



# ALZHEIMER'S ASSOCIATION INCLUSIVE LANGUAGE GUIDE

*Guidance for Describing Social Identities and Characteristics of Individuals and Populations and Communicating About Health Disparities*

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# 1. Introducing the Language Guide

## **About the Language Guide**

The purpose of the Alzheimer’s Association Inclusive Language Guide is to provide guidance on inclusive language and communication practices for researchers and scientists working to address Alzheimer’s disease and Alzheimer’s disease–related dementias (AD/ADRD). A broad nomenclature may be used to refer to individual diseases or to the family of brain diseases that cause dementia. These names may be used in different contexts and may be reflective of how someone identifies with their particular situation and/or based on the information available at the time. For purposes of communication in this Guide, the Alzheimer’s Association workgroup uses AD/ADRD as the nomenclature for communication. Guidance focuses on approaches to describing social identities and characteristics of individuals and populations, as well as best practices for communicating about health disparities—topics that are germane to the study of AD/ADRD across diverse populations.

## **Who Is the Language Guide for?**

The Language Guide is primarily intended for researchers and scientists, although others engaged in policy, advocacy and scientific communication, among other areas, may also find these recommendations useful.

## **What Is Included in the Language Guide?**

The Language Guide suggests minimum standards for some specific topics as well as more general guidance for how AD/ADRD scientists should approach communicating about social identities and characteristics of individuals and populations (i.e., race and ethnicity) and health disparities. Recommendations recognize the considerable variability in global, regional and local contexts that necessitate flexibility in specific nomenclature and communication style. In addition, some guidance may not be sufficiently tailored to contexts outside of the United States or English-speaking contexts wherein some concepts presented may not be immediately transferrable. To that end, this Language Guide is designed to complement other resources and style guides that may be consulted for more specific guidance on issues such as capitalization and specific terminology used in a particular country or region (e.g., Publication Manual of the American Psychological Association, Australian Style Guide, Oxford Style Manual).

## **The Role of Language**

Words carry meaning and create opportunities for shared understanding. A majority of AD/ADRD scientists communicate science with peers, trainees entering the field and the general public as a crucial part of their work. The language we use to refer to individuals and groups of people can convey respect, or it can reflect and perpetuate biases and stereotypes. Because the language we use is deeply engrained in social and cultural norms, we may not always recognize ways that biases or inaccuracies are intertwined with certain terminology or approaches to grouping and describing people and populations. Inclusive language acknowledges differences and conveys regard and respect. Defining and describing different groups, individual social factors and population disparities measured in AD/ADRD research is also important to facilitating communication of research findings across contexts.

## **Why Is How We Communicate About Social Identities and Health Disparities in AD/ADRD Research Important?**

Differences in AD/ADRD disease risk and outcomes among groups that are often referred to as underrepresented, marginalized and/or understudied are well documented. While these terms are not interchangeable, they are often used when referring to various groups of individuals or populations with shared identities and characteristics that systematically expose them to discrimination, marginalization, disadvantage and/or exclusion from social institutions, including in AD/ADRD research. Throughout the Language Guide, we refer to these characteristics as social identities and characteristics. We posit that these identities and characteristics represent a dynamic confluence of how we see ourselves and how others in our social world see us, as well as our perceptions of those labels.<sup>1</sup> Social identities and characteristics are nuanced and not always visible. Examples of identity include, but are not limited to, race, ethnicity, gender identity/expression, ability, nationality and socioeconomic status. A broad range of social identities and characteristics may expose an individual or a group to discrimination or marginalization, and these identities intersect in dynamic ways to shape our lived experience—and ultimately risk for and experiences with AD/ADRD.

Observed differences in disease risk and outcomes tied to socially linked inequities in fact represent **health disparities**, defined as “a particular type of health difference that is closely linked with social, economic and/or environmental disadvantage”.<sup>2</sup> Health disparities “adversely affect groups of people (with) characteristics historically linked to discrimination or exclusion.” It is essential that researchers working to address AD/ADRD both engender deep sensitivity toward these inequities and treat these factors with the same degree of rigor and care provided to any other research measure. Cultivating a culture of appreciation for inclusive language when referring to and communicating about individuals, populations and health disparities—and the broader scientific constructs this terminology represents—is both an ethical and scientific imperative to advancing equitable AD/ADRD research, care, and treatments.

