

Historical and Cultural Perspectives: Trust and Rapport



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Trust

one in whom confidence is placed.

Rapport

relationship between two or more people
who relate well to each other.

Trust

Trust is a crucial component of any relationship, especially in the medical field. Having patients' and participants' trust will determine whether they will consider, enroll, and remain in your clinical trials. There are many factors that affect building and maintaining trust. Let's first examine the historical perspectives that have led to medical mistrust among minorities in America.

Historical Events Leading to Mistrust of Medical Research

1932-1972



Tuskegee Study
of Untreated
Syphilis in Negro
Male

1946-1948



Syphilis
Experiment in
Guatemala

1951



Henrietta Lacks
Origin of the HeLa
Cell Line

1990-1994



Havasupai Tribe
Biosample
Misusage

1932-1972

“Tuskegee Study of Untreated Syphilis in the Negro Male”

John Cutler, M.D.

- To examine the natural history of syphilis infection.
- 600 African American men (399 active infection).
- Deceptive disclosure.
- Participants did not receive proper treatment.
- Of those who had active infection:
 - 28 died of syphilis.
 - 100 died of untreated disease-related complications.
 - 40 wives were subsequently infected.
 - 19 children were born with congenital syphilis.



1946-1948

Syphilis Experiment in Guatemala

John Cutler, M.D.

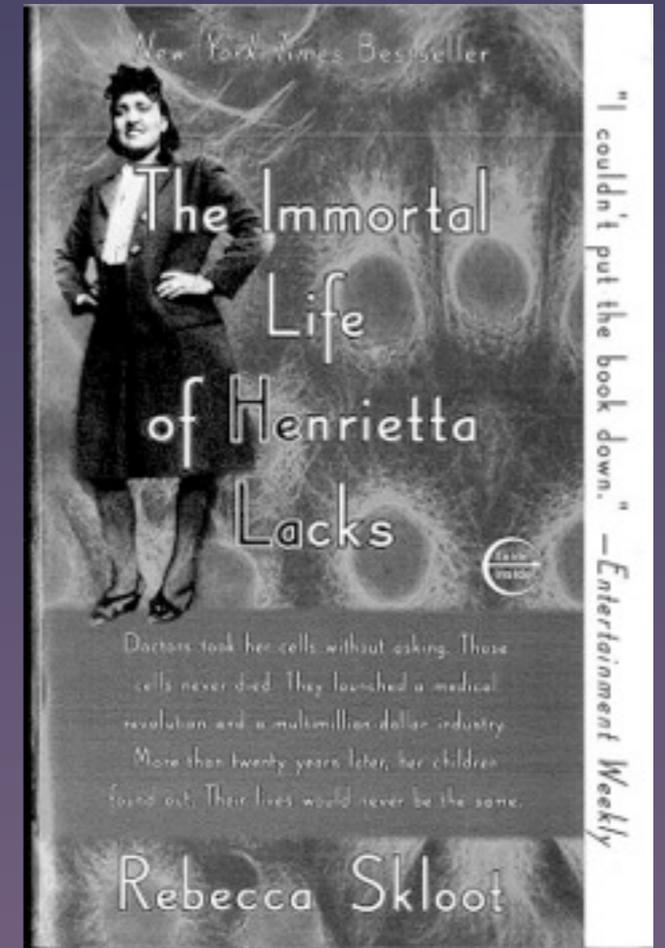
- Goal: Study effect of penicillin on prevention and treatment of venereal disease.
- 1500 subjects: prostitutes, prisoners, mental patients, and children.
- Study population received, complete, *partial* or *no* therapy.
- Ethical violations: vulnerable populations, consent, and deception.



1951

Henrietta Lacks - Origin of the HeLa Cell Line

- African American patient who died of cervical cancer in 1951.
- Her cancer cells were obtained without consent and have been used in research since 1950s.
- HeLa is the first human cell line that could be grown indefinitely in the lab.



“HeLa cells were vital for developing the polio vaccine; uncovered secrets of cancer, viruses, and the atom bomb’s effects; helped lead to important advances like in vitro fertilization, cloning, and gene mapping; and have been bought and sold by the billions. Yet Henrietta Lacks remains virtually unknown, buried in an unmarked grave.”

