

# Practical guidance for Primary Care to optimise HIV testing and re-engagement of people living with HIV

## Aim of the guidance

This guidance is for primary care professionals interested in increasing HIV testing and re-engagement of people living with HIV lost to follow-up in their practice. It is based on learning from the Elton John AIDS Foundation Zero HIV Social Impact Bond (SIB) Primary Care HIV testing and re-engagement, which was informed by BHIVA/BASHH/BIA HIV testing guidance<sup>1</sup>, NICE Guidance (2016)<sup>2</sup> and previous Primary Care HIV testing initiatives such as the RHIVA study<sup>3</sup>.

## Top tips from the Elton John AIDS Foundation HIV GP Champion group

Changes require time and energy. You may consider implementing one of these changes at a time and work your way down the list!

- 1. Add HIV test as an opt out/offer everyone an HIV blood test**

In all routine yearly bloods, NHS health checks and new patient registration. No counselling involved, just informing “we are including HIV in all our MOT/yearly tests” is enough. It can be helpful to attach an explanatory slip to the blood forms (see example in appendix 1).
- 2. Get your team on board**

Ensure all primary care staff including reception and administrative staff are involved and aware of your HIV testing policies. Offer training and answer questions to help combat HIV stigma.
- 3. Set up electronic reminder alerting**

Electronic reminder alerts for patients who've never had an HIV test or not for the last year can be very helpful (see EMIS alert in appendix 2).
- 4. Make sure your patients living with HIV are not lost to follow-up**

Ensure they have at least one hospital review every year. Check that their HIV diagnosis is properly coded and their antiviral medication is recorded as “hospital prescription” on the GP system. This avoids risk of serious drug interactions. (Remember to offer pneumococcal and flu vaccinations.)
- 5. Don't forget other blood borne viruses**

Screen your population for blood borne viruses, offering simultaneously a test for HIV, Hepatitis B Surface antibody and Hepatitis C serologies. This is particularly indicated for all new patient registrations and NHS checks.
- 6. Code patients' notes who decline an HIV test**

Almost no one will opt out. Often the ones who do are those who perceive themselves most at risk. Please code “HIV test declined” and, if unable to discuss then, make a note to do so at next opportunity.
- 7. Strengthen collaboration with secondary care HIV clinics and community organisations**

This contributes to offering cohesive care and support for our patients living with HIV. Good communication will also facilitate detection and reconnection of patients lost to follow-up.
- 8. Help patients living with HIV to disclose their status**

Research shows that around 8% of patients living with HIV have not disclosed their condition to their GPs due to fear of stigma. By offering an HIV test routinely, and talking about and treating it as any other chronic condition, you will be contributing to reducing stigma.

## Key points to increase early diagnosis of HIV through testing

- Make the most of every contact and normalise conversation about HIV testing.
- Health checks and new patient registrations protocols are great opportunities to include HIV tests as routine.
- Discuss with your lab if HIV tests can be added to test packages such as those for investigation of anaemia, tiredness, dementia, lymphadenopathy and neuropathy.
- Check how primary care HIV testing is being commissioned in your local Integrated Care System.



## Context

Following the HIV Commission Report (2021)<sup>4</sup> the English government launched the HIV Action Plan (2021)<sup>5</sup>, which commits to achieving the 2030 zero HIV transmission target in England, with an interim target of an 80% reduction in new diagnoses by 2025. The number of undiagnosed people living with HIV in the UK is estimated at 5,150<sup>6</sup>; as this number decreases, traditional approaches to HIV testing may become less productive, and opt out HIV testing in primary care increases in importance.

NICE guidance (2016) and BHIVA/BASHH/BIA HIV testing guidance (2021) state that primary care HIV testing should be undertaken, but this is not always commissioned, and some practice staff are wary of offering HIV tests for fear of patients reacting adversely. Changing the conversation in primary care from targeted to routine screening (“at our clinic we regularly screen all patients for HIV as this is an area with high/very high HIV incidence, unless you ask us not to”) is vital to identifying undiagnosed people living with HIV. Normalising HIV testing reduces professionals’ concerns that they might be accused of stereotyping their patients, and routine opt out HIV testing reduces the anxiety or stigma that patients may feel as they accept that it is standard clinical practice.

