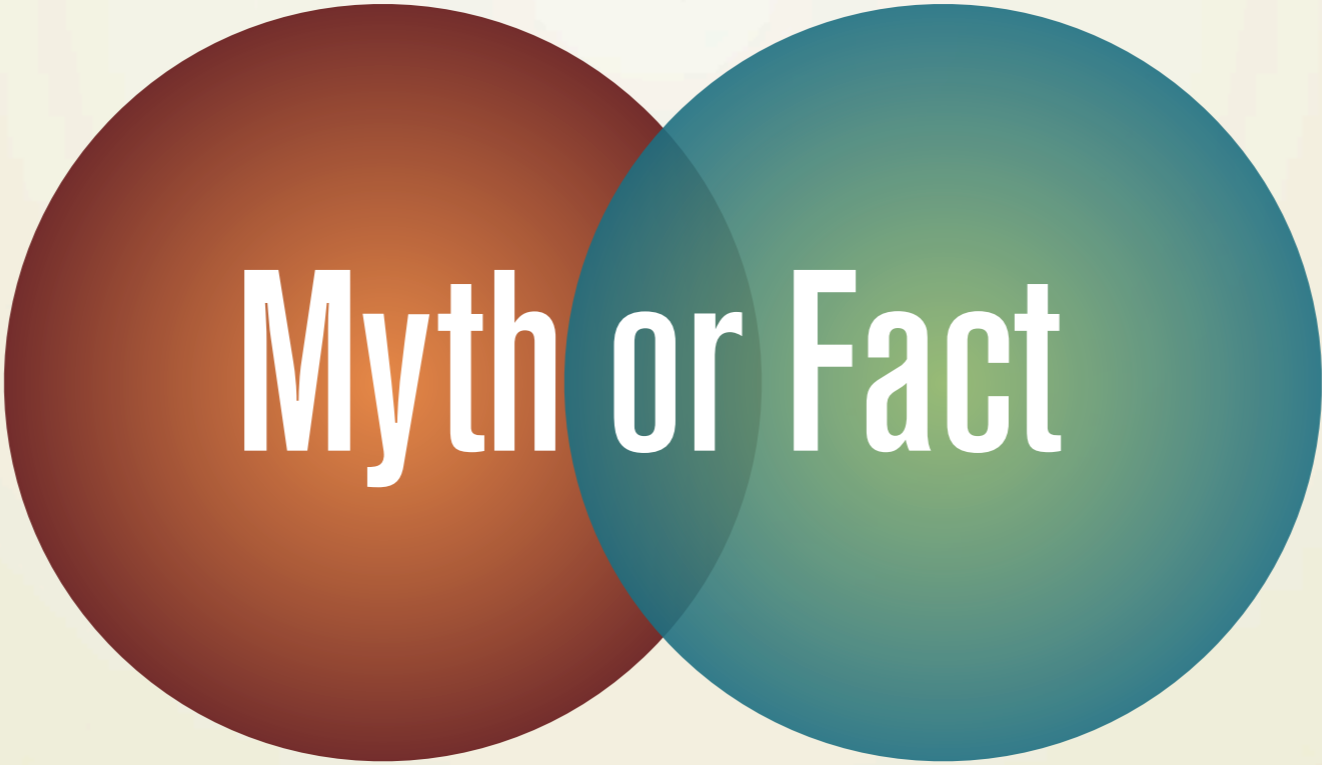




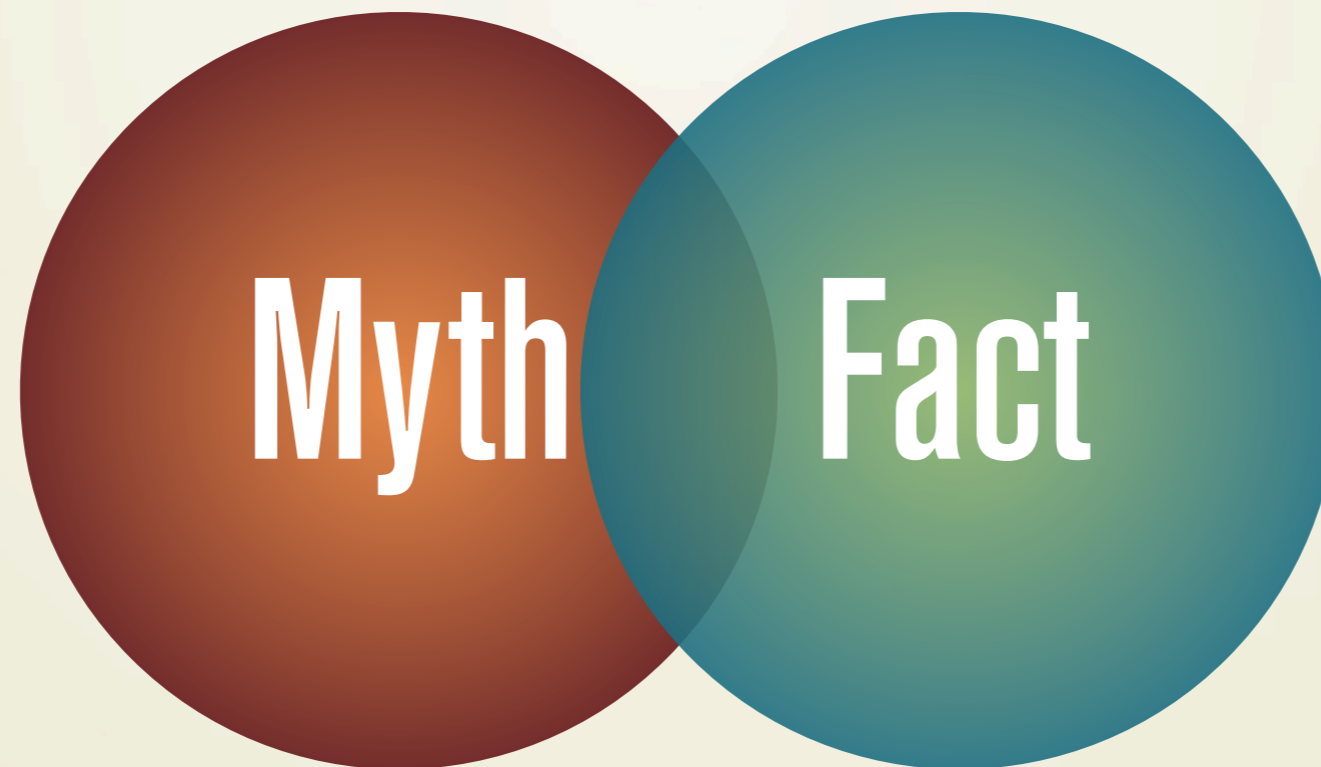
Identify and Address the Cultural Barriers to Minority Recruitment to Clinical Trials

