**Equitable Medical Research Guide v1.0**

Congratulations on your pursuit of equitable representation in medical research! This guide is for *all* clinical researchers. It has been adapted in large part from [Urban Institute's Guide for Racial Equity in the Research Process](https://www.urban.org/sites/default/files/publication/103102/urban_institute_guide_for_racial_equity_in_research_process_0.pdf)1 and is a collaborative living document built on input from the community of clinical researchers at large. We share this guide with humility and recognize that there is always room for improvement. Please direct any questions, suggestions or notification of errors to [www.pledgetorise.org/contact-us](http://www.pledgetorise.org/contact-us).

***Change is Hard***

We recognize that medical research is inherently difficult and deeply appreciate your commitment towards equitable health practices for all patients. We ask that you approach this guide with an open mind. If nothing else, **please report the breakdown of underrepresented populations in your research project.** Even if there is ultimately zero participation from underrepresented populations in your research study due to extenuating circumstances, reporting it plays a critical role in illuminating this pervasive barrier to equitable representation in medical research. Please find an example below of population breakdown categories by ethnicity/race. Additional population breakdown examples can be found in Appendix A.

**Table 1.** Example breakdown of underrepresented populations by race/ethnicity (data depicts U.S. population as reported by [census.gov](https://www.census.gov/quickfacts/fact/table/US/PST045221)2\*)

|  |  |
| --- | --- |
| **Race/Ethnicity** | **Percentage** (to be replaced with your data) |
| American Indian or Alaska Native | 1.3% |
| Asian | 5.9% |
| Black or African American | 13.4% |
| Hispanic or Latino | 18.5% |
| Native Hawaiian or Other Pacific Islander | 0.2% |
| Middle Eastern or North African (MENA)\* | 0.4%\* |
| White | 59.9% |
| Other (*e.g.*, two or more races) | 2.8% |

\*Please note that the [projected MENA population](https://www.migrationpolicy.org/article/middle-eastern-and-north-african-immigrants-united-states)3 is not currently recognized by the US government as an [ethnic category](https://www.pnas.org/doi/10.1073/pnas.2117940119),4 but they are instead instructed by the government to identify as White. This projected percentage has been subtracted from the White alone percentage that is listed on [census.gov](https://www.census.gov/quickfacts/fact/table/US/PST045221).2

***Using this Guide***

This guide is divided into four parts. Researchers are recommended to consider all of the following questions prior to starting a new research project and to revisit the appropriate parts when creating the problem statement, developing the study design, collecting data, and communicating their research.

***Pro-tip:*** *Not sure how this guide applies to your project(s)? Try sitting down with (a couple members of) your research team and go through the questions together as a casual discussion. You may be surprised by how the scope of the project expands or changes before and after the discussion! Moreover, an added health-equity lens to your next (or current) research study may make your manuscript more competitive for publication as compared to other studies of a similar topic.*

**Problem Statement/Literature Search/Team-Forming**

* What problem does this research address?
* Is this problem exacerbated in communities of color or in systemically divested populations?
  + *For prospective studies/clinical trials:* Consider engaging community stakeholders to promote effective communication with historically underrepresented populations. Establishing trust with the community helps to ensure that the research will benefit the community.
* Can this project be completed with integrity without including sub-analyses of underrepresented populations?
  + Please see Appendix A for examples of population breakdowns and consider using the [PROGRESS method](https://pubmed.ncbi.nlm.nih.gov/24189091/)5 (see Appendix A) when evaluating social determinants of health.
* Has an equity-focused literature review of the research topic been performed? How have other researchers stratified their sub-analyses?
* Does the research team reflect diverse perspectives, including voices of *all* team members and members of underrepresented populations? If not, is it possible to either include or consult underrepresented perspectives?
* *Going above and beyond:* If regional factors contribute to a known lack of available data from underrepresented populations, can an intentional multi-center team of researchers be formed synergistically to create a research cohort with more equitable representation? We understand that multi-center studies can become complex and bulky to manage, thank you for considering this reach option as appropriate for your next study.

