



# Guidelines for Reporting HIV

Advice for editors and journalists writing about HIV in the UK



# Foreword by Deborah Jack

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HIV first emerged in the 1980s. Since then the global HIV pandemic has rarely been out of the news for long. It is still one of the most pressing health challenges facing the world.

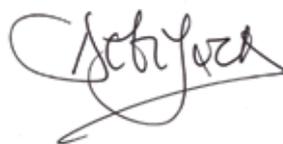
In the early days of the epidemic little was known about the virus. There was a great deal of fear about how it was spread and many people died from HIV-related illnesses. Today, treatment has revolutionised what it means to live with HIV. Someone with HIV who gets tested, is diagnosed early and is treated effectively will not go on to develop AIDS and instead can live a long life, work, exercise, even have a family if they choose.

Despite advances in treatment, social attitudes are changing much more slowly. Evidence shows public knowledge of HIV in the UK is declining and there is a worrying lack of understanding about HIV.

The media play an important role in communicating to the public what exactly it means to live with HIV today. Understanding the advances in knowledge and treatment around HIV is vital to reporting accurately about HIV. Accurate reporting benefits public health, dispels myths, undermines prejudice and increases understanding. It contributes positively to the way HIV is addressed around the world.

We know that reporting accurately on HIV has always been – and still is – a challenge. HIV and its ramifications are complex to report. These guidelines are intended for journalists working in the UK. They enable journalists and editors to check the facts and ensure that the final story is accurate.

NAT works hard to improve reporting about HIV and we are always on hand to advise journalists to report accurately on these issues.



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# HIV – the facts

## What are HIV and AIDS?

HIV stands for the Human Immunodeficiency Virus. HIV damages the body's immune system so that it can no longer effectively fight off infections.

HIV is the virus that may result in AIDS but having HIV does not mean you have AIDS.

AIDS stands for Acquired Immune Deficiency Syndrome. AIDS was first defined by scientists in the early 1980s as a marker point in the disease process caused by HIV. Over time, HIV damages the body's immune system, leaving people vulnerable to cancers and infections that healthy immune systems beat off. These are called 'opportunistic' infections, because they take the opportunity to cause disease when immune systems are damaged.

The process by which HIV damages the body is very slow, which means that people can live for many years before showing any signs of illness. Even without the benefit of HIV treatment, a person with HIV can be well and live with the virus for many years without developing AIDS. Now that effective treatment is available, AIDS is no longer an inevitable later stage of HIV infection in the many countries where treatment is accessible, including the UK.

## Distinguishing between HIV and AIDS in reports

HIV and AIDS are different, and it's important to make this clear. As it is a syndrome, a collection of symptoms, AIDS cannot itself be transmitted, nor can there be an AIDS virus, nor an AIDS carrier. Someone either does or does not have AIDS. There are no degrees of AIDS, so the expression 'full blown AIDS' is meaningless.

Most people in the UK with HIV do not have AIDS, which means that immense care must be taken before describing someone as having AIDS.

Knowing when someone is in pain or distress because of HIV is difficult. The term 'HIV-sufferer' is also seen by most people as patronising, so is best avoided.

Most people who are HIV positive prefer to be referred to as 'people living with HIV' and this is the recommended terminology both in the UK and internationally. Where space is important, use 'people with HIV'.

Since, with the arrival of effective HIV treatments, HIV infection does not necessarily lead to AIDS, it is important to reflect this in reporting. Phrases such as, 'HIV, the deadly virus' or 'HIV, the virus that causes AIDS' are no longer considered accurate. 'HIV/AIDS' as a term is also not accurate as the two diagnoses are very different. Either use the correct term or use 'HIV and AIDS' to differentiate between the two.

Even though HIV and AIDS are different, everyday use of the terms varies greatly between the USA and other parts of the world. Consequently, many reports originating in the USA may well use AIDS inappropriately. Copy from wire services such as AP and Reuters should be read – and, if necessary, subbed – very carefully. In the UK, AP may just 'top-and-tail' other agency copy before sending it on, so it's important to pay attention to all HIV stories on the wires.

# HIV as a long term condition

The development of effective treatment means HIV is now a long term condition. People diagnosed with HIV today can expect a near normal life expectancy if they start treatment early and take it correctly.

Research published in the Lancet in 2008 showed that a patient diagnosed today at 20 can expect to live to nearly 70. At 35, the average age of diagnosis in the UK, life expectancy is over 72. And it is believed that life expectancy will only continue to improve.

The tolerability of treatments has also dramatically improved. Complex regimes with many side-effects have been replaced with just one or two pills, with fewer side-effects. One pill a day is now the initial treatment for someone newly diagnosed with HIV. This means that today someone who is diagnosed early and responds well to treatment will have a very different experience to someone who has been living with HIV for some time and gone through many different treatment options.