Myth or Fact



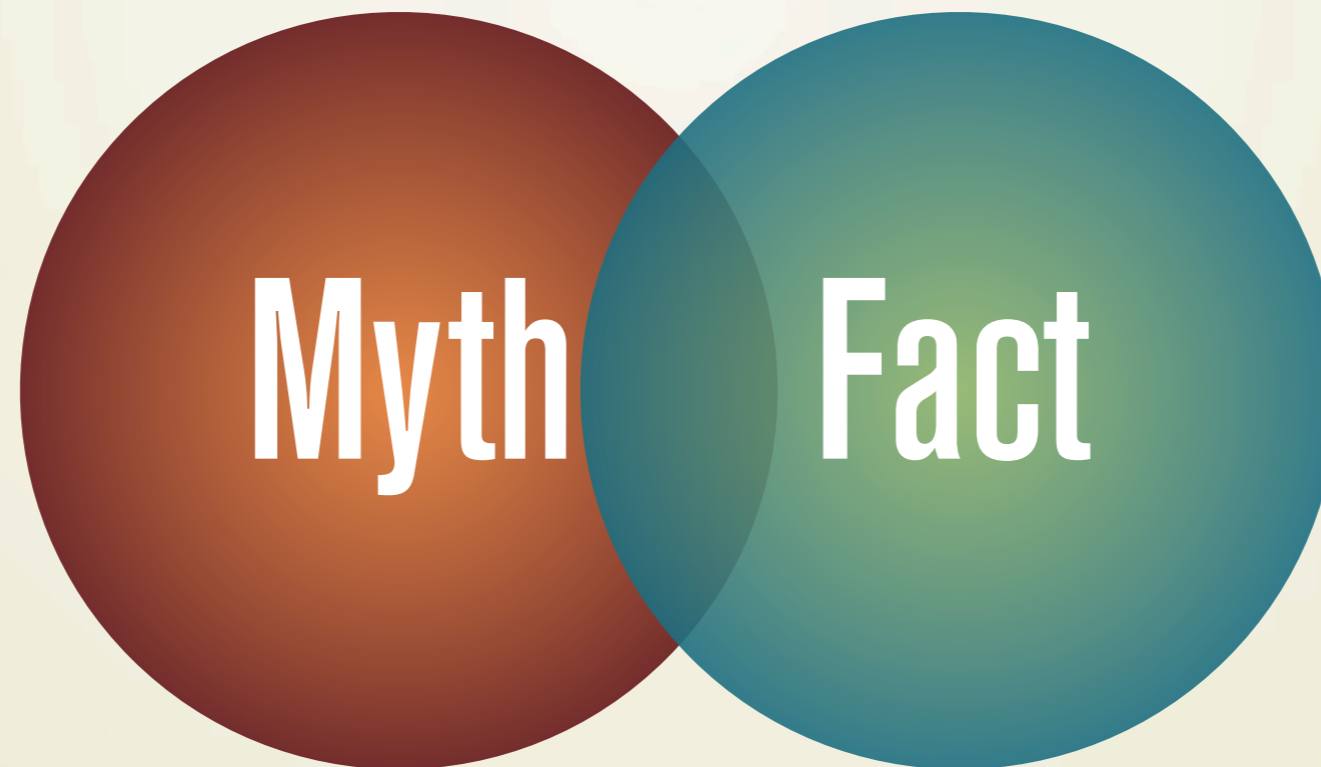
Myth or Fact

Race means the same thing to everyone.



People define race in many different ways. Some people, for example, define race based on skin color, while others define it based on cultural practice.

People categorized under the same racial group share many if not all cultural similarities and this is true across all races.



Describing an entire cultural group implies that all members within that group is exactly the same. This is stereotyping and can be dangerous when applied to clinical trials recruitment. It is important to remember that diversity exists within groups and every situation should be treated as a case-by-case scenario.

Complexities of Culture

Even within cultures, subcultures exist and researchers must be mindful of generalizing versus stereotyping.



Cultural Barriers to Minority Recruitment to Clinical Trials



Source: Ford et al. Cancer 2008; 112:228-42

Awareness

- Lack of culturally appropriate, cognitively empowering and linguistically diverse patient education materials to inform participants on clinical trials.
- Primary care physician's lack of knowledge on existing and available clinical trials to recommend to his or her patients.
- Community or family's lack of education on clinical trials negative affect on the enrollment rates of participants.

Cultural Barriers to Minority Recruitment to Clinical Trials



Source: Ford et al. Cancer 2008; 112:228-42

Opportunity

- Researchers may feel that ethnically diverse populations are harder to reach (due to cultural and language barriers), therefore do not present clinical trials opportunities to these populations.
- Lack of interpreters at research sites.
- Researchers may not adequately address the cultural barriers participants feel are important to them.

Cultural Barriers to Minority Recruitment to Clinical Trials



Source: Ford et al. Cancer 2008; 112:228-42

Acceptance

- Participants may refuse to enroll because of their past or communal experiences with health care institutions.
- Participants may refuse to enroll due to staff's lack of cultural compromise.
- Studies that interfere with a participant's cultural beliefs and attitudes may affect their decision to enroll.

Case Study: Robert Philips' Story

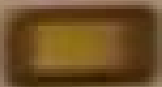
Robert Philips is an African American who has end-stage renal disease (ESRD), severe and permanent kidney failure. He is on hemodialysis and is on the waiting list for renal transplantation. Robert voices clearly how he feels the treatment of African Americans who need renal transplants differs from that of others.

Source: Worlds Apart by Grainger-Monsen, Maren, MD and Haslett, Julia.

