HIV re-engagement work in SE London

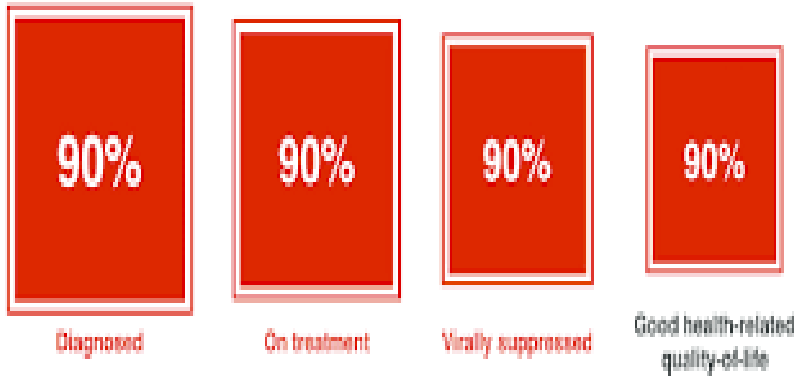
Dr Kate Childs , Kings College Hospital NHS Foundation Trust

KCH: Hayley Cheetham, Imogen Paton, Maddie Angus, Ayoma Ratnapulli
North Midd: Dr Hannah Alexander
GSTT: Dr Goli Haidari, Rose Mower
UHL: Dr Mel Rosenvinge, Lucy Wood

What I'll cover

- UNAIDS targets
- UK data
- SE London reengagement work
- Background, funding
- Outcomes
- How big is the problem?
- What can be done to replicate this work?

UNAIDS targets



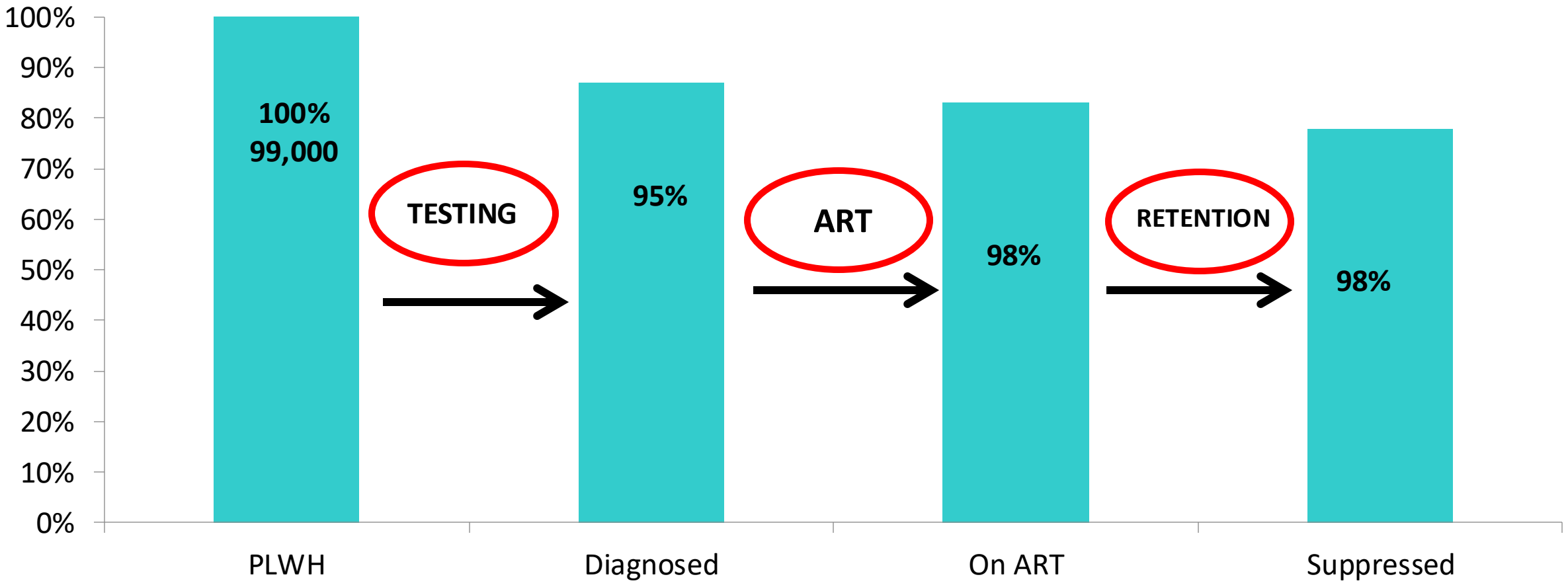
- At the 20th International AIDS Conference in Melbourne,, in 2014, UNAIDS launched new global targets.
- Known as the three 90's (by 2020, 90% of all people living with HIV will know their HIV status; by 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy (ART); by 2020, 90% of all people receiving ART will have viral suppression)
- Same target 95/95/95 by 2025
- Aim is to ending AIDS as a public health threat by 2030. These three overarching goals include:
  - (1). Reduce new HIV infections by 90% from 2010 and a continued 5% decline per year after 2030.
  - (2). Reduce AIDS-related deaths by 90% from 2010.
  - (3). Secure the sustainability of the HIV response through 2030 and beyond.

How does the UK produce it’s HIV data?

How does the UK produce it's HIV data?

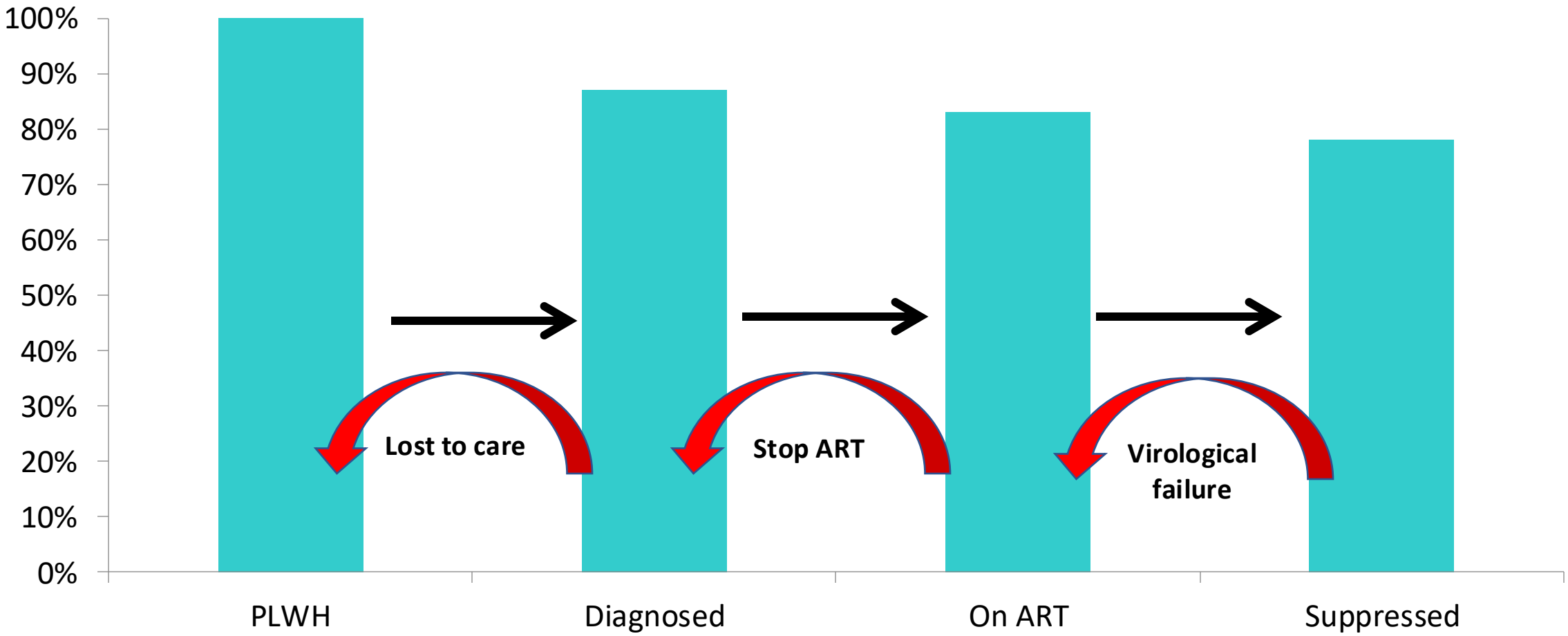
- **HARS: HIV and AIDS reporting system**
- This system collects quarterly, attendance-based data on HIV outpatient care in NHS-funded clinics in England
- UKHSA - All collected data is consolidated and de-duplicated, resulting in a definitive dataset produced annually that includes all HIV diagnoses in the UK.
- The UK Health Security Agency (UKHSA) publishes annual reports and data tables on HIV, including information on new diagnoses, people in care, testing, and other relevant data.

