

# Loss to follow-up: Determining outcomes for adults enrolled in HIV services in Kenya

William Reidy<sup>1</sup>, Mansi Agarwal<sup>1</sup>, Matthew Lamb<sup>1</sup>, Mark Hawken<sup>1</sup>, Duncan Chege<sup>1</sup>, Batya Elul<sup>1</sup>, Elaine J Abrams<sup>1</sup>, Elvin Geng<sup>2</sup>.

<sup>1</sup>ICAP-Columbia University, New York, NY USA; <sup>2</sup>University of California, San Francisco

## Background

- Lost to follow-up (LTF) is an administrative classification indicating that a patient is no longer actively receiving care in a clinic, and clinic records do not indicate that the patient has died or transferred to another facility.
- High rates of LTF from HIV programs can present a barrier to effective evaluation of patient outcomes, such as death, and may be misinterpreted as a proxy for high levels of disengagement from HIV care. Specifically, this is due to the fact that LTF includes patients who 'silently' transfer to another clinic and patients who have died
- Selection of a random sample of patients considered LTF from an HIV clinic could produce a representative sample of all patients LTF from that facility. Locating and interviewing a random sample of patients LTF from a facility enables better estimates of true retention in HIV care and mortality.
- Previous studies have used such methods to assess retention and mortality among ART and ART-eligible patient cohorts<sup>1,2</sup>; these methods have not been used among a general pre-ART population.

<sup>1</sup>Geng EH, et al. J Acquir Immune Defic Syndr. 2013 Jun 1; 63(2):e64-71.

<sup>2</sup>Geng EH, et al. PLoS ONE 6(7): e21797. doi:10.1371/journal.pone.0021797.