A Four-Part Series on Cross-Cultural Healthcare by the Stanford University Center for Biomedical Ethics

ICARUS Films, 32 Court Street, 21st Floor, Brooklyn, NY 11201

TEST



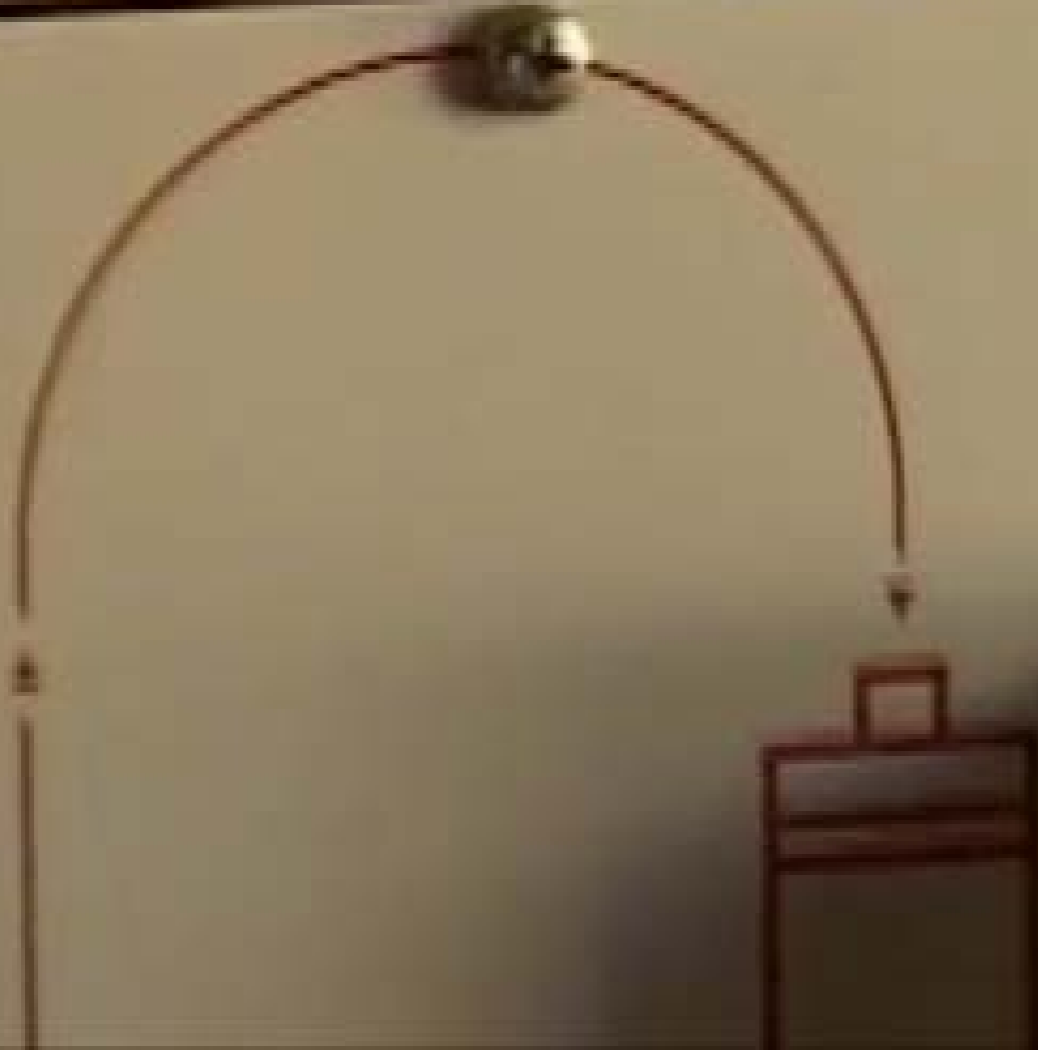
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Things to Consider: Robert Philips' Story

How might mistrust affect a participant's attitude towards clinical trials ?