HIV in the UK: A success story



HIV Action Plan monitoring and evaluation framework 2023 report
Progress towards the UNAIDS 95-95-95, England
Updated 28 November 2024

Moving backwards through the treatment cascade

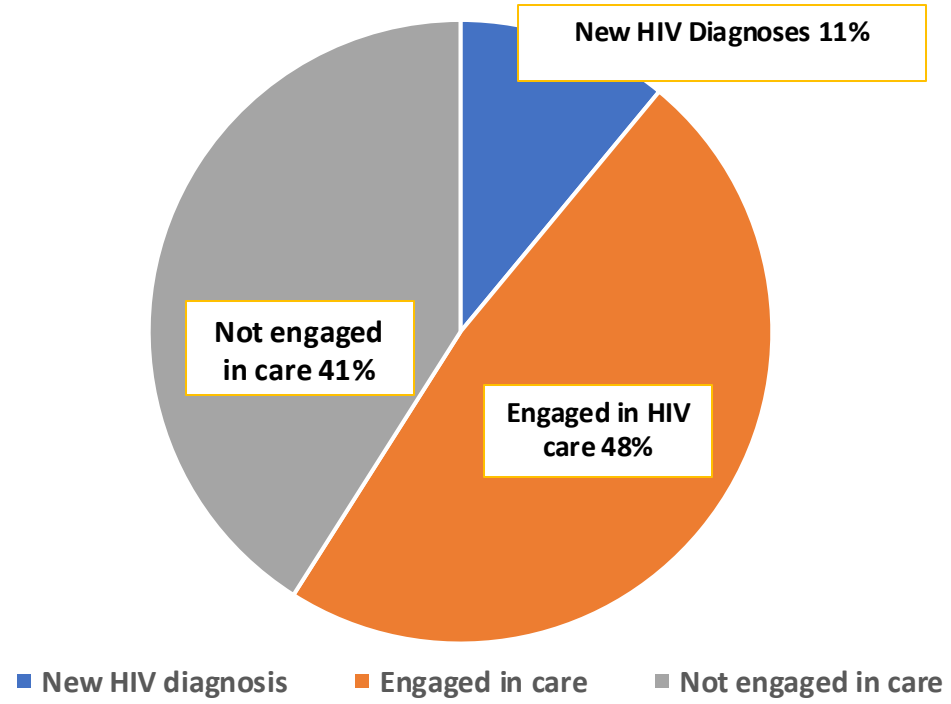


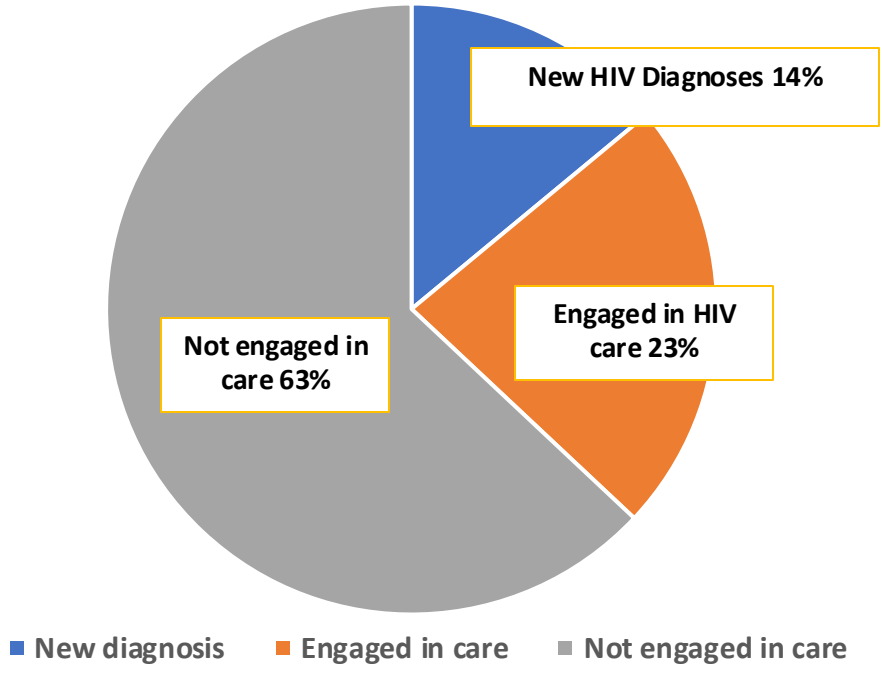
Jose et al 2018 Lancet ID A continuum of HIV care describing mortality and loss to follow-up- a longitudinal cohort study

Human cost of not being in care: Cases known to us personally

- 36 year old woman, out of care 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, out of care 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, out of care 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.

NHS: Amongst PLWH hospitalised with HIV related illnesses at KCH and GSST, the proportion of those not in care is higher than the proportion of new diagnoses





Guy's and St Thomas' NHS Foundation Trust

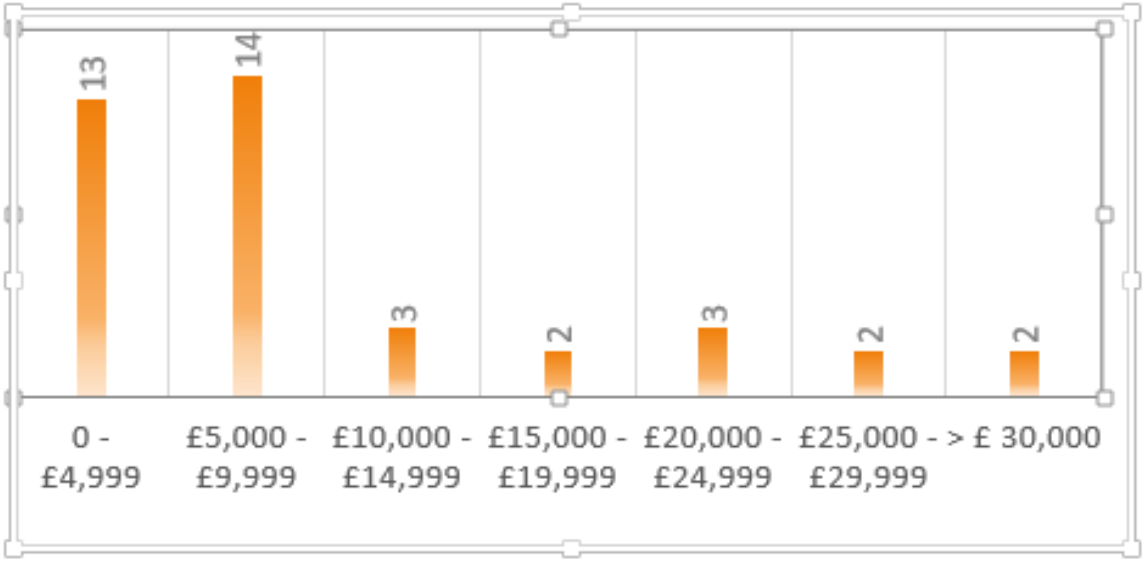
King's College Hospital NHS Foundation Trust

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

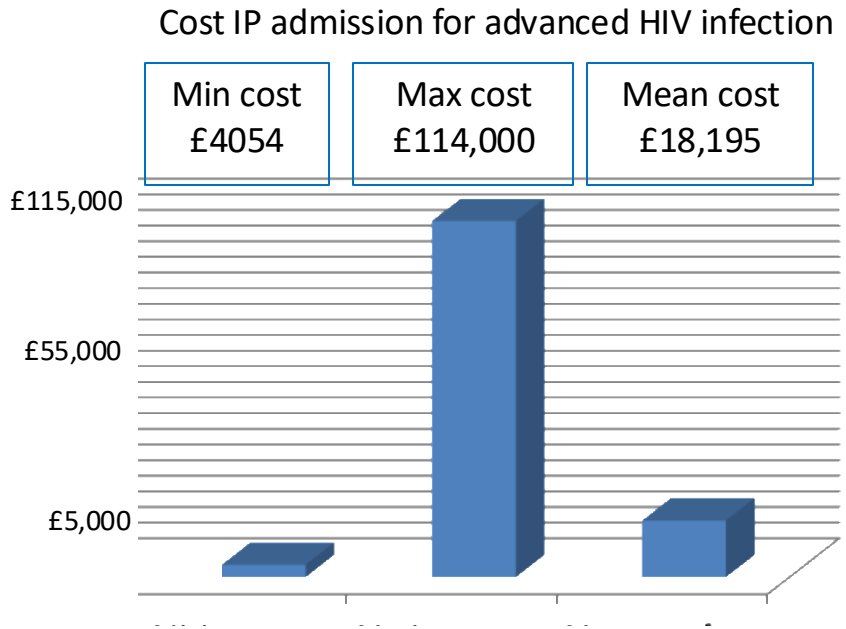
COST OF HOSPITAL ADMISSION FOR PATIENTS NOT ENGAGED IN HIV CARE

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

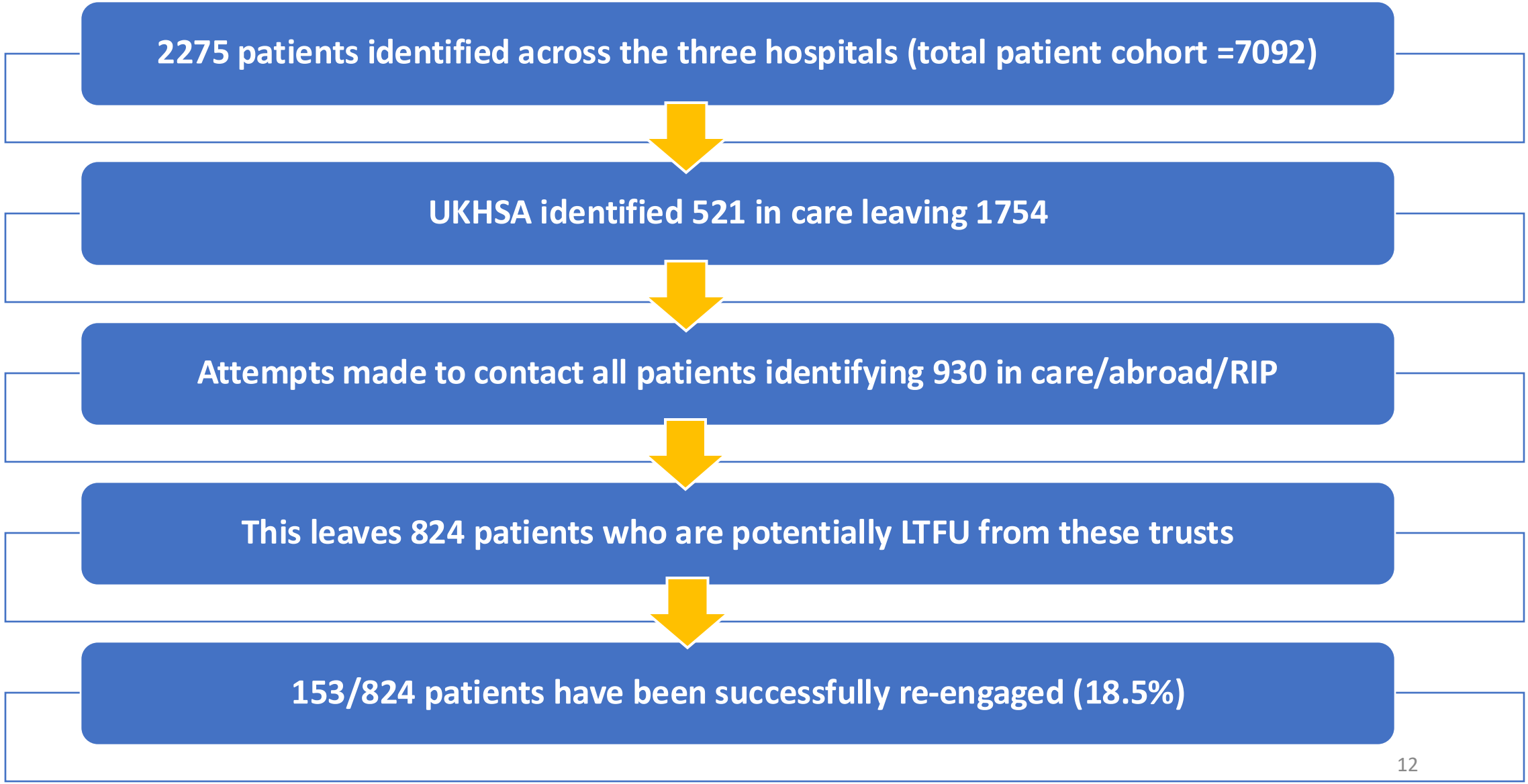


Guy's and St Thomas' NHS Foundation Trust

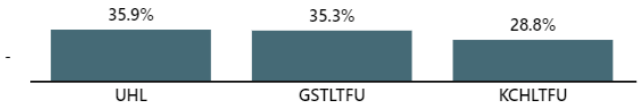
‘Lost to Follow up’ (LTFU) work in Lambeth, Southwark and Lewisham (LSL)

