

April 2007

# Guidelines

for reporting HIV



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## Key points

- HIV and AIDS are different. It is important to make the distinction.
- Ensure you understand, and don't overstate, the risks of infection.
- The epidemiology of HIV is changing. Ensure you use up-to-date sources for statistics.
- Always check the facts – particularly when covering legal proceedings.
- Language is important. Be careful of the terminology you use and avoid perpetuating myths and stereotypes.
- Respect the privacy of people living with HIV.
- Don't be afraid to ask 'experts' follow-up questions to clarify a point or make the language accessible.

# HIV and the need for accurate reporting

The global HIV pandemic is one of the most pressing crises facing the world and is rarely out of the news for long. It affects not only individuals and communities, but also regions and continents. Accurately reporting on HIV has always been – and still is – a challenge.

HIV science is complex and continually developing. The social context is important too – not only how people become infected and the impact of HIV infection on them but also the various political, social and economic systems around them.

So, covering HIV can mean covering vaccine research, workplace disability, women's rights and children's rights, legal proceedings and so on.

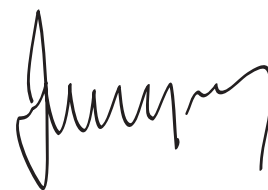
Accurate reporting about HIV is necessary not only to meet journalistic standards but because individual health and public health may benefit too: myths are dispelled, prejudice is undermined and understanding increased. Accurate reporting contributes positively to the way HIV is countered around the world.

These guidelines highlight pitfalls to avoid and suggest alternatives. They are intended for NUJ members working in the UK and focus on the context and realities of HIV here but they also provide a broader picture and identify key sources of further information.

We don't pretend that every circumstance is covered, but a practical starting point is provided for clearer coverage of a topic that can affect everyone, personally and professionally.



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# HIV and the 21<sup>st</sup> century

## Introduction

More than a quarter of a century has now passed since the effects of a previously unknown virus first became apparent.

Those 25 years saw unprecedented research and responses as individuals, activists, scientists, doctors and nurses around the world tried to find out what was happening and how to stop it.

The consequences have not only been loss of life, with millions of people dying around the world from HIV-related illnesses. HIV has touched every aspect of life – from economics to culture, politics to religion.

Still that learning goes on. Research into improving treatments continues, as does the hunt for protective vaccines and new barrier products (microbicides) that will prevent infection.

Some facts have now become established. Ways in which this virus can – and cannot – be passed from one person to another have been identified. The early period of speculation and fear is now over.

HIV and its ramifications are complex issues to report. Dealing with these complexities in 200-word or 25-second news reports is not always straightforward.

## HIV – the facts

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

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

Even without the benefit of HIV treatment, a person living 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 many countries where treatment is accessible.

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. Some are 'AIDS-defining illnesses' and they can be fatal for people with HIV.

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. Drug therapies make the process even slower, so developing AIDS is no longer inevitable.

So, 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. Use of 'HIV/AIDS' as a term is no longer considered accurate. 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, PA 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.

## Passing on HIV – distinguishing the facts from the myths

**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 found in greater concentrations in semen, seminal fluid (pre-ejaculate or 'pre-cum'), blood, vaginal and rectal mucous and breast milk. HIV is not found in urine, unless there is blood present too.

**HIV can be passed on during: –**

**Anal or vaginal intercourse without a condom;** globally, this is the most frequent route by which the virus gets from one person to another. There is a much lower risk from oral sex (oral-penile sex, [fellatio]; the risk is only for the person performing fellatio). Transmission may occur if a man with HIV ejaculates into the mouth of his sexual partner, particularly if the partner's mouth has open sores, ulcers, excessively bleeding gums or has recently

undergone invasive dental procedures (such as root canal work).

**Blood-to-blood' contact,** such as when injecting equipment is shared, presents a much higher risk of HIV transmission than sexual contact. Although there could be risks from tattooing and other practices – such as piercing and blood-sharing rituals – which potentially expose someone to blood, this may only occur if new or sterilised needles and syringes are not used. Also, around the world, a few healthcare workers have been infected with HIV through 'needle stick injuries'.

Blood transfusions and blood clotting factors for haemophilia also passed on HIV early in the UK epidemic. These 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.

**From mothers to babies, known as 'vertical transmission'.** This can happen during pregnancy, birth or breastfeeding. However, there are proven steps mothers can take with clinical support to minimise the possibility of their unborn child acquiring HIV, which reduces the risk of transmission to less than one per cent.

### 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.

HIV is actually a weak virus that cannot survive for long outside the body, so it's very unlikely indeed that it could be passed on from a needle discarded in a public place or used as a weapon.

Claims that HIV can be passed on by biting should be regarded very sceptically. In a handful of cases in the early 1980s, people alleged this, but other possible means of infection were never fully eliminated from the evidence.

### 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) is not the same as automatically becoming infected and it is important that reporting does not imply this.

In 2006, the risk of being infected with HIV during the most risky sexual activity – unprotected receptive anal intercourse – was estimated to be 1 in 33. The risk of HIV passing from a woman to a

man during unprotected vaginal intercourse was 1 in 1666.

Of course, the more often someone takes risks, the more likely transmission becomes. Being unlucky just that once does mean having HIV for life.

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

If someone has a cut, an ulcer or is bleeding and the wound comes into contact with body fluids containing HIV, then the risks of infection may increase too.

Data collected over the last 20 years has also revealed that 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'. (It's these antibodies which diagnostic tests identify.)

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

### 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 synonymous with gay men. 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, needle exchanges to avoid sharing needles, as well as harm-reduction methods such as sterilising 'works', have meant a decrease in rates of HIV transmission.

### After the event

If someone believes they have possibly been exposed to HIV, Post Exposure Prophylaxis, known as PEP, is believed to reduce the likelihood of HIV infection becoming established. This has been

used for some time for healthcare workers and should now be available from genito-urinary clinics (GU clinics, often called sexual health clinics) and in Accident & Emergency (A&E) Departments in the UK for anyone who may have been exposed to HIV infection through high-risk sexual activities. PEP involves taking a 28-day course of HIV medication, usually two to three pills a day. There are often side-effects such as diarrhoea, headaches and vomiting. To be most effective, PEP should be commenced within one hour of exposure but can be started up to 72 hours after exposure.

## Further information

### Risks of transmission

**AVERT** [www.avert.org/trans.htm](http://www.avert.org/trans.htm)

### Sero-conversion

**NAM** [www.aidsmap.com/cms1031850.asp](http://www.aidsmap.com/cms1031850.asp)

### Mother to child transmission

**NAM** [www.aidsmap.com/cms1036608.asp](http://www.aidsmap.com/cms1036608.asp)

**BHIVA - Pregnancy Guidelines** [www.bhiva.org/](http://www.bhiva.org/)

### Needle stick injuries

**HPA** [www.hpa.org.uk/publications/PublicationDisplay.asp?PublicationID=54](http://www.hpa.org.uk/publications/PublicationDisplay.asp?PublicationID=54)

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

### Blood transfusion and HIV screening

**HPA** [www.hpa.org.uk/infections/topics\\_az/hiv\\_and\\_sti/hiv/epidemiology/epidemiology.htm#bp](http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/hiv/epidemiology/epidemiology.htm#bp)  
[www.hpa.org.uk/infections/topics\\_az/BIBD/est\\_freq\\_uk.htm](http://www.hpa.org.uk/infections/topics_az/BIBD/est_freq_uk.htm)

### PEP

**EAGA** [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4083638](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4083638)  
[www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH\\_4132844](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_4132844)

**NAM** [www.aidsmap.com/en/docs/BFF46A66-B1D0-11D5-8D13-00508B9ACEB1.asp](http://www.aidsmap.com/en/docs/BFF46A66-B1D0-11D5-8D13-00508B9ACEB1.asp)

# Testing and HIV

The 'HIV test' is not a test for HIV per se, but for antibodies caused by the body's response to infection, and is an 'HIV antibody test'. It is not a test for AIDS.

In the UK, once someone has tested positive for antibodies to HIV 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'.

In most GU clinics in the UK, a small blood sample is taken from a vein in the arm. Saliva can also be used for antibody tests, but these were – in 2006 – mostly in 'rapid testing' sites, generally outside clinics and hospitals.

HIV antibody tests have become increasingly available at places such as GPs' surgeries and outreach services. They are also a routine part of ante-natal screening for pregnant women.

Producing antibodies usually takes 8-12 weeks after someone is infected with HIV. This sero-conversion time is also called the window period because someone newly-infected with HIV could pass the virus on without the antibodies being identifiable in their blood. Antibody tests may not diagnose HIV acquired during the previous three months, so someone worried about the possibility of recent infection would normally be advised to have another test after 12 weeks.

Not everyone with HIV has been tested or diagnosed.

People can live for many years with HIV even though they don't have any treatment or medical attention. Indeed, 2006 estimates for the UK indicated that about 33 per cent of those with HIV had not been diagnosed and therefore didn't know they had been infected

Most GU clinics send blood to laboratories for testing. Sometimes, this can take two or three weeks.

Anyone being tested should go back to get the results in person so they can get the necessary support and follow-up care, rather than being told by letter, email or phone.

Many clinics have started offering same-day or next-day results. These lessen the waiting but may need more complicated and time-consuming confirmatory tests.

The wait for an HIV antibody test result is no doubt stressful for many people but writing about someone's 'agonising wait' can be misleading, particularly when the test is part of routine screening or the actual risk of infection is extremely low, as is the case with discarded needles. Find out what the probable risk of infection was. Find out what the individual really thought and felt.

Someone infected with HIV should only be described as HIV positive once the diagnosis is confirmed, because this is short for 'HIV antibody positive'.

## Further information

### HIV antibody tests

**NAM** [www.aidsmap.com/cms1031849.asp](http://www.aidsmap.com/cms1031849.asp)

### The window period

**NAM** [www.aidsmap.com/en/docs/7406D7A6-4857-4550-929D-1F7C0713E091.asp](http://www.aidsmap.com/en/docs/7406D7A6-4857-4550-929D-1F7C0713E091.asp)

### Ante-natal HIV screening

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

# The HIV pandemic

The ways HIV is passed from one person to another are now clear, as is the reality that anyone could be infected if they behave in particular ways.

But 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. Detailed information for each country of the world is available at the UNAIDS website [www.unaids.org](http://www.unaids.org).

The majority of HIV infections occurring in the UK are among men who have sex with men (73% in 2005). But the majority of people living with HIV in the UK are heterosexual. This is because of the migration of people to the UK who were infected with HIV overseas, particularly in Africa (68% of heterosexual infections diagnosed in 2005 were acquired in Africa). Statistics on HIV in the UK are updated annually by the Health Protection Agency ([www.hpa.org](http://www.hpa.org)).

It is as important not to assume that HIV only happens to 'other people'. HIV transmission amongst heterosexuals in the UK is increasing, albeit from a low base.

# Life and HIV

There is currently (early 2007) no cure for HIV – once someone is infected with HIV, it's for life – nor is there a vaccine or microbicide to prevent HIV infection.

However, treatments have been developed which significantly slow the speed at which HIV damages the body.

The implications of HIV infection have dramatically changed since the introduction in the second half of the 1990s (1996 in the UK) of effective treatment known as highly active anti-retroviral therapy (or HAART, also known as 'combination therapy', 'potent anti-HIV therapy' or now simply antiretroviral therapy or ART). Clinical practice varies between countries as to when ART should be started but in the UK it is not begun until monitoring shows a significant decline in the immune system. Currently about one third of people diagnosed with HIV in the UK are not as yet on ART.

It is vitally important that the combination of (usually three) ART drugs are taken regularly, without interruption, and as prescribed. Such 'adherence' is important to avoid the development of drug-resistant strains of HIV.

ART does have side effects. Some are short-term, while others can last a long time. Short-term side-effects can include fatigue, nausea, sleep disturbance, rash and diarrhoea. Long-term side-effects can include changes in body shape (fat loss or fat gain), depression and liver or kidney damage. There is more recent evidence that some ART drugs are associated with an increased risk of cardio-vascular disease and/or diabetes.