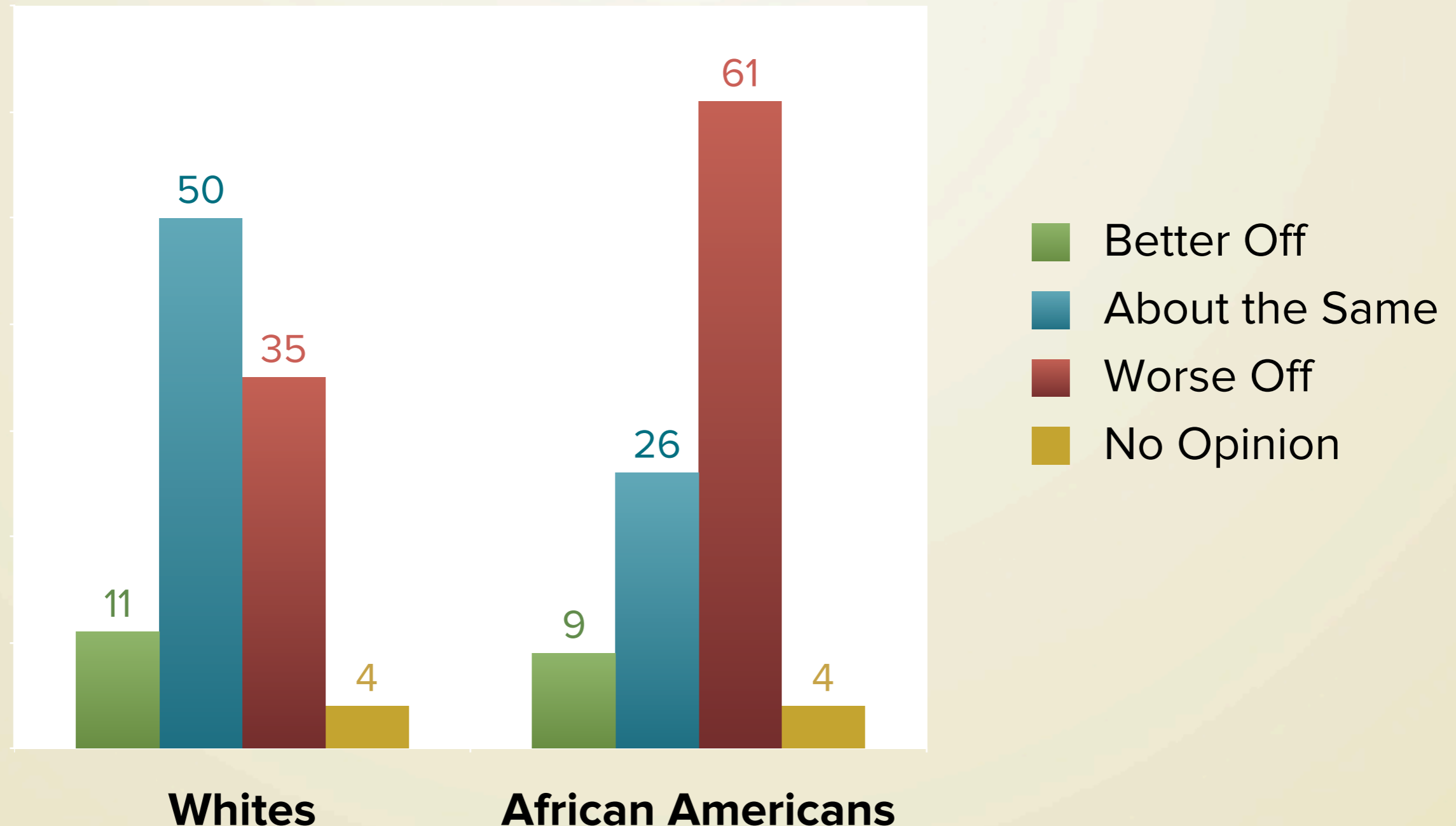
How would you approach a participant who doesn't trust the designs of your study?

Mistrust is Deeply Rooted



Tuskegee Syphilis Experiment (1932-1972) was a clinical study conducted in Tuskegee, Alabama where information and medicine to treat those infected with syphilis were withheld from the African American community. Numerous people died and/or contracted the disease.

Do you think the average African American is better off, worse off, or just about as well off as the average white person in terms of access to health care?



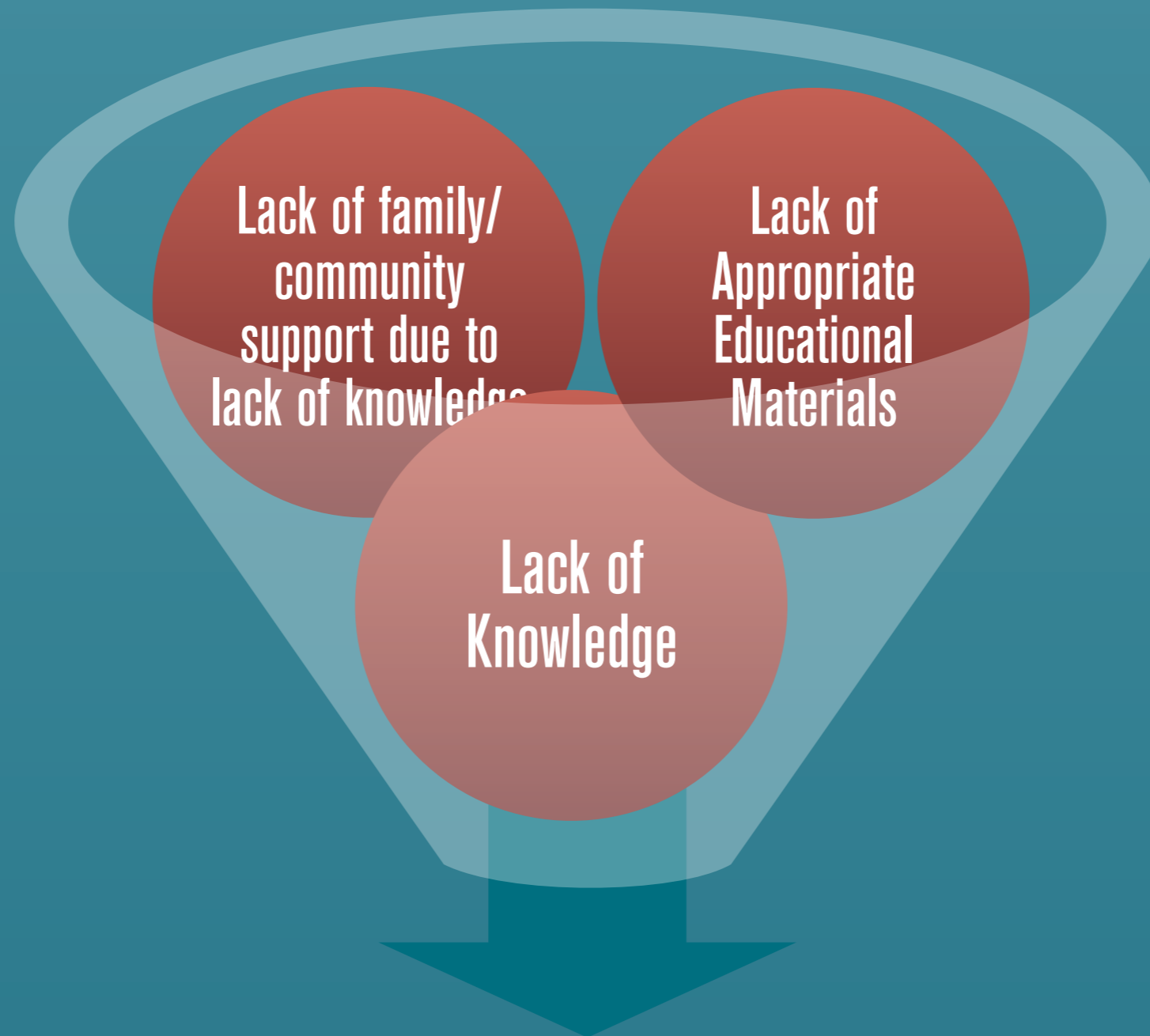
Source: Morin, 2001

Cultural Barriers to Minority Recruitment to