# 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.

Since members of ACT UP and other HIV and AIDS advocates published the self-empowerment manifesto known as *The* 

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

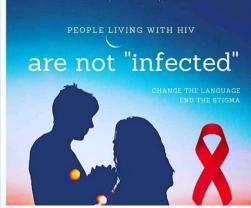
*Denver Principles* in 1983, language has been a central theme in efforts to dismantle stigma around HIV. Many HIV advocacy groups and media outlets embrace slogans such as "language matters" and promote primers on using empowering language, as do other organizations that advocate for other health conditions 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.

Dric HIV Adoni\_Official @DricHIVAdoni1

Change the language to end HIV stigma. Hope I have communicated clearly.

#YPlusPageant19 #PeersMakingItHappen #NdiMusogaLivingWithHIV



Ugandan advocate Dric Adoni tweets about stigmatizing language around HIV from a popular youth HIV awareness event, the Y Plus Beauty Pageant. This guide includes language suggestions for communicating about HIV and related topics. Below are a few examples of the impact such language can have.



Silvia @HIV\_SpeakingUp · Jun 22, 2017 There are not "difficult to reach people' only services which are not well designed , **#language** is part of creating **#stigma #NHIVNA #HIV** 

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.



Morénike Giwa Onaiwu @MorenikeGO · 23 Jun 2018 OMG! The current #ACTG2018 plenary presenter stopped herself in mid-sentence from almost saying "HIV-infected" participants & changed it to "participants with HIV." ☺♥

@ACTGNetwork is embracing inclusion & making efforts to avoid #HIV stigmatizing terms! TY! #LanguageMatters

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

## 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 <u>HIV/AIDS Clinical Trials Networks</u> 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, <u>Community Partners</u>, the Tuberculosis Trials Consortium <u>Community Research Advisors Group</u>, the AIDS Clinical Trials Group <u>Underrepresented</u> <u>Populations Committee</u>, the <u>Women's Health Inter-Network Scientific Committee</u>, the Cross-Network Transgender Working Group, and the <u>Legacy Project Working Group</u> and <u>Women's HIV Research</u> <u>Collaborative</u> of the <u>Office of HIV/AIDS Network Coordination</u> (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 <u>HIV Stigma Language Guide</u> and "Why Language Matters: Facing HIV Stigma in Our Own Words" by <u>Vickie Lynn</u>, Ph.D., MSW, MPH, and other members of <u>the Well</u> <u>Project</u> have been a tremendously valuable resources on stigmatizing language around HIV. Materials included in the University of California San Francisco HIVE Online <u>#LanguageMatters campaign</u> 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, "<u>Guidance on the Use of Gender-Inclusive HIV Research</u> <u>Practices</u>" 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 <u>2019-2023 Trans-NIH Strategic Plan for Women's Health</u> <u>Research</u>, compiled by ORWH, also informed this chapter. NIAID HIV Language Guide

Language guidance for the "Substance Use" was informed by a 2017 Office of National Drug Control Policy <u>memorandum</u> entitled, "Changing Federal Terminology Regarding Substance Use and Substance Use Disorders," as well as by <u>training resources</u> 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 <u>NIAIDNews@niaid.nih.gov</u>.

# 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 infection	"Infection" carries the stigma of being contagious, a threat, unclean. HIV advocates
HIV transmissions new HIV diagnoses	new HIV infections	frequently highlight the damaging consequences of this word choice.
transmit	infect	
acquired	became infected	
prevents HIV prevents transmission of HIV prevents acquisition of HIV	prevents HIV infection	
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.

NIAID HIV Language Guide Try this	Instead of this	HIV Basics Because
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.

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**HIV Basics** 

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Try this	Instead of this	Because
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	unprotected sex unsafe sex protected 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.
and/or other prevention tools	safe sex	
has multiple sexual partners	promiscuous	Avoid "promiscuity" and its derivatives, as it is an unnecessary value judgement.

