



# Reporting HIV:

## how to get it right



**D**espite huge advances, people with HIV can still unfortunately face stigma and discrimination. Stigma is created by many contributing factors including stereotypes; intersecting prejudices (such as racism, homophobia and transphobia); myths and misinformation about HIV and fear. Stigma leads to discrimination against and marginalisation of people living with HIV; it affects their health and well-being; discourages open discussion about HIV; stops people from testing for HIV and ultimately, it drives the epidemic.

Most of the public engage with information on HIV and related issues only through reading about them in the media, therefore, journalists have an important role in challenging factors that lead to stigma.

NAT (National AIDS Trust) monitors news coverage of HIV in the UK and frequently responds to incorrect and stigmatising stories. The information in this document is developed based on common issues we come across. It can be used as an update of and supplement to NAT's Guidelines for Reporting HIV, which were published in 2010.

### Life with HIV

When diagnosed in good time, people living with HIV in the UK can expect to lead long, healthy and fulfilling lives. HIV is not a barrier to people being able to do any job, have relationships and start families. There are a significant minority of people living with HIV with more serious health problems, particularly if diagnosed late. A late diagnosis increases the likelihood of developing AIDS-defining illnesses. People diagnosed before effective treatment became available are more likely to experience health issues and for some HIV can be a fluctuating condition, with

times of poorer health. HIV treatment has massively improved over recent years with fewer people experiencing side effects.

For many people living with HIV, the virus itself may not be a key challenge they face. However, experiences of HIV-related stigma and discrimination can have a significant negative impact on their well-being. Despite being protected by HIV-related discrimination by law, people with HIV continue to encounter stigma and discrimination, including in the workplace and in healthcare settings. The knock-on effects of stigma are far-reaching; people living with HIV are more likely to suffer from depression, social isolation or live in poverty.

# DOS & DON'TS



**DON'T** say AIDS (unless you really mean it) or HIV/AIDS.

**DON'T** write that a person has been at risk of HIV when they have not.

**DON'T** refer to 'HIV sufferers' or 'HIV victims' or to HIV as a 'death sentence' or a 'terminal disease'.

**DON'T** imply that only gay men can acquire HIV.

**DON'T** report that condoms are the only way to prevent HIV.

**DON'T** put HIV in a story, or disclose a person's HIV status, when it's not relevant.

**DO** say HIV and, if relevant, HIV and AIDS.

**DO** remember most people living with HIV in the UK are on effective treatment and cannot transmit the virus and that you cannot get HIV from spitting, biting or from discarded needles.

**DO** refer to 'people living with HIV' and to HIV as a long-term condition, remembering that people diagnosed with HIV in good time have the same life expectancy as anyone else.

**DO** remember lots of people living with HIV are heterosexual (roughly half in the UK) and that HIV disproportionately affects groups that face wider prejudice such as gay and bisexual men, trans people and people from BAME groups.

**DO** report that condoms are an important aspect of HIV and STI prevention, but that there is also a pill you can take to protect yourself from HIV (PrEP) and that HIV treatment means that most people living with HIV cannot transmit the virus.

**DO** remove unnecessary references to HIV and protect the right to confidentiality of a person living with HIV wherever possible.

## ...and how it can't

**SPITTING AND BITING:** Although being spat at may be unpleasant, those who have been attacked in this way are not at risk of HIV. This applies even when the spit contains blood. *There has never been a case of HIV being transmitted through spitting.* There have been five cases internationally where it is thought that HIV may have been transmitted via human bite. However, these were all in extreme and highly unusual circumstances. *Biting it is not considered an HIV risk by medics.*

You may come across information from news sources that suggest there has been an HIV risk from an assault involving spitting or biting. *This is based on misinformation and you should avoid reproducing this misinformation and damaging public understanding.* If you have a from quote somebody who has said spitting or biting has posed an HIV risk, consider approaching the source to clarify their position. If they maintain this aspect of their statement, you might remove the quote or follow the quote with a clear, clarifying point that they are incorrect. NAT can always provide you with statements to clarify.

**DISCARDED NEEDLES:** Because it is widely known that sharing of needles is a transmission risk, people also associate discarded needles with HIV. As well as the fact that HIV prevalence is very low amongst people who inject drugs in the UK, HIV itself is a very fragile virus that does not survive for long outside the body. *There have been no cases of HIV transmission from an injury from a needle discarded in public.*

If writing about a discarded needle problem in an area, HIV would not be relevant and referring to HIV risk would cause unnecessary worry. If you must quote someone who cites HIV worries, consider adding a clarifying point that there have been no cases caused this way.