Clinical Trials



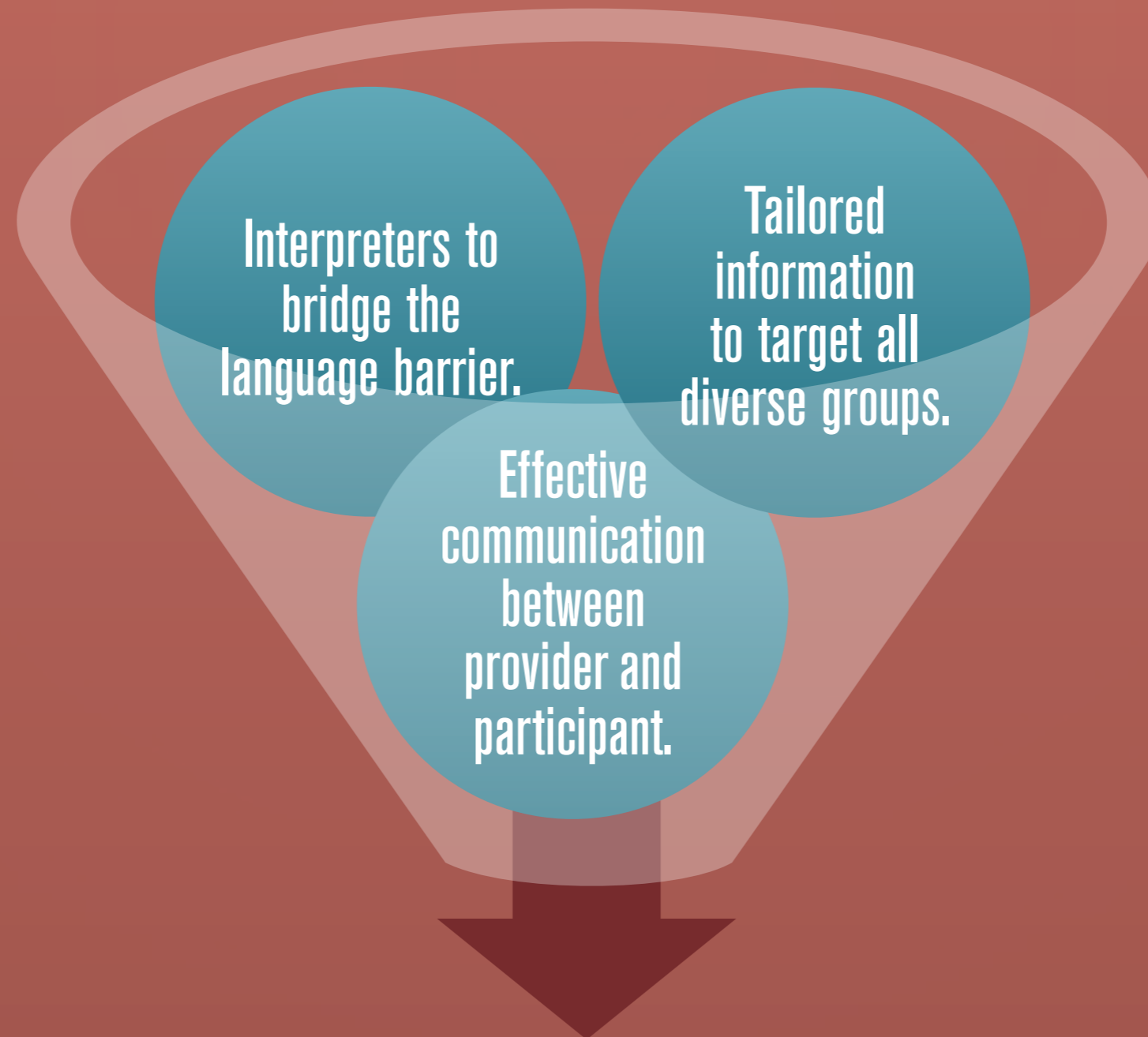
Source: Ford et al. Cancer 2008; 112:228-42

