



**NATIONAL  
AIDS  
TRUST**

Securing rights  
Stopping HIV

August 2021



# HIV testing is everyone's business

Toolkit to enhance HIV testing in people with indicator conditions





# 1. Introduction

Every part of the health service, every health professional, in primary care and secondary care, will be seeing people with common indicator conditions of HIV.

This short guide is a toolkit to support healthcare professionals, commissioners and health service planners increase HIV testing in people presenting in their services with HIV indicator conditions. It will provide answers to some of the regular questions which arise when discussing indicator condition testing including:

- what HIV and HIV indicator conditions are
- the evidence base and current guidance
- where and amongst who HIV indicator conditions are commonly found
- patient views, reactions and expectations
- funding, training and resourcing.

HIV indicator conditions testing is a vital part of the strategy for increasing HIV testing and reducing the far too high levels of late HIV diagnosis. This will be a crucial component of the nation's mission to end new HIV transmissions by 2030. Indicator condition

testing is an evidence-based approach to identifying those living with HIV, who may not be identified by other approaches to regular HIV testing.

We are currently not doing enough nationally, and national NICE and HIV guidance is not being fully implemented in this area. HIV testing is everyone's business – every part of the health service, every health professional, in primary care and secondary care, will be seeing people with common indicator conditions of HIV. By prioritising the implementation of systems to ensure patients with indicator conditions are offered HIV tests, all parts of the health system can help to achieve the aim of reducing late diagnosis and improving outcomes for people. Offering HIV tests to patients with indicator conditions should be a matter of priority.

## 2. What HIV and HIV indicator conditions are

### 2.1 What is HIV?

HIV (Human Immunodeficiency Virus) is a virus which, when untreated, attacks the immune system - the body's defence against diseases. There are more than 105,000 people living with HIV in the UK.

HIV can be passed on through some bodily fluids such as semen, vaginal fluids, blood, breast milk and rectal secretions. It cannot be passed on via saliva, urine or faeces. The most common way HIV is transmitted is through sex without a condom or without another form of protection (such as the HIV prevention drug, PrEP, or if one partner living with HIV is on effective treatment for HIV).

HIV stays in the body for life, but treatment can keep the virus under control and the immune system healthy. HIV treatment is extremely effective and most people now start treatment as soon as they are diagnosed. Someone living with HIV, diagnosed in good time and on treatment, can lead a full, active life with a normal life expectancy. Treatment reduces the level of HIV in the body to what is called an 'undetectable viral load'. People living with HIV with an undetectable

viral load (the vast majority of people with diagnosed HIV in the UK) cannot pass the virus on to sexual partners. This is known as U=U (Undetectable = Untransmittable).

Without medication people with HIV can develop AIDS. AIDS (Acquired Immune Deficiency Syndrome) is the most advanced stage of an HIV infection when the immune system can no longer fight infections.

### 2.2 What is an HIV indicator condition?

This is a medical condition that is significantly associated with underlying HIV. The threshold usually being more than 1 in every 1000 cases. According to the OptTest project there are 25 AIDS defining conditions and 49 other conditions strongly associated with HIV.<sup>1</sup> There are 37 indicator conditions strongly associated with HIV and identified by British HIV Association (BHIVA) and British Association for Sexual Health and HIV (BASHH) guidelines.

They cover a range of clinical specialty areas that any hospital or GP surgery will deal with on a day-to-day basis.<sup>2</sup>



<sup>1</sup>HIV in Europe, Guidance for Implementing HIV Testing in Adults in Health Care Settings <https://www.eurotest.org/HIV-Indicator-Conditions>

<sup>2</sup>BHIVA, BASHH & BIA (2020) Adult HIV Testing Guidelines 2020 <https://www.bhiva.org/file/5f68c0dd7aefb/HIV-testing-guidelines-2020.pdf>

**Table 1. AIDS-defining conditions in people living with HIV and indicator conditions by specialty<sup>3</sup>**

Clinical specialty	AIDS-defining indicator conditions in people living with HIV	Broader indicator conditions
Dentistry	Kaposi's sarcoma	Unexplained oral candidiasis
		Oral hairy leukoplakia
Dermatology	Herpes simplex, ulcer(s) >1 month	Seborrhoeic dermatitis
	Kaposi's sarcoma	Severe or atypical psoriasis
		Herpes zoster
Ear, nose and throat		Exanthema
		Mononucleosis-like syndrome
		Unexplained oral candidiasis
		Oral hairy leukoplakia
Gastroenterology		Unexplained lymphadenopathy
	Candidiasis, oesophageal	Anal cancer/dysplasia
	Isosporiasis >1 month	Hepatitis A
	Cryptosporidiosis diarrhoea >1 month	Hepatitis B or C
		Chronic diarrhoea of unknown cause
Genitourinary medicine		Weight loss of unknown cause
	Herpes simplex, ulcer(s) >1 month	Any sexually transmitted infection
Haematology	Lymphoma	Unexplained leukocytopenia/ thrombocytopenia >4 weeks
		Unexplained lymphadenopathy
Infectious diseases /internal medicine	Mycobacterium avium complex or Mycobacterium kansasii, disseminated or extrapulmonary	Herpes zoster
	Mycobacterium, other species or unidentified species, disseminated or extrapulmonary	Invasive pneumococcal disease
	Salmonella septicaemia, recurrent	Mononucleosis-like illness
	Cytomegalovirus, other (except liver, spleen, glands)	Oral hairy leukoplakia
	Herpes simplex, ulcer(s) >1 month/ bronchitis/ pneumonitis	Unexplained chronic renal impairment
	Atypical disseminated leishmaniasis	Unexplained fever
	Reactivation of American trypanosomiasis (meningoencephalitis or myocarditis)	Unexplained lymphadenopathy
	Cryptococcosis, extrapulmonary	Unexplained oral candidiasis
	Histoplasmosis, disseminated/extrapulmonary	Unexplained weight loss
	Coccidioidomycosis, disseminated/ extrapulmonary	Visceral leishmaniasis
	Talaromyces (penicilliosis), disseminated	Candidaemia

