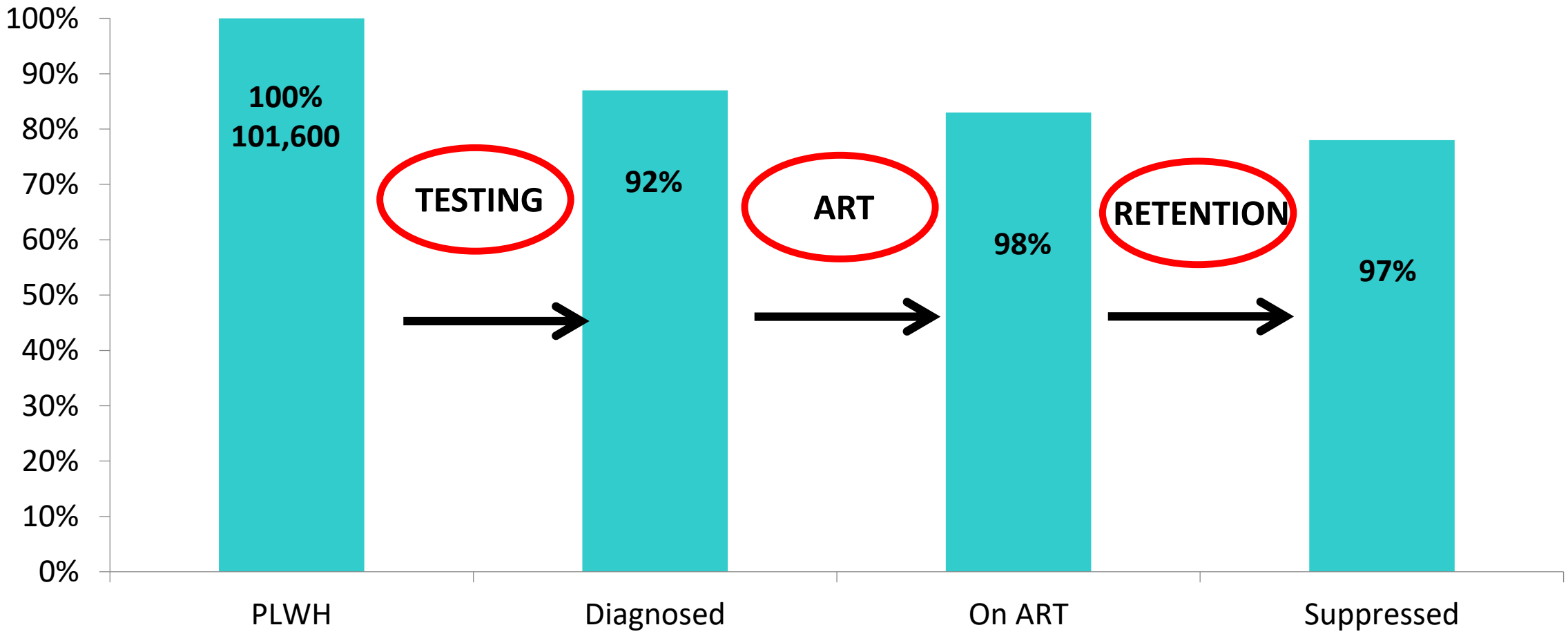
Lost to Follow up for HIV care: a significant problem

