HIV Learning Network
The CQUIN Project for Differentiated Service Delivery

Who really disengages from HIV care:

Tracing outcomes and characteristics of men lost-to-follow-up at 20 health facilities in Malawi

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CQUIN Differentiated Service Delivery Across the HIV Cascade Workshop
August 15 – 19, 2022 | Kigali, Rwanda

Men's engagement in ART services

Men are at higher risk of not initiating ART, disengaging from care, and remaining out of care once disengaged

Three categories of disengagement

- **Not initiated ART** > 14days after testing HIV-positive
- **Initiated but not returned** for a refill appointment
  - > 14days late for first ART refill appointment
- **Defaulted** from ART care
  - ≥ 1 follow-up appointment and > 28days late for last appointment

Other important characteristics: Length of time outside of care; # of episodes outside of care (cyclical engagement)

Men's engagement in ART services – continued

Gaps in Knowledge

- What is men's actual disengagement from care?
  - Limits of routine data: silent transfers; poor data entry
  - Clients present as ART naïve for re-engagement
- Characteristics of those disengaged
  - Do characteristics/needs vary by categories of disengagement?
    - What support do they need?

ENGAGE and IDEaL Trials

ENGAGE

- **Title:** Engaging men through differentiated care to improve ART initiation and viral suppression (Funder: NIMH)
- **Intervention:** 3-months ART distribution at home + "warm" handover at 4-months
- **Location:** 10 health facilities in Malawi
- **Status:** Enrollment ongoing
- **Timeline:** Data collection complete early 2024

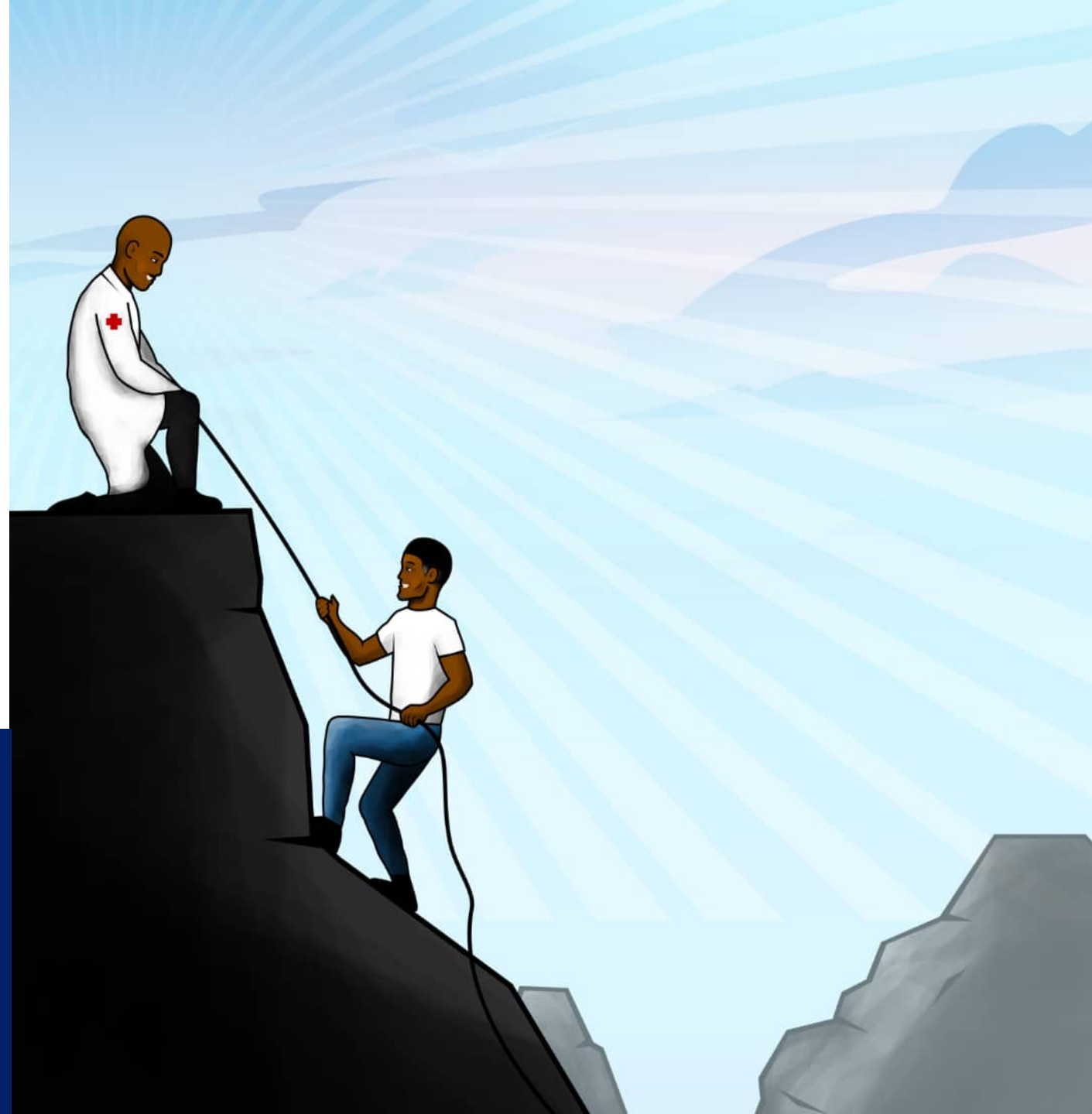
IDEaL

- **Title:** Identifying efficient linkage strategies for men in Malawi (Funder: BMGF)
- **Intervention:** Male-tailored counseling, mentorship, and home-based initiation (stepped strategies)
- **Location:** 10 health facilities in Malawi
- **Status:** Enrollment ongoing
- **Timeline:** Data collection complete early 2023

Combined 1243 men living with HIV but disengaged from care to be enrolled

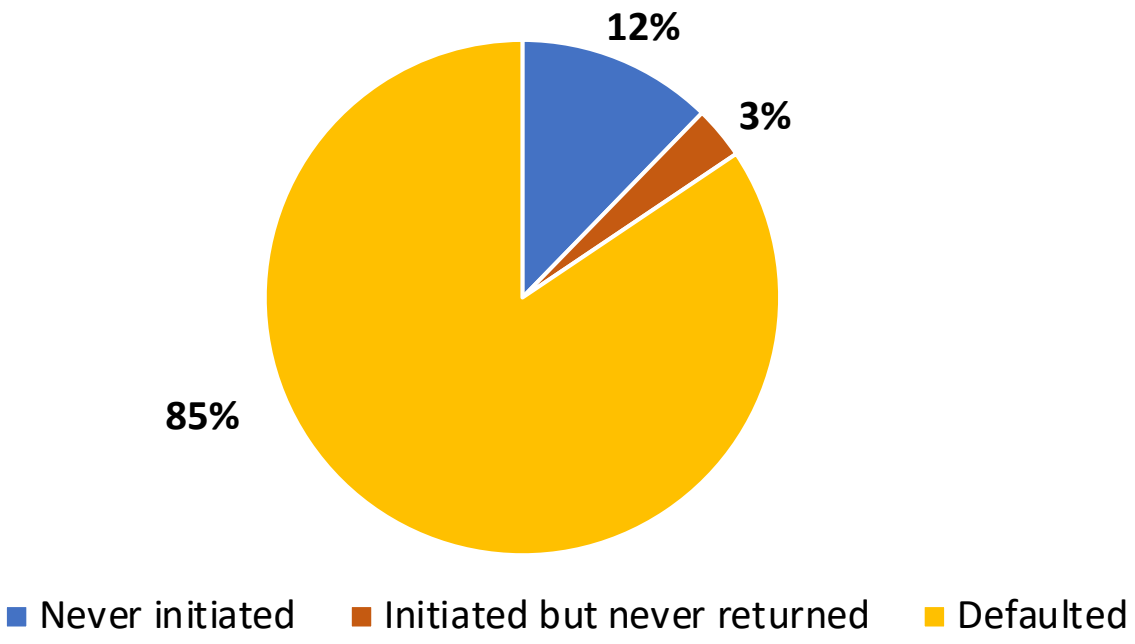
Understand

Outcomes for men documented as disengaged



Tracing attempts among men documented as disengaged

Men documented as disengaged, by category (n=1303)