<sup>3</sup>BHIVA, BASHH & BIA (2020) Adult HIV Testing Guidelines 2020, Appendix 1 <https://www.bhiva.org/file/5f68c0dd7aefb/HIV-testing-guidelines-2020.pdf>

Clinical specialty	AIDS-defining indicator conditions in people living with HIV	Broader indicator conditions
<b>Nephrology</b>		Unexplained chronic renal impairment
<b>Neurology</b>	Progressive multifocal leukoencephalopathy	Guillain–Barré syndrome
	Cerebral toxoplasmosis	Mononeuritis
		Multiple sclerosis-like disease
		Peripheral neuropathy
		Subcortical dementia
<b>Oncology</b>	Cervical cancer	Anal cancer/dysplasia
	Non-Hodgkin lymphoma	Malignant lymphoma
	Kaposi’s sarcoma	Primary lung cancer
		Unexplained lymphadenopathy
		Unexplained weight loss
<b>Obstetrics and gynaecology</b>		Cervical dysplasia
<b>Ophthalmology</b>	Cytomegalovirus retinitis	
<b>Respiratory</b>	Pneumonia, recurrent (two or more episodes in 12 months)	Community-acquired pneumonia
	Mycobacterium tuberculosis, pulmonary or extrapulmonary	Invasive pneumococcal disease
	Pneumocystis carinii pneumonia	
	Candidiasis, bronchial/tracheal/ pulmonary	



# 3. The evidence base and current guidance

## 3.1 Why does indicator condition testing matter?

There are over 6,000 people living with undiagnosed HIV in the UK<sup>4</sup>. This means that they are at risk of getting seriously ill unless they receive treatment promptly. In 2019, there were still 472 HIV-related deaths in England, despite HIV now being a treatable condition<sup>5</sup>. There were also 240 people diagnosed with AIDS at HIV diagnosis, most likely because they were diagnosed with HIV late<sup>6</sup>.

Late diagnosis is defined as those with a CD4 cell count below 350 cell/mm<sup>3</sup>. Late diagnosis leaves an individual 10 times more likely to die within a year of diagnosis. Those with a CD4 count less than 200/mm<sup>3</sup> at diagnosis could have a life expectancy around ten years shorter than someone who starts treatment before reaching this point. This is why early diagnosis of HIV is extremely important.

Of those currently diagnosed with HIV, far too many are diagnosed late - over 40%<sup>7</sup>. For some groups, such as those born abroad, this is over 50%. Again, this means they are likely to have worse health outcomes and may increase the risk of onward HIV transmission.

Despite improvements in testing and increasing rates of diagnosis, still, around 1 in 17 people living with HIV in the UK do not know that they have the virus. This means that they may unknowingly pass on the virus to others.

Evidence suggests that those diagnosed late have many prior interactions with health services and often missed opportunities to diagnose HIV much earlier. Most people who test positive for HIV have visited a GP in the prior year – one study suggested 62% of those who tested positive for HIV had visited an average of three times prior to their diagnosis.<sup>8</sup>

A review of 10 UK studies reporting HIV testing rates in patients presenting with HIV indicator conditions showed that just 22% received an HIV test.<sup>9</sup> Practice is clearly still far too variable and more must be done to ensure guidance (outlined below) is routinely implemented.

Testing for HIV proactively where people present with indicator conditions is a key part of the strategy for getting those living with HIV on effective treatment, reducing and ending HIV transmissions by 2030. All clinical areas have their part to play in this goal.

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“I was throwing up and having diarrhoea so the food which I was eating wasn't staying in my body and I became ill and very thin. And then after all this investigation that's when they referred me to go for a test.”

— 58-year-old female diagnosed late

<sup>4</sup>PHE (2019) Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/939478/hpr2020\\_hiv19.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/939478/hpr2020_hiv19.pdf)

<sup>5</sup>HIV Commission (2020) How England will end new cases of HIV <https://www.hivcommission.org.uk/final-report-and-recommendations/>

<sup>6</sup>PHE (2019) National HIV surveillance data tables <https://www.gov.uk/government/statistics/hiv-annual-data-tables>

<sup>7</sup>Ibid.

<sup>8</sup>Hosein, S. (2015) Uncovering HIV by looking for indicator conditions <https://www.catie.ca/en/treatmentupdate/treatmentupdate-210/anti-hiv-therapy/uncovering-hiv-looking-indicator-conditions>

<sup>9</sup>Elmahdi, R et al, (2014) Low levels of HIV test coverage in clinical settings in the UK: a systematic review of adherence to 2008 guidelines [https://sti.bmj.com/content/90/2/119?ijkey=cac504b252d12eb3e84ac40f073f7d520b68abb4&keytype=tf\\_ipsecsha](https://sti.bmj.com/content/90/2/119?ijkey=cac504b252d12eb3e84ac40f073f7d520b68abb4&keytype=tf_ipsecsha)

### 3.2 What does current guidance say?

National guidance is clear that HIV tests should be offered wherever patients present with indicator conditions, whether at GPs or in hospitals.

#### **NICE guideline (NG60) 2016<sup>10</sup> HIV testing: increasing uptake among people who may have undiagnosed HIV**

In all areas, offer and recommend HIV testing on admission to hospital, including emergency departments, to everyone who has not previously been diagnosed with HIV and who:

- has symptoms that may indicate HIV or HIV is part of the differential diagnosis (for example, infectious mononucleosis-like syndrome), in line with HIV in Europe's HIV indicator conditions.

