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Suggested citation:
Contributors

Initial guidelines developed by

Clair Kronk, Ph.D. (she/her)
Center for Medical Informatics
Yale University School of Medicine
New Haven, CT

Oliver J. Bear Don’t Walk IV, Ph.D., MS
(co-chair, AMIA DEI Committee)
University of Washington
Seattle, WA

Randi Foraker, Ph.D. MA, FAHA, FAMIA
(she/her)
Washington University School of Medicine
St. Louis, MO

Tiffani J. Bright, Ph.D., FACMI (she/her)
(Founding Chair, AMIA DEI Committee)
Washington University School of Medicine
St. Louis, MO

AMIA DEI Communications Subcommittee
Contributors

J. Wilfred (Fred) Fan, Ph.D. (he/him)
Mayo Clinic
Rochester, MN

Vipina K. Keloth, Ph.D. (she/her)
Yale University
New Haven, CT

Duo (Helen) Wei, Ph.D. (she/her)
Stockton University, Galloway, NJ

Tiffany I. Leung, MD, MPH (she/her)
JMIR Publications
Toronto, Canada
Southern Illinois University School of Medicine
Springfield, IL

Nathan Yung, MD (he/him)
UC San Diego Health
San Diego, CA

Sиру Liu, Ph.D. (she/her)
Vanderbilt University Medical Center
Nashville, TN

Omolola Ogunyemi, Ph.D., FACMI (she/her)
Charles R. Drew University of Medicine and Science
Los Angeles, CA

Rebecca L. Rivera, Ph.D., MPH (she/her)
(former co-chair)
Indiana University School of Medicine;
Regenstrief Institute
Indianapolis, IN

Shefali Haldar, Ph.D. (she/her) (co-chair)
Merck & Co., Inc.
Boston, MA

Hu T. Huang, Ph.D., ACHIP (he/him) (co-chair)
McKesson Corporation
Irving, TX

AMIA Member Contributors

Melissa D. Clarkson, Ph.D.
Pooja Desai, BA
Diane M. Kornliegel, DPhil
Lisa Grossman Liu, MD, Ph.D.
Adrienne Pichon, MPH, MPHill, MA
Vignesh Subbian, Ph.D.
Anthony (Tony) Solomonides, MD
Jeff Williams, M.Ed.
Laura K. Wiley, Ph.D.
Gretchen P. Jackson, MD, Ph.D., FACMI, FAMIA

Thoughtful feedback was provided by the following colleagues external to the AMIA DEI committee:
Irene Dankwa-Mullan, MD, MPH, Lisa G. Dirks, Avery Rose Everhart, Ph.D., Andrea Grimes Parker, Ph.D., Bradley lott, Ph.D., and Kristopher Velasco, Ph.D.

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Introduction

The Importance of Inclusive Language

The American Medical Informatics Association (AMIA) is committed to diversity, equity, and inclusion (DEI). Inclusive language helps AMIA promote DEI-oriented communication and serve a diverse community of informaticians. Specifically, inclusive language facilitates this by

1) respecting the autonomy, dignity, and experiences of marginalized and historically excluded communities,
2) incorporating just and equitable scientific practices through the language used to accurately generate and precisely describe scientific knowledge, and
3) attracting researchers to contribute valuable insights new to AMIA's scientific understanding.

AMIA recognizes that inclusive language has a place not only in our academic communications but also in our professional and personal interactions with other AMIA members and various communities. To that end, the Inclusive Language and Context Style Guidelines (ILCSG) serve as an educational resource for creating a more diverse, equitable, and inclusive

AMIA as we learn to enact these commitments to DEI in our professional and personal lives. The ILCSG is intended for authors, researchers, and AMIA community members looking to incorporate inclusive language into their research, work, and personal lives.

Using language that affirms lived experiences and accurately describes diverse ranges of expertise and science is important to advancing AMIA's DEI commitment. However, incorporating inclusive language cannot be the only step in this direction, and we must be careful to avoid mechanical processes that make AMIA seem welcoming and inclusive while not addressing the underlying culture and behaviors. To that end, it is important for us to internalize and apply the information in this document while creating our science and community within AMIA. As it stands, this document is intended for authors, reviewers, and AMIA members as a resource for AMIA annual symposium submissions and will be expanded to other forms of communications (e.g., policy response letters, press releases from AMIA, leadership communications, working group products, etc).