### **Balancing Standardization and Flexibility**

Diverse terminologies exist to communicate about an individual’s or a population’s racial, ethnic and/or cultural identities (socially based) and the geographic contexts that shape their lived experiences. Variability in the terminology used to describe racial, ethnic or cultural identities arises largely from geographic, sociocultural or communal differences in word use or preferences and changes in those preferences over time. We understand that AD/ADRD is a *global* health priority and recognize that the meaning of certain terms and their use vary considerably globally.

In recognition of the highly context-specific nature of terminology use, this document emphasizes guiding principles for the AD/ADRD scientific community in communicating about social identities, characteristics, health disparities and minimum standards for communication practices. It is paramount that investigators carefully consider communication practices related to social identities and characteristics at all stages of research (design, conduct and reporting of results), while prioritizing flexibility and adaptability as language changes over time.

### **Language Guide Format and Recommendations**

This Alzheimer’s Association Inclusive Language Guide aims to provide guidance for communicating about social identities and health disparities. Current recommendations address the following: (1) Guiding Principles, (2) Race and Ethnicity, (3) Geographic, Social and Economic Contextual Factors, (4)

Sex and Gender Identity, and (5) Sexual Orientation Identity. While this is not an exhaustive set of dimensions relevant to AD/ADRD research, current guidance prioritizes domains that are commonly measured, demonstrated to be particularly relevant to the study of AD/ADRD health disparities, and represent rapidly growing areas of focus in AD/ADRD research.

As noted, the Language Guide includes both broad recommendations and minimum standards. Recommendations serve to provide guidance to AD/ADRD researchers regarding the following: (1) principles for research to inform communication practices, (2) communication with research participants and communities, and (3) communication with the scientific community. Standards specify criteria that are considered to represent a mandatory communication practice that may be further enforced by the Association, such as through author guideline requirements.

### **Developing and Revising the Language Guide**

Recommendations were developed through a series of discussions with an interdisciplinary workgroup of experts in AD/ADRD health disparities research, which involved review of numerous existing standards and guidelines. Recommendations underwent peer review and further revision following a public Request for Information process soliciting input from stakeholders in the AD/ADRD research and care community. It is expected that the Language Guide will undergo ongoing revisions that are responsive to growth in our understanding of these constructs and best practices.

## 2. Guiding Principles

***There is no universal standard terminology for describing individual and population-level social identities such as racial or ethnic identity or for communicating about health disparities. Here we highlight common guiding principles for reducing bias and stigmatizing language that should be prioritized in making decisions about terminology and communication approach.***

01. Adopt terminology that does not exclude certain groups.

- Use gender-inclusive language if not referring to a specific individual or group by either avoiding the use of pronouns or using they or he/she/they.

02. Avoid language or communication that implies biological significance of race, ethnicity or cultural/population background. Self-reported race, ethnicity and cultural/heritage background are social constructs with no biological meaning or basis. Crucially, they cannot be conflated with genetic ancestry.

03. Health disparities are distinct from population differences and should be contextualized within frameworks of socially linked inequities and related exposures such as the social determinants of health. Avoid framing questions or findings in a way that implies an individual, a community or a population is responsible for health risks or outcomes.

- A common example of poorly contextualized framing of health disparities is failing to recognize that some groups that are disproportionately affected by AD/ADRD may have systematically limited access to resources that would have enabled them to follow certain health guidelines or recommendations.
- Another common example of poorly contextualized framing of disparities is suggesting that addressing individual behavior can overcome challenges with structural determinants.
- Do not use language that posits a social identity as a risk factor. An example of this common problem is this statement: “Risk factors for poor sleep included older age, higher BMI and Black race.” Correlations of identity and outcome should be framed in ways that center on personhood, such as, “Black participants were at greater risk for poor sleep.” In addition, such correlations should be contextualized with empirically supported reasons why the identity factor is associated with risk or confers heightened risk.

04. Carefully review language for use of blame, stigmatizing language or stereotypes.

- An example of language that may be stigmatizing is the term “uneducated Black population” when referring to older adults who were unable to complete schooling because of segregation. The following is an example of language that contextualizes the effects of social inequities and does not blame individuals: “Individuals who did not have access to education because of segregation.”
- Consider using the term “culturally and linguistically diverse communities/populations” when describing individuals who are immigrants to a particular setting/environment.

05. Use language in a manner that acknowledges and respects different identities and groups.

- Populations with shared social identities are not monolithic or homogenous in their lived experiences, preferences or other characteristics, and this should be explicitly stated.
- Be cautious in generalizing about a community.

