



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

The Culture Iceberg

Behaviors and Practices

Characteristics which are apparent to the casual observer

Observable

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

Behaviors and Practices

Characteristics which are apparent to the casual observer

Observable

Not observable

Institutions of Influence

The forces which create, define, and mold a culture's core values

History

The Media

Attitudes

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

Economics

Religion

Core Values

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

Family

Educational System

What is Cultural Competency: A Moving Target

“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

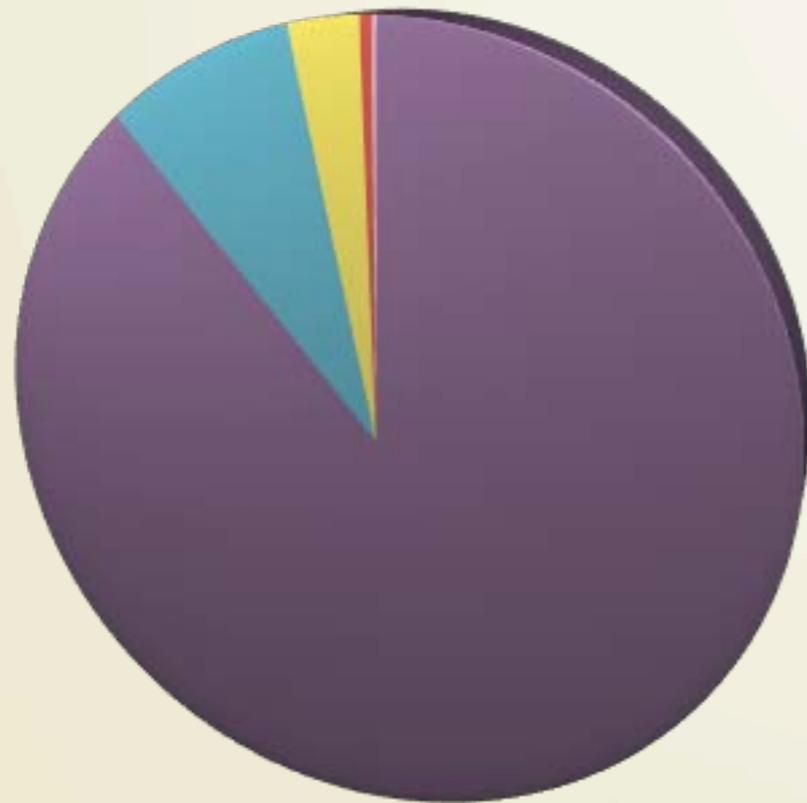
Cultural competency provides researchers with the tools necessary to communicate and deliver services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients, bridging the gap between participant concerns and that of the researcher.

Retention of Clinical Trials Participants

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

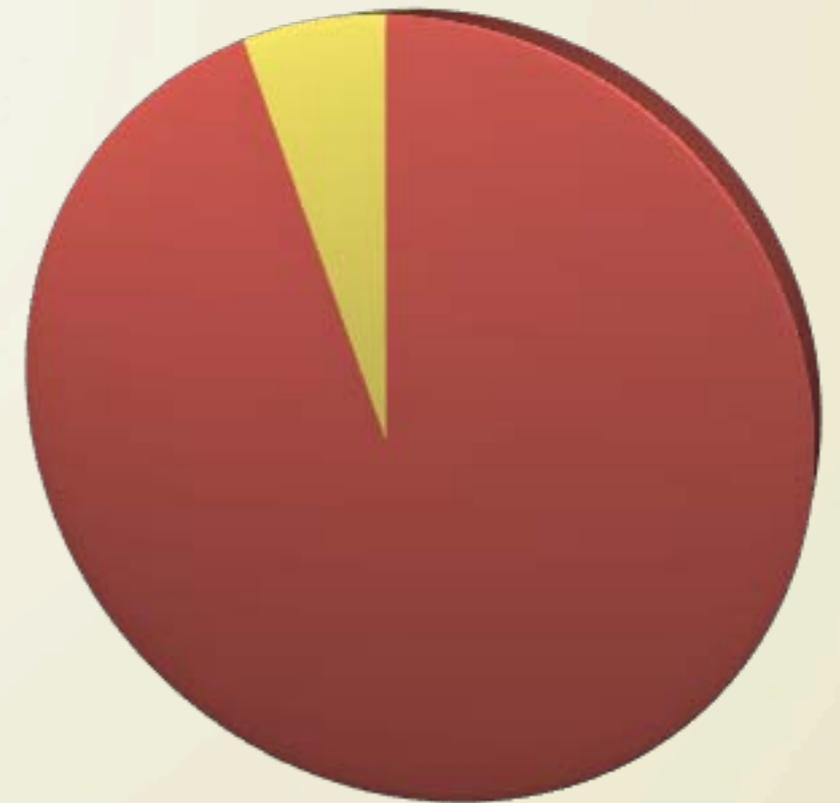
Enrollment by Race and Ethnicity

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%

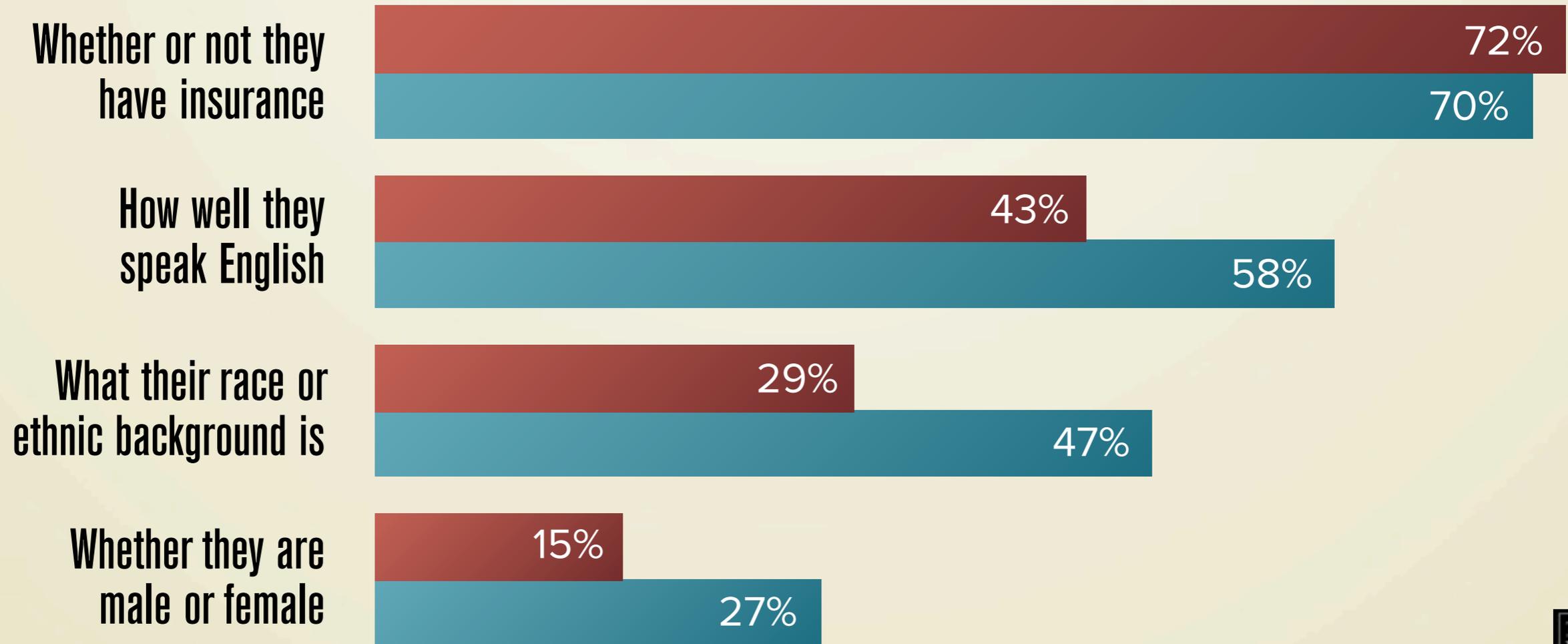
Source: "Baseline Study of Patient Accrual Onto Publicly Sponsored Trials," Coalition of Cancer Cooperative Groups for the Global Access Project, National Patient Advocate Foundation, April 2006.

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”

■ Doctors ■ The Public



Source: Kaiser Family Foundation, *National Survey of Physicians*, March 2002 (conducted March-October 2001); *Survey of Race, Ethnicity and Medical Care: Public Perceptions and Experiences*, October 1999 (Conducted July – Sept., 1999)

