

Addressing Diversity in Study Populations: African Americans

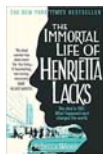
Why?

- Mandates from funding agencies requiring and emphasizing the need to include racially diverse populations in clinical research
- Growing and/or continuing health disparities gap

The Issues and Challenges

Historical issues and abuses

- Tuskegee Study, forced sterilizations, Henrietta Lacks (HeLa cells)



Study Participant Issues

- Participant literacy and lack of knowledge about the proposed research
- Fear and mistrust
- Urban legends

Researcher Issues

- Lack of understanding and respect of cultural norms of the target group
- Cultural competency
- Lack of openness and collaboration with the target group
- Proposals written and submitted without input from the target group
- Lack of training and skill sets to engage minorities

Recruitment Barriers and Retention

Recruitment concerns

- Fear, distrust, confidentiality, sharing data
- Stigma associated with participating
- Family/peer concerns
- Socioeconomic stressors



Recruitment concerns

- Low compensation
- Rigid and demanding research protocols
- Other priorities/needs (work, illness, family responsibilities)
- Lack of knowledge/misinformed about the proposed research

Strategies to Effect Change

- Convey participant benefits of research (e.g., diabetic gaining understanding)
- Giving back/helping others (e.g., Alzheimer’s disease)
- Establish relationships to build trust and promote researcher and community partnership investment within the community

Strategies to Effect Change

- Hold listening sessions to educate community about various aspects of research
- Convey how research has benefitted individuals, groups and communities
- Engage African American non-profits, 100 Black Men, African American Health Network, Foundation for Black Women’s Wellness, sororities, fraternities (they all have health components)

Strategies to Effect Change

- Encourage participant storytelling about experiences
- Engage clergy, church leaders, community and community leaders (beauty salons, community centers, barbershops)
- Promote co-learning and capacity building among all partners

Strategies to Effect Change

- Generate and disseminate findings in newsletters, radio (e.g., WORT), Umoja, flyers, listening sessions
- Develop community resource guides related to health, social services, etc.
- Engage community stakeholders BEFORE beginning the initial phase of research and establish a Community Advisory Board (CAB)

Strategies to Effect Change

- Elicit suggestions and assessments from community stakeholders about concerns, problem identification, etc.
- Utilization of community health workers
