Misclassification of HIV care outcomes in a population-representative sample of people living with HIV in KwaZulu-Natal Province, South Africa

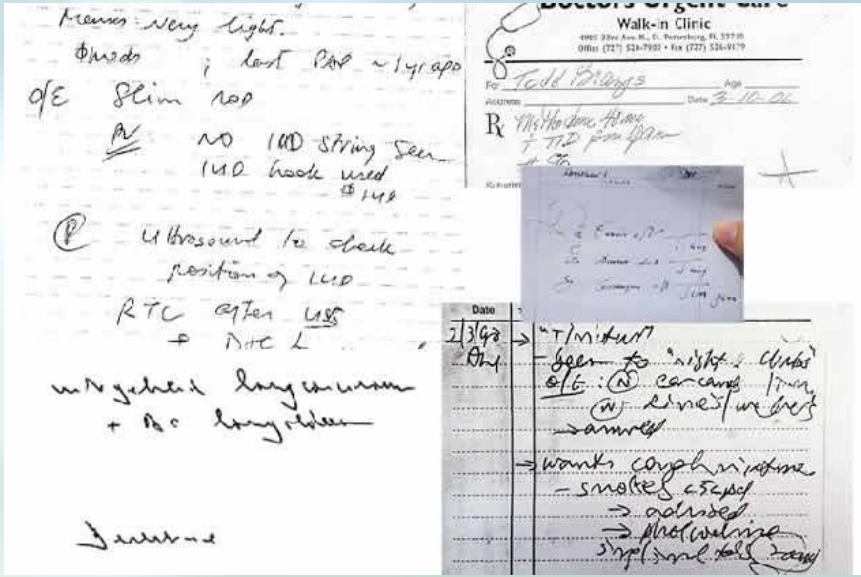
Lindsey M. Filiatreau, PhD, MPH
Assistant Professor, Division of Infectious Diseases, WUSTL

Continuum 2024 • June 9-11, 2024 • Puerto Rico

Rationale

Commonly used methods for estimating retention in HIV care fail to adequately account for the limitations of the data source being used.

- Patient files- incomplete (missing labs, diagnoses, dates, medications), illegible, undocumented transfers
- Electronic registers (missing demographics, dates, patient IDs and linkage across clinics)
- Patient-reported outcomes (social desirability bias, non-response)



Endriyas et al. 2022. Health Informatics Journal; Radebe et al. 2022. BMC Public Health; Mooney et al. 2018. AIDS & Behavior.

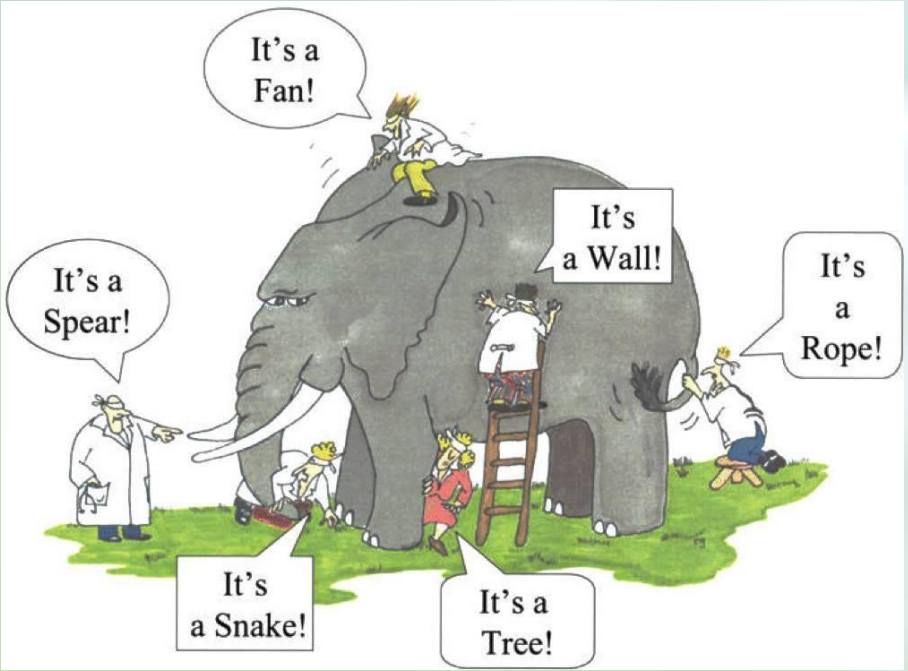
Poor integration of care systems means that it is difficult to capture true outcomes, particularly in settings where undocumented deaths or silent transfers are common.

