Patterns of engagement in care across the cyclical HIV cascade: *Insights for the CQUIN Network*

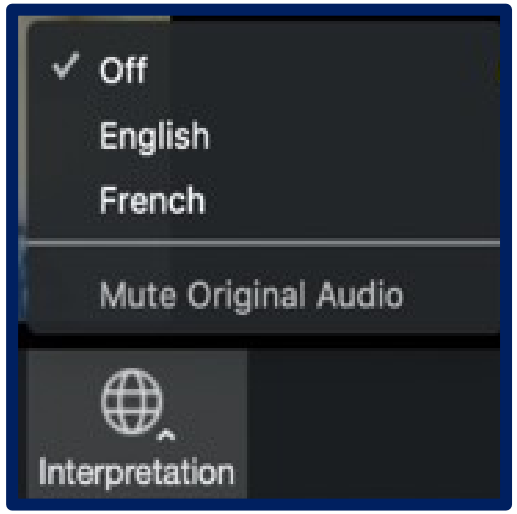
August 6, 2024

HIV Coverage, Quality, and Impact Network

Welcome/ Bienvenue

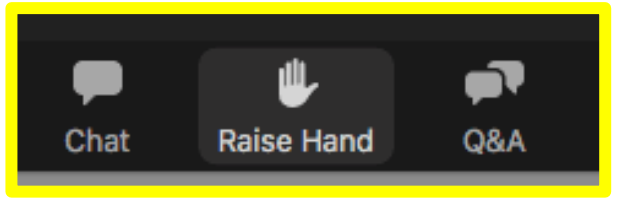
Bill Reidy
Deputy Director,
Strategic Information
ICAP at Columbia University

- Be sure you have selected the language of your choice using the “Interpretation” menu on the bottom of your screen.
- Assurez-vous d’avoir sélectionné la langue de votre choix à l’aide du menu <<Interprétation>> en bas de votre écran Zoom.



Housekeeping

- 60-minute webinar with two presentations followed by a brief Q&A
- Slides and recording will be available on the CQUIN website (www.cquin.icap.columbia.edu)
- Please type questions in the Q&A box located on the toolbar at the bottom of your screen
- If you would prefer to speak, please use the “raise hand” function on the toolbar and we will unmute you so that you have control of your microphone
- If you are a French or English speaker, please ask your question in your language of choice and the interpreters will translate as needed



Agenda

1. **Welcome and Introductions**: Bill Reidy, Deputy Director, Strategic Information, ICAP/CQUIN
2. **Presentation 1**: How person-centred data could improve the accuracy of HIV care cascade reporting : David Etoori, Research Fellow University College, London Institute for Global Health
3. **Presentation 2:** Using routine health data to explore patterns of patient engagement with antiretroviral care: Claire Keene, PhD Student, University of Oxford
4. **Q&A Discussion**: Bill Reidy, ICAP/CQUIN (Moderator)
5. **Closing Remarks**

Supporting re-engagement in HIV treatment services

Policy brief

World Health Organization

Key messages

- People who have been diagnosed with HIV may disengage from care after starting antiretroviral therapy (ART) and may do so more than once.
- Individuals with interrupted HIV care and treatment may re-engage to care with advanced HIV disease and a range of clinical, psychosocial and service delivery needs.
- WHO recommends tracing people who have disengaged from care and providing support for re-engagement back in care, including adherence support and differentiated service delivery for HIV treatment to reduce the risk of future disengagement.
- Health-care providers must refrain from punitive actions and ensure a welcoming, non-stigmatizing environment and equitable access to services.
- Programmes should engage communities at different levels to ensure effective re-engagement strategies tailored to clients' needs.
- When differentiated service delivery pathways are designed at re-engagement, factors such as the clinical profile, the diverse needs and reasons for disengagement and specific population needs should be considered; person-centred solutions should be explored.
- How engagement in care and treatment is supported and measured urgently needs to be improved, including close monitoring of treatment adherence and viral suppression and identifying and responding to inconsistent patterns of retention in care.
- Sustained engagement in HIV care and treatment is critical to achieving sustained undetectable viral load and optimal clinical and public health outcomes.

David Etoori
Research Fellow,
University College London
Institute for Global Health, UK

icap Global Health

THE CQUIN NETWORK

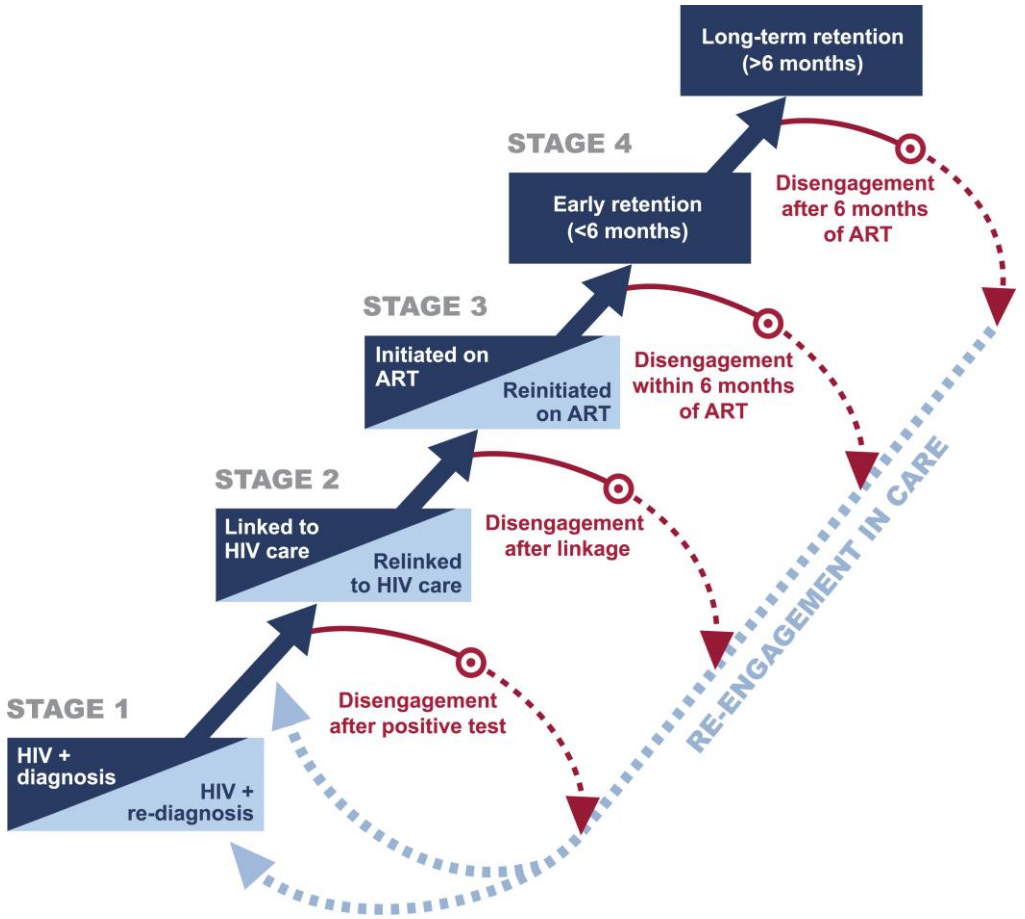
How person-centred data could improve the accuracy of HIV care cascade reporting

Dr David Etoori

HIV Coverage, Quality, and Impact Network

Background:

- Changes in the aims of national treatment programmes
- Changes in the treatment cohorts of these programmes
  - Healthier individuals initiating antiretroviral therapy (ART)
  - Loss to follow-up no longer synonymous with mortality
  - Increasing instances of re-engagement in care



Ehrenkranz P, Rosen S, Boulle A, Eaton JW, Ford N, Fox MP, et al. (2021) The revolving door of HIV care: Revising the service delivery cascade to achieve the UNAIDS 95-95-95 goals. PLoS Med 18(5): e1003651.

Background

Misreporting of Patient Outcomes in the South African National HIV Treatment Database: Consequences for Programme Planning, Monitoring, and Evaluation

David Etoori[1*], Alison Wringe[1], Chodziwadziwa Whiteson Kabudula[2], Jenny Renju[1,3], Brian Rice[4], F. Xavier Gomez-Olive[2] and Georges Reniers[1,2]

Outcomes After Being Lost to Follow-up Differ for Pregnant and Postpartum Women When Compared With the General HIV Treatment Population in Rural South Africa

David Etoori, MPH,[a] Francesc Xavier Gomez-Olive, PhD,[b] Georges Reniers, PhD,[a,b] Brian Rice, PhD,[c] Jenny Renju, PhD,[a,d] Chodziwadziwa W. Kabudula, PhD,[b] and Alison Wringe, PhD[a]

RESEARCH ARTICLE

Investigating clinic transfers among HIV patients considered lost to follow-up to improve understanding of the HIV care cascade: Findings from a cohort study in rural north-eastern South Africa

David Etoori[1*], Chodziwadziwa Whiteson Kabudula[2], Alison Wringe[1], Brian Rice[1], Jenny Renju[1,3], Francesc Xavier Gomez-Olive[2], Georges Reniers[1,2]

RESEARCH Open Access

Patterns of engagement in HIV care during pregnancy and breastfeeding: findings from a cohort study in North-Eastern South Africa

David Etoori[1*], Brian Rice[2], Georges Reniers[1,3], Francesc Xavier Gomez-Olive[3], Jenny Renju[1,4], Chodziwadziwa Whiteson Kabudula[3] and Alison Wringe[1]

Background: Inspiration

- Work with Prof. Maya Petersen back in 2013
- MACH14: A Multi-Site Collaboration on ART Adherence Among 14 Institutions
  - Use electronic Medical Event Monitoring System (MEMS) to measure adherence

Pill box – (https://www.amazon.co.uk/Personal-Pill-Organizers)
Pill bottle – Pillsy (https://www.theverge.com/circuitbreaker/2017/5/2/15507102/smart-pill-cap-pillsy-launch)

Research paper

Etoori D, Wringe A, Reniers G, Gomez-Olive FX, Rice B (2024) Moving towards a person-centred HIV care cascade: An exploration of potential biases and errors in routine data in South Africa. PLOS Glob Public Health 4(6): e0002509.