Some people with HIV do suffer treatment side-effects including nausea, diarrhoea and prolonged headaches. Others experience changes in body shape, depression and mental health issues.

## A cure for HIV?

There is no cure for HIV but work continues to develop a vaccine and microbicide (barrier product) to prevent HIV.

From time to time individuals or organisations emerge with claims that their particular research, product or discovery offers hope of a 'cure' for HIV. Sometimes patently ridiculous claims can be given inappropriate credence by media reporting. This creates false hope and confusion.

Claims of a 'cure', or other major scientific breakthrough around HIV, should be met with great caution. Scientific claims arising from Phase 3 randomised control trials, or published in reputable medical journals, are of course worth reporting.

Inflated claims elsewhere are worth first checking thoroughly with reputable experts or trusted HIV organisations.

## Working with HIV

Many people with HIV work and there are very few jobs people with HIV cannot do. In a 2009 NAT survey into the experience of HIV positive gay men in the workplace, the majority of respondents said they had not made any changes to their working lives because of their HIV status. Although one in ten people noted side-effects from drugs had had some impact, over a third had not taken any days off to attend HIV clinic appointments in the previous 12 months. The health effects of HIV are having little impact on those who are in work and protections in the Equality Act make it unlawful for employers to discriminate against someone with HIV and for employers to ask questions about HIV status prior to a job offer. However stigma, fear of discrimination and international travel restrictions remain barriers to people with HIV in the workplace.

## Having a family

There are many women with HIV who have had healthy children. Modern drugs are highly effective at preventing HIV transmission during pregnancy, labour and delivery. With appropriate interventions, the vast majority (over 98 per cent) of HIV positive women give birth to healthy, uninfected babies.

The British HIV Association (BHIVA) reports that an increasing number of HIV positive women and couples are requesting assistance with conception. Of particular concern for people living with HIV who wish to conceive is 'serodiscordancy' in their relationship: that is, when one partner is HIV positive and the other HIV negative. The standard recommendation for serodiscordant couples is

to practice safer sex to prevent HIV transmission from one partner to the other – but of course this is not helpful for those who wish to conceive. However, there are a range of options available to assist couples to conceive safely, including self-insemination, donor sperm and sperm-washing.

## Ageing and HIV

One in six people with HIV in the UK are over 50. This is due to people with HIV growing older as well as new infections occurring in this age group. Research suggests that people with HIV are more

susceptible to conditions associated with ageing such as cardiovascular disease, cancers, dementia and osteoporosis. Research into the relationship between HIV and the long term impacts of anti-retroviral treatment is still developing. As more research is conducted into this area we will have a better understanding of how HIV affects the ageing process.

### Further information

NAT - Working with HIV, 2009 - [www.nat.org.uk/Our-thinking/Every-day-issues/Employment.aspx](http://www.nat.org.uk/Our-thinking/Every-day-issues/Employment.aspx)

## Who is affected by HIV?

HIV is a virus and can infect anyone. However, the epidemic has developed in different ways in different regions and countries of the world.

With increasing movement of people around the world, the epidemiology of HIV is complex. It is always important to find out more information on the HIV epidemic in the particular country or region on which you are reporting and in which your report will be read. For example, the epidemic in Ukraine began through the sharing of injecting equipment by injecting drug users, although it has now become more generalised. In sub-Saharan Africa, however, the epidemic began mainly through heterosexual sex and HIV continues to be transmitted mainly heterosexually.

The two groups most affected in the UK are gay and bisexual men and black African heterosexuals. Three-quarters of people diagnosed in 2008 were among these two groups. Migration of people to the UK who were infected with HIV overseas, particularly in Africa, is one of the reasons for high rates of HIV among black

Africans in the UK. There is also increasing heterosexual transmission occurring in the UK. It is important not to assume that HIV only happens to 'other people'. HIV transmission amongst people who are not gay and bisexual men or black African heterosexuals in the UK is increasing, albeit from a low base.

Over 70 per cent of people with diagnosed HIV in the UK are over 34 years old. It is a misconception to assume HIV in the UK predominantly affects young people.

### HIV statistics

UNAIDS publishes detailed information for each country of the world at [www.unaids.org](http://www.unaids.org)

Statistics on HIV in the UK are updated annually by the Health Protection Agency [www.hpa.org](http://www.hpa.org)

Statistics can also be found on the NAT website [www.nat.org.uk/HIV-Facts.aspx](http://www.nat.org.uk/HIV-Facts.aspx)

# Understanding and communicating risk

## How HIV is and isn't passed on

For HIV to be passed – transmitted – from one person to another, a certain amount of the virus has to be present. While it can be found in saliva or sweat, the concentration is too low for infection to occur.