#### **NICE Quality standard [QS157] 2017<sup>11</sup> HIV testing: encouraging uptake**

- Young people and adults newly diagnosed with an HIV indicator condition are offered an HIV test.

#### **British HIV Association (BHIVA)/ British Association for Sexual Health and HIV (BASHH)/ British Infection Association Adult HIV Testing Guidelines 2020<sup>12</sup>**

People presenting with symptoms and/or signs consistent with an HIV indicator condition:

- All individuals presenting to any healthcare provider in any healthcare setting with an indicator condition should be recommended to have an HIV test (Grade 1C–2D; 1D for AIDS-defining conditions). See Appendix 1 for indicator condition tables, including by specialty (Table 3).
- Individuals who decline on first offer should have at least one repeat offer made at a subsequent visit (Grade 1D).
- Services providing HIV testing should have adequate results governance and agreed documented transfer to care pathways (Grade 1D).

### 3.3 What is the evidence on effectiveness of indicator condition testing?

There is strong evidence about the clinical and cost-effectiveness of HIV indicator condition testing. As BHIVA guidance states – 'An undiagnosed prevalence of 0.1% is consistently considered to be cost-effective for HIV screening'.<sup>13</sup>

Each of the named indicator conditions have been identified because there is a higher prevalence of HIV amongst those living with these conditions. This means that in every 1000 people with this clinical condition there is likely to be 1 person living with HIV.

There have been several large-scale studies, looking at a variety of locations, that have evidenced this. HIDES 1<sup>14</sup> and HIDES 2<sup>15</sup> were significant European wide studies, and both pieces of research showed significant correlation between the indicator conditions studied and HIV prevalence. The median HIV positive rate was 0.9 per cent. It also concluded that testing rates in well-established HIV indicator conditions remain surprisingly low across Europe, despite these high HIV prevalence rates, reflecting serious and significant missed opportunities for earlier diagnosis and care.

<sup>10</sup>NICE (2016) HIV testing: increasing uptake among people who may have undiagnosed HIV <https://www.nice.org.uk/guidance/ng60>

<sup>11</sup>NICE (2017) HIV testing: encouraging uptake <https://www.nice.org.uk/guidance/qs157/chapter/quality-statement-3-hiv-indicator-conditions>

<sup>12</sup>BHIVA, BASHH & BIA (2020) Adult HIV testing guidelines 2020 <https://www.bhiva.org/file/5f68c0dd7aefb/HIV-testing-guidelines-2020.pdf>

<sup>13</sup>Ibid.

<sup>14</sup>Sullivan, A et al (2013) Feasibility and effectiveness of indicator condition-guided testing for HIV: results from HIDES 1 <https://pubmed.ncbi.nlm.nih.gov/23341910/>

<sup>15</sup>D Raben et al, (2019) Auditing HIV Testing Rates across Europe: Results from the HIDES 2 Study <https://pubmed.ncbi.nlm.nih.gov/26560105/>

# 4. Where and amongst who HIV indicator conditions are commonly found

## 4.1 Doesn't HIV affect certain groups and areas disproportionately, and perhaps not people in our area or service?

HIV affects every group in society and every community. Every hospital will likely have people with HIV using their services, and those undiagnosed will likely be accessing GPs and Hospital Trusts regularly across the country.

While certain groups are at higher risk, and certain areas have higher overall prevalence rates of HIV, finding every person with undiagnosed HIV is vital to ending the epidemic by 2030. Indicator condition testing is also a critical strategy for reaching those people undiagnosed who are not from 'at risk' groups and therefore who may be less likely to be tested through targeted public health testing opportunities and messaging.

It is important to reflect on the changing face of HIV and ensure that assumptions are not made about particular demographic factors when deciding whether or not to offer an HIV test – the crucial decision should be – does the patient have an indicator condition or not?

“

“My other regret is that my GPs did not ask questions about my social/ personal circumstances.

“I am sure that as I'm a white middle-aged professional woman it never crossed their minds I could be at risk of HIV.

“The preconceived assumptions of a typical person with HIV prevented an earlier diagnosis.

“You should never use societal stereotypes or typical norms when diagnosing.”

— A woman diagnosed late with HIV having presented with several indicator conditions

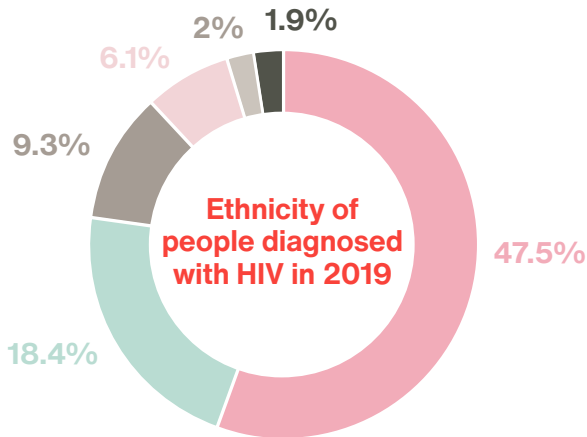






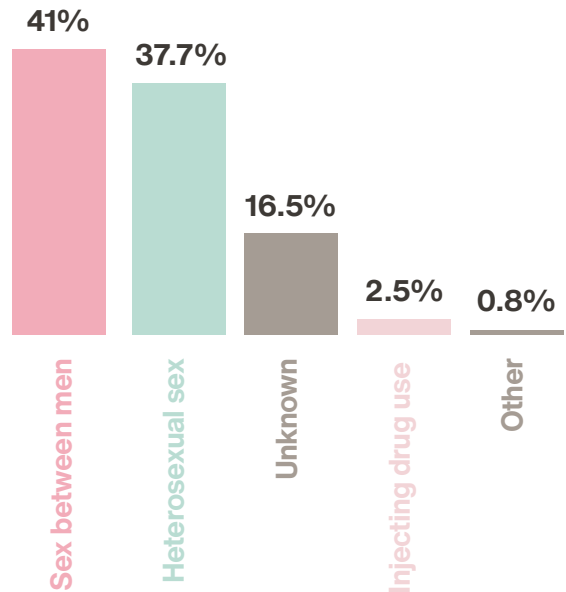
# 1 in 3

Around 1 in 3 people diagnosed with HIV are female



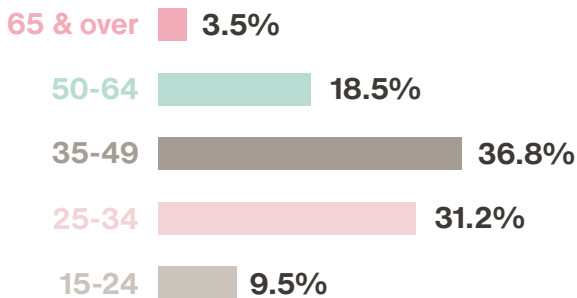
- White (1,965)
- Black African (762)
- 'Other/mixed' ethnicity (383)
- Asian (253)
- Black Caribbean (83)
- Black other (78)

### Those newly diagnosed in 2019 - mode of transmission



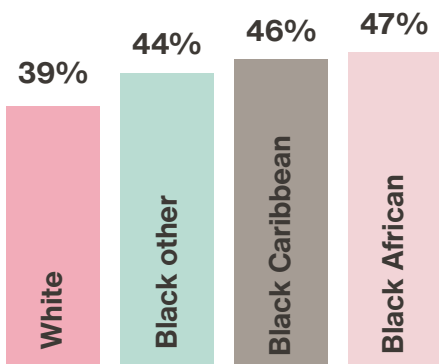
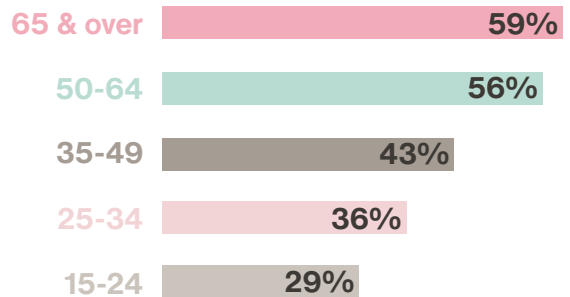
### Age of people diagnosed with HIV in 2019

More people are now being diagnosed with HIV later in life, with 1 in 5 now diagnosed over 50.

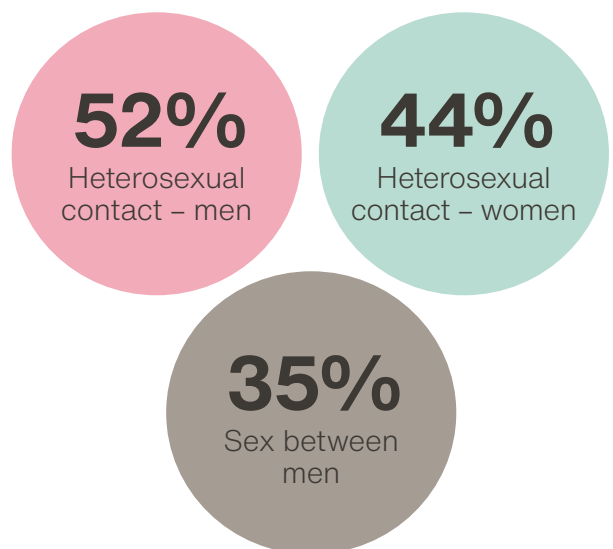


### Late diagnosis with HIV by age in 2019

Older people are much more likely to be diagnosed late.



Late diagnosis with HIV in 2019 by ethnicity



Late diagnosis with HIV in 2019 by probable route of HIV exposure



#### 4.2 Isn't HIV testing something for Sexual Health Services to do?

Sexual Health Services (SHS) do offer HIV tests to thousands of people a year. Increased proactive HIV testing at SHS, online and in other settings has contributed to decreases in HIV diagnoses and acquisitions in the last decade.

However, we know that certain groups are more likely to use SHS than other groups. Not everyone with undiagnosed HIV will access these services and not everyone who does accepts an HIV test. SHS are also not always accessible for everyone, particularly outside of urban areas.

On the other hand, we do know that those with indicator conditions, because of these health issues, will often regularly engage with primary care or hospitals. These are vital opportunities to test and diagnose HIV that should not be missed.

HIV is everyone's business in the health system, there are no reasons why HIV testing, like many diagnostic tests, should only be reserved for sexual health services. Referring patients back to SHS for HIV tests is likely to mean many fall through the gaps.

HIV testing is offered and carried out already in many other health settings successfully. Whether this is GP practices on registration, opt-out screening in maternity services, in A&Es in some high prevalence areas or in some clinical specialties where indicator conditions are found. It is important as well that health professionals themselves do not reinforce that HIV testing is in any way stigmatised, should be singled out or linked only to sexual health. It should and could be openly discussed and offered in any health setting.

“

“By the time that I was diagnosed with HIV, the virus had progressed to the point where my CD4 [count] was very low and my Viral Load was extremely high.

“I had been to my GP in Hackney and also to a private GP (through work) at least 6 times a year for at least 5 years. I was never offered an HIV test.

“My GP had never spoken to me about sex or sexuality – I think that some GPs believe that sexually transmitted infections are to be dealt with by sexual health treatment centres.

“Had my GP(s) had an open discussion with me about my sexuality and sexual practices, it may well have occurred to him to have ordered an HIV test. In this case I believe I would not have suffered so many opportunistic infections – the last infection being PCP which was identified after being admitted to A&E.”

— A man diagnosed late with HIV having presented with several indicator conditions

### 4.3 Isn't this just for high prevalence areas/the prevalence is so low in my area does this really matter?

Not everyone will be proactively accessing testing in SHS. In some areas of the country, often lower prevalence areas, SHS can be less accessible than local GPs and hospitals.

While naturally the areas of high prevalence have the most people living with HIV undiagnosed, there are still hundreds of people living with undiagnosed HIV outside of these areas. Wider indicator condition testing is vital particularly in lower prevalence areas in providing an evidence-based way of identifying those more likely to have HIV. In these areas they may not be coming across opportunities to test through targeted public health initiatives otherwise.

Region	Positivity per thousand tests
East Midlands	1.82
East of England	1.45
London	3.21
North East	1.36
North West	0.74
South East	1.31
South West	0.45
West Midlands	1.74
Yorkshire & Humber	1.29
National	1.65

**Table 2. Antenatal HIV screening positivity in England in 2010<sup>16</sup>**

As data from antenatal HIV screening shows, there are significant positivity rates reported across regions in England. All but two regions saw rates above 1 per 1000 in testing which was universally done on an opt-out basis, not specially targeted to those with risk factors associated with HIV.

To end HIV by 2030, we will have to find everyone living with the condition, diagnose them and move them onto successful HIV treatment so they can live well and will not pass on the virus.

As we diagnose more people and hopefully prevalence reduces nationally, it will become more challenging to find people. We must test more people for every positive test. But the overall gains for the health system, society, and our mission to end HIV become greater. It is important, in the context of the aim of ending HIV transmissions by 2030, that traditional cost-effective arguments are not relied upon alone to dictate decisions around testing. There are significant relative benefits from greater reduction in the number of cases of HIV in pushing us further towards the achievable but ambitious outcome of ending new HIV transmissions.



“It remains the case that we see people diagnosed with HIV at a late stage, with a lower CD4 count and, far too frequently, with an AIDS defining diagnosis.

“This is a tragedy in 2021, and many have had missed opportunities for diagnosis in the past, either in primary care or when attending other healthcare settings. While falling infection rates in urban men who have sex with men are to be celebrated, we must look at ways to ensure others with HIV are diagnosed in a timely way, ensuring early access to treatment and better life expectancy.

“It tends to be the case that late diagnoses occur more commonly in areas of lower HIV prevalence. For this reason, it is even more essential that ‘indicator conditions’ are widely publicised, understood, and HIV testing recommendations adhered to.”

— Dr Tristan Barber, Consultant in HIV medicine

<sup>16</sup>Health Protection Agency (2011) Time to test for HIV: Expanding HIV testing in healthcare and community services in England: [https://www.bhiva.org/file/gMSwfxmXnFQeb/Time\\_to\\_test\\_final\\_report\\_Sept\\_2011.pdf](https://www.bhiva.org/file/gMSwfxmXnFQeb/Time_to_test_final_report_Sept_2011.pdf)

# 5. Patient views, reactions and expectations

## 5.1 What should I do to inform and support my patients – what consents are needed?

HIV testing does not require any special form of consent or information for patients beyond any other standard clinical testing. No pre-test counselling or information needs to be provided. You don't need to take any sexual history, check someone's country of origin, or any other demographic factors – anyone can have HIV and the presence of an indicator condition is more than enough to warrant a precautionary test. There does not need to be any specific justification given apart from the presence of an indicator condition. The more routine offers of testing are, the more acceptable they are to patients.

It is always in a patient's best interests to know about any underlying health conditions, including HIV. Prompt diagnosis is vital in improving outcomes, ensuring patients are on effective HIV treatment and achieve an undetectable viral load so they cannot pass on the virus. Indeed, if a person living with HIV is already presenting with other health conditions, then it may be that they have already had HIV for some time and prompt diagnosis is critical.



“While healthcare providers report concerns around offering testing, patient surveys have shown that people expect to be tested for conditions that are treatable, including blood borne viruses such as HIV.

“An offer of a test should treat this as routine, with no specific consent process required. ‘We test for blood borne viruses including HIV, is that ok?’ is usually all that is required.”

— Dr Tristan Barber, Consultant in HIV medicine



## Top tips:

- no additional consents are needed beyond your usual consent process for other routine clinical testing – apply the same procedures and practices
- no written consents are needed
- you do not need to introduce a specific HIV testing consent form – this is not needed and HIV testing should not be exceptionalised.

## 5.2 Will patients want to be tested for HIV?

Like any long-term health condition, it is important people are aware of underlying health conditions and can access timely treatment. It is in every patient's interest, and the health system's interests to support early diagnosis.

There is no evidence that people do not want to be given the opportunity to be tested for HIV. Where tests are offered routinely, without fuss, and recommended by health professionals in a precautionary way to rule out HIV as they would any other health condition, opt-out rates are extremely low. Some people even assume it will be covered as part of blood tests they receive. Further, receiving a late diagnosis of HIV when there have been clear missed opportunities to test can hugely erode a patient's trust in healthcare.

