

Cultural Competence

In the Responsible Conduct of Research (RCR)



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Today's Objectives

- **Define** cultural competence in research
- **Recognize** that culture is multi-faceted and the importance of integrating cultural considerations into the research process
- **Describe** one action to begin the process of integrating cultural considerations into your research efforts



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What is Cultural Competence? Part I

Awareness of unique and defining characteristics of the populations for which health professionals provide care and from which they wish to enroll clinical research participants.

Requires that organizations (and PIs/Study Personnel!):

- Have a defined set of values and principles
- Demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively and cross-culturally
- Have the capacity to
 - Value diversity
 - Conduct self-assessment
 - Manage the dynamics of difference
 - Acquire and institutionalize cultural knowledge
 - Adapt to diversity and the cultural context of the communities they serve
- Incorporate the above in all aspects of policy making, administration, and practice



We don't see
things as they
are, we see them
as we are.

— ” —
ANAI'S NIN

Let's Discuss Culture

Why does it matter?



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What is Culture?

Pattern of learned beliefs, values, and behavior that are shared within a group

(Betancourt et al., 2005)



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What is your cultural identity?



Please tell me by
posting in the chat

Shaping “Culture”

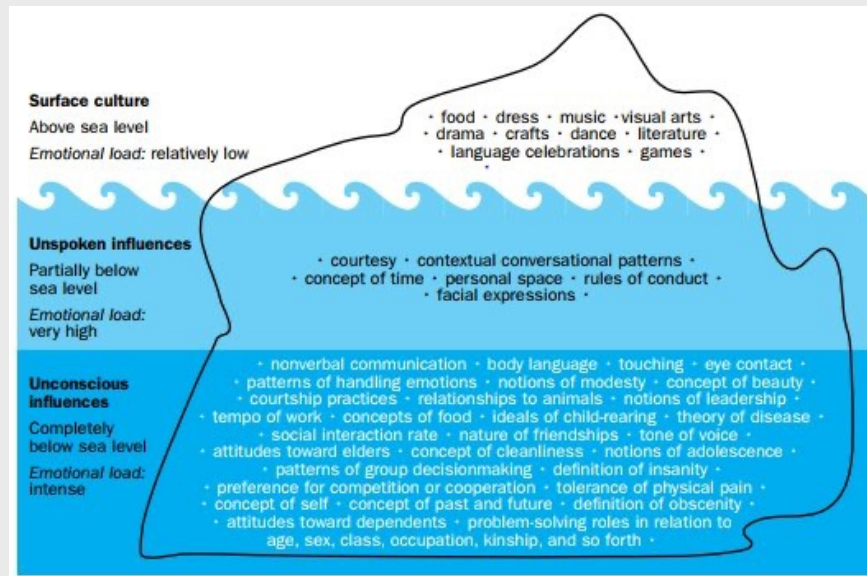
Culture is complex
and context is critical

- Race
- Ethnicity
- Religion/Spirituality
- Language
- Nationality
- Region
- Gender
- Sexual Orientation
- Education
- Customs
- Socio-Economic Status (SES)



The Iceberg Concept of Culture

Like an iceberg, nine-tenths of cultural influence is below the surface



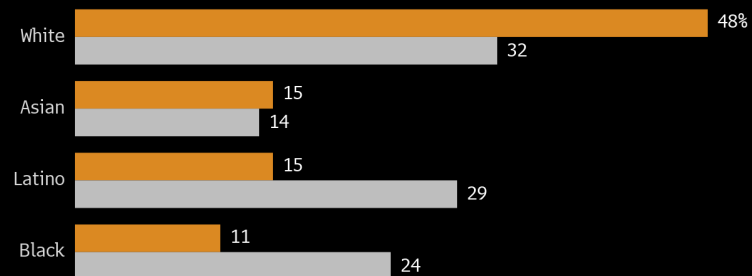
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Who
cares
?

Vaccine Disparity

White NYC residents get disproportionate number of Covid-19 vaccines

■ Percentage of vaccinated ■ Percentage of population

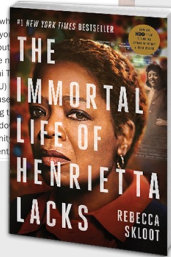
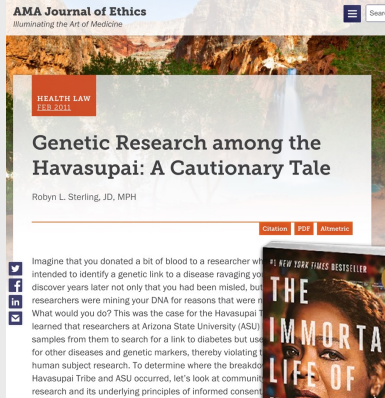


Vaccination data from New York City Health Department; Population data from 2019 U.S. Census
Vaccination data represent those who have received at least one dose of vaccine with known race/ethnicity

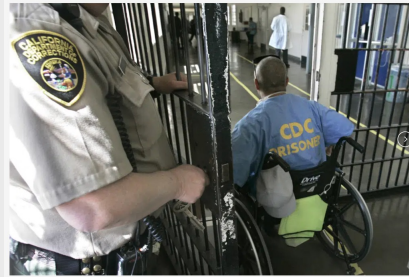
Bloomberg

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Why the Distrust?



