NIAID HIV

Language Guide

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# About this Guide

When scientists and administrators write or speak about HIV, the words they choose have the power to passively perpetuate ignorance and bias. Conversely, they have the power to respectfully and accurately represent people and ideas. This guide was designed to help those at NIAID communicate about their work using empowering rather than stigmatizing language, especially as it relates to HIV.

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

– *The Denver Principles*, 1983

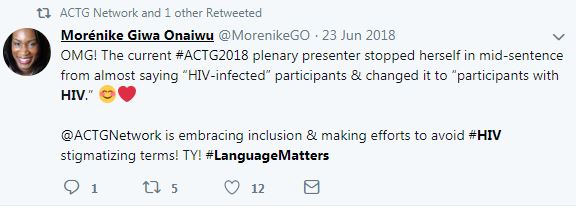
Since a group of people with AIDS wrote the self-empowerment manifesto known as *The Denver Principles* in 1983, language has been a central theme in efforts to dismantle stigma around HIV.[[1]](#footnote-1) Many HIV advocacy groups and media outlets embrace slogans such as “language matters” and promote primers on using empowering language, as do other organizations that advocate for other health conditions and marginalized groups. Conversations about language choice frequently come up during demonstrations, conferences and listening sessions.

Empowering language remains an important focus for such organizations because language perpetuates stigma, and as studies continue to bear out, stigma helps perpetuate the HIV epidemic. While many factors that contribute to health-related and societal stigmas are entrenched and systemic, NIAID officials have the immediate power and opportunity to improve language and lead by example.

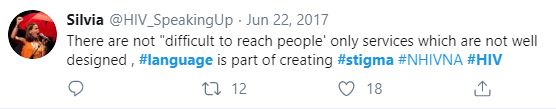
This guide includes language suggestions for communicating about HIV and related topics. Below are a few examples of the impact such language can have.



Ugandan advocate Dric Adoni tweets about stigmatizing language around HIV from a popular youth HIV awareness event, the Y Plus Beauty Pageant.



This tweet from American educator and autism and HIV advocate Morénike Giwa Onaiwu complimented person-first language used by a presenter at ACTG 2018.



Tweeting from a 2017 National HIV Nurses Association meeting, UK-based HIV advocate Silvia Petretti makes the point that “difficult to reach people” puts the onus of obtaining HIV services on individuals facing adversity rather than on public health efforts.

# Methodology

This guide was created by the NIAID Office of Communications & Government Relations (OCGR) News & Science Writing Branch (NSWB) with input from the Division of AIDS (DAIDS) Workforce Operations, Communications, and Reporting Branch (WOCRB). This guide is a living document, subject to change as language standards in various fields may evolve. This guide was last updated on February 19, 2020.

Before finalizing the first version, multiple representatives from NIH, other public health organizations and community-based advocacy groups had the opportunity to review and contribute to relevant sections of this guide to help ensure scientific accuracy, community buy-in, and cultural competence. Reviewers included subject matter experts and communications experts from other NIH institutes and centers, including the National Institute of Mental Health (NIMH), National Institute of Drug Abuse (NIDA), National Institute of Alcohol Abuse and Alcoholism (NIAAA), National Institute on Minority Health and Health Disparities (NIMHD), the NIH Office of Research on Women’s Health (ORWH) and the NIH Sexual & Gender Minority Research Office (SGMRO). Multiple DAIDS officials, including leaders in the Office of the Director, were also consulted.

For a non-federal perspective, WOCRB facilitated review of this document by a diverse group of community members serving the NIH-funded [HIV/AIDS Clinical Trials Networks](https://www.niaid.nih.gov/research/hivaids-clinical-trials-networks) in various community liaison and advisory capacities. This group consisted of community advocates who are or have been involved with Networks’ Global Community Advisory Boards, [Community Partners](https://www.niaid.nih.gov/research/community-partners), the Tuberculosis Trials Consortium [Community Research Advisors Group](http://www.treatmentactiongroup.org/tb/community-engagement/crag), the AIDS Clinical Trials Group [Underrepresented Populations Committee](https://actgnetwork.org/underrepresented-populations/), the [Women’s Health Inter-Network Scientific Committee](https://actgnetwork.org/underrepresented-populations/), the Cross-Network Transgender Working Group, and the [Legacy Project Working Group](https://www.hanc.info/legacy/Pages/default.aspx) and [Women's HIV Research Collaborative](https://www.hanc.info/legacy/Pages/workingGroups.aspx) of the [Office of HIV/AIDS Network Coordination](https://www.hanc.info/Pages/default.aspx) (HANC). We extend our sincere gratitude to all community reviewers, which included people living with HIV, people in communities disproportionately affected by HIV, citizens of the Global South, people of color, cisgender women, transgender people, people in the LGBTQ community, sex workers, people with substance use disorder, older people and young people, among others.