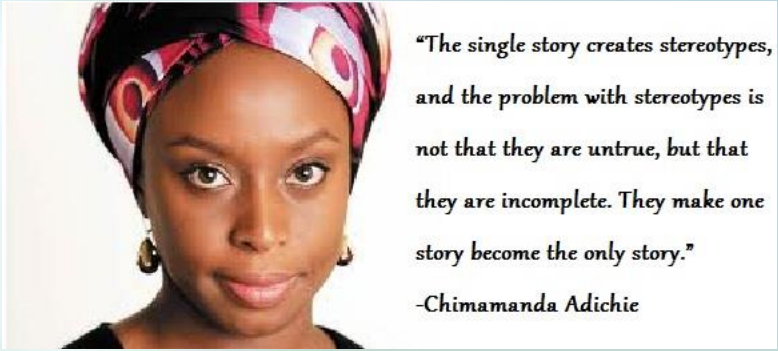
Reasons for clinic switching:

- Affordability (travel to clinic, medications, consultations)
- Availability (hours of operation, service offerings, medication)
- Acceptability (treatment by clinic staff, wait times, quality of care, confidentiality)

Pry et al. 2023. BMJ Open; Goudge et. al. 2009. BMC Health Services Research; Sikazwe et al. 2021. Clinical Infect. Diseases.

Understanding the limitations of reliance on a single data source for estimating HIV care outcomes is important to correcting biased estimates and designing reliable interventions.





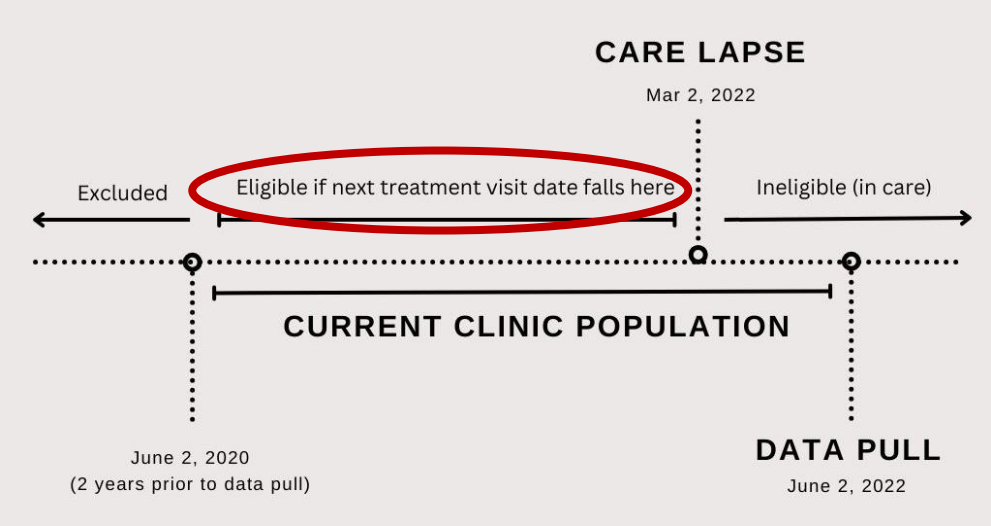
Our objective is to understand variation in population-level HIV care outcomes across data sources to supplement our understanding of the "truth" and better inform appropriate allocation of resources and program planning and implementation more broadly.

