

Inclusive Language in Life Science Research and Communications

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Date

To RTI Inclusive Language Webinar Attendees

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Subject Inclusive Language in Life Science Research and Communications

"Scientists and scientific journals have the opportunity to facilitate best practices and ultimately impact racial and ethnic disparities. The written interpretations of science by a few shape the future creation of history and science for many."

Dr. Khadijah Breathett, lead author, *Circulation, Cardiovascular Quality and Outcomes*

Common Acronyms

Acronym	Definition
DEI	Diversity, Equity, and Inclusion
EDIB	Equity, Diversity, Inclusion, and Belonging
LGBTQ+	Lesbian, gay, bisexual, transgender, and queer The "plus" is used to signify all of the additional identities that are not specifically covered by the other 5 initials.
MENA	Middle Eastern and/or North African
POC	people of color

WHY IS INCLUSIVE LANGUAGE IMPORTANT?

- People may use a variety of terms to self-identify based on their gender identity, race, ethnicity, and/or sexual orientation. It is important to honor that self-identification and include it in research, where applicable.
- Inclusive language contributes to health equity efforts (e.g., achieving more diverse study populations, acquiring more robust data on historically underserved communities, and better understanding gaps in healthcare access for people of color and members of the LGBTQ+ community).

- Companies that embrace inclusive language are better equipped to identify the needs of historically marginalized groups and can more intentionally and strategically reach patient populations that have been medically underserved or that have faced systemic discrimination in the healthcare system.

Key Takeaways

- Keeping up to date with and understanding the nuances between key terms helps researchers, healthcare organizations, and life science communicators better serve the patients who make our work possible.
- For greater inclusivity and participation in biomedical research, it is important to let people self-identify their race, ethnicity, gender identity, sex assigned at birth, and sexual orientation when possible and relevant.
- Alphabetize survey response options to avoid unintended prioritization of groups.
- Obtaining more robust data on medically underserved groups, such as people of color and members of the LGBTQ+ community, contributes to greater healthcare access and better health outcomes and helps prevent further stigmatization and erasure of historically marginalized communities.

Race and Ethnicity

Race and *ethnicity* are separate—yet often intersecting—concepts and should not be conflated.

- *Race* is a social construct and a human-invented classification system based on observable characteristics such as skin color (e.g., Black, White, Asian)
- *Ethnicity* relates to groups of people classed according to common racial, national, tribal, religious, linguistic, and/or cultural origin or background (e.g., Haitian, Hispanic or Latina/o, Italian, Filipino)

Gender Identity

- One's innermost concept of self as female, male, neither female nor male (e.g., nonbinary), a blend of genders, or no gender
- May not necessarily align with one's sex assigned at birth and is not dependent on one's sexual orientation

Sex Assigned at Birth

- The assignment (female, male, or intersex) that a doctor or midwife uses to describe a child at birth, generally based on external genitalia
- May not necessarily align with one's gender identity

Outdated Terms

- **Caucasian** is derived from one of the first racial classification systems used to compare White people more favorably against other races. It's also specific to people from the Caucasus region in Europe and should not be used for people who are not from this region. The best practice is to use White.
- **Minority** is vague, implies a hierarchy among groups, and—depending on contextual factors such as setting and changing demographics—may be inaccurate. Instead, name the specific groups being referenced, then consider “people of color,” “historically marginalized” groups or individuals, or underserved populations (e.g., when referring to health disparities among groups).
- **Mixed race** has negative connotations due to its history of racist descriptors for people who are multiracial. Instead use biracial, multiracial, or people who identify as more than one race.
- **Non-White** is othering and sets up an implied hierarchy where White is assumed as the default. When possible, be specific about the racial or ethnic groups being referenced. If the groups are not known or have already been defined, some preferred substitutions include people of color, historically underserved populations/communities, medically underserved populations, or historically marginalized groups.
- **Other** is nonspecific, uninformative, and could be considered pejorative. In surveys, the preferred option would be “A race or ethnicity not listed” or “A gender identity not listed.”

** If these terms are used within reports that use historical data or database wording that cannot be changed, use a footnote to define the groups and/or state that no other data were provided.*

HIGHLIGHTS OF QUESTIONS ANSWERED DURING THE Q&A

Have you started using BIPOC (Black, Indigenous, and other People of Color) as an acronym to capture the specific anti-Blackness that exists structurally and systemically in our country?