Guidelines for Editorial Process

The current edition is an official resource approved by the AMIA Board of Directors. These guidelines are presented to authors and reviewers alike so that both parties can make informed decisions about what kind of language should or should not be used in AMIA submissions and why. All accepted submissions will be reviewed using these guidelines. Reviewers will provide feedback to authors in the same way that all other reviews are provided. That is, revisions and feedback concerning language will contain context drawn from the ILCSG and be found alongside the previously standard revisions.

Authors will have the opportunity to address reviews by incorporating revisions into their submissions or by discussing alternatives to the suggested revisions. This dialogue approach stems from the fact that language is nuanced and contextual and the principle that inclusive language revisions should not be a mechanical process. Rather, conversations between reviewers, authors, and the creators of the ILCSG are encouraged. To this end, authors are expected to incorporate edits or contact reviewers about alternatives before submitting their final version.

https://amia.org/InclusiveLanguage

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Presentation Considerations

While presentation materials are not formally reviewed by AMIA, we encourage authors to incorporate the ILCSG into their presentations. The information and principles in this document apply to many kinds of scholarly work and social interactions.

Reviewer feedback can extend to the language used in presentation materials. For new material that was not reviewed during the submission process, authors should carefully consider how this document applies to the information they will present to the AMIA community.

Guideline Updating Process

The authors of this document approached this work with humility and the knowledge that iterations of feedback and revision are necessary for AMIA to truly incorporate inclusive language. Language is ever-evolving, and the ILCSG should be considered a living document as our knowledge and contextual awareness change. In this first version of the ILCSG, we focused on language concerning race, ethnicity, sex, gender, and sexuality.

In the future, we will expand the discussions to include social and behavioral determinants of health, disabilities, and xenophobia. If there are questions, comments, or concerns about the information in this document, please contact the AMIA DEI Communications Subcommittee via https://amia.org/inclusivelanguage.
Four Guiding Principles

Principle 1: Plurality

The principle of **plurality** encompasses the idea that there may not be a single correct way to refer to a person or people and calls for flexibility. When referring to research participants, authors are encouraged to inquire about and honor their preferred terms even if these terms go against the guidelines provided here.

This principle is informed by the importance of context and personal preference for language use and that there may not be one term that all people from a specific group agree on. In the examples below, we strike a balance between generally agreed-upon terms and research participants’ preferences and identities.

<table>
<thead>
<tr>
<th>Example 1.1</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>We often had difficulty reaching Native American patients because of a lack of internet throughout the reservation.</td>
<td>We often had difficulty reaching Native American patients because of a lack of internet throughout the reservation. One participant stated, <em>&quot;Indians have always known how to live out here. It's only recently that not having the internet made it harder to be out here.&quot;</em></td>
<td></td>
</tr>
</tbody>
</table>

**Context**

Though some Native American people may refer to themselves and others using the term 'Indian', it is generally not appropriate to do so in publications as it is outdated and ambiguous. If specific participants request to be referred to in this manner, then it is best practice to do so when referring to them or using their quotes. Depending on the regional context, it would be appropriate to differentiate Native American and First Nations people. For more information on the terms "Native American", "Indigenous", and "First Nations", refer to *Indigenous Peoples: Language Guidelines* (Kessler, 2021).

<table>
<thead>
<tr>
<th>Example 1.2</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our survey included 42 Latino individuals, and many participants from this group preferred intervention x over intervention y. One Latino participant stated that “[intervention x] was more in line with their goals for an active lifestyle”.</td>
<td>Our survey included 42 Latino individuals, and many participants from this group preferred intervention x over intervention y. One participant who was assigned Latino for this study stated that “[intervention x] was more in line with their goals for an active lifestyle”. In this work, we have chosen to use the broad grouping of Latinos, while not all participants readily identified with this term.</td>
<td></td>
</tr>
</tbody>
</table>

**Context**

Whenever ethical, respectful, and possible, note the identities participants prefer or that they were assigned a category when they differ from the general category name. While Latino is an acceptable term to use because of its standardization through previous literature, there might be instances where patients do not describe themselves with that term. In this example, a patient has been assigned the category of Latino and contributed to these results overall; however, when discussing this patient in particular, authors should honor the fact that this patient does not use the term Latino to describe themselves. This is generally true for any group name used during research but is especially pertinent for Latino/Latina/Latine patients, given the variety of terminology preferences documented within this group (Noe-Bustamante et al., 2020).