Dr Hannah Alexander
Dr Kate Childs
Dr Melanie Rosenvinge
Dr Goli Haidari

Introduction

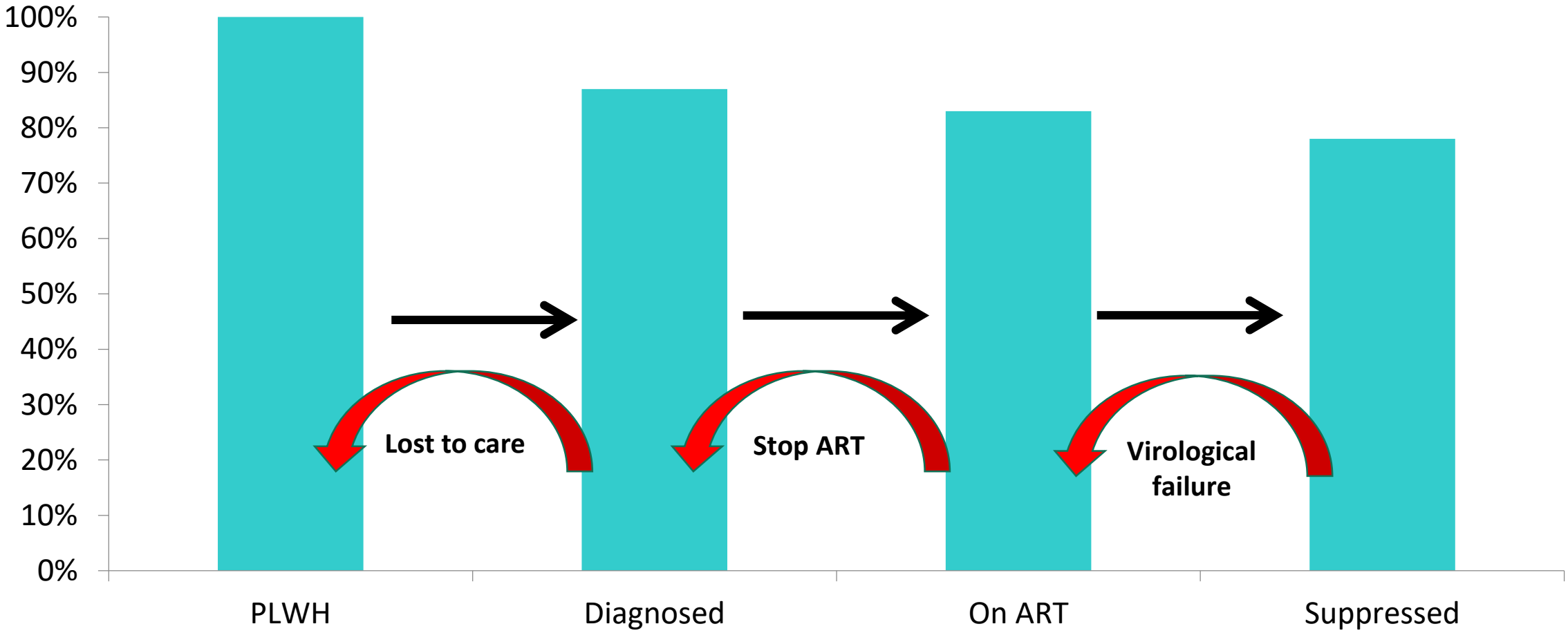
King's College Hospital NHS
NHS Foundation Trust

HIV in the UK: A success story



HIV in the UK - 2018 report.. Public Health England, London.

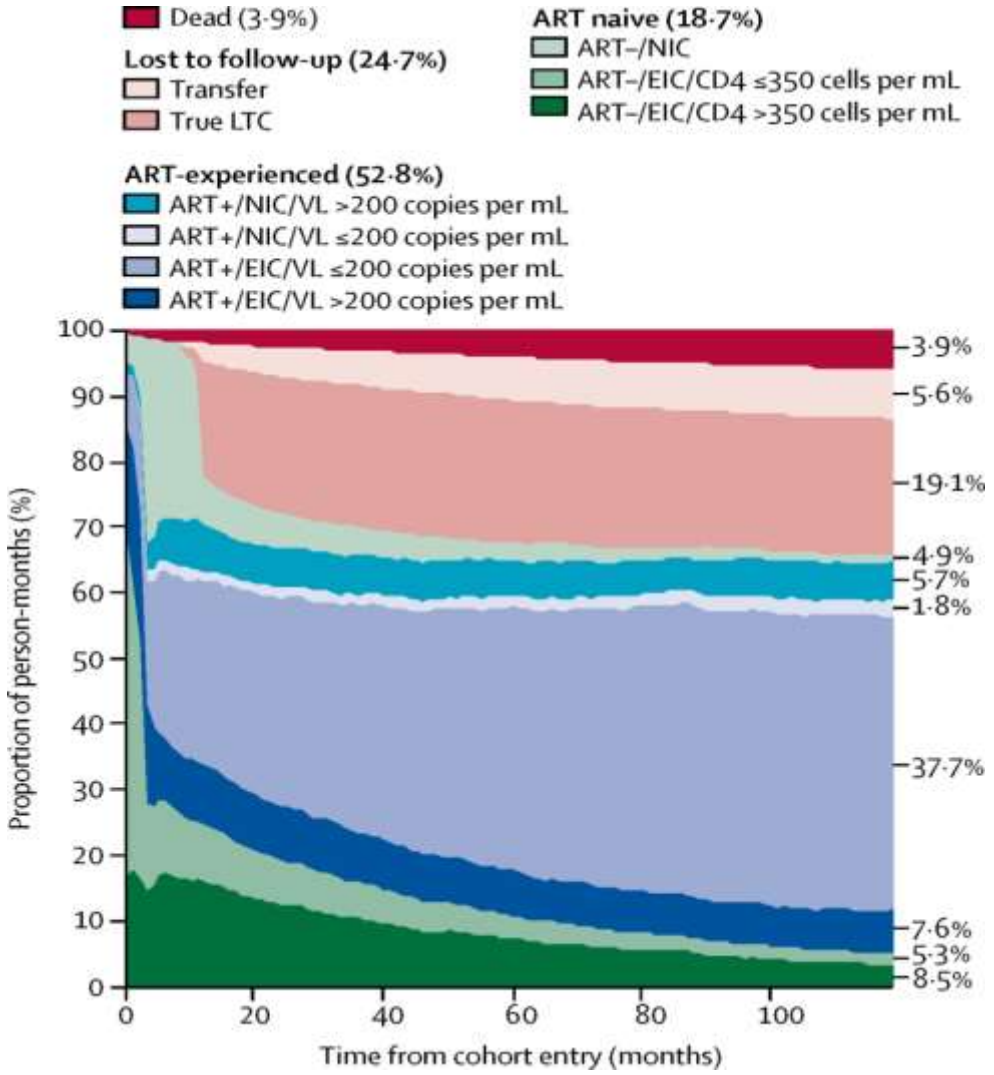
Not a one way path: Moving backwards through the treatment cascade