- On behalf of Dr Hannah Alexander, Dr Goli Haidari GSTT and Dr Mel Rosenvinge UHL. This project was conducted at Guys, King’s and Lewisham and ran from July 2020-Dec 2021.
- Targeted at people living with HIV who are not in care.
- SE London has the highest prevalence of HIV in the UK. Lambeth, Southwark and Lewisham are diverse boroughs with high levels of deprivation
- This project was funded by the Elton John AIDS Foundation (EJAF) and aimed to reengage patients in care.

824 patients were potentially LTFU across 3 sites



LTFU Outcome demographics



Outcomes (%)

153 (100.0%)

Re-engagaged	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

	LTFU Outcomes	% of LTFU payment outc...
Female	87.0	56.9%
Male	66.0	43.1%

57% female

Outcomes by Ethnic group

	LTFU Outc...	% of LTFU ...
Black African & Black Caribbean & Black other	109.0	71.2%
White & White other	30.0	19.6%
Other	11.0	7.2%
Asian	3.0	2.0%

71% Black African/Caribbean

Outcomes by Age group

	LTFU Outcomes	% of LTFU payment outco...
35 - 49	76.0	49.7%
50 - 64	57.0	37.3%
25 - 34	18.0	11.8%
15 - 24	1.0	0.7%
65 and over	1.0	0.7%

Outcomes by CD4 range

	LTFU Outcomes	% of LTFU payment outc...
<=350	82.0	53.6%
500+	40.0	26.1%
350-500	31.0	20.3%

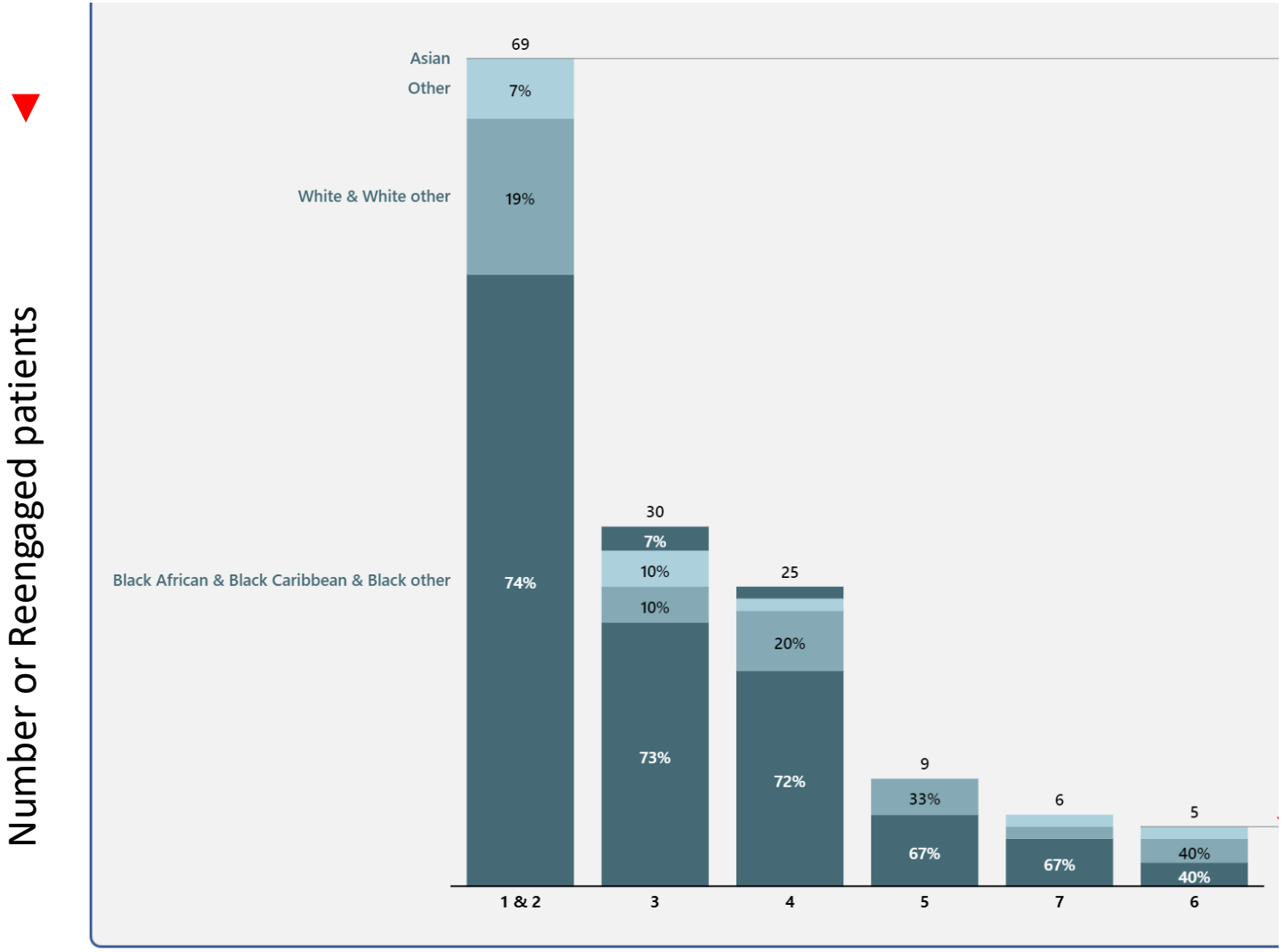
Outcomes by Exposure category

	LTFU Outcomes	% of LTFU payment ...
Heterosexual contact	109.0	71.2%
Sex between men	33.0	21.6%
Injecting drug use	4.0	2.6%
Mother to child transmissior	4.0	2.6%
MSM and PWID	2.0	1.3%
Undetermined	1.0	0.7%

Outcomes by Borough

	LTFU Outcomes	% of LTFU payment ...
Lewisham	42.0	27.5%
Lambeth	33.0	21.6%
Southwark	32.0	20.9%
Greenwich	10.0	6.5%
Bromley	7.0	4.6%
Outside London	7.0	4.6%
Croydon	6.0	3.9%
Wandsworth	3.0	2.0%
Barking and Dagenhan	2.0	1.3%
Harrow	2.0	1.3%
Others	9.0	5.9%

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



In SE London, this issue disproportionately affects women of black ethnicity from areas of social deprivation.

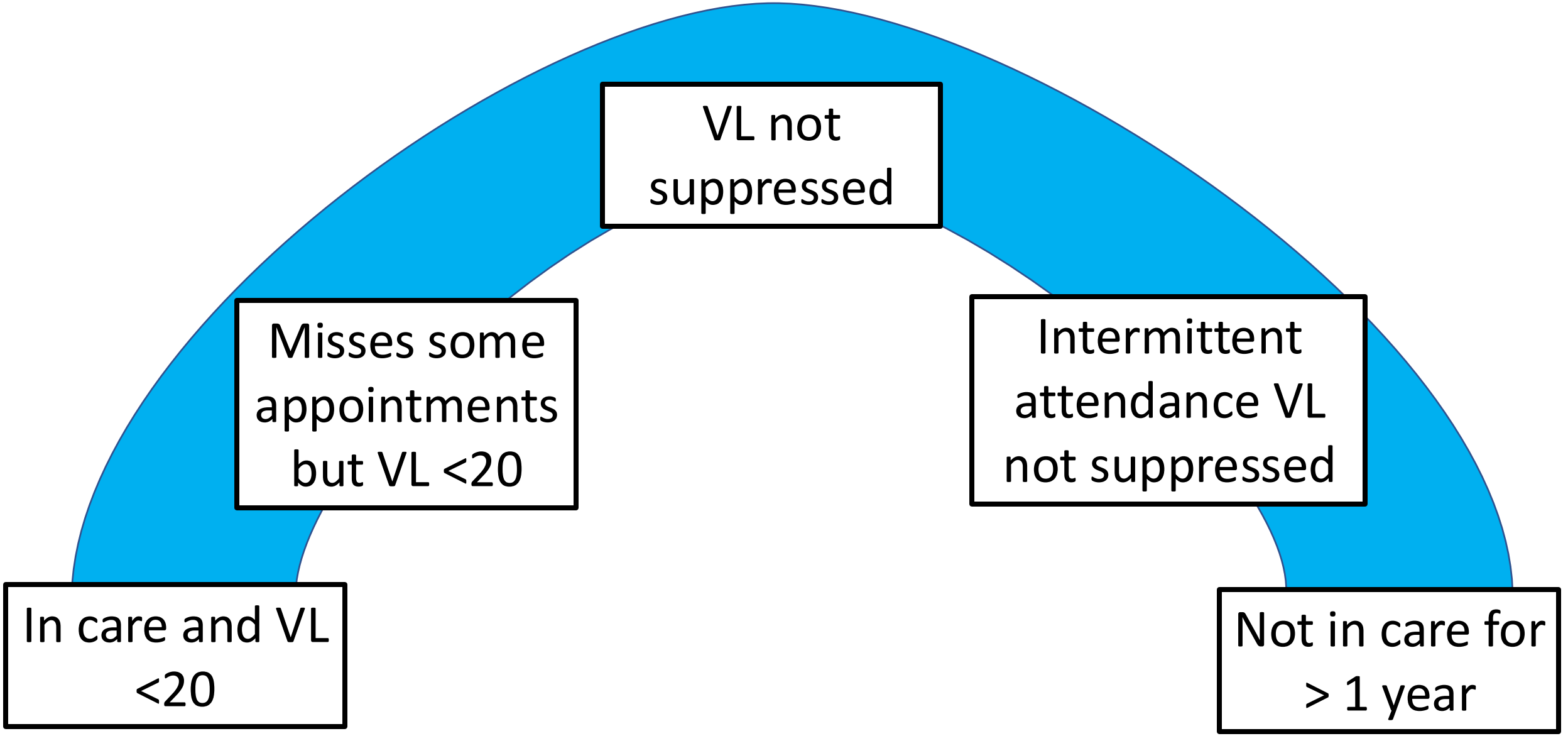
As such it represents a significant health inequality.