06. Use language that is preferred by the group to which one is referring. For example, some groups have published guidance regarding their *own* preferences for how they are referred to, and not all groups prefer person-first language, especially in referring to people living with dementia. Person-first (i.e., person with disabilities) and identity-first (i.e., disabled person) language preferences vary across communities and individuals. Examples of these preferences include the following: people with disabilities, person living with dementia, autistic person, and deaf people (although some may prefer person-first language). Avoid use of terms such as “demented” or “impaired” when describing people living with dementia. *Word count concerns do not outweigh the need to use preferred language.*

07. Recognize that there is likely not universal consensus for terminology, that preferences likely vary by region and context, and that language is always evolving. Seek continual learning about the meaning of words, and how groups self-identify and would like to be identified by researchers.

08. Describe a person or group at the appropriate level of specificity. To avoid objectification, identify a group or an individual as a member of a group only when it is relevant to your message.

09. Avoid dehumanizing language. Avoid use of the term “subjects” when referring to research participants and “sufferers” and/or “victims” when referring to people living with dementia as these words often have stigmatizing, demeaning and/or derogatory connotations. Use adjectival forms (e.g., older adults) or nouns with descriptive phrases (e.g., individuals experiencing/affected by poverty, justice system-involved persons, people experiencing homelessness) rather than labels (the elderly, the poor, the homeless, the Blacks).

10. When possible, avoid the use of abbreviations such as PWD, PLWD (person with dementia, person living with dementia) as multiple advocacy groups composed of people living with dementia have released statements requesting these abbreviations not be used. An exception is situations where the abbreviation is broadly accepted and in use by the population to which it refers. For example, the abbreviation LGBTQIA, which stands for “lesbian, gay, bisexual, transgender, queer and/or questioning, intersex, asexual/aromantic/agender,” is commonly used by members who identify within this community.

11. As needed, consult additional guidance for use of inclusive language for people with disabilities because those living with dementia may have or acquire disabilities. Important principles to remember are that not all disabilities are visible, and not all individuals are comfortable disclosing disabilities. Use descriptors that emphasize abilities rather than limitations (e.g., “person who uses a wheelchair” instead of “confined to a wheelchair”). Use language that emphasizes accessibility needs rather than limitations (e.g., “accessible walkway” instead of “disabled walkway”).



# 3. Communicating About Race and Ethnicity

Whether AD/DRD scientists are communicating with research participants through data collection, with communities through outreach events or news media, or with other scientists through dissemination, training activities or daily discourses, several common foundational tenets that should shape language can be identified.

Consistent with the American Medical Association, American Psychological Association and other style guides, we recognize that race and ethnicity are social, not biological, constructs. Social constructions are systems of ideas that are produced, accepted, and acted out by societies.<sup>3</sup> Race and ethnicity as social constructions are exemplified by change over time in the racial and ethnic classifications in the U.S. Census; these changes are clearly shaped by the political and social agendas of particular times. For example, the Mexican American population has been coded on the Census with terms including Mexican, White, and Hispanic or Latino, all of which are related to historical politics in the United States.<sup>4</sup> Further, until 1970, racial data were based on Census interviewer perception rather than self-report.<sup>5</sup> Classifications—in the U.S. Census, research, and practice—influence law, policy and allocation of resources that, in turn, influence disease risk, diagnostics and management (e.g., access to and quality of health care).

The approaches used to group people and the terms used to describe those groups reverberate through AD/DRD discourse and developments. They can reinforce stereotypes, particularly those suggesting that social identities such as race emanate from biological differences. Because discrimination that results from the social construction of racial identities influences lived experience and downstream **biological sequelae** in ways that modify disease risk, health care access and outcomes, inquiring about and categorizing people by self-identified race can ultimately support measurement, acknowledgment, and redress of health disparities.<sup>6</sup> Additionally, grouping without intentionality and transparency can obscure heterogeneity within broader racial and ethnic categories and misrepresent generalizability of findings. Cultural identities are often considered alongside but not interchangeable with race or ethnicity, and may include characteristics such as language, religion, nationality or immigration status.<sup>7</sup>

Notably, genetic ancestry correlates with race and ethnicity to differing and often limited degrees<sup>8</sup>; it should be operationalized and addressed separately as ancestral background and not referred to as race and ethnicity if genetic risk factors are of primary scientific interest.