Jose et al 2018 Lancet ID A continuum of HIV care describing mortality and loss to follow-up- a longitudinal cohort study

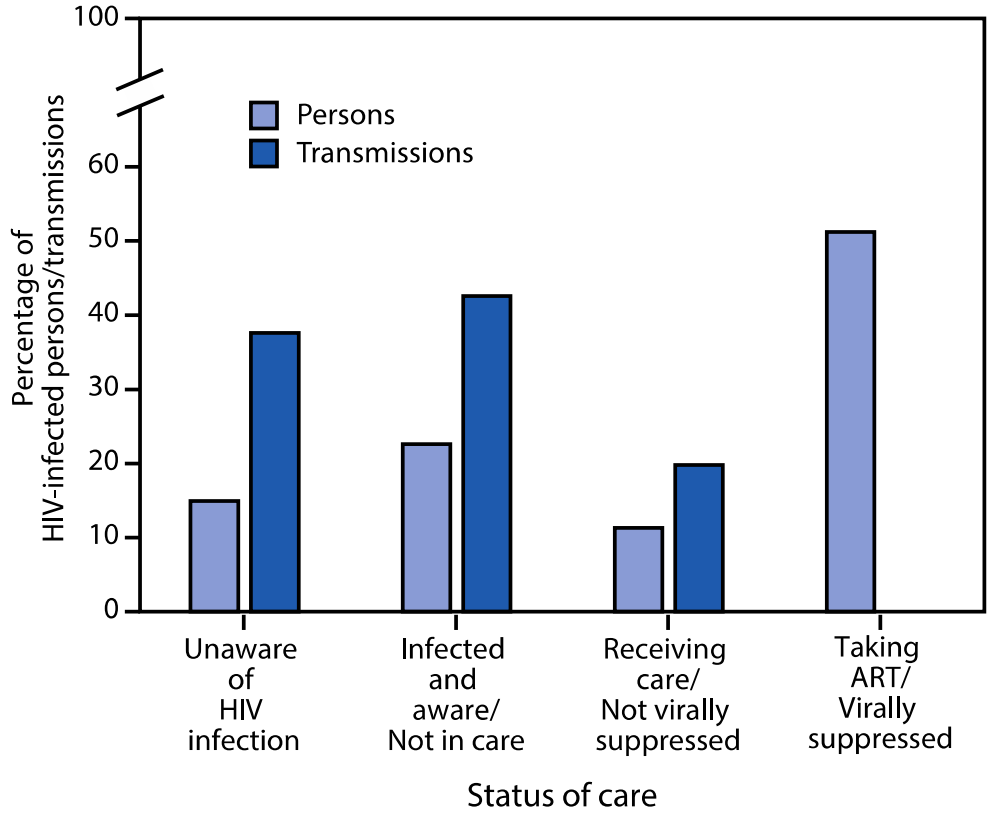
10 years after entering care (2000-2004), 19% of patients living with HIV in the UK are lost to clinical care.

Jose et al 2018, Lancet ID 'A continuum of HIV care describing mortality and loss to follow-up- a longitudinal cohort study'



The majority of HIV transmissions arise from people unaware of their HIV status or aware and not on effective treatment

FIGURE 1. Percentage of persons* with human immunodeficiency virus (HIV) infection and percentage of transmissions along the continuum of HIV care† — United States, 2016§,¶



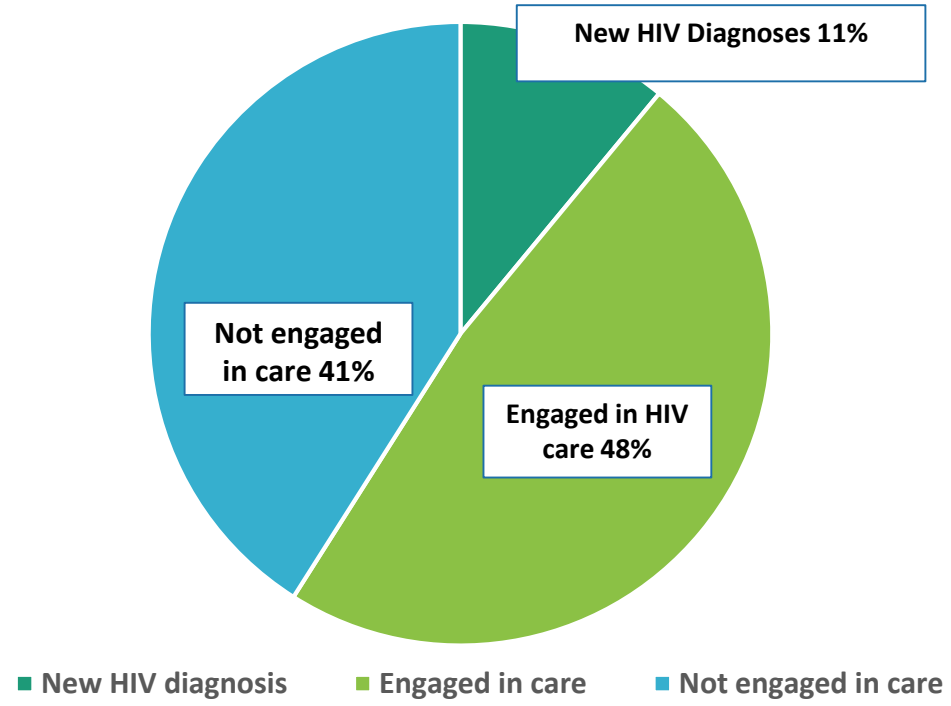
Along the HIV continuum of care, percentage of overall HIV transmissions were as follows:

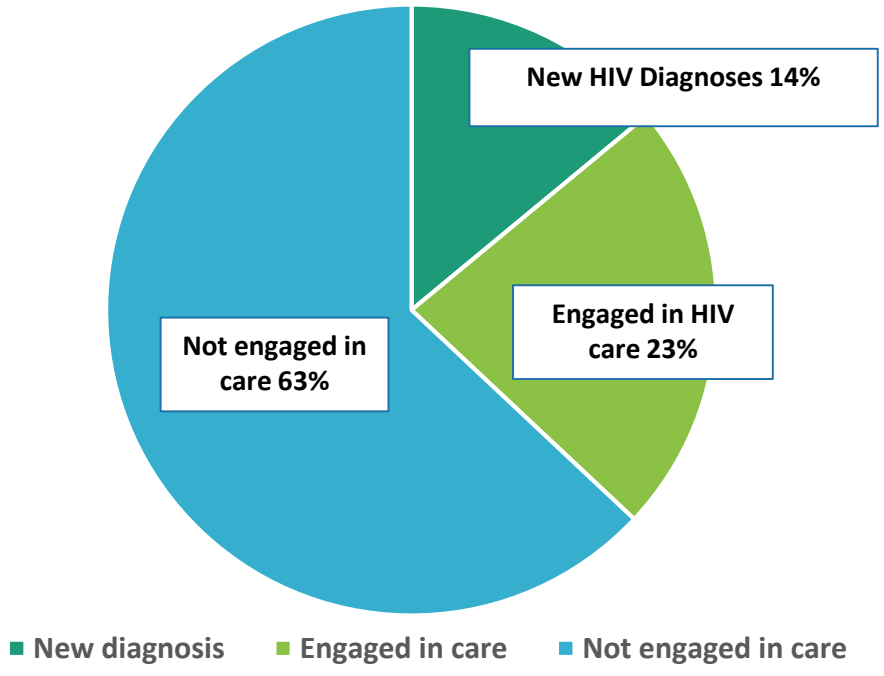
1) Acutely infected and unaware of their infection **4.0%**
2) Non-acutely infected and unaware **33.6%**
3) Aware of HIV infection but not in care **42.6%**
4) Receiving HIV care but not virally suppressed **19.8%**
5) Taking ART and virally suppressed **0%**

- Li Z, Purcell DW, Sansom SL, Hayes D, Hall HI. HIV transmission along the continuum of care — United States, 2016. MMWR Morb Mortal Wkly Rep 2019;68: 267-72.

LTFU in LSL is driving morbidity and mortality and NHS expenditure

Poor engagement is driving hospital admissions in PLWH at GSTT and KCH





NHS
Guy's and St Thomas'
NHS Foundation Trust

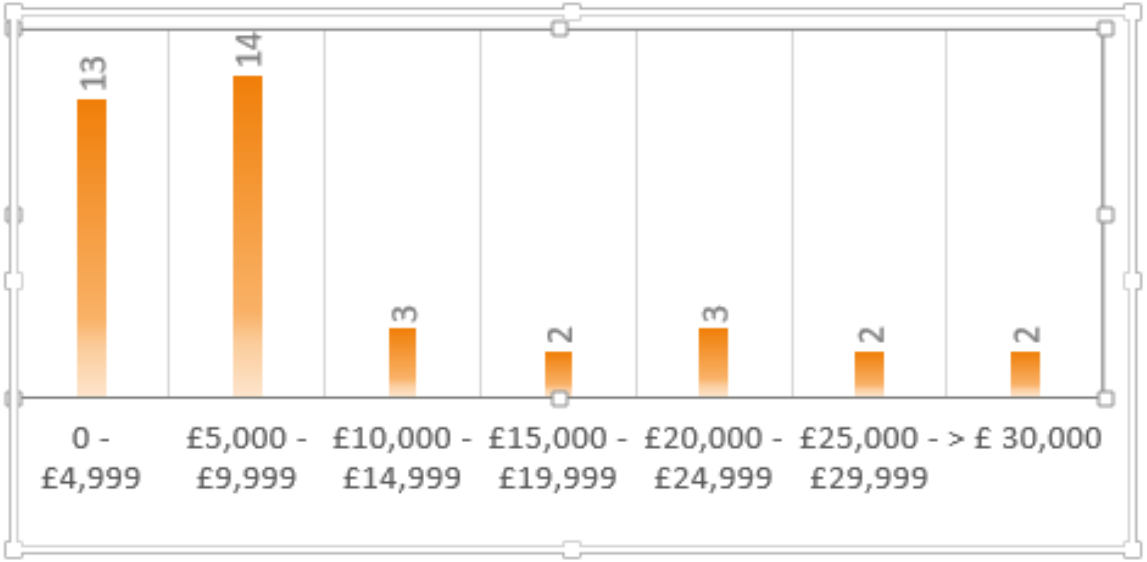
NHS
King's College Hospital
NHS Foundation Trust