Methods

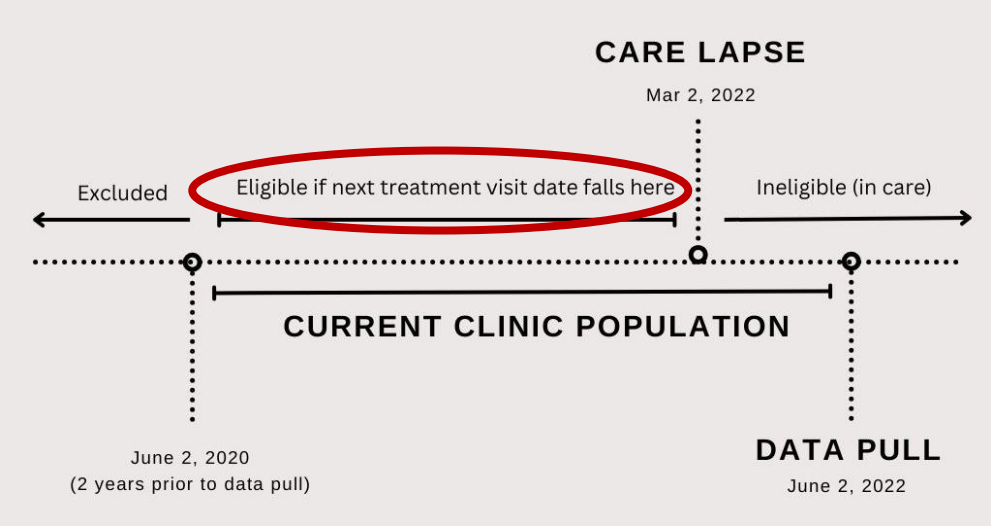
We used data from Uhambo Lwami, a population representative study in KwaZulu-Natal, South Africa for this analysis.

The **primary objective** of Uhambo Lwami (BetterInfo SA) is to track the care journey of PWH in South Africa from linkage to care forward to generate meaningful estimates of retention in care that account for when, how often, and how long individuals lapse in care.

We sampled 4,500 individuals living with HIV across 36 clinics in KZN who were out of care at the time of sampling (i.e., 90 or more days late) but had at least one visit in the prior 2 years.

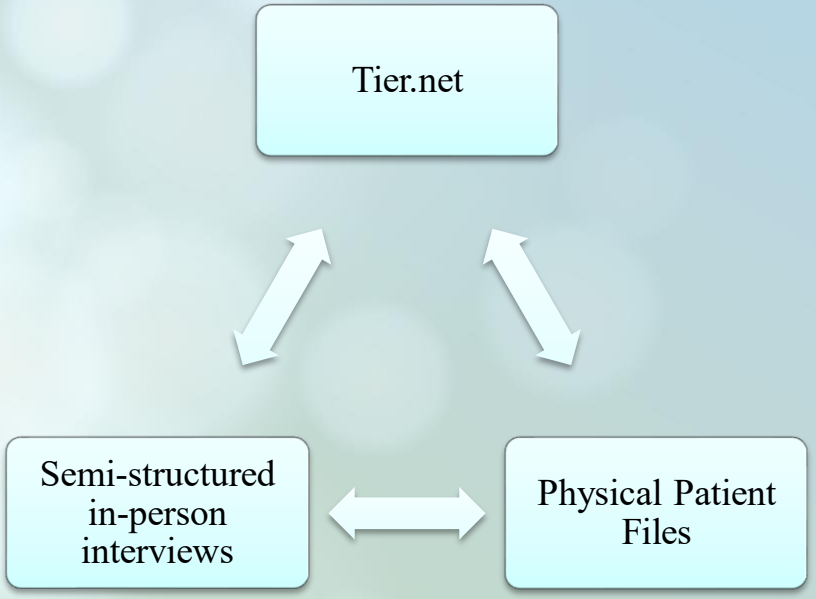


In this analysis, we used data from 5 clinics (N=625) in which data collection activities were largely complete at the time of analysis.