Where treatment is available HIV is a long-term, serious but in most cases manageable condition. People with HIV work, have relationships and families, keeping active economically and socially.

This has always been the case but now more people with HIV are doing so, and for longer.

Describing people living with HIV as 'AIDS sufferers' or 'AIDS victims' confuses HIV and AIDS, but these terms also imply helplessness and invite pity, which many people living with HIV find unhelpful. Furthermore, the word 'victim' has connotations of guilt and innocence which are inappropriate.

Where ART is available, as it is in the UK, it is inaccurate to describe HIV infection as a death sentence. It is also inaccurate to assume that the infected person's life-span will be significantly reduced as a direct result of HIV infection. Some news stories still like to describe the life of someone living with HIV as permanently blighted by fear of developing AIDS. With the development of ART this is not an accurate description of the experience of most people living with HIV. Of course, there are continuing health concerns, but living with HIV and the side effects of treatment no longer conform to the old template of HIV infection followed eventually but inevitably by the onset of AIDS. Even more inaccurate is to describe someone living with HIV with phrases such as 'AIDS timebomb'. The major issue for someone living with HIV in the UK today is often not their health, but rather the twin issues of stigma and discrimination.

## Further information

### Anti retroviral therapy (ART)

**AVERT** [www.avert.org/introtrt.htm](http://www.avert.org/introtrt.htm)

### Side-effects of ART

**NAM** [www.aidsmap.com/cms1032082.asp](http://www.aidsmap.com/cms1032082.asp)

### UK Treatment guidelines

**BHIVA** [www.bhiva.org/guidelines/2006/hiv/hivfs06.html](http://www.bhiva.org/guidelines/2006/hiv/hivfs06.html)

### HIV & conception

**BHIVA Guidelines** [www.bhiva.org](http://www.bhiva.org)

**NAT** [www.nat.org.uk/HIV-prevention/How-to-prevent-HIV/Conception](http://www.nat.org.uk/HIV-prevention/How-to-prevent-HIV/Conception)

### HIV vaccine research

**International AIDS Vaccine Initiative (IAVI)** [www.iavi.org](http://www.iavi.org)

### Microbicide development

**International Partnership for Microbicides (IPM)** [www.ipm-microbicides.org/](http://www.ipm-microbicides.org/)

### General

**Positive Nation magazine** [www.positivenation.co.uk](http://www.positivenation.co.uk) 020 7564 2121

# UK law and HIV

Discrimination against people with HIV has become illegal in the UK.

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

## 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', while in the Republic of Ireland, charges could, theoretically, be brought under the Non Fatal Offences Against the Person Act of 1997.

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 should, however, be recognised that there are many reasons why disclosure of HIV status can be difficult for an individual.

It is also 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.

By early 2007, 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.

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.

## Further information

### DDA (2005)

National AIDS Trust

[www.nat.org.uk/Stigma-And-Discrimination/Employment/Disability-Discrimination-Act](http://www.nat.org.uk/Stigma-And-Discrimination/Employment/Disability-Discrimination-Act)

### Data Protection (1998)

Information Commissioner's Office

[www.informationcommissioner.gov.uk](http://www.informationcommissioner.gov.uk)

### Criminal prosecutions for reckless HIV transmission

National AIDS Trust

[www.nat.org.uk/Stigma-And-Discrimination/Government-%26-the-Law/Prosecutions](http://www.nat.org.uk/Stigma-And-Discrimination/Government-%26-the-Law/Prosecutions)

## Recommended reading

### 'Criminal HIV transmission'

Available from NAM [info@nam.org.uk](mailto:info@nam.org.uk)

ISBN 978-0-09551678-3-6 £34.95

# HIV and work

HIV cannot be transmitted through usual contact in the workplace. For journalists there should generally be no occupational-related risks of HIV transmission.

Health and Safety training procedures should always meet 'universal precautions' to prevent infections, especially blood-borne viruses, being passed on.