At GSST in one year, admissions for LTFU patients with HIV infection cost £408,135

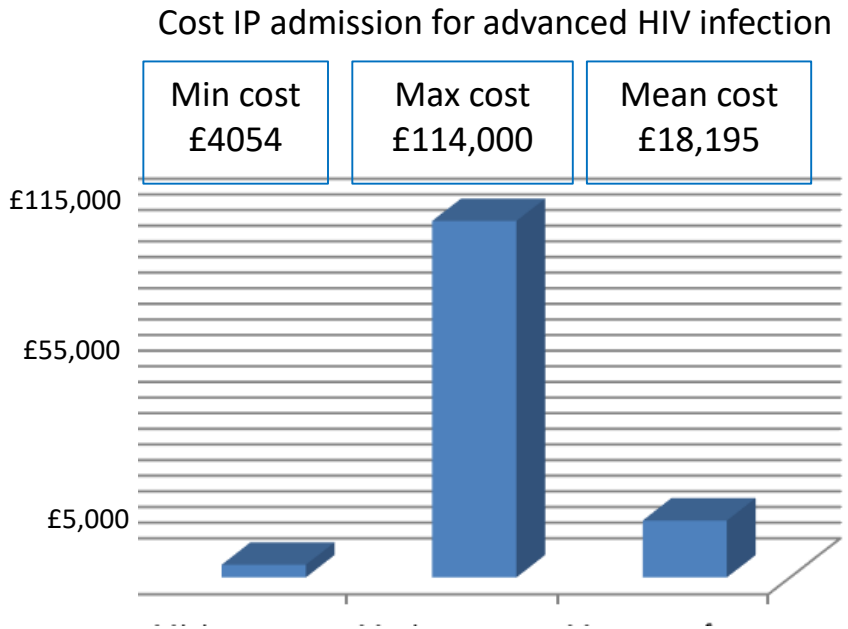
COST OF HOSPITAL ADMISSION FOR PATIENTS NOT ENGAGED IN HIV CARE

1.8.2018 - 31.8.2019 (n=41)

The total cost for hospital admissions accumulated by PLHIV disengaged from care was £408,135



At UHL in one year, maximum cost of a single inpatient stay was £114,000



Guy's and St Thomas' NHS Foundation Trust

Cases known to us personally

- 36 year old woman, LTFU from 2017 presented with confusion, has PML, 2.5 month hospital admission, discharged to a nursing home, wheelchair bound, PEG fed, not able to verbalise, 9 year old son now being raised by a family member
- 45 yr old man, LTFU for several years, presented with headache, CD4 8, cryptococcal meningitis, Went blind despite appropriate treatment, died following a 3 month hospital admission
- 39 yr old woman, LTFU from 2004, attended another ED with headache 11/2/20 did not mention HIV, attended Kings ED 13/2/20, died within 12 hours, cryptococcosis.

Method

- This project was conducted at Guys, King's and Lewisham, funded by the Elton John AIDS Foundation and ran from July 2020-Dec 2021.
- Aimed to identify patients living with HIV who are LTFU and link them back into care and treatment.
- A fixed payment was received for each outcome achieved. An outcome was defined as a patient re-engaged who has been out of care for > 1 year or off treatment.

The LTFU process

1) Data: Identify LTFU patients

- We identified patients from clinic records who last attended between 2012 and 2020 but have not been seen for at least 12 months
- Cross matched with Public Health England to check which patients were attending other clinics in the UK and which were not.