Our goal was to use multiple approaches and data sources to establish individuals' true outcomes and correct national estimates of retention.

- Tier.net- electronic, national HIV treatment register
- Physical patient files- retrieved from each of the sampled clinics (April-December 2023)
- Tracking and tracing + completion of individual or next of kin interviews (April-December 2023)



Ultimately, we aimed to group individuals into four distinct outcomes: In care, LTFU, TFO, RIP.

	Tier.net	Patient File	Tracking and tracing
In care at original clinic	-	documented visit within prior 90 days	self- or informant-reported
Lost to original clinic	90 or more days late for most recent documented visit	90 or more days late for most recent documented visit	self- or informant-reported
Transfer out	Documentation of transfer	Documentation of transfer (official or unofficial)	self- or informant-reported
Death	Documentation of death	Documentation of death	self- or informant-reported

We used descriptive statistics to compare outcomes by data source.

- N/%
- Comparisons:
  - Tier.net x Tracking and tracing
  - Patient file x Tracking and tracing

Findings

In our analysis, we used data from 5 clinics and 625 sampled individuals.

- Tier.net: N=625 (100%)
- Patient files: N=530 (84.8%)
- Tracking and tracing: N=380 (60.8%)

At the aggregate level, there was moderate variation in outcomes by data source...

Outcome	Data Source		
	Tier.net n (col %)	Patient File n (col %)	Tracking and tracing n (col %)
Lost to care	339 (54.2)	297 (56.0)	100 (26.3)
In care at original clinic	-	30 (5.7)	60 (15.8)
Transferred out	251 (40.2)	176 (33.2)	167 (43.9)
Died	35 (5.6)	27 (5.1)	53 (13.9)
Missing	0	95	245
Total (non-Missing)	625	530	380

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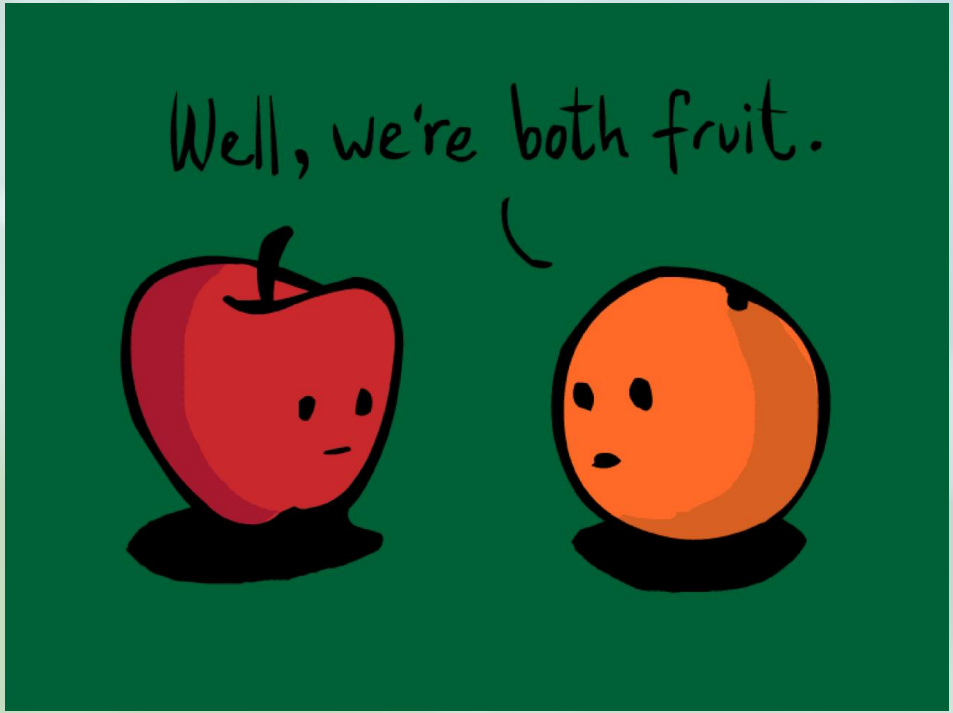
Total (non-Missing)	625	530	380

But when we compared apples to apples, the observed variation in outcomes was even greater...



