

EMPACT

Identify and Address the Cultural Barriers to Minority Recruit- ment to Clinical Tri- als

A presentation by the EMPACT consortium

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Myth or Fact?

Race means the same thing to everyone.

Myth.

The fact is 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.

Myth or Fact?

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

Myth.

The fact is that people of the same race have unique cultural practices and beliefs. 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.

There are 3 types of cultural barriers to minority recruitment to clinical trials:

Awareness... Acceptance... and Opportunity

Cultural barrier: *Awareness*

The lack of culturally appropriate, cognitively empowering and linguistically diverse patient education materials to inform participants on clinical trials will prevent minorities from knowing about the clinical trials available to them.

Primary care physicians may not know of existing and available clinical trials to recommend to their patients.

Or perhaps a community or family's lack of education on clinical trials may have a negative effect on the enrollment rates of participants.

Cultural barrier: *Opportunity*.

Researchers may feel that ethnically diverse populations are harder to reach (due to cultural and language barriers), therefore they do not present clinical trials opportunities to these populations.

Opportunities may also be missed when there is a lack of interpreters at research sites.

Researchers may not adequately address the cultural barriers participants feel are important to them. As a result, participants may not be willing to continue with the study activities.

Cultural barrier: *Acceptance*.

Participants may refuse to enroll because of their past or communal experiences with health care institutions.

Participants may refuse to enroll due to the staff's lack of cultural compromise. Or studies that interfere with a participant's cultural beliefs and attitudes may affect their decision to enroll.

Let's view a 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.

Things to consider:

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?

Past occurrences explain why there is patient mistrust in clinical trials. For example:

The Tuskegee Syphilis Experiment, was a clinical study conducted by the [U.S. Public Health Service](#) in Tuskegee, Alabama between 1932 and 1972. The purpose of the experiment was to study the natural progression of untreated [syphilis](#) in poor, rural African American men. Information and medicine to treat those infected with syphilis were withheld from the African American community. Numerous people died and/or contracted the disease.

As a result, Whites and African Americans have contrasting views on access to health care in the U.S.

When asked in a survey "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?"

11% of whites responded with "better off" while 9% of African Americans responded with "better off".

50% of Whites responded with "about the same", but only 26% of African Americans responded with "about the same".

35% of Whites and 61% of African Americans said "worse off".

4% of whites had "no opinion", while the same percentage of African Americans had "no opinion".

With all the barriers encountered in trying to reach out to minorities for clinical trials recruitment, there are methods to overcome them.

To address the *Awareness* barriers:

...lack of family and or community support due to lack of knowledge, lack of appropriate educational material, and lack of knowledge.

Outreach programs and materials must be developed 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.

To address the *Opportunity* barriers:

...lack of interpreters to bridge the language barrier, lack of tailored information to target all diverse groups, and lack of effective communication between provider and participant.

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

To address the *Acceptance* barriers

...such as mistrust, differences in cultural beliefs, and cultural compromise.

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?

You can learn more from the [National Cancer Institute](#) and [foundation for National Institutes of Health](#).

This presentation has been brought to you by EMPACT, enhancing minority participation in clinical trials.