

Best Practices^{1,2,3} 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.

Equitable Research Best Practices: **General**

1. As a result of our natural cognitive processes, experiences, and social environments, all individuals have implicit biases (unintentional unconscious associations we make about groups or individuals). Researchers and teams should engage in ongoing efforts to acknowledge the impact of implicit bias when conducting research, identify areas of personal implicit biases, and engage in constant self-reflection and strategies to mitigate the impact of implicit biases.

- Attend trainings, read articles (research and popular), listen to podcasts, etc. on topics related to implicit bias
- Utilize strategies shown to reduce the impact of implicit biases^{4,5}
 - 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 (collaborate with participants/families to accomplish goals)
 - Persist in finding possible alternative reasons for decisions
 - Question stereotypes
 - Monitor others for implicit bias
 - When EBP/clinical and/or research guidelines are available, use consistently in every situation

- Perform teach-back in every situation to ensure potential or actual research participants understand the information presented

2. Contextualize the use of race as a variable in all research⁶⁻¹⁰

- 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 groups
- 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
- 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
 - 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 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 such as uneven geographical distribution of preventative care/specialty care services, localized environmental hazards, and/or differences in state-sponsored health insurance availability

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?

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 the Community Partnership Guide for Engaging With Academic Researchers:
<https://www.iths.org/community/partners/isp/>

Equitable Research Best Practices: **Study Design**

1. Researchers should consider the following questions:

- Are the community's values represented in the research questions?
- Have the researchers identified how the answers to the research questions will benefit the community?
- Do the research questions account for the cultural and historical context of the community?
- How does the community like to be approached and through what gateway?
- Does the community respect & trust the research design & 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 recruitment; research shows diverse teams more productive, innovative¹¹

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 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
- Ensure adequate time to educate patient/family and discuss questions/concerns
- Interpreter must always be present when applicable & have team employ teach-back every time; consider hiring bilingual study staff so interpretation is not required
- Have lay community members 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 or short-form consent processes

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 stipends to compensate for time/travel
- Ensure the type of stipend does not cause concern for some groups (e.g. social security numbers requirement, usability of store-specific gift cards)
- Provide child care/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
 - Exploring the intersectionality of race with other dimensions of identity
 - Asking why the trends revealed in this intersectional analysis may occur

- Involve community members in qualitative analyses (e.g. have a community member code themes and compensate them for this work)

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 findings to community in formats that are accessible and address community needs

2. If a profit may be made from study findings, share profits with the community

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