Comparing Tier.net outcomes to tracking and tracing outcomes…

Of those who appeared to be lost to care in Tier.net, 23% stated they were in care when we interviewed them...

Patient or informant-reported outcome	Clinical outcome as documented in Tier.net				
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Total
Lost to care	80 (40.0)	-	20 (13.6)	0 (0.0)	100
In care at original clinic	**46 (23.0)**	-	14 (9.5)	0 (0.0)	60
Transferred out	60 (30.0)	-	107 (72.8)	0 (0.0)	167
Died	14 (7.0)	-	6 (4.1)	33 (100.0)	53
Unable to interview	139	-	104	2	245
Total	339	-	251	35	625

….30% stated they had transferred care…

Patient or informant-reported outcome	Clinical outcome as documented in Tier.net				
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Total
Lost to care	80 (40.0)	-	20 (13.6)	0 (0.0)	100
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Died	14 (7.0)	-	6 (4.1)	33 (100.0)	53
Unable to interview	139	-	104	2	245
Total	339	-	251	35	625

… and 7% had died.

Patient or informant-reported outcome	Clinical outcome as documented in Tier.net				
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Total
Lost to care	80 (40.0)	-	20 (13.6)	0 (0.0)	100
In care at original clinic	46 (23.0)	-	14 (9.5)	0 (0.0)	60
Transferred out	60 (30.0)	-	107 (72.8)	0 (0.0)	167
Died	**14 (7.0)**	-	6 (4.1)	33 (100.0)	53
Unable to interview	139	-	104	2	245
Total	339	-	251	35	625

Of those who had a documented transfer in Tier.net, 14% stated they were truly out of care when we interviewed them…

Patient or informant-reported outcome	Clinical outcome as documented in Tier.net				
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Total
Lost to care	80 (40.0)	-	**20 (13.6)**	0 (0.0)	100
In care at original clinic	46 (23.0)	-	14 (9.5)	0 (0.0)	60
Transferred out	60 (30.0)	-	107 (72.8)	0 (0.0)	167
Died	14 (7.0)	-	6 (4.1)	33 (100.0)	53
Unable to interview	139	-	104	2	245
Total	339	-	251	35	625

…10% stated they were in care at their original clinic.

Patient or informant-reported outcome	Clinical outcome as documented in Tier.net				
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Total
Lost to care	80 (40.0)	-	20 (13.6)	0 (0.0)	100
In care at original clinic	46 (23.0)	-	**14 (9.5)**	0 (0.0)	60
Transferred out	60 (30.0)	-	107 (72.8)	0 (0.0)	167
Died	14 (7.0)	-	6 (4.1)	33 (100.0)	53
Unable to interview	139	-	104	2	245
Total	339	-	251	35	625

Comparing patient file outcomes to tracking and tracing outcomes…

Of those who appeared to be out of care according to their physical file, over 35% told us they had transferred…

Patient or informant-reported outcome	Clinical outcome as documented in physical patient file					
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Unable to find file	Total
Lost to care	65 (36.3)	5 (20.8)	11 (10.8)	0 (0.0)	19	100
In care at original clinic	32 (17.9)	15 (62.5)	10 (9.8)	0 (0.0)	3	60
Transferred out	**63 (35.2)**	3 (12.5)	75 (73.5)	0 (0.0)	26	167
Died	19 (10.6)	1 (4.2)	6 (5.9)	24 (100.0)	3	53
Unable to interview	118	6	74	3	44	245
Total	297	30	176	27	93	625

...and 11% had died.