EJAF funding Jan 2020-Jan 2021
SEL ICB funding 2021-2025

NHS
South London
Office of
Specialised Services

The project costs SEL ICB 170k per year

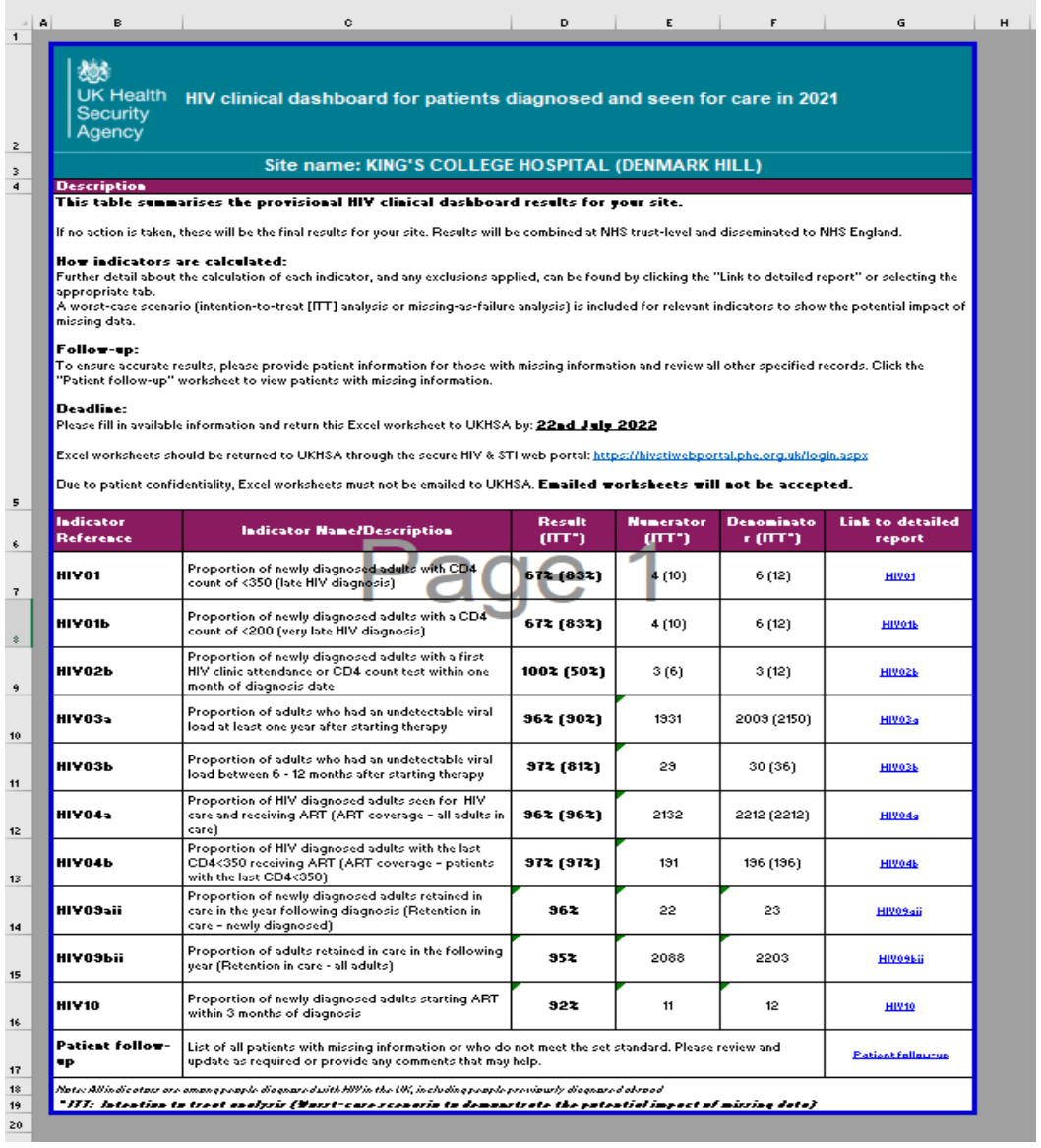
- Each of the three trusts in SEL receives ~56k per year of the project
- Each trust has a reengagement team made up of 4 hours of consultant time and a portion of a CNS role
- Each trust devotes some budget to consumables such as bus passes & vouchers to support re-engagement



The spectrum of engagement and retention in HIV care

UKHSA dashboard is the starting point for reengagement work.

- UKHSA send every clinic their HIV dashboard every year.
- New from 2022 you sent us all a list of patients last seen at our clinics but not seen for > 1 year
- To identify who is truly out of care and who is not
- You have done the cross referencing so patients on this list have not been seen at another UK clinics



UK Health Security Agency

HIV clinical dashboard for patients diagnosed and seen for care in 2021

Site name: KING'S COLLEGE HOSPITAL (DENMARK HILL)

Description

This table summarises the provisional HIV clinical dashboard results for your site.

If no action is taken, these will be the final results for your site. Results will be combined at NHS trust-level and disseminated to NHS England.

How indicators are calculated:
Further detail about the calculation of each indicator, and any exclusions applied, can be found by clicking the "Link to detailed report" or selecting the appropriate tab.
A worst-case scenario (intention-to-treat [ITT] analysis or missing-as-failure analysis) is included for relevant indicators to show the potential impact of missing data.

Follow-up:
To ensure accurate results, please provide patient information for those with missing information and review all other specified records. Click the "Patient follow-up" worksheet to view patients with missing information.

Deadline:
Please fill in available information and return this Excel worksheet to UKHSA by: **22nd July 2022**

Excel worksheets should be returned to UKHSA through the secure HIV & STI web portal: https://hivstiwebportal.phe.org.uk/login.aspx

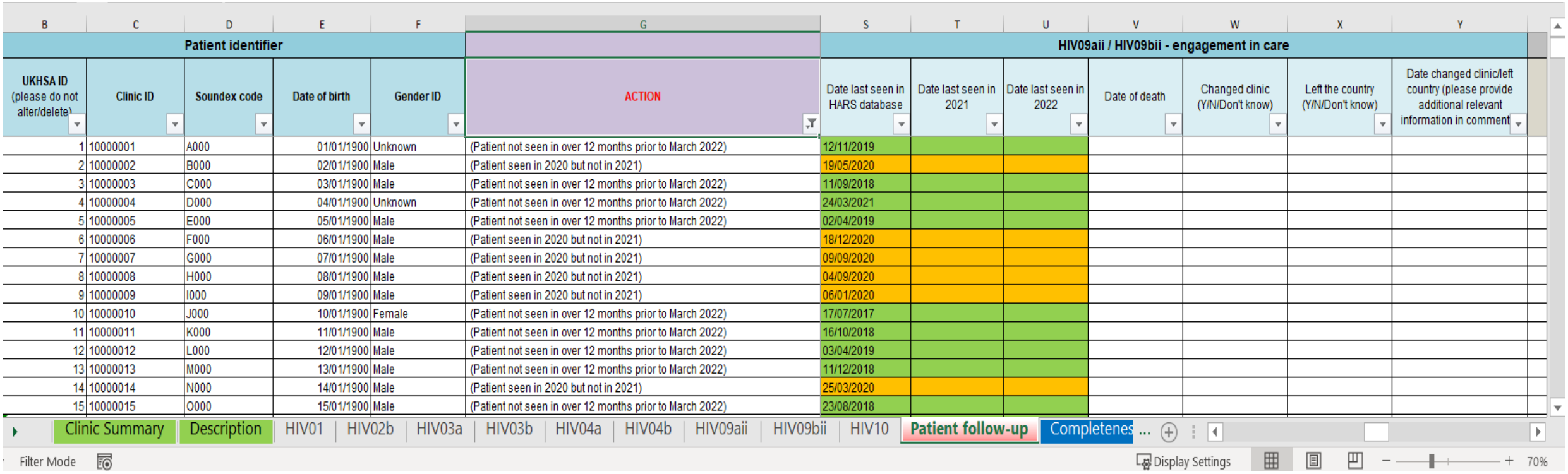
Due to patient confidentiality, Excel worksheets must not be emailed to UKHSA. **Emailed worksheets will not be accepted.**

Indicator Reference	Indicator Name/Description	Result (ITT*)	Numerator (ITT*)	Denominator (ITT*)	Link to detailed report
HIV01	Proportion of newly diagnosed adults with CD4 count of <350 (late HIV diagnosis)	67% (83%)	4 (10)	6 (12)	HIV01
HIV01b	Proportion of newly diagnosed adults with a CD4 count of <200 (very late HIV diagnosis)	67% (83%)	4 (10)	6 (12)	HIV01b
HIV02b	Proportion of newly diagnosed adults with a first HIV clinic attendance or CD4 count test within one month of diagnosis date	100% (50%)	3 (6)	3 (12)	HIV02b
HIV03a	Proportion of adults who had an undetectable viral load at least one year after starting therapy	96% (90%)	1931	2009 (2150)	HIV03a
HIV03b	Proportion of adults who had an undetectable viral load between 6 - 12 months after starting therapy	97% (81%)	29	30 (36)	HIV03b
HIV04a	Proportion of HIV diagnosed adults seen for HIV care and receiving ART (ART coverage - all adults in care)	96% (96%)	2132	2212 (2212)	HIV04a
HIV04b	Proportion of HIV diagnosed adults with the last CD4<350 receiving ART (ART coverage - patients with the last CD4<350)	97% (97%)	191	196 (196)	HIV04b
HIV09aii	Proportion of newly diagnosed adults retained in care in the year following diagnosis (Retention in care - newly diagnosed)	96%	22	23	HIV09aii
HIV09bii	Proportion of adults retained in care in the following year (Retention in care - all adults)	95%	2088	2203	HIV09bii
HIV10	Proportion of newly diagnosed adults starting ART within 3 months of diagnosis	92%	11	12	HIV10
Patient follow-up	List of all patients with missing information or who do not meet the set standard. Please review and update as required or provide any comments that may help.				Patient follow-up

Note: All indicators are among people diagnosed with HIV in the UK, including people previously diagnosed abroad
"ITT: Intention to treat analysis (Worst-case scenario to demonstrate the potential impact of missing data)

Page 1

Patient follow up sheet – please ensure it gets to the right person.