BIPOC stands for Black, Indigenous, (and) People of Color. BIPOC is not a term that we see used frequently in the medical literature. However, the rationale for the acronym has a powerful genesis, as it aims to acknowledge that not all people of color have faced or face equal levels of injustice or discrimination. Authors should be aware that the term has been critiqued by some for potentially creating a hierarchy within these marginalized groups or erasing the identities of other groups.

How can we best capture data on patients who may be transgender? This is so important from a health equity and access standpoint.

Indeed, transgender people have historically not been adequately represented in clinical research and continue to face significant barriers to accessing healthcare. Capturing more comprehensive data and striving for greater access and outcomes for patients who identify as transgender are vital, and ensuring the use of inclusive language in biomedical surveys is a way to address these pressing needs. When designing a survey, best practice is to ask respondents to indicate their gender identity, with response options that include, at a minimum, "female, gender fluid, male, and nonbinary" and "a gender identity not listed." This can then be directly followed by a question asking respondents to indicate their sex assigned at birth, with response options that include "female, intersex, and male." This approach ensures that researchers are asking sensitively and appropriately worded questions and providing inclusive and expansive response options, thereby eliciting more accurate data. Additionally, this type of survey design signals to transgender respondents and those who self-identify outside the female/male gender binary that the study team understands the difference between gender identity and sex assigned at birth and that their inclusion in the study would be welcomed. Ensuring that survey respondents and study participants who identify as transgender feel acknowledged, included, and respected can greatly reduce stigma and improve health access.

Is "people of color" an appropriate term?

Yes, especially when the alternative is a catch-all or convenience term such as non-White or minorities, which sets up a clear hierarchical default. In the US, people of color is used to describe individuals who do not identify as "White." "People of color" is also broadly used as a means of individual and community self-identification in spaces and organizations where health equity is discussed and centered.

Of course, this isn't a perfect solution, as members of these communities may prefer to self-identify differently. The best practice is always to first define the specific groups being referenced. But on subsequent reference or when the individuals being referred to are not White, people of color can be an appropriate substitution in report summaries.

Would expanding survey options to include gender identities like “nonbinary” and “gender fluid” potentially be confusing for people filling out a survey?

When questions about gender identity are included in a survey, best practice is always to allow respondents to self-identify. Limiting gender identity response options to just “female” and “male” is exclusionary and greatly restricts the ability to expand health access to historically marginalized groups. Expanding gender identity options to also include “nonbinary” and “gender fluid” (at a minimum) signals to survey respondents that the study team 1). genuinely has their health interests in mind, 2). understands that gender identity does not only include the binary options of “female” and “male,” and 3). greatly increases the likelihood that respondents with gender expansive identities will feel validated and respected. Respondents know themselves best, and individuals who self-identify as nonbinary or gender fluid will know which response option to select, just as individuals who identify as female or male will know which response option to select for themselves.

Are “Black” and “African American” interchangeable terms? Could you substitute one for the other? Is it wrong to use just one?

In general, the term African American is intended to refer to Black people in the United States. African American should not be used as a catch-all term for people of African descent worldwide because it can obscure other ethnicities and ancestries.

For example, there are many people living in the United States of Dominican, Haitian, Caribbean, African, or other ancestry who may identify as Black but may not identify as African American.

At the same time, there are many Black people whose families have been in the US for generations and may self-identify as Black and African American or prefer one term over the other.

The AMA advises, “when a study includes individuals of African ancestry in the African diaspora, the term Black may be appropriate because it does not obscure cultural and linguistic nuances and national origins.”

The best practice, especially for surveys, is to include both African American and Black.

I noticed that you suggest including “intersex” as a response option for the “sex assigned at birth” survey question. If intersex individuals account for a very small portion of the population, why is it important to capture data on people who are intersex?

Although concrete data on the number of intersex people per-population are difficult to determine, it is estimated that intersex variations may be present in anywhere from 1 in 1,500 to 1 in 2,000 births.¹ However, a larger number of individuals may be born with subtler forms of sex anatomy variations, some of which don’t show up until later in life. These realities—coupled with a lack of self-reporting, persistent stigma, and limited education on what it means to be intersex—have all contributed to a dearth of data regarding the lived experiences of intersex people. However, by including “intersex” as a response option for survey questions asking about sex assigned at birth, study teams can ensure greater inclusion of intersex individuals in medical research, thereby contributing to better healthcare access and outcomes, reduced stigma towards intersex people, and less erasure of intersex identities.

¹ <https://www.nap.edu/catalog/25877/understanding-the-well-being-of-lgbtqi-populations>

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