HIV is passed on through infected blood, semen, anal mucus, vaginal fluids or breast milk. The most common ways HIV is passed on are:

- ▶ Through unprotected vaginal or anal intercourse with someone living with HIV. Globally, this is the most frequent route by which the virus gets from one person to another.
- ▶ Sharing infected needles, syringes or other injecting equipment.
- ▶ From an HIV positive mother to her child during pregnancy, birth or breastfeeding if no preventative steps are taken. If preventative steps are taken during pregnancy and birth the risk of mother to child transmission is less than 2 per cent.

Oral sex carries a very low risk, but if cuts, ulcers or diseased gums come into contact with infected bodily fluids HIV can be passed on.

## Putting the risks into perspective

While HIV can be passed from one person to another during a single sexual act or sharing needles just once, it is not inevitable. Being exposed (put at risk if HIV is present) does not mean that one is automatically infected and it is important that reporting does not imply this. Of course, the more often someone takes risks, the more likely transmission becomes.

Transmission risks during sex increase greatly if either of the sexual partners has another sexually transmitted infection (STI).

The risks of passing on HIV are much higher in the first few months after someone has become infected. During this time, there is an extremely high level of HIV in the body, and it can take some time before the immune system can react and produce antibodies; a process called 'sero-conversion'. Of course so soon after infection most people are still unaware that they have been infected and therefore HIV can be unwittingly passed on.

HIV treatments, which greatly reduce the amount of HIV in the body, also reduce the chances of onward transmission. However, since the risk is not completely eliminated, unprotected sex or

## Blood transfusions and blood donor bans

Early in the epidemic a number of haemophilia patients became infected with HIV via blood transfusions and blood clotting factors. Blood transfusions may still be dangerous in parts of the world where screening is not rigorous. However, in the UK all blood products are now screened for HIV and most other blood-borne viruses.

Restrictions still apply in the UK on who can donate blood. Currently any man who has ever had sex with another man (MSM) is permanently banned from giving blood. Similar exclusions apply to anyone who has ever been paid for sex and anyone who has ever injected drugs. These restrictions are currently under review by the Safety Advisory Committee on Blood Tissues and Organs and may change soon.

sharing needles remain a transmission risk even if the person living with HIV is on treatment.

### PEP – Post-Exposure Prophylaxis

Post-Exposure Prophylaxis, commonly known as PEP, is a course of treatment lasting one month that may prevent HIV infection after the virus has entered the body. In order for PEP to have a chance of working, it needs to be started as soon as possible and definitely within 72 hours of exposure to HIV. PEP can be prescribed by hospitals including A&E departments, GUM or sexual health clinics and GPs experienced in treating HIV.

### Preventing HIV transmission

The most effective way to prevent HIV being passed from one person to another during sex is by using a condom.

While using condoms properly is very effective in stopping HIV infection, no one method ever provides 100 per cent protection, so 'safer sex' is a far more honest expression than 'safe sex'.

Anal intercourse is considered by many as synonymous with gay men's sexual activity. But many gay men do not practice anal sex and, in many cultures, heterosexuals do. So it is important not to make assumptions.

For injecting drug users, HIV is mainly transmitted through the sharing of needles and injecting equipment – so not sharing needles and injecting equipment but instead accessing clean needles/equipment is an effective way to prevent HIV transmission. In the UK needle exchange centres can provide clean needles free of charge.

### No risk and low risk

HIV is not contagious; it cannot be transmitted through surface-to-skin contact or through the air, so HIV can't be 'caught'. It is inaccurate to suggest HIV can be passed on by:

- ordinary social or physical contact
- kissing (including 'French kissing')
- coughing or sneezing
- sharing toilet seats or washing facilities
- sharing cutlery, food or drink
- using swimming pools
- spitting.

In addition, there are some activities or events which may carry a theoretical risk of infection but where in fact the risk of HIV infection is so negligible as not to warrant concern or any action (see next section, *Misconceptions about risk*).

### Further information

#### Risks of transmission

AVERT – [www.avert.org/transmission.htm](http://www.avert.org/transmission.htm)

#### Preventing HIV

NAM – [www.aidsmap.com/cms1330379.aspx](http://www.aidsmap.com/cms1330379.aspx)

#### PEP

CHAPS Online – [www.pep.chapsonline.org.uk/pep\\_basics.htm](http://www.pep.chapsonline.org.uk/pep_basics.htm)

BASHH, UK Guideline for the use of post-exposure prophylaxis for HIV following sexual exposure, [www.bashh.org/documents/58/58.pdf](http://www.bashh.org/documents/58/58.pdf)

# Misconceptions about risk

Understanding the risk of HIV can be difficult. It is important that media reporting of HIV presents accurate information on how HIV is transmitted and degrees of risk. The idea that HIV can be easily passed on feeds stigma and discrimination and can result in people living with HIV being treated unfairly and becoming very isolated.

## Risk of HIV from needles

Injuries from discarded needles can cause a great deal of worry for the individual affected. People may, for example, step on a discarded needle in the street, on a beach, in a park or play area. However, the actual risk of acquiring HIV from a discarded needle is extremely low.