It should not be left to patients to request an HIV test. One study looked at acceptability in several 'non-traditional' settings for HIV testing, including Acute Care, Dermatology, Primary Care and Accident & Emergency, and found that take up of HIV tests was high ranging from 61% to 75% across the sites. They also found that individuals who have not been tested for HIV before, were in

fact more likely to accept a test and there was no association between uptake and sexuality. This suggests that HIV tests are acceptable not only to those who may be more exposed to targeted information on HIV and testing. Offering HIV tests across healthcare settings is a good route to widen access to those not accessing testing already via sexual health services.<sup>17</sup>

Maternity services have a rate of over 99 percent coverage for HIV testing for all expectant mothers, which shows how opt-out HIV testing can be provided with high take up rates. There was no measurable decline in access to maternity services because of offering HIV testing and it is now a normalised feature of midwife care in early pregnancy.

While tests offered in pregnancy may be thought of in terms of the interests of the unborn child, and this may change attitudes towards the offer of the test from providers, the interests of the expectant mother should also be paramount, as should the interests of patients more generally; it is always better to know your HIV status.

The high rate of uptake in other services can be seen again in the Time to Test pilots with take up of between 62-91% in hospitals (across a range of settings from emergency departments, outpatient clinics and acute care units), this study found patients attending services found it overwhelmingly acceptable to be offered HIV tests.<sup>18</sup>

“

“My biggest regret is that the multiple GPs I saw before my diagnosis didn’t look back on my notes and make connections with the health problems I had presented with over a period of several years.

“Each time I went with a new symptom it was dealt with in isolation. If they had looked back on previous consultations they may have made the connection that my symptoms, taken together, indicated a low immune system.”

– Woman diagnosed late with HIV



## Top tips:

- use language that infers that HIV testing is routine, precautionary and something you as a clinician recommend without any judgment
- don’t ask the patient if they would like one arranged or whether they as a patient feel this is needed.



<sup>17</sup>Rayment, M. et al, (2012) HIV Testing in Non-Traditional Settings – The HINTS Study: A Multi-Centre Observational Study of Feasibility and Acceptability <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0039530>

<sup>18</sup>Health Protection Agency (2011) Time to test for HIV: Expanding HIV testing in healthcare and community services in England: [https://www.bhiva.org/file/gMSwfxmXnFQeb/Time\\_to\\_test\\_final\\_report\\_Sept\\_2011.pdf](https://www.bhiva.org/file/gMSwfxmXnFQeb/Time_to_test_final_report_Sept_2011.pdf)

### 5.3 What do we do with positive HIV results – is there a pathway for support?

While it is never good news to be told you have a long-term health condition, knowing about a diagnosis enables better health outcomes through early treatment. It is important to share a positive HIV result with patients clearly, confidentially and sensitively.

Reassuring messaging about what the diagnosis means should be provided. People's understanding of HIV may not be up to date – i.e. that HIV is not a death sentence, but a manageable long-term condition. Let a person know that treatment is available and is effective at enabling people to live full, healthy lives. Most people are on successful treatment, and this means they cannot pass the virus on.

It is important to ensure patients with positive results are linked to HIV care promptly. This can easily be arranged by your local HIV team and service which may even be based in your hospital. If you require help and support doing so, you can and should reach out first for support from local HIV and sexual health services. Being told your diagnosis in the right way, with all the support lined up and linkage to care set up, is pivotal.

It would also be helpful to ensure patients are aware there are voluntary and community sector groups who can support them, including online, which can be found via the [NHS HIV support services locator](#), or from national HIV organisations.



“Most results will be negative, but where a reactive result is returned local HIV services should be only too happy to help with giving results, and ensuring a newly diagnosed patient is rapidly seen, assessed, supported, and counselled about their HIV diagnosis and plans for subsequent treatment.”

— Dr Tristan Barber, Consultant in HIV medicine



## Top tips:

- it is important to convey clear messages to people promptly, as many are unaware of the huge advances we have made in treating HIV in recent years
- HIV treatment is extremely effective and most people now start treatment as soon as they are diagnosed. Someone living with HIV, diagnosed in good time and on treatment can lead a full, active life with a normal life expectancy
- treatment reduces the level of HIV in the body to what is called an 'undetectable viral load'. People living with HIV with an undetectable viral load cannot pass the virus on to sexual partners. This is known as U=U (Undetectable = Untransmittable)
- 98% of people diagnosed with HIV in the UK are on treatment, and 97% of those on treatment are virally suppressed which means they cannot pass the virus on.

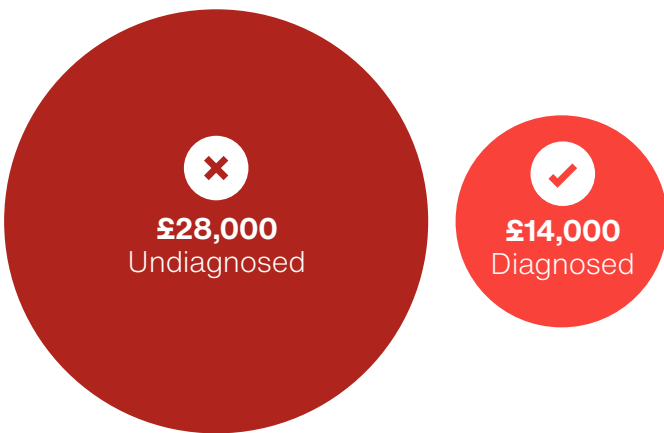


# 6. Funding, training and resourcing

## 6.1 Who should fund HIV indicator condition testing?

- ① Clinical Commissioning Groups are responsible for funding testing in secondary care specialties for clinical indicator conditions (with ICSs expected to have an increasing role in the future).
- ② NHS England are responsible for commissioning HIV testing for clinically indicated reasons in any NHS England commissioned services.
- ③ NHS England are responsible for HIV testing in primary care where this is clinically indicated, such as an indicator condition.