RESEARCH ARTICLE

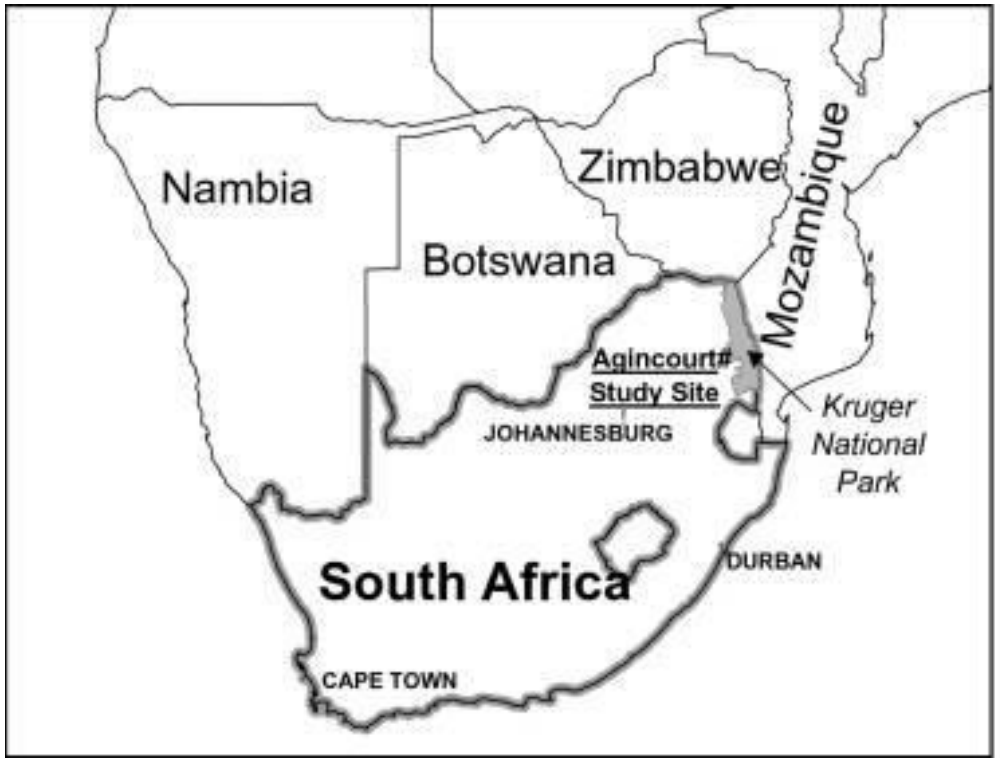
Moving towards a person-centred HIV care cascade: An exploration of potential biases and errors in routine data in South Africa

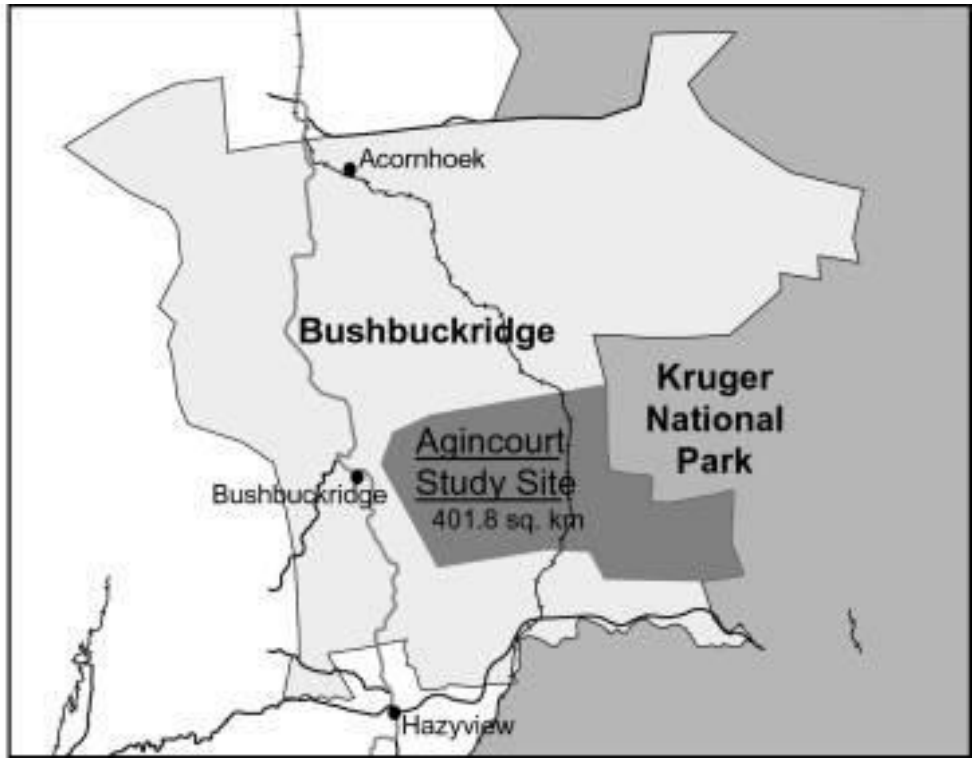
David Etoori[1]*, Alison Wringe[2], Georges Reniers[2,3], Francesc Xavier Gomez-Olive[3], Brian Rice[2,4]

1 University College London, London, United Kingdom, **2** London School of Hygiene and Tropical Medicine, London, United Kingdom, **3** MRC/WITS Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, University of Witwatersrand, Johannesburg, South Africa, **4** University of Sheffield, School of Health and Related Research, Sheffield, United Kingdom

Methods: Setting & Data

Agincourt Health and Demographic surveillance system





Methods: Building sequences & cluster analysis

- HIV positive not on ART
- On ART
- Deceased
- Transferred
- Late for an appointment
- Lost to follow-up
- Re-engaged

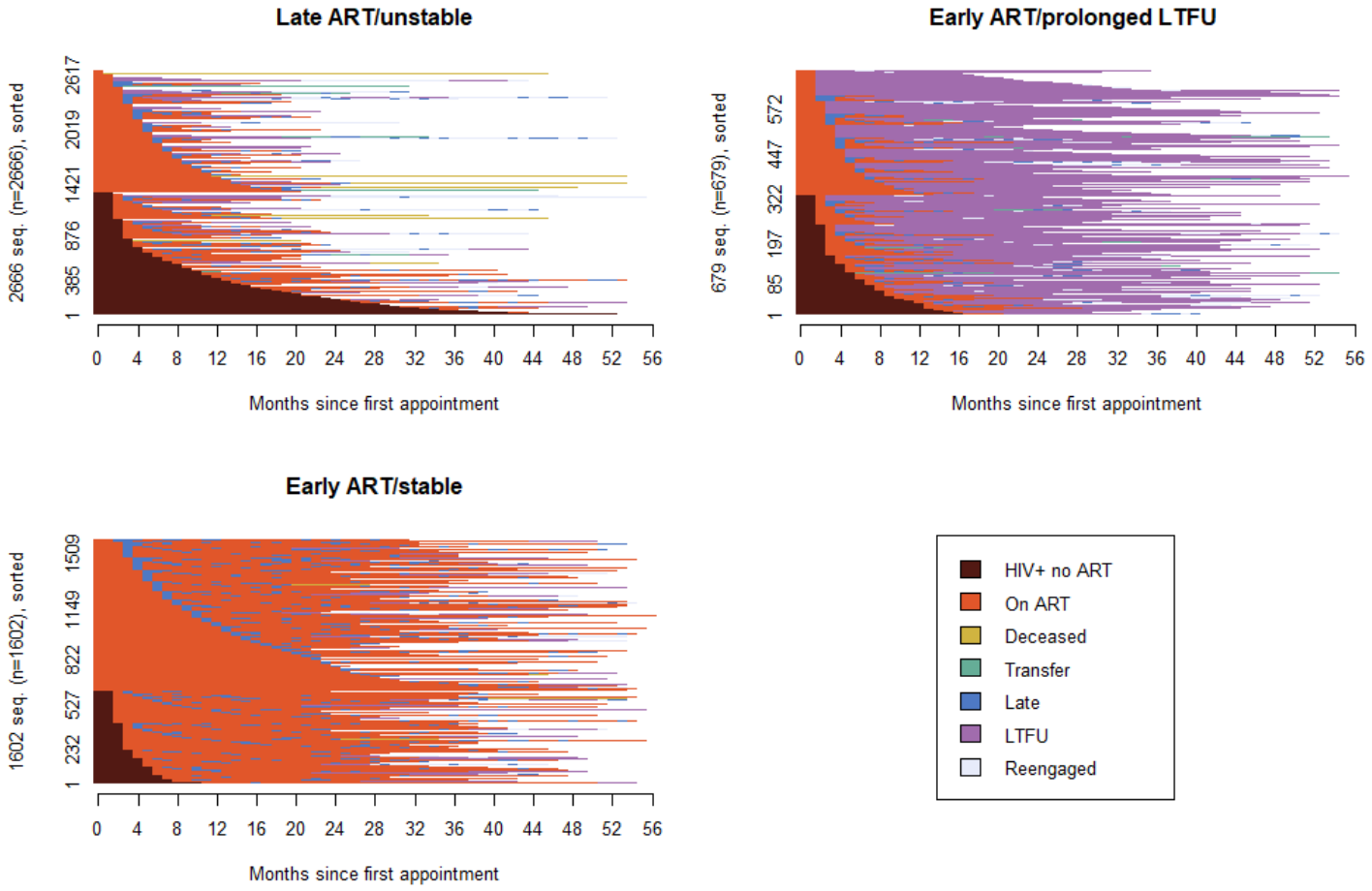
- Clinics typically run 28-day refill schedules
- Assume treatment taken as prescribed
- Identified care pathway clusters using Optimal Matching
  - Identified factors associated with cluster membership

Results:

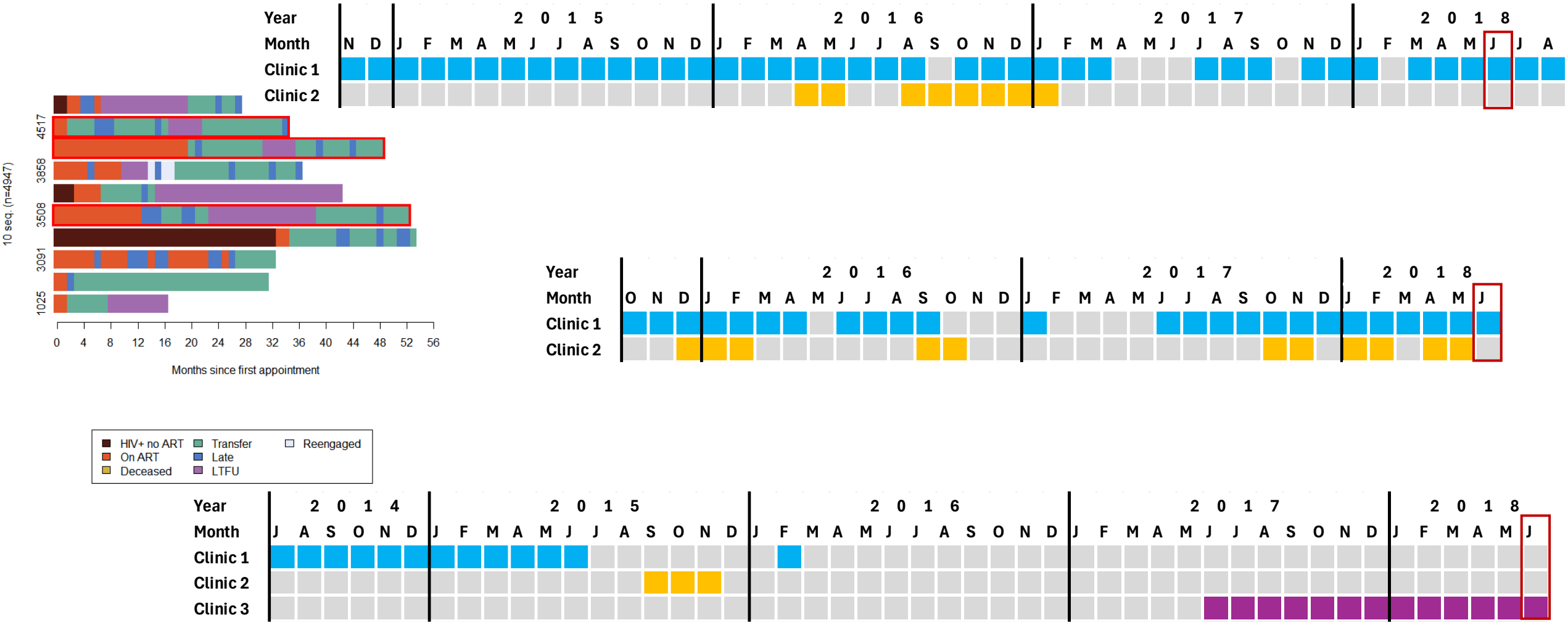
5084 patient records linked to 4947 unique individuals	133 total transfers	93 of 4947 [1.9% (95% C.I: 1.5-23)] had multiple HIV tests
• 134 individuals linked to multiple records	• 106 (79.7%) undocumented	• Repeat testing associated with undocumented transfers

Results: Engagement clusters

- 2,666 (53.9%) late ART, unstable engagement
- 679 (13.7%) early ART, prolonged disengagement
  - Younger, PMTCT, Males
- 1,602 (32.4%) early ART, stable engagement
  - Older, ART before ‘treat all’

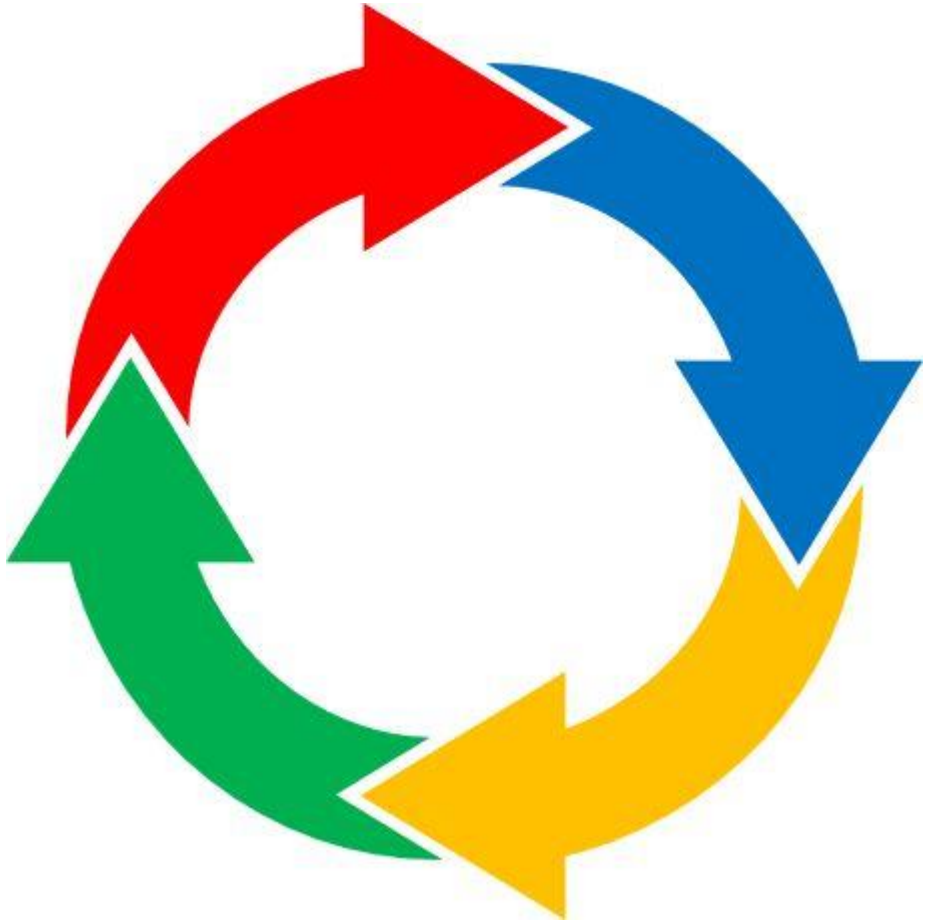


Case studies



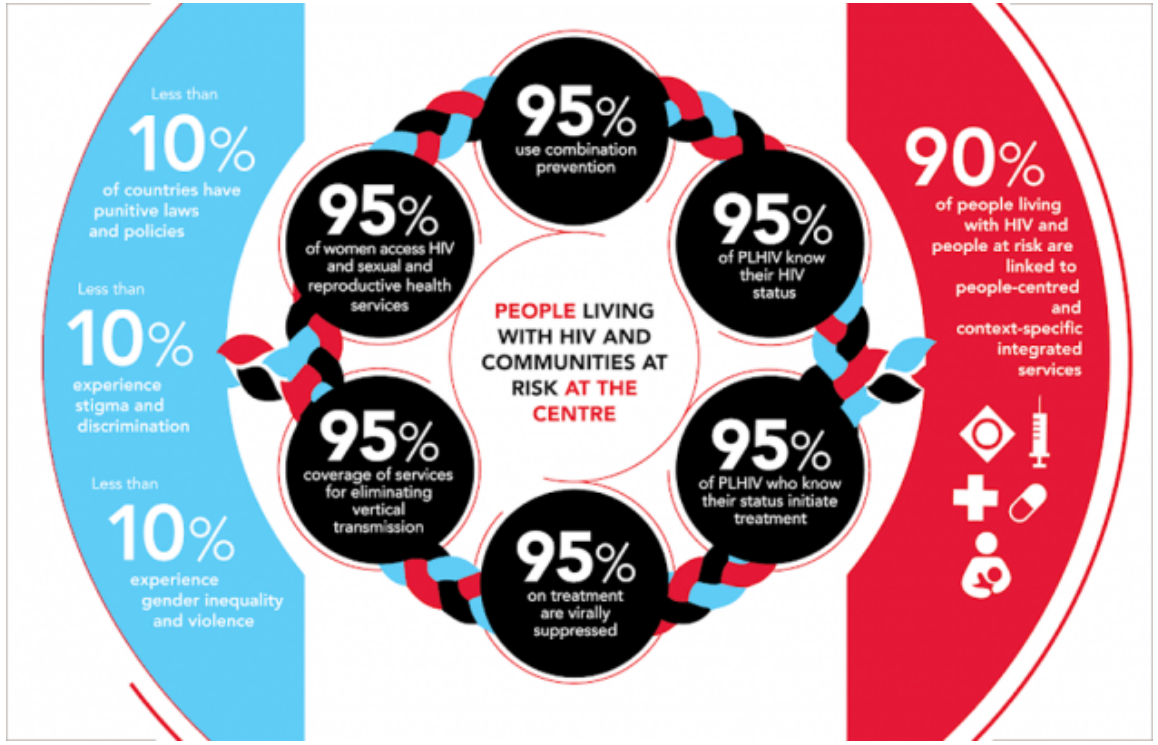
Implications

- Cyclical engagement patterns (2/3) more common than traditional linear patterns (1/3)
  - Movement between periods of engagement and disengagement
- Undocumented transfers associated with
  - Loss to follow-up
  - Repeat testing
  - Double counting of individuals



Conclusions

- Aggregate data lacks the nuance necessary for accurately reporting 95-95-95 goals
- As treatment cohorts become healthier, treatment programmes will require more robust cascades
  - Able to follow an individual across their treatment journey
  - Account for movement between clinics and regions



UNAIDS - https://www.unaids.org/en/resources/presscentre/featurestories/2021/july/20210721_2025-aids-targets

Acknowledgements

- Dr. Alison Wringe
- Dr. Georges Reniers
- Dr. Brian Rice
- Dr. Francesc X. Gomez-Olive
- Dr. Chodziwadziwa Kabudula

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

MeSH Consortium
Measurement & Surveillance of HIV Epidemics

WITS UNIVERSITY

AGINCOURT
Health & Population Unit

icap Global Health

THE CQUIN NETWORK

www.cquin.icap.columbia.edu

Thank you!