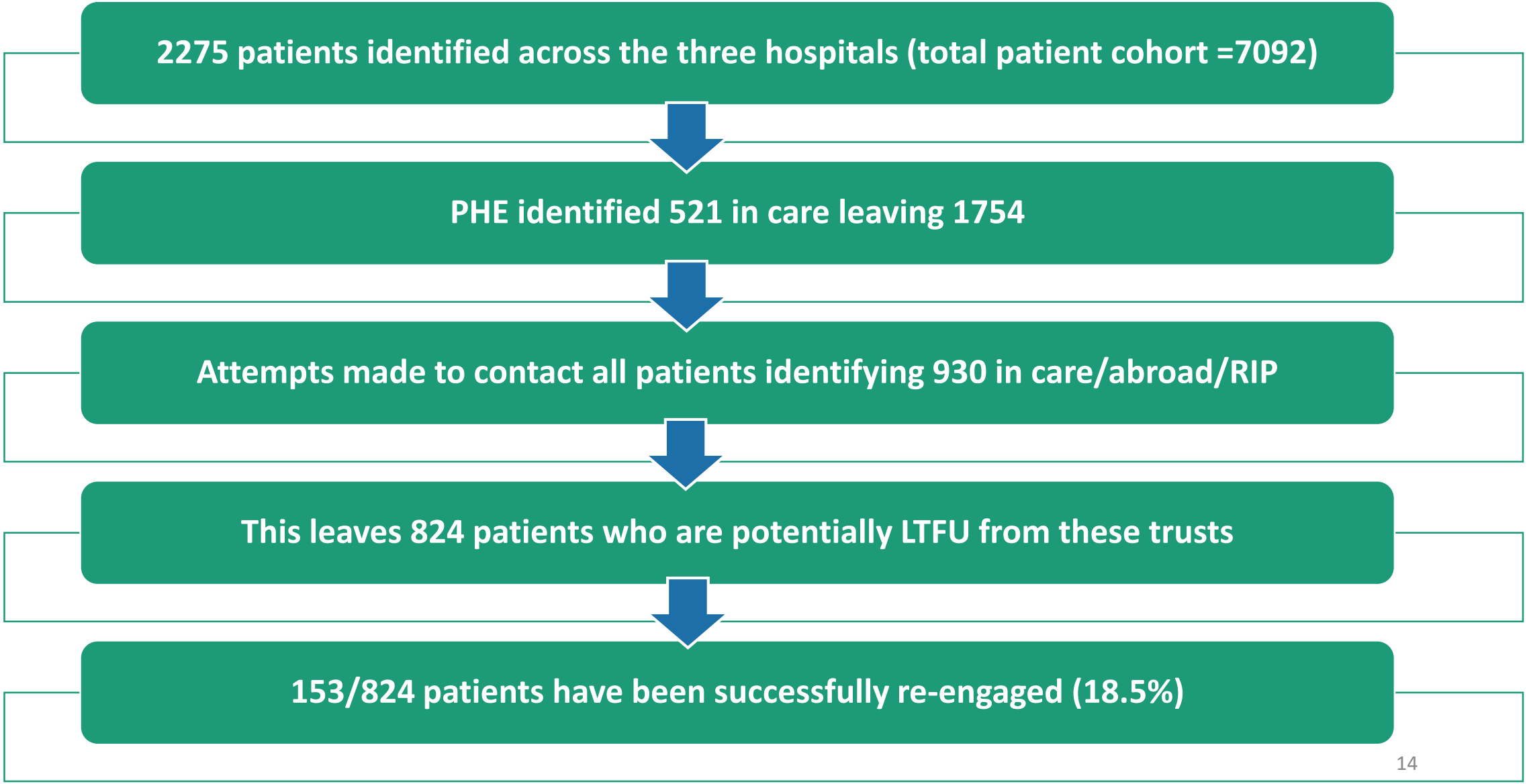
2) Contact: Invite patients to reengage.

- Dedicated nurse or administrator to contact patient
- For every patient on the database we phone/text/email/check NHS spine for mobile number/check electronic database for info/home letter/EPR letter/GP letter
- Alerts set up on electronic care records, LTFU alert letter on EPR (under documents)
- Once patient has been contacted, requires frequent calls to remind them to attend/keep in close contact

Maintain engagement

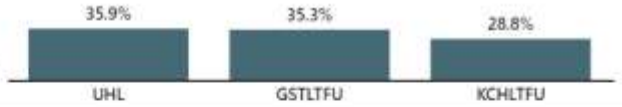
- There are many barriers to accessing services (cognitive impairment, mobility, stigma, drug/alcohol, poverty, immigration, housing and childcare issues)
- Appointments offered in alternative venues/at flexible times
- Dedicated contact smart phone
- Food and travel vouchers, outreach to hostels
- Liaise with support workers – mental health/social work/drug and alcohol support

824 patients were potentially LTFU across 3 sites



ELTON JOHN AIDS FOUNDATION

LTFU Outcome demographics



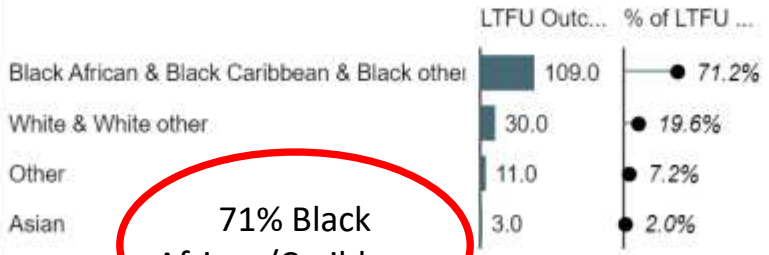
Outcomes (%)
153 (100.0%)

