

Best Practices¹⁻³ for Equitable Research at Each Step of the Research Process

The best practices below are strategies for integrating the value of equity into the research process. Equity refers to fair and just access to opportunities, power, and resources. The questions included in this document are intended to help generate ideas on how to engage underrepresented research populations in each step of the research process. These practices can serve as a starting point for building long-term partnerships with communities underrepresented in research. We recognize that many researchers, whether through lived experience and/or current efforts to make research more equitable, already employ many of the methods presented here. Indeed, there are whole disciplines dedicated to this, including community-based participatory research. We offer these approaches for the consideration of researchers who have yet to begin or have not fully engaged methods to make their research more equitable. We also acknowledge that there are additional and emerging ways to make research more equitable that may not be included here. We consider this a 'living document' and will provide updates as necessary.

Equitable Research Best Practices: **General**

1. Approach research using an equity- and anti-racism-focused lens

- Use an equity- and anti-racism-focused framework to inform research⁴⁻⁶
- Become familiar with issues related to the colonization of research^{7,8}
- Consider how research questions/health care problems can be answered from a strengths-based approach rather than a deficits-based approach⁷

2. As a result of our natural cognitive processes, experiences, and social environments that are influenced by structural racism and other forms of oppression, all individuals have implicit biases (unintentional unconscious associations we make about groups or individuals). Researchers and teams should engage in ongoing efforts to 1) actively promote antiracist policies, practices, and norms, 2) acknowledge the impact of implicit bias when conducting research, 3) identify areas of personal implicit biases, and 4) engage in constant self-reflection, training/education, and strategies to mitigate the impact of implicit biases.

- Understand the current and historical context of racism in health care, medicine, and research and learn to talk about racism in the context of health care and research^{9,10}
- Attend trainings, read articles (research and popular), listen to podcasts, etc. on topics related to implicit bias and anti-racism
- Utilize strategies shown to reduce the impact of implicit biases^{11,12}
 - Become aware of what your own personal biases are and constantly reflect on how you can minimize their impact (take multiple Implicit Association Tests at

<https://implicit.harvard.edu/implicit/takeatest.html> and/or go to www.lookdifferent.org)

- Understand and respect the magnitude of implicit bias on health care quality and outcomes (read the research)
- Practice emotional regulation (enter all encounters feeling positive)
- Practice individuation (treat all patients/participants/families as individuals w/unique needs and desires rather than lumping into groups)
- Practice perspective-taking (consider alternative experiences/realities)
- Partnership-building (create bi-directional collaborations with participants/families to accomplish goals)
- Persist in finding possible alternative reasons for decisions made by self, others
- Question stereotypes in self, others
- Identify when implicit bias impacts the statements/actions of self/others; address bias if able based on context
- Perform teach-back in every situation to ensure potential or actual research participants understand the information presented

3. Develop authentic relationships with and meaningfully involve communities impacted by the research¹³⁻¹⁵

- Building relationships and establishing trust takes time, ensure sufficient time and transparency to develop relationships with and within communities before or at the start of and throughout the research process, including dissemination
- Ensure intent is true collaboration with community and participation is meaningful (community involvement and voice is represented in all steps in the research process including interpretation and dissemination)
- Compensate community members commensurate with other academic consultants
- Partner with community members to present the work and/or acknowledge community contributions to the work through authorship, etc.
- Ensure the research provides opportunities for BIPOC and early career investigators

4. Contextualize the use of race as a variable in all research¹⁶⁻²⁰

- Race is a socially-constructed categorization that has no biological basis

- Genomic research has consistently established that all humans are 99.5-99.9% genetically identical; the 0.1% - 0.5% genetic variation is greater *within* the same racial groups than *between* different racial groups¹⁷
- Social & environmental factors associated with the social identity of race (e.g. chronic stress related to frequent experiences of racial discrimination, relatively lower socio-economic status [SES] resulting from the impact of systemic racism) can result in differing biological outcomes
 - E.g. 'weathering' describes the process of premature cellular aging as a result of chronic fight-or-flight responses to external stressors (like racism) that has been linked to diabetes and cardiovascular disease^{21,22}
- Race as a variable in research may be useful to identify community-/population-level disparities; however, race must always be contextualized to identify the social determinants of differences based on race rather than innate biological differences; avoid conflating 'race' with 'racism'²⁰
 - SES data should always be collected with data on race and if not available, should be imputed using rigorous approaches (see the [Harvard Public Health Disparities Geocoding Project](#))
 - Clearly state and/or explore social determinants that may explain differences based on race (e.g. SES)
 - Include measures of structural²³ and interpersonal discrimination such as the widely-used [Everyday Discrimination Scale](#) and/or measures of chronic stress such as cortisol levels whenever feasible
 - Identify/explore confounding factors that are structural or systemic, such as uneven geographical distribution of preventative care/specialty care services, localized environmental hazards, and/or differences in state-sponsored health insurance availability
- Review the latest guidance on the reporting of race and ethnicity in publications²⁴

Equitable Research Best Practices: **Study Development**

1. Conduct a 'Landscape Assessment':

- Who is affected—positively or negatively—by the issue you plan to study? Why? How?
- What are the historical and cultural experiences and contexts of the community regarding research in general and/or the issue you plan to study?