A variety of source materials were consulted in the writing of this language guide. Notably, the Centers for Disease Control and Prevention’s [HIV Stigma Language Guide](https://www.cdc.gov/stophivtogether/campaigns/hiv-stigma/stop-hiv-stigma/index.html#Stigma-Language-Guide) and “Why Language Matters: Facing HIV Stigma in Our Own Words” by [Vickie Lynn](https://www.thewellproject.org/team-member/vickie-lynn), Ph.D., MSW, MPH, and other members of [the Well Project](https://www.thewellproject.org/hiv-information/why-language-matters-facing-hiv-stigma-our-own-words) have been a tremendously valuable resources on stigmatizing language around HIV. Materials included in the University of California San Francisco HIVE Online [#LanguageMatters campaign](https://hiveonline.org/language-matters/) also informed this “HIV Basics” chapter of this guide and beyond.

Additionally, guidance documents and learning modules compiled by the DAIDS Cross-Network Transgender Working Group informed language standards around sex and gender in this guide’s “Sex, Gender & Sexuality” chapter. Specifically, “[Guidance on the Use of Gender-Inclusive HIV Research Practices](https://www.hanc.info/legacy/Documents/Guidance%20for%20Transgender%20Inclusive%20Research%20FINAL%2011-19-2019.pdf)” and its Appendix, “Use of Non-Stigmatizing, Gender Inclusive Language,” outlined language preferences reiterated in this document. The Working Group drew on insights of community representatives of trans experience. The [2019-2023 Trans-NIH Strategic Plan for Women’s Health Research](https://orwh.od.nih.gov/sites/orwh/files/docs/ORWH_Strategic_Plan_2019_02_21_19_V2_508C.pdf), compiled by ORWH, also informed this chapter.

Language guidance for the “Substance Use” was informed by a 2017 Office of National Drug Control Policy [memorandum](https://www.whitehouse.gov/sites/whitehouse.gov/files/images/Memo%20-%20Changing%20Federal%20Terminology%20Regrading%20Substance%20Use%20and%20Substance%20Use%20Disorders.pdf) entitled, “Changing Federal Terminology Regarding Substance Use and Substance Use Disorders,” as well as by [training resources](https://www.samhsa.gov/sites/default/files/programs_campaigns/02._webcast_1_resources-508.pdf) compiled by the Substance Abuse and Mental Health Services Administration and its partners.

## Limitations

The language preferences described in this guide apply primarily to English speakers in the United States. Language preferences may vary in a global context. Translation can also change the connotation of certain phrases.

While great care was taken to incorporate many perspectives from the community, individual language preferences vary. Similarly, while OCGR and WOCRB will continually review this document for accuracy and relevance, preferred language is subject to change.

# General Considerations

## Context

Choosing appropriate language always depends on the context in which the language appears. Generally, this guide applies to language appropriate for official government communication. While these principles may be applied broadly to scientific talks, funding opportunity announcements (FOAs), requests for proposals (RFPs), media interviews and public calls for clinical research participation, other contexts may call for specific language that does not fit neatly into the following guidelines.

## Images

Written and spoken word are only one facet of communication. Images and body language also convey messages, tone and—unfortunately—stigma. Be mindful of how an image you use may affect its audience. In the context of HIV, most advocates prefer images that highlight people living vibrantly with HIV to those that may show graphic depictions of AIDS symptoms. Similarly, substance use disorder advocates caution against using images of alcohol, syringes or pills in relation to substance use, as these may trigger someone in recovery.

## The Platinum Rule

Many learn as children that the best way to respect others is to follow the Golden Rule: “Treat others as you wish to be treated.” Many advocates in the HIV community promote the Platinum Rule: “Treat others as *they* wish to be treated.” This guide aims to help scientists and administrators use fair, accurate and respectful language, but preferences can change and vary across groups and individuals. They can also evolve overtime.

Remain receptive to feedback from those who are most affected by stigmatizing language and prioritize expertise from their lived experiences. When possible, proactively seek input from marginalized voices. Recognize that there may not be a universal “right” answer for how to discuss a certain topic and that finding the most appropriate language may mean rephrasing or reframing a message instead of just replacing terms. While some may find this to be a frustrating challenge, investing in respectful communication can strengthen the relationship between government officials and the public they are trying to reach.