The Immortal Life of Henrietta Lacks

Rebecca Skloot (2010)

1990-1994

Arizona Board of Regents and the Havasupai Tribe

- Havasupai is an American Indian tribe that resides within the Grand Canyon.
- The tribe gave consent to Arizona State University to use 400 DNA samples for the research of Type 2 Diabetes.
- ASU also used the samples to study schizophrenia and other diseases without obtaining additional consent.
- The tribe successfully sued ASU for medical and research misdeeds.
- The case was settled out of court in April 2010.



Historical Perspectives on Trust

These historical events are among the medical misdeeds in minority communities that have eroded societal trust towards clinical research.

Historical events, in combination with cultural factors and social values shape the community's perception of clinical medicine and research.

Research Subject Protection

- National Research Act of 1974:
 - National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.
 - Institutional Review Board (1978).
 - The Belmont Report: Ethical Principles and Guidelines for Protection of Human Subjects of Biomedical and Behavioral Research (1979).
- NIH regulatory mandates expanded to protect vulnerable populations.

Distrust and Race

Two studies that evaluated trust towards clinical research found African Americans were more likely than whites to...

Not trust physicians to fully explain research participation.

Feel that doctors would expose them to unnecessary risks.

Believe physicians would ask them to participate in harmful research.

Have fear of being used as guinea pigs.

Distrust and Culture

Minority and immigrant population's lack of familiarity with clinical research.	Do not understand, trust or see value in participation
Cultural practices and belief in health care.	Eastern philosophy, distrust of western medicine.
Religious beliefs, values and preferences preclude participation in research.	Will participation in clinical trials violate my religious beliefs and guidelines?
Systems distrust.	Will they charge me for services? Will I be deported?

Distrust Leads to Underutilization

Fear, apprehension,
and uncertainty.

Physicians may not
suggest clinical trials
as an option for
cancer care.

Language and literacy
barriers may make it
difficult for minority
groups to understand and
consider participating.

Access confronts
many people.

Misdefining Community Trust

Social norms delineated within a population determine the definition of high levels of trust.

Don't assume that people trust you until you know how they define trust.

Avoid projecting your own definition of "trust" onto the population.

When thinking about the communities from which participants are recruited, we need to ask: "Do minority and underserved communities really have low trust or is it *perceived* low trust".

Dimensions of Diversity

Internal

- Age
- Gender
- Race
- Sexual Orientation
- Ethnicity
- Physical Ability

External

- Education
- Income
- Geographic Location
- Marital Status
- Military Experience
- Parental Status
- Religious Belief
- Work Background
- Community

Cancer Center

- Work Conditions
- Cultures
- Environment



Overcoming Barriers to Trust

Understand the **complex range of barriers** to achieving diversity in research participation that may impact different cultures, i.e. urban vs. rural.

Be aware of the **historical and ethical issues** related to trial participation and understand that these issues continue to impact participation.

Promote **transdisciplinary integration** of research literacy among researchers and communities, and provide information on how to achieve it.

Continue to develop **best practice models** for fostering public trust in research, diversity in clinical trial participation and retention among underserved populations.

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Rapport Optimizes the Participant Encounter

Rapport promotes efficient use of often time-limited participant interaction and avoids “door-handle confessions” – the problem of having potential participants withhold study related concerns until they are leaving the recruitment encounter.

Is Rapport Present?

Variable	Rapport is Present	Rapport is Absent
Conversation	Increased give-and-take	Sudden withdrawal
Body language	Relaxed and open	Defensive
Eye contact	Increased	Absent
Sensitive information	Disclosed	Withheld
Listening/Responding	Automatic, natural	Brief responses, long silences

Communication Strategies to Improve Rapport

Respect confidentiality.

Focus attention on participant concerns and comfort and avoid interruptions.

Ask open-ended questions, and ensure communication is clear by avoiding jargon and technical language.

Provide rationales for procedures, treatments, and decisions.

Building and Maintaining Rapport Can Provide Benefits

These benefits include:

Potential increase in recruitment and retention.

Positive participation outcomes, in part from protocol compliance.

Reduction in miscommunications.

Improvement of the community's perception of the clinical trial team and cancer center.

ACTIVITY: Rapport

Think about a recent situation with a potential or current clinical trial participant in which you approached her or him to discuss a challenging aspect of their clinical trial participation.

How did you establish rapport?

How did they respond to your approach?

What problems did you encounter?

What could you have done differently?

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Enhancing
Minority
Participation
in Clinical Trials