Re-engaged	CD4 < 200	CD4 < 350	% CD4 < 350	Median CD4	Average CD4	Median Age	Average Age
153	48	82	53.6%	305.00	386	46	46

Outcomes by Gender

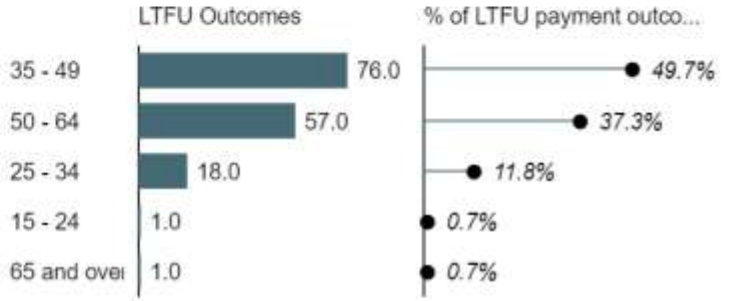
57% female

Outcomes by Ethnic group

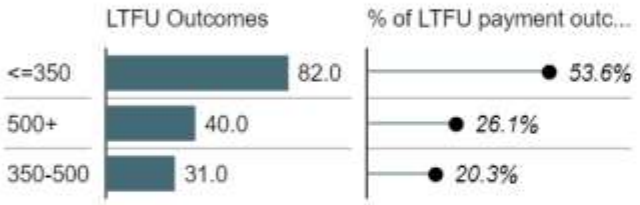


71% Black African/Caribbean

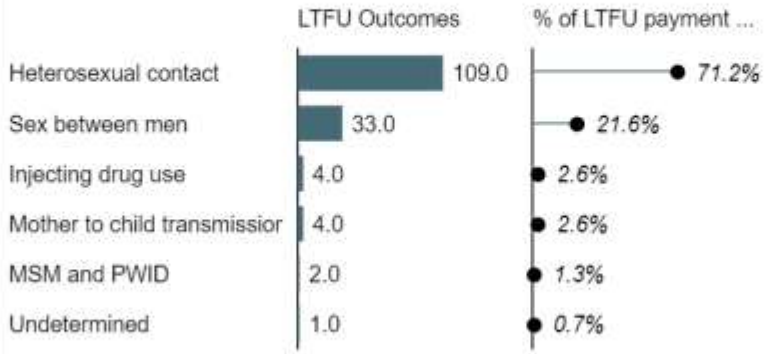
Outcomes by Age group



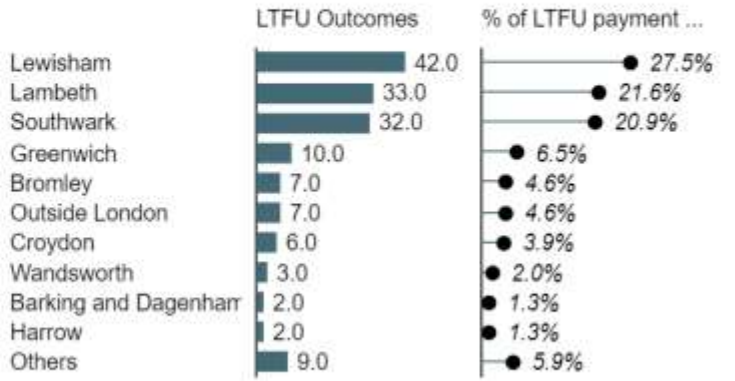
Outcomes by CD4 range



Outcomes by Exposure category

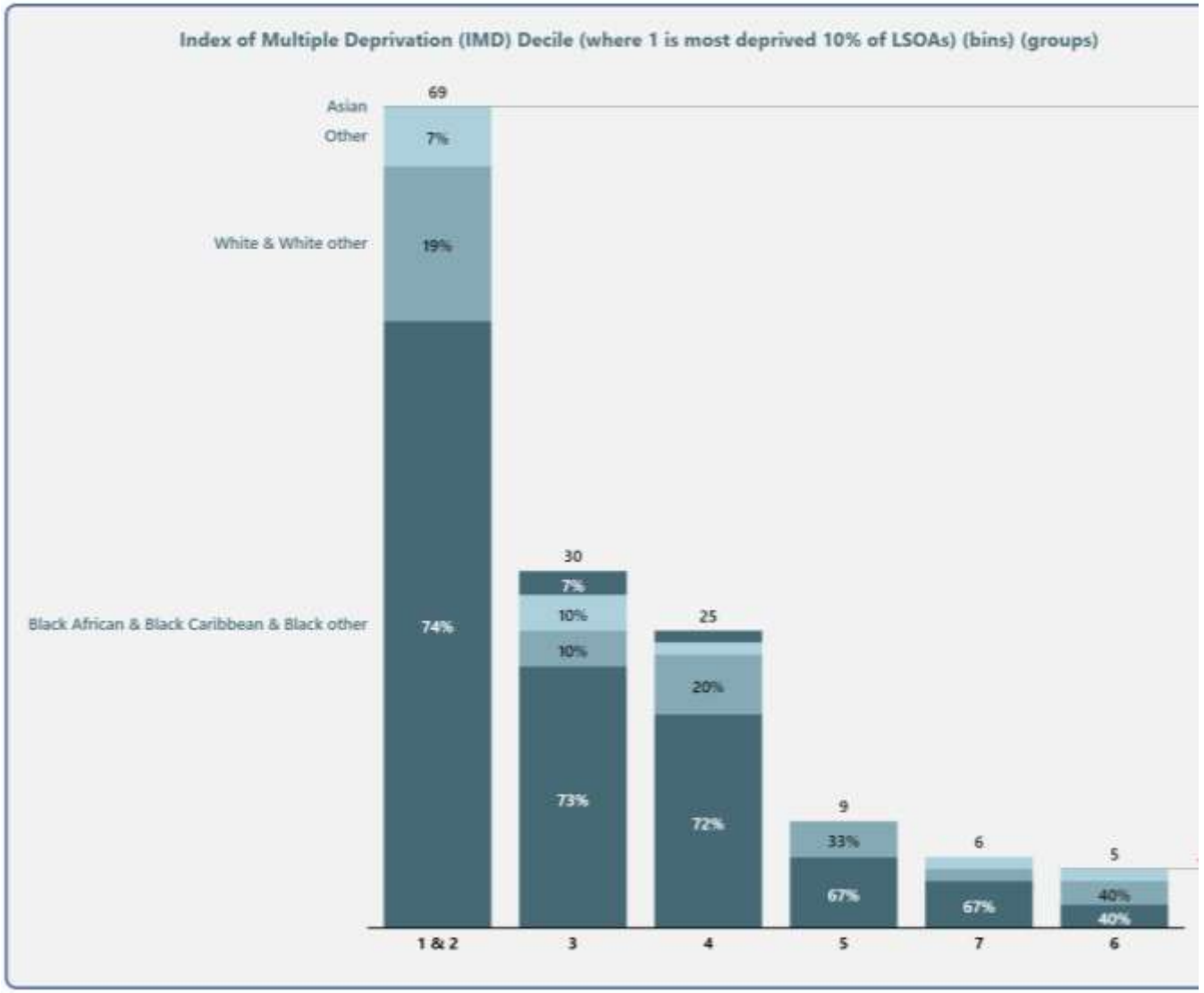


Outcomes by Borough



ELTON JOHN AIDS FOUNDATION

LTFU Outcomes vs Index of Multiple Deprivation



Number or Reengaged patients

Increasing Deprivation

69 (45%) re-engaged patients came from the 20% most deprived areas in the UK

...got busy forgot own health, child with autism, not communicating, lots going on at home

'Didn't want to come to Caldecot or anywhere in hospital as is a beautician and knows lots of Kings staff, esp nurses. Doesn't care if people know about her status but doesn't want her teenage son 'tarred'.'
'He says he still feels guilty about the HIV and tries not to think about it. He doesn't like to make close friends as he doesn't want to have to lie about it.'

LTFU since 2017. Stopped coming after HW moved from STH to Guy's. Ex partner was v negative about HIV and taking medication - pt says this wore off on her, but they are now separated and she has been thinking about coming back to clinic 'to find the courage'. Has been reading up about ART and updates - aware of U=U.

