Effective Methods of Communication Between Researcher and Participants
Why is culturally competent communication important in clinical trials recruitment?

• Clear and effective communication is the first step in establishing a trusting relationship between you and study participants, a key element in the recruitment of minorities to clinical trials.

• Successful communication can lead to full transparency of research protocol for both you and your participant.
However, **Cultural Barriers** May Hamper Traditional Communication Methods

Cognitive Constraints

- Cognitive constraints are the ways people view the world based on their past experiences and can be based on a myriad of factors, including:

  - Religion
  - Area in which you live
  - Literacy rate
  - Socio-economic status
  - Educational attainment

- Cognitive constraints can affect a participant’s healthcare decisions and how a participant may respond to clinical trials.

- Based on historical accounts of unethical research designs.

History of Uninformed Consent

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Event</th>
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<tbody>
<tr>
<td>1840’s</td>
<td>J. Marion Sims: Gynecological experiments on African American slaves</td>
</tr>
<tr>
<td>1932-1972</td>
<td>Tuskegee Syphilis Experiment</td>
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<tr>
<td>1933-1945</td>
<td>Special Japanese military units conducted experiments on civilians and POWs in China.</td>
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<tr>
<td>1989-2008</td>
<td>Havasupai Indians: Blood samples used for genetic research on schizophrenia</td>
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Balancing Ethics and Medical Research
Behavior Constraints

- Behavior constraints are the differences in culturally acceptable behavior, affecting both how a participant behaves and how he/she perceives others' behaviors.

**Asian Culture**
- Direct eye contact, especially between two people of different age range, is considered rude
- It is polite to look down when speaking with those of higher social ranking i.e. an elder

**Western Culture**
- Direct eye contact is a sign of honesty and attentiveness
- A lack of eye contact indicates dishonesty or a lack of interest

Emotional Constraints

• Emotional constraints are differences in cultural level of acceptability toward displays of emotion, especially in social situations. Therefore, although the same emotion can be felt across cultures, the method of displaying these emotions can vary widely.

For Example, Grief

Emotional displays showcasing grief varies widely amongst cultures.

• Public display of negative emotions, such as grief, is generally not acceptable in Asian cultures.
• In Middle Eastern and African-American culture, public display of grief is permitted, and even encouraged.

Communication Models

There are multiple communication models available to help facilitate culturally competent communication between researcher and participant.

**L.E.A.R.N.**
- Listen
- Explain
- Acknowledge
- Recommend
- Negotiate

**E.T.H.N.I.C.**
- Explanation
- Treatment
- Healers
- Negotiate
- Intervention
- Collaboration

**R.E.S.P.E.C.T.**
- Rapport/Recognition
- Empathy
- Support
- Partnership
- Explanations
- Cultural Competence
- Trust


Source: Steven J. Levin, M.D., Robert C. Like, M.D., Jan E. Gottlitlieb, MPH. Center for Healthy Families and Cultural Diversity, Department of Family Medicine, UMDNJ-Robert Wood Johnson Medical School

In-depth Example: The L.E.A.R.N. Model

Case Study: Alicia Mercado’s Story

Alicia Mercado is a 60-year-old woman from Puerto Rico. As she gets older, her day-to-day life revolves more and more around her chronic illness – most predominately diabetes, hypertension, and asthma. Her mother passed away from cancer and Alicia fears she will face the same fate. She has missed many appointments and can be classified as a non-compliant/disjointed patient.

Dr. Afua Forson is Ms. Mercado’s physician. Today, Ms. Mercado will be coming in for an appointment.

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
I grew up in Puerto Rico.
Listen

• **Listen** with empathy to fully understand your participant’s point of view, concerns, confusions.

• **Ask** open ended questions that will illicit an explanatory answer from your participant

• **Identify** potential barriers and be sure to address them

• Actively listen in order to differentiate between your point of view and the participant’s point of view.

Dr. Forson’s asked multiple open-ended questions to Ms. Mercado in order to develop a comprehensive view of the situation:

• “Can you tell me why you haven’t been able to make your appointments or why it has been difficult for you to come into the office?”

• “Would you be comfortable talking about the problems or the distractions that have been going on since we last saw each other?”

Through this, it is identified that Ms. Mercado is suffering from social stressors that make it hard for her to be compliant with the required medical treatment.
• **Simplify** complicated medical terms – determine and meet your participant health literacy needs
  –Reading Assessment tool:
    • [http://www.wordscount.info/wc/jsp/clear/analyze_smog.jsp](http://www.wordscount.info/wc/jsp/clear/analyze_smog.jsp)

• **Address** participant’s concerns and offer an explanation that does not impede on cultural beliefs

For Ms. Mercado, someone with no medical background, complicated medical terms can be confusing, especially since English is not her native language.

Dr. Forson explained and showed Ms. Mercado what a peripheral neuropathy pen is, addressing Ms. Mercado’s fear of needles.
• **Acknowledge** the differences between your participant’s point of view and your own point of view.

• Do not dismiss concerns based on your own beliefs.

In reality, I couldn't do it with one thing alone.

**Play clip 6:08-6:53, 8:10-8:40**
Ms. Mercado believes in a combination of prescription drugs and homeopathic remedies, such as taking hypertension drugs as well as garlic to control her blood pressure.

Dr. Forson acknowledged everything that Ms. Mercado was taking, including the use of homeopathic medicine. This is important in establishing a sense of trust.

A combination of homeopathic care (from cultural and/or religious beliefs) and prescription drug is common among patients. Many times, as long as the homeopathic remedies does not interfere with the prescription drug, it is not harmful for patients to use both.
• **Recommend** solutions that respect and work in conjunction with the participant’s cultural beliefs and still adhere to study protocols.

• **Negotiate** a plan to move forward that incorporates the participant’s inputs, concerns, and agreement to adhere to study protocols.

• Remember that incorporation of traditional cultural treatment may not interfere with participation in clinical trials.

Recommend and Negotiate

In this clip, Dr. Forson and Ms. Mercado compromise on a treatment plan. Dr. Forson focused on the most crucial of Ms. Mercado’s chronic health conditions, diabetes. Dr. Forson provided Ms. Mercado with a book to track her blood sugar level and, in exchange, Ms. Mercado agrees to return for a follow up appointment in two weeks. The plan of treatment is feasible for Ms. Mercado to comply with and still functional in helping her control her diabetes.

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
Successful application of the L.E.A.R.N. model can result in:

**Cultural Competency**
- Culturally competent communication between researcher and participant

**Cognitive Restructuring**
- Cognitive restructuring of a participant’s view towards clinical trial

**A Trusting Relationship**
- Establishment of a trusting relationship
Try to Remember

• The steps of the L.E.A.R.N. model are not always in sequential order and need not be applied that way. In each interaction with the participant, one or more steps of the model can be applied.

• Body language is as much a part communication as verbal language so be sure your body language is congruent with your spoken words.
Where can I learn more?