2. Avoid biases & clarify topic of study as appropriate:

- Collect background data from the neighborhood or community
- Review publicly available datasets, reports, or media accounts

- Conduct interviews, focus groups, and community dialogues to gather key stakeholders' perspectives in a way that is consistent with community preferences/norms; provide opportunities for community members to share feedback on the issue and whom it affects and compensate stakeholders for their time

3. Consult community partnership guides, other resources for engaging in community-academic partnerships^{1, 25-27}

Equitable Research Best Practices: **Study Design**

1. Researchers should consider the following questions:

- Is the community involved in the research design process?
- How will answers to the research questions benefit the community?
- Do the research questions account for the cultural and historical context of the community?
- How do community members desire to be approached and through what processes?
- Does the community respect & trust the research design and types of data collected?

Equitable Research Best Practices: **Study Recruitment and Participation**

1. Research teams should be diverse & ideally include members of the community (-ies) being recruited

- Goes beyond research participant recruitment within diverse communities; research shows diverse teams are more productive, innovative²⁸

2. Ensure all team members are well-versed on purpose of research in general, all specifics of the study they are recruiting for, basics of the related diseases/conditions, and the benefit or relevance to affected communities

3. Ensure accountability to approach all potential participants/families regardless of language, race/ethnicity, other identities

- Don't assume patients/families will not be interested based on identities—race/ethnicity, language preference, disability, etc.

4. During the consent process, have team members:

- Emphasize participant rights, that individual consent should be respected and consent should be an ongoing conversation with participants and communities as appropriate
- Acknowledge current and past abuses/exploitations (e.g. Tuskegee, Henrietta Lacks) in the name of 'research'
- Promote transparency by introducing the study PI/team

5. Reduce language, cultural barriers

- Partner with community organizations/leaders to understand language, cultural, and other community-level factors that could impact research engagement. Compensate community partners at rates similar to other academic partners (e.g. consultants, co-investigators); for federal grants and others with available indirect or F&A costs, creating subcontracts would allow community-based organizations to recover these costs
- Ensure adequate time to educate patient/family and discuss questions/concerns
- Confirm an interpreter is always present when applicable & have team employ teach-back every time; prioritize hiring bilingual study staff
- Have (ideally local) native, bi-, or multi-lingual speakers review translations (native-speakers often report that while words are technically translated correctly, the grammar does not make sense)
- Ensure consent form language regarding the 'government', 'federal agencies', or related terms are clear and concise (e.g. would wording raise concerns related to immigration status?)
- Consult with IRB to consider the use of alternative consent processes such as verbal/video/visual-based options to consent

6. Reduce logistical barriers

- Minimize time requirements (preferably conduct study activities in the community or offer to complete study activities before/after clinic visits; consider remote or virtual visits if feasible)
- Provide adequate compensate for time/travel
- Ensure the type of participation incentives and process to obtain and use incentives does not cause concern for some groups (e.g. social security numbers requirement, usability of store-specific gift cards)
- Provide childcare/activities, food when needed
- Provide transportation alternatives when needed (e.g., use of Uber/Lyft rather than asking participants to take multiple buses)

Equitable Research Best Practices: **Data Analysis**

1. During all steps of data analysis, researchers should:

- Disaggregate data in quantitative analyses
 - Examine data stratified by at minimum race, ethnicity, language; consider others as applicable (e.g. age, gender identity, insurance type, sexual orientation, zip code); consider potential privacy concerns if individuals may be identified when stratifying small samples

- Explore the intersectionality of race, age, other commonly collected variables with other dimensions of identity
 - Seek out opportunities to learn new & emerging approaches for analysis of intersectionality as applicable
 - [The Intersectionality Training Institute](#)²⁹
 - Ask why the trends revealed in this intersectional analysis may occur
- Involve community members in analyses and/or interpretation of findings (e.g. have a community member code themes from qualitative data and compensate at rates similar to other academic partners)

Equitable Research Best Practices: **Dissemination**

1. Researchers should consider the community as a primary audience

- Solicit feedback on meaning of study results from key community members
- Present and discuss implications/next steps of findings to community in formats that are accessible and address community needs
- Incorporate community feedback in interpretation of findings

2. If a profit may be made from study findings, ensure that participants are aware of this potentiality and, if profitable, share profits with the community from which the findings were derived

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