## Questions?

If you are an NIH employee, the NIAID Office of Communications & Government Relations is available to assist with your communications needs and can consult on the appropriate use of language. Contact them at [NIAIDNews@niaid.nih.gov](mailto:NIAIDNews@niaid.nih.gov).

# 5 Quick Tips

| *Try this…* | *Instead of this…* | *Because…* |
| --- | --- | --- |
| HIV  HIV disease  people living with HIV | HIV infection  HIV-infected people | “Infection” carries the stigma of being contagious, a threat, unclean. HIV advocates frequently highlight the damaging consequences of this word choice. When referring to people, person-first language emphasizes humanity. “Living with” is an affirmation of life many advocates prefer. “People with HIV” is also acceptable. |
| HIV | HIV/AIDS | AIDS evokes suffering and death and should be used only when describing specifically AIDS. HIV is inclusive of both HIV and AIDS when the reference is not specific, as in “the HIV epidemic.” |
| affected community/population or  high-incidence population | high-risk people/population/group | People and communities are not inherently risky. The preferred terms acknowledge societal challenges and accurately reflect disease dynamics. |
| condomless sex or  sex without the use of prevention tools | unprotected sex  unsafe sex | The preferred terms are more specific, accurate and remove judgement. Condomless sex may still involve protection in the form of U=U or PrEP. |
| perinatal transmission  vertical transmission | mother-to-child transmission | The preferred terms do not place blame on women. |

# HIV Basics

| *Try this…* | *Instead of this…* | *Because…* |
| --- | --- | --- |
| HIV | HIV/AIDS | AIDS evokes suffering and death and should be used only when specifically describing AIDS. HIV is inclusive of both HIV and AIDS when the reference is not specific, as in “the HIV epidemic.” |
| HIV  HIV disease  HIV transmissions  new HIV diagnoses  transmit  acquired  prevents HIV  prevents transmission of HIV  prevents acquisition of HIV | HIV infection  new HIV infections  infect  became infected  prevents HIV infection | “Infection” carries the stigma of being contagious, a threat, unclean. HIV advocates frequently highlight the damaging consequences of this word choice. |
| people living with HIV  people without HIV | HIV-infected people  HIV positives  HIVers  HIV carriers  people infected with HIV  HIV-uninfected people | Person-first language emphasizes humanity. “Living with” is an affirmation of life many advocates prefer. “People with HIV” is also acceptable. “HIV-positive people” is generally not preferred but still used by some community members. “Poz” also is sometimes used by community members. |
| died from complications related to HIV or died of an AIDS-related illness | died of AIDS | The preferred terms avoid the incorrect assumption that AIDS is uniformly fatal and clarify that opportunistic infections are the acute cause of death. |
| HIV response | HIV elimination  HIV eradication | To some in the community, these terms have a paternalistic and militaristic connotation and imply people living with HIV must disappear to achieve an end to the epidemic. |
| people living with HIV  new HIV diagnoses  people newly diagnosed with HIV | HIV cases  new HIV cases | People should not be described as “case,” as this term deemphasizes humanity and implies burden. |
| research participant  volunteer | research subject  patient | “Subject” is dehumanizing. Not all participants are patients. |
| client | patient | When describing a person using the healthcare system, “client” is considered empowering. |
| engage a population  priority population/group  key population/group | target a population  target(ed) population/group | These preferred terms emphasize community-oriented, participatory approaches to ending an epidemic, instead of paternalistic, top-down approaches. |
| perinatal transmission  vertical transmission | mother-to-child transmission | The preferred terms do not place blame on women. |
| infant exposed to HIV | HIV-exposed infant | Person-first language emphasizes humanity. |
| sero-different | sero-discordant | “Discordant” implies a couple is unsuitable for each other. “Magnetic” and “mixed status” are also terms used to describe couples comprised of one person with HIV and one without HIV. |
| affected community/population or  high-incidence population | high-risk people/population/group | People and communities are not inherently risky. The preferred terms acknowledge societal challenges and accurately reflect disease dynamics. |
| person behaviorally vulnerable to HIV | at-risk person  person who engages in risk behaviors  person who puts themselves at risk | People do not have inherent risk. Certain communities—including sexual and gender minorities, as well as people of color—are often labeled as the “people who engage in risk behaviors,” while populations with lower community viral load may engage in a similar or higher frequency of the same behaviors but remain less likely to acquire HIV because of the community viral load. Where possible, specify the activity and provide appropriate context. |
| likelihood, chance | risk | The preferred terms help reduce passivity applied to populations. |
| hardly reached or unsuccessfully engaged  populations/individuals | hard to reach populations/individuals | The preferred terms put the onus on the health sector rather than an individual. |
| condomless sex or  sex without the use of prevention tools  sex with the use of condoms and/or other prevention tools | unprotected sex  unsafe sex  protected sex  safe sex | The preferred terms are more specific, accurate and remove judgement. Condomless sex may still involve protection in the form of U=U or PrEP. |
| has multiple sexual partners | promiscuous | Avoid “promiscuity” and its derivatives, as it is an unnecessary value judgement. |
| treatment non-completion | treatment default | “Default” is a negative term that implies a value judgement about the person who did not complete treatment. |
| adherence | compliance | “Compliance” implies passive behavior/following instructions, while “adherence” acknowledges a person’s active engagement in care. |
| internal condom | female condom | Some transgender men and nonbinary people may use internal condoms vaginally, and people of all genders can use internal condoms for anal sex. |
| external condom  condom | male condom | Some transgender women and nonbinary people may use external condoms for intercourse; people of all genders may cut external condoms to create dental dams. |
| [people with undetectable viral load] do not transmit HIV  no risk  zero risk  [viral suppression] prevents HIV  eliminates onward sexual transmission | extremely unlikely to transmit HIV  nearly impossible to transmit HIV  almost no risk  greatly reduces risk  close to zero risk  helps prevent HIV  makes it hard to sexually transmit HIV | Describe the principal of treatment as prevention, or “Undetectable equals Untransmittable” clearly and consistently. Using qualifiers that suggest U=U is only somewhat effective is inaccurate and is seen by some in the community as a result of paternalistic mistrust of people living with HIV. Unnecessary qualifiers also stigmatize by perpetuating the overestimation of transmission HIV risk. |