	B	C	D	E	F	G	S	T	U	V	W	X	Y
	Patient identifier						HIV09aii / HIV09bii - engagement in care						
	UKHSA ID (please do not alter/delete)	Clinic ID	Soundex code	Date of birth	Gender ID	ACTION	Date last seen in HARS database	Date last seen in 2021	Date last seen in 2022	Date of death	Changed clinic (Y/N/Don't know)	Left the country (Y/N/Don't know)	Date changed clinic/left country (please provide additional relevant information in comment
1	10000001	A000	01/01/1900	Unknown	(Patient not seen in over 12 months prior to March 2022)	12/11/2019						
2	10000002	B000	02/01/1900	Male	(Patient seen in 2020 but not in 2021)	19/05/2020						
3	10000003	C000	03/01/1900	Male	(Patient not seen in over 12 months prior to March 2022)	11/09/2018						
4	10000004	D000	04/01/1900	Unknown	(Patient not seen in over 12 months prior to March 2022)	24/03/2021						
5	10000005	E000	05/01/1900	Male	(Patient not seen in over 12 months prior to March 2022)	02/04/2019						
6	10000006	F000	06/01/1900	Male	(Patient seen in 2020 but not in 2021)	18/12/2020						
7	10000007	G000	07/01/1900	Male	(Patient seen in 2020 but not in 2021)	09/09/2020						
8	10000008	H000	08/01/1900	Male	(Patient seen in 2020 but not in 2021)	04/09/2020						
9	10000009	I000	09/01/1900	Male	(Patient seen in 2020 but not in 2021)	06/01/2020						
10	10000010	J000	10/01/1900	Female	(Patient not seen in over 12 months prior to March 2022)	17/07/2017						
11	10000011	K000	11/01/1900	Male	(Patient not seen in over 12 months prior to March 2022)	16/10/2018						
12	10000012	L000	12/01/1900	Male	(Patient not seen in over 12 months prior to March 2022)	03/04/2019						
13	10000013	M000	13/01/1900	Male	(Patient not seen in over 12 months prior to March 2022)	11/12/2018						
14	10000014	N000	14/01/1900	Male	(Patient seen in 2020 but not in 2021)	25/03/2020						
15	10000015	O000	15/01/1900	Male	(Patient not seen in over 12 months prior to March 2022)	23/08/2018						

Clinic Summary | Description | HIV01 | HIV02b | HIV03a | HIV03b | HIV04a | HIV04b | HIV09aii | HIV09bii | HIV10 | Patient follow-up | Completenes ...

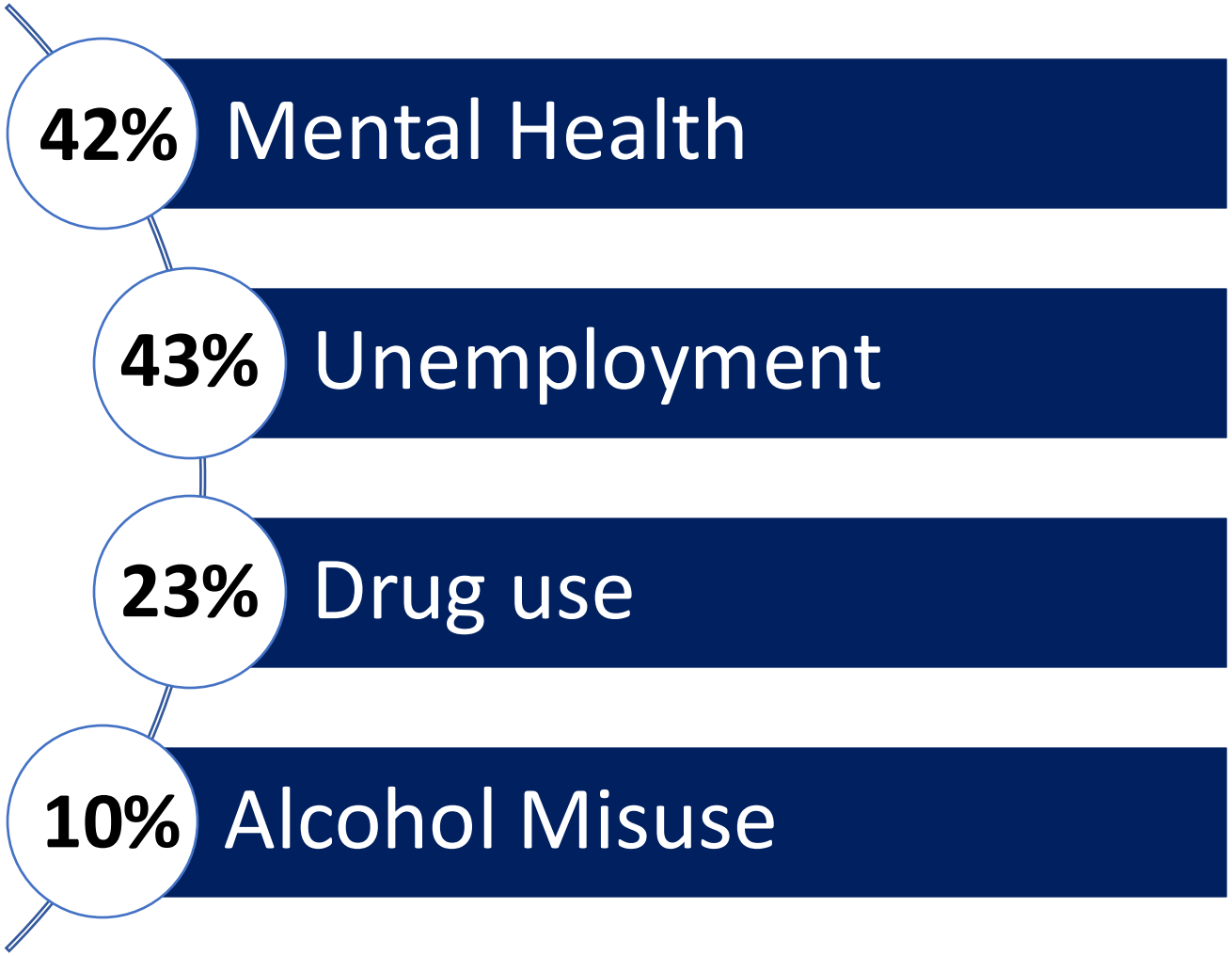
Filter Mode | Display Settings | 70%

Numbers of patients reengaged in SE London

- 2000- March 2021 EJAF funded first year of the project. Across SE London we reengaged 153 patients
- 22/23 96 PLWH reengaged
- 23/24 101 PLWH reengaged

- So grand total 350 PLWH from 2020 till end March 2024.

Barriers to non-engagement



The re-engaged cohort are experiencing a range of barriers to engagement into care, with **high proportions of competing social and economic needs.**

These findings underscore the critical challenges in re-engaging patients with HIV in care.

Removing barriers to attendance

- Appointments at venues outside the traditional clinic setting and at flexible times.
- Dedicated smart phone.
- Supermarket and travel vouchers.
- Liaise with support workers – mental health/social work/drug and alcohol support
- Case management approach
- Helping patients transfer to new centres near where they live.

Out of care risk factors: validation of REACH study

Evidence base: the REACH study 2017

The REACH study developed an algorithm to assess which individuals are most likely to disengage.

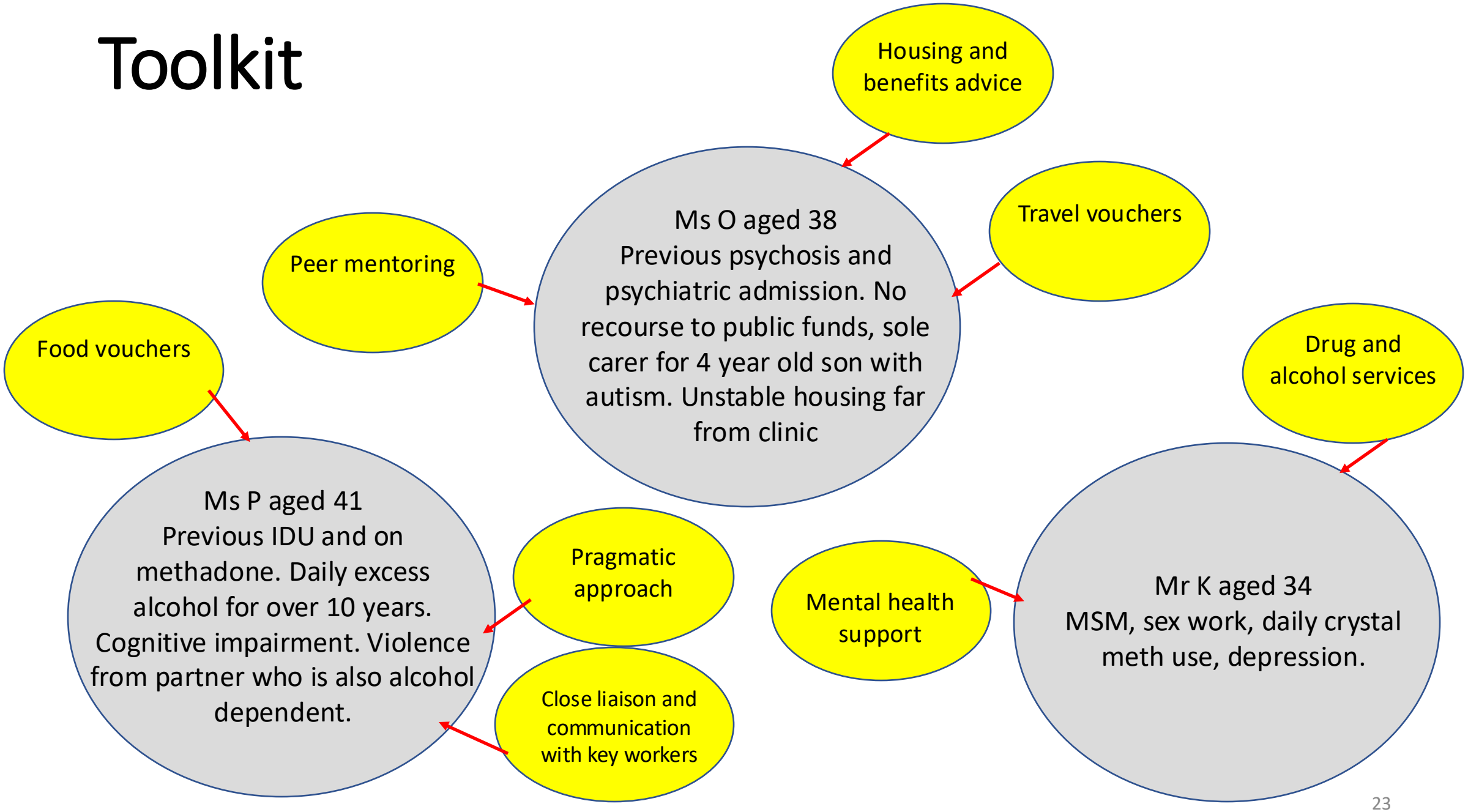
Key features that they identified are:

- Drug + alcohol misuse
- Insufficient money for basic needs and use of public transport to get to clinic (poverty)
- Stigma
- Younger age at diagnosis
- Having children

Our findings: common themes

- Drug + alcohol misuse
- Mental Health
- Poverty
- (Sole) responsibility for children
- Housing and immigration uncertainty
- Stigma/fear of discovery
- Pill/medication fatigue
- Discouraging partners
- Never been unwell

Toolkit


Housing and benefits advice
Peer mentoring
Ms O aged 38
Previous psychosis and psychiatric admission. No recourse to public funds, sole carer for 4 year old son with autism. Unstable housing far from clinic
Travel vouchers
Food vouchers
Drug and alcohol services
Ms P aged 41
Previous IDU and on methadone. Daily excess alcohol for over 10 years. Cognitive impairment. Violence from partner who is also alcohol dependent.
Pragmatic approach
Mental health support
Mr K aged 34
MSM, sex work, daily crystal meth use, depression.
Close liaison and communication with key workers

This project embodies the vision laid out by SE London ICS

Our vision for future health and care

1 Health and wellbeing

Reduces illness and hospitalization

2 Convenient and responsive care

Flexible appointment time and location

3 Whole-person care

Address mental health, social factors, stigma, co-morbidities

4 Reducing health inequalities

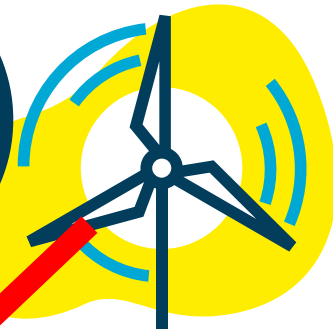
Non-engagement in HIV *is* a health inequality

5 Partnership with our staff and communities

Our community has the highest prevalence of HIV in the UK

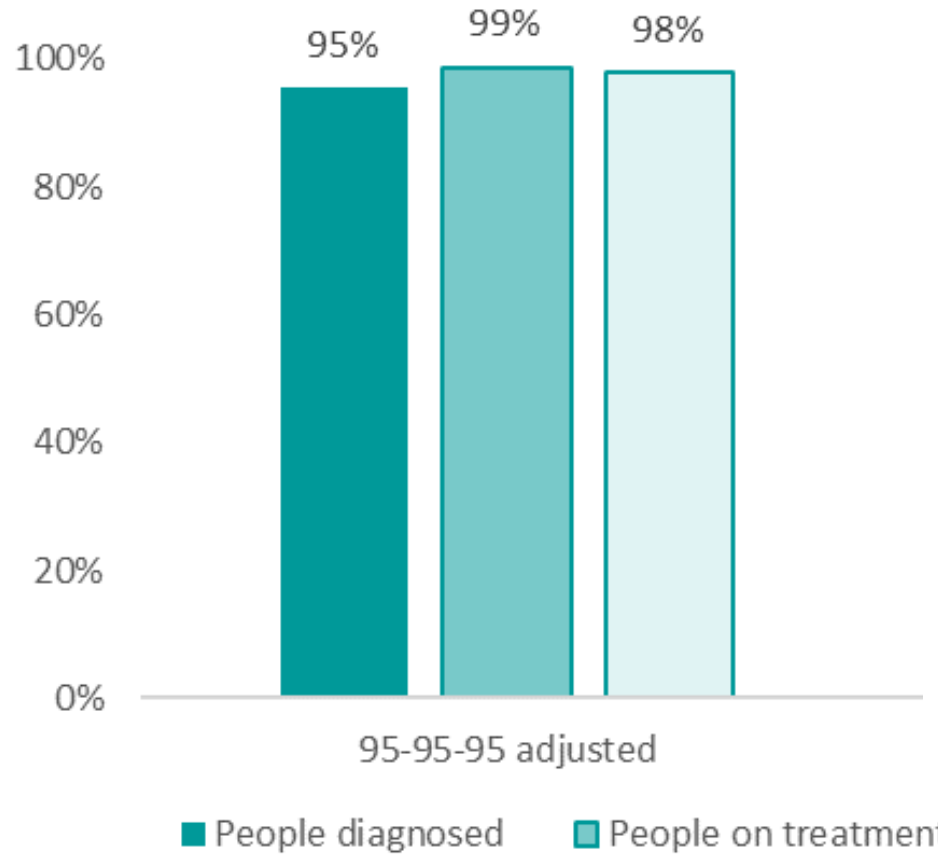
6 Protecting our finances and the environment

Inpatient HIV care is lengthy and very costly



Is this just a SE London problem? How big is the problem?

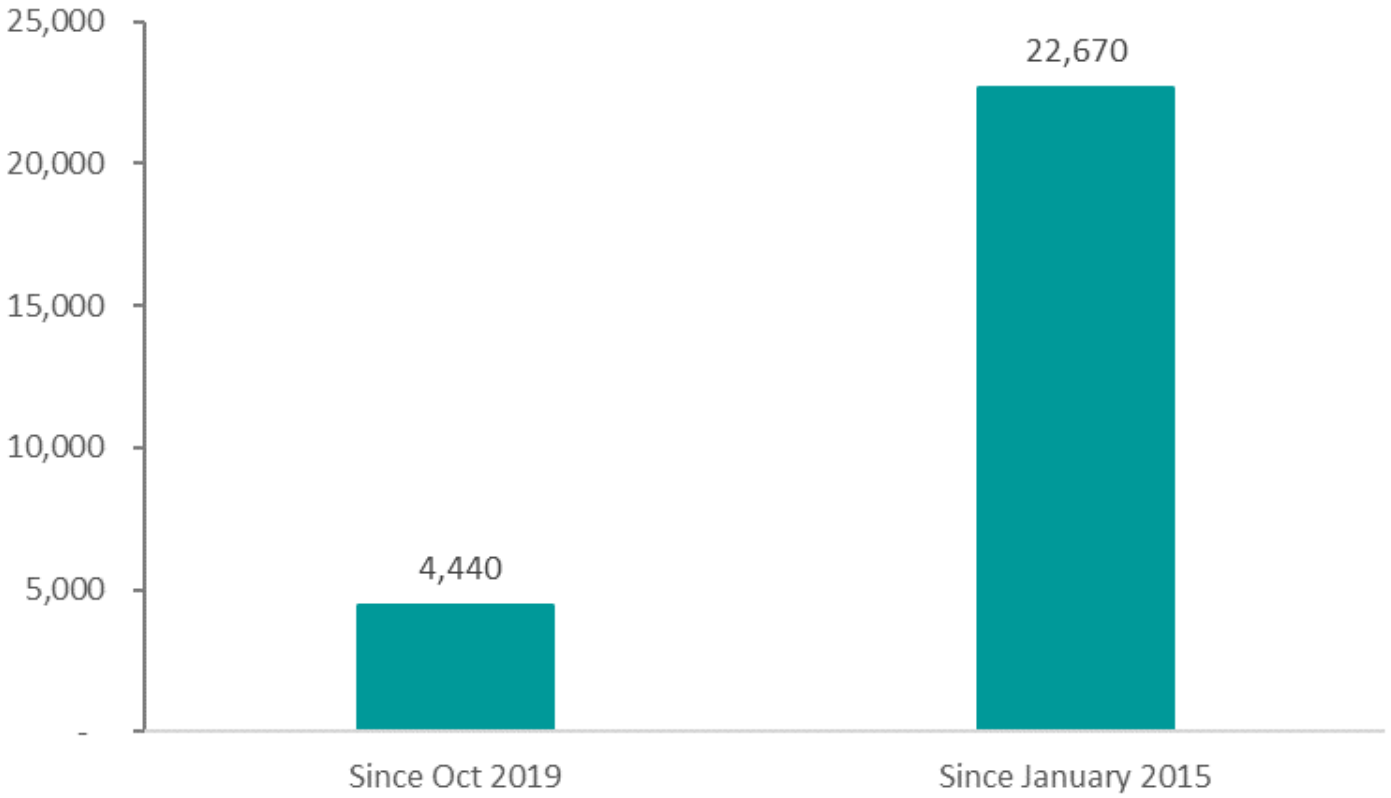
Continuum of HIV care: England, 2021.