## **Understanding Uniform Classification Systems for Collecting Race and Ethnicity Data**

Systems of racial and ethnic classification are used globally, and in many cases they are driven by efforts to count and categorize a region or nation's population. According to data from the United Nations derived from global census questionnaires, 65% of countries classify their population by identity-based factors such as nationality or ethnic group identity (United Nations Statistical Division, 2003). The specific language used in these classification systems varies considerably. The *meaning* of terms used in classification systems is often inconsistent or vague. For example, terms may be used interchangeably or a characteristic that is referred to as an “ethnic” identity in one country may be labeled as “nationality” or “race” in another. These classification systems may be derived from historical or sociopolitical understandings and motivations that may or may not be sufficiently specific, accurate or inclusive for the purposes of a given research study.

For example, the contemporary classification of Indigenous citizens and descendants of sovereign First Nations as “American Indian/Alaska Natives” in the United States is derived from the racialization of these people and not the politicization of these identities as legal entities. For these reasons, it is important for researchers to become familiar with policies or practices that have informed data collection practices relevant to their region and population(s), including the format of questions and response options about racial, ethnic, nationality or other cultural identities.

### **Broad Categorizations of Race and Ethnicity: *Limitations and Considerations for AD/ADRD Research.***

In the United States, common minimum standards remain in use by federal agencies including the National Institutes of Health and the U.S. Census<sup>9</sup>; such guidelines include as few as five race categories (Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, White) and two ethnicity categories (Hispanic or Latino, Not Hispanic or Latino). It is important to acknowledge that administrative data can be limited as a result of requirements within these classification systems. Likewise, research data collection protocols that mimic and rely solely on such data structures are bound by substantial constraints. First, participants may not recognize themselves in or accept the categories provided; for example, several studies have documented the hesitation of Dominican Americans to define themselves racially, as Black or White, as opposed to by nationality.<sup>10-12</sup> Second, such broad categorizations do not allow scientists to communicate clearly regarding the characteristics of their samples or the validity and generalizability of their study results. For example, in 2011 the U.S. Department of Health and Human Services modified the broad category of “Asian” to include seven additional categories in data collection guidance to document and track health disparities in more granularity, reflecting the diversity of experiences and contexts that exist within this racial group (<https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>). The translational implications of ignoring granular origin data are empirically clear: In a large, population-based and nationally representative survey of U.S. adults pertaining to their health care experiences, nationality and origin were major sources of heterogeneity within racial and ethnic groups, not only in socioeconomic status but also in healthcare access and quality of care. Mexican Americans and South/Central Americans, as well as Korean Americans, Chinese Americans and Vietnamese Americans, reported worse experiences than their Hispanic/Latino and Asian peers, whose self-reported experiences did not differ from those of White Americans in this cohort.<sup>13</sup> It is acknowledged that aggregation during data analysis is often required to achieve adequately powered analytic samples and harmonize datasets. However, the initial collection of granular ethnicity and origin data, tailored to the source population, provides researchers with the opportunity to describe the subgroups represented within larger aggregated groups and facilitates future within-group research endeavors.

### **Recommendations**

- Identify nationally, regionally and/or locally specific uniform classification systems for collecting and reporting on race, ethnicity and other cultural identity-based factors such as nationality. These classification systems may shape some requirements for data reporting and aggregation but may not be sufficiently specific or diverse with respect to question and format options for your research.
- Whenever possible, data collection and reporting should be informed by the characteristics and preferences of the communities involved in your study.
- Dissemination of findings should include description of and justification for aggregation decisions and absence of data from race and ethnicity categories.
- Information on granular sample characteristics also should be provided as appropriate and ethical.
- The relationship of racial and ethnic categories to systemic structural inequities, such as presence of discrimination or quality of education, should be addressed in your research wherever possible.

# Principles for Research to Inform Communication Practices

*Because what is most appropriate varies considerably by context, including national, regional and local differences in language preferences, our guidance for terminology on race and ethnicity focuses first on how to approach communication and decision-making for specific terminology. We then provide specific guidance on avoiding use of noninclusive or discriminatory terminology and minimal standards for reporting.*

## **1. Know the community(ies) in your studies.**

Where feasible, investigators should consider identifying terminology preferred and used by individuals within their studies. In some situations, investigators may decide to use multiple terms such as "African American/Black", "Latina/Latino/Latinx/Latine", or "American Indian/Alaska Native/Native/Indigenous/Aboriginal/First Nations".

