Trustworthiness and Equity: Establishing Trustworthiness when Conducting Research in COVID-19 Testing

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Road Map

Distinguish the concept of “trust” from the concept of “trustworthiness”.

Examine motivators of trustworthiness in collaborative relationships.

Explore strategies that enhance trustworthiness in research relationships with communities.

Take Home Lesson: Identify with attendees some norms for trustworthiness when conducting research in COVID-19 testing.
Concepts of Trust Examined

Conditions of Trust Examined

-- A relationship developed between two individual moral agents – trustor and trustee.

-- Trustor is willing to be vulnerable when she depends on Trustee.

Two forms: Personal, Institutional (Mayer 1995; Rousseau 1998; Kerasidou 2017)

-- Common Characteristics or Moral Component and Underpinnings of Trust (Holton 1994; Wright 2010)

  • Trustor’s assumption of a ‘participant stance’ out of necessity rather than choice may increase vulnerability

  • Trustee’s attitude of ‘good will’ or such expectations towards the trustor may be present, but not necessarily so (Baier 1986; O’Neil 2002a).

  • Requires “Reliance”: an act of dependence based on the likely prediction of other’s behavior not necessarily entailing ‘good will’ (Jones 1996).

  • Requires “Voluntariness” to give, not upon demand (Kingory 2015).

  • Trust kept = gratitude

  • Trust not kept = betrayal (Holton 1994; Wright 2010).
Conditions of Trustworthiness Examined

-- Relates to the person or institution (trustee) being trusted by the trustor (Wright 2010)

-- A person or moral agent (trustee) is trustworthy when she ‘acknowledges the value of the trust that is invested in her by the trustor, and uses that to help or rationally decide how to act rightly’ (Wright 2010)

-- Building and restoring trust relationships in effect means building or restoring individuals’ and institutions’ trustworthiness.

-- If trust is something that is voluntarily given and cannot be demanded….,

--- Then the only way of restoring trust is by enhancing trustworthiness and thus creating the conditions for trust relationships to ensue and flourish (O’Neil 2002a; Yarborough et al 2002, 2009; Sulmasy 2006)

QUESTION: Brain teaser!

• Which comes first, the chicken or the egg?

-- Some have argued that “Trustworthiness” must come before Trust” (Warren et al, 2020)
MOTIVATORS OF TRUST AND TRUSTWORTHINESS: What do we know? How do we know it? What ought we to do?

Why do we need trust and trustworthiness in biomedical or in COVID-19 research?

- Researcher experiences have shown that:
  -- Some trust voluntarily given is better than no trust at all.
  -- Trust, even when warranted, is risky and can be dangerous (Stanford Encyclopedia of Philosophy, 2015)
  -- Trust allows us to form relationships with people and to depend on them.
  -- Lack of trust can jeopardize the research enterprise (Kass et al. 1996; Mastroianni 2008)
  -- Lack of trust is a barrier for consenting to research (Sugarman et al. 1998; Cobie-Smith et al. 1999)

THEREFORE:

- Researchers should concentrate on building trust relationship with participants and communities (Marshall and Rotimi 2001; Faden 2005; Slegers et al. 2015)

Contextualizing “Trust and Trustworthiness Relationship”: Two Paradigmatic Cases
Paradigmatic Case 1: USPHS Syphilis Study (1932-1972)

The Story

Purpose: To study the natural course of syphilis in the negro male.

Study:

- 600 black men (399 with syphilis, 201 without)
- Men told they had “bad blood,”
- Observed without treatment
- Penicillin, 1942 not given to men

Q: What is particularly troubling to you in this case?

Q: What “ought” we to do about it?
Paradigmatic Case 2: Havasupai Indians v. ASU Board of Regents (2004-2010)

Carletta Tilousi

The story

• Blood Journey (1989-2010)


Q: What is particularly disturbing to you in this cases?

Q: What “ought” we to do about it?
Motivators of Trustworthiness: One Example of Perspectives on the dyadic “Trust-Trustworthiness” relationship.
Motivators of Trustworthiness

GROUP ENGAGEMENT EXERCISE

• Register your own perspectives on the dyadic “Trust - Trustworthiness” relationship in the Chat Box
Enhancing Strategy: What “ought” we to do as we conduct COVID-19 research?

“The only way out of today’s misery is for people to become worthy of each other’s trust”—Albert Schweitzer

-- Invest in “Structural Competency” (SC)

• SC requires a new approach to understanding the relationships among race, class, and symptom expressions, mindful of the “common humanity” that we all share.

• SC ideally bridges research on social determinants of health to clinical interventions.

• SC prepares clinical trainees and researchers to act on systemic causes of health inequalities.

(Metzla and Hansen, 2014; Kingori, 2015; Kerasidou, 2017)
Take Home Lessons: Soft Norms of COVID-19 Testing Research (1 of 2)

- Recognize the “dignity of persons” to boost equitable distribution of testing in vulnerable communities.
- Develop and nurture long-term relationships with the communities we serve.
- Institutions should collaborate to manage uncertainties, safeguard communities, and guide practice.
- Focus on educating for informed decision-making.
- Be transparent! (Explain motives, what we know, what we don’t know, risks, benefits)
Consider the socio-cultural interests of the communities we serve as ethical.

Engage and treat communities as valuable partners who can identify challenges and formulate lasting solutions.

Be mindful of group, cultural, and dignitary harms as legitimate risks worth preventing in ethical research.

Compensate those willing to participate in research for injury and incentives accordingly.

Humility on the part of “trustee” earns “trust” from partners and enhances trustworthiness, making it easier to work together for mutual benefits. Practice it.
Helpful References (1 of 3)


Helpful References (2 of 3)

Helpful References (3 of 3)


Questions and Comments?

THANK YOU