Claire Keene
PhD Student
University of Oxford

Applying precision public health concepts to HIV services:

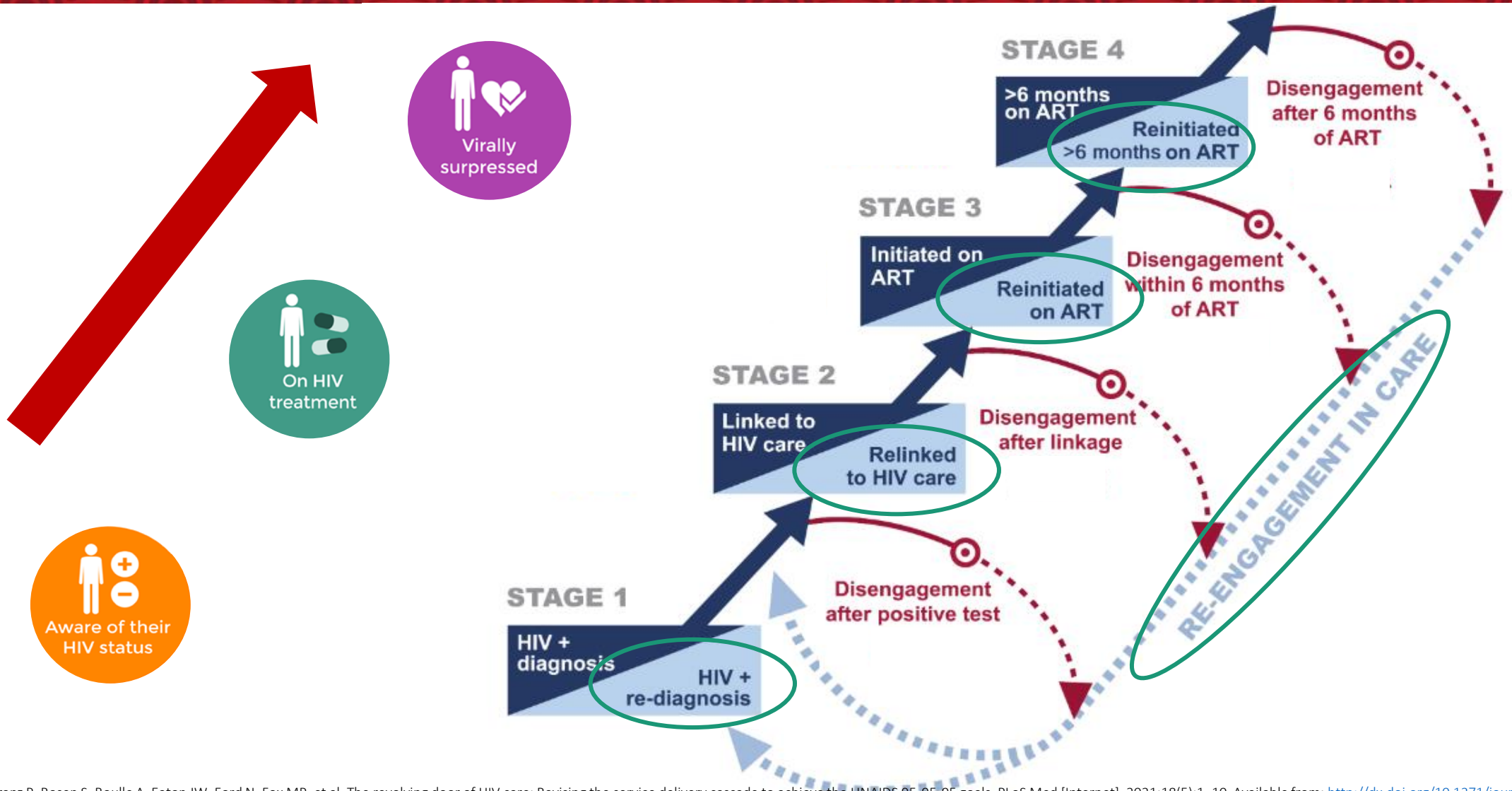
Using routine health data to explore patterns of patient engagement with antiretroviral care

Dr Claire Keene

Insights for the CQUIN Network

6th August 2024

Monitoring the HIV epidemic



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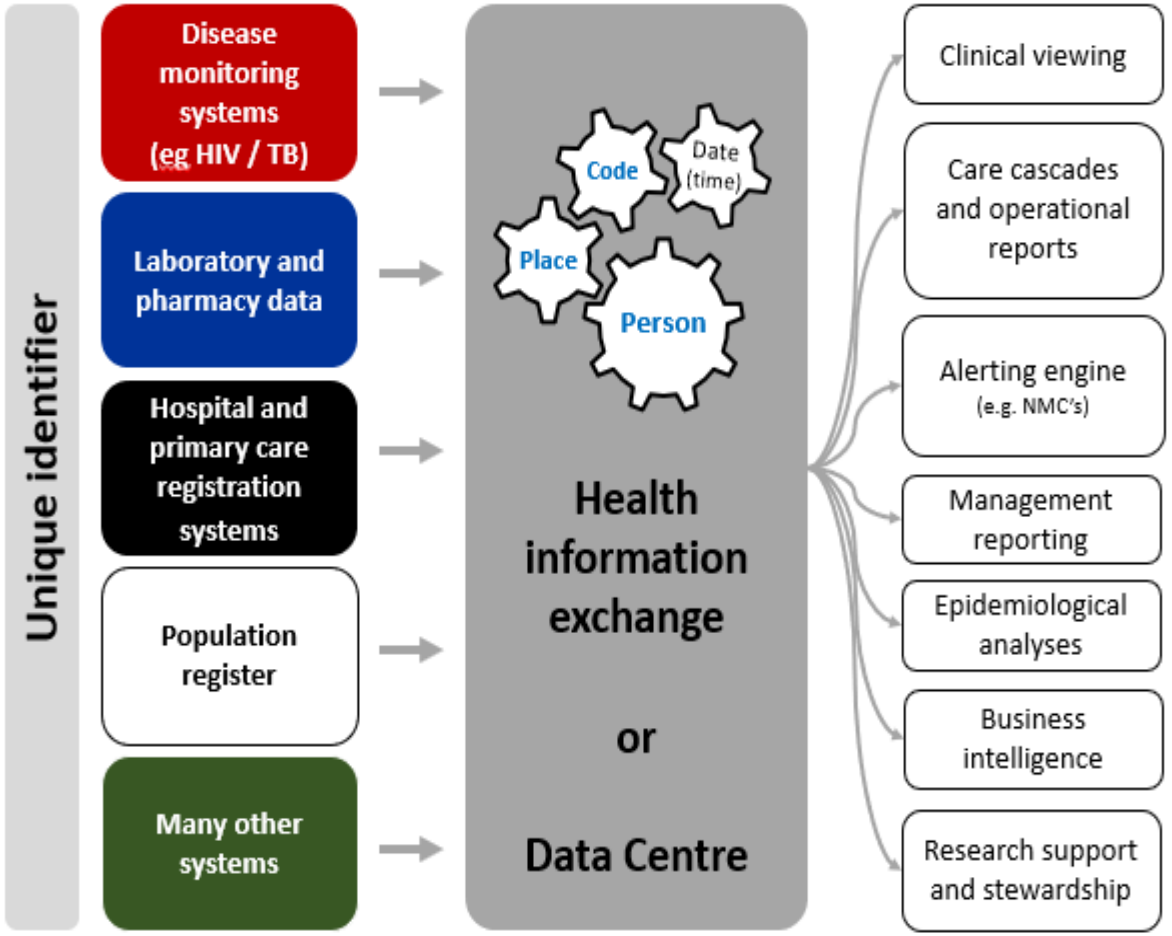
Euvrard J, Timmerman V, Keene CM, Phelanyane F, Heekes A, Rice BD, Grimsrud A, Ehrenkranz P, Boulle A. The cyclical cascade of HIV care: Temporal care engagement trends within a population-wide cohort. PLoS Med. 2024 May 10;21(5):e1004407. doi: 10.1371/journal.pmed.1004407

Exploring churning and patterns of engagement over time

Context: Khayelitsha and Gugulethu

Provincial Health Data Centre (PHDC)

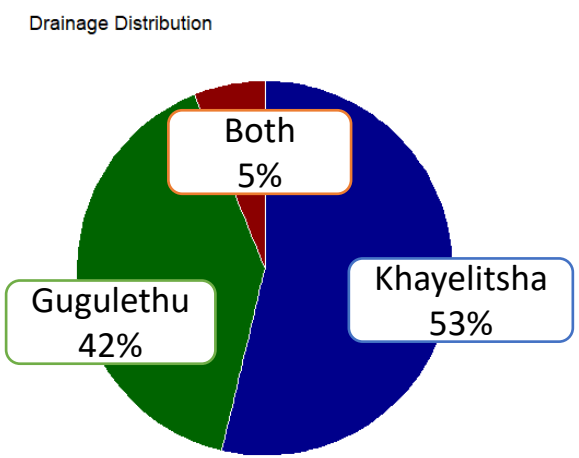


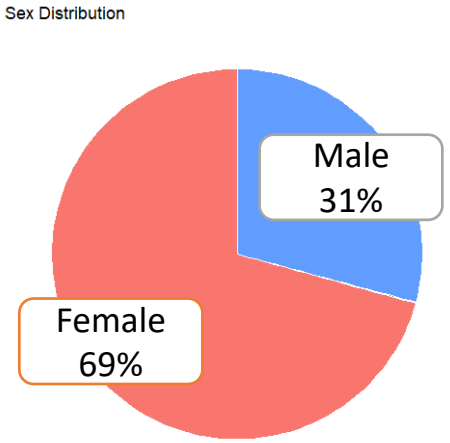
Boulle A, Heekes A, N T, et al. Data Centre Profile : The Provincial Health Data Centre of the Western Cape. *Int J Popul Data Sci*. 2019;4(2):06. doi:https://doi.org/10.23889/ijpds.v4i2.1143 / Graphic taken from a presentation by Andrew Boulle at Open HIE 2018: Where there is no EMR - Functional health information exchange in poorer countries – South African experience

