

Title Slide (#1)

JAMIA:

Welcome! Today's presentation addresses racial and ethnic categories: impact on medical subject headings.

Introduction Slide(#2):

I am Jamia Williams, a health sciences librarian and member of the Medical Library Association(MLA).

AIDY:

And I am Aidy Weeks, a health sciences librarian and member of MLA.

JAMIA:

Our presentation is on behalf of the Medical Library Association (MLA) comprising more than 400 institutions and 2,500 professional health sciences and medical librarians. We work with these medical subject headings that impact research, education and patient care, ensuring that everyone in need has access to the most relevant, accurate, and timely information.

Outline Slide (#3)

JAMIA:

We will cover the items outlined on this slide

Presentation Focus Slide (#4)

AIDY:

We will address whether the minimum reporting categories should be changed and how to best address detailed race and ethnicity groups in the standards.

As health sciences librarians, we hope to impact how racial and ethnic reporting categories are updated and adopted by the National Library of Medicine's controlled vocabulary known as medical subject headings or MeSH.

To provide context, we will also address how the minimum reporting categories connect to health sciences librarianship and how they impact our work.

How is this all connected slide? (#5)

AIDY:

First and most important is the federal definitions workflow mandated by the OMB that requires adoption by other federal agencies. This workflow of adopting minimum reporting categories at the federal level informs the medical subject headings or MESH that are used to index or tag nearly 34 million citations and abstracts in the National Library of Medicine's PubMed/Medline

database.

MESH headings help to tag relevant research and related patient populations. Limiting the expansion of racial and ethnic categories makes it harder for MESH indexers to assign more granular and also emerging racial/ethnic terminology to publication abstracts which can limit the findability of health equity research that impacts communities of color. This, in turn, limits librarians' abilities to search the literature and provide timely, accurate, and relevant information.

To illustrate this, we highlight two racial/ethnic categories from the minimum reporting standards:

Black or African American and
Hispanic or Latino

Black or AA Populations Slide (#6)

JAMIA:

NLM borrows from OMB's definitions to use in its databases. The part of the definition that is highlighted is part of the MeSH scoping note. A scoping note tells a researcher the definition of the medical subject heading. Due to this outdated and problematic scoping note, 700+ signatories globally wrote a letter to NLM advocating that the MeSH term Blacks, and the scoping note, which borrowed language from OMB's definition of Black/AA, be changed.

Black or AA Populations (#7)

It is important to recognize that selecting terminology to describe a racial group is a very nuanced issue, as there is no one global term for individuals of the African Diaspora. Individuals may identify as Black, African American, or by their country of origin.

Hispanic or Latino Populations (#8)

AIDY:

NLM also borrows from the Hispanic or Latino ethnic term, as seen on the slide. Directive 15 history shows that "Hispanic" first appeared in 1977 and later expanded to "Hispanic or Latino" in 1997. The reason for expanding the term was due to regional differences in how the diaspora identified itself (the term "Hispanic" being more common on the east coast and "Latino" on the west coast).

Here we have an opportunity to once again expand the term and make visible, invisible communities and also recognize that not everyone self-identifies as Hispanic or Latino.

The gender-inclusive term Latinx or Latine would help capture individuals who do not use Hispanic/Latino/Latina as identifiers. The term "Latinx" emerged around 2016 on topics adversely affecting the LGBTQIA+ community including the Pulse Nightclub Shooting & HIV prevention medication, PReP. As racial and ethnic categories continue to evolve, certain

terminologies no longer apply to certain populations. This is especially true for the LGBTQIA+ community. However, there has been debate on whether Latinx or Latine would be the ideal gender-inclusive identifier. MLA's Latinx Caucus underwent scoping assessment and saw a steady increase in the use of Latinx within style guides, social media, and Google searches. However, we recommend that the Interagency review resources that we've provided on this debate and to engage with Latin Diaspora scholars to understand the differences in both terms.

Lastly, the debate on National Origins for this population goes back to articles published in 1987 by public health scholars, Hayes-Bautista & Chapa and also Treviño, who argued for and against using the terms Latino or Hispanic. Hayes-Bautista & Chapa argued that national origin was the most accurate and apt identifier for this group as it more accurately portrayed the US/Latin American socio/political history and moved away from an amalgamation of assigning identifiers based on a combination of language, culture, and birthplace depending on regional differences.