# Sex, Gender & Sexuality

| *Try this…* | *Instead of this…* | *Because…* |
| --- | --- | --- |
| sexual orientation | sexual preference | “Preference” suggests that non-heterosexuality is a choice, a concept often used to discriminate against the LGBTQ community. “Preference” also suggests a selection from two or more choices, excluding bisexual people and pansexual people, among others. |
| assigned male/female at birth  sex assigned at birth  transgender man  transgender woman | born male/female  biological sex  sex at birth  used to be a woman  born a woman  female-to-male (FTM)  used to be a man  born a man  male-to-female (MTF) | The preferred terms affirm gender identity. |
| transgender  trans  transgender people/person  people/a person who is transgender  people/person of trans experience | transgendered  transgenders/a transgender | “Transgendered” is a dated term that suggests a point in time when a person “became” transgender, which diverges from the lived experiences of most transgender people. Similarly, “transgenders” is dated and does not emphasize humanity. |
| trans man  trans woman | transman  transwoman | “Trans” is an adjective that helps describe someone's gender identity, and it should be treated like other adjectives. Merging the adjective and the noun risks suggesting that a trans man or woman is more (or less) than just a man or just a woman, which goes against how many trans people identify themselves. |
| gender affirmation  gender confirmation  transition  transitioning | transgendering  sex change  the surgery  pre-operative/post-operative | “Gender affirmation” and “transition” define the interpersonal, interactive process whereby a person receives social recognition and support for their gender identity and expression. This process can but does not necessarily involve medical intervention, which can include hormone therapy and one or more surgeries to affirm one’s gender. “Pre-/post-operative” may still be used in medical literature but should not be applied to a specific person without their consent. |
| person with a difference in sex development (DSD)  intersex person  person who is intersex | hermaphrodite | Differences in sex development (DSD) is an inclusive umbrella term that refers to congenital atypical variations in the development of chromosomal, gonadal, or anatomical sex. Many but not all people with DSD identify as intersex. When using the term intersex, also use and define DSD. Classical understandings of the term “hermaphrodite” are usually limited to individuals with both traditionally male and female anatomical features, particularly genitalia. This term also is considered offensive because of its mythical origin and historically derogatory use. |
| people of childbearing potential | women of childbearing potential | People of all genders and sexes may have childbearing potential. |
| people with reproductive potential | men with reproductive potential | People of all gender may have reproductive potential. |
| people  individuals of all genders  or be specific—cisgender men and cisgender women | men and women  both genders/either gender | Using “men and women” as a proxy for “everyone” excludes transgender people, nonbinary people and other sexual and gender minorities. |