NIAID HIV Language Guide Try this	Instead of this	HIV Basics
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] <b>do not transmit HIV</b> no risk zero risk	extremely unlikely to transmit HIV nearly impossible to transmit HIV almost no risk greatly reduces risk	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
[viral suppression] prevents	close to zero risk helps prevent HIV	inaccurate and is seen by some in the community as a result of paternalistic mistrust of people
HIV eliminates onward sexual transmission	makes it hard to sexually transmit HIV	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	born male/female	The preferred terms affirm gender identity.
sex assigned at birth	biological sex sex at birth	
transgender man	used to be a woman born a woman female-to-male (FTM)	
transgender woman	used to be a man born a man male-to-female (MTF)	
transgender trans	transgendered	"Transgendered" is a dated term that suggests a point in time when a person "became"
transgender people/person people/a person who is transgender people/person of trans experience	transgenders/a transgender	transgender, which diverges from the lived experiences of most transgender people. Similarly, "transgenders" is dated and does not emphasize humanity.

NIAID HIV Language Guide		Sex, Gender & Sexuality
Try this	Instead of this	Because
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	<ul> <li>"Gender affirmation" and</li> <li>"transition" define the</li> <li>interpersonal, interactive</li> <li>process whereby a person</li> <li>receives social recognition and</li> <li>support for their gender</li> <li>identity and expression. This</li> <li>process can but does not</li> <li>necessarily involve medical</li> <li>intervention, which can include</li> <li>hormone therapy and one or</li> <li>more surgeries to affirm one's</li> <li>gender. "Pre-/post-operative"</li> <li>may still be used in medical</li> <li>literature but should not be</li> <li>applied to a specific person</li> <li>without their consent.</li> </ul>
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

NIAID HIV Language Guide		Sex, Gender & Sexuality
Try this	Instead of this	Because
		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	men and women	Using "men and women" as a proxy for "everyone" excludes
individuals of all genders or be specific—cisgender men and cisgender women	both genders/either gender	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

NIAID HIV Language Guide <b>queer</b>	Sex, Gender & Sexuality 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

NIAID HIV Language Guide	Sex, Gender & Sexuality
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
<b>trans*</b> [sometimes] <b>transgender</b>	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

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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)	clean syringes	"Clean" and "dirty/contaminated" evoke unnecessary value judgements, as well as specific visual
used syringes (and works)	dirty syringes contaminated syringes	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	injection drug user (IDU) drug user/abuser drug addict drug-addicted	Person-first language emphasizes humanity.
person with alcohol use disorder	alcoholic	
substance use disorder	drug addiction drug dependence drug habit drug abuse	This preferred term aligns with the medical community's and federal government's initiatives to raise awareness that compulsive substance use is a
alcohol use disorder	alcoholism alcohol abuse alcohol dependence	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.

NIAID HIV Language Guide		Substance Use
Try this	Instead of this	Because
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

Instead of this...

terms should not be applied without that person's consent.

Because...

### **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

NIAID HIV Language Guide <i>Try this</i>	Instead of this	Miscellaneous Terms & Topics Because
		each include relevant violence outside of a shared home.
person who has experienced violence	abuse victim	Use more empowering or neutral terms than "victim," which evokes defeat and
survivor of violence		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	tuberculosis control	"Control" evokes paternalism.
prevention of TB transmission		
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.

NIAID HIV Language Guide <i>Try this</i>	Instead of this	Miscellaneous Terms & Topics Because
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.
<b>people with disabilities</b> <b>disabled people</b> (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
person with [specific mental disorder]	mentally ill person insane person the mentally ill	limitation. Person-first language emphasizes humanity and dispels the misconception that

NIAID HIV Language Guide Try this	Instead of this	Miscellaneous Terms & Topics <i>Because</i>
E.g. person with bipolar disorder	[specific person] is bipolar	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 <u>Office of Management and</u> <u>Budget (OMB) standards</u> 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	<u>OMB</u> : 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: 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."

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American Indian or Alaskan Native	OMB: 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	<u>OMB</u> : having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands	
Asian	OMB: 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).

NIAID HIV Language Guide 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	Miscellaneous Terms & Topics 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.

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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.