HIV indicator condition testing is extremely cost effective. Costs for HIV testing can vary, but on average testing is approximately around £7 per test.<sup>19</sup> The average cost of treatment and care per-year after HIV diagnosis is significantly more when diagnosed late.



Cost of treatment per year <sup>20</sup>

Every HIV diagnosis also reduces onward transmissions, saving significant lifetime costs. Each HIV infection costs the NHS between £280,000 and £360,000 over that individual's lifetime<sup>21</sup>.

NICE estimates that if its testing guidance, which includes indicator condition testing as routine practice, were to be implemented, 3,500 cases of onward transmission would be prevented within 5 years, saving £18 million a year in treatment costs.<sup>22</sup>

Further evidence indicated that preventing just 1 per cent of acquisitions would save between £14.5m to £18.7m to the NHS.<sup>23</sup>



“NICE guidance states that HIV testing should be offered and recommended to any patient who has symptoms that may indicate HIV or HIV is part of the differential diagnosis (HIV in Europe’s HIV indicator conditions).”

“Delineated commissioning responsibilities for HIV testing are complex, and may depend on both the healthcare setting that the patient is in and the rationale for testing.”

“However, the general principle holds that the organisation responsible for commissioning a particular service area is responsible for commissioning testing when clinically indicated within that service. So, for example, CCGs are responsible for indicator conditions testing in A&E, and NHS England are responsible for commissioning indicator conditions testing in General Practice”

— English HIV and Sexual Health Commissioners Group

<sup>19</sup>NICE (2016) Resource impact report: HIV testing: increasing uptake among people who may have undiagnosed HIV <https://www.nice.org.uk/guidance/ng60/documents/economic-report>

<sup>20</sup>NICE briefing paper (undated) HIV testing <https://www.nice.org.uk/guidance/qs157/documents/briefing-paper>

<sup>21</sup>NICE (2016) Resource impact report: HIV testing: increasing uptake among people who may have undiagnosed HIV <https://www.nice.org.uk/guidance/ng60/documents/economic-report>

<sup>22</sup>Halve It Position Paper (2017) A roadmap for eliminating late diagnosis of HIV in England [https://static1.squarespace.com/static/5b7d333855b02cc3853805ce/t/5bcf315b4785d396581ad0d9/1540305246477/halve\\_it\\_main\\_briefing\\_paper\\_FINAL\\_web%5B1%5D.pdf](https://static1.squarespace.com/static/5b7d333855b02cc3853805ce/t/5bcf315b4785d396581ad0d9/1540305246477/halve_it_main_briefing_paper_FINAL_web%5B1%5D.pdf)

<sup>23</sup>NICE (2016) Resource impact report: HIV testing: increasing uptake among people who may have undiagnosed HIV <https://www.nice.org.uk/guidance/ng60/documents/economic-report>

## 6.2 What training is needed for staff?

Staff do not necessarily need any specialist training about HIV testing. However, healthcare staff should know basic up-to-date information on HIV (including the effectiveness of HIV treatment) and successful implementation should include for staff:

- support to understand any new procedures and practices
- detail on what HIV indicator conditions are, which they should be identifying and why
- support with wording/phrasing (e.g. some of the top tips in this guide) that will encourage take up
- support on communicating a positive result and details on referral pathways for treatment and support.

There are a number of existing tools that can be used for support and learning including:

- [online training](#) available from Health Education England about HIV, including HIV testing, provided in association with BASHH
- National AIDS Trust resources for health providers including a [PowerPoint](#) and [training guide](#)
- National AIDS Trust – [HIV the facts](#), a guide to key facts about HIV for staff and patients.

## 6.3 How do you have the time in clinic to deliver extra tests?

When not requiring a long or additional paper-based consents system for HIV testing, it should not take any more time to recommend an HIV test compared to any other diagnostic tests.

If testing takes place at the same appointment, which is optimal, it may take a little extra time (particularly if no other blood screening is taking place), but may still be more efficient than arranging separately. However, it is vital that a few extra minutes is not a reason to avoid testing and risk a more costly late HIV diagnosis which can, if untreated, lead to further healthcare appointments, cost and poorer quality of life and outcomes.

If it is not possible to offer a test at that specific appointment, there are a range of options for referring to tests elsewhere or offering self-sampling kits. These are explored further on the next page.





## 6.4 What HIV test should we use?

Any HIV test is better than no HIV test. Choosing the exact method to introduce will sometimes depend on the practicalities of the service setting and resources available.

The types of testing in order of preferability are outlined here:

### ① Laboratory testing

### ② Point of care testing

Rapid tests usually for example by collecting a finger prick blood sample and offer quick results usually in a matter of minutes. These have a lower specificity rate but are quicker.

### ③ Home sampling or HIV self-testing kits

These are kits that in many areas can be ordered and used at home. Home sampling gives an individual the opportunity to collect their own samples and return them either by post or in person for analysis. Positive results are delivered by phone but will need a confirmatory test in a sexual health clinic. Self-testing enables people to both collect a sample and get the results themselves at home.

### ④ Referring people to other avenues for testing

Services can refer people to local sexual health services. However, this is not the preferred method as this is likely to delay diagnosis and lead to significant drop out.

A test being offered at the same clinical appointment is recommended. National guidelines recommend fourth-generation HIV laboratory tests with venous sampling as the first-line choice for testing. Point of care testing (POCTs) is also supported (which are largely third-generation tests). Where a positive test result is received, it is recommended that there is further confirmatory testing as determined by local care pathways.