Reducing HIV stigma is something that every member of the practice can help with, including reception staff, HCAs, nurses, GPs and other team members. Several training resources are available, including [Sexual Health In Practice \(SHIP\) training](#) and the [LGBT Foundation ‘Pride in Practice’ scheme](#).

## Learning from the Zero HIV SIB

The Elton John AIDS Foundation set up the Zero HIV SIB programme to provide evidence of the effectiveness of HIV interventions and the potential NHS costs that could be avoided. The SIB was commissioned by LB Lambeth on behalf of Lambeth, Southwark and Lewisham councils, supported by funding by the National Lottery Community Fund, and operated between 2018 and 2021. It linked over 460 people to HIV care through opt out HIV testing at Kings College Hospital ED, University Hospital Lewisham ED and four primary care GP federations, targeted outreach by four community organisations, and recall of those lost to follow-up by three HIV clinics and primary care. The SIB generated evidence of what works and how to implement these interventions. The SIB found that:

- Of the 36 people newly diagnosed with HIV in primary care, over 62% had a CD4 count of less than 350, meaning that they were diagnosed late, at risk of AIDS-defining illnesses, and potentially required expensive NHS treatment. This shows the importance of taking every opportunity to test for HIV.
- The average cost of finding an undiagnosed person living with HIV in primary care was under £10,000, whereas the potential NHS cost for someone being diagnosed late is over £200,000.
- Primary Care HIV testing is very effective at addressing health inequalities through reaching Black African, Black Caribbean and Black Other community members, who were 70% of all new HIV diagnoses identified by primary care. This figure is higher than the SIB's Emergency Department HIV testing (55%), and greatly exceeds the percentages of this community newly diagnosed in either Public Health England's 'Spotlight on London' (2017)<sup>7</sup> figures at 31%, or UKHSA's (2021)<sup>8</sup> national figure of 30% (Table 1 - unknown ethnicity excluded).

<b>Table 1: Health inequalities impact of primary care HIV testing in Lambeth, Southwark and Lewisham</b>	Black African, Black Caribbean, Black Other community members as % of total new HIV diagnoses ( <i>unknown ethnicity excluded</i> )
SIB Primary Care HIV testing (2018-21)	70%
SIB ED HIV testing (2018-21)	55%
Public Health England 'London HIV Spotlight' (2018) (Black African, Black Caribbean data only)	22%
UK Health Security Agency (2021) England	30%

- Primary Care HIV testing is also effective in identifying new diagnoses in people aged 50 plus, who were 40% of all new diagnoses.
- People diagnosed with HIV in emergency departments often had previous multiple encounters with primary care and 'missed opportunities' for testing. In a sample of 24 patients diagnosed with HIV at University Hospital Lewisham Emergency Department, 17 had seen a GP within the previous two years, with a total of 32 attendance of HIV indicator diseases or seroconversion symptoms, 100 blood tests were ordered, but only 3 HIV tests offered<sup>9</sup>.
- More than 50% of people newly diagnosed were found through opportunistic HIV testing, including testing at routine health checks and new patient registrations, more than those found by HIV tests undertaken because of clinical indications.