## **2. Recognize that racial/ethnic identity is not dichotomous.**

Individuals may identify with multiple racial, ethnic and/or cultural identities. It is important to maximize flexibility in self-classification options for participants, meaning that they can be provided with options to identify in more than one category. For example, a participant could select African American and Asian.

## **3. Consider generational differences in terminology.**

Examples of differences in preference might be the use of “Negro vs. Black,” “Chicano/a vs. Latinx” or “Eskimo vs. Inuit.” Note there may be generational differences in how some terminology is viewed; for example, some older African Americans may embrace the term “negro”, whereas younger generations may find the term offensive. In the event that certain terminology is preferred by participants from a specific generation of interest, as is often the case with AD/ADRD cohorts, investigators can explain in publications that their terminology use is informed by the preferences of study participants.

## **4. Prioritize flexibility and adaptability.**

What is “right” or preferred often changes over time. Investigators from outside the community being studied will find that nuanced information about identity is likely to emerge as a function of continuing engagement with community members.

## **5. Participants should have the opportunity to self-identify their race and ethnicity with as much flexibility as possible.**

Researchers should acknowledge that self-identified race represents a confluence of how participants perceive themselves (racial identity) and the impacts of racialization by others. During data dissemination, researchers are obligated to transparently describe and justify any aggregation that occurred for analytic purposes (i.e., sample size) and note how preaggregation nuances might limit inference or shape future directions.

## **6. Do not conflate self-reported race with ancestry.**

Genetic risk and resilience, and parsing heritable from modifiable contributors to cognitive aging, is a major area of work within AD/ADRD research. As described earlier, however, racial and ethnic identities are not surrogates for genetic ancestry, with which they often are only weakly correlated.<sup>8</sup> The reverse is also true: Ancestry should never be used to “confirm” or infer race or to assign individuals to racial categories.

# Standards for Describing and Communicating About Race and Ethnicity

*The following communication standards should be adhered to in all descriptors of and communication regarding race and ethnicity.*

1. Collect and report self-identification of race and ethnicity.
2. Do not assign or label individuals to racial or ethnic identities based on researchers' perceptions.
3. Avoid using adjectives as nouns to label people such as stating "Blacks" or "the poor." Instead, adopt phrases such as "Black older adults," "people living in poverty," and "people with limited literacy."
4. Avoid the use of terminology with roots in eugenics or racist philosophies, while recognizing that the meanings of these terms may vary by region and country.
5. Do not conflate self-reported race and ethnicity with ancestry.

# 4. Communicating About Geographic, Social, and Economic Contextual Factors

## Background

Investigations into determinants of health disparities in AD/ADRD frequently emphasize individual-level experiences with structural and social determinants of health, which include “the conditions in the environments where people are born, live, learn, work, play, worship, and age.”<sup>2</sup> These typically include one’s economic position, experiences with health care access and quality, social and community settings, neighborhood, built and natural environment, and education access and quality. However, the influence of these individual experiences with the structural and social determinants of health often depends on the geographic, social and economic context in which an individual resides.

Defined as geographically and environmentally situated contextual factors, these factors may include rural versus urban settings or the built environment where one lives. It may also include broader nongeographic features such as intergenerational inheritances, immigration policy, political and physical environment including sovereign Tribal lands, or historical and institutional discrimination against groups to which an individual belongs. Relevant constructs in AD/ADRD studies may vary across international contexts. Resources from the World Health Organization, United Nations, and World Bank (e.g., Global Health Observatory, Sustainable Development Goals, Multidimensional Poverty Measure) can aid investigators in understanding country- and region-specific differences in salient contextual factors. For example, implications resource allocations within rural/urban or urban/suburban settings vary widely, regionally and globally, and has unique implications for AD/ADRD.

Geographically and environmentally situated contextual factors have been shown to exert independent and multifactorial impacts, above and beyond individual-level factors, on a range of health-related outcomes, including AD/ADRD. While these factors have been studied and measured for decades in other fields (e.g., sociology, demography, international development, economics, epidemiology), their use in the AD/ADRD field is relatively new. Given the breadth of disciplines that have studied contextual socioeconomic factors, terminology in this area is frequently inconsistent but often includes the following: geographic factors, socioeconomic factors, sociocontextual disadvantage, deprivation, poverty, and disadvantage (and variants therein, including geographic, sociocontextual, neighborhood-level deprivation and/or emergent group properties).

Individual-level social and economic factors, such as socioeconomic status, are often associated with—yet are distinct from—situational and contextual-level factors. Conflation and lack of specificity regarding attribution of contextual factors to the individual are not uncommon and have important implications regarding the accuracy of inferences about social forces that operate at distinct levels, as well as regarding the inappropriate attribution of social context to persons within those populations. Understanding an individual through the lens of macrosystems (e.g., law, policies, education, culture) is paramount when contrasting/comparing study results regionally, nationally and internationally. The following recommendations and guidance are offered to aid AD/ADRD researchers in addressing these constructs.

## Recommendations

- Consistently specify the geospatial region/level of contextual and geographically based measures used. For example, do not substitute “neighborhood-level disadvantage” with a broader or vaguer term such as “area disadvantage.” *Avoid the use of shorthand descriptors such as “disadvantage” (without the contextual adjective) that risk conflation with individual-level factors.*
- Detail the dimensions measured or included in descriptions of applied contextual or geographically based measures to improve transparency and rigor. For example, a composite measure such as a Multidimensional Poverty Index has multiple indicators (years of schooling, attendance) that are weighted to constitute a single dimension (education) out of the global composite.
- Consistently specify the geographic scale for contextual-level descriptors that are congruent with measurements/metrics applied. For example, if the measurement of geographic disadvantage is operationalized at a neighborhood level, this should be anchored to established discrete and validated geographic and/or social science constructs. Metrics should be specified with consistent terminology, accompanied by descriptors of how the neighborhood—or any other geographic/social area of measure—was defined and operationalized in analyses.
- Use language that respects and is sensitive to the unequal distribution of historically excluded and minoritized populations within regions characterized as having higher levels of deprivation or disadvantage. Such language attributes descriptors of geographic region to the context and not to individuals or communities. For example, “persons with exposure to neighborhood-level disadvantage” is preferred to “people from disadvantaged neighborhoods.”
- Describe the methods for collecting, defining, and analyzing/coding geographic and contextually based data of socioeconomic status and any limitations associated with those methods.

# 5. Communicating About Sex, Gender, Gender Identity and Sexual Orientation

Sex, gender, gender identity, and sexual orientation, though related, are conceptually complex and distinct. They each demand attention in AD/ABRD science. Sex is a multidimensional construct based on a cluster of anatomical and physiological traits that include external genitalia, secondary sex characteristics, gonads, chromosomes, and hormones.<sup>14,15</sup> Historically, sex has been thought of as a binary construct whereby sexually dimorphic qualities and reproductive roles have been used as phenotypes to discern men and women. However, sex is not binary (e.g., male, female, intersex), but health care professionals most often assign a sex to an infant at birth based on the appearance of external genitalia.<sup>14</sup> Intersex traits, also referred to as differences of sex development, include diverse congenital differences relating to gonads, chromosomes, sex-specific hormones and genitals that fall outside of binary notions of male and female sex.<sup>16</sup> “Natal sex” and “biological sex” are terms that have previously been used to refer to an individual’s sex assigned to them at birth.<sup>17</sup> “Sex assigned at birth” is the recommended term when referring to the sex assigned to a person (i.e., male, female, intersex).<sup>14,17</sup>

Gender refers to socially constructed and enacted roles and behaviors that occur in a historical, cultural and social context.<sup>18</sup> This means that the construct of gender varies over time and across cultures. Like sex, the construct of gender comprises a range of attributes such as gender identity, expression, and social and cultural expectations about status, characteristics and behaviors that are associated with sex traits.<sup>14</sup> Gender identity refers to a person’s individual sense of self as being a man, woman, both, neither, or another identity.<sup>14</sup> An individual’s gender identity can evolve and change across their lifespan.

Transgender, an adjective, describes persons whose gender identity and sex assigned at birth do not correspond based on traditional cultural and social expectations.<sup>14</sup> People with alignment between their gender identity and sex assigned at birth are referred to as cisgender.<sup>14</sup> The transgender population includes individuals whose gender identities are both within the gender binary (i.e., man/woman) and outside the binary (i.e., agender, nonbinary, genderqueer and gender nonconforming).<sup>14,16</sup> However, some individuals who identify outside of the gender binary may not use the term “transgender” when describing themselves.<sup>14</sup> Transgender people can be of any sexual orientation.

