Person-Centered Language "Style Guide"

Purpose

Advancing health equity requires a shift in how professionals talk about health disparities and how we describe individuals and communities most impacted by negative health outcomes. Language reflects our thoughts and attitudes and has a profound impact on efforts to advance health equity. This "style guide" was born with the acknowledgement that the field has learned hard lessons about the negative impact of language that has been used. The "style guide" is a starting point to invite readers to understand key concepts and explore language that is affirming to communities that are marginalized by thoughts, language, and policies. The "style guide" will evolve over time and feedback is welcomed to inform the evolution of the document.

Fostering equitable workspaces, partnerships, research, programming, and policy are part of achieving an inclusive environment; using person-centered language when disseminating information and findings on diverse communities is also critical. Person-centered language focuses on the individual and their experience, emphasizing that things happen **to** a person, not that they have defined or created the situation themselves (e.g., slaves v. enslaved persons, diabetics v. persons living with diabetes). This guide aims to ensure that all forms of organizational communication (e.g., reports, emails, presentations, etc.) acknowledge cultural humility, the impact of systemic racism, and the marginalization of communities, while demonstrating the complexities of the care, needs, preferences, and circumstances of all.

Cultural Humility is defined by the National Institutes of Health as "a lifelong process of self-reflection and critique whereby the individual not only learns about another's culture, but one starts with an examination of [their] own beliefs and cultural identities."[1] ***When communicating about vulnerable populations, it is important not to assign feelings based on assumptions of one's own experiences or beliefs.*** Microaggressions are a common form of privileged language wherein accidental or purposeful biased statements are made towards or about a vulnerable population (e.g., telling someone who is a person of color that they are "very articulate" or a person living with a physical disability that they "move well for their situation").

Systematic Racism presents itself through 1) *institutional racism*: discrimination formed by following the dictated prejudice and biases of another and/or society, and 2) *structural racism*: bigotry founded in systems-based inequalities that isolate, penalize, or harm a person or persons based on their cultural identify and/or beliefs. ***According to the National Juvenile Justice Network, we must continuously recognize and reflect upon white power structures and privilege and how communications can actively counteract those principles.***[2]

Marginalized populations are "groups and communities that experience discrimination and exclusion (social, political and economic) because of unequal power relationships across economic, political, social

[1] Yeager KA, Bauer-Wu S. Cultural humility: essential foundation for clinical researchers. *Appl Nurs Res*. 2013;26(4):251-256. doi:10.1016/j.apnr.2013.06.008

[2] National Juvenile Justice Network. *Four Questions to Ask Yourself about Your Campaign*. https://www.njjn.org/our-work/training-and-resources

and cultural dimensions" (National Collaborating Centre for Determinants).[3] This includes notions such as homophobia, ableism, sexism, ageism, xenophobia, anti-Semitism, and anti-Arabism. ***Social Determinants of Health (SDOH) are not a construct of the client or community but are instead a result of policies and systems of which many are racist and oppressive. As such, social determinants of health can either have a positive or negative impact on a person's health.***

Examples of Biased Language and Adapted Person-Centered Language (Written and Verbal)

Biased Language	Person-Centered Language
A diabetic patient…	A patient living with diabetes…
A person afflicted with HIV, HIV-positive, HIV infected	A person living with HIV…
People of color are incarcerated more often…	Institutional racism increases the rate of incarceration amongst people of color
Crowded housing	Multi-generational housing
Drug Addicts/Alcoholics	Individuals living with a substance use disorder
Elderly/Geriatric	Older Adults; Elders; Aging; Aging Populations; People over the age of…
Foreign Language	Preferred Primary Language other than English/Native Language
Foreigners/Aliens	Immigrants, Refugees, Persons born outside of the US
Handicapped	Instead of noting a person as disabled, specify their need, such as: Visually Impaired, Hearing-Impaired, Uses a wheelchair. You can say, "Person living with a disability."
Homeless	Individuals experiencing unstable housing/without housing
Illegal Immigrants/Illegal Aliens	Undocumented Individuals or Immigrants without papers
Inmates/Felons/Prisoners	Individuals currently (or previously) incarcerated; justice-involved person[4]; returning resident
Insane/Crazy	Individuals living with a mental illness or cognitive impairment
Minority Populations	Not all groups considered "minorities" are in fact minority (e.g., the Latinx community in Texas); Instead, use words like: Diverse, Multicultural, People or Communities of Color[5]
Native Americans have some of the highest rates of alcoholism…	Structural Racism has contributed to elevated levels of alcoholism within the Native American community…
Poor People	Persons living at or below the federal poverty level; people with low income or limited resources; underprivileged…
Uneducated	Those with a high school diploma…; Those who have completed 8th grade…;
Weird name	Unique name. Ask how to say a person's name[6] and ***not*** the "American", English, or easier version of their name[7].