Why did you stop attending the HIV clinic? Initial shock of diagnosis was too great. Now thinks was in denial and distanced herself from services.

x sex many years - does not want to infect others-- Unaware of U=U.

Has been LTFU , emotional issues and low self-worth mental withdrew form getting HIV treatment, belief not deserving of treatments
Feels very lonely, lives in room in shared house but not social, can see is viscous circle, pushes people away when really wants intimacy and emotional connection, increased anxiety, describes panic attacks at times

King's College Hospital NHS
NHS Foundation Trust

Take home messages

- Patients who were lost to follow up are critically immunosuppressed
- This issue disproportionately affects women of black ethnicity from areas of social deprivation. As such it represents a significant health inequality.
- Thanks to the funding from EJAF we have been able to link 153 patients back into care and give them the opportunity to restore their health.

Acknowledgements

- Elton John AIDS Foundation – Jennifer Warner, Steve Hindle, Anne Aslett, Tony Maclaren
- Kings – Kate Childs, Noeleen Bennet, Zoe Ottoway, Ayoma Ratnappuli, Julie Barker, Liz Hamlyn, Maureen Salmon.
- GSTT – Goli Haidari, Rose Mower, Julia Bilinska
- UHL – Melanie Rosenvinge, Lucy Wood
- UKHSA – Cuong Chau, Veronique Martin