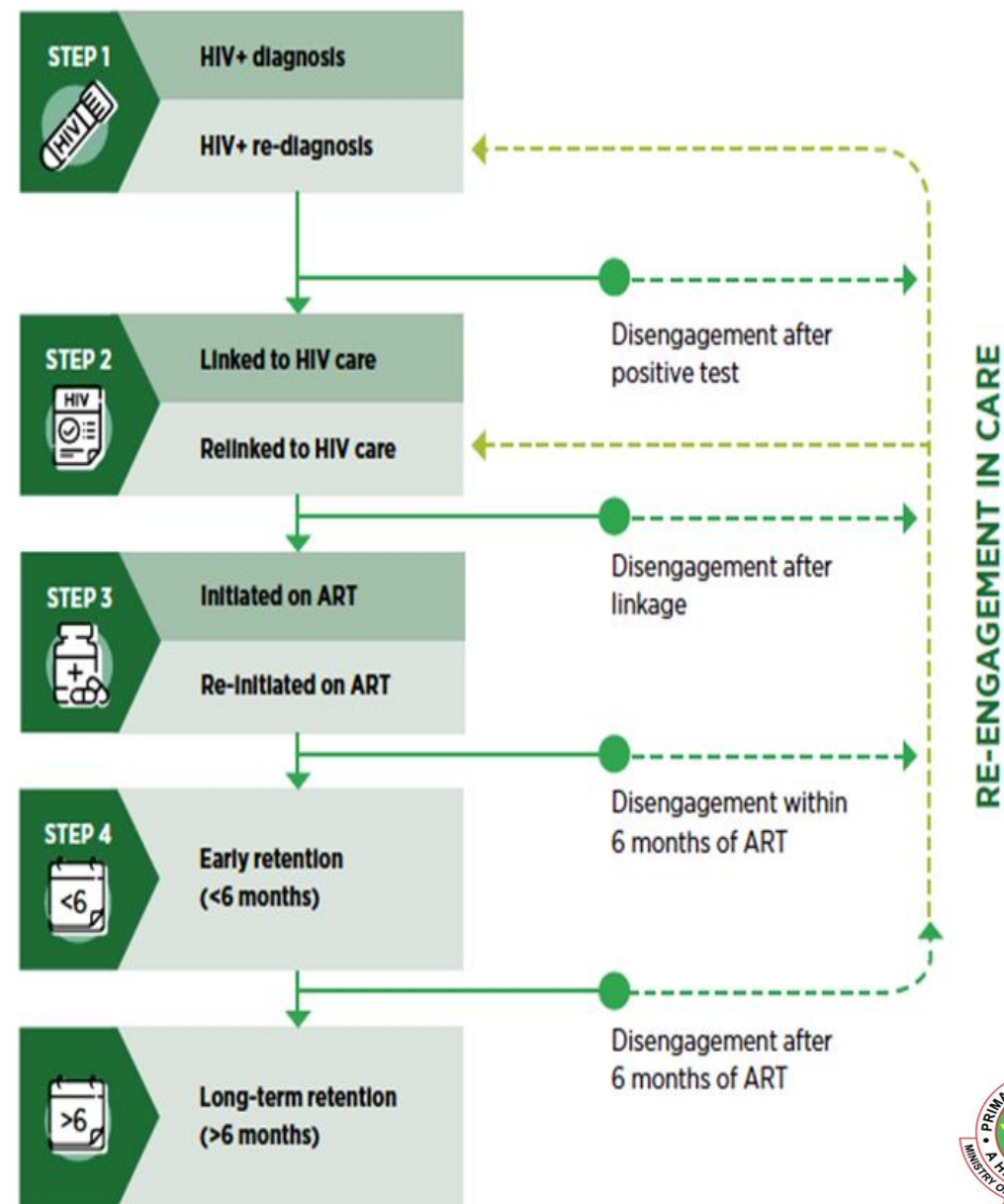
Re-engagement refers to any RoC who is presenting to HIV services who has:

- Previously tested positive but never linked to treatment
- Previously been on ART but stopped

The RoC may re-engage:

- At HIV testing sites or through HIV self-testing
- At an ART site where they are known or not known

Figure 4: Re-engagement cycle across the HIV care and treatment cascade



# Re-engagement in care

“Re-engagement services should ensure that RoCs who re-engage are received with dignity, are assisted and clinically managed and receive quality psychosocial services from healthcare workers. RoCs re-engaging in care are often those struggling the most with adherence and should not be penalized by being asked to attend more frequently unless there is a clinical indication.”

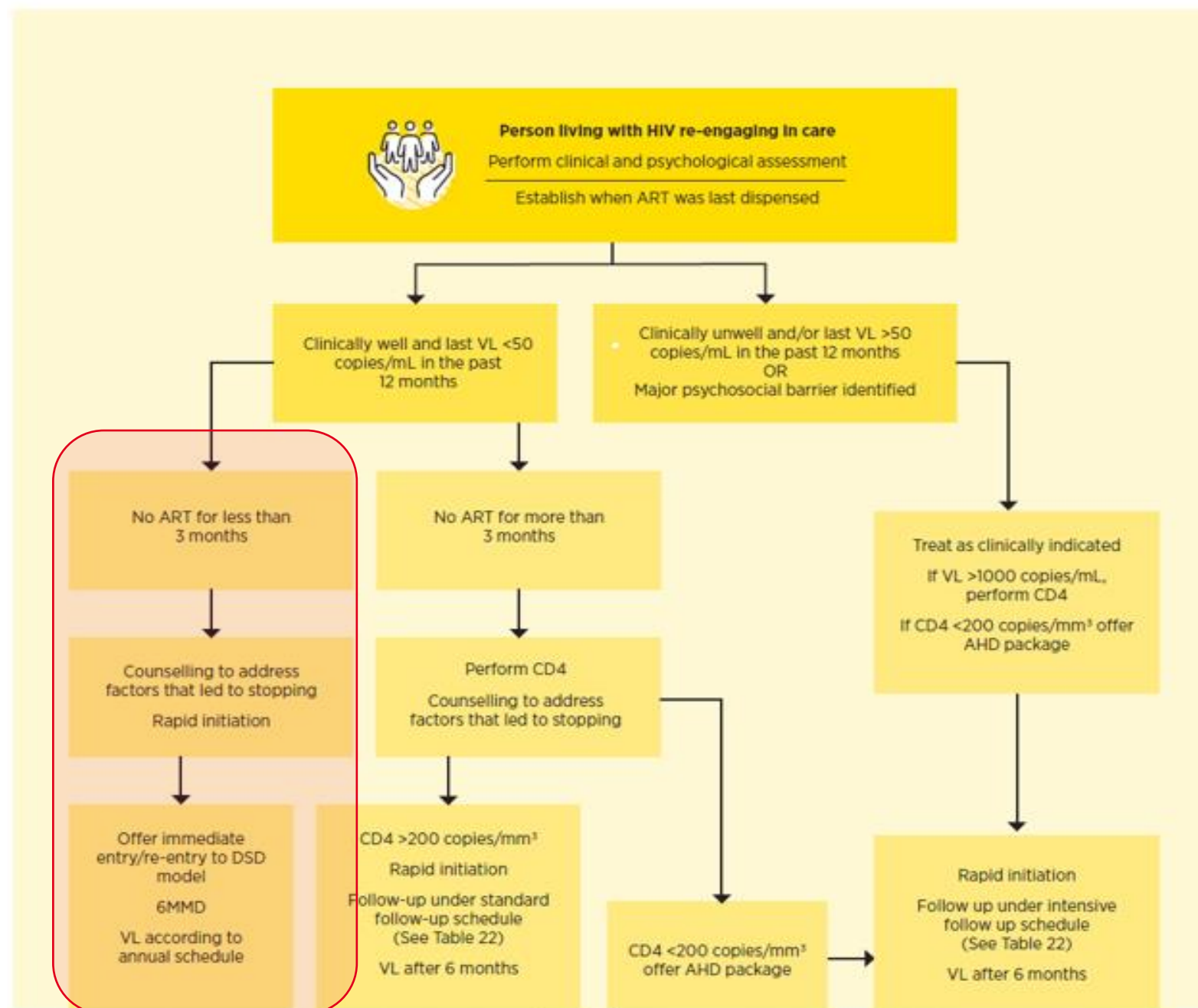
Counselling for a RoC re-engaging in care should include:

- Exploring treatment literacy
- Addressing the reasons for stopping ART
- Identifying motivational factors for starting ART
- Identifying mental health issues



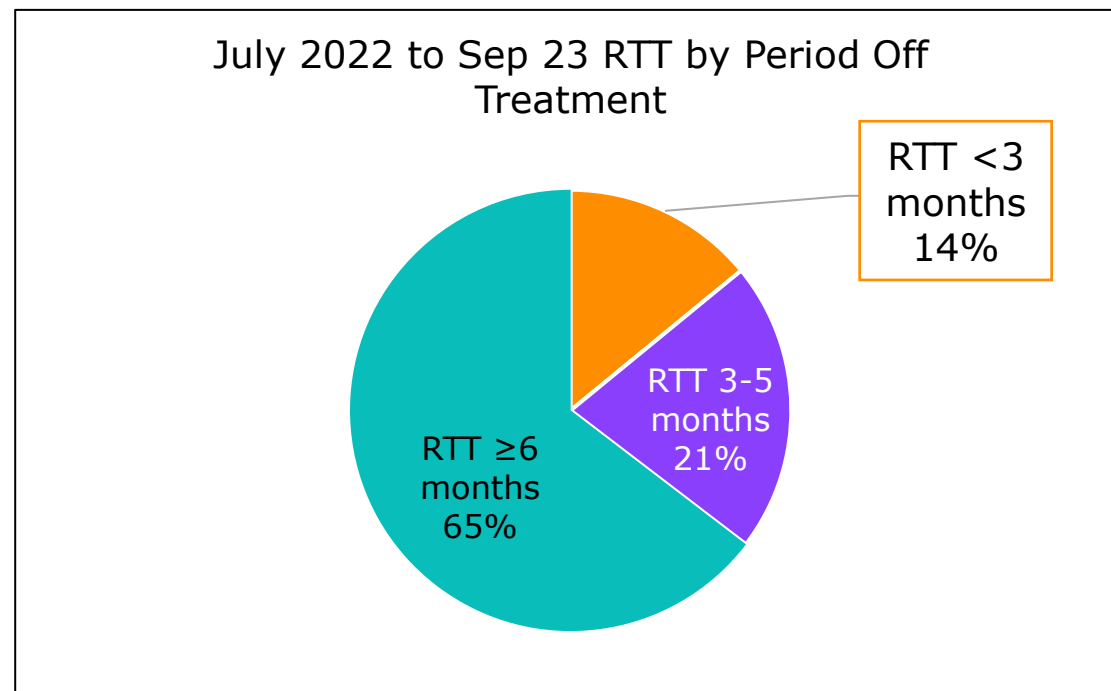
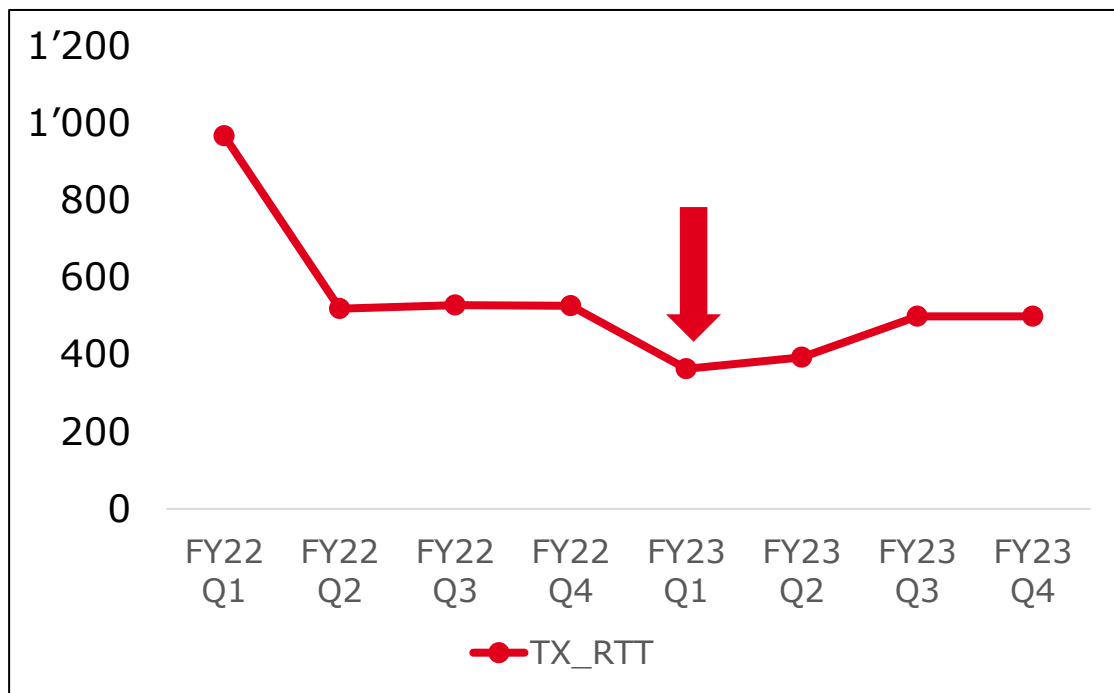
Healthcare worker attitudes are key to supporting those returning to care and should be non-judgemental and welcoming.

Figure 17: Algorithm for the management of a RoC re-engaging in care





# Return to treatment trend over time

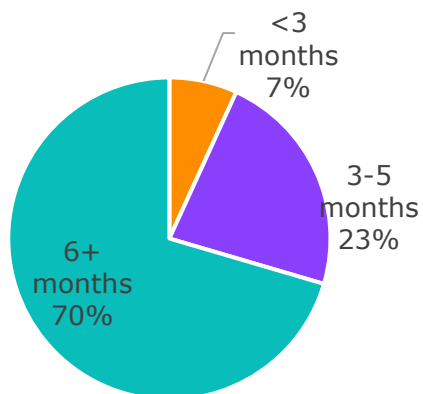


- 1,754 recipients of care RTT in the past 12 months in 321 facilities
- RTT peaked in FY22Q1(Oct-Dec,2021) due to follow-ups of RoCs who had interrupted treatment during the Delta Wave of COVID-19
- Increasing trend in RoCs returned to treatment since period Oct-Dec 2022 (pointer), due to intensified program tracking and tracing efforts through Community Healthcare workers
- In the period Jul 2022-Sept 2023, most RoCs (65%) returned to treatment had interrupted treatment/ lost to follow-up for more than 6 months

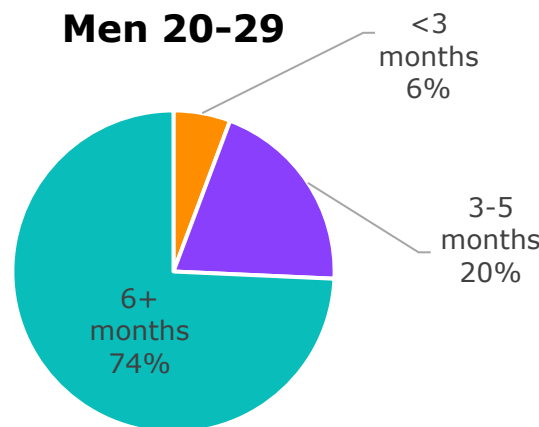


## Period of treatment interruption before RTT by population

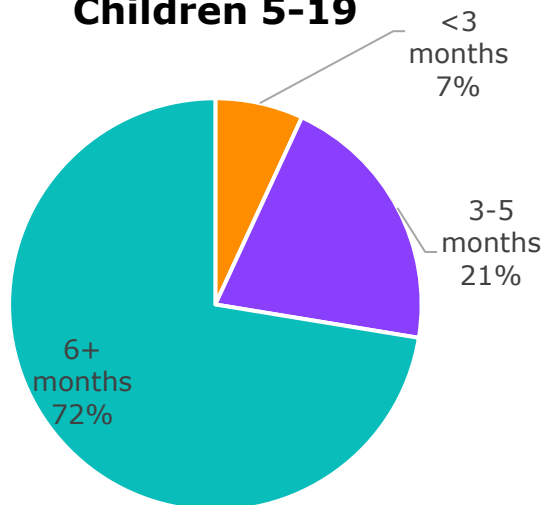
**AGYW**



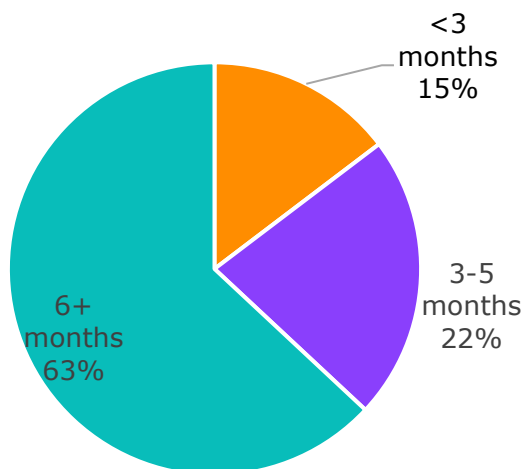
**Men 20-29**



**Children 5-19**



**Adults 40+ yrs**



## Insights

- RTT among priority populations is mainly among those who have interrupted treatment for more than 6 months
- High proportion of adults 40+ are returned to treatment following treatment interruption < 3 months (compared to other sub-populations)
  - Older adults are generally more accessible in the community when compared to younger individuals who may be involved in economic activities that require high mobility
- Differentiated approaches essential in ensuring RoC are returned to treatment

# Reasons for not linking to treatment or stopping ART

## Patient factors

- Stigma
- Non-disclosure
- Socio economic status
- Faith healers

## Facility factors

- Staff attitude
- Long waiting time
- Long distance to facility
- Drug stockouts

# Lessons learned

**Community Engagement and Support:** Involving PLHIV and their communities in the design, implementation, and monitoring of HIV programs has proven effective. Engaging community leaders, peer educators, and support groups can help reduce stigma, improve access to care, and ensure the relevance and acceptance of interventions

**Addressing Socioeconomic Determinants:** Recognizing and addressing the socioeconomic factors that hinder engagement in care can be vital. This includes implementing strategies to reduce poverty, improve access to education, and provide financial support for healthcare expenses (DREAMS project)

**Innovative Approaches:** Leveraging technology, such as mobile health applications, telemedicine, and text messaging, can help overcome geographical barriers and improve access to care. Such innovations can facilitate appointment reminders, medication adherence support, and access to health information.

**Strengthening Health Systems:** Investing in health system strengthening efforts, including infrastructure development, supply chain management, and healthcare financing, is crucial. This helps ensure the availability of essential medications, laboratory services, and trained healthcare providers, facilitating engagement in care.

# Acknowledgements

- MOHCC – programme managers, implementers (HCWs)
- PEPFAR and IP
- Non – PEPFAR partners
- Global Fund
- National AIDS Council
- Representatives of PLHIV
- CSOs and Recipients of Care
- IAS