**Study Design/Protocol Development/Proposal Drafting**

* Are the inclusion and exclusion criteria of the study broadly defined with intention to avoid systematic exclusion of underrepresented populations?
* How can representation of underrepresented populations in this research project be improved towards a representative sample?
  + *For prospective studies/clinical trials*: Has the institutional review board been engaged in study design and proposal drafting with an effort to include historically underrepresented populations?
  + Can assistance or resources be provided from a departmental, institutional, national diversity or health equity committee/council/organization in your field?
  + If an equity-focused literature review of the research topic has been performed, how did prior similar equity-focused studies/projects on this research topic recruit and/or represent underrepresented populations?
  + If blinding/randomization/etc provides a potential barrier to sub-analyses, can PROGRESS labels (e.g., race/ethnicity) be re-assigned *after* completed data collection or later in the study design as appropriate to at least report the data?
  + Can a colleague, mentor, friend, local advocacy group, or other community member weigh in with a health equity lens?
    - Think outside the box and don’t be afraid to ask your community for help! If you feel comfortable, asking for help on #MedTwitter can often provide insights and lead to solutions and partnerships you would otherwise not have considered. Remember to stay professional on social media and consider consulting the AMA/AAMC [Advancing Health Equity: Guide to Language, Narrative and Concepts](https://www.ama-assn.org/system/files/ama-aamc-equity-guide.pdf)6 when drafting your post.
* Can subgroup analyses be performed on the basis of racial and social inequities?
  + Take caution when differentiating between social, racial and other inequities to avoid perpetuating stereotypes or [offering genetic interpretations of race](https://static1.squarespace.com/static/5e94e4feaa92821de07e3682/t/5f0b40ab2d6235002617d565/1594572974864/Toward+the+Abolition+of+Biological+Race+in+Medicine+FINAL.pdf).7
* If there are data constraints surrounding inclusion of underrepresented populations (*e.g.,* lack of data, bias in available data, etc.), are these acknowledged in the proposal?
* Has the AMA/AAMC [Advancing Health Equity: Guide to Language, Narrative and Concepts](https://www.ama-assn.org/system/files/ama-aamc-equity-guide.pdf)6 been consulted when drafting the proposal?

**Data Collection & Analyses**

* Have data collection and analyses gone according to plan? If changes have occurred (as they often do), how have these changes impacted previously planned analyses or sub-analyses to evaluate racial and social inequities?
* How can the impact of unexpected changes be alleviated from a health equity standpoint? Consider revisiting questions from bullet point 1 of the *Proposal Drafting* section.
* ***\*\*Has the breakdown of underrepresented populations in the research project been reported?\*\**** *(see Table 1 and Appendix A for examples)*

**Communication/Publication (Discussion Section) Writing**

* Can a racial equity lens distinguish your research from similar competing research projects?
* Were sub-analyses performed? Does the discussion section explore concrete recommendations to address any health disparity findings observed in the study? What role is racism rather than race a contributing factor to racial disparities observed?
  + If subgroup analyses are performed by race/ethnicity, include [an explicit discussion of racial equity](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)30569-X.pdf),8 instead of simply reporting the results
  + If subgroup analyses are performed, include a diversity statement to indicate whether the study cohort reflects the demographic and clinical characteristics of the target population.
* What factors have shaped the health inequities around this problem or research topic? What would need to change in order to reduce these inequities (policies, protocols, stakeholders, etc.)?
* Are there specific policies, protocols or stakeholders that are inadvertently perpetuating racial inequity?
  + ““All policy is health policy,” and all research on racial health inequities has implications for broader public policy and clinical practice.”- [Boyd et al. 2020](https://www.healthaffairs.org/do/10.1377/forefront.20200630.939347/)9
* What populations or groups have been left out? Are they acknowledged? How are these populations affected by this problem compared to the study population? (Are they more or less affected?)
* Are researchers who have considered this research topic from a racial equity perspective cited?
* Has the manuscript, including [figures, schematics, tables,](https://urban-institute.medium.com/applying-racial-equity-awareness-in-data-visualization-bd359bf7a7ff)10 and associated communications been reviewed to be inclusive and not perpetuate stereotypes or [offer genetic interpretations of race](https://static1.squarespace.com/static/5e94e4feaa92821de07e3682/t/5f0b40ab2d6235002617d565/1594572974864/Toward+the+Abolition+of+Biological+Race+in+Medicine+FINAL.pdf)7?
  + Can a colleague, mentor, friend, local advocacy group, or other community member weigh in with a health equity lens?
* Has the AMA/AAMC [Advancing Health Equity: Guide to Language, Narrative and Concepts](https://www.ama-assn.org/system/files/ama-aamc-equity-guide.pdf)6 been consulted when drafting/reviewing the manuscript and labelling figures/tables?
* For published manuscripts with outcomes that can potentially benefit a underrepresented population, has prompt communication of the research findings with the community been initiated? Does the communication include guidance on potential changes that can benefit the community in light of the new findings?