Out of over 60 million HIV infections world-wide there has never been a recorded case of someone being infected with HIV from a needle injury outside a healthcare setting. For HIV infection to occur, a person must be exposed to infectious quantities of HIV. But HIV is a fragile virus that does not usually survive for long outside the body.

The only cases of HIV infection from 'needle stick' or other injuries have been in healthcare settings. These have involved puncture wounds or cuts that have been exposed to the fresh blood of HIV positive individuals. In the five recorded cases of occupational infection after needle-stick injuries in the UK, the injuries occurred seconds or at most minutes after blood was drawn from the HIV-infected patient.

Too often fear of HIV infection is used in the headline or first paragraph of a story about discarded needles for sensational effect, when in fact risk of other infections is vastly greater. Reporting the risks of discarded needles accurately will help avoid the anxiety people who are injured can experience.

Reports on discarded needles outside healthcare settings should not either in the headline or in the story give prominence to HIV risk, given the fact there has never been a single example of infection from such a source anywhere in the world.

## Risk of HIV from attack with a needle

Reports occur in the media of people threatening others or actually assaulting them with needles. Sometimes the attacker may also tell their victim they have HIV or 'AIDS'.

There is not a single recorded case anywhere in the world of someone being infected with HIV through such an attack.

In the vast majority of cases there is no reason to believe the attacker is actually infected with HIV, even when they make such a claim.

Such attacks are clearly a serious criminal matter, but it does not help the victim to exaggerate the risk of HIV infection. Reports should also avoid giving credence to claims by attackers of HIV infection which are not substantiated by a diagnosis.

## Risk of HIV from biting

Because of the ability to draw blood with a bite, there can be considerable anxiety over the likelihood of HIV being transmitted in this way. There are two scenarios that can result in concern over transmission:

- An HIV positive person bites an HIV negative person
- An HIV negative person bites an HIV positive person.

However, the risk of HIV transmission from biting is negligible. In order for transmission to take place

## Discrimination and HIV

Misunderstanding about the risk of HIV can lead to people with HIV facing discrimination. Recent examples in the UK include children with HIV being excluded from school for fear of them infecting another child by biting in the playground, and people with HIV being refused jobs working with people with mental health problems because of fear of them being bitten. Discrimination also still occurs in the workplace and even in the health service.

there would need to be both exposure to blood and a route into the body for that blood. In both scenarios, for transmission to occur blood from both individuals would need to be present, as HIV is not transmitted through saliva alone.

There have been no cases of HIV transmission from an HIV negative person biting an HIV positive person and only ever four reports of HIV being transmitted from an HIV positive person biting an HIV negative person. These instances occurred in extremely specific and unusual circumstances, in which the HIV positive person had advanced HIV disease and blood in their saliva.

It is important to stress, however, that there have been numerous reports where a bite by somebody with HIV did not result in HIV infection.

Reporting of biting incidents involving HIV positive individuals should therefore avoid using language that suggests there is a real risk of HIV transmission occurring via this route. As with discarded needles, this will only serve to cause unnecessary anxiety and add to the stigma surrounding HIV.

## Risk of HIV from spitting

There has never been a case of HIV infection resulting from spitting. HIV is only present in saliva in very low quantities, making infection from saliva impossible. There is therefore no risk of acquiring HIV from being spat at.

The only time a risk becomes theoretically possible is when there is significant blood present in the saliva. But there has never been a recorded case of this happening. Saliva has an inhibitory effect on HIV that may be present in blood. There has never been a recorded case of HIV infection after the mucus membranes in the eye or nose were exposed to HIV-infected blood. There is no risk of HIV infection from blood contact on unbroken skin.

Reports that suggest HIV can be transmitted by saliva are therefore misleading and inaccurate and should never be made.

## Further information

### Needle-stick injuries

AVERT – [www.avert.org/needlestick.htm](http://www.avert.org/needlestick.htm)

HPA – Eye of the Needle, 2008 - [http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb\\_C/1227688080528](http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1227688080528)

# Testing and HIV

Early diagnosis of HIV is very important. Getting tested and diagnosed early not only improves the health outcomes for the individual but also means people are less likely to pass HIV on. In the UK over a quarter of people with HIV are undiagnosed, so encouraging people to get tested is very important.

Technology for testing HIV and knowledge about the signs of possible HIV infection have improved greatly over recent years.

## Early signs

Over 70 per cent of people show symptoms of HIV in the first few weeks after infection. Normally flu-like or glandular fever-like symptoms, they can easily be missed, even by doctors. But three symptoms – a fever, a rash and a sore throat, all occurring together are actually unusual in an otherwise healthy person. If someone has put themselves at risk recently these symptoms are signs they should get an HIV test. The symptoms normally pass naturally within a few weeks. This stage of HIV is called ‘primary HIV infection’ or ‘sero-conversion illness.’ After this stage these symptoms disappear and there may be no further symptoms of infection for many years.

## Types of test

The HIV test is not a test for HIV per se, but for HIV antigens or antibodies produced by the body in its response to HIV infection. It is not a test for AIDS.

The majority of HIV tests in the UK are in sexual health or antenatal clinics, but increasingly tests are being promoted in other hospital settings, in GP surgeries, in pharmacies and outside traditional healthcare settings.

In most sexual health clinics in the UK, a small blood sample is taken from a vein in the arm. Saliva can also be used for antibody tests. In the UK, once someone has tested positive for antibodies to HIV or for HIV antigens and they find themselves within the healthcare system, they should then have a test that directly measures levels of HIV, known as their ‘viral load’.

**Writing about someone’s ‘agonising’ three- or six-month wait before being able to test is misleading, particularly when there is an extremely low level of risk, and can create unnecessary anxiety as well as discourage people from coming forward for early testing**

## Early tests

There is no longer a need to wait for a three-month 'window period' after possible exposure before testing for HIV. New tests – fourth generation assay tests – which are common in the UK can detect both antibodies and p24 antigens of HIV. As p24 antigens are produced before antibodies, these new tests can detect HIV one month after infection and provide a high degree of reassurance when the test result is negative. An additional test three months after possible exposure to HIV is offered to definitively exclude HIV infection. There is never a need to wait more than three months to receive a definitive result.

Writing about someone's 'agonising' three- or six-month wait before being able to test is misleading, particularly when there is an extremely low level of risk, and can create unnecessary anxiety as well as discourage people from coming forward for early testing.

## Rapid tests

Rapid HIV tests are available in many clinics across the UK and allow people to take a test and receive the result in one visit. Fourth generation rapid tests are now available which can also reliably diagnose HIV one month after infection.

## At home

Home sampling kits are also available to purchase in the UK. These require that a person take a blood or saliva sample in their own home. The individual then mails the sample to a laboratory and later receives their results via telephone or online. If the test produces a 'reactive result' – in other words, one which indicates the possibility of HIV infection – the person is strongly advised to seek a

confirmatory test in a clinic to diagnose HIV. Home sampling for HIV is legal in the UK.

Technology also exists for home testing kits, a rapid HIV test conducted by the person in their home giving results in minutes. These test kits are currently illegal in the UK.

## Further information

### National Guidelines for HIV Testing 2008

BHIVA – [www.bhiva.org/HIVTesting2008.aspx](http://www.bhiva.org/HIVTesting2008.aspx)

### HIV Testing

NAM – [www.aidsmap.com/cms1320696.aspx](http://www.aidsmap.com/cms1320696.aspx)

### Ante-natal HIV screening

[www.avert.org/hiv-testing-pregnancy.htm](http://www.avert.org/hiv-testing-pregnancy.htm)

# UK law and HIV

Discrimination against people with HIV is unlawful in the UK. There are a number of ways people with HIV are protected from discrimination in UK law.

The Equality Act 2010, which now incorporates the protections of the Disability Discrimination Act (DDA) 2005, defines everyone diagnosed with HIV as disabled and, therefore, entitled to the same protection against discrimination – in employment, getting goods and services, education, trade union membership and accommodation (including letting and selling property) – as any other disabled person. The Act also contains provisions to protect people with HIV from dual discrimination, based on their HIV status and their sexual orientation or their HIV status and race for example. It prohibits discrimination by association and perception, thereby protecting partners, families and carers of people living with HIV, as well as those sometimes assumed to be HIV positive such as gay or bisexual men or African men and women from high prevalence countries.

The UK Data Protection Act 1998 also protects people with HIV. Personal details, including health information, cannot be used or disclosed without authorisation.

People with HIV are also further protected in the law against hate crime. This means that if a person is a victim of crime because of their HIV status, this is considered an aggravating factor by the courts, leading to enhanced sentences for the perpetrators of such crimes.

## Infection and the law

Since 2003, prosecutions for the ‘reckless transmission’ of HIV have been brought under section 20 of the 1861 Offences Against the Person Act (OAPA) in England and Wales. In Scotland, someone can be charged with ‘reckless injury’.

Recklessness (‘the conscious taking of an unjustifiable risk’) occurs when a person, knowing that they are HIV positive, doesn’t act as responsibly as they should to avoid passing on HIV and, as a result, someone else is infected. It is important not to include in a report unfounded speculation as to why someone acted recklessly.

## **As at July 2010, there had been no prosecutions in the UK for the intentional transmission of HIV**

It is important to describe this charge/offence accurately. It is misleading to state that reckless transmission involves ‘knowingly infecting’ a sexual partner. HIV infection is not inevitable following exposure and it is therefore impossible to ‘know’ that you have infected someone from a particular action.

