How Cultural Factors Affect Minority Recruitment to Clinical Trials
What is Culture?

Culture refers to the integrated patterns of human behavior that include language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups.

Office of Minority Health 2000
Culture Affects

Language
Social and Health Behaviors
Self-care
Celebrations
Lifestyle Attitudes
Communication Styles
Death
Art and Music
Social Expectations
Clothing
When we see an iceberg the only portion that is visible is what is above water. Similarly when individuals think of culture they only think about what they can “see” (i.e, clothing, music, food, behaviors etc). Below the surface, culture is ingrained in the beliefs, attitudes and values individuals bring with them everywhere they go.
The Culture Iceberg

**Institutions of Influence**
The forces which create, define, and mold a culture’s core values

- Religion
- History
- The Media
- Economics
- Family
- Educational System

**Core Values**
Learned ideas of what is considered GOOD or BAD DESIRABLE or UNDESIRABLE ACCEPTABLE or UNACCEPTABLE

**Attitudes**
How the core values are reflected in specific situations in daily life such as working and socializing

**Behaviors and Practices**
Characteristics which are apparent to the casual observer

Source: http://thecrossculturalconnector.com/?tag=the-cultural-iceberg
“Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. 'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups....
What is Cultural Competency: A Moving Target

'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities. (Adapted from Cross, 1989).

–Office of Minority Health
What is Cultural Competency: A Moving Target

Elements of culture influence beliefs and belief systems surrounding...

Health
Healing
Wellness
Illness
Disease
Delivery of health services
Why is Cultural Competency Important to Clinical Trials Recruitment?

**Recruitment for Clinical Trials**

Cultural competency provides researchers with the tools necessary to communicate and deliver services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients, bridging the gap between participant concerns and that of the researcher.

**Retention of Clinical Trials Participants**

It is crucial for the researcher to maintain trust and respect by continually providing culturally competent care.
Enrollment by Race and Ethnicity

National Cancer Institute, Publicly Funded Cancer Clinic (Phase I-III Treatment Studies)  
January 1, 2003 - June 30, 2005

Race
- White - 88.6%
- Black/African American - 8%
- Asian/Pacific Islander - 2.8%
- Native American/Alaskan Native - 0.5%
- Multiple - 0.1%

Ethnicity
- Non-Hispanic/Latino - 94.4%
- Hispanic/Latino - 5.6%

# Perceptions of Disparities in Health Care

Generally speaking, how often do you think our health care system treats people unfairly based on...

## Percent Saying “Very/Somewhat Often”

<table>
<thead>
<tr>
<th>Perception</th>
<th>Doctors</th>
<th>The Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whether or not they have insurance</td>
<td>72%</td>
<td>70%</td>
</tr>
<tr>
<td>How well they speak English</td>
<td>43%</td>
<td>58%</td>
</tr>
<tr>
<td>What their race or ethnic background is</td>
<td>29%</td>
<td>47%</td>
</tr>
<tr>
<td>Whether they are male or female</td>
<td>15%</td>
<td>27%</td>
</tr>
</tbody>
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Case Study: Justine’s Story

Justine Chitsena is a young Khmu-American girl who has an atrial septic defect, a hole in the wall of her heart. Her cardiologist recommends open chest surgery to seal up the hole but her grandmother is very opposed to the idea.

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
Different Views on Health

Chitsena Family

Justine appears healthy, not sick.

A surgical scar, or any scar inflicted on a body stays with you even into your next lives.

It is better to have a shorter life than to be scarred forever.

U.S. Medical Professionals

Justine has a hole in the muscle wall of her heart.

Justine needs open chest surgery in order to seal the hole in her heart.

The surgery can extend Justine’s life and prevent her from having heart complications later on.
Things to Consider

**Reflection**

- How would you approach a participant whose cultural background and family dynamics is different from yours?
- How will you ensure that you are being respectful of their cultural beliefs?
- How can you ensure your own cultural biases will not affect your interactions with study participants?
The Five Elements of the Culturally Competent Care System

- **Valuing Diversity**: Recognize and respect that diversity is important. Accept differences in communication, one’s view on life, health, and family.

- **Cultural Self-Assessment**: Realize that aside from being a trained researcher who does interact with diverse groups of people, you are also someone who comes from a unique cultural background.

- **Dynamics of Difference**: Two or more cultures may clash with each other. Be aware and pay attention to the dynamics that surround cultural interactions.

- **Institutionalize Cultural Knowledge**: Incorporate newly attained knowledge into ongoing development of practice skills.

- **Adaptation to Diversity**: This demonstrates the approaches and actions necessary to incorporate cultural competency into the health system.

Source:

Cultural Competency Spectrum

**Cultural Destructiveness**
- Differences seen as a problem; identifies one superior culture
- Lacks awareness & skill; perpetuates stereotypes; paternalistic toward non-dominant groups

**Cultural Incapacity**
- All cultures are alike; culture does not account for differences

**Cultural Blindness**
- Recognizes differences; complacent in making change

**Cultural Pre-Competence**
- Accepts, appreciates & values differences; seeks opinions of diverse groups

**Basic Competency**
- Actively educates less informed; seeks to interact with diverse groups

Source: Obtained from Mutha et al, 2002, and adapted from Cross et al, 1989
Case Study: Justine’s Story Continued

During one of Justine’s visits to the cardiologist, the cardiologist explained to Justine’s mother why she believes it is important for Justine to get the surgery.

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 Ethnics ICARUS Films, 32 Court Street, 21st Floor, Brooklyn, NY 11201
My mom wants me to wait until I go to the Lao temple.
Things to Consider

How did the cardiologist respond to the family’s cultural beliefs?

How did Justine’s mother respond to the cardiologist?

Is this a good example of cultural competency? Why or why not?
Recognize, respect, and accept that the participant’s family dynamics and cultural beliefs can be very different from your own. Apply this to future clinical trials recruitment efforts.

Pay attention to non-verbal cues such as participant mannerisms. It is important to not only listen to what is being said, but also to hear what isn’t being said. Pay attention to how a participant behaves.

If put into a similar situation, how would you approach, react, and communicate with the study participants?
To Learn More About Each Ethnicity

African American

American Indian/Alaskan Natives
http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf

Asian American

Hispanic/Latino Americans
Where Can I Learn More?


2. The NIH Office of Minority Health pages on "Cultural Competency" are available online at http://www.omhrc.gov/templates/browse.aspx?lvl=1&lvlID=3 and include nationwide standards, policies, training tools, information about relevant laws, and other resources.


