ELTON JOHN AIDS FOUNDATION

AN END TO THE AIDS EPIDEMIC

Evidence on HIV Testing and Reengagement from the Elton John AIDS Foundation Zero HIV Social Impact Bond.

Steve Hindle and Jennifer Warner, June 2021.

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The Elton John AIDS Foundation's Zero HIV Social Impact Bond team.

Summary and key recommendations

0. Emergency Department (ED) HIV testing on an opt out basis.

- Our work builds on existing guidance[1][2] to further demonstrate that opt out HIV testing in EDs when blood is drawn is effective, acceptable to patients, and feasible to implement at national scale. We found that it is particularly effective at reaching those Black African, Black Caribbean and Black other, and older people, who are currently not engaged by services where HIV testing occurs.
- Amongst SIB providers the cost per person newly diagnosed in ED testing is currently in the range £5,200 - £6,300, which compares favourably to the £200,000+ cost avoided by linking a person living with HIV into care.
- There is an urgent requirement for those Trusts in high/very high incidence areas who have not yet introduced ED HIV testing to do so, and progress of this roll out should be included in the government's annual HIV report.
- The government should provide an ongoing mechanism for systematic funding of ED HIV testing to ensure sustainability, including initial project management, staff training and virology supplies.
- Expansion into acute medical and surgical units should be urgently explored, as well as outpatient departments.
- Hospital Trust Boards should be required to publish a plan to implement national guidelines on HIV testing[1][2] across their Trust over a three-year period, and the extent of completion and implementation of these plans should be reported in the government's annual HIV report.

1. HIV testing on an opt out basis in primary care.

- Our works builds on existing guidance[1][2] to show that HIV testing in primary care when blood is drawn is effective and acceptable to patients. Methods found to increase effectiveness include incentivising practices, and funding HIV GP Champions in Federations to share best practice.
- The SIB found that cost per person newly diagnosed in primary care is less than £10,000 per person.
- The government should provide a requirement that HIV testing on an opt out basis be introduced at new patient registration, NHS Health checks, and when blood is drawn[1][2]. The implementation of this at ICS level should be part of the government's annual HIV report.

2. HIV testing for specific target groups through community organisations.

- The lived experience that community group staff and volunteers bring to their work means that they can engage community members in HIV testing in a way that other HIV testing channels cannot. These services should be seen as an integral extension of the health system into the community and eligible for funding as they are vital to reaching vulnerable people.
- Contracts for HIV testing services should include funding for the effort required to support people with a reactive test to attend an HIV clinic.
- The SIB found that cost per person newly diagnosed through community care are less than £10,000 per person.

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[1] BHIVA/BASHH/BIA Adult HIV Testing guidelines 2020

[2] Overview | HIV testing: increasing uptake among people who may have undiagnosed HIV | Guidance | NICE

3. **Dedicated reengagement work of people lost to follow up by HIV clinics.**
    - Reengaging people lost to follow up can require sustained focus over many weeks to engage them, and once they are reengaged, they may require more intensive support to ensure that they remain in care.
    - There should be an identified lead for reengagement work in every HIV service[3], who will undertake regular audits of those lost to follow up.
    - The SIB found that current contracts do not consistently reflect the resources required for this work, which might include a funded dedicated consultant session each week, nursing and additional administrative time.
    - The SIB found that the cost per person reengaged through HIV clinic recall work is less than £3,000 per person, though this will vary according to the level of HIV incidence within the area and the number disengaged.

4. **Dedicated reengagement work of people lost to follow up by primary care.**
    - GP Federations should be required to undertake audits of patient records of those people who have disclosed to the practice that they have HIV on at least an annual basis, if not quarterly.
    - Practices should follow up those people who appear to not be in HIV care.
    - The SIB found that the cost per person reengaged in primary care is less than £10,000 per person.

[3] British HIV Association Standards of care for people living with HIV 2018 (bhiva.org)

1. Achieving the UK government target of no new HIV transmission by 2030

There are 6,600 people unaware that they are living with HIV in the UK, and 5,350 people aware of their HIV positive status but not engaging in HIV care (PHE 2020)[4]. Not receiving treatment has damaging effects on individual health and wellbeing outcomes, while also creating costly demand upon health services through admissions for AIDS-defining illnesses and possible onward HIV transmission. Reaching the 2030 target will require a dramatic reduction in the number of people living with HIV who are not on treatment. We know from the EJAF Zero HIV SIB and other initiatives how both to increase HIV testing to find new diagnoses, and how to reengage those who are lost to follow up. Now is the time to roll this out at national scale. This will take time and resources, but this paper will show that the costs to find or reengage one person are less than £10,000, whereas each person living with HIV newly linked or reengaged to care could avoid NHS costs of over £200,000[5].

An opt out approach to HIV testing in areas of high/extremely high HIV incidence is already established good practice (NICE 2016, BHIVA/BASHH/BIA 2020). National roll out of good practice has been inhibited by a lack of dedicated funding, the need to train ED staff and the need to address the stigma that people face if they are diagnosed with HIV. As the number of people unaware of their HIV condition reduces, it will become more difficult and expensive to reach those who need HIV care, but without HIV testing at national scale it will be impossible to reach the 'no new HIV transmissions' 2030 targets.
It may be most practical to focus first on areas of England with higher levels of HIV incidence. The 2019 PHE HIV incidence levels of people aged 15-59 by regional and authority level[6] shows that of the 32,629,321 in England aged 15-59, 12,654,523 live in areas of high (2 to 4.99 per 1,000) or very high (5+ per 1,000) HIV incidence, this is 68 of the 149 Upper Tier Local Authorities. ONS population data for 2019[7] shows there are 46,094,872 people aged 15+ in England. Applying the ratio of 15-59 who live in high or very high areas to the complete adult population implies 17,876,823 people aged 15+ years live in areas of high or very high HIV incidence.

The number of people not in HIV treatment may become bigger than those undiagnosed in the next few years, meaning the higher risk of new transmissions may be more from those who are aware of their diagnosis but not linked to care. PREP may mitigate that for certain groups eg MSM, though it is unclear whether it will be taken up at scale across all groups at potential risk. The BHIVA Standards of Care 2018[8] state that 'HIV services should have mechanisms to identify and follow up people registered with their service, who become disengaged from care, who miss appointments or run low on medication.' Sadly, the pressure on many HIV teams means there is little time for this intensive work, so if people stop treatment, their physical and mental health may deteriorate, their viral load may increases meaning that they may transmit HIV to sexual partners.