People with HIV are banned from very few professions. These are mostly health-related, such as surgery, dentistry or midwifery where 'invasive procedures' take place.

The (UK) Disability Discrimination Act 2005 outlaws discrimination against people with HIV at work, and covers recruitment, terms and conditions, promotion, transfer, training, other benefits, unfair dismissal and less favourable treatment, as well as protecting someone with HIV from harassment and victimisation.

Employers are obliged to provide 'reasonable adjustments' for disabled people. Working practices as well as workplaces are covered, so flexible working to allow for the side-effects of medication or hospital appointments could be required. Anyone whose immune system is significantly weakened (indicated by a CD4 count below 200 cells/m<sup>3</sup>) may also need to avoid assignments in environments where there is an increased risk of opportunistic infection.

Benefiting from DDA protection often means people with HIV have to disclose their status. Some don't want to do this, because they fear further or different discrimination or because they do not consider themselves sick.

The Data Protection Act 1998 prohibits any unauthorised use or dissemination of your personal information by an employer to others, including colleagues.

## HIV and working abroad

Some countries have entry restrictions for people with HIV, from outright bans to special permission requirements, among them the USA.

While the rules are not hard-and-fast, someone who has HIV and is prevented from taking up an assignment outside the UK should not face discrimination from their employer nor should anyone's career be adversely affected. A responsible, law-abiding employer should find alternative work which avoids such difficulties.

People with HIV may also need specialist guidance about immunisations and vaccinations for travelling, knowing how to adhere to their drugs when changing time zones, having insurance which provides the necessary cover and knowing where to get quality health care.

If someone believes that they have been discriminated against at work because of their HIV status, they should seek further advice from their union representative or the NUJ Equality Office at Headland House or speak to their human resources department.

There should be internal grievance processes in place but should they not resolve matters there are external processes available, culminating as a last resort in an employment tribunal.

## Further information

### **DDA (2005) and 'reasonable adjustments'**

**DRC**

[www.drc-gb.org/employers\\_and\\_service\\_provider/employment/a\\_practical\\_guide\\_to\\_the\\_law\\_a/section\\_22\\_reasonable\\_adjustm.aspx](http://www.drc-gb.org/employers_and_service_provider/employment/a_practical_guide_to_the_law_a/section_22_reasonable_adjustm.aspx)

### **HIV in the workplace**

**NAT**

[www.nat.org.uk/Stigma-And-Discrimination/Employment](http://www.nat.org.uk/Stigma-And-Discrimination/Employment)

### **Employment tribunals**

[www.employmenttribunals.gov.uk](http://www.employmenttribunals.gov.uk)

### **HIV-related travel guidance**

**NAM**

[www.aidsmap.com/en/docs/E7087F82-2C0F-4039-8F58-9CED023E1E81.asp](http://www.aidsmap.com/en/docs/E7087F82-2C0F-4039-8F58-9CED023E1E81.asp)

### **International guidelines**

[http://doc.ilga.org/ilga/publications/other\\_publications/hiv\\_aids\\_regulations](http://doc.ilga.org/ilga/publications/other_publications/hiv_aids_regulations)

### **Data Protection Act (1998)**

**Information Commissioner's Office**

[www.informationcommissioner.gov.uk](http://www.informationcommissioner.gov.uk)

# HIV and professional standards

## **Be accurate**

The NUJ Code of Conduct, as well as the newspaper and magazine industry's Code of Practice, administered by the Press Complaints Commission, and other media codes state that journalists should ensure that their work is fair and accurate.

Checking HIV stories is important. However, while there are expert government and non-governmental bodies who provide information and comment, those sources should never be above criticism or question. Do not be afraid to challenge 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 NUJ's Code of Conduct and other media codes also state that, subject to overriding considerations of the public interest, journalists should not intrude into private grief or distress. 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. People living with HIV should not be pressured into revealing their identities, however good a story.

Contact details for people with HIV should not be passed on unless they have given permission, ideally in writing.

If someone living with HIV asks for anonymity during a radio or television interview, this should be respected. Ideally, 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.

