HIV Media Guide



The media plays a key role in educating the public and shaping narratives around HIV



Journalists and media agencies play a key role in helping to reduce HIV stigma, discrimination and sensationalism, correct misinformation, and promote access to life-saving HIV prevention and treatment.

These guidelines have been developed to support people working in HIV media to provide advice around language, representation, medical accuracy, ethics and data reporting.



What is HIV

HIV stands for human immunodeficiency virus. Infection with HIV damages the body's immune system, which makes it more difficult to fight off infections and some cancers.

How is HIV spread?

HIV is transmitted through body fluids. Treatments are available for HIV infection, but there is no vaccine and no cure.

HIV is in the blood, semen, vaginal fluid or breast milk of an infected person and can be transmitted:

during anal or vaginal sex without the protection of a condom

- by sharing drug injecting equipment (contaminated needles, syringes and other injecting equipment and drug solutions)
- by unsafe injections, tattoos and other procedures that involve unsterile cutting or piercing
- to a baby during pregnancy, childbirth or breastfeeding.

HIV is not transmitted by kissing or cuddling, by day-to-day social contact such as shaking hands, by sharing cutlery, cups or glasses, by eating food prepared by someone with HIV, through toilet seats, or by mosquito or other insect bites.

Are HIV and AIDS the same thing?

No; AIDS (Acquired Immune Deficiency Syndrome) is a late stage of HIV infection. AIDS is diagnosed when a person with HIV infection has a severely damaged immune system which means they may develop a disease caused by an infection that doesn't usually affect healthy people. People with HIV infection who are on effective treatment do not develop AIDS, as the treatment stops damage to the immune system.

What are the symptoms of HIV infection?

Most people have mild symptoms or no symptoms when they are first infected with HIV. Some people develop a flu-like illness with fever, sore throat, swollen glands or a rash a few weeks after being infected. These symptoms usually disappear without treatment after a week or two. This is called the seroconversion illness. After the initial illness, people with HIV infection usually have no symptoms for many years, despite the virus living in their body.

Living a healthy life with HIV is now reality

Treatment with antiretroviral drugs is very effective at protecting the immune system from HIV damage. It helps people with HIV reduce their viral load to undetectable levels. This means they can live full, long, and healthy lives. Starting HIV treatment right away has many health benefits. When the treatment is successful, it lowers the amount of virus in the blood and other bodily fluids, which prevents the virus from spreading to others. This is known as Undetectable equals Untransmittable (U=U).

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How HIV is talked about and reported on matters

It is critical that people reporting on HIV publicly use respectful and person-centred language, as recommended by leading HIV organisations.

Don't confuse HIV and AIDS

HIV is the Human Immunodeficiency Virus; AIDS is Acquired Immunodeficiency Syndrome. Don't confuse or use the terms interchangeably, as they have distinct clinical meanings and are not interchangeable.

Avoid labelling

Many people living with HIV find terms like 'victim' and 'sufferer' patronising and disempowering. Referring to 'innocent victims' such as children with HIV, or people with medically acquired HIV can fuel stigma for people who acquired HIV in other ways.

Avoid stereotyping

People living with HIV come from diverse backgrounds. While some groups are disproportionately affected, the misconception that HIV only affects men who have sex with men, people who inject drugs, and sex workers hinders efforts aimed at educating the public about risk. It is important to avoid making value judgments about how people acquire HIV or that their behaviours put them at inherent risk.

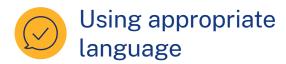
Do:

- Use correct and non-stigmatising language to describe HIV and affected people
- Include voices and perspectives from people living with HIV
- Educate accurately using verified facts from credible sources
- Highlight medical advancements improving quality of life
- Challenge stereotypes by elevating diverse personal stories
- Report sensitively without promoting fear, myths, misconceptions, sensationalism or judgment
- Protect privacy and avoid unintended disclosure of a person's HIV status
- Hold governments and institutions accountable in addressing HIV

Respect confidentiality

<u>Never</u> reveal or imply someone's HIV status unless they have explicitly understood the context and given informed consent. Even where someone's HIV status or how they acquired HIV is on public record, it is crucial to consider whether this information is relevant to the matter. It is expected that you gain someone's consent before publishing information relating to their HIV status. Unauthorised disclosure can lead to discrimination, violence, and other harmful and serious consequences.