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[4] HIV testing trends, new diagnoses and people receiving HIV-related care in UK: data to the end December 2019 (publishing.service.gov.uk)
[5] HIV Commission Report 2020, based on EJAF calculations.
[6] Sexual and Reproductive Health Profiles - PHE
[7] Overview of the UK population - Office for National Statistics (ons.gov.uk)
[8] British HIV Association Standards of care for people living with HIV 2018 (bhiva.org)

2. Aims and implementation approach of the Elton John AIDS Foundation Zero HIV Social impact Bond.

The EJAF Zero HIV Social Impact Bond has produced detailed, costed evidence of the effectiveness of opt out HIV testing, targeted community interventions, and dedicated audit and recall interventions in three London local authorities with very high incidence. The aim of the SIB is to use outcome-based payments to demonstrate the effectiveness and acceptability of interventions in linking people living with HIV to care and influence change in English HIV policy, commissioning, and practice.

Outcome based contracts were agreed with provider organisations to undertake one or more of five interventions:

- HIV testing on an opt out basis in Hospital Emergency Department.
- HIV testing on an opt out basis in GP practices.
- HIV testing for specific target groups through community organisations.
- Dedicated reengagement work of people lost to follow up by HIV clinics.
- Dedicated reengagement work of people lost to follow up by GP practices.

Outcomes are defined as: (1) New patient diagnosed with HIV and engaged into HIV care, and (2) Previously diagnosed patient re-engaged into HIV care.

Our SIB providers report the total HIV tests undertaken and use the PHE HARS dataset to report the demographics of all individuals linked to HIV care on an anonymised basis. These include gender, ethnicity, exposure category, test result (reactive, indeterminate, insufficient), CD4 count, lower super output area (geographical hierarchy in England), case outcome (known positive/new positive/negative/re-engaged/non contactable/disengaged/awaiting outcome). This data can be aggregated to provide profiles to examine impact across different variables.

Service providers state indicative costs to deliver the service as part of the contracting process, though payments are made on outcomes achieved rather than actual costs incurred.

3. HIV testing to find new diagnoses of people living with HIV

The SIB contracted with Kings College Hospital and University Hospital Lewisham to achieve outcomes through ED HIV Testing of either newly diagnosed people living with HIV linked to care or reengagement of people who have had an HIV diagnosis but stopped treatment. We used an outcomes-based payment contract approach. This meant payment was made only when an outcome was identified and enabled the providers to adapt and innovate their service to increase the chances of achieving an outcome.

Process flow of intervention

HIV Consultants who led the set up and current implementation for Kings College Hospital ED HIV testing described the process and time taken *(process flow 1).*

Process flow 1: Process of setting up A&E HIV testing King's College Hospital

1. FUNDING SECURED
   Bid written to EJAF including local prevalence, testing rates, all costings/time/resources required.

2. RECRUITMENT 3 months – marginal recruitment costs plus band 5 nurse costs and allocation of consultant time.
   a. Internal recruitment of band 5 nurse to run service.
   b. Allocation of a named HIV consultant to oversee service.
   c. Allocation of a named A&E consultant to oversee running in A&E.
      i. A&E champions identified within department.
   d. Allocation of named virologist to manage lab aspects.

3. ELECTRONIC PATIENT RECORD SET UP 4 weeks – undertaken within existing resource.
   a. Direct liaison with EPR team to develop an order com to create an automatic alert when requesting bloods in A&E and to print off a sticker with any blood test.
   b. Development of symphony alerts (A&E computer systems) for uncontactable patients
   c. Set up of monthly audit to determine testing rates in A&E (in combination with failsafe list – see below).

4. VIROLOGY 4 weeks – undertaken within existing resource.
   a. Set up linkage of HIV tests with virology via order codes.
   b. Allocate staff member to create and send out weekly failsafe list created via virology computer systems to band 5, to review and contact non-negative results.

5. Standard Operating Procedure (SOP) development - undertaken within existing resource
   a. Protocols including chase up of uncontactable positive/indeterminate tests.
   b. Processes for uncontactable patients including flow diagrams for contact/recorded delivery letters/letter to GP/when to close case.
   c. Processes for informing patients and engaging into care.
   d. Letter templates – to patient, and GP if uncontactable.
   e. Final SOP agreed by local risk and governance group.

f. Precedent in place for opt-out testing so no additional ethical approvals/discussion needed.

6. STAFF TRAINING Monthly sessions (~1 hour/session) for first 6 months – undertaken within existing resource.
    a. Training sessions delivered to A&E staff.

7. PUBLICISE TO PATIENTS - 2 weeks to arrange leaflets/banners.
    a. Patient flyers developed to explain what happening, opt-out nature and how to get results/contact if positive.
    b. Careful to explain though we aim to test all, this is not guaranteed so patients do not presume tested if missed.
    c. Flyers translated into multiple languages, ran through corporate communications, and placed in several locations in A&E.
    d. Later posters developed for every booth and room in A&E.
    e. Also publicised via the A&E website.

8. COMMENCE ED HIV TESTING – HIV tests costing between £4 - 7 a test.

9. AUDIT AND REVIEW – no extra costs involved.
    a. Monthly testing rates.
    b. Monthly meetings set up between band 5 and HIV consultant to discuss uncontactable cases.
    c. Survey monkey to address barriers to testing in A&E.

L Mulka & K Quinn 18.05.2021

The above process flow can be used as a blueprint for other hospitals to adapt as necessary as they introduce ED HIV testing.

The most important principle in setting up a new ED HIV testing, as reported by our service partners, is that the HIV service have complete governance over the response to people who have reactive tests.

UHL followed a similar process to introduce ED HIV testing, although chose to have a Band 6 clinical nurse specialist within the HIV clinic managing the ED testing, alongside the LTFU work. As the ED HIV testing work became established over the first year, the CNS's focus was able to turn more to the audit and reengagement of those LTFU. UHL also employed a part time Health Care Assistant in year one which helped to reassure ED colleagues that testing would not be a drain on their resources. Once the HIV testing was running, it was clear that the extra HCA was not necessary.