Patient or informant-reported outcome	Clinical outcome as documented in physical patient file					
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Unable to find file	Total
Lost to care	65 (36.3)	5 (20.8)	11 (10.8)	0 (0.0)	19	100
In care at original clinic	32 (17.9)	15 (62.5)	10 (9.8)	0 (0.0)	3	60
Transferred out	63 (35.2)	3 (12.5)	75 (73.5)	0 (0.0)	26	167
Died	**19 (10.6)**	1 (4.2)	6 (5.9)	24 (100.0)	3	53
Unable to interview	118	6	74	3	44	245
Total	297	30	176	27	93	625

Of those whose file stated they had transferred, around 11% told us they were out of care…

Patient or informant-reported outcome	Clinical outcome as documented in physical patient file					
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Unable to find file	Total
Lost to care	65 (36.3)	5 (20.8)	**11 (10.8)**	0 (0.0)	19	100
In care at original clinic	32 (17.9)	15 (62.5)	10 (9.8)	0 (0.0)	3	60
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Died	19 (10.6)	1 (4.2)	6 (5.9)	24 (100.0)	3	53
Unable to interview	118	6	74	3	44	245
Total	297	30	176	27	93	625

And 6% had died.

Patient or informant-reported outcome	Clinical outcome as documented in physical patient file					
	Lost to clinic n (col %)	In care at original clinic n (col %)	Transferred out n (col %)	Died n (col %)	Unable to find file	Total
Lost to care	65 (36.3)	5 (20.8)	11 (10.8)	0 (0.0)	19	100
In care at original clinic	32 (17.9)	15 (62.5)	10 (9.8)	0 (0.0)	3	60
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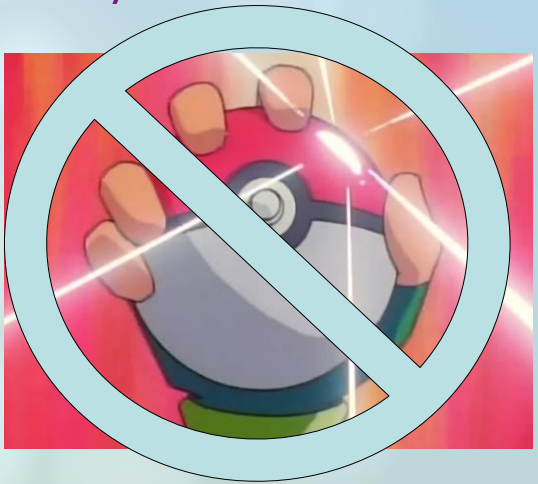
Died	19 (10.6)	1 (4.2)	**6 (5.9)**	24 (100.0)	3	53
Unable to interview	118	6	74	3	44	245
Total	297	30	176	27	93	625

Implications

Global estimates of retention in HIV care, which are often based on national electronic treatment registers or patient file data are likely to be highly biased.

- Inconsistent/illegible record-keeping
- High degree of missing files (improved clinic performance?)
- Limited/no verification of "official" transfers
- Reliance on community/family reports of death
- Lack of communication across systems (e.g., death registries, clinics)

Methodological techniques such as double-sampling and patient tracking and tracing can help us remedy these issues.



- Can't catch 'em all, but can catch some!
- More robust data collection and monitoring systems are needed (clinic-based EHR systems; standardized patient identifiers, etc.)
- Cross-referencing across data sources=GOOD
- Can more appropriately plan for (financing!) and implement needed interventions

A special thanks to co-authors and funding sources.

Human Sciences Research Council

- Franco Musiello
- Buyisile Chibe
- Candice Groenewald
- Kombi Sausi
- Zaynab Essack
- Alastair van Heerden

Centre for Infectious Diseases Research in Zambia

- Kombatende Sikombe
- Anjali Sharma

Washington University in St. Louis

- Aaloke Mody
- Elvin Geng

University of Sussex

- Collins Iwuji

Institute of Tropical Medicine Antwerp

- Alfred Keter

BILL & MELINDA GATES foundation

Questions?

flindsey@wustl.edu