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[3] National Collaborating Centre for Determinants of Health. https://nccdh.ca/glossary/entry/marginalized-populations

[4] https://lincnc.org/language-of-incarceration/

[5] https://www.newsweek.com/bipoc-isnt-doing-what-you-think-its-doing-opinion-1582494

[6] https://hbr.org/2020/01/if-you-dont-know-how-to-say-someones-name-just-ask

[7] https://www.huffingtonpost.co.uk/entry/difficult-names_uk_5e286f0ec5b67d8874aabe67

Language and Health Literacy

While many individuals may speak the English language, *it may not always be* the primary language spoken at home and/or the language in which individuals would like to receive information or medical care. Over 60 million Americans speak more than one language, and it is not always one that can be assumed (e.g., not all individuals who are Latinx speak Spanish). Identifying a person's "preferred" primary and/or secondary language is favored over assumptions. This becomes critically important when sharing health-related information such as medication directions or consent forms. ***A person may be completely literate in their language(s) yet find it difficult to understand medical jargon and technical research terms – also known as health literacy.*** Age, education, and other factors may affect individuals' health literacy.

Sexual Orientation, Gender Identity, Pronouns, and Gender-Neutral Neologisms

Like other marginalized populations, it is critical not to assume or guess individuals' sex, gender, preferred pronouns, or physical/behavioral health needs or wishes (e.g., not every woman is feminine or desires to have a baby.) For example, not every person who identifies as a man has the same medical needs (e.g., transgender men may still need to receive critical screenings like cervical and breast cancer) regardless of their physical appearance. It is also important to remember that ***the concepts of sexual orientation and gender identity (often referred to as SO/GI) are social constructs, like race, and should be communicated about as non-binary ideologies (i.e., not just male/female).***

Examples of Affirmative Sexual Orientation and Gender Identity Language

Topic	Affirmative Language
Gender Identity	<u>Agender</u>: An individual who does not identify as a specific gender (aka. Gender-Neutral or Genderless) <u>Cisgender</u>: An individual who identifies as the biological sex they were born as (e.g., I was born as a male and identify as a man) <u>Gender Fluid</u>: An individual who moves between genders. <u>Non-Binary</u>: Not composed of only two things; Gender is multifaceted and can be fluid. <u>Queer/Genderqueer</u>: An umbrella term used for the LGBTQIA+ population, also used to describe individuals who may be gender non-conforming or non-binary. <u>Transgender</u>: An individual who self-identifies as a gender they were not biologically born as [e.g., MTF (male-to-female) or FTM (female-to-male); this may be non-binary, as well, where an individual does not conform to any specific gender.
Gender-Neutral Neologism	Removing the gender or sex from words (e.g., Latinx instead of Latino/Latina, Womxn instead of Woman, Mx. Instead of Mr./Ms./Mrs.)[8,9] Also consider this idea when writing about individuals' occupations (e.g., firefighter, not fireman; mail carrier, not mailman, etc.)
Pronouns	He/Him/His; She/Her/Hers; They/Them/Theirs; Ze ["Zee"] /Hir ["Here"] (non-binary, alternative gender-neutral pronouns); Any language that is respectful
Sexual Orientation	Lesbian, Gay, Bisexual, Queer, Asexual, Pansexual, Straight, Questioning, Demisexual, etc.[10]

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[8] https://young.scot/get-informed/national/gender-identity-terms