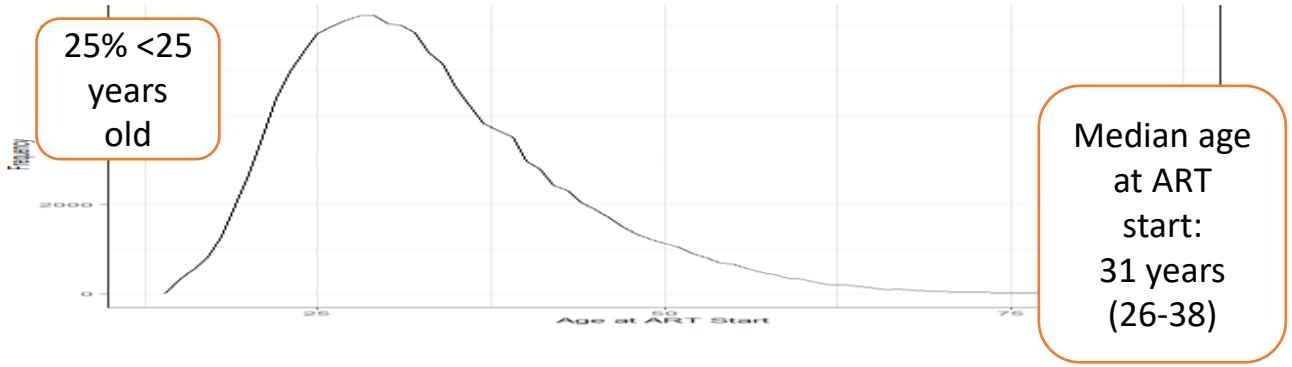
Khayelitsha and Gugulethu Cohort

Cohort: 68 888 people

- **Adults** 15 to 85 years old at ART start
- **Initiated ART** in the era of UTT
- Have **≥ 1 year possible follow-up** to database closure
- Have sought care at some point in **Khayelitsha and/or Gugulethu**







ART history	
Follow up time (median [IQR])	4 years (2.75-5.08)
Proportion with ≥ 60 months follow-up	26422 (38%)

95-95-95 Cascade

Treatment success

84% of those on treatment with a VL
(50% of cohort)

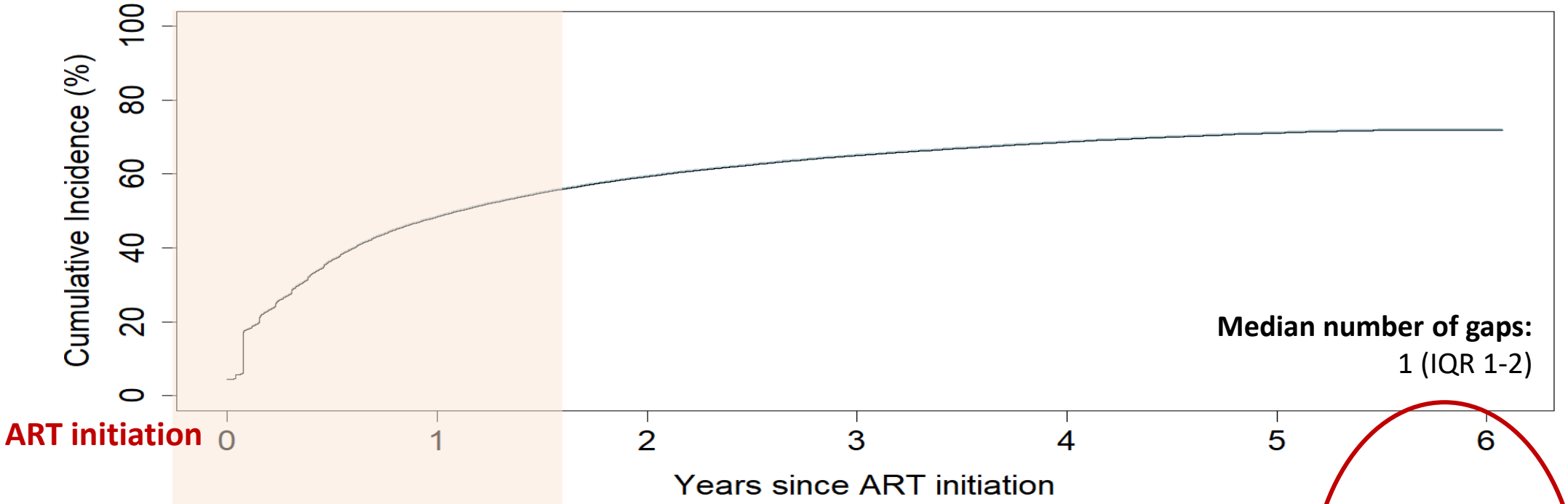
Access

53% of those alive at database closure
(30th September 2022)

Testing

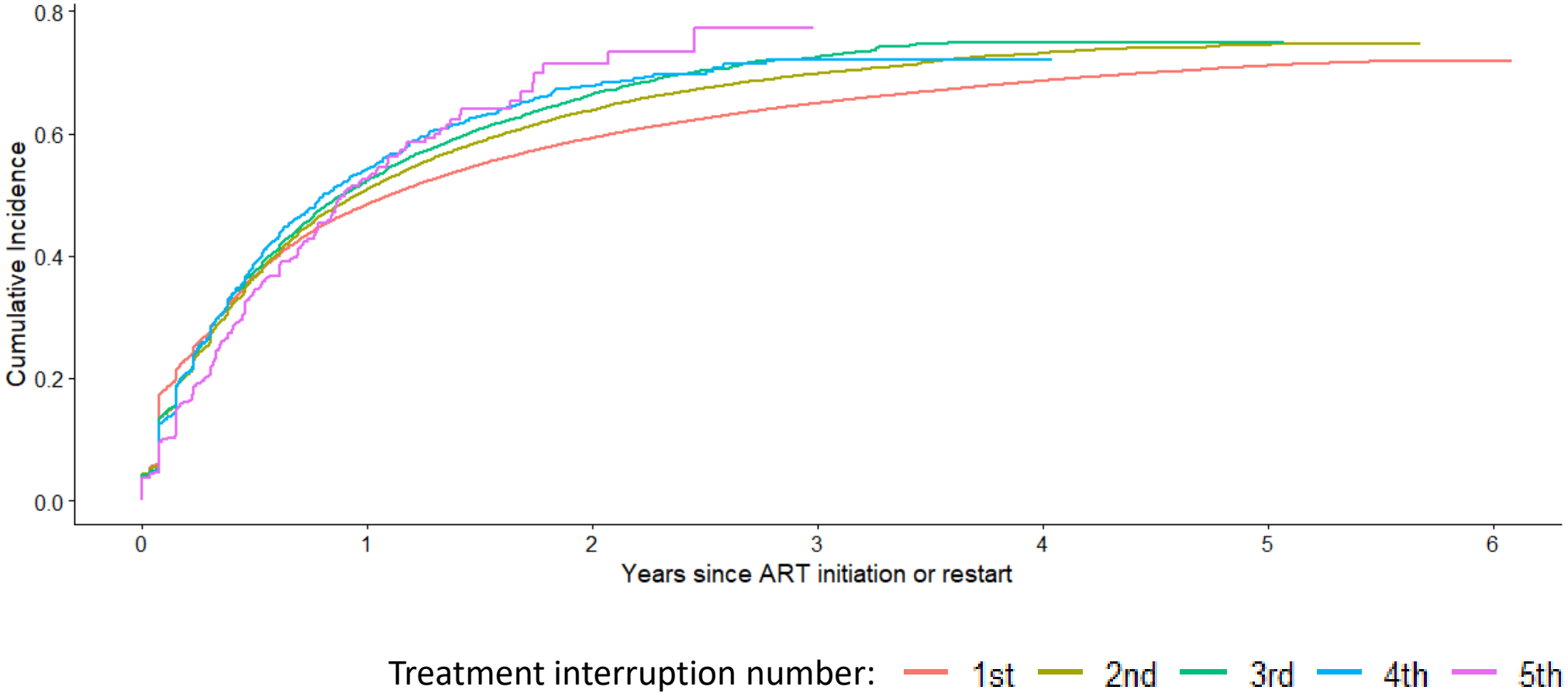
?