The phrase also gives the impression of deliberate or intentional infection which is not the charge in cases of reckless transmission.

As at July 2010, there had been no prosecutions in the UK for the intentional transmission of HIV, an entirely different offence under Section 18 of the OAPA Act 1861 in England and Wales.

Scotland has a different legal system to the rest of the UK. In Scotland there has been a case where a man was convicted of ‘reckless endangerment’ – in other words, exposing sexual partners to the risk of HIV infection without actually infecting them. Such

## **The Equality Act 2010 defines everyone diagnosed with HIV as disabled and, therefore, entitled to the same protection against discrimination – in employment, getting goods and services, education, trade union membership and accommodation – as any other disabled person**

a charge is not possible in the rest of the UK.

UK law surrounding court reporting is far stricter than in some countries. Formally trained and qualified journalists appreciate how legal proceedings and evidence are covered by complex rules of privilege which do not extend to comments made outside. Incorrectly reporting charges or someone's criminal record could be defamatory, so – regardless of any question about the morality of someone's (sexual) behaviour – accuracy is vital.

### **Reporting Court Cases**

On occasion the HIV positive status of an individual may be referred to in court, coroner or tribunal proceedings even when not directly relevant to the matter being considered. Although the information has been put in the public domain, journalists should consider carefully whether the HIV status of the individual is relevant to the story they are reporting. If their HIV status is not relevant it should be left out of the story, even if it has been mentioned in court proceedings. It is personal medical information and its dissemination may cause significant distress and difficulties for an individual and his/her family. Irrelevant reporting of HIV status could possibly also be in breach of the Press Complaints Commission Code.

### **Further information**

#### **Equality Act and Legal Protection**

NAT – [www.nat.org.uk/Our-thinking/Law-stigma-and-discrimination/Human-rights-and-discrimination.aspx](http://www.nat.org.uk/Our-thinking/Law-stigma-and-discrimination/Human-rights-and-discrimination.aspx)

#### **Criminal prosecutions for reckless HIV transmission**

NAT – [www.nat.org.uk/Our-thinking/Law-stigma-and-discrimination/Criminal-prosecutions.aspx](http://www.nat.org.uk/Our-thinking/Law-stigma-and-discrimination/Criminal-prosecutions.aspx)

Criminal HIV Transmission Blog – <http://criminalhivtransmission.blogspot.com>

# Myth of HIV health tourism

Migration has been one of the most seriously debated issues in UK politics recently. As such, it is vitally important to separate out the facts and evidence around migration from the fears and misinformation.

In recent years, allegations have been made about health tourism to the UK both in general and in relation to HIV specifically. 'Health tourism' generally describes the practice of choosing to travel abroad in search of medical treatment that is either unavailable or too expensive to access at home. 'HIV health tourism' refers in particular to the claim that foreign nationals are leaving their home country with the main and sole purpose of receiving free HIV care in the UK.

These claims were first made in a series of newspaper articles that portrayed HIV positive migrants – including asylum applicants – as 'HIV health tourists'. Although unsubstantiated, these allegations gained widespread currency in media commentary and politics, affecting both popular perception and Government policy.

HIV health tourism to the UK is a myth.

Isolated cases may occur but there is no evidence to demonstrate that HIV health tourism to the UK exists as a significant phenomenon. In fact, there is much evidence to the contrary. Recent data from the Health Protection Agency show that the average time between a migrant infected with HIV arriving in the UK and their diagnosis was almost five years. Levels of HIV amongst migrants to the UK are significantly below HIV levels in their countries of origin. Home Office reports state there is no evidence to suggest asylum applicants have detailed knowledge of the UK's asylum policies, welfare benefits or entitlement to treatment prior to arriving in the UK.

## **There is no evidence to demonstrate that HIV health tourism to the UK exists as a significant phenomenon**

Journalists should ensure accuracy in their reporting on migration to the UK and not suggest that HIV health tourism is taking or has taken place without evidence to support their claims.

### **Further information**

#### **NAT – The Myth of HIV Health Tourism**

[www.nat.org.uk/Our-thinking/People-in-great-est-need/Asylum%20and%20migration.aspx](http://www.nat.org.uk/Our-thinking/People-in-great-est-need/Asylum%20and%20migration.aspx)

# HIV and professional standards

A number of professional codes advise journalists about professional standards in reporting, including the Editors' Code of Practice which is administered and upheld by the Press Complaints Commission (PCC) and the National Union of Journalists (NUJ) Code of Conduct.

**Be accurate.** Do your best to ensure work is fair and accurate. Checking HIV stories is important and while there are expert government and voluntary sector bodies who provide information and comment, those sources should never be above criticism or question.

**Keep language simple.** Do not be afraid to question statements or ask for clarification. Professional or scientific words may sound authoritative, but everyday language should improve the wider understanding of HIV.