## Other Sex, Gender & Sexuality Vocabulary

|  |  |
| --- | --- |
| sex | biological category based on reproductive, anatomical and genetic characteristics, generally defined as male, female and intersex |
| gender | a composite of socially constructed roles, behaviors, activities and/or attributes that a given society considers appropriate for members of a given sex |
| queer | people who identify as queer may think of their sexual orientation and/or gender identity as characterized by non-binary constructs of sexual orientation, gender and/or sex  (The term is considered more fluid and inclusive than traditional categories for sexual orientation and gender identity, and some even use the term to describe their political beliefs. Once considered a pejorative term, queer has been reclaimed by some LGBT people to describe themselves; however, it is not a universally accepted term even within the LGBT community.) |
| bisexual | having the potential to be emotionally, romantically and/or sexually attracted to people of the same and different gender—not necessarily at the same time, in the same way or to the same degree |
| pansexual | not limited in sexual attraction with regard to sex, gender identity or gender expression |
| cisgender person | person who identifies with the gender that was assigned to them at birth; sometimes abbreviated as cis |
| gender identity | an individual’s sense of being male, female, intersex, genderqueer, gender nonconforming, etc.; not necessarily visible to others |
| gender expression | how one chooses to convey one’s gender identity through behavior, clothing and other external characteristics |
| nonbinary person | person who identifies outside of a gender binary by seeing themselves as neither male nor female |
| genderqueer person | person who does not identify as a man or woman or subscribe to conventional gender distinctions |
| gender non-conforming person | person whose gender expression is not consistent with the societal or cultural norms expected of that gender |
| gender fluid person | person whose gender identity shifts between different genders (or no gender) or across the spectrum |
| agender person | person who does not identify with any gender; agender people may wish to have no gender expression at all, which many find difficult to achieve in our gendered society |
| bigender person | person who identifies as two genders |
| pangender person | person who identifies as all genders |
| trans\*  [sometimes] transgender | an umbrella term that refers to many identities within the gender identity spectrum |
| misgender | to refer to someone, especially a transgender person, using a word or address that does not correctly reflect their gender identity |

## Pronouns

Though exceptions exist, as a rule, use pronouns that correspond to a person’s gender identity. Because gender identity is an internal characteristic that should not be assumed, it is best practice to ask for a person’s pronouns. In addition to the binary English pronouns “she/her” and “he/his,” some people may use non-binary pronouns, including the pronouns “they/their” used as singular terms, among others. When using the singular “they,” still conjugate the verb as a plural, as in, “they are gender nonbinary.”

It is considered by some to be extremely offensive and even violent to misgender someone by using inappropriate pronouns. When writing about a hypothetical person, like an anonymous participant in a study enrolling people of all genders, use the singular “they” rather than “he or she” to be inclusive.

## Identity & Specificity

In certain contexts, it may be appropriate to use language that explicitly references sexual behaviors instead of referencing sexual orientations and gender identities. For example, a study may evaluate the ability of an experimental modality to prevent HIV transmission during anal intercourse between people assigned male at birth who identify as men. While many enrolled in this study are likely to identify as gay or bisexual, there may be others who do not identify this way but nonetheless have anal intercourse with other cisgender men. In other words, medical specificity to describe behavior should be accounted for outside of individuals’ identity around sexual orientation. In this case, an accurate description of the enrolled participants is “cisgender men who have sex with men.”

In other contexts, it may be appropriate to highlight sexual orientation. Using this language can honor the contributions of these communities or connect with people on an identity level. For example, one might say, “The first cases of AIDS were reported in young gay men,” or “The advocacy group aims to increase PrEP use among gay and bisexual men of color.” All science takes place in a cultural context, which must be considered when we prepare written materials for the general public.

## Relationships

Avoid language that assumes the nature of a given relationship. For example, be mindful that not all sexual partners are romantically involved, which may be implied by terms like “couples.” Similarly, do not assume sexual partners are monogamous or value monogamy. Use the terminology preferred by the individuals described when possible, or simply use the neutral term “sexual partner(s).”

## Pregnancy & Family

Do not assume a given family dynamic or relationship between parent and child. Be mindful that children are raised by biological mothers and/or fathers, as well as by adoptive parents and other caregivers. Often, language around pregnancy, childrearing and family can reinforce gender-stereotyped roles, particularly for women. Avoid language that implies childcare or ensuring a child’s health is the sole responsibility of mothers. Similarly, avoid language that portrays pregnant or breastfeeding people as mere vessels supporting a child.