Terms used to denote an individual’s gender or gender identity include man/boy, woman/girl, transgender man/boy, transgender woman/girl, nonbinary person, gender nonconforming person. Individuals may use multiple terms when describing their gender or gender identity.

Sexual orientation refers to the characteristics of those to whom one is sexually, romantically and/or emotionally attracted, as well as sexual behavior.<sup>18</sup> Research suggests that sexual orientation occurs on a continuum.<sup>19-22</sup> Individuals may use multiple terms when describing their sexual orientation.

Individuals may identify as heterosexual (straight), gay, lesbian, queer, asexual, bisexual and/or another sexual orientation.<sup>17</sup> One’s sexual orientation and their attraction and behavior do not need to align for their sexual orientation/identity to be valid.<sup>16</sup> Like gender identity, one’s sexual orientation can change and evolve across their lifespan.

## Intersectional Identities

Sex, gender, gender identity and sexual orientation are identities. While gender/gender identity and sexual orientation are often conceived of as being defined by an individual according to their self-concept, sex can both reflect society's expectations of an individual's social identity, such as sex assigned at birth, and/or an individual's self-concept. The existence and operation of these identities are often actualized via conceptual models related to gendered behaviors, gender roles, sexual identity development, gender-as-performance and other factors.

Sex, gender, gender identity and sexual orientation identities are intersectional, meaning they can inform each other. Sexual orientation, for example, relies on sex to inform its categorization. These identities can also compound systemic oppression within social systems. A woman, for example, who is in a spousal relationship with another woman may experience effects of the systemic oppression of women directly and via her wife's experiences. In addition, aspects of identity related to sex, gender, gender identity and sexual orientation intersect with other identities. A Black trans woman, for example, can experience transphobia and sexism in combination with systemic racial oppression. These identities and their social consequences are context dependent. The effects of these experiences on social, psychological and biological outcomes are not well understood.

Here, we offer considerations and recommendations for addressing these constructs in peer-reviewed, scientific publications.

## Recommendations

- Use language that respects that sex, gender, gender identity, and sexual orientation may have biological and social underpinnings and correlates.
- Use language that respects that self-reported sex, gender, gender identity and/or sexual orientation are (1) aspects of identity, (2) can exist along a continuum and be nonbinary and (3) are appropriately measured by one's self-report of their identity.
- Recognize that sexual orientation and gender identity are not binary and can evolve and change across the lifespan.
- Describe the methods for collecting, defining and analyzing/coding sex, gender identity and sexual orientation variables and any limitations associated with those methods.
- Include the reasons justifying exclusion/inclusion of individuals based on sex, gender, gender identity and/or sexual orientation.
- If results are reported that statistically adjust for sex, gender identity and/or sexual orientation, results of stratified analyses also should be reported when statistically appropriate/sample size allows.
- Report on representation of sex, gender, gender identity and sexual orientation identities in research samples and/or state explicitly the unrepresented (or unmeasured/uncounted) groups that may be relevant to the study focus.
- When reporting on and/or interpreting the meaning of scientific results that are based on identity data related to sex and/or gender, particularly in scenarios such as secondary analysis of archival data where it may be unclear which construct was assessed, "sex/gender" may often be the most appropriate term of art.



- Avoid making biological inferences when reporting on and/or interpreting the meaning of scientific results that are based on identity data related to sex, gender, gender identity and/or sexual orientation. These groupings reflect sociocultural classifications. While they may have biological correlates and most likely correspond to complex pathways between lived experience and biological mechanisms, biological inference in the absence of biological data risks invoking ideas of biological essentialism and social prejudices.
- As scientists report and interpret findings based on identity data, it is essential that variabilities in lived experience that are due to these groupings be considered, minimally, as potential confounders and, more productively, as active agents in investigative pathways.
- Consult and apply the most current guidelines and resources:
  - Consideration of Sex as a Biological Variable in NIH-Funded Research. [https://orwh.od.nih.gov/sites/orwh/files/docs/NOT-OD-15-102\\_Guidance.pdf](https://orwh.od.nih.gov/sites/orwh/files/docs/NOT-OD-15-102_Guidance.pdf)
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- Consider the relevance of sex, gender, gender identity and sexual orientation to AD/ADRD research, clinical outcomes, translation and implementation:
  - How might findings related to sex, gender, gender identity and/or sexual orientation be indicative of AD/ADRD disparities and diversity that warrant further investigation?, or
  - How might representation of sex, gender, gender identity and/or sexual orientation of individuals help inform understanding of or address a gap in the phenomenon under study?, or
  - How might sex, gender, gender identity and/or sexual orientation be interacting with the mechanisms of the study?, or
- How might sex, gender, gender identity and/or sexual orientation impact theory efficacy or effectiveness of interventions under study?