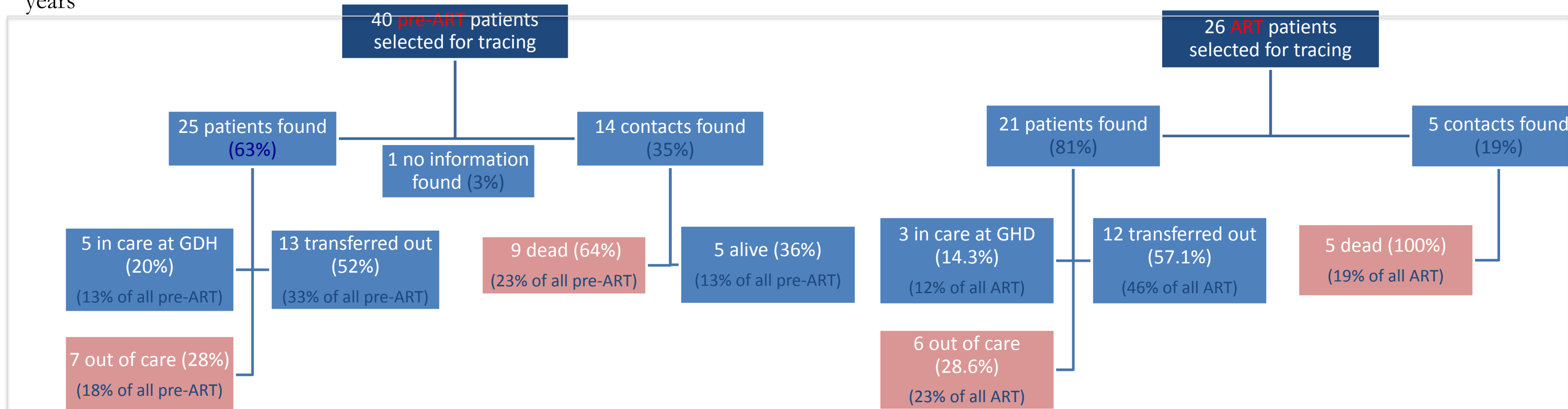
## Methods

- This study involved analyses of existing, routinely-collected electronic patient-level data from one PEPFAR-supported HIV clinic in Kenya supplemented with data collected prospectively from a random sample of pre-ART and ART patients we classified as LTF from this clinic.
- Patients of the HIV clinic at Gatundu District Hospital (GDH) in Kenya with at least 1 clinic visit between April 2008-April 2012 were assessed for LTF status using electronic data. This population included patients who had newly enrolled in care during April 2008-April 2012 as well as patients enrolled prior to April 2008 and had been retained in care into this period.
- LTF was defined as no visit in the past 3 months (for ART patients) or 6 months (for pre-ART patients) and not documented as dead or transferred-out to another HIV clinic.
- Approximately 15% of those LTF before ART initiation, and 15% of those LTF after ART initiation, were randomly selected for study tracing.
- Clinic tracers tracked patients and completed a questionnaire for patients or contacts found, collecting information including patient vital status (alive/dead) and, for patients found, reasons for going LTF and current engagement in care (in care/disengaged) and ART use.
- Data collected from the random sample of patients LTF was used to adjust death estimates and estimate true disengagement from care for the larger population from which the sample was derived using inverse probability weighting techniques.
- Rates and percent dead and in care were presented using the initial clinic data and data updated with outcomes from tracing, weighted to represent all patients LTF. Weights for traced patients were equal to the total number of patients LTF from the clinic divided by the number of these patients who were successfully traced<sup>3</sup>.
- For the subset of traced patients who were not found, but for whom a contact was found and interviewed, patients reported as alive were classified as in care (optimistic scenario) or disengaged (pessimistic scenario) in separate analyses.
- We also conducted a sub-analysis of the sampled patients who were found and directly interviewed to identify these patients' self-reported reasons for going LTF, and the proportions of patients within each category who reported subsequently re-engaging in HIV care.

Table 1: Characteristics of patient population, patients LTF, and patients tracked

	All Patients* (n=1974)	All patients LTF (n=423)	Patients tracked (n=65)
Age (median)	34	32	33
Female (n, %)	1346 (68.2)	303 (71.6)	38 (58.5)
Newly enrolled in 4-yr period (n, %)	1260 (63.8)	333 (78.7)	52 (80.0)
Enrollment CD4 count (median)	203	287	300
missing enrollment CD4 (n, %)	544 (27.6)	158 (37.4)	23 (35.4)
Enrollment WHO Stage (n, %)			
Stage 1-2	521 (26.4)	124 (29.3)	16 (24.6)
Stage 3-4	552 (28.0)	85 (20.1)	13 (20.0)
Missing enrollment WHO stage	900 (45.6)	214 (50.6)	36 (55.4)
Enrollment TB status (n, %)			
No diagnosed TB	1182 (59.9)	274 (64.8)	45 (64.8)
Diagnosed TB	193 (9.8)	50 (11.8)	10 (15.4)
Unknown	599 (30.3)	89 (23.4)	10 (15.4)
Ever started ART (n, %)	1234 (62.5)	142 (33.6)	26 (40.0)
Last CD4 count (median)	397	359	373
no CD4 information (n, %)	160 (8.1)	90 (21.3)	16 (24.6)
Last WHO Stage (n, %)			
Stage 1-2	891 (45.1)	155 (36.6)	22 (33.8)
Stage 3-4	788 (39.9)	105 (24.8)	18 (27.7)
No WHO Stage information	295 (14.9)	163 (38.5)	25 (38.5)

\*All patients with 1 or more visits in the past 4 years



<sup>3</sup>denominator for percentage of all pre-ART patients is 39 – the number of patients with information found

Figure 1a.-b.: Randomly-sampled LTF pre-ART and ART patients traced and outcomes\*