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**Appendix A**

**Examples of underrepresented population breakdowns by PROGRESS categories**

**Table A1.** Example of table format to report the breakdown of underrepresented populations

|  |  |
| --- | --- |
| **Category Type** (e.g., gender/sex) | **Percentage** (your population data) |
| Category A | % |
| Category B | % |
| Category C | % |
| etc. | % |

**Factors to consider when evaluating social determinants of health (PROGRESS)**5

**P**: place of residence

**R**: race/ethnicity/culture/language

**O**: occupation

**G**: gender/sex

**R**: religion - when considering children or others who do not have the opportunity to make choices about their religion

**E**: education/environment

**S**: socioeconomic status

**S**: social capital

**Examples of PROGRESS breakdown categories** (adapted from O’Neill *et al.* 20145 unless otherwise noted)

The following are neither all-inclusive nor prescriptive. There is currently no standard breakdown for any of the PROGRESS factors. Please build your breakdown as appropriate for your research study.

1. **Place of Residence**

Density

Rural, suburban, urban, inner city

Gross domestic product

High-, middle-, low-income countries (alternatively, high- vs. middle/low-income countries)

Zip code/city/county

Labels based on region of study cohort

1. **Race/Ethnicity** (including culture and language)

White

Technically specific to people originating from the Caucasus region in Eurasia,11 this term is defined by the census.gov as “a person having origins in any of the original peoples of Europe, the Middle East, or North Africa. It includes people who indicate their race as "White" or report entries such as Irish, German, Italian, Lebanese, Arab, Moroccan, or Caucasian.”12

Middle Eastern and North African (MENA)

This population is currently not recognized as a separate ethnic category by census.gov despite reported self-identification as MENA, resulting in underreported and hidden disparities in this population.4 Persons who self-identify as MENA may include countries of origin such as Algeria, Bahrain, Egypt, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Qatar, Saudi Arabia, Syria, Tunisia, United Arab Emirates and Yemen.3,13

***The below sections in quotations are reproduced directly from Flanagin et al’s JAMA article, “***[***Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals***](https://jamanetwork.com/journals/jama/fullarticle/2783090)***,”****11* ***please consider reviewing the full article prior to reporting on race/ethnicity.***

African American or Black

“The terms African American or Black may be used to describe participants in studies involving populations in the US, following how such information was recorded or collected for the study. However, the 2 terms should not be used interchangeably in reports of research unless both terms were formally used in the study, and the terms should be used consistently within a specific article. For example, among Black people residing in the US, those from the Caribbean may identify as Black but not as African American, whereas Black people whose families have been in the US for several generations may identify as Black and African American. When a study includes individuals of African ancestry in the diaspora, the term Black may be appropriate because it does not obscure cultural and linguistic nuances and national origins, such as Dominican, Haitian, and those of African sovereign states (eg, Kenyan, Nigerian, Sudanese), provided that the term was used in the study.”

Asian

“The term Asian is a broad category that can include numerous countries of origin (e.g., Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, Vietnam, and others) and regions (e.g., East Asia, South Asia, Southeast Asia). The term may be combined with those from the Pacific Islands as in Asian or Pacific Islander. The term Asian American is acceptable when describing those who identify with Asian descent among the US population. However, reporting of individuals’ self-identified countries of origin is preferred when known. As with other categories, the formal terms used in research collection should be used in reports of studies.”