## A patient's perspective

“ Having moved home, I decided to change my GP. I was invited to a routine welcome check-up. At the end of the check-up, the nurse asked me if I wanted to take an HIV test. I was not in a hurry, so I thought “why not”. I was actually putting my coat on to leave the surgery when I was given the bad news, it was positive! Please remember it was just a routine “medical”, and I didn't visit because I was feeling sick. Push the testing. Although there is currently no cure, it can be totally eradicated by getting HIV positive people on treatment. Tell them my story, encouragement will save lives and unnecessary suffering. ” (male, 60s)

## A case study: HIV testing and lost to follow-up interventions implemented by One Health Lewisham GP Federation

Dr Grace Bottoni, GP, One Health Lewisham (OHL) GP Federation

### 1. Funding secured and plan agreed

- Business case was developed between the Elton John AIDS Foundation and OHL for opt-out HIV testing for every patient who had a renal function blood test requested in primary care.
- Each practice to carry out an audit to identify their patients who were living with HIV who had not been seen in an HIV clinic in a year (lost to follow-up/LTFU).

### 2. Pilot practices selected

- Practices ranked according to their HIV prevalence and HIV testing rates. Five practices were chosen from those with high prevalence and low testing rates.
- 'Frequently Asked Questions' support package sent to each practice containing training and contact details of the project manager.

### 3. Challenges of automating ordering of HIV tests

- It was not possible for our federation to automate the EMIS system to order HIV tests for every person who had a renal blood test taken due to shared phlebotomy commissioning arrangements with other federations. GPs had to physically tick the HIV test request on the system. Automating the request for HIV tests would have been preferable.

### 4. Development of an EMIS alert protocol

- EMIS alert protocol adapted from Southwark alerted the healthcare professional if the patient had never had an HIV test or if they had not had an HIV test in the last 12 months.

### 5. Development of patient information

- Patient information material including posters and leaflets were developed explaining that practices would be offering routine HIV testing with each blood test.
- Reviewed by a patient participation focus group to ensure the language was appropriate.

### 6. Roll out to all practices

- EMIS alert protocol uploaded to all GP practices not just the pilot practices.
- The federation offered financial incentives to practices to increase HIV testing, diagnose new cases of HIV and carry out an audit of patients LTFU.

### 7. Identifying people living with HIV who are LTFU

- To support practices to identify patients LTFU, OHL worked with the UK Health Security Agency (UKSHA). If a patient was not contactable, the UKSHA could let the practice know if the patient had been seen in a clinic (only the month and year, no further detail). This allowed primary care teams to focus on those who were truly LTFU.
- A note was made in the patient records that they were identified as potentially LTFU and to discuss this at the next primary care contact.
- HIV clinics were also contacted to collaborate on re-engagement.

## HIV GP Champions support enhanced HIV testing and care

HIV clinical leadership within primary care is vital to enhance the collaboration across the patient pathway, and to offer support and guidance to those practices wishing to optimise their HIV testing and patient care. The Elton John AIDS Foundation recruited five HIV GP Champions through the Zero HIV SIB. Their main roles were:

- Coordinating care across primary and secondary care
- Offering educational support across practices
- Sharing innovation and best practice
- Offering training to GP trainees.

A role description for HIV GP Champions is shown in appendix 3. Including such roles within the clinical leadership of the new ICS systems will be advantageous in enhancing HIV testing and care.

## Acknowledgements

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### Elton John AIDS Foundation

The Foundation harnesses local expertise across four continents to challenge discrimination, prevent infections, provide treatment for marginalised groups, as well as mobilising governments to end AIDS.

**We will not stop until the AIDS epidemic is over.**

### HIV Prevention England

The National HIV Prevention Programme connects key stakeholders across England to deliver a nationally co-ordinated programme of HIV prevention work. It is funded by The Office of Health Improvement and Disparities.

## References

<sup>1</sup> [NICE Clinical Guidance HIV testing: increasing uptake among people who may have undiagnosed HIV.](#)

<sup>2</sup> [BHIVA/BASHH/BIA Adult HIV Testing Guidelines 2020.](#)

<sup>3</sup> [Evaluating the impact of post-trial implementation of RHIVA nurse-led HIV screening on HIV testing, diagnosis and earlier diagnosis in general practice in London, UK \(cam.ac.uk\).](#)

<sup>4</sup> [HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report, UK Health Security Agency.](#)

<sup>5</sup> [HIV Commission Report and Recommendations 2020.](#)

<sup>6</sup> [Towards Zero - the HIV action plan for England 2022 to 2025.](#)

<sup>7</sup> [Annual epidemiological spotlight on HIV in London 2017 data. Public Health England 2018.](#)

<sup>8</sup> [England National HIV surveillance data tables No. 1: 2021 UKHSA.](#)

<sup>9</sup> 'Missed opportunities for diagnosing HIV in primary care' Poster presentation, Dr Grace Bottoni, Dr Georgina Thomas, Dr Helen Walker, Lucy Wood, Fast Track City conference 2021.