[9] https://www.nytimes.com/2019/03/14/style/womxn.html

[10] https://www.thehealthsite.com/sexual-health/whats-your-sexual-orientation-p915-325062/

Bias in Big Data

Large research study datasets and outcomes are often referenced in policy narratives as highly rigorous due to the many hundreds or thousands of human subjects that may have participated in the study. ***Being aware of biases in data and research are essential when disseminating outcomes and/or citing findings is crucial, as the haphazard framing of data may imply blame or causation.*** For example, when reporting higher rates of COVID-19 incidence and prevalence in communities of color, failing to provide adequate context as to *why* these communities have experienced higher rates of COVID-19 insinuated damaging causal linkages between race and ethnicity and infection.

Concerns over technological redlining (racism in technological access, literacy, and inclusion within automated decision-making systems) and weighted data analyses (multiplying results by an over or under rate based on the assumed total to more accurately reflect a population) have real consequences when focusing on person-centered language (Noble, Safiya Umoja).[11] ***If communities of color have not been included in, informed about, or equitably provided the opportunity to participate in social behavioral or clinical research studies due to systemic racism and the effects of social determinants of health, making statements about these populations is not practicing cultural humility or inclusivity.*** Data algorithms, medical guidelines, and other large health and policy outcomes cannot instinctively recognize discrimination.[12] Thus, it is important that when writing about data and research, these limitations should be included as a part of the narrative and/or a different study be considered altogether.

Furthermore, current federal reporting guidelines only include the following standardized variables when discussing individual demographics. These limitations often result in the generalization of communities (e.g., Asian v Indian, Japanese, Chinese, etc.). ****Adding a disclosure to publications acknowledging that these variables do not represent the breadth of communities' uniqueness is encouraged.***

Federal Reporting Demographic Variables[13]

Demographic Category	Standardized Responses
Age	Children; Adults; Older Adults
Ethnicity	Hispanic or Latino/a; Non-Hispanic or Latino/a
Gender Identity	Male; Female; Transgender Man/Male; Transgender Woman/Female; Other; Choose not to disclose; Unknown
Language	Best Served in a Language Other than English
Race	White; Black or African American; Asian; Native Hawaiian or Other Pacific Islander; American Indian or Alaskan Native; More than one race
Sexual Orientation	Lesbian or Gay; Heterosexual or Straight; Bisexual; Something else; Don't Know; Choose not to disclose; Unknown

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[11] Noble, Safiya Umoja. *Algorithms of Oppression: How Search Engines Reinforce Racism*. New York University Press, 2018.

[12] Williams, Betsy Anne, et al. "How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications." *Journal of Information Policy*, vol. 8, 2018, pp. 78–115. *JSTOR*, www.jstor.org/stable/10.5325/jinfopoli.8.2018.0078. Accessed 19 Oct. 2020.

[13] https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/2020-uds-manual.pdf

Example of Data Bias Disclosure
"The data variables described in this [paper, article, brief] were developed by and disseminated in alignment with Federal reporting guidelines. NACHC recognizes that these variables are not 100% inclusive and may result in unintended biases. Whenever possible, NACHC believes in the equitable inclusion and dissemination of data on all communities."

Key take-aways

1. We are all on a journey towards a more equitable and just society and each of us are learning more about how we as individuals, teams, organizations, and communities can make changes in our thoughts, attitudes, and language to advance health equity. The "style guide" is a starting point and is meant to be a conversation starter. There are organizations that are subject matter experts that have developed comprehensive tools and resources for those looking to take a deeper dive within their respective areas of focus. We encourage you to explore the following resources and tools related to the use of person-centered communication:

   - [A Progressive's Style Guide](#) – Sum of Us
   - [Applying Racial Equity Awareness in Data Visualization](#) - Urban Institute

2. It is widely recommended that we ask individuals and communities about how they would like to be identified and described since preferences will vary. For example, it is encouraged to ask individuals if they identify as Latino, Hispanic, or Latinx or if there is another way they prefer to describe their ethnicity.

3. Have grace for yourself and others on this journey. When we make a mistake and someone corrects us, thank them for doing so and grow from the experience. Likewise, if someone's language or words cause harm, let them know your preferences.

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