Protect your sources. Once sacrificed, confidentiality can never be retrieved. Journalists should discuss the consequences of disclosure – or “coming out” – before identifying an interviewee or source. Similarly, such revelations may have devastating implications for partners, families, friends and children if they are not considered fully. Remember that disclosing someone's job and the general area where they live may be enough to identify them; a visible tattoo could too.

## **Be relevant**

The NUJ's Code of Conduct and other media codes state that 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.

If HIV is seen as “someone else's problem” affecting particular groups, then others who do not identify with those groups may be less careful, so more people could become infected. It can also perpetuate discrimination and stigma, potentially adding to prejudice, abuse, assaults and the loss of homes and jobs for people identified as members of these groups.

## **Avoid sensationalism**

The NUJ has always urged journalists to 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.

## Reflecting reality

Stigma and discrimination have been linked to HIV from the outset. This is in part due to ignorance and fear, but it is also because the groups and individuals who are infected are frequently already targets of prejudice, be they men who have sex with men, injecting drug users or migrants. Wider, better and more balanced coverage can help break this link so that such attitudes are not perpetuated or reinforced. And, because HIV first affected clearly identifiable groups, stereotypes emerged. Challenging this, 25 years on, means reflecting the more varied voices of those with HIV.

In the UK, non-profit organisations such as the National AIDS Trust, the Terrence Higgins Trust, Positively Women, the African HIV Policy Network (AHPN) or the UK Coalition (of People Living with HIV and AIDS) can put journalists in touch with people with HIV so that such wider views and experiences can be reported. But such individuals will speak about their own lives and thoughts and cannot claim to represent everyone with HIV or be expert on all aspects of the condition.

## Useful organisations

### HIV organisations

#### 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 Women

Tel: 020 7713 0444

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

#### AHPN

Tel: 020 7017 8910

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

#### UK Coalition of People Living with HIV and AIDS

Tel: 020 7564 2180

Email: [reception@ukcoalition.org](mailto:reception@ukcoalition.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

#### Society of Editors

Tel: 01223 304080

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

#### Press Complaints Commission

Tel: 020 7831 0022

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

# 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 as 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.
- 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
<p><b>HIV</b></p> <p><b>HIV and AIDS</b></p>	<p>AIDS virus</p> <p>Full-blown AIDS</p> <p>HIV/AIDS</p>
<p><b>A person living with HIV [PLWH]</b></p> <p><b>A person who is HIV-positive</b> (if diagnosed)</p> <p><b>A person who is HIV-infected</b> (if undiagnosed)</p>	<p>AIDS or HIV carrier</p> <p>AIDS 'timebomb'</p> <p>A person is HIV</p> <p>A(n) (HIV or AIDS)</p> <p>victim/sufferer</p>
<p><b>HIV antibody test</b></p>	<p>AIDS test</p> <p>HIV test</p>
<p><b>Transmitting HIV</b></p> <p><b>Infected by HIV</b></p> <p><b>Acquiring HIV</b></p>	<p>Transmitting AIDS</p> <p>Infected by AIDS</p> <p>Catching HIV (or AIDS)</p>
<p><b>Recklessly infecting</b></p>	<p>Intentionally/deliberately/knowingly infecting (when applied to a reckless transmission charge)</p>
<p><b>Safer sex</b></p>	<p>Safe sex</p>

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, more accurately describes 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)



## Thanks

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Cover photograph: Tom Elkins



The National AIDS Trust is the UK's leading independent policy and campaigning voice on HIV and AIDS. A registered charity, we develop policies and campaign to halt the spread of HIV and improve the quality of life of people affected by HIV, both in the UK and internationally.

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London EC1V 9FR

Telephone: 0207 814 6767

Web: [www.nat.org.uk](http://www.nat.org.uk)



The NUJ is one of the biggest and best-established journalists' unions in the world with over 35,000 members covering the whole range of editorial work – staff and freelance, writers and reporters, editors and sub-editors, photographers and illustrators. NUJ members work in broadcasting, newspapers, magazines, books, on the internet and in public relations.

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