## Results

- 423 (21%) of the 1,974 clinic patients were categorized as LTF, of which 66 (15.6%; 40 pre-ART, 26 ART) were sampled.
- Among the 66 sampled patients, tracers were able to collect information for 65 (98%) patients. The sampled and tracked population was similar to the larger LTF population across a range of demographic and health characteristics. However, a lower proportion of the tracked population was female (59% vs. 72%) (Table 1).
- Interviews were conducted directly with 46 tracked patients (25 pre-ART, 21 ART), and with 19 patient contacts (14 pre-ART, 5 ART) (Fig. 1).
- Among all of these 65 patients, 9 (23%) pre-ART and 5 (19%) ART patients were reported to have died. Among the 46 patients found, 7 (28%) pre-ART and 6 (29%) ART patients reported being disengaged from HIV care.
- Adjusting the initial data with sample outcomes increased overall retention in care for pre-ART patients from 52% to 70% (pessimistic) or 75% (optimistic) and for ART patients from 81% to 88% (Table Figure 2a-b). Deaths increased from 10% to 19% for pre-ART patients and from 8% to 10% for ART patients. The proportion of pre-ART and ART patients LTF in the initial data was 38% and 12%, respectively; in the adjusted data, 12% (pessimistic) or 7% (optimistic) of all pre-ART and 3% of all ART patients were recorded as alive and disengaged from care.
- Among patients directly interviewed, the most common reasons for patient default from care were distance to the clinic or generally preferring another clinic (20% each), work preventing attendance at appointments (17%), moving (15%), and having no transport (11%). With the exception of health-related reasons for defaulting – i.e., felt well, felt too sick, ARVs have side effects, the majority of patients reporting each reason also reported current engagement in HIV care (Figure 3).

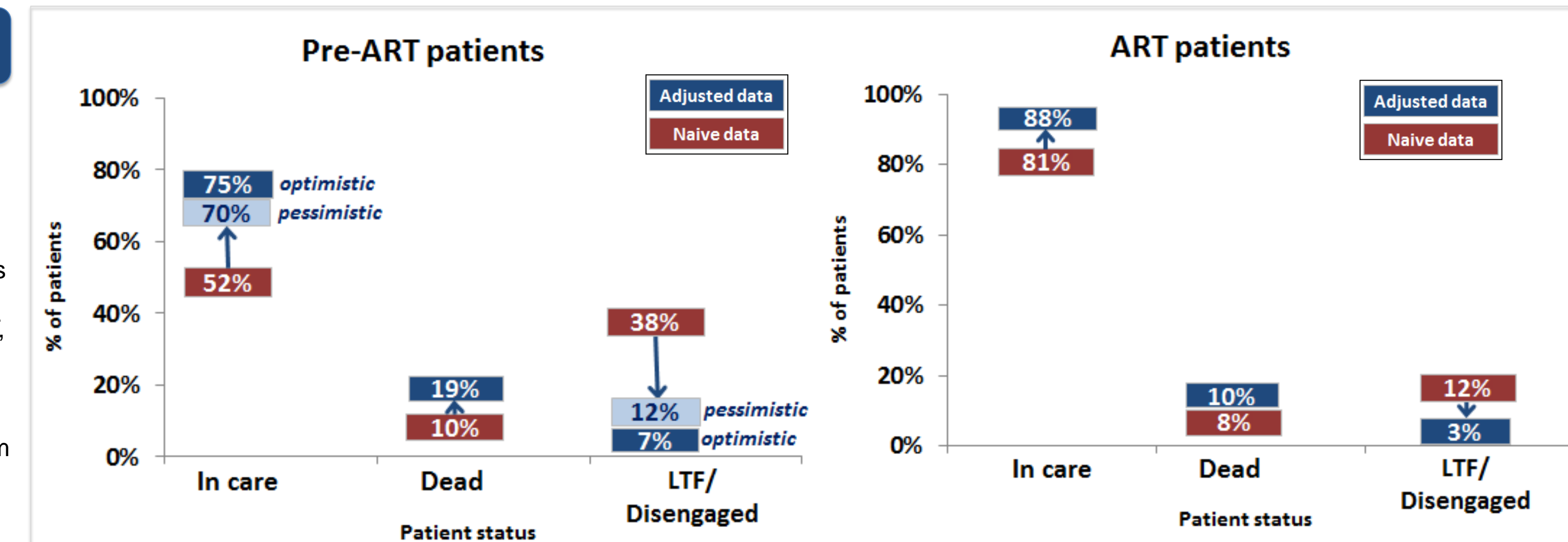


Figure 2a.-b.: Cumulative proportions of pre-ART and ART patients in care, dead, and LTF/disengaged, naive and adjusted datasets