Key to success is ensuring ongoing training and support for ED staff, which at UHL includes a monthly newsletter with case studies. This has helped them to achieve a current ED HIV testing rate of 78% against all bloods taken.

Costs and results of interventions

As most pathology services for HIV testing are commissioned by individual hospitals and GP federations, the costs vary according to the agreement reached by each organisation, partly driven by the volumes required. Within the SIB providers pathology costs fall within the range of £4 to £7 per test. Costs for ED HIV testing include staffing, the cost per test, and blood bottles *(Table 1).*

Table 1: Costs for setting up and running KCH ED HIV testing year one	
Cost of HIV testing for 22,000 patients	£113,080
Band 5 nurse (results management and patient contact)	£39,351
Blood bottles for 22,000 patients	£2,200
Total	£154,631

Together KCH and UHL have newly diagnosed and brought into care 113 people living with HIV since the SIB began operating in November 2018. Average costs per outcome are in the range of £5,242 - £6,300, and this will vary according to the level of undiagnosed people within the area.

There are several other examples of effective ED HIV testing work in England. These include St Thomas' Hospital, who found twenty new diagnoses in 2020. Croydon University Hospital was able to secure funding for ED HIV testing through the COVID -19 response budget, and achieved twenty new diagnoses and ten people reengaged since they started. Pathology costs for both are similar to those within the SIB range, and average costs per outcome are less than £10,000 per person.

Opportunities for improvement and expansion

There are many opportunities for HIV testing where blood is taken within hospitals. Expanding testing to acute medical & surgical wards should be a priority. Although most patients who end up on these wards come via a route through ED, when there is not a 100% ED testing rate, a proportion of patients may slip through the net and not receive a test. Such testing and starting HIV treatment for those who need it can drastically reduce the number of days that they require inpatient care.

Some out-patient departments currently routinely test for HIV such as TB clinics, viral hepatitis clinics. Others would not, such as diabetes. Our service provider partners have suggested that there are specific departments well suited for HIV testing which do not yet include testing and provide dermatology as one example as an opportunity for expansion. To encourage clear forward planning, we recommend that each Hospital Trust Board should be required to publish a three-year plan for rolling out HIV testing across their Trust, and that the government include the extent of completion and impletion of these Trust plans within their annual report.

4. Primary care HIV testing and reengagement

The Social Impact Bond contracted with four GP Federations to provide HIV testing in primary care, which can reach people who might otherwise never receive a test. We also commissioned work to reengage those who had previously shared their HIV positive status with their GP but had now left HIV care. The GP who led the set up for One Health Lewisham testing and reengagement described the process and time taken *(process flow 2).*

Process flow 2: Process of setting up HIV testing and reengagement in primary care: One Health Lewisham GP Federation

1. FUNDING SECURED
    a. Bid written to EJAF including local prevalence, testing rates, all costings/time/resources required.
    b. Initial plan was for an automatic prompt to all GPs requesting a renal function blood test to say that an HIV test would be requested unless patient opted out.

2. PILOTS SELECTED
    a. Ranked each GP practice according to HIV prevalence and their HIV testing rates. Those with high prevalence and low testing rates to be included in the pilot programme.
    b. Planned to try in 5 practices to ensure that the lab would not be overstretched with HIV tests and could troubleshoot issues in practices, then expand to further practices after six months.

3. PATHOLOGY SERVICES
    a. Several months of negotiation with pathology and commissioners, main issues:
        - Concern about potential number of increased HIV tests and that the lab would not be able to cope with the processing, mitigated by sharing calculated volume of tests, and dedicated funding.
        - Inability to add HIV test automatically, would have to be added on by the clinician through selecting a different 'renal profile' which was linked with the HIV test. This would have to be 'searched' and would not show up automatically in the main orderables - which went against original idea of opt-out testing.
        - Including HIV testing into the renal profile is possible via tQuest. This is a single system shared across three boroughs, but not possible to create a profile that will only be available to selected GP practices. Concerns that the HIV test request would be visible to practices outside the Federation and thus increase tests requests in other CCGs.
    b. LEARNING – not possible to move forward with this opt-out testing option when lab catchment area includes non-opt out HIV testing practices. Pivot to GPs ordering tests.

4. EMIS ALERT PROTOCOL (4 hours)
    a. Created an EMIS alert protocol for signed up GP practices to flash up when the patient has not been offered an HIV test in the last 12 months. Adapted from GP Dr Guillar's EMIS alert protocol that she uses in her Southwark practice.
    b. 5 practices initially started using the EMIS alert protocol.

5. PATIENT PUBLICITY INFORMATION DEVELOPED: focus group fees (£35), design fees (£90) and printing fees (£384).
    a. Publicity material developed explaining that practices would be offering routine HIV testing with each blood test.
    b. The posters and leaflets were reviewed by a focus group.

6. EMBEDDED IN EXISTING SCHEME
    a. As the HIV testing took long to get started, decided to include the EJAF project within the Federation's Population Health Scheme (PHS) which aimed to pull together all strands of work which occur at population level. It rewards Practices for ongoing engagement by including areas that are separately funded / incentivised and brings together other work happening in the borough.
    b. This included all GP practices within Lewisham, and incentivised them to increase HIV testing, diagnose new cases and carry out the audit for LTFU.
    c. EMIS pop up protocol was uploaded to all GP practices.

7. COMMENCED PHE HARS AUDIT FOR PEOPLE LTFU.
    a. Contact HIV Data Manager, Blood Safety, Hepatitis, STIs and HIV, PHE and arrange call to go through process, who will give log in details for the PHE system to enable secure upload and download documents onto the system.
    b. Generate an EMIS list of all patients with HIV through the Federation. Search for any code that could be used to describe someone with HIV, potentially broaden the search to pick up people who have been coded incorrectly.
    c. This list will only include patients who HAVE TOLD their GPs that they are HIV positive, avoiding any issue of breaking the patient's confidentiality when contacting the HIV clinics for information.
    d. Upload this list to the PHE system and the HIV Data Manager will run the search and upload the results onto the system for download. The HARS list will state:
    - When the patient was last seen in an HIV clinic (month and year)
    - If the clinic was IN London or OUTSIDE of London
    - If the patient is not matched (not matched to their records - no information available)
    e. Decide which patients to focus on, such as 'Patients who were last seen on or before August 2018'.
    f. Look through their notes on EMIS to see if they had any letters from the clinic or if they had moved GP/moved abroad.