- Dr Veronique Martin UKHSA data 2022
- The annual cascade of care is a snapshot
- The 2021 data shows patients who attended in 2020 but not 2021 – this group are ‘out of care’.
- But what about patients who defaulted from care in 2016 for example?
- Numbers of patients out of care have been underestimated

Source: UKHSA HARS dataset – 19 Oct 2022

People not retained in HIV care (not seen for 15 months): England, 2021



Patients seen in 2019 and not in 2020

Patients last seen in 2015 - 2019 and not since

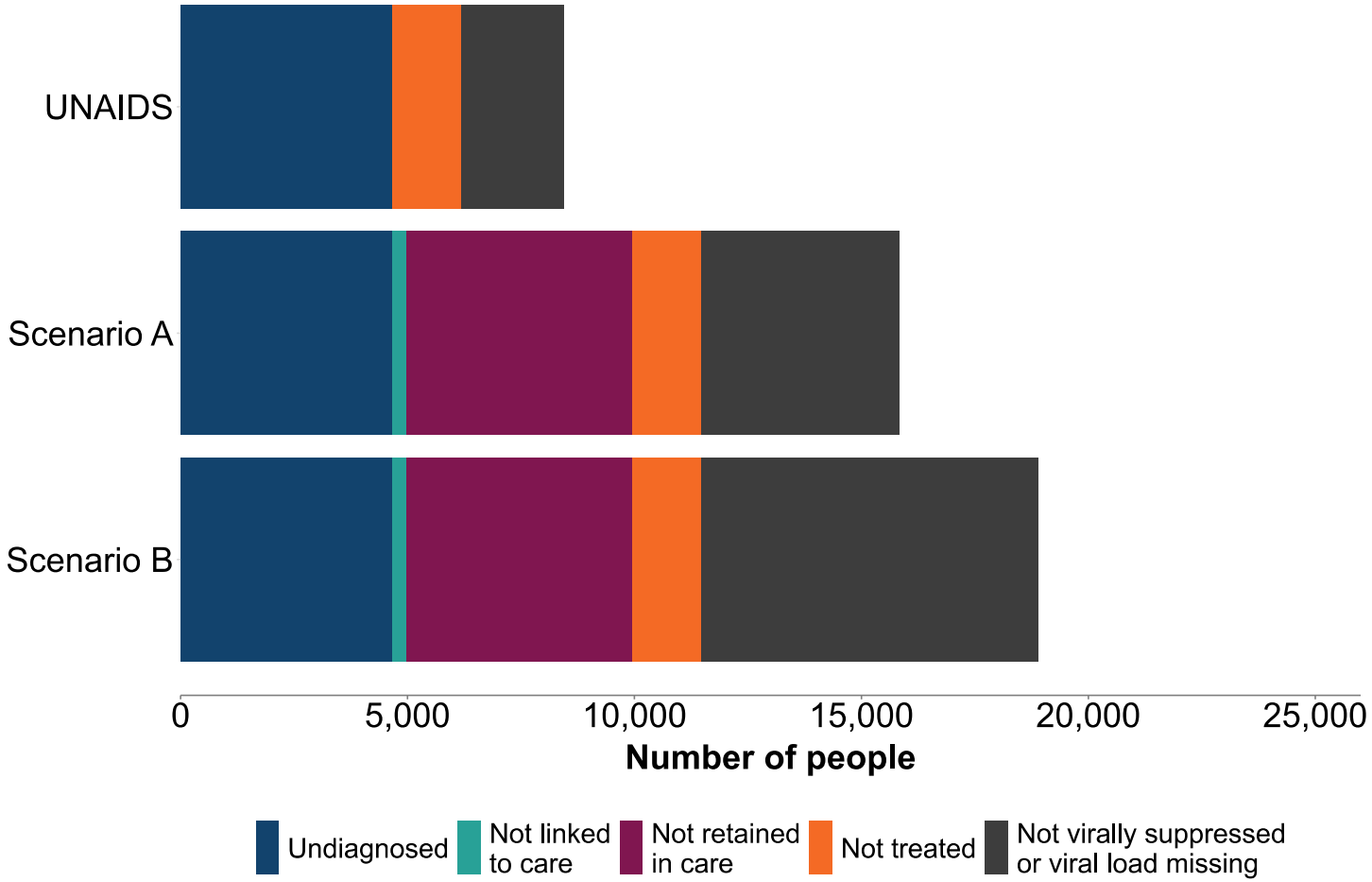
Source: UKHSA HARS dataset – 19 Oct 2022

HIV Action Plan monitoring and evaluation framework 2024 report - GOV.

- An estimated 104,000 (95% credible interval (CrI) 102,700 to 105,800) adults are living with HIV in England in 2023
- An estimated 4,700 (95% CrI 3,700 to 6,300) of adults living with HIV were undiagnosed in 2023
- The UNAIDS 95-95-95 targets were met in England in 2023, with 95% of all those with HIV being diagnosed, 98% of those diagnosed receiving treatment, and 98% of those treated being virally suppressed and thus unable to pass on the virus – also expressed as 95%-98%-98%
- When missing data and information for those not in care are taken into account, the UNAIDS 95-95-95 estimates for 2023 range from 96%-94%-96% to 96%-94%-92%
- Between 5,000 and 12,000 people were not retained in care in 2023 if we consider people who attended in the previous year or the previous 5 years respectively

HIV Action Plan monitoring and evaluation framework 2024 report - GOV.

Figure 21. Estimates for the number of adults living with transmissible levels of virus, England, 2023



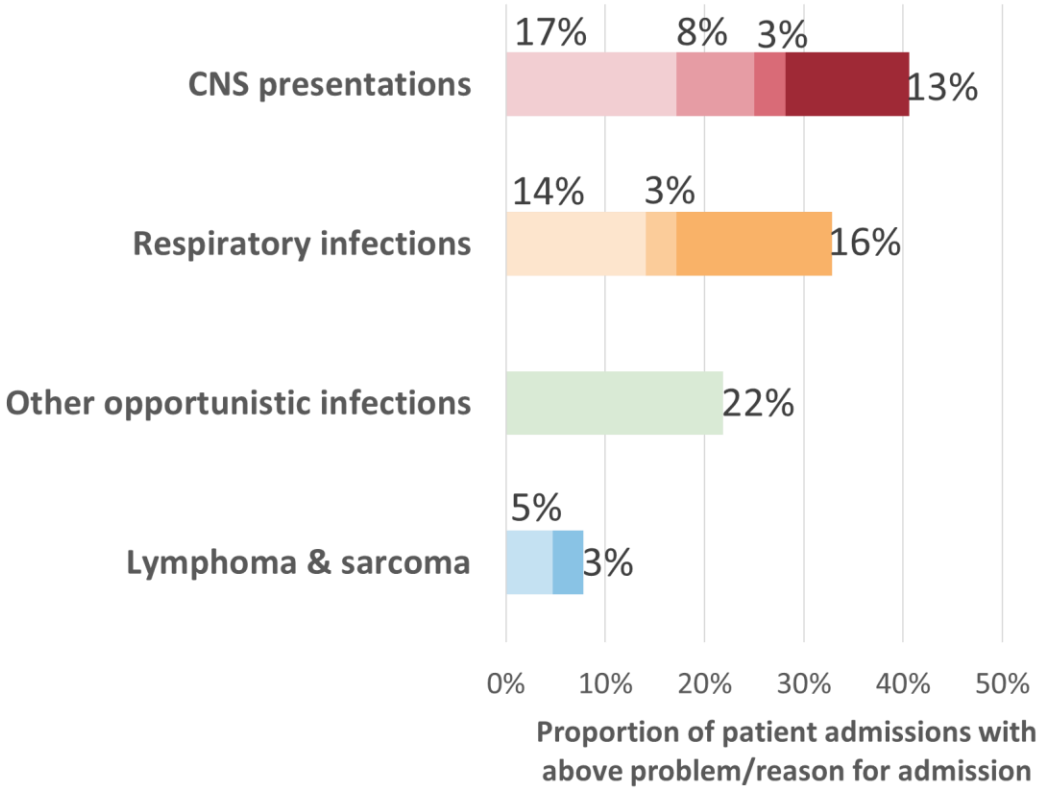
HIV Action Plan monitoring and evaluation framework 2024 report - GOV.
Appendix 2 Indicators for Theme 3: reduce the number of people living with transmissible levels of virus

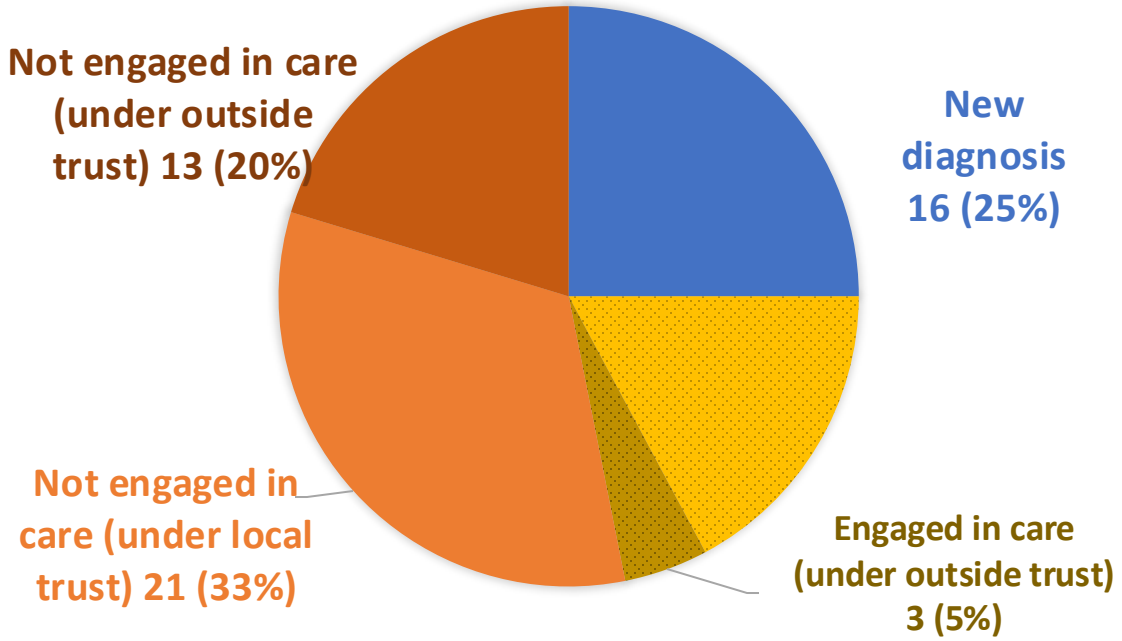
	2019	2020	2021	2022	2023
Number (and proportion) of adults treated who are not virally suppressed (viral load over 200 copies per mL)	2,095 (2.6%)	1,906 (2.6%)	1,798 (2.2%)	1,991 (2.3%)	2,139 (2.3%)
Number (and proportion) of adults not attending care for at least 15 months ('not retained in HIV care')	4,732 (5.5%)	6,670 (7.5%)	6,608 (7.4%)	4,974 (5.5%)	4,960 (5.3%)