Treatment interruptions: *>90 days late for an expected visit*



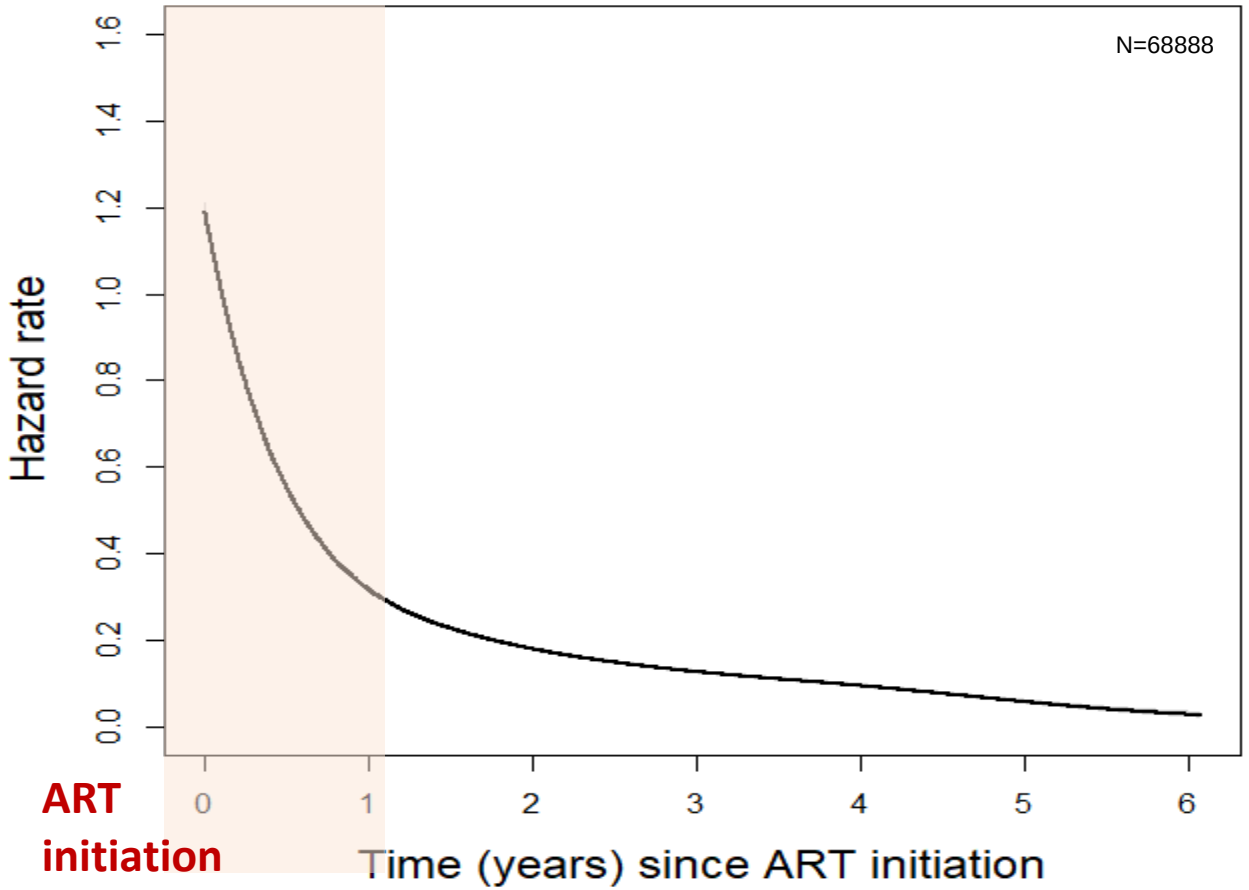
Time since ART initiation/ restart:	6 months	1 year	2 years	3 years	4 years	5 years	6 years
Cumulative incidence of a gap (% [95% CI])	36.4% [36.1-36.8]	48.4% [48.0-48.8]	59.2% [58.9-59.6]	65% [64.6-65.3]	68.6% [68.2-69.0]	71.1% [70.7-71.5]	71.8% [71.4-72.3]

Recurrent treatment interruptions



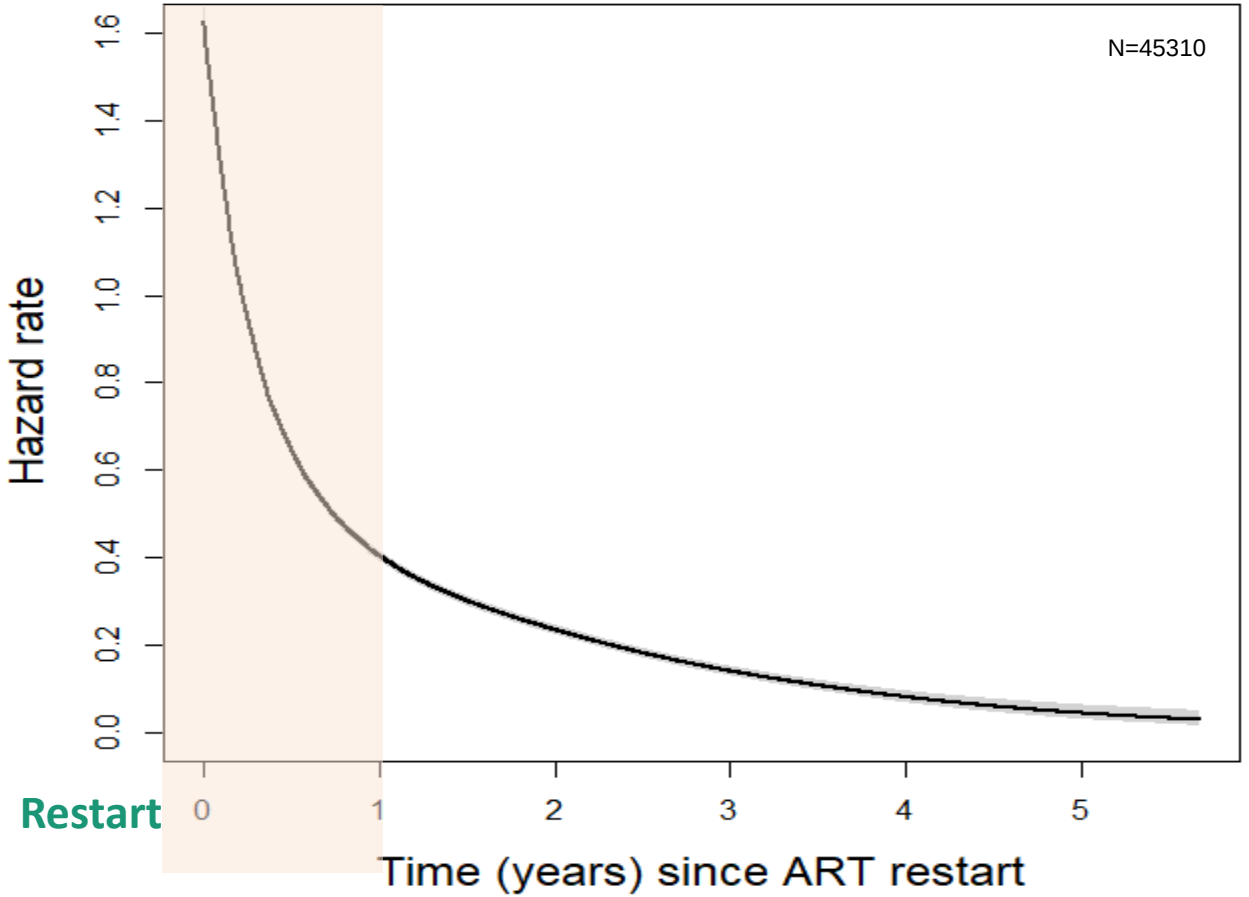
Hazard highest in 1st year after ART start/ restart

Hazard function of time to 1st treatment interruption



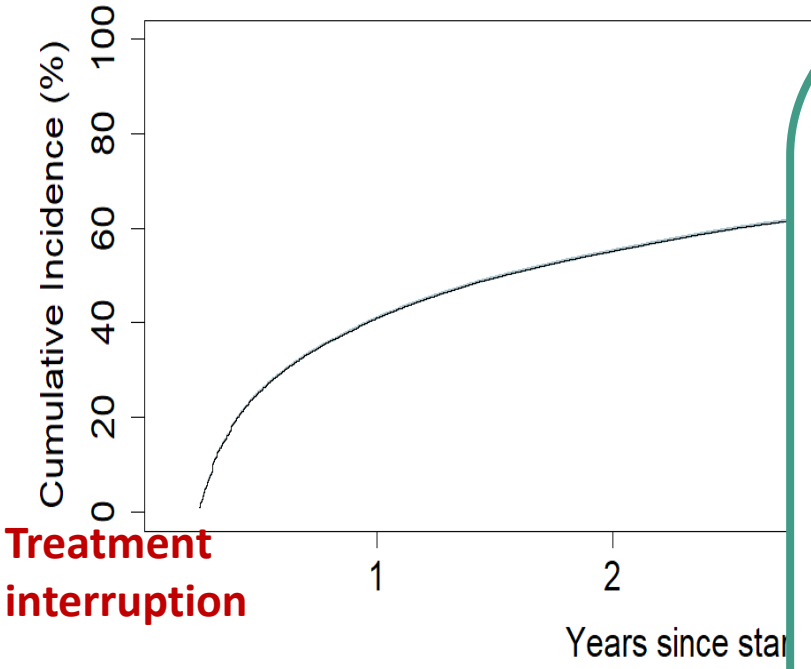
ART initiation

Hazard function of time to subsequent interruptions



Restart

Return to HIV care



Treatment interruption

A year after restarting ART on return from a gap:

RIC: 67%

VL suppression: 50%

(88% of those RIC with a VL completed)

vs those who never had a gap a year after initiating ART

VL suppression: 82%

(97% of those RIC with a VL completed)

Time since ART initiation/ restart:	**6 months**	**1 year**	**2 years**				
Cumulative incidence of a gap (% [95% CI])	24.9% [24.5-25.2]	41.0% [40.6-41.3]	55.1% [54.7-55.5]	[62.9-63.7]	[68.0-68.9]	[72.0-73.0]	[74.8-76.4]

- Moved and re-engaged

Why does it matter?

Poor retention driving gaps in 95-**95-95**

- Treatment interruptions are common
- Lead to poor viral suppression

How do we structure the **health system** to encourage people to **engage with care** long term with limited resources?