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Costs and results of interventions

Overall, the SIB GP federations have achieved 17 new diagnoses and 33 people reengaged into care from May 2019 – present, including 5 new diagnoses and 18 reengagements from Lambeth Health Ltd. This shows the effectiveness of reengagement work based on primary care audits of records of people who have disclosed their HIV status to their GPs.

We can calculate an approximate cost per outcome for primary care using the indicative budget of £148,768 supplied by One Health Lewisham (OHL) for year one. This included funding for an HIV champion, HIV facilitator, incentives to member practices, other costs (intranet, marketing), management overheads, and blood tests. For the first twelve months June 2019 – May 2020 OHL achieved sixteen outcomes (nine new diagnoses, seven reengagements). Comparing this against their indicative budget gives a cost of about £9,300 per outcome. This figure is representative rather than an absolute – the cost will vary as the number of people undiagnosed reduces, the number of people LTFU reduces, the experience and composition of the team changes, any system improvements are introduced, collaboration across the primary care and secondary care sector is enhanced. What is clear is that this is hugely cost effective compared to the £200,000 per person avoided costs estimated for each person returning to care and staying engaged.

As a comparator, the RHIVA primary care study in Hackney looking at cost effectiveness of screening for HIV in primary care[9] . That study found an average cost to find a newly diagnosed person living with HIV to be £7,096 at 2012 costs. Allowing for average inflation 2012-2020 at 2.4%[10] would give approx. current cost of £8,600.

Opportunities for improvement and expansion

There is a huge variation in HIV Testing practice across GP surgeries and between GP Federations. There are clear NICE recommendations for GPs, however these are not always followed, with a variety of reasons, of cost, of concern for the time that a discussion will take, lack of awareness of the need for HIV testing or a sense that this is an issue for another part of the health system, and finally lack of confidence/ease in raising the subject. It is recognised that GPs are most influenced by other GPs, who can demonstrate in-depth understanding of primary care issues. The SIB engaged six HIV GP Champions on one session a month to influence practice and to share and develop tools, materials and evidence across Federations, and to maximise collaborative working across the primary and community sectors. This has been very successful, and a small Innovation Fund enables them to access funding for discrete projects such as audits.

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[9] Cost-effectiveness of screening for HIV in primary care: a health economics modelling analysis - PubMed (nih.gov)

[10] Inflation calculator | Bank of England

5. Community HIV testing/reengagement

Community organisations are recognised to have a unique ability through their lived experience to reach members of their community and build trusting relationships. They are a proven tool in reaching people who are not accessing traditional health services[11] and are very effective in reaching MSM and black African populations[12]. This is particularly important for those who are unfamiliar with the English health care system or those who may have concerns about their immigration status and how they will be treated if they engage with a state-run system.

'Well designed, community-led and culturally competent testing can overcome some of the barriers to testing we see such as concerns around stigma, lack of trust in services, or low perception of personal risk. It also provides opportunities to open up conversations about HIV and sexual health, providing a gateway to broader services.'[13]

The ability of community organisations to provide close support to someone who has had a reactive POTC test is key to ensuring that very vulnerable people can be confident enough to go to a HIV clinic for the confirmatory test and start treatment. This may often extend to accompanying the person to clinic if they are concerned about the stigma that they might face.

Community organisation providers within the SIB have so far enabled 37 people living with HIV to be newly diagnosed, and two people reengaged to care after having stopped treatment. This includes 26 people newly diagnosed amongst the Latin American community found by Naz Project London, and 10 people linked to care through Metro City Ltd/ GMI Partnership. The restrictions imposed through the COVID-19 response particularly impacted upon the ability of community organisations to engage with people, and we hope that the current lessening of restrictions will enable them to reach more people in the next few months.

Due to current competitive tendering commissioning arrangements, there is commercial sensitivity in sharing data of any organisation's individual costs per outcome but aggregated across the providers are broadly in line with the costs of achieving new diagnoses in other settings at under £10,000 per person.

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[11] Croxford S et al., 2019, Community-based HIV testing in Europe: a systematic review (Poster), HepHIV 2019 Conference, 28-30 January 2019, Bucharest, Romania [https://www.eurotest.org/Portals/0/PS4_04.pdf]

[12] economic-report (nice.org.uk)

[13] HIV-Commission-Testing_pages_final.pdf (hivcommission.org.uk)

6. Key populations identified by the SIB-funded testing interventions

It was estimated that there were 1,000 people unaware they were living with HIV in Lambeth, Southwark and Lewisham (LSL) in 2019[14], and 2,000 people unaware they were living with HIV in London that year[15]. The below table shows the total new HIV diagnoses in each SIB borough and how many of those new diagnoses were delivered through SIB funded activity.

ED HIV testing can be seen to make a significant impact, with 30% of the total 284 new diagnoses in LSL in 2019 being found through ED HIV testing at KCH and UHL. 80% of all newly diagnosed people in Lewisham were found through SIB interventions, suggesting that ED and primary care are very effective in reaching groups who were not previously engaged with HIV testing *(table 2).*

Table 2: SIB intervention contributions to LSL new diagnoses of people living with HIV in 2019

Date of analysis 23/04/2021	PHE SPLASH 2021 using 2019 data			SIB using 2019 data					SIB as a % of all diagnoses	
	HIV prevalence per 1,000 aged 15-59 in 2019	Number of new HIV diagnoses among 15+ in 2019	Number of late HIV diagnoses (CD4 ≤350 (2017-19)	Number of new HIV diagnoses through SIB	Number of HIV diagnoses CD ≤350 through SIB	SIB ED testing	SIB Primary care	SIB Community	SIB new diagnoses, of all new diagnoses in Borough	SIB late diagnoses, of all late diagnoses in Borough
Lambeth	13.7	111	40	25	14	17	5	3	**23%**	**35%**
Southwark	12	108	43	35	22	32	0	3	**32%**	**51%**
Lewisham	8	65	29	52	18	35	12	5	**80%**	**62%**

[14] Lambeth, Southwark and Lewisham Sexual and Reproductive Health Strategy 2019-24.