We’ve chosen to place this example in plurality because, in this hypothetical, the participant does not identify with the broader Latino term and instead uses a different term. Referring to this participant using a term other than their stated term is disrespectful.

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**Principle 2: Precision**

The principle of **precision** refers to the idea that thoughtful reflection on the specificity and relevance of the language used to define terms and describe study aspects will result in more accurate scientific knowledge, particularly around the generalizability of study results. Avoid generalizations while also ensuring that the use of specific terms is relevant to the findings.

The use of undefined or ill-defined terms results in ambiguity. To the extent possible, try to follow internationally accepted definitions. When using alternative terms, make sure to precisely describe them in relation to the context in which the term is used.

<table>
<thead>
<tr>
<th>Example 2.1</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our dataset included 12,398 African American/Black individuals.</td>
<td>Our dataset included information about 12,398 <strong>African American and/or Black</strong> individuals. Because of data limitations, we cannot determine how many individuals were Black, African American, or both.</td>
<td></td>
</tr>
</tbody>
</table>

**Context**

While often combined into one group, Black and African American are not interchangeable, and people may identify with both terms or only one (African American, African-American, Black, Black – Diversity Style Guide, 2015). It is important to note the diversity in cultural backgrounds, histories, and experiences of people of African descent. People might identify with the term African American for a variety of reasons, such as how the term highlights a shared origin in Africa and histories in the Americas. It is important to note that the histories of African Americans go beyond enslavement in the Americas and include resilience and unique contributions to art, science, and culture. Black might be a preferred term for certain individuals if they are recent immigrants from Africa or the Caribbean and do not share the histories and experiences of African Americans (Simms, 2018). If one is looking for a broad term to use, Black would be more appropriate than African American. African American is not representative of other ethnicities and nationalities, such as Afro-Caribbean, Haitian, and those from the African continent.

<table>
<thead>
<tr>
<th>Example 2.2</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>A majority of <strong>BIPOC</strong> participants noted that their interactions with clinicians improved.</td>
<td>A majority of <strong>Black, African American, and Indigenous participants</strong> noted that their interactions with clinicians improved.</td>
<td></td>
</tr>
</tbody>
</table>

**Context**

The term “BIPOC” (Black, Indigenous, and people of color) expands on the term “POC” (Garcia, 2020). Though this term can be used to refer to a group that is made up of ALL the aforementioned identities, it should not be used for quantitative reporting. This avoids BIPOC being used as a catch-all term for “non-white” groups, which can be especially problematic when the research participants being discussed do not fully represent the term BIPOC.

<table>
<thead>
<tr>
<th>Example 2.3</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our study population was composed of entirely minority status/underrepresented minority individuals.</td>
<td>Our study population was composed of individuals from groups historically and currently marginalized due to race within the U.S.</td>
<td></td>
</tr>
</tbody>
</table>
The term “minority” is considered a pejorative. Furthermore, because “minority status” can be extended beyond racial groups (e.g., ethnic, gender, religious, etc.), it is important to be explicit about which groups are being discussed.

The term “underrepresented minority” (URM) is often used to refer to racial groups which are underrepresented in specific settings. We recommend avoiding this term for the same reasons as avoiding the terms disadvantaged/under-resourced/under-served (see below). Furthermore, this term runs into issues of erasing exactly what groups are being discussed, similar to the term BIPOC.

<table>
<thead>
<tr>
<th>Example 2.4</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>The population is disadvantaged/under-resources/under-served when compared to other populations across the U.S.</td>
<td>The population continues to be intentionally excluded/disinvested when compared to other populations across the U.S.</td>
<td></td>
</tr>
</tbody>
</table>

Terms like “disadvantaged,” “under-resourced,” and “under-served” do not accurately capture why certain communities have been historically and continue to be intentionally excluded (AMA & AAMC Center for Health Justice, 2021). Health inequities do not happen by accident and are the product of historical and current policies that continue to impact many communities negatively. Furthermore, there are differences between not receiving enough services/resources and being intentionally excluded, and this should be acknowledged in how we frame our science.