**Respect privacy.** The privacy of people living with HIV and those around them – their families, friends and colleagues – should be respected. Identities and addresses should not be disclosed, or even hinted at, without permission.

**Be relevant.** Someone's age, sex, race, colour, creed, legal status, disability, marital status and sexual orientation should only be mentioned where they are directly relevant to a story. Such irrelevant references perpetuate stigma and discrimination.

**Avoid sensationalism.** Resist the temptation to sensationalise issues in ways which could be harmful. Sensational language and images can cause unnecessary anxiety for people with HIV as well as more widespread fear. In the past, poor reporting of HIV has cost people living with HIV their jobs and their homes.

## Press Complaints Commission The Editors' Code of Practice

The three most relevant sections of the Editors' Code of Practice are:

**Clause 1. Accuracy:** The Press must take care not to publish inaccurate, misleading or distorted information, including pictures. A significant inaccuracy, misleading statement or distortion once recognised must be corrected, promptly and with due prominence, and – where appropriate – an apology published.

**Clause 3. Privacy:** Everyone is entitled to respect for his or her private and family life, home, health and correspondence, including digital communications. Editors will be expected to justify intrusions into any individual's private life without consent. Account will be taken of the complainant's own public disclosures of information. It is unacceptable to photograph individuals in private places without their consent.

**Clause 12. Discrimination:** The press must avoid prejudicial or pejorative reference to an individual's race, colour, religion, gender, sexual orientation or to any physical or mental illness or disability. Details of an individual's race, colour, religion, sexual orientation, physical or mental illness or disability must be avoided unless genuinely relevant to the story.

## Further information

### NUJ Code of Conduct

[www.nuj.org.uk/innerPagenuj.html?docid=174](http://www.nuj.org.uk/innerPagenuj.html?docid=174)

### Press Complaints Commission

[www.pcc.org.uk](http://www.pcc.org.uk)

# Telling real stories

One of the best ways to communicate the often complex and varied realities of living with HIV in the UK today is through real life stories. Whilst people living with HIV see improved public understanding of HIV as important and want to help this process, for many of them making the decision to be open in the media about their status is a significant step. The stigma that surrounds HIV means that many people will need to consider carefully the impacts on their family, job or relationships before agreeing to tell their story to the media.

There are a number of steps journalists can take to help people with HIV tell their story to the media.

**People living with HIV should not be pressured into revealing their identities, however good a story. Being open about HIV status can have implications for partners, families, friends and children if they are not considered fully**

- ▶ People living with HIV should not be pressured into revealing their identities, however good a story. If someone living with HIV asks to be anonymous this should be respected. Remember that disclosing someone's job and the general area where they live may be enough to identify them. During a radio or television interview, voices and appearances should be disguised during recording, rather than in post-production, and original material should be clearly – and permanently – marked so that an interviewee's identity is protected, whenever and however, it may be transmitted.
- ▶ If an interviewee agrees to be named make sure you have discussed the consequences of disclosure. Being open about HIV status can have implications for partners, families, friends and children if they are not considered fully.
- ▶ Ensure beforehand you have discussed with the individual any areas that they would not be comfortable answering questions about in the interview, and respect these during the interview.
- ▶ If possible, offering to read the final copy to the interviewee is a good way of reassuring them that they will be presented fairly. Remember to also make sure that when the copy is passed on to an editor or sub-editor that headlines and pull-out quotes remain sensitive and accurate.
- ▶ Contact details for people with HIV should not be passed on unless they have given permission, ideally in writing.

## Further information

### People's experiences of living with HIV

NamLife – [www.namlife.org](http://www.namlife.org)

NAT – [www.nat.org.uk/living-with-HIV.aspx](http://www.nat.org.uk/living-with-HIV.aspx)

# HIV and the media food chain

Changes in the way news is gathered, with more journalists based in newsrooms, following up stories on the phone, have affected the way all news, including health, science and medical stories, are reported. Often on medical and treatment issues publicists or PRs originate a story, which makes checking facts and cross-checking with others particularly necessary. Similarly, reports on court cases are frequently accessed from news agencies or a wire service.

These developments make it even more likely that errors can creep in when reporting a matter as sensitive and complex as HIV. Extra attention must therefore be paid to get things right, checking the accuracy of third party reporting. This applies also and especially where pictures are being used to illustrate a story. When captioning pictures, photographers must be exceedingly careful not to allege wrongly that someone has HIV. The issues of privacy and consent are also very important.

## Some tips

### For publicists and PRs:

Get it right. Increasingly, you're at the head of the media food chain. Your accuracy can make a real difference for good – your errors will be disseminated and elaborated, and possibly cause harm.

Even if those publicising HIV stories work for organisations seen as having authority, you should still ask questions.

Check whether others are publicising the same story – and make sure you all get it right together.