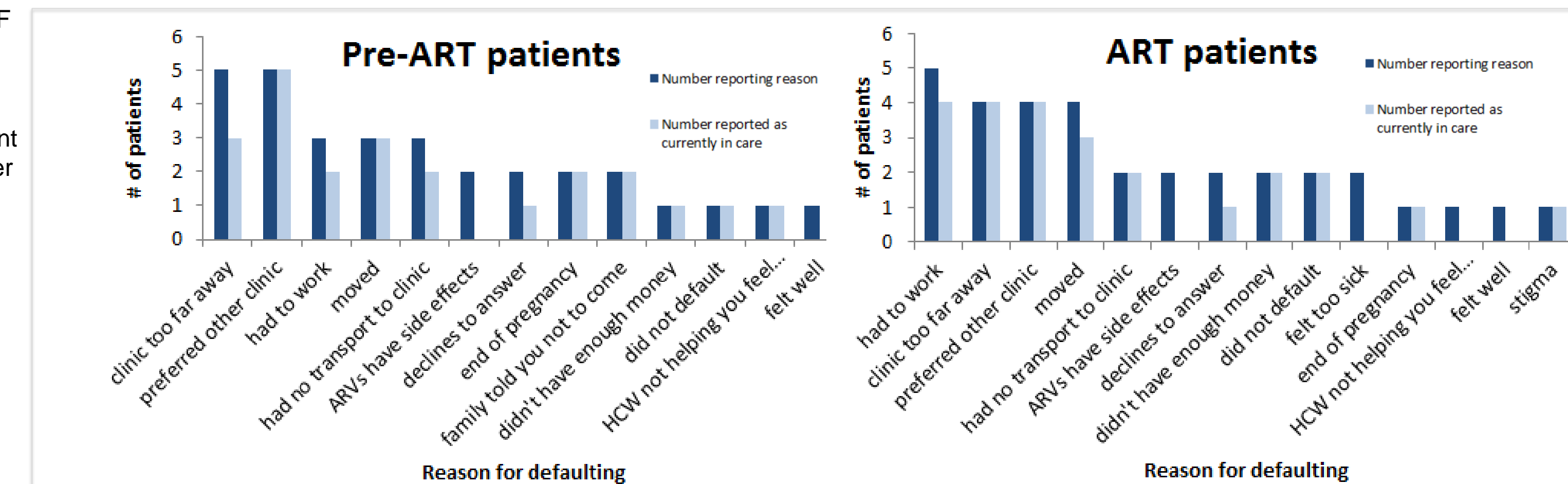


Figure 3a.-b.: Reasons for defaulting and reported engagement in care for LTF pre-ART and ART patients interviewed

## Conclusions

- These findings suggest that only a minority of patients classified as LTF by one large HIV clinic in Kenya are actually disengaged from HIV care. Many patients LTF transferred or returned to care or died following their last clinic visit.
- Accordingly, death rates calculated before correction from tracing were underestimated, especially among pre-ART patients.
- Patients in the sample reporting the most common reasons for defaulting (i.e., access) were likely to report re-engaging in care; the smaller number who reported reasons related to health status or ARV side effects did not re-engage in care.
- While our data are from a single facility and relies on self-reported information, these findings suggest that high levels of LTF observed in routinely-collected data may be a poor proxy for disengagement from care and obscure higher death rates.

**Acknowledgements** Kenya Ministry of Health, government staff at Gatundu District Hospital, ICAP staff in-country and in New York.

This research was supported by the President's Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC) under the terms of Cooperative Agreement #5U2GPS001537. The contents are the responsibility of ICAP and do not necessarily reflect the views of the United States Government.

ICAP is a global leader in HIV and public health. Founded in 2004 at Columbia University's Mailman School of Public Health, ICAP has supported work at more than 3,995 health facilities across 21 countries. Nearly 1.8 million people have received HIV services through ICAP-supported programs. [icap.columbia.edu](http://icap.columbia.edu)