Hispanic or Latino Populations (#9)

AIDY:

So we recommend the revised category and definition be:

Hispanic or Latino or Latinx/Latine: A person of or descendent from Latin American national origin, regardless of race.

This revision includes gender-inclusive terminology and replaces specific countries with a more accurate representation of Latin American national origin. It more accurately connects national origin as the primary identifier for individuals in this diaspora and can encourage reporting within the diaspora's LGBTQIA+ community which in turn helps with locating related health studies impacting this population.

Additional Race/Ethnic Categories:(#10)

JAMIA:

Because of our lived experience and areas of expertise, we are limited in speaking for other minimum reporting categories, such as:

American Indian or Alaska Native
Asian
Native Hawaiian or Other Pacific Islander
and
White

However, we can share what other information professional scholars have written related to these categories, which is available in the handout that we created.

- Alaska Native Subject Headings Project:
<https://www.aklib.net/wp-content/uploads/2022/11/AKNSH-Implementation-Plan.pdf>
- Misrepresentation in the Surrogate: Author Critiques of "Indians of North America"
Subject Headings:

- <https://www.tandfonline.com/doi/full/10.1080/01639374.2022.2090039>
- Improving Library Subject Headings for Iowa Indigenous Peoples:
<https://www.iastatedigitalpress.com/iscor/article/id/14466/>
- Rooted in the Past: Use of “East Indians” in Library of Congress Subject Headings:
https://www.tandfonline.com/doi/full/10.1080/01639374.2017.1386253?casa_token=Dn7ZioUMX2AAAAAA%3AO6irfr7J2uAzmU1Sx9nUo0P0NTI2tmgzoLwEisDGsBE4kD-C3IOgKk76_RDxMrR9PZOMYBA3dec
- Searching for Paumanok: Methodology for a Study of Library of Congress Authorities and Classifications for Indigenous Long Island, New York:
https://www.tandfonline.com/doi/full/10.1080/01639374.2021.1989640?casa_token=zdojb_XkVPEAAAAA%3AzEYPKjta5ZSOoaVIJHqvdswh39StX_aBige2MRyDcFpOOO61OK7hhuethpF69jG_wa9L4IpR_9o

Broad Implications: (#11)

JAMIA:

Before we get to our final recommendations, we also want to point out the broad implications of these changes. As mentioned in the AAMC’s presentation, racial and ethnic categories directly impact the work of biomedical and health sciences researchers and scholars. Whereas our research colleagues are focused on collecting racial/ethnic data to better reflect the granularity of populations and have more precise outcomes, librarians focus on ensuring that granularity makes biomedical information searchable and less problematic.

In addition, researchers and scholars within the biomedical and health sciences must adopt the minimum reporting categories, and include them as author keywords in manuscript submissions so that their research is findable.

Patients participating in studies are required to identify their racial and ethnic identities. What happens when an identifier is not available? Patient self-identification in studies is important. Being limited to certain categories can create hidden patient populations, making it more difficult to accurately study health disparities and making that information readily findable.

And finally, there are also real commercial implications as proprietary databases will more often than not follow the lead of NLM/PubMed and its corresponding MeSH terms. When they get updated at the federal level, it often informs the controlled vocabulary used in other biomedical and health sciences databases outlined on the slide.

Our Recommendations: (Slide #12)

When it comes to the minimum reporting categories, our recommendations are to:

- Continue using the category of “Black or African American,” but more accurately reflect the diaspora’s varied identities while eliminating problematic terms.

- Update the category of “Hispanic or Latino” to include gender-inclusive terms such as “Latinx or Latine” **and** update the definition to focus on Latin American national origin.

Our Recommendations: (Slide #13)

- Health sciences librarians can and should engage with all three stakeholders and take notice when terms become too restrictive, problematic, or miss an opportunity to capture emerging identities.
- Because of the national and global impact on documenting, indexing, and retrieving biomedical and health sciences scholarship, we recommend OMB share changes directly with the NLM.
- We also recommend encouraging federal and non-federal partnerships that can quickly share updates on changing racial and ethnic terminologies, including the MLA and the NLM. We also recommend that non-federal librarians as community stakeholders be considered in this process.

Q & A: (Slide #14)

BOTH:

Thank you for the opportunity to participate in this listening session. We are pleased to answer your questions.