[15] HIV testing trends, new diagnoses and people receiving HIV-related care in UK: data to the end December 2019 (publishing.service.gov.uk)

Demographics of those who were newly diagnosed by SIB interventions

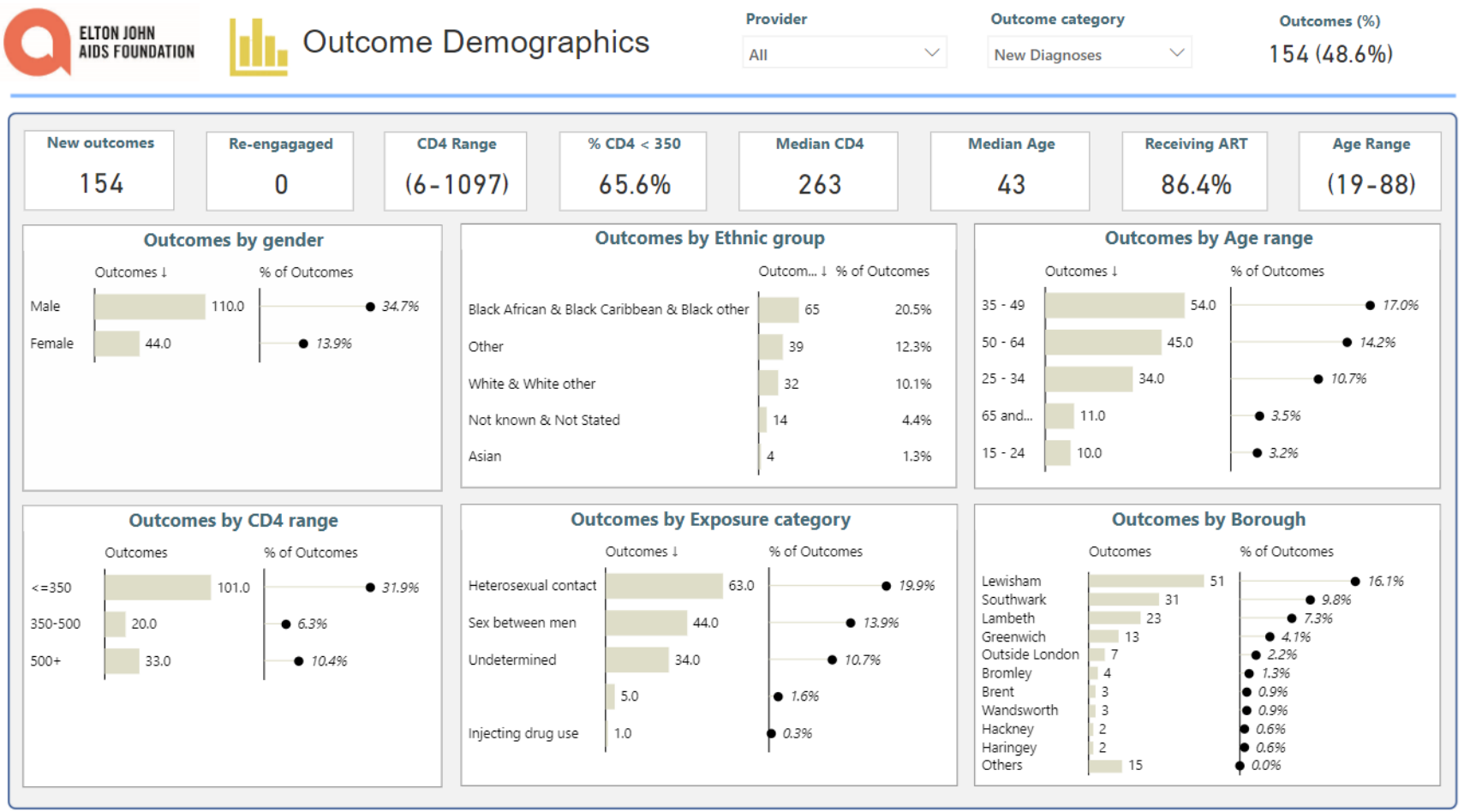
The inclusion of anonymized demographic data for all those linked to care through the SIB allows us to draw insights about who the SIB has found and whether that population differs from those found through other modes of testing. Trends in the data suggest that those newly diagnosed through the SIB differ significantly from those diagnosed through other modes of testing. They highlight the importance of ED testing in reaching those who are late in the progression of their illness. They also surface a path to reduce ethnic, gender, and age-related disparities in HIV outcomes.

PHE surveillance data for 2019[16] reports substantial decreases in new diagnoses across all demographic categories, including ethnicity, gender, and age. The data shows a decrease in late (CD4<350) diagnoses, although late diagnoses have risen as a proportion of all diagnoses, from 39% in 2018 to 42% in 2019. This shows that whilst there is a decreasing number of people living with HIV, some people are falling through the cracks of current HIV testing services. Late diagnosis leads to poorer health outcomes and increased risk of mortality[17] and is more likely to happen to women, Black African, Black Caribbean, and Black Other ethnicities, and people aged 65 years plus[18].