# Substance Use

| *Try this…* | *Instead of this…* | *Because…* |
| --- | --- | --- |
| new syringes (and works)  unused syringes (and works)  sterile syringes (and works)  used syringes (and works) | clean syringes  dirty syringes  contaminated syringes | “Clean” and “dirty/contaminated” evoke unnecessary value judgements, as well as specific visual assumptions that may not be accurate. The preferred terms are clearer and more accurate. “Needles” may also be used when engaging a community that is more likely to use that terminology. |
| person who injects drugs  person who uses drugs  person with substance use disorder  person with alcohol use disorder | injection drug user (IDU)  drug user/abuser  drug addict  drug-addicted  alcoholic | Person-first language emphasizes humanity. |
| substance use disorder  alcohol use disorder | drug addiction  drug dependence  drug habit  drug abuse  alcoholism  alcohol abuse  alcohol dependence | This preferred term aligns with the medical community’s and federal government’s initiatives to raise awareness that compulsive substance use is a complex brain disorder rather than a moral failing or personality flaw.  “Abuse” is a negative term that invites a value judgement. Addiction is not a diagnostic term although it is an acceptable synonym for moderate or severe substance use disorder. Dependence, on the other hand, is not synonymous with substance use disorder; see “Dependence vs. Addiction,” below. |
| born in withdrawal  born dependent on [drug]  infant with neonatal abstinence syndrome | born addicted  addicted infant | Despite any dependence that may be present, infants are not capable of the compulsive substance use despite negative consequences that defines addiction. |
| not currently using substances  negative [for a toxicology screen]  currently using substances  positive [for a toxicology screen] | clean  dirty | Labeling the use of drugs as “dirty” and the absence of drug use as “clean” invites a value judgement that stigmatizes people who use drugs and does not accurately reflect the complexities of substance use disorder and recovery. |
| medication for opioid use disorder (MOUD)  medication-assisted treatment (MAT) [when referring to or inclusive of medications used to treat alcohol use disorder] | opioid replacement  methadone maintenance  drug substitution | “Replacement” and “substitution” imply medications merely “substitute” one drug or “one addiction” for another, fueling a stigmatizing misconception that prevents people from accessing treatment. MAT should not be used when referring to treatment for opioid use disorder, since “assisted” implies medications are secondary to other forms of treatment, which is no longer considered to be the case. |
| treatment center | rehab  detox center | “Rehab” and “detox center” carry cultural stigmas and misconceptions. |
| person in recovery | former addict/alcoholic  recovered addict/alcoholic  reformed addict/alcoholic | These person-first terms honor the belief of many clinicians and people with substance use disorder that recovery is an ongoing and variable process. Some individuals may claim a term like “addict,” but such terms should not be applied without that person’s consent. |

## Dependence vs. Addiction

“Dependence” and “addiction” are related but frequently confused terms. Addiction is defined as a pattern of compulsive substance use—marked by a change in behavior caused by biochemical changes in the brain—despite negative consequences related to that substance use. Addiction is not a diagnostic term but is considered synonymous with moderate to severe substance use disorder. Dependence, however, is characterized by the physical potential for withdrawal symptoms. Importantly, it is possible for someone to be dependent on a substance used for medical purposes without experiencing addiction. It is best to explicitly define these terms or else avoid them.

## Drug Misuse

While the term “drug abuse” is generally frowned upon, there is disagreement about the utility of “drug misuse.” Many people find the term helpful when discussing substances that have medical as well as illicit uses, such as prescription opioids. Others claim this terminology suggests fault on the part of people with substance use disorders and creates a stigma that they may deserve consequences of such “misuse.”

Regardless, it is important to not use “misuse” and “substance use disorder” interchangeably, as not all people who use substances recreationally experience substance use disorder or require treatment to stop using substances. For example, a single occasion of binge drinking is considered alcohol misuse but may not reflect alcohol use disorder in a given individual.

# Miscellaneous Terms & Topics

The following terms and topics were recommended for inclusion in this guide because they have previously arisen in communication related to HIV research. The inclusion of a population or group in this section does not necessarily indicate that this population or group has a high incidence of or is behaviorally vulnerable to HIV.

| *Try this…* | *Instead of this…* | *Because…* |
| --- | --- | --- |
| sex worker  sex work  transactional sex  sale of sexual services | prostitute  prostitution  commercial sex work | “Sex work” implies ownership over a person’s own career choice, while “prostitution” and its derivatives carry engrained cultural stigmas. Specifying “sex work” as commercial is redundant and otherizes. |
| sex trafficking  sex trafficking of minors | sexual slavery  forced prostitution  child prostitution | In the context of forced or coerced transactional sex by minors, the preferred terms emphasize role of exploiters because children cannot consent to sex work. Some community members prefer the term “youth sex work” to describe transactional sex by minors they feel is not coerced or forced. However, this is controversial. |
| survivor of sexual assault | rape victim | “Survivor” is more empowering than “victim,” which evokes defeat and helplessness. When referring to a specific person, always use a term they approve. |
| intimate partner violence  gender-based violence | domestic violence | The preferred terms are more specific to two separate ideas: violence between intimate partners and violence specifically based on gendered power imbalances. They also each include relevant violence outside of a shared home. |
| person who has experienced violence  survivor of violence | abuse victim | Use more empowering or neutral terms than “victim,” which evokes defeat and helplessness. When referring to a specific person, always use a term they approve. |
| person to be evaluated for tuberculosis  person at risk of TB disease | tuberculosis suspect | “Suspect” evokes suspicion and personal fault. |
| tuberculosis prevention and care  prevention of TB transmission | tuberculosis control | “Control” evokes paternalism. |
| people/participants with concomitant hepatitis or concomitant TB | TB or hepatitis coinfected people/participants | “Coinfect” and its derivatives carry the same stigma as “infect.” |
| people with tuberculosis/TB  new TB diagnoses  people newly diagnosed with TB | TB cases  new TB cases | People should not be described as “case,” as this term deemphasizes humanity and implies burden. |
| older adults  people over [age X] | the aged  elders  (the) elderly  seniors/senior citizens | “Adults” affirms agency and personhood, as does person-first language. Stigmatizing terms such as “elders” can evoke frailty. When possible, use a specific age. |
| care partners  family and friends [in appropriate contexts] | caregivers  caretakers | When describing people engaged in an older adult’s care, use care partner to emphasize collaboration and the adult’s autonomy. |
| person who has been arrested/convicted of a felony  person who is incarcerated  person in prison | felon  convict  offender  inmate  prisoner  the incarcerated | Person-first language emphasizes humanity. Also, some of these terms have specific legal definitions that may be confused. |
| people who are overweight  people with [BMI or other metabolic score] of X  people with obesity | overweight people  obese people  the obese | Use specific, neutral, person-first language when describing weight and fat distribution. Because obesity and overweight are diagnoses, it is acceptable to use “people with obesity” and its derivatives. |
| people with disabilities  disabled people (preference varies) | handicapped  handi-capable  differently-abled  the disabled | Community preference for person-first or identity-first (“disabled people”) varies, but most agree euphemistic language further otherizes people with disabilities. |
| abled  non-disabled  does not have a disability  enabled | able-bodied  normal  healthy, in contrast to people with disabilities | “Abled” to refer to all people without disabilities is preferable to “able-bodied” in order to be inclusive of cognitive disabilities and other disabilities not considered primarily physical. “Enabled” acknowledges the role of systems that privilege certain ability levels above others. |
| assistive device/technology  accommodation  wheelchair user  person who uses a wheelchair | corrective device/technology  wheelchair-bound  confined to a wheelchair | Assistive technologies and services should be portrayed as helping and accommodating a person rather than making them “correct” or emphasizing limitation. |
| person with [specific mental disorder]  E.g. person with bipolar disorder | mentally ill person  insane person  the mentally ill  [specific person] is bipolar | Person-first language emphasizes humanity and dispels the misconception that mental disorders are untreatable. Also, insanity is a legal—not medical—definition. |
| died by suicide | committed suicide | “Committed” evokes associations with the legal or moral issues of “committing” a crime or sin, whereas suicide is often the consequence of an unaddressed illness. |

## Racial, Ethnic & Cultural Identities

Generally, NIH uses race and ethnicity terminology aligning with the 1997 [Office of Management and Budget (OMB) standards](https://www.census.gov/topics/population/race/about.html) on race and ethnicity. According to the OMB, these terms “generally reflect a social definition of race recognized in this country and not an attempt to define race biologically, anthropologically, or genetically.”

In addition, it is recognized that the categories of the race item include racial and national origin or sociocultural groups. People may choose to report more than one race to indicate their racial mixture, such as “American Indian” and “White.” People who identify their origin as Hispanic, Latino, or Spanish may be of any race.

The table below offers language considerations for describing racial, ethnic and cultural identities identified by the OMB. With few exceptions, terms used to describe a people’s race or ethnicity should be capitalized.

|  |  |  |
| --- | --- | --- |
| *Group/Population* | *Definition* | *Language Considerations* |
| White  Non-Hispanic White | [OMB](https://www.census.gov/topics/population/race/about.html): having origins in any of the original peoples of Europe, the Middle East, or North Africa | Avoid language that frames being White as a default, normal or “raceless” identity. Non-Hispanic White is sometimes used to clarify that the described group does not include White Hispanic people. |
| Black or African American | [OMB](https://www.census.gov/topics/population/race/about.html): having origins in any of the Black racial groups of Africa | African American is acceptable in certain contexts but excludes other members of the African diaspora. “African American” is not considered more respectful than “Black.” |
| American Indian or Alaskan Native | [OMB](https://www.census.gov/topics/population/race/about.html): having origins in any of the original peoples of North or South America (including Central America) and who maintains tribal affiliation or community attachment | When referring to a specific person or group of people, best practice is to use a specific tribal identity whenever possible. When referring to the diverse group of people with indigenous ancestry in the United States as a whole, the term “American Indian” is usually preferred over “Native American,” which is seen by some as euphemistic. Never use pejorative terms, which include “Eskimo” instead of Alaska Native. |
| Native Hawaiian or Other Pacific Islander | [OMB](https://www.census.gov/topics/population/race/about.html): having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands |  |
| Asian | [OMB](https://www.census.gov/topics/population/race/about.html): having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam | **East Asian** may be used to describe people with origins in China, Korea, Japan, Taiwan or Mongolia. **South Asian** may be used to describe people with origins in Afghanistan, Pakistan, India, Bangladesh, Nepal, Bhutan, Sri Lanka or Maldives. **Southeast Asian** may be used to describe people with origins in areas south of China but east of India (Thailand, Vietnam, Malaysia, Singapore, the Philippines, Laos, Indonesia, Brunei, Burma (Myanmar), Cambodia and Timor-Leste). |
| Latino/a or Latinx  Hispanic | being from or descending from people who are from Latin America, including Cuba, Mexico, Puerto Rico, South America or Central America  descended from Spanish-speaking populations | According to the OMB, "People who identify their origin as Hispanic, Latino, or Spanish may be of any race.”  Most people with origins in Brazil are considered Latino but not Hispanic because most Brazilians speak Portuguese. Similary, Spanish people may be considered Hispanic but not Latino.  Some people identify as “Spanish” as a synonym for Hispanic, but others do not prefer the term because it implies origins in Spain. |
| person of color (POC) | a person who is not White or of European origin | Many prefer this term to “racial minorities” and consider it inclusive of all non-White races, while individuals with some non-White identities may not relate to the term. Still others consider it euphemistic or irrelevant. Do not use “people of color” when referring to one specific nonwhite racial group; use a term specific to that group. |
| racialized communities | group being assigned or categorized in a racial hierarchy | In the United States and Canada, this term is sometimes preferred to “racial minorities” because it encompasses non-White groups that may make up a majority of individuals in a given geographical area. The term also defines race as an ascribed identity, acknowledging an individual’s identity may differ from another person’s perception, which may be useful to distinguish from self-reported race and ethnicity information. |
| biracial  multiracial  of mixed race | having parents or ancestors of different racial backgrounds | Some consider using “mixed” alone to be stigmatizing, while others claim the term positively. “Mixed race” is used frequently in academia and elsewhere, though some again highlight it as having stigmatizing potential. |
| Indigenous peoples  First peoples  First Nations  Aboriginal peoples  Native peoples | having origins in the original or earliest known inhabitants of an area, in contrast to groups that have settled, occupied or colonized the area more recently in human history | These terms may be useful to describe Indigenous people in a global context. |

## Person-First vs. Identity-First Language

People with disabilities are not a monolith, and this diverse community holds different views about whether person-first (person with disabilities) or identity-first (disabled person) language is appropriate in most contexts. Generally, most people prefer person-first language that emphasizes humanity, highlights autonomy, and promotes the idea that most people’s disabilities are just one facet of their life and identity. This is particularly true for people with an acquired, chronic illness (i.e. person with diabetes instead of diabetic).

However, some disabled people explain that their disability is an intrinsic part of their identity and should not be appended after “person.” For example, many autistic people prefer identity-first language because they view autism as a way of thinking and living rather than a disorder. This is sometimes called the “social model” of disability, as opposed to the “medical model.” This concept is also related to disability pride movements. For example, because deafness is associated with a unique education system, language and subculture, most people in this population prefer to be called “Deaf.”

As a rule, if you are writing or speaking about people with disabilities or health conditions with which you are unfamiliar, look up the preferred terms for that population and rely on resources put together by those immediately affected.

1. An earlier iteration of the NIAID HIV Language Guide incorrectly attributed the creation of *The Denver Principles* to ACT-UP. [↑](#footnote-ref-1)