Target high risk

Associations with interruptions: Cox Regression

		adjHR (95% CI)	p value
Demographics	**Youth <25 at ART initiation**	1.25 [1.22-1.28]	<0.0001
	Male sex	1.20 [1.18-1.23]	<0.0001
Clinical history	**Comorbidity at ART initiation**	0.79 [0.76-0.82)	<0.0001
	Comorbidity diagnosed while on ART	0.66 [0.64-0.69)	<0.0001
	Pivotal event at ART initiation		
	- Effect of pivotal event at initiation in the first 180 days	0.76 [0.70-0.81]	<0.0001
	- Effect of pivotal event at initiation after 180 days	1.41 [1.37-1.46]	<0.0001
	Has pivotal while on ART	1.22 [1.19-1.25]	<0.0001
HIV history	**ART initiation year**	0.86 [0.85-0.87]	<0.0001
	CD4 at ART initiation (ref CD4 >200)		
	- Advanced HIV Disease (CD4 ≤200)	0.93 [0.91-0.96]	<0.0001
	- No CD4 at baseline	1.27 [1.25-1.30]	<0.0001
	Regimen at ART initiation (ref NNRTI-based)		
	- PI-based	1.61 [1.48-1.75]	<0.0001
	- INSTI-based	0.91 [0.88-0.94]	<0.0001
	- Unknown	1.43 [1.35-1.52]	<0.0001
World events	**Has follow-up time during the pandemic**	1.76 [1.72-1.81]	<0.0001

Gap vs no gap

- Subtle differences

Those out of care are:

  - Younger
  - Have lower rates of NCDs
  - More likely to be pregnant, have TB or be admitted at ART initiation or while on ART
  - Longer ART duration/ follow-up time
  - Fewer on DTG at ART start

- **Mostly similar**
  - *Most middle-aged women with no chronic disease or pivotal event, on an NNRTI regimen at initiation*

Characteristic	Never had an interruption		Had an interruption
Demographics			
Number (n[%])	23578 [34%]		45310 [66%]
Age at ART initiation (median [IQR] in years)	33 [27-41]	>	**30 [25-37]**
Clinical history			
Chronic disease diagnoses (n [%]):			
~ Hypertension	4376 [19%]		**4657 [10%]**
~ Diabetes	1222 [5%]	>	**1308 [2.9%]**
~ Mental health diagnosis	1147 [4.9%]		2266 [5%]
Pivotal events (n [%]):			
~ Pregnancy as a proportion of females	6165 [37%]		**13907 [45%]**
~ Tuberculosis	3874 [16%]	<	**8705 [19%]**
~ Hospital admission	5363 [23%]		**11472 [25%]**
~ COVID-19 diagnosis	1095 [4.6%]		1690 [3.7%]
HIV history			
ART duration at censoring(median [IQR] in years)	3.58 [2.17-4.84]	<	**4.18 [3.01-5.18]**
ART initiation year (median [IQR])	2019 [2017-2020]		2018 [2017-2019]
Regimen at ART initiation (n [%])			
~ NNRTI-based	16959 [72%]		36955 [82%]
~ PI-based	134 [0.6%]		656 [1.4%]
~ INSTI-based	6189 [26%]	>	**6326 [14%]**
~ Unknown	296 [1.3%]		1373 [3.0%]

Other ways to stratify the population?

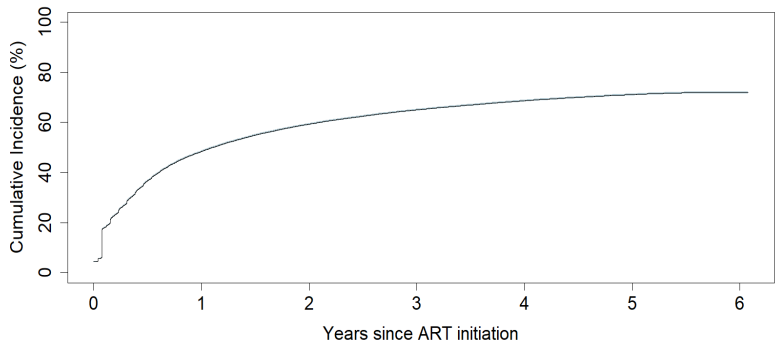
Different approaches

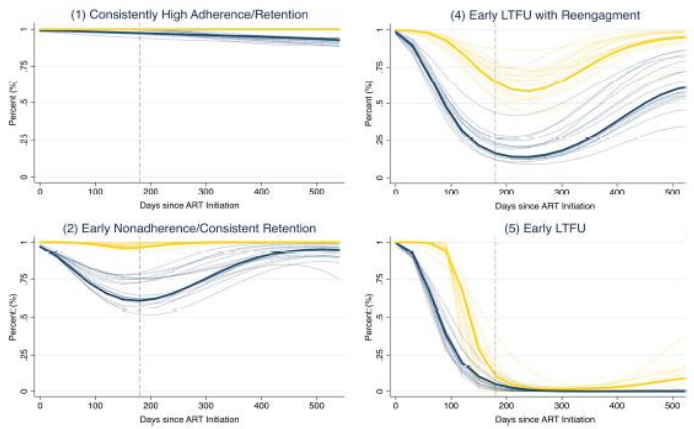
Population level

GROUP-BASED TRAJECTORY MODELING

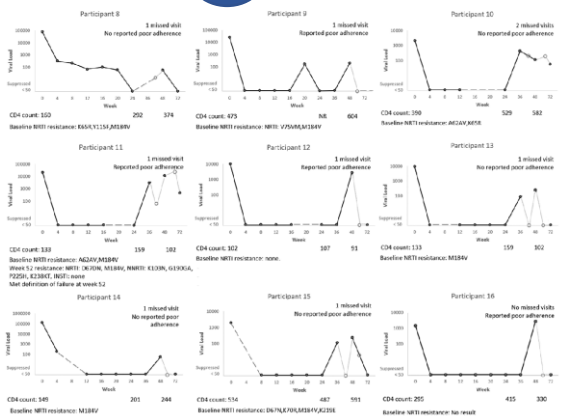
Ideal

One model to describe all individuals - average





Each individual has their own model

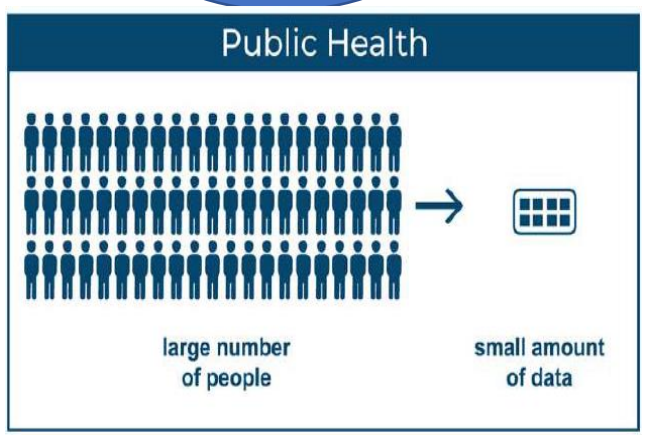


Mody A, Eshun-Wilson I, Sikombe K, et al. Longitudinal engagement trajectories and risk of death among new ART starters in Zambia: A group-based multi-trajectory analysis. *PLoS Med*. 2019;16(10):1-25. doi:10.1371/journal.pmed.1002959
Keene et al. Recycling Tenofovir in Second-line Antiretroviral Treatment With Dolutegravir: Outcomes and Viral Load Trajectories to 72 weeks. *JAIDS.* 2023; 92(5): 422-429. DOI: 10.1097/QAI.0000000000003157

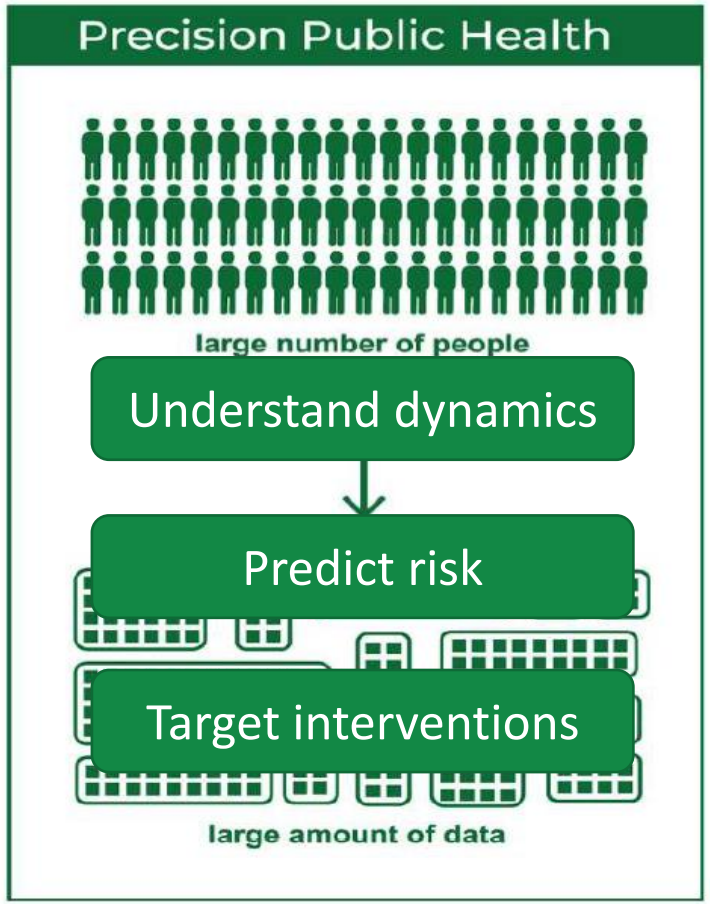
How does this relate to precision public health?

Population level

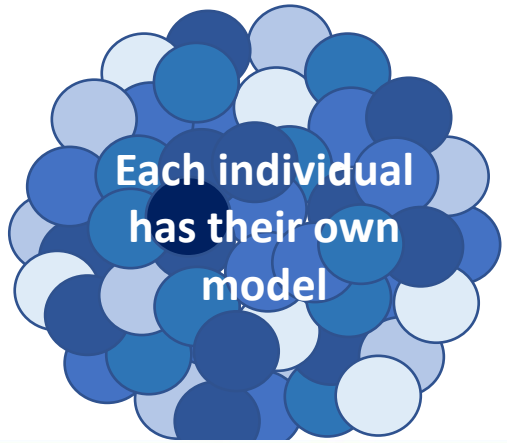
One model to describe all individuals - average