<table>
<thead>
<tr>
<th>Example 2.5</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>A significant number of Caucasian patients reported being unhappy with their interactions with the clinicians compared to Black patients.</td>
<td>A significant number of white patients reported being unhappy with their interactions with the clinicians compared to Black patients.</td>
<td></td>
</tr>
</tbody>
</table>

Caucasian was originally described as a biological taxon of people from Europe, Western Asia, Central Asia, South Asia, North Africa, and the Horn of Africa. In the U.S., this term is used synonymously with white or people with European, Middle Eastern, and North African ancestry. Because of its origin as a pseudoscientific biological view of race (also referred to in contemporary texts as “race realism” or “human biodiversity” in an attempt to eschew racist roots) and its ambiguity (S. Kimmel, 2018), it should not be used. More specific terms that are appropriate for the study should be used instead. For more information on pseudoscientific biological views of race, refer to The Anti-racism Digital Library Glossary and Superior: The Return of Race Science (Saini, 2019).

<table>
<thead>
<tr>
<th>Example 2.6</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our survey was conducted with 23 Native Americans who are citizens of various tribes in the US.</td>
<td>Our survey was conducted with 23 Native Americans. The breakdown of tribal citizenship is five Crow participants, eight Lakota participants, and 10 Blackfoot participants.</td>
<td></td>
</tr>
</tbody>
</table>

Whenever ethical, respectful, and possible, name the tribal citizenship or Indigenous community of Native American participants. An example where this might not be possible is when there are not enough participants to preserve privacy.
<table>
<thead>
<tr>
<th>Example 2.7</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Of note, white patients had a much higher risk of disease x when compared to black patients.</td>
<td>Of note, white patients had a much higher risk of disease x when compared to Black patients.</td>
<td></td>
</tr>
</tbody>
</table>

**Context**

Following AP style guidelines (Explaining AP Style on Black and White, 2020), the “B” in Black is capitalized primarily to indicate group membership and common experiences of Blackness, which are unconnected to the uncapitalized color that is black. As Temple University instructor Lori L. Tharps explained: “Black with a capital ‘B’ refers to a group of people whose ancestors were born in Africa, were brought to the United States against their will, spilled their blood, sweat, and tears to build this nation into a world power and along the way managed to create glorious works of art, passionate music, scientific discoveries, a marvelous cuisine, and untold literary masterpieces... When a copyeditor deletes the capital ‘B,’ they are in effect deleting the history and contributions of my people.” The practice of capitalization of Black identity terms began with W. E. B. Du Bois, who remarked poignantly, “Eight million Americans are entitled to a capital letter.”

Furthermore, AP style guidelines suggest not capitalizing the “w” in white as the AP did not find as much support for action. The AP “will watch closely how usage and thought evolve on these questions, and we will review our decision periodically” (Explaining AP Style on Black and White, 2020).
Principle 3: Transparency

Transparency in describing how data are collected, measured, and analyzed is greatly scrutinized in the scientific search for evidence. Transparency allows the research community to identify limitations to further contextualize results and conclusions and provide avenues for future research.

To promote greater openness in research, always address the limitations in the information, data and research we present and acknowledge the biases and resulting implications. Without transparency, our research can contribute to bias, suboptimal treatments, and discriminatory access availability to appropriate healthcare.

<table>
<thead>
<tr>
<th>Example 3.1</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our dataset included information about 12,398 African American and/or Black individuals. Because of data limitations, we cannot determine how many individuals were Black, African American, or both.</td>
<td>Our dataset included information about 12,398 African American and/or Black individuals. Because of data limitations, we cannot determine how many individuals were identified as Black, African American, or both. Furthermore, data collection standards for race and ethnicity at the hospital during this time are not guaranteed to be self-identified.</td>
<td></td>
</tr>
</tbody>
</table>

Context

If an identity is not self-identified, it is assigned and should be mentioned as such, while also mentioning the context and potential issues regarding that assignment. For example, if identities are inferred using modeling techniques then it is important to provide details on how many patients this affected and the limitations of such an approach.