**BLOOD PRODUCTS:** Before HIV transmission was well understood, some individuals received blood products which resulted in HIV infection. All donated blood is now screened for HIV in the UK and there are also other measures put in place to minimise risk. 0.9% of people living with HIV in the UK acquired HIV from receiving blood products in the past.

## How HIV can be transmitted

**SEX:** Most people acquire HIV through sex. Anal or vaginal intercourse can pose an HIV transmission risk. The risk of HIV transmission from oral sex is very small. Condoms massively reduce the risk of transmission of HIV and other STIs. Taking the HIV prevention pill PrEP eliminates the risk of HIV. There is *no risk* of getting HIV from sexual contact with someone who is diagnosed with HIV but whose viral load is undetectable (see U=U).

**SHARING OF INJECTING EQUIPMENT:** HIV can be transmitted when sharing needles due to the immediacy of the exchange of blood. However, because of harm reduction efforts (like needle exchanges) this route accounts for only a very small proportion of HIV transmissions in the UK (around 2%).

**VERTICAL TRANSMISSION:** HIV can be transmitted in the womb, during birth, and through breastfeeding, but this is preventable through medication. In the UK, fewer than 0.5% of children born to mothers living with HIV in the UK will be HIV positive. Only 1.6% of people living with HIV in the UK acquired HIV from their mother in infancy.

## Aid AIDS awareness

AIDS and HIV are not the same thing, and writing one when you mean the other could make your copy medically inaccurate and add to unhelpful confusion between the two. HIV is a virus that 101,000 people in the UK have. Because of treatment, the vast majority do not develop AIDS (a syndrome when serious illnesses are caused by a weakened immune system). Don't say AIDS (unless you are sure you mean it) and remember there is no such thing as an 'AIDS test,' only an HIV test.

In the UK people with HIV *can* still develop AIDS-defining illnesses which is especially likely if when their HIV is undiagnosed for long periods, or when they are not accessing healthcare, however, this is uncommon in the UK. So, in most stories you can simply refer to HIV and *avoid the word 'AIDS'* unless you are clearly writing about the specific syndrome.

### WHEN MIGHT IT BE APPROPRIATE TO REFER TO AIDS:

**HISTORY:** You are referring to a time in the 80s and 90s when more people with HIV developed AIDS.

**GEOGRAPHY:** You are writing about HIV and AIDS in countries where treatment access is limited. But the rules still apply - it is still important to understand the distinction between HIV and AIDS.

**IN MEMORY:** You are writing about key figures or other individuals who were lost to AIDS such as Freddie Mercury.

## U=U: read all about it

A community of researchers, clinicians and organisations have signed up to a consensus statement, U=U; this stands for Undetectable = Untransmittable.

The overwhelming majority of people living with HIV in the UK are on medication which reduces the amount of the virus in their body to the point of being undetectable.

***HIV cannot be transmitted from a person with an undetectable viral load.***

Therefore, we now understand that hardly anyone gets HIV from somebody who knows they have it (because such a person is likely to be undetectable or taking precautions) – people are far more likely to acquire HIV from those who are undiagnosed. This highlights the importance of HIV testing.

## Be PrEPared

PrEP is a daily pill that can be taken by HIV negative people to prevent them from acquiring HIV. There are no doubts over its medical effectiveness. Trial results don't report 100% effectiveness but this is because a small number of participants didn't adhere strictly to taking the pill. PrEP can be life-changing for those who are at increased risk of HIV. PrEP is available on the NHS in Scotland and Wales. In 2016 NAT won a landmark court case against NHS England over their decision not to consider providing PrEP; it is now being rolled out in England through the PrEP Impact Trial.

## Criminal transmission

People knowingly risking the transmission of HIV to someone else is rare. Even rarer still is someone deliberately passing the virus on to a partner (indeed, there has only been one conviction for this crime in the UK). If reporting on these cases, bear in mind the important legal distinction between reckless transmission (knowing there is a risk of transmission and not taking precautions) and intentional transmission (setting out to deliberately transmit the virus).

Do not write anything that implies people living with HIV are obliged to disclose their status to their sexual partners. While being open about sexual health is good, there is no legal obligation to disclose. Most people living with HIV cannot pass the virus on and do not pose a transmission risk.

It is regrettable that these stories can dominate media coverage of HIV, when they bear no resemblance to the experiences of the vast majority of people with HIV. If you are reporting on a criminal transmission issue, please avoid sensationalist language, or anything that implies this is a common occurrence.



## We will call you, so why not call us first?

Any questions? Give us a call on **020 7814 6767**

We will call you if you get it wrong, so if you're feeling unsure you may as well call us first to get it right!

## Are you on board?

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