Similarly, our data indicates that those found with a late diagnosis through the SIB's ED HIV testing are disproportionately women, Black African, Black Caribbean, and Black Other ethnicities, and older adults. Of those found through the SIB, 65.6% are diagnosed late, 28.6% are women, 42.2% are Black, and 7.1% are aged 65+ *(table 3 below).* These trends are especially true in the subset of diagnoses found through ED testing, with 75.0% diagnosed late, 35.0% women, 54.0% Black, and 10.0% aged 65+ *(table 4 below).*

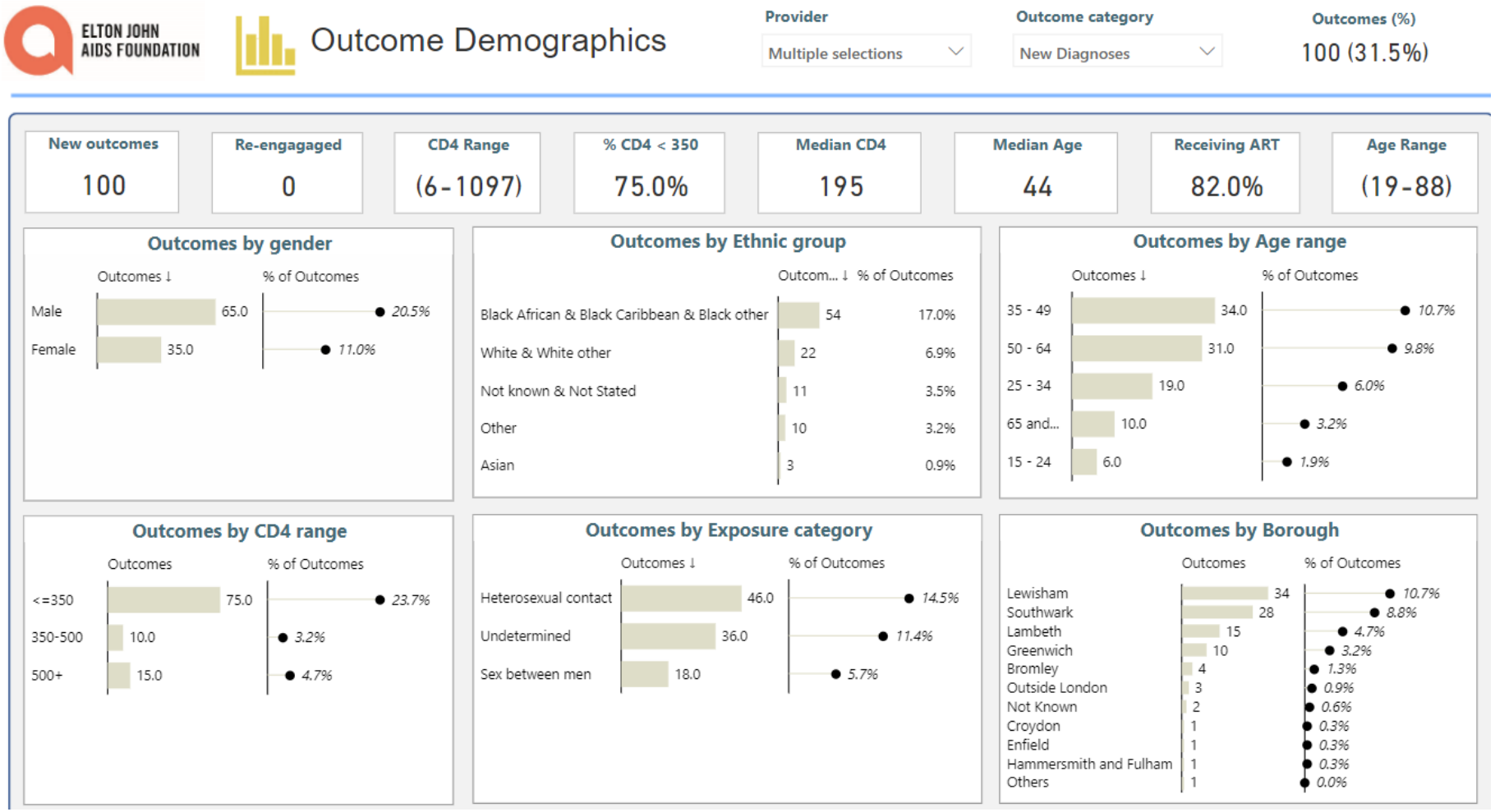
[16] https://www.gov.uk/government/statistics/hiv-annual-data-tables
[17] https://www.bmj.com/content/343/bmj.d6016
[18] HIV testing trends, new diagnoses and people receiving HIV-related care in UK: data to the end December 2019 (publishing.service.gov.uk)

Table 3. All newly diagnosed via all SIB



The % figures relate to the total number of new diagnoses of people living with HIV and linked to care plus those reengaged into care through the SIB.

Table 4. All newly diagnosed via SIB ED testing



The disproportionate impact is especially noticeable *(table 5)* when compared to the PHE's UK figures of 41.8% late, 27.5% women, 22.3% Black, and 3.5% of people aged 65+.[15] Similar trends are found in PHE's 2017 Spotlight on London, with 35% late, 29% women, and 31% Black.[19]

Table 5: Comparison of demographic groups reached	**Late diagnoses**	**Women**	**Black African, Black Caribbean, Black Other**	**People aged 65+**
SIB new diagnoses found	65.6%	28.6%	42.2%	7.1%
SIB ED HIV opt out testing	75.0%	35.0%	54.0%	10%
SIB Primary care HIV testing	68.4%	20.0%	45.0%	5.0%
PHE London[15]	35.0%	29.0%	31%	-
PHE UK[20]	41.8%	27.5%	22.3%	3.5%

While SHS and specialist testing are an essential bedrock to HIV testing in the UK, there is evidence to suggest that Black ethnic populations may tend to avoid interacting with SHS services[21]. Qualitative experiences of women and older adults in this programme have indicated that they did not view themselves as "at-risk" and thought HIV "only happened to other people." This may be because they are not using other services that would enable them to discover their HIV diagnosis, that those services are also less likely to offer an HIV test if they do use the service, and they are most likely to decline a test. Opt out HIV testing within an ED service that has successfully normalised HIV testing is a crucial mechanism in ensuring these people have access to testing that will increase their chance of being diagnosed at an earlier stage, with less impact on their health and wellbeing outcomes.

7. Reengagement of those lost to follow up

Haworth et al (2017)[22] in the landmark REACH study emphasised the need for accountable staff with time dedicated to tracing people living with HIV who were LTFU, whether a consultant, HIV clinic nurse or GP. The same study explored why people who had been disengaged for over a year became LTFU finding causes related to motivation and opportunity to attend, with a clear relationship between stigma associated with being HIV positive and disengagement from care, especially among black African patients. Difficulties with ART could lead to changes to adherence resulting in disengaging from care to avoid perceived censure of health professionals. Patients generally thought well of clinic staff, though some described becoming disengaged after a breakdown in those relationships. Reasons patients returned to care include that they became ill, familiarity with the clinic and staff, strong peer support, and staff inviting people to attend.