Under Section 56 of the Public Health Act 2010 (NSW) (No 127), unauthorised disclosure of another person's HIV status is a criminal offence punishable by a fine of up to \$11,000.00, or imprisonment for six months or both.



Use respectful language for people who are affected by HIV

When referring to populations affected by HIV use respectful terminology:

- Person living with HIV (including women and heterosexual people) (not "HIV positive")
 - For more information, contact Positive Life NSW
- Gay, bisexual, and other men who have sex with men (not all men who have sex with men may identify as gay or bisexual, and recognise that sexuality can be fluid)
 - For more information, contact <u>ACON</u> and/or Positive Life NSW
- Person who uses drugs (not "junkie," "addict," or "injecting drug user")
 - For more information, contact <u>NUAA</u>
- Sex worker (not "prostitute")
 - For more information, contact <u>SWOP</u>

Don't use stigmatising terms like "high-risk group" which wrongly implies that certain groups of people are at a higher risk of getting HIV, regardless of their individual behaviours.

Including the terms 'living with' is important to people living with HIV. This phrasing recognises that today with effective care and treatment, people are living with, rather than dying from HIV. It also acknowledges the price that countless men and women who have passed from HIV/AIDS have paid so people living with HIV today can live healthy, full lives.

Avoid the use of stigmatising phrases around treatment such as 'compliant', and instead use 'taking medication as recommended'. Similarly, avoid using language such as 'poorly adherent' or 'people with poor adherence', in favour of 'experiencing or reporting difficulty in maintaining regular medication' or 'experiencing challenges with medication adherence'. People do not 'fail' treatment, although sometimes treatment fails people.

Avoid: AIDS – if referring specifically to HIV

AIDS is a syndrome encompassing various medical conditions that can occur when HIV has severely damaged the immune system. A person living with HIV may not have developed any of the illnesses that define AIDS.

Avoid: AIDS virus, HIV virus

There is no "AIDS virus" - HIV is the virus that can progress to AIDS if untreated. Only use "HIV/AIDS" when specifically discussing the advanced stage of untreated HIV that has resulted in the condition of AIDS.

Use "HIV" as a general term when referring to the HIV virus. Although HIV and AIDS are connected, their names refer to separate diagnoses and should not be used interchangeably. In Australia most people living with HIV do not have or progress to an AIDS defining illness.

When reporting on the virtual elimination of HIV transmission, either use this full definition, or the phrase 'Ending HIV transmission' or 'acquisition', rather than 'Ending HIV'.

Avoid: AIDS victim, HIV sufferer, AIDS sufferer

People living with HIV are not "victims" or "sufferers." HIV is something people live with and manage as a chronic condition.

Avoid reporting HIV in combative terms such as a "battle" or "fight" that someone can "lose". Instead of describing someone's 'battle' with HIV, consider the use of phrases such as response, management of, measure against, initiative, action, or effort.

Describe it as:

- A person's HIV diagnosis
- A person's experience with HIV
- A person's HIV journey
- That a person died from HIV/AIDS-related causes

Avoid: HIV/AIDS patients

HIV is a personal experience that affects individuals in different ways. A HIV diagnosis does not necessarily make someone a "patient." Many people live long, healthy and happy lives while managing HIV through effective treatment.

Use person-first language which puts people before their health condition recognising people are not defined by their condition. Use "person/people living with HIV" instead of labelling them as "HIV/AIDS patients," unless specifically discussing a clinical treatment situation.

Avoid: HIV carrier, HIV-infected

HIV is a manageable, chronic condition and is spread via body fluids including blood, semen, vaginal fluids, and breast milk. HIV cannot be transmitted through saliva, sweat, urine, tears, hugging/kissing or being physically close to someone.

People living with HIV are not "infected", 'vectors of infection or disease', or 'hosts for a virus.' They have agency and have played a pivotal role in creating awareness around HIV. Many have been collaborators in the medical and scientific achievements around HIV prevention, care, and treatment initiatives since the inception of the epidemic.

Instead of infectious terminology ('caught', 'got', 'infected with' etc), use 'acquired', 'contracted' or 'transmitted'. No-one can be 'infected' with AIDS. As a syndrome, it is not an infectious agent.