# 6. Glossary of Key Terms

**Ancestry:** As a term may be used in various ways, sometimes referencing a person’s ethnic origin or descent, “roots” or heritage; the place of birth of the person or the person’s parents or ancestors (geographic ancestry). To avoid confusion, we recommend it be reserved as a term specific to the biological descent of an individual (genetic ancestry).

**Cisgender:** People with alignment between their gender identity and sex assigned at birth.

**Discrimination:** Differential, unjust or prejudicial treatment of the members of a group based on characteristics such as race, ethnicity, gender, age, sexual orientation, gender identity or expression, religious identity, nationality, ability status or other factors.

**Diversity:** A wide range of variation among people and population groups, and can include such factors as age, gender, sexuality, race, ethnicity, nationality and religion, as well as education, livelihood and marital status.

**Ethnicity:** Characteristics such as country of origin, language, religion, history or cultural traditions that are shared among a group of people.

**Ethnicization:** Akin to racialization, it is the social process of defining individuals as belonging to a certain ethnic group, on the basis of features such as country of origin, language, religion, cultural traditions, food or style of dress.

**Gender:** Socially constructed and enacted roles and behaviors that occur in a historical, cultural and social context.

**Gender Identity:** A person’s individual sense of self as being a man, woman, both, neither or another identity. An individual’s gender identity can evolve and change across their lifespan.

**Health Disparity:** A health difference that is closely linked with social, economic and/or environmental disadvantage.

**Health Equity:** The absence of unfair, avoidable or remediable differences in health. Health equity allows all individuals to achieve their full potential for health.

**Marginalization:** A process through which an individual or a group becomes identified as one not accepted fully into a larger or more “dominant” group that is treated as preferential.

**Racialization:** The social process of defining individuals as belonging to a certain racial group, on the basis of features such as skin color, hair texture or facial features. These definitions are applied to individuals or groups of people by others who typically are in a more powerful social position. Over time, groupings such as “race” can appear to be grounded in biological differences as the origins of racialization as a social process are forgotten.

**Race:** A socially constructed concept that refers to groups of people who are categorized by physical characteristics (e.g., skin color/complexion, facial features). Individuals may identify with a single race or identify as biracial or multiracial, and the meaning of race can vary across individuals within each racial group.

**Sex:** A multidimensional construct based on a cluster of anatomical and physiological traits that include external genitalia, secondary sex characteristics, gonads, chromosomes and hormones.

**Sex Assigned at Birth:** Health care professionals most often assign a sex to an infant at birth based on the appearance of external genitalia. “Natal sex” and “biological sex” are terms that have previously been used to refer to an individual’s sex assigned to them at birth. “Sex assigned at birth” is the recommended term when referring to the sex assigned to a person (i.e., male, female, intersex).

**Sexual Orientation:** The characteristics of those to whom one is sexually, romantically and/or emotionally attracted, as well as sexual behavior.

**Social Determinants of Health:** The nonmedical factors that influence health outcomes. They are the conditions in the environments where people are born, live, learn, work, play, worship and age, and they include aspects such as economic stability and working conditions, education access and quality, health care access and quality, neighborhood and built environment, and social context. Social determinants of health have an important influence on the presence of health disparities.

**Social Identities:** The self-concept derived from memberships in social groups or categories, representing a dynamic confluence between how we see ourselves and how others in our social world see us. Examples of social identities are race, ethnicity, gender, social class/socioeconomic status, sexual orientation, presence of (dis)abilities or religion/religious beliefs.

**Systemic and Structural Racism:** A system in which public policies, institutional practices and cultural representations often reinforce one another to perpetuate racial group inequity by limiting opportunities, resources or justice in a standard and systematic manner.

**Transgender:** An adjective used to describe persons whose gender identity and sex assigned at birth do not correspond based on traditional cultural and social expectations. The transgender population includes individuals whose gender identities are both within the gender binary (i.e., man/woman) and outside the binary (i.e., agender, nonbinary, genderqueer and gender nonconforming). However, some individuals who identify outside of the gender binary may not use the term “transgender” when describing themselves.<sup>14</sup> Transgender people can be of any sexual orientation.

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