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[19] https://www.gov.uk/government/publications/hiv-london-annual-data-spotlight

[20] HIV testing trends, new diagnoses and people receiving HIV-related care in UK: data to the end December 2019 (publishing.service.gov.uk)

[21] https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-13-196

[22] REACH: a mixed-methods study to investigate the measurement, prediction and improvement of retention and engagement in outpatient HIV care - UCL Discovery

The SIB funded dedicated reengagement work at three hospitals, University Hospital Lewisham, St Thomas Hospital and Kings College Hospital.
The Consultants who set up reengagement at GSTT and KCH describe the process *(process flow 3).*

Process flow 3: Process of setting up reengagement in HIV Clinics: St Thomas Hospital and Kings College Hospital

1. COLLABORATIVE PROCESS
   a. This was a collaborative process between two separate hospital trusts, Public Health England, and community partners.
   b. The process continues to evolve with the involvement of patients and GPs.

2. CREATE LISTS OF PATIENTS NOT SEEN
   a. Both King's and GSTT created lists of all patients who had not been seen in their HIV departments for the preceding 12 months.
   b. These lists were submitted to Public Health England who cross referenced with the HARS dataset to determine whether patients had subsequently accessed care elsewhere.
   c. This enabled the removal of 30% of the patients on the initial lists.

3. DEVELOP PROTOCOL
   a. King's and GSTT worked together to write a protocol detailing what techniques would be employed.
   b. They looked at published evidence of what had proven successful in other similar projects.

4. ENGAGE COMMUNITY HIV TEAM
   a. They met with the community HIV nursing team about what the team would recommend to maximise engagement.
   b. The team made suggestions such as travel vouchers and the value of satellite clinics. (These are already running at King's, and GSTT has referred some of the LTFU patients to these clinics where they have felt unable to present to an HIV unit).

5. FURTHER COLLABORATION
   c. As the work progressed they started to work more closely with UHL and local GPs.
   d. They have streamlined communication between the three hospital trusts and local GPs, thanks to EJAF HIV GP champions, which has improved patient outcomes.

6. PATIENT QUESTIONNAIRES
   a. All patients linked back in are asked to fill in a questionnaire asking why they become LTFU and what would prevent this happening again.
   b. Their responses will be used to inform future service delivery.

K. Childs and H Alexander 20/05/21

Results and costs of interventions

The approach of outcomes-based payments for reengaging people living with HIV who have become lost to follow up, has been very successful. Since the SIB began, UHL have reengaged 49 people, GSTT 40 people, and KCH 23 people, a total of 112 people brought back into care. There is an issue of how long people will remain engaged, but initial indications are that more than 75% of patients reengaged 6 months or more ago are still engaged *(table 6 and 7).*

Table 6: Guys and St Thomas' HIV Clinic reengagement work July 20 - May 21	Total reengaged	Patients reengaged > 6 months ago: still engaged/total.	Patients reengaged between 3 to 6 months ago: still engaged/total.	Patients reengaged < 3 months ago: still engaged/total.	Disengaged.
Patients not seen for > 12 months.	36	20/27	4/4	4/5	8/36
Patients seen within the last 12/12 but pharmacy records demonstrated that they would have run out of ART.	4	-	4/4	-	0/4

Table 7: King's College Hospital HIV Clinic HIV reengagement work July 20 - May 21	Total reengaged	Patients reengaged > 6 months ago: still engaged/total.	Patients reengaged between 3 to 6 months ago: still engaged/total.	Patients reengaged < 3 months ago: still engaged/total.	Disengaged
Patients not seen for > 12 months.	19	7/10	0/1	7/8	5/19
Patients seen within the last 12/12 but pharmacy records demonstrated that they would have run out of ART.	4	1/1	1/1	2/2	0/4

Generally NHS consultants are meant to spent 90% of their time on direct clinical contact - that is ward rounds and clinics, and 10% on other matters, including the time that they spent on this project, other service development, supervising junior colleagues, any research, audit or teaching and CPD. Reengagement is meant to be part of their service, but they are so stretched just being reactive to clients - that is the ones who turn up and make demands and are unwell, that the considerable work involved in being proactive and reaching out to lost patients can be difficult to find time for.

Funding a further consultant session a week will enable this kind of reengagement activity to be effective - particularly when setting up a reengagement project. The initial work of getting the data/cross refencing with PHE/setting up the database and devising the recall process, communication to all the staff in clinic as well as the pathways for communicating with GPs and other teams such as mental health and the community HIV team, takes considerable time.

The University Hospital Lewisham budget combined resources across ED HIV testing and reengagement, whereas GSTT and KCH had separate budgets *(table 8).*

Table 8: Indicative budget for GSTT HIV reengagement work July 2020 - June 2021.	4 month cost	Comparable 12 month cost
Administrator - Band 4	£6,766	£20,298
Transport costs taxi travel	£600	£1,800
Transport costs – bus vouchers	£135	£405
Food vouchers	£150	£450
Phone for EIC team	£500	£500
Sub total	£8,151	£23,453
20 % overhead costs	£1.630	£4,691
Total	**£9,781**	**£28,144**

Using this indicative budget we can calculate that at GSTT with 40 patients linked back to care, the cost per outcome is £704, and at KCH with 16 patients linked to care, the cost per outcome is £1,759, with two months of their first year remaining, which may mean further people reengaged lessening the overall average cost. Even with an additional consultant session @ £8,000 per year these costs would less than £1,000 at GSTT, and £2,300 at KCH.

UHL chose to fund an additional CNS Band 6 role based in the HIV clinic whose time was split between ED HIV testing and reengagement work. As the ED HIV testing work become established, she was able to focus more time on the reengagement work.

Opportunities for improvement and expansion

There are three separate issues with the patients that have been re-engaged. The first is that where they haven't disengaged it takes a lot of work to keep them engaged, the best demonstration of this would be their DNA rates – they tend to miss many appointments and need a lot of chasing. The second is the issue of whether or not they take ART. A number have refused treatment or have had poor or basically non-existent adherence so while they are in care, and the team keep negotiating with them, their prognosis effectively remains unchanged. The third is that this group disengage at a higher rate than the usual cohort. It is worth noting though that this is very difficult to currently monitor as people potentially lost to care went abroad between lockdowns and may not be able to return. Further work and study may illuminate new learnings and better ways of sustaining adherence to treatment.