Avoid using 'co-infected person, people or populations', and instead describe the person or population as 'living with HIV and [an additional condition]' e.g. 'living with HIV and hepatitis C.'

When referring to perinatally acquired HIV, do not use 'mother to child transmission', and instead use 'perinatal transmission.' Perinatal transmission of HIV means passing HIV from the mother or birthing parent to their child during pregnancy, childbirth, or breastfeeding.

Consistent and accurate medical terminology

Ensure proper use of clinical HIV terminology, eg:

- Viral load, undetectable viral load, antiretroviral treatment
- Pre/post-exposure prophylaxis (PrEP, PEP)
- Modes of HIV transmission
- · Current prevention methods
 - Refer to <u>HIV management in Australia</u> -Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM)

Consult medical experts and explore resources from reputable HIV-related organisations, such as those listed below, to ensure that any clinical information is accurate. This is especially important when discussing complex scientific topics related to HIV's virology and treatment.



Positive messaging and solutions

A positive message is a message that is displayed to the public about a topic in a supportive and factual way to influence the way the public thinks or acts. The message could include credible data from reputable sources that demonstrate a positive norm.

To incorporate positive messaging to improve public health outcomes:

- Include voices and perspectives from those living with HIV in NSW.
 - Contact the Positive Life NSW's Positive Speaker Bureau
- For HIV prevention, refer to <u>HIV testing locations</u>, <u>PrEP resources</u> and the <u>NSW needle and syringe</u> <u>program</u>.
- Highlight effective HIV management through modern antiretroviral treatment.
- Highlight U=U. or Treatment as Prevention (TasP), where effective antiretroviral treatment reduces the amount of the virus in the blood to undetectable levels. This means the levels of HIV are so low that the virus cannot be passed on sexually. Refer to:
 - NAPWHA U=U media guidelines
 - Positive Life NSW Treatment as Prevention (TasP)



HIV data and statistics

It is journalists' responsibility to report on HIV accurately and in a way that can be easily understood so that there is less potential for misunderstanding.

When reporting HIV data and statistics:

 Clearly and properly use terms like incidence, prevalence, new diagnoses

- · Cite the latest credible data sources:
 - For NSW based data, the NSW Health <u>HIV Data</u> <u>Reports</u>
 - For Australian data, use The <u>Kirby Institute</u> <u>Surveillance Reports</u>
 - For global data, use sources like UNAIDS or The World Health Organisation (WHO), and Centre for Disease Control.
- Ensure that data is accurately interpreted and presented. All data should be contextualised to avoid sensationalism or misinformation.

Three HIV data terms often confused are 'incidence,' 'prevalence,' and 'newly diagnosed.' These terms have distinct meanings and should not be used interchangeably.

- HIV incidence refers to the number of new HIV infections that occur within a specific period, typically expressed per 100,000 people in the population.
- HIV prevalence is the total number of people living with HIV at a specific point in time, regardless of when they were infected. It is typically expressed as a percentage of the population.
- Newly diagnosed refers to individuals who receive their first positive HIV test result within a specific period. This term does not necessarily indicate when the infection occurred, as some individuals may have lived with the virus for years before being diagnosed.



The NSW HIV Strategy 2021–2025

New ways to prevent, test and treat mean that the virtual elimination of HIV transmission in NSW, once inconceivable, is now a realistic and achievable goal. The NSW HIV Strategy 2021–2025 is a plan for the virtual elimination of HIV transmission in NSW for all. The goals of the strategy are to prevent transmission, normalise testing, start and maintain treatment soon after diagnosis and reduce stigma.

Media enquiries

The NSW Health Media team is responsible for all media enquiries and interviews with NSW Health staff members. The unit regularly advises on major public health issues and disease outbreaks through media releases and media conferences.

Contact the Media Team for interviews, speakers and special requests. Staff in the unit are available 24 hours a day, seven days a week via an on-call service.

Email: media@health.nsw.gov.au

Looking for more HIV media resources and information?

Visit:

HIV media guidelines

Health Equity Matters HIV Media Guide

NAPWHA U=U media guidelines

The People First Charter

HIV-related organisations

ACON Health Limited

Positive Life NSW

Bobby Goldsmith Foundation

SWOP (Sex Workers Outreach Project)

<u>Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM)</u>

NSW Users and AIDS Association (NUAA)