California university apologizes for prisoner experiments



SAN FRANCISCO (AP) — A prominent California medical school has apologized for conducting dozens of unethical medical experiments on at least 2,600 incarcerated men in the 1960s and 1970s, including putting pesticides and herbicides on the men's skin and injecting them with viruses.

Row erupts over child aggression study

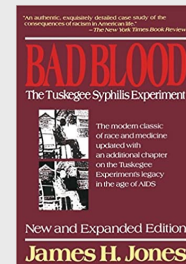
Psychiatrists under attack for using the drug thioridazine in a trial examining aggression in poor, non-white, inner-city boys last week defended themselves along with those who gave ethical approval to the experiments, against criticism appearing in the press.

Critics of researchers at the New York State Psychiatric Institute (NYSI) in Manhattan claim that a paper published last year in the *Archives of General Psychiatry* shows the research was in flagrant breach of federal ethics rules governing research on children.

For non-therapeutic research involving a "minor increase over minimal risk" — the category in which the IRB at the psychiatric institute considered the trial — federal rules say that children may be subjected only to experiences that are "reasonably commensurate" with their actual or expected medical situations. Also, the study must be likely to produce "generalizable" knowledge about the subject's "disorder or condition" which is essential for understanding or improving it.

Disability Advocates, a public-interest law office in Albany, New York, which comments on the NYIRB's decision, says the study should have worried the IRB. One was the racial composition of the group, which was 44 per cent black and 56 per cent Hispanic, a "highly disturbing" alone, according to Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania.

Racial balance is particularly important in research with direct benefits to subjects and that is of more than minimal risk, says Robert Levine, a professor of medicine who



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How did this happen?

- Race-based physiological myths
 - **Race as a social construct developed to justify slavery**
- For 400+ years groups of people in the U.S. were viewed as being inferior to others based on how they looked
- Think of:
 - **Black Code laws**
 - **Jim Crow laws**
 - **Indian Removal Act**
 - **Chinese Exclusion Act**

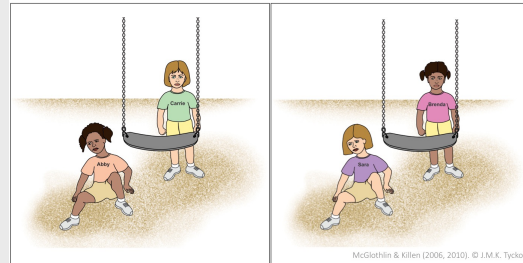


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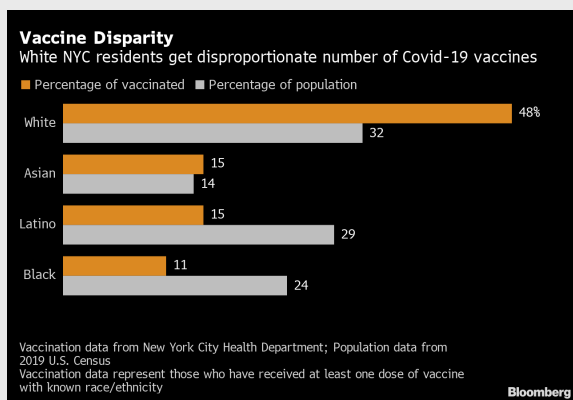
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The Internalization of Racial (Mis)Perceptions

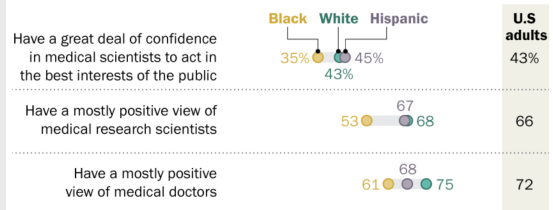


Effects on Research



Black adults have less positive views of medical scientists than Hispanic and white adults

% of U.S. adults who ...



Note: Whites and blacks include those who report being only one race and are non-Hispanic. Hispanics are of any race.

Source: Surveys conducted April 20-26 and April 29-May 5, 2020.

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Cultural Competence in Research



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The Belmont Principles

Respect for Persons

How can we ensure that the consent process is truly adequate if we do not have a basic cultural awareness of the person in front of us?

Beneficence

Are we ensuring we are ameliorating harm if we do not know the cultural needs of others?

Justice

How can we ascertain that we are distributing benefits adequately if we are not educating ourselves about the needs of other cultures different from ours?