Addressing Awareness Barriers



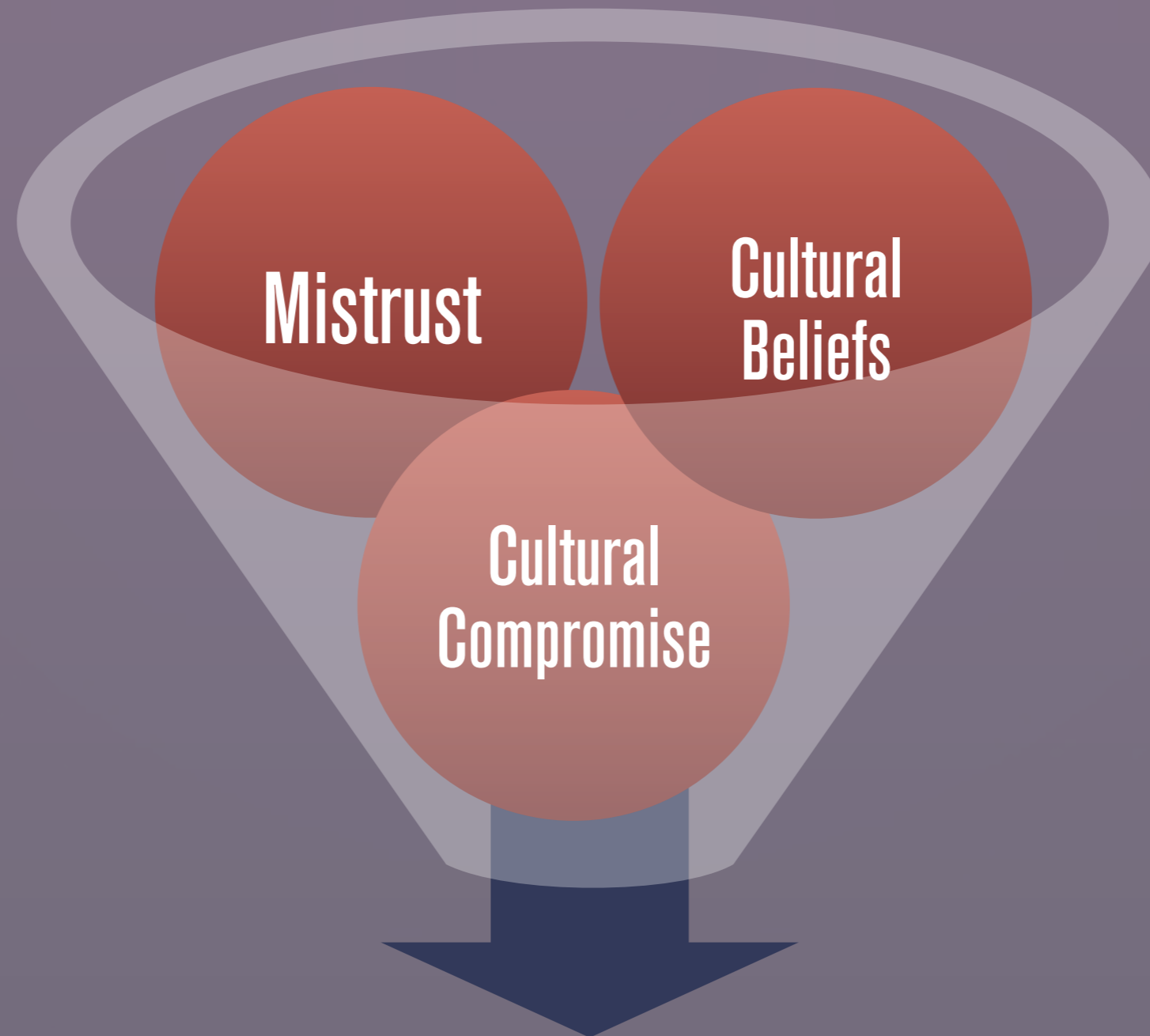
Develop outreach programs and materials with culturally appropriate messages that are relevant to all economic and age ranges. Community involvement will lay the foundation of built trust for participants to be more open to new information. These materials must also answer all concerns and correct all misconceptions about clinical trials. Pilot testing will also prove beneficial and allow for design improvements.

Addressing Opportunity Barriers



Eliminating all forms of miscommunication and allowing for information to cross all cultures will pave the way for increased clinical trials knowledge and enrollment.

Addressing Acceptance Barriers



Culturally competent communication is key: when researchers are respectful, open, honest, and sensitive to a participant's culture; trust can be built and participants are more willing to enroll into clinical trials.

Where Can I Learn More?

- National Cancer Institute
<http://www.cancer.gov/clinicaltrials>
- Foundation for National Institutes of Health
<http://www.fnih.org/work/areas/clinical-patient-support/overcoming-barriers>