## Appendix

### Appendix 1: Example of information slip to be attached to routine blood forms

Dear patient,

Please find attached a request form for your routine blood tests. You may notice that it also includes a request for an HIV test. This is in line with current national recommendations for areas of high rate of HIV.

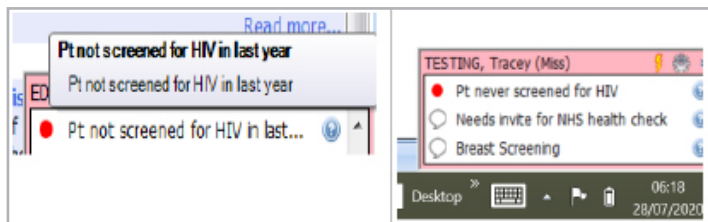
Nowadays HIV is an entirely treatable condition. If diagnosed and treated early, people living with HIV can enjoy a completely normal life and they are no longer infectious to other people. However, one in ten people infected are not yet aware of their condition. By testing routinely all our adult patients once a year whilst having other blood tests, we shall be able to detect those who are infected before they become unwell. This way we will save lives and avoid further infections.

We hope our policy meets your approval. However, if you decide you do not want to know your HIV status, please omit the page with the request when you attend for your test or speak to a staff member who will make sure the test is cancelled.

Do not hesitate to contact us if you have any questions or wish to discuss HIV testing further.

Thanks,  
**The practice team**

## Appendix 2: examples of EMIS alerts



## Appendix 3: HIV GP Champion role description

### Summary of purpose:

The main features of this role will involve clinical education and supporting quality improvement; helping local practices and teams to review their ways of working and consider implementing new models to improve HIV testing and care. The role will include presenting evidence, working closely and collaboratively with local practices and clusters and will require strong facilitation and influencing skills.

It is expected that the post holder will have (or quickly develop) an understanding of themes from HIV research and practice around HIV testing and early diagnosis, and re-engagement and retention in ongoing support for people living with HIV.

### Key responsibilities:

- To work collaboratively with local practices and clusters within their GP Federation to influence and facilitate change and service improvement in the delivery of HIV testing and care provided to people living with HIV.
- To strengthen and facilitate the educational development and skill set of primary care teams in relation to HIV testing and care by promoting relevant courses, tools and resources.
- To provide input to existing and new educational projects to enhance primary care teams' HIV knowledge, developing resources where necessary.
- To undertake small projects, audit or research, which may be pan Lambeth, Southwark and Lewisham.
- To support local evaluation of the Programme.
- To communicate the aims and work of the Programme through meetings, conferences and other events.
- To provide professional clinical leadership and advice on relevant issues from a primary care perspective.
- To engage with local authority public health and sexual health commissioners to increase the visibility and benefits of HIV testing and re-engagement into care for people living with HIV.

### Person specification

Essential	Desirable
Qualifications and Registration	Registered Medical Practitioner
Full registration and Licence to Practice with the GMC	Membership of the Royal College of General Practitioners
On GP Performance List	Or membership of equivalent organisation
Knowledge and Experience	
Understanding of issues affecting HIV testing practice within primary care	
Demonstrable experience of working to influence/affect change within HIV care at primary care level	
Credibility with peers and local primary care colleagues	
Ability to influence at all levels	
Ability to form effective working relationships across sectors	
3 years' experience in general practice	
Experience of developing and delivering educational events or programmes	