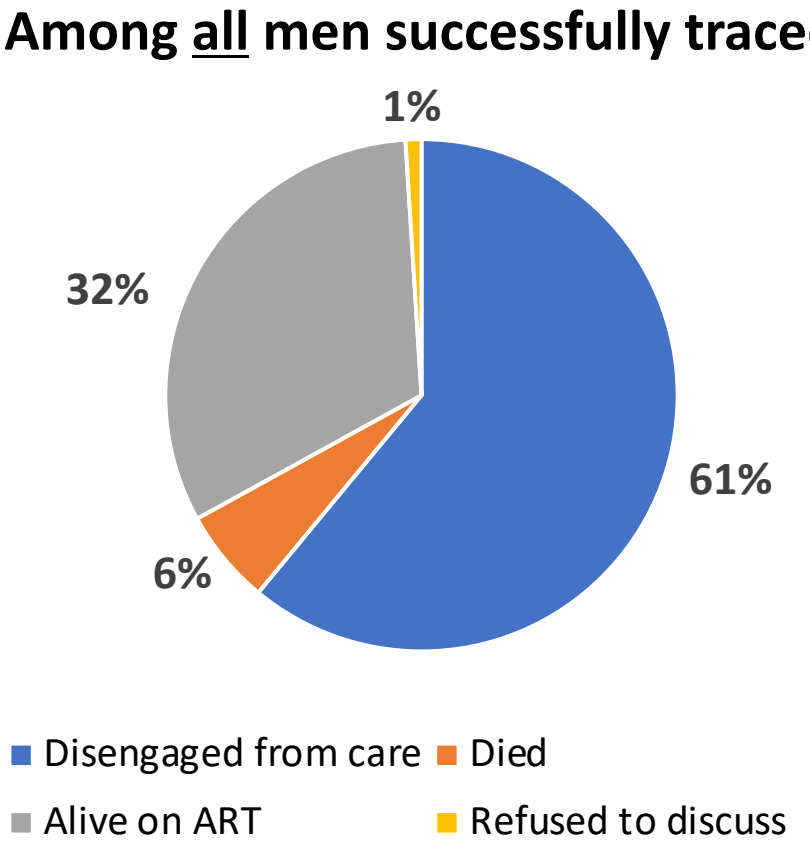


Men in need of tracing in the past 12-months (n=1303)	
Has a phone	290 (22%)
Median tracing attempts (IQR)	2 (1-2)
Successfully traced	682 (52%)

Common reasons for failed tracing:

- *Inaccurate residential details*
- *Moved outside facility catchment area*
- *Temporary travelled*

Outcomes among men successfully traced (n=682)