## Top tips:

- while you should actively encourage testing and include it as part of routine monitoring, it is possible a small number may decline a test. For those who decline a test, it is recommended that they are informed that they should take a precautionary test at some point in the near future, and they should be referred to other nearby testing services – for example let them know they can visit local sexual health testing services and also tell them that usually it is possible for them to order tests online. Many people are unaware of such services
- the NHS has an [online directory](#) of local HIV testing services.



## 6.5 How do I set up indicator condition testing in my service?

There is a step-by-step guide for services about what to consider, from pre-test, through testing and post-test support. This resource has been developed for lead clinicians or managers across Europe who are planning to introduce indicator condition guided HIV testing in their service: <https://www.opttest.eu/planningguide>



### Top tips:

- appointing a local champion for testing can help drive forward and embed change, speaking to staff and team leaders to ensure they are comfortable with new practices and a key point of contact internally for staff
- auditing and evaluation are key; schedule regular reviews of performance across the service. When people with HIV indicator conditions presented in your service, were tests offered and what was the level of uptake?

## 6.6 How do we make indicator conditions a local priority?

Leadership is key, within a GP practice, Primary Care Network, hospital department or across a whole Hospital Trust. It is important to ensure there is clear direction from leaders that this is a clinical priority, and messaging on why HIV indicator condition testing is important. Services need to ensure there is ongoing monitoring of the level of testing, with checks on progress.

Service commissioners and planners can also consider the role of performance incentives, payments and KPIs. There is evidence that this can provide a route to increase the uptake of indicator condition testing in practice as has been seen through various pilots and standalone areas of focus e.g., in 2012, 66.8% of eligible individuals with Tuberculosis (TB) were tested for HIV, however following greater clinical leadership and priority in the system, this climbed to 81.1% in 2013, in just one year. The reason was that routine HIV testing was included as a key performance indicator for this clinical area.



“There have been some very successful pilots to increase the offer and uptake of testing.

“The provision of training can also dispel myths and increase confidence of clinicians, and could usefully be rolled out across the wider workforce such as pharmacy and dentistry. However, unless HIV testing is embedded in standard systems it may not become routine. Practical barriers can be overcome e.g. making HIV more prominent and easier to find on blood test request forms. But a cultural shift is also necessary, so that HIV testing becomes normalised and seen as relevant to wider healthcare, with clinicians feeling confident to talk about HIV just as they would any other long-term condition.”

— English HIV and Sexual Health Commissioners Group

## 7. Other resources

**British HIV Association for testing guidelines and standards:**

🔗 <https://www.bhiva.org/>

**British HIV Association/British Association for Sexual Health and HIV/British Infection Association Adult HIV Testing Guidelines 2020:**

🔗 <https://www.bhiva.org/HIV-testing-guidelines>

**British HIV Association - consensus statement on U=U:**

🔗 <https://www.bhiva.org/BHIVA-encourages-universal-promotion-of-U-U>

**HIV for non-specialists: Diagnosing the undiagnosed – a guide to a number of clinical areas and HIV indicator conditions:**

🔗 [https://www.nat.org.uk/sites/default/files/publications/hiv\\_for\\_non-hiv\\_specialists.pdf](https://www.nat.org.uk/sites/default/files/publications/hiv_for_non-hiv_specialists.pdf)

**HIV in Europe - HIV indicator conditions: guidance for implementing HIV testing in adults in health care settings:**

🔗 [https://webgate.ec.europa.eu/chafea\\_pdb/assets/files/pdb/20114202/20114202\\_d7\\_en\\_ps.pdf](https://webgate.ec.europa.eu/chafea_pdb/assets/files/pdb/20114202/20114202_d7_en_ps.pdf)

**HIV Prevention England - resources for GPs and primary care professionals:**

🔗 <https://www.hivpreventionengland.org.uk/evidence-and-guidance/gps-and-primary-care-professionals/>

**i-base - Free U=U Resources:**

🔗 <https://i-base.info/u-equals-u-resources/>

**NICE - for up-to-date guidance in HIV testing:**

🔗 <https://www.nice.org.uk/guidance/ng60>

**NICE - guideline for encouraging the uptake of HIV testing:**

🔗 <https://www.nice.org.uk/guidance/qs157>

**OptTest - a range of tools including an indicator condition testing planning tool for services:**

🔗 <https://www.opttest.eu/Tools>

**Saving Lives - useful resources including patient leaflets:**

🔗 <https://www.savinglivesuk.com/resources/clinical-indicator-leaflets/>

**ViiV - links to their 'change the face of HIV' video:**

🔗 <https://www.youtube.com/watch?v=L5IJSTo4SxU>

## 8. Acknowledgements

The National AIDS Trust would like to thank those who have provided advice and support across a range of clinical specialties and professional bodies. A special thank you in particular for those who gave their time as part of our advisory group including:

**Dr Tristan Barber, HIV Consultant** - Royal Free London NHS Foundation Trust

**Dr Ann Sullivan, HIV Consultant** - Chelsea and Westminster NHS Foundation Trust

**Dr Rebecca Marcus, HIV Consultant** - North Middlesex University Hospital NHS Trust

**Dr Adil Sheraz, Consultant Dermatologist** - Royal Free London NHS Foundation Trust

**Dr Ian Gabriel, Consultant Haematologist** - Chelsea and Westminster Hospital

**Dr Alison Wright, Consultant Obstetrician & Gynaecologist** - Royal Free London NHS Foundation Trust

We are also grateful for those with lived experience of HIV and late diagnosis who have shared their experiences with us and helped inform this project including David Williams.

Finally, thank you to Gilead for their generous contribution to National AIDS Trust's work on HIV Indicator Condition testing, which supported the research and writing of this best practice guide.



# NATIONAL AIDS TRUST

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**We're the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions.**

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