<table>
<thead>
<tr>
<th>Example 3.2</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our dataset consisted of 1,876 Native American individuals.</td>
<td>Our dataset consisted of 1,876 Native American individuals. Because we are performing a secondary analysis of the data, we are not able to determine more specific tribal citizenship or Indigenous community for these patients.</td>
<td></td>
</tr>
</tbody>
</table>

Context

It might not always be possible to represent a patient’s identity accurately, especially when using secondary data such as the electronic health record. This data can often be presented as is. In these cases, it is best to acknowledge the limitation of the data and how that might impact the results and discussion.

<table>
<thead>
<tr>
<th>Example 3.3</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>We surveyed Hawaiians regarding their opinions on tourism.</td>
<td>We surveyed residents of the U.S. state of Hawaii regarding their opinions on tourism. It is of note that Hawaiians (Kānaka Maoli) were a minority of the population surveyed, and the results of the survey may not reflect their voice.</td>
<td></td>
</tr>
</tbody>
</table>

Context

Note that Hawaiians refers to the Indigenous people of Hawaii, also known as the Kānaka Maoli. If interviewing citizens or residents of the U.S. state of Hawaii, be clear about it and note how it may dilute opinions from Indigenous Hawaiians.
### Example 3.4

**Common sentence**

Hijra, trans women living in India, are especially susceptible to poverty.

**Principle-based revision**

Hijra (Hindi: हिजरा) are individuals who fulfill specific cultural and ceremonial roles in many areas of the Indian subcontinent. Hijra may also be transgender, intersex, or have any of other various identities. Hijra in India experience poverty due to socioeconomic and cultural forces.

### Context

Avoid false cultural equivalences. When a term is unfamiliar to a general readership, be clear about existing false equivalences, and dispute them. This acts to push back against existing biases.

Avoid italicization when a term does not have a proper English translation, including the original script if possible, so as to allow individuals to search in multiple languages if they are interested in a topic.

### Example 3.5

**Common sentence**

Gay people tended to engage in high-risk sexual behaviors more often.

**Principle-based revision**

Gay people represented in our dataset reported fewer safer sex provisions than their heterosexual counterparts. However, it is important to note that the provisions were written from a heterosexual perspective and may not have as much applicability in the context of non-heterosexual practices.

### Context

It is important to note how current systems are often not designed for various groups of people, which may mean the tools are the limitations themselves.
**Principle 4: Destigmatization**

Many of the common terms used to describe people (e.g., addict, abuser) can assign stereotypes resulting in exclusion from communities and discrimination. Such terms in all forms of communication can induce implicit cognitive biases that perpetuate stigma and may influence public opinion and health policies for addressing these issues. With careful attention to language and the use of non-judgmental language, we can reduce the burden of stigma and negative health outcomes.

<table>
<thead>
<tr>
<th>Example 4.1</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>In our study, the Blacks had an average age of 46 years.</td>
<td>In our study, Black participants had an average age of 46 years.</td>
<td></td>
</tr>
</tbody>
</table>

**Context**

Using “the” before “Blacks” turns this phrase into a noun and distances the author from the group while having an othering effect. This is not fixed by dropping “the” because the author is talking about people. Using race to describe people is fine, but not to define people. This would go similarly for other terms like “the Jews,” “the whites,” and “the Indians.” Though some of these terms have more history tied with discrimination than others.

<table>
<thead>
<tr>
<th>Example 4.2</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>28% of individuals reported being ‘bisexual,’ but this could not be confirmed in practice.</td>
<td>28% of individuals represented in our dataset were bisexual.</td>
<td></td>
</tr>
</tbody>
</table>

**Context**

Survey research is built on a certain amount of trust in participants. No one writes about questioning individuals who say they are heterosexual. Likewise, there should not be an interrogation of any individual’s bisexuality. If they say they are bisexual, they are. For more information on the bisexual definition, refer to GLAAD Media Reference Guide - 11th Edition, 2022.

<table>
<thead>
<tr>
<th>Example 4.3</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>The adult individual presented with a male gender identity and testicular pain and, upon examination, was discovered to be a true hermaphrodite.</td>
<td>A man who was not aware of their intersex status, presented with testicular pain. Differential diagnosis showcased that he possessed ovotestes.</td>
<td></td>
</tr>
</tbody>
</table>

**Context**

“Hermaphrodite” is an outdated and potentially offensive term, which originally refers to an organism that can produce viable oocytes and spermatozoa. Only use “hermaphrodite” when referring to such non-human organisms. Use intersex when referring to people (i.e. “intersex people”). Always use more specific differential diagnostic information where available and avoid over-pathologization (for instance, using “ovotestes” instead of “ovotesticular disorder”). Further, do not position individuals as being “true” or “false” in relation to gender and sex diversity; and do not refer to persons as “presenting” a gender identity, as they are that gender.

<table>
<thead>
<tr>
<th>Example 4.4</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males in our dataset were defined as individuals born male, including transsexual and non-transsexual males.</td>
<td>Due to the influence of genetic makeup in relationship to Y-linked infertility, all individuals in our dataset were karyotyped, and cohort analytics were based on karyotyping results and gender identity.</td>
<td></td>
</tr>
</tbody>
</table>
### Context
Do not refer to trans women as “males” as they are women. If an individual’s chromosomal makeup is theorized to be important, you can report it after the genetic screening; if genetic screening is performed on everyone, do not single out trans people. For instance, “trans women were confirmed 46, XY because of [insert reasoning]. All cisgender women in the cohort were likewise confirmed as 46, XX.” If the study does not have a genetic screening component, then forming cohorts is scientifically spurious and makes underlying assumptions about populations that may be false. In general, if a biological entity or capacity is a study target (such as the prostate, uterus, ability to breastfeed, ability to give birth, etc.), then the biological entities or capacities involved in those processes should be determined as existing or functioning as accurately as possible. Otherwise, the study is incomplete, lacks reproducibility, and contributes to the erasure of diversity.

<table>
<thead>
<tr>
<th>Example 4.5</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homosexuals tended to engage in high-risk sexual behaviors more often.</td>
<td>Gay people represented in our dataset reported fewer safer sex provisions than their heterosexual counterparts. However, it is important to note that the provisions were written from a heterosexual perspective and may not have as much applicability in the context of non-heterosexual practices.</td>
<td></td>
</tr>
</tbody>
</table>

### Context
Sweeping generalizations should be avoided, as should the term “homosexuals” in favor of gay people. While scientific results should generalize outside of the study population, it is important to provide context (historical, social, political, etc) for why this might be and to acknowledge limitations.

<table>
<thead>
<tr>
<th>Example 4.6</th>
<th>Common sentence</th>
<th>Principle-based revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transgender Latino participants who identify as men...</td>
<td>Latino transgender men...</td>
<td></td>
</tr>
</tbody>
</table>

### Context
In this example, there is no need to discuss how the individual identifies, as one would not use this kind of language for other groups. example (one wouldn't do this for all groups), and it is enough to say they are transgender Latino participants. In general, saying that people "are" rather than "identify as" is important; respect for persons is an important component of biomedical practice, as outlined in the Belmont Report.

Furthermore, Latinx is not a preferred term in these guidelines. If one must use a gender-neutral term, Latine is preferred.

For more information on using the terms Latino, Latina, Latinx, Latine, and Hispanic, see the Pew Research Center’s article, “Hispanic Americans’ Trust in and Engagement With Science” (Funk & Lopez, 2022) and the SUNY Oswego Library Guide entry, “Latina/o/x Heritage Month” (Resource Guides: Latina/o/x Heritage Month: Introduction, 2022).
Resources

In this section, we provide additional resources for readers to further their understanding of the context of the language in practice. Note that the categories below are fluid and that the same reference may appear in multiple categories. Such separation is meant to facilitate ease of use but may be removed in future versions if found not to be useful. The list is by no means exhaustive, and additional suggestions and feedback are highly encouraged.

Style Guides, Glossaries, Ontologies, Vocabularies, and Standards of Care

### Style Guides


### Class and Caste

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Background Reading

Technical Details

Class and Caste

Disability and Neurodiversity

Incarceration

Migration
Race and Ethnicity


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### Inclusive Language and Context Style Guidelines

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