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What is Cultural Competence? Part II

The integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of your project, thereby producing better data.

Principles of cultural competence include:

- Define culture broadly
- Value participants' cultural beliefs
- Recognize complexity in language interpretation
- Involve the community in defining and addressing their needs
- Collaborate with other agencies
- Professionalize team hiring and training
- Institutionalize cultural competence



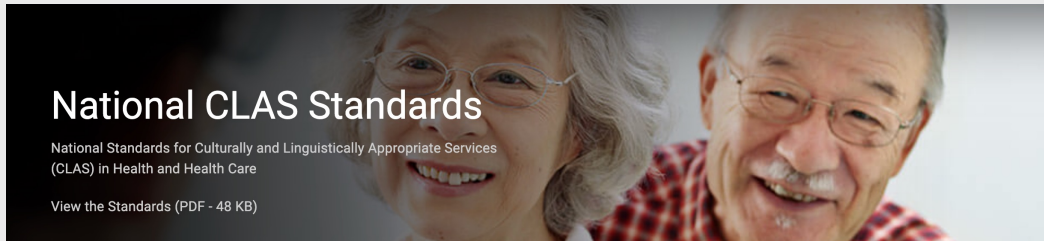
Cultural Competence in Research



What is it?

- The ability of researchers and research staff to provide high quality research that takes into account the culture and diversity of a population when:
 - **Developing research ideas**
 - **Conducting research**
 - **Generalizing research findings**
- No one singular definition
 - **Cultural awareness, Cultural humility, Cultural knowledge, Cultural sensitivity, Cultural proficiency**

Cultural Competence in Research



Why is it Important?

- Understand the needs and perspectives of different groups
- Community outreach and engagement
- Contextualization of research knowledge
- Increase in the community the relevance of research findings

"Healthcare organizations should use a variety of methods to collect demographic data and become informed about ethical and cultural needs"

Cultural Competence in Research

- Basic Science Research
 - Clinical Research
- Community-based Participatory Research
- Community Engagement

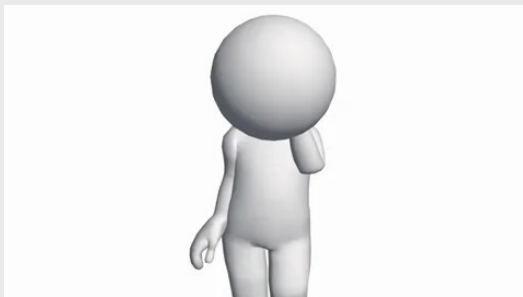
Case Study

You are recruiting for a study focused on translating findings from cell-based research on breast cancer to populations of women at risk for breast cancer. Japanese-American women are one population with a high risk. The study will include an in-depth, open-ended interview that will be conducted by a research assistant who is fluent in Japanese. The research assistant will also assist with the informed consent process to ensure that all participants fully understand the details of the study and their rights as a participant. It is anticipated that 50 women will be enrolled in the study.

You attend a cultural event in a predominantly Japanese-American neighborhood. You're prepared with study flyers that are translated into English and Japanese. Some of the women take the flyer, place it in their purses, and walk away from the table. Others smile and engage in conversation. They appear very interested in participating in the study, but state that they will discuss the information with their spouses. Following the event, you have spoken to approximately 75 women and believe that the event was a success.

You decide to continue using the same strategy and attend numerous community events to recruit participants for the study. After three months of speaking to over 150 women, you realize that only 8 women have enrolled in the study.

Consequences



- **Stereotyping**
- **Tokenism**
- **Mistrust**
- **Inability to engage certain communities**
- **Poor health and research outcomes**

Cultural Competence in Research

What it *IS*

- An ongoing process
- Value and respect for others
- A willingness and openness to change attitudes and behaviors

What it *ISN'T*

- A checklist of "do"s and "don't"s
 - Does YOUR cultural group have a checklist?
- Creating a 'formula'
 - Does a formula apply to YOUR group?
- Following "The Golden Rule"
 - They're not snowballs!

Can I Learn Cultural Competence?

Awareness

- Self-awareness
 - Individual and Institutional-level
- Acknowledging cultural differences
- Attitudes towards research (general and project-specific)

Knowledge

- Continuing Education
- Cross-cultural Encounters

Skills

- Incorporate knowledge into research efforts
- Be sensitive to cultural differences
- Take action!

Cultural Competence and the Research Process



To Summarize, Cultural Competence:

Starts with Awareness

Grows with Knowledge

Is Enhanced with Specific Skills

Is Polished through Cross-Cultural Encounters

Need help?



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Join us for our February METS

Thursday, February 16th, 2023

11:00am – 12 noon

Data Security in Research: PHI, Email, HIPAA, and You

Thursday, March 16th, 2023

11:00am – 12 noon

Submitting Your Study to the IRB: A Step-by-Step Guide



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