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

Cultural Background

Family Dynamics

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

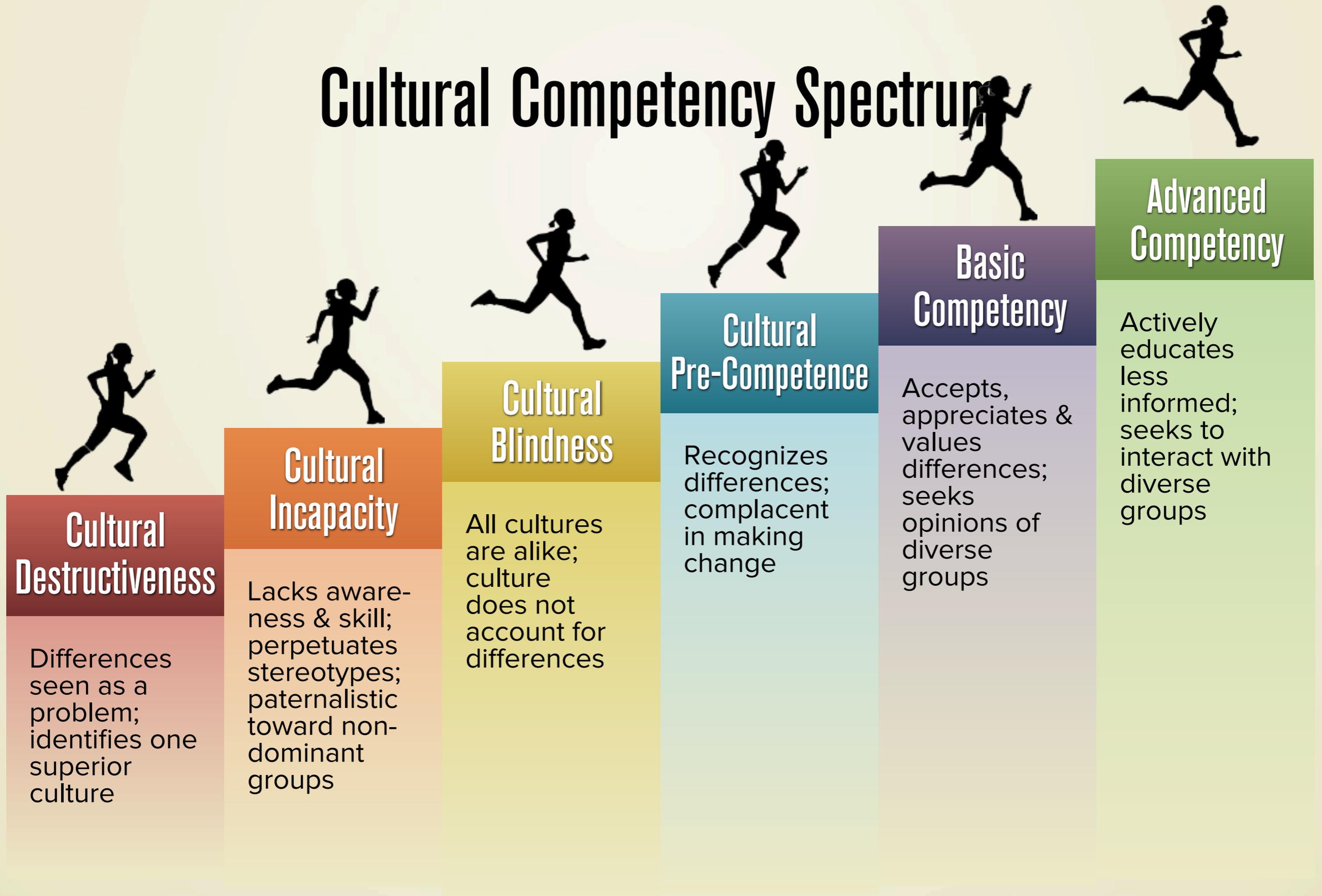
This demonstrates the approaches and actions necessary to incorporate cultural competency into the health system.

Source:

1. Cross TL, Bazron B, Dennis KW, Isaacs MR (1989) Towards a Culturally Competent System of Care. Vol. 1. Georgetown University Child Development Center, Washington, DC.

2. Thorton, S. Addressing Cultural Competency in Research: Integrating a Community-Based Participatory Research Approach. ALCOHOLISM: CLINICAL AND EXPERIMENTAL RESEARCH. Vol. 27, No. 8 August 2003

Cultural Competency Spectrum



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.

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**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?

Lessons Learned

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

<http://iccnetwork.org/cancerfacts/ICC-CFS1.pdf>



American Indian/Alaskan Natives

<http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf>



Asian American

<http://iccnetwork.org/cancerfacts/ICC-CFS3.pdf>



Hispanic/Latino Americans

<http://iccnetwork.org/cancerfacts/ICC-CFS4.pdf>

Where Can I Learn More?

1. Much of the information widely used concerning cultural competency derives from groundbreaking series of monographs on development of a culturally competent system of care called, Towards a culturally competent system of care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed (Terry L. Cross *et al.*, 1989). More information is available at <http://www11.georgetown.edu/research/gucchd/nccc/>.
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.
3. Georgetown University Center for Cultural Competence, <http://www11.georgetown.edu/research/gucchd/nccc/>
4. Georgetown University Center for Cultural Competence, Self-Assessment Checklist for Personnel Providing Behavioral Health Services and Supports to Children, Youth and their Families, <http://www11.georgetown.edu/research/gucchd/nccc/documents/ChecklistBehavioralHealth.pdf> (PDF - 84 KB)
5. "Improving Cultural Competency: Overview and Introduction," National Diabetes Education Program, <http://betterdiabetescare.nih.gov/ISSUESculturalcompetency.htm>
6. "Cultural Competency," National Women's Health Information Center, <http://www.womenshealth.gov/healthpro/cultural/>
7. "Cultural and Linguistic Competency," Agency for Healthcare Research and Quality, <http://www.ahrq.gov/path/compath.htm>
8. "Cultural Competency," Multi-Cultural Resources for Health Information available from the National Library of Medicine, <http://sis.nlm.nih.gov/outreach/multicultural.html#a0>
9. "Culture, Diversity & Health Disparities in Medicine," Bioethics Resources on the Web, <http://bioethics.od.nih.gov/culturalcomp.html>