

People First Charter: recommended terminology for research and publications related to HIV

Please avoid	Alternatives
AIDS patient	Person with complications of advanced HIV, person with an AIDS-defining illness
AIDS test	HIV test
AIDS virus	HIV
Catch HIV	Acquire HIV
Compliant	Taking medication as recommended, adherent, concordant
Contagious/infectious	Person with transmittable HIV or detectable viral load
Dirty or clean in the context of people or injecting equipment	Just don't use! Shared needles, injecting equipment or drug paraphernalia acceptable
HIV-infected person, people, individual(s), populations	Person/people living with HIV HIV-positive individual(s) or populations
Prostitute, prostitution	Sex worker, transactional sex
Consider avoiding	Alternatives
Abbreviations	Avoid abbreviating e.g. people who inject drugs (PWID), women living with HIV (WLWH) if possible
Co-infected person or people	Person living with HIV and <additional condition> e.g. person living with HIV and hepatitis B. Treating 'HIV/hepatitis co-infection' or living with HIV/HBV is acceptable, treating the 'HIV/hepatitis co-infected' is not
Detectable or viraemic patients	People with a detectable HIV-RNA or viral load, or people with viraemia
Disclose HIV status	Share or discuss HIV status
Ending HIV, ending AIDS	Ending HIV transmission, ending late HIV presentation or preventable HIV-related deaths
HIV exposed infant	Infant exposed to HIV
HIV exposed uninfected infant	HIV-negative infant exposed to HIV
Intravenous drug user/IVDU; drug addict; drug abuser	People who inject drugs; People who use drugs
Spread, infect	Transmit, pass on
HIV deaths	HIV-related mortality or HIV-related deaths
Mother to child transmission	Vertical transmission, perinatally acquired HIV
People failing therapy; failing patients	People experiencing treatment failure, people on failing therapy
Risk group or transmission risk	Mode of HIV acquisition or acquisition risk
Poorly adherent	Person/people with poor adherence
Resistant patients	People with resistant virus
Serodiscordant	Serodifferent, partners with differing HIV status
Trial subjects	Trial participants, volunteers
Unprotected sex	Sex without a condom, condomless sex
Zero infections	Zero transmissions, zero new cases of HIV/newly acquired HIV

People living with HIV are not just hosts for a virus, vectors of infection, or trial subjects - they have awareness and agency. People living with HIV have been prominent in advocating for better medical care, treatment expansion and have been collaborators in the medical progress made. The language used to refer to people with HIV in research and publications, should reflect this.

We recognise that language is not universal, and that there are always challenges when translating words, including medical terminology. However, we believe that there are some terms that should no longer be used and others that we should consider moving away from.

There is terminology that is may or may not be acceptable depending on the context in which it is used. *Infection*, *infected* and *failures* are terms that should not be used in the context of people, person or populations but may be acceptable in other contexts:

- HIV infections or HIV/hepatitis co-infections e.g. in terms of epidemiology
- Acute infection and chronic infection e.g. in terms of HIV stage
- HIV-infected cells e.g. in terms of in vitro research
- Treatment failure e.g. in the context of epidemiology

Similarly, whilst people are encouraged to avoid abbreviations where possible, it may be necessary to do so for readability or word counts in tables, graphs and abstracts.

This document is intentionally brief and designed as a first stop for people and organisations seeking to use People First language. More information about appropriate language is available from other organisations, including UNAIDS [1], NHIVNA [2], The Salamander Trust [3] and The George House Trust [4]. Additional resources will be added regularly.

There is ongoing debate about the appropriateness of ‘patients’ as opposed to ‘clients’ or ‘service users’. We advise that all are acceptable currently but, ideally, people accessing services should be asked about their preferred terminology. UK research in mental health services show that people prefer ‘patient’ when consulted by a psychiatrist or nurse, and ‘patient’ or ‘client’ when consulted by social workers and occupational therapists; ‘service user’ was not preferred [5].

References

- 1) UNAIDS Terminology Guidance 2015; accessed at https://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf 18th October 2021
- 2) Watson S et al. The language of HIV: a guide for nurses. HIV Nursing 2019; 19(2): BP1–BP4.
- 3) Salamander Trust. The Power of Language. Accessed at <https://salamandertrust.net/project/the-power-of-language/> 18th October 2021
- 4) The George House Trust. HIV language guide. Accessed at <https://ght.org.uk/hiv-language-guide> 4th February 2022
- 5) Simmons P et al. Service user, patient, client, user or survivor: Describing recipients of mental health services. The Psychiatrist 2010; 34(1): 20-23.