Be clear about timings and the use of tenses. There could be months, if not years, between data being collected, analysed and published.

When covering court reporting, check all 'the legals' – from being contemporaneous to making sure that charges are stated correctly.

### For reporters and sub-editors:

Don't be afraid to put the follow-up question to even the most eminent expert, to clarify a point or make the language accessible.

Don't be afraid to go back and check a quote.

Don't assume the press release which has just landed on your desk is the 'whole truth' on a given subject.

Be willing to check the accuracy of material from wire services and news agencies. Check the original 'primary source' material.

### For photographers:

In captioning, make sure pictures don't wrongly allege someone has HIV.

Make sure photographs do not breach the confidentiality or privacy of people living with HIV.

### For broadcasters:

Trails and promos need care too.

When interviewing, topping and tailing interviews and clips to get the context right is very important.

It is important to brief experts clearly in advance of interview, to avoid overly technical language.

### For sub-editors:

When in doubt, check. If still in doubt, leave out.

Headline stories accurately and without distortion or misleading emphasis.

Knowing which terms to avoid could save you criticism from colleagues, your audience and those working in HIV.

# Finding the right words

There is increased consensus about the appropriate terminology to use when reporting on HIV and it is important to know the terms to avoid.

Preferred	Inaccurate/ Inappropriate
HIV HIV and AIDS	AIDS virus Full-blown AIDS HIV/AIDS
A person living with HIV [PLWH] A person who is HIV positive (if diagnosed)	AIDS or HIV carrier AIDS 'timebomb' A person is HIV A(n) (HIV or AIDS) victim/sufferer
HIV test HIV antibody test HIV antigen test	AIDS test
Transmitting HIV Infected by HIV Acquiring HIV	Transmitting AIDS Infected by AIDS Catching HIV (or AIDS)
Recklessly infecting	Intentionally/ deliberately/knowingly infecting (when applied to a reckless transmission charge)
Safer sex	Safe sex

The UNAIDS Terminology Guide – also known as its 'Editors' Notes For Authors' – provides an extensive account of recommended usage in the field of HIV and AIDS. Below are some additional terminology drawn from this Guide which journalists might find useful.

**Gay men/Men who have sex with men** – the phrase 'gay men' is used to describe people who self-identify as gay (i.e. there is a 'gay' cultural, as well as sexual identity). The broader term used internationally, 'men who have sex with men', sometimes abbreviated to MSM, can be used to describe all men who engage in same-sex sexual activity, irrespective of how they identify themselves and what other sexual relationships they engage in.

**Injecting Drug User** – abbreviated as IDU – this is now the preferred term rather than intravenous drug user (not all drugs injected are injected intravenously).

An **epidemic** is said to occur when more people are found to have an illness in a relatively large, but specific area, over a set time than would normally be expected, while an **outbreak** is far more localised. A **pandemic** affects an entire continent or the whole world. Preferred usage is to write 'pandemic' when referring to global disease and to use 'epidemic' when referring to country or regional level.

**Sex worker** – this is increasingly the preferred term rather than prostitute. Prostitute and prostitution are used to refer to juvenile prostitution.

## Further information

UNAIDS Editors' Notes for Authors  
[www.unaids.org](http://www.unaids.org)

International Federation of Journalists media guide  
[www.ifj.org](http://www.ifj.org)

# Useful organisations

## **NAT (National AIDS Trust)**

Tel: 020 7814 6767

Email: [info@nat.org.uk](mailto:info@nat.org.uk)

## **Terrence Higgins Trust**

Tel: 020 7812 1600

Email: [info@tht.org.uk](mailto:info@tht.org.uk)

## **Positively UK**

Tel: 020 7713 0444

Email: [info@positivelyuk.org](mailto:info@positivelyuk.org)

## **AHPN**

Tel: 020 7017 8910

Email: [info@ahpn.org](mailto:info@ahpn.org)

## **HIV Scotland**

Tel: 0131 558 3713

Email: [info@hivscotland.com](mailto:info@hivscotland.com)

## **THT Cymru**

Tel: 029 2066 6465 (Cardiff)

Email: [info.cymru@tht.org.uk](mailto:info.cymru@tht.org.uk)

## **Professional organisations**

### **National Union of Journalists**

Tel: 020 7278 7916

Email: [info@nuj.org.uk](mailto:info@nuj.org.uk)

### **Society of Editors**

Tel: 01223 304080

Email: [info@societyofeditors.org](mailto:info@societyofeditors.org)

### **Press Complaints Commission (PCC)**

Tel: 020 7813 0022

Email: [complaints@pcc.org.uk](mailto:complaints@pcc.org.uk)

**The PCC gives confidential pre-publication advice to journalists and complainants and can be contacted 24 hours a day.**



TRANSFORMING  
THE UK'S  
RESPONSE  
TO HIV



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PRESS COMPLAINTS COMMISSION



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# SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

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