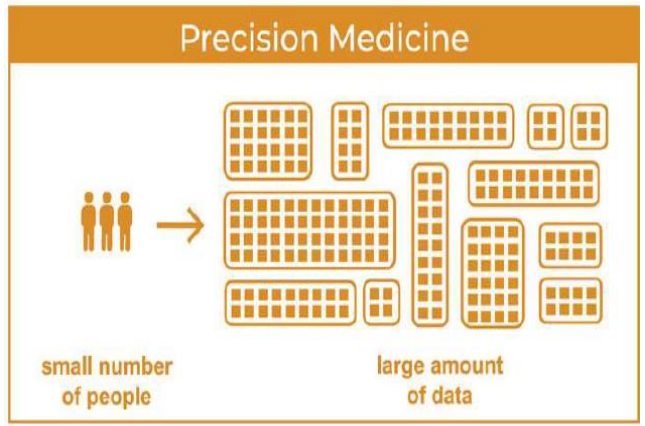


GROUP-BASED TRAJECTORY MODELING



Ideal



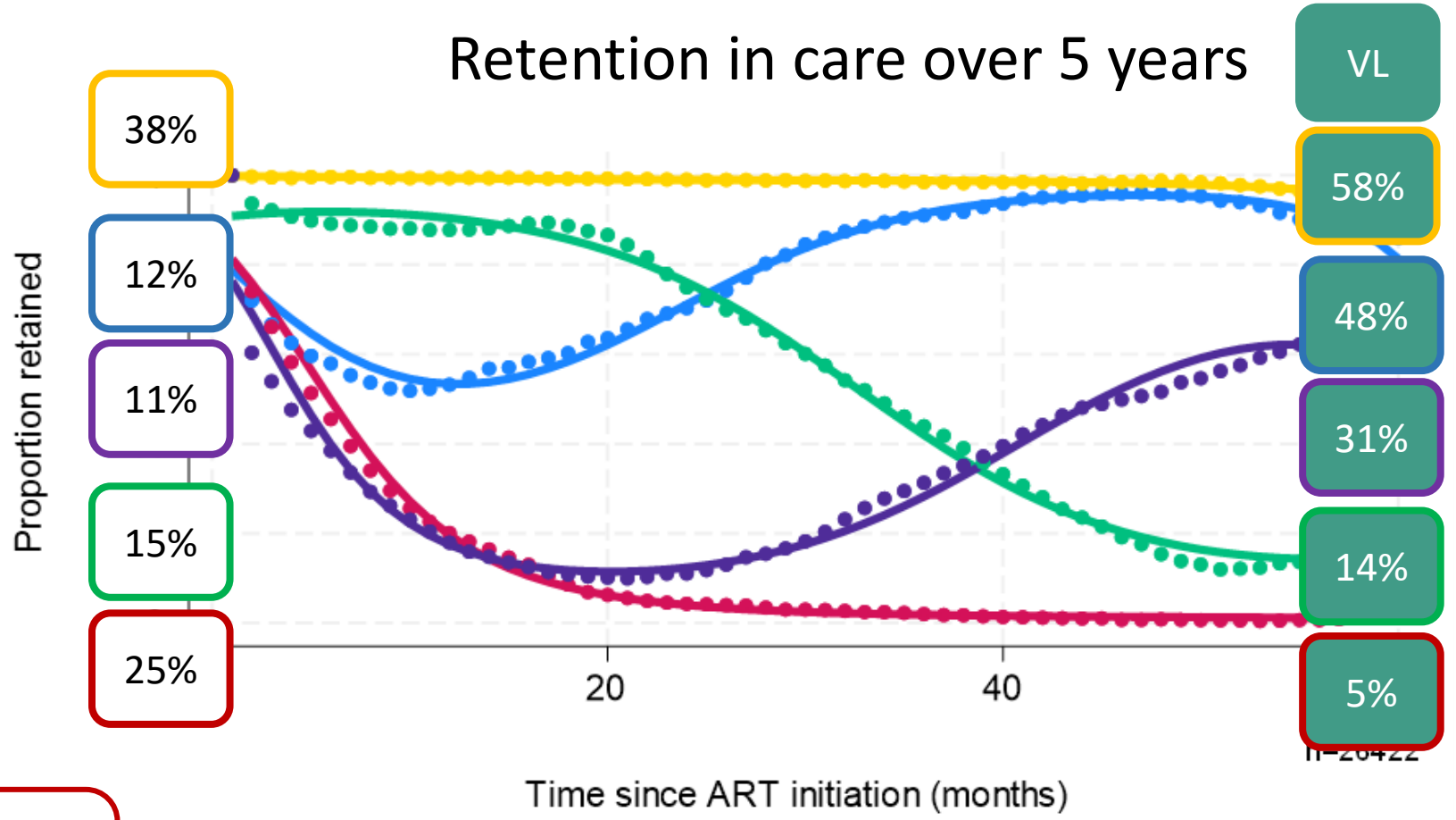


Mody A, Eshun-Wilson I, Sikombe K, et al. Longitudinal engagement trajectories and risk of death among new ART starters in Zambia: A group-based multi-trajectory analysis. *PLoS Med.* 2019;16(10):1-25. doi:10.1371/journal.pmed.1002959
Keene et al. Recycling Tenofovir in Second-line Antiretroviral Treatment With Dolutegravir: Outcomes and Viral Load Trajectories to 72 weeks. *JAIDS.* 2023; 92(5): 422-429. DOI: 10.1097/QAI.0000000000003157

Subgroups of retention in care
(treatment interruptions)

5 groups

1. Optimal engagement
2. Early disengagement and return
3. Early disengagement and delayed return
4. Delayed disengagement
5. Early disengagement



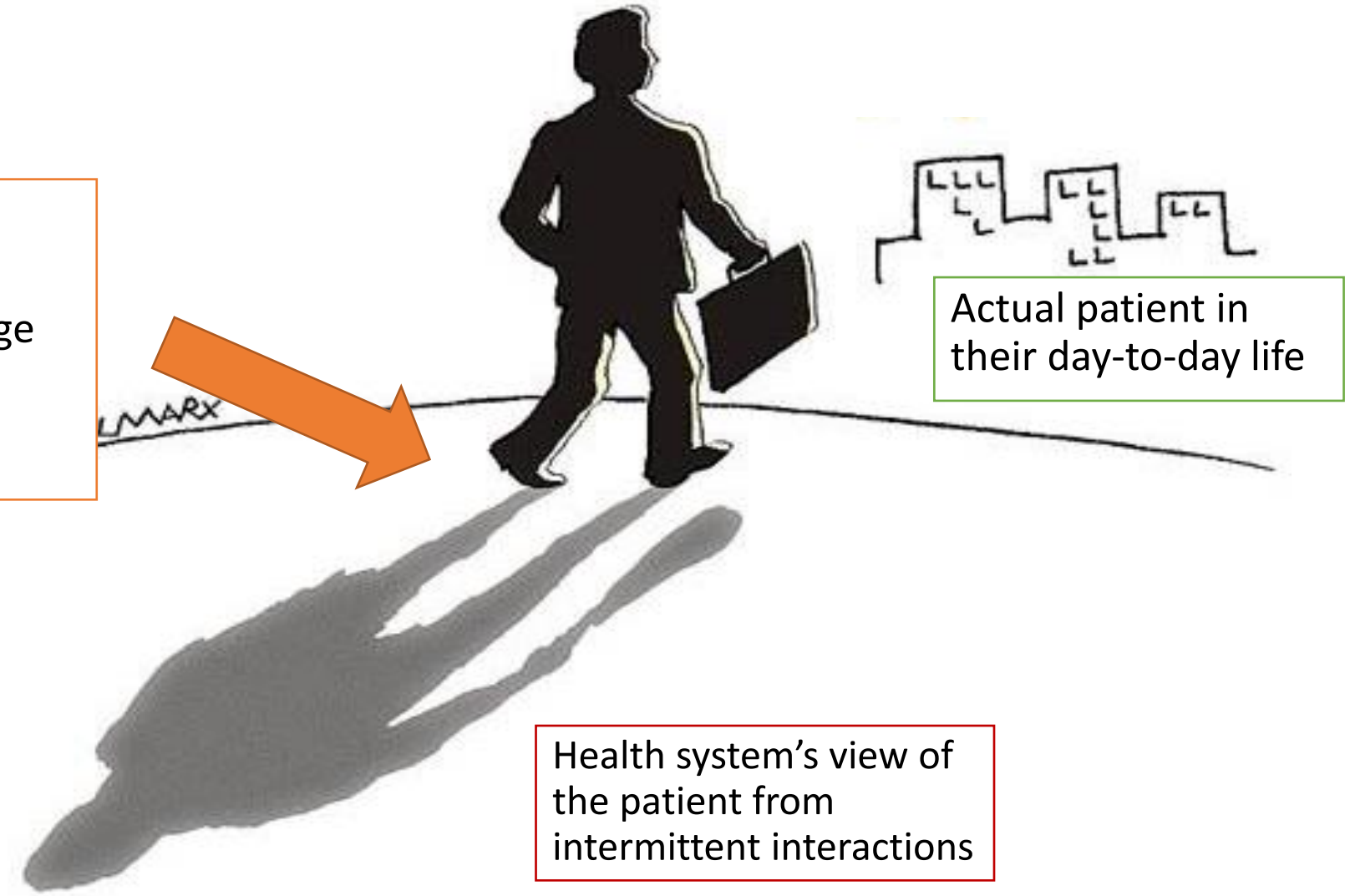
Options
- Return..
- Died
- Moved and re-engaged elsewhere

N= 26422 (38%)

Some caveats to using routine data

Fill the gap

- More extensive data linkage
- New analytic methods
- Collecting more data



Actual patient in their day-to-day life

Health system's view of the patient from intermittent interactions

Deeny, S and Steventon A. Making sense of the shadows: priorities for creating a learning healthcare system based on routinely collected data. *BMJ Qual Saf*. 2015:24:505-515

Implications

Insights

- Retention is the bottleneck to achieve population-level viral suppression
- Treatment interruptions are common
  - Nearly universal given sufficient follow-up time
  - Normal part of a lifetime relationship with ART?
- Most return to care
  - Similar patterns after initiation and restart
  - But worse outcomes with a history of non-retention
- Engagement is not binary
  - Disengagement is heterogenous
  - Difficult to predict (with routine data)

→ → Precision public health approach

Target interventions to subgroups of similar engagement behaviour?

Behavioural subgroups capture some of the heterogeneity

Need to understand what determines different trajectories

(its not demographics)

Thanks

- Provincial Health Data Centre and team
- Supervisors: Prof Catherine Orrell, Dr Jake McKnight and Prof Mike English
- Jonathan Euvrard
- Tali Cassidy
- Scott Colwell and Aaloke Mody
- All the people who have given me input
  - CoCT
  - Health Systems Collaborative Team
  - Palindrome
  - PHDC
  - Stats Coven at Primary Care, University of Oxford
  - Thesis Committee: Adrian Smith, Neo Tapela, and Jason Oke

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Thank you!

Q&A Discussion

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The next webinar will be held on September 3: Client Satisfaction

HIV Coverage, Quality, and Impact Network