BHIVA audit 2023: Engagement in HIV care and impact on HIV inpatient admissions

- To understand the circumstances resulting in hospital admission for people living with HIV, focused on whether this was because they were undiagnosed or had disengaged from HIV care
- Case-note review of the last 20 admissions, in a 12-month period, in which the HIV team had active input into some aspect of clinical management
- 975 admissions.
- **60% of admissions were either a new diagnosis (22%) or someone with sub-optimal engagement (38%)**
- Level of engagement on admission
  - Unknown 2%
  - Not attended for >12 months 17%
  - Missed 1 or more appts, in 12 months 21%
  - Attending regularly 37%
  - New diagnosis 22%

Kings Inpatients admissions June 2023- June 2024
Dr Gerald Gan, Dr Tamzin Hull





Transmissions: anecdotal only

- 1) 50yr old man, never engaged, often in prison. His RFP of whom we were unaware did a home test.
- 2) 65yr old Jamaican woman, fluctuating psychosis, on and off ART, new 82 yrs old male partner – we were unaware.
- 3) 42yr old man, history of drug use, mental health but was out of care until 18 months ago mainly due to bereavement. His RFP diagnosed same time he reengaged.
- 4) GSTT transmission
- 5) UHL transmission – patient from overseas who did not engage in care on arrival in UK

Action taken so far

- Ongoing funding for ED testing
- Funding – reengagement work has been funded by the ICS in SE London since Jan 2022
- Data – UKHSA are sending everyone a list of all pts not seen in > 1 year from their service, lack of awareness of this amongst clinicians.
- ‘LTFU’ day in SE London Nov 2022, attended by 100 attendees from clinics, policy makers, third sector
- HIV-AP ISG have set up a task and finish group on PLWH not in care.
- BHIVA audit is on patients admitted with HIV related illnesses and whether they are in care or not.
- New BHIVA guidelines are being written

HIV in 2024: a tale of two outcomes

Antiretroviral therapy

Suppressed HIV virus

Strong immune system (High CD4)

Normal life expectancy

Work, have relationships and children, do not transmit infection

Not in care, no treatment

Inevitable increase of HIV viral load and decline in CD4 count

Onward transmission

AIDS related infection and cancers

Hospitalization and death

Reengagement work is transferable across disciplines: relevant for all long term conditions eg diabetes and for mental health care

Traditional model of secondary care
Fixed appointments and locations
Treat all patients the same
Discharge patients who do not attend

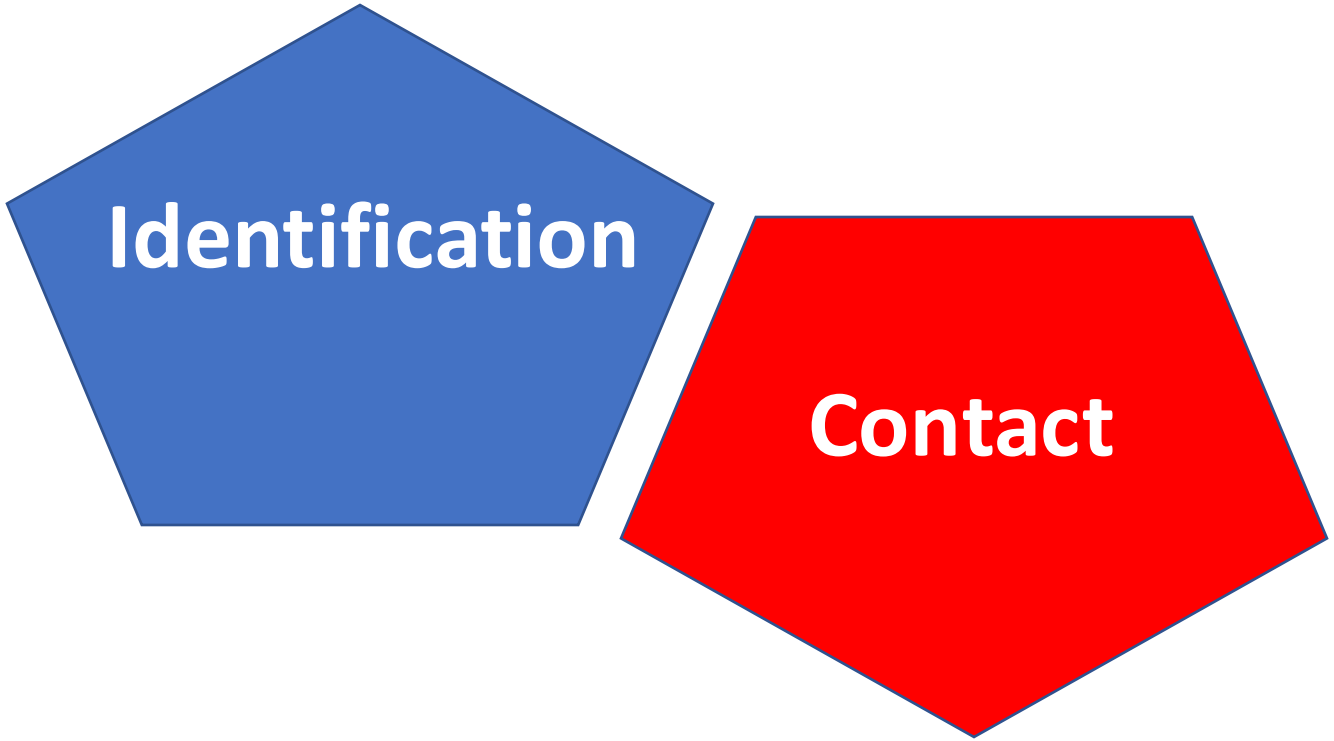
- Disengagement from care and treatment
- Poor outcomes
- Disadvantages those who cannot navigate the system
- Fuels health inequalities

Reengagement model of secondary care
Flexible appointments and locations
Individualised approach for varying needs
Consistent contact with patients who DNA

- Engagement with care and treatment
- Improved health and patient reported outcomes
- Removes barriers to care
- More equitable

Themes for key elements of reengagement work

- Rapport
- Relationships – between organisations
- Persistence
- Case management
- Individualised approach: prioritise the patients' needs



Kings College Hospital: Caldecot centre

- We have pivoted to priorotise the patients most in need
- Streamlined the process for very stable patients, annual review, annual bloods, phone appointments and home delivery
- Clinic priority is patients in need
  - Do not turn away
  - Flex clinic
  - Reengagement team
  - Weekly reengagement clinic
  - Monthly vulnerable patients MDT
  - Individualised plans

HO aged 47

- Nigerian lady, three children, married works as health care assistant
- 1) HIV diagnosed 2011, poor adherence and periods put of care. EJAF reengagement in 2021
- 2) Significant proteinuria UPCR 143 = 1.4g/day --> 32.7 on ART - likely HIVAN with good biochemical response
- 3) hypertension-
- 3) housing
- 4) husband not tested - but aware
- 5) Sinus problems, has seen ENT and told will have surgery
- 6) Migraines
- 7) Hyperparathyroidism
-
- Symtuza
- amlodipine
- Vitamin D/calcium

- Referred for housing support
- Referred to renal doctors
- Referred to ENT, had ENT surgery
- Call when misses appointments, usually loking after kids or at work

MG aged 22

- Vertical transmission, PCP aged 3/12
- In care as a child and had lots of side effects from ART
- Parents both unkeen on treatment for a while and mother suffered serious health problems asa consequence
- Both parents now under my care
- I met him in 2022, at that point his CD4 was 220, not on treatment.
- Went to uni, very well, very sporty
- Sustained attempt to reengage him for past 3 years

Wed 4th June

- Finally attended on same day as parents
- Feels very well, looks well, no symptoms
- Long discussion
- CD4 136
- Started treatment

Minimum aim

- All clinics to have a LTFU contact
- All clinics to look at the UKHSA data and revert back
- Flexible and understanding attitude
- Better communication between clinics and community organisations

Nice to have

- Better/formal links with housing/drug and alcohol
- Funded teams of case-workers who will outreach into community to find patients and help them navigate the system
- Better links between primary and secondary care
- ART with methadone prescribing

Ambitious

- Public Health campaign ‘Our door is open’
- Dedicated navigation phone line/website/email
- Functional networks of clinical and third sector organisations
- Outreach into the non-HIV community to try and address stigma

What can the community sector do?

- Aim to reduce stigma and educate the general population
- Provide flexible and intense support to inviduals even if just for a short period of time
- Help people navigate the health care system and housing system – systems generally
- Be someone to talk to
- Go to where clients are

‘Not in Care’ take home messages 1

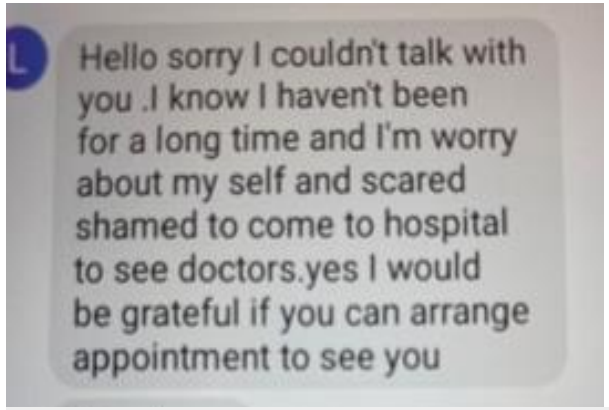
- Patients can go backwards on the cascade of care and fall out of care.
- The number of PLWH not in care outweighs the number who are undiagnosed.
- In SE London, this is driving considerable morbidity and mortality.
- It is expensive for the NHS and society, threatens HIV elimination, achieving UNAIDS targets and may drive transmission.
- This issue disproportionately affects women of black ethnicity from areas of social deprivation. As such it represents a significant health inequality.

‘Not in Care’ take home messages 2

- Thanks to the initial funding from EJAF and subsequent ICB funding, a total of 350 patients have been linked back into care and given the opportunity to restore their health.
- Actions are required to make HIV care easier to access and to create more reengagement projects across London and the UK.
- Re-engagement work is resource intensive but cost saving.
- It is transferrable to many other long term conditions

What do patients say?

...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'.’

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

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.

‘Around us, everyone thinks that HIV is a different sickness to diabetes, bloods pressure, even COVID. People in the community will push you to the side. I was running from the clinic. They were calling, calling me.’

‘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.’

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