



3RD ANNUAL CCTS PARTNERSHIP BIOETHICS FORUM: TRUST AND TRUSTWORTHINESS SERIES

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ACKNOWLEDGMENT

- **PLANNING COMMITTEE**

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- **Clayton Yates, PhD**
- **Mariko Nakano, PhD**
- **Becky Reamey, PhD**
- **Ms. Chquita Lee, Program Manager**
- **Stephen Olufemi Sodeke, PhD, MA**

TRUST AND TRUSTWORTHINESS IN GENETIC AND GENOMIC RESEARCH: BARRIERS TO PARTICIPATION

OVERVIEW OF FORUM SERIES (1 OF 2)

• PURPOSE

- 1. To provide the ‘reflective space’ that stakeholders (prospective participants, researchers and research personnel, institutions) engaged in the research enterprise need for critical reