Re-engagement in HIV treatment services
Welcome and overview

Baker Bakashaba, AIDS Information Center (AIC), Uganda
Peter Ehrenkranz, Bill and Melinda Gates Foundation, USA
The HIV cascade is cyclical... not linear
Increasingly, those initiating ART are not treatment-naive

In the Western Cape province of South Africa, among those starting ART now, 2/3rds have previously been on ART
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
- Chipo 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
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

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

Kathryn Dovel, Kelvin Balakasi, Julie Hubbard, Khumbo Phiri, Brooke E. Nichols, Thomas J Coates, Michal Kulich, Elijah Chikuse, Sam Phiri, Lawrence C Long, Risa M Hoffman, Augustine T Choko

AIDS and Behavior (2022) 26:674-685
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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, Misheck Mphande, Khumbo Phiri, Pericles Kalande, Kathryn Dovel

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

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**Interview topics**
- Reasons for missed ART appointment(s)
- Barriers to re-engagement
- What facilitated their return to care
- Positive or negative experiences with providers upon returning to the clinic
- Perceived risks and benefits regarding ART
- Adherence, including concerns regarding missed ART doses
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

"I thought maybe I could die anytime." - 47 year-old, unmarried woman

"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

"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, >28 days late for any ART appointment), >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?

**Challenge**

- Inflexible services
  - DSDs
  - MMD, CAD, Teen Club, MIP Clinic, IHCC

- Non-tailored services
  - Population specific services
  - Youth Friendly, Men’s Clinics

- Lack of support
  - Active outreach
  - Appointment reminders

- Fear of negative HCW interactions
  - Positive HCW experiences + welcoming atmosphere

- Unanticipated risk
  - Risk Stratification
  - Client support services referral (for moderate or high)

- Lack of holistic services
  - Holistic screening
  - Mental health screening (PHQ-9 Tool), Substance use screening (AUDIT-C Tool)

**Solution**

- Inflexible services
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  - MMD, CAD, Teen Club, MIP Clinic, IHCC

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**Activities**

- Tracing at 7- and 28-days after missed appointments
- Welcome-back services
- Individual and group counseling, case managers, home visit, phone counselling
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Client and HCW participants
How late is too late? Definitions of interruptions and the impact on supportive interventions

Re-engagement in HIV treatment services, ICASA 2023
Chipo Mutyambizi, Anova
In South Africa, large gap between the first and second 95

95-95-95 Cascade – 2nd 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

**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)

- 42%, n=890
- 58%, n=1,211

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

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

- 2-4 weeks: 219, 25%
- 4-12 weeks: 408, 46%
- > 12 weeks: 263, 30%

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

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

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
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.
Uptake and implementation

- 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
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)
What's in OSDM on HIV care and treatment?

01. Re-engagement in care

02. Differentiated ART initiation

03. Integration of other medical needs into DSD models for RoCs established on treatment SRH/HIV, DM and HPTN and mental health integration

04. Differentiated service delivery for advanced HIV
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

- Step 1: HIV diagnosis
- Step 2: HIV re-diagnosis
- Step 3: Initiated on ART
- Step 4: Early retention (<6 months)

- Disengagement after positive test
- Disengagement after linkage
- Disengagement within 6 months of ART
- Disengagement after 6 months of ART
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.”
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-Sep 2023, most RoCs (65%) returned to treatment had interrupted treatment/lost to follow-up for more than 6 months
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.
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