American Indian or Alaska Native

“In reference to persons indigenous to North America (and their descendants), American Indian or Alaska Native is generally preferred to the broader term Native American. However, the term Indigenous is also acceptable. There are also other specific designations for people from other locations, such as Native Hawaiian and Pacific Islander.29,30 If appropriate, specify the nation or peoples (eg, Inuit, Iroquois, Mayan, Navajo, Nez Perce, Samoan). Many countries have specific categories for Indigenous peoples (eg, First Nations in Canada and Aboriginal in Australia). Capitalize the first word and use lowercase for people when describing persons who are Indigenous or Aboriginal (eg, Indigenous people, Indigenous peoples of Canada, Aboriginal people). Lowercase indigenous when referring to objects, such as indigenous plants.”

Hispanic or Latinx

“Hispanic, Latino or Latina, Latinx, and Latine are terms that have been used for people living in the US of Spanish-speaking or Latin American descent or heritage, but as with other terms, they can include people from other geographic locations.29,30﻿ Hispanic historically has been associated with people from Spain or other Spanish-speaking countries in the Western hemisphere (eg, Cuba, Central and South America, Mexico, Puerto Rico); however, individuals and some government agencies may prefer to specify country of origin.29-31﻿ Latino or Latina are broad terms that have been used for people of origin or descent from Cuba, Mexico, Puerto Rico, and some countries in Central America, South America, and the Caribbean, but again, individuals may prefer to specify their country of origin.29-31 When possible, a more specific term (eg, Cuban, Cuban American, Guatemalan, Latin American, Mexican, Mexican American, Puerto Rican) should be used. However, as with other categories, the formal terms used in research collection should be used for reports of studies. For example, some US agencies also include Spanish origin when listing Hispanic and Latino. The terms Latinx and Latine are acceptable as gender-inclusive or nonbinary terms for people of Latin American cultural or ethnic identity in the US. However, editors should avoid reflexively changing Latino and Latina to Latinx or vice versa and should follow author preference. Authors of research reports, in turn, should use the terms that were prespecified in their study (eg, via participant self-report or selection, investigator observed, database, electronic health record, survey instrument).”

1. **Occupation**

Type of Employment

Unemployed, informal (undocumented worker), underemployed, fully employed

Working Class (adapted from [census.gov](https://www.census.gov/topics/employment/industry-occupation/about/class-of-worker.html))14

Private sector

* For-profit
* Non-profit

Government

* Local (e.g., city or county school district)
* State (includes state colleges/universities)
* Active duty US Armed Forces or Commissioned Corps
* Federal

Self-Employed

* Owner of non-incorporated business, professional practice, or farm
* Owner of incorporated business, professional practice, or farm
* Worked without pay in a for-profit family business or farm for 15 hours or more per week

Employee Benefits

Presence vs. absence of employer-funded health insurance

1. **Gender/Sex** (adapted from [npr.org](https://www.npr.org/2021/06/02/996319297/gender-identity-pronouns-expression-guide-lgbtq)15 unless otherwise noted)

Sex *“assigned at birth”*

Intersex, female, male

Gender *“social construct of norms/behaviors/roles that varies between societies and over time”*

Nonbinary, female, male

Gender Identity *“one’s own internal sense of self and gender […] not outwardly visible to others”*

Woman, man, neither, both

Alignment of Gender Identity

Transgender *“someone whose gender identity differs from the sex assigned at birth”*

Cisgender *“person whose gender identity aligns with the sex they were assigned at birth”*

Sexual Orientation

Lesbian, gay, bisexual, queer, heterosexual

Pronouns (adapted from lgbt.ucsf.edu)16

Ze (*“zee”*)/Hir (*“heer”*), they/them, she/her, he/him

1. **Religion**

Presence vs. absence of religious-affiliation influencing health treatment

1. **Education** (adapted from census.gov)17

Less than high school graduate, high school graduate (includes equivalency), some college or associate’s degree, bachelor’s degree or higher

1. **Socioeconomic Status & Social Capital (Other)**

Income

* above/below poverty line (dependent on city/state)
* by tax bracket (adjusted annually by the internal revenue service)

Marital Status

Single, married, dependent

Other

Citizenship status

Disability status

Mental Illness

Adverse Childhood Events (ACEs)

Community support (involvement in community organizations)

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