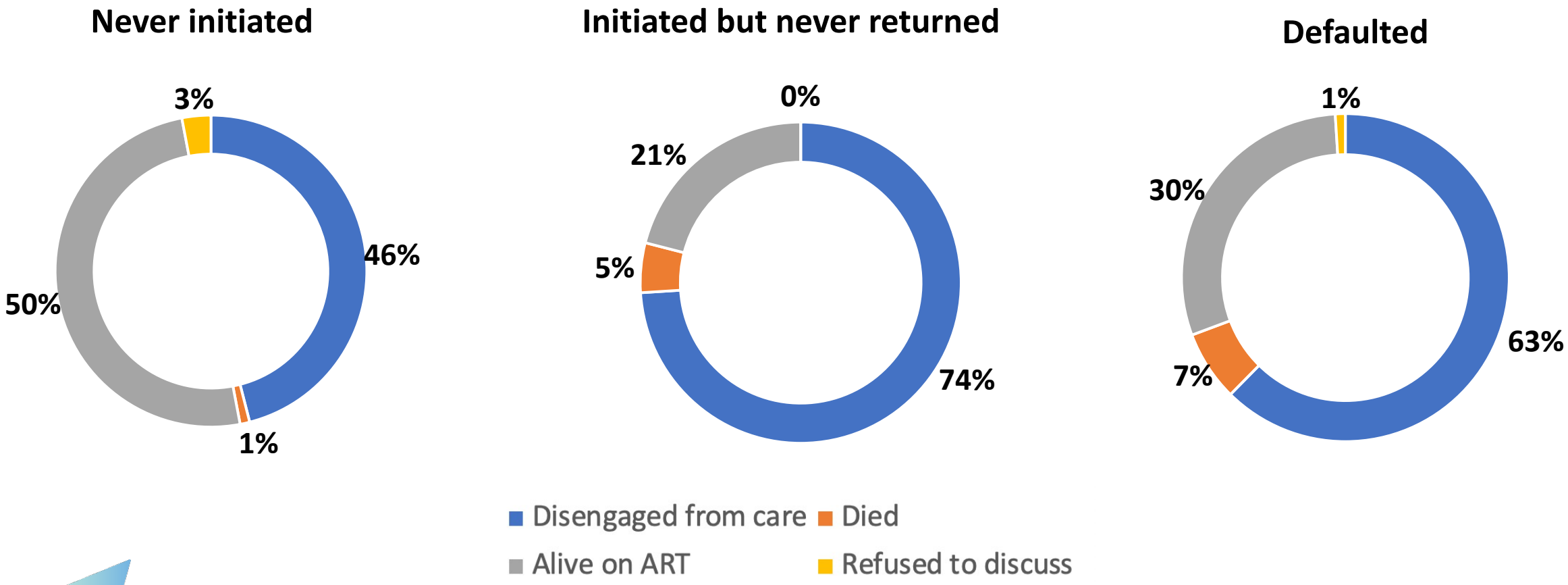


32% of men categorized as disengaged who were traced were alive and on ART

Among these:

- 53% silent transfer
- 46% active at study facility but poor documentation

Outcomes by disengagement category (n=682)



Lessons from tracing outcomes

Men are doing better than we think

- More accurate records and easier transfer systems are needed so:
  - Have a true picture of how men (and everyone) are doing
  - Optimize resource allocation between tracing and systems improvement
    - Clients who appear as out of care are actually still in care

Programs should focus on how to keep men in care – initiation is not enough

- More focus should be on targeting strategies to improve long term retention among men

Explore

Characteristics of men disengaged from care

Preliminary findings: Characteristics of those disengaged (n=416)

Variable	Total n (%)
Demographics	
Median age (IQR)	39 (35-46)
History with ART Services	
Median time since first initiated ART (years, IQR)	2.5 (2.1-3.0)
Median time outside of care prior to being traced (days, IQR)	40 (25-52)
Stopped taking ART >1x (cyclical engagement) (%, n)	31% (129)

Preliminary findings: Characteristics of those disengaged (n=416)

Variable	Total n(%)
Barriers to care	
Had not disclosed their HIV status to anyone besides their spouse	41% (171)
Anticipated stigma/discrimination from status disclosure	73% (304)
Talk to someone in social network about HIV/ART at least once per month	68% (283)
Never talk to someone about HIV/ART	27% (112)
Believe most people experience side-effects from ART	52% (216)
Mobility (≥14 days spent away from home in the past 12-months)	32% (133)
Among mobile men, median nights away from home (IQR)	60 (30-90)

Travel among disengaged men

32 in-depth interviews with highly mobile men

- **Travel is essential**
  - *"If we have enough maize [food], we settle [stay home]"*
- **Travel is unpredictable**
  - Work travel is highly vulnerable to whims of employer
- **Men make major efforts to stay in care**
  - Guardian refills (11/32)
  - Emergency refills (8/32)
  - Returning from travel just to refill (8/32)
- **Most run out of ART at least once while traveling**
  - (23/28)
- **Men try to come back to care**
  - *Immediately* re-engaged upon return (8/23)
  - *Cited fear of provider treatment* as a reason to avoid re-engaging (4/23)
- **Those who did come back experienced poor/rude treatment from providers**
  - (12/21)

Summary

- Over 30% of men believed to be disengaged are actively in care

- Defaulters comprise the majority of men who disengage from care (as compared to those never initiated or initiated and never came back)
  - Most are mid- to older-age men (35-46years of age)
  - Extended time on ART (2-3 years)

- Men want to stay on ART, but barriers to care are significant
  - Highly mobile population
  - Fear of stigma (and therefore avoiding disclosure and social support)
  - Fear of side effects
  - Negative provider responses and other barriers to re-engagement

Remaining Questions

Cyclical reality of care amidst massive social/familial pressures:

- Length of time outside of care;
- # of episodes outside of care (cyclical engagement)

Characteristics of those disengaged

- What support do they need to stay in care AND re-engage time and time again?

Acknowledgements

- *Collaborating Institutions:*
  - Division of Infectious Diseases, David Geffen School of Medicine, UCLA
  - Partners in Hope Medical Center, Lilongwe, Malawi
  - Department of Global Health, School of Public Health, Boston University, Boston, USA.

- *Funding:*
  - The Bill and Melinda Gates Foundation,
  - NIMH Grant No. R01-MH122308,
  - Fogarty Grant No. K01-TW011484

- *Acknowledgements*:
  - CQUIN Consortium: For making this dissemination possible
  - Clients and providers who participated in multiple studies, and
  - MOH and Care and Treatment Team at PIH who continue to make this body of research possible

Thank you!