Demographics of those who were reengaged to care in the SIB

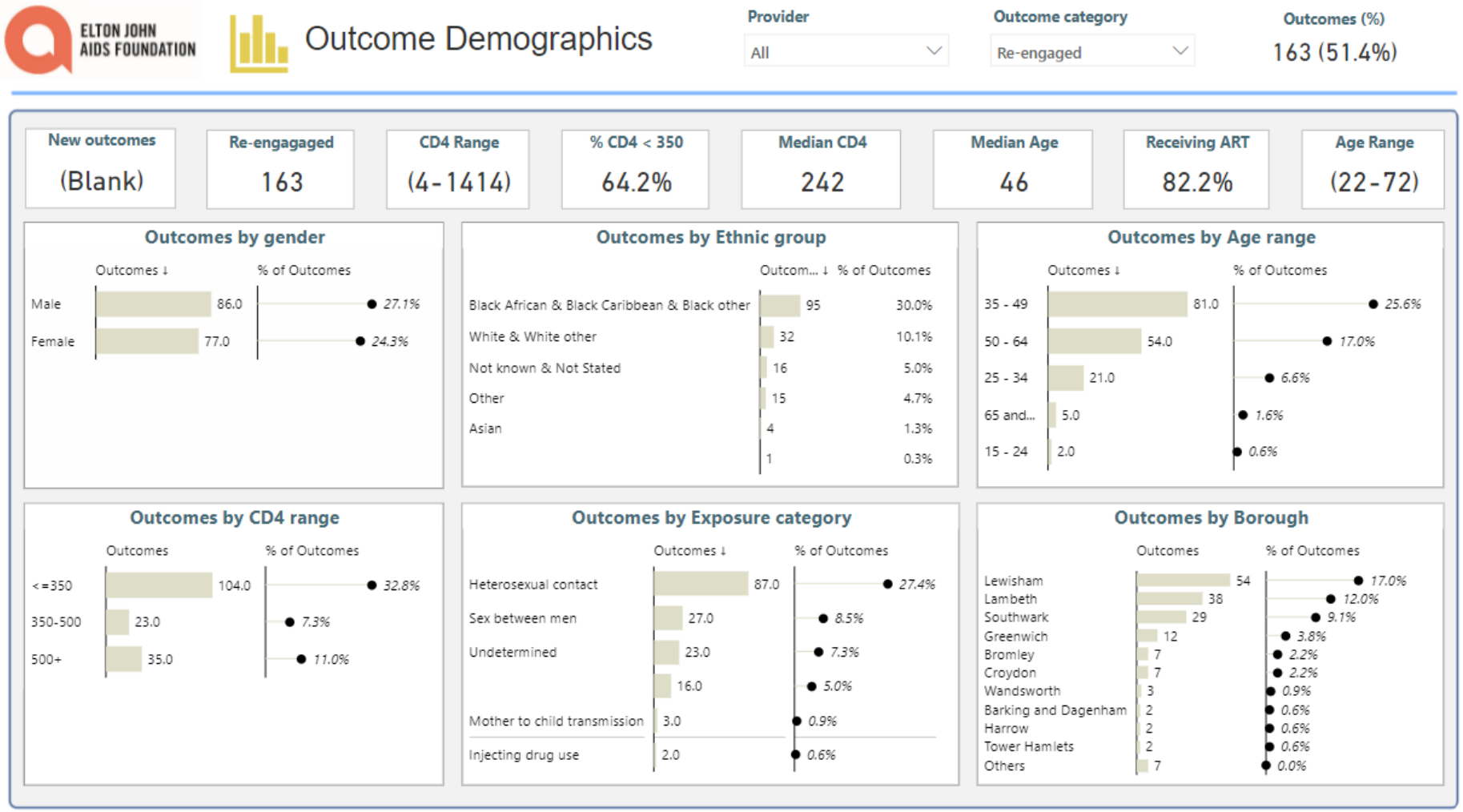
Reengagement of people living with HIV who know their status but are not currently on treatment is essential to ending the HIV epidemic in the UK, with one large-scale longitudinal study in finding 28.1% of people who entered HIV care were lost to care within 10 years.[23] Unfortunately, robust surveillance data on these lost to care populations does not currently exist. In its most recent surveillance report, PHE concluded that "further improvements can be maximised through focussing attention among those lost from care."[24]

Through the SIB re-engagement activities, we have started to focus needed attention on those who have discontinued their HIV care. We have found important demographic differences in this population, similar to the trends found in our new diagnoses. Of those we have reengaged into HIV through the SIB, 64.2% are at a late (CD4<350) stage when linked back to care, 47.2% are women, 58.2% are Black, and 3.1% are aged 65+ *(table 9 below).* Compare this to the PHE's UK figures of 41.8% late, 27.5% women, 22.3% Black, and 3.5% aged 65+, and London-specific figures of 35% late, 29% women, and 31% Black.[25] Unlike new diagnosis through ED testing, re-engagement does not engage disproportionate numbers of older adults. However, the trend toward supporting women and people with Black ethnicity is even stronger than the same trend in new diagnoses. Many of these people are also engaging at a late stage of their HIV progression, so their reengagement is essential to improve their health outcomes and minimize risk of mortality.

Reengagement work has historically had significantly less research and funding investment than new diagnosis, but challenges adhering to treatment along the HIV continuum have been reported previously[5,26]. Some studies in high income counties have found especially pronounced effects on ethnic minorities.[27] Among our own cohort, the disproportionate identification of and linkage into treatment for women and people with Black ethnicity highlights significant need in these communities, which needs to be further explored and addressed to help people get to a point of virological suppression.

[23] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5990495/
[24] https://www.gov.uk/government/publications/hiv-in-the-united-kingdom
[25] https://www.gov.uk/government/statistics/hiv-annual-data-tables ; https://www.gov.uk/government/publications/hiv-london-annual-data-spotlight
[26] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4480684/
[27] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4584644/; https://link.springer.com/article/10.1186/s12939-017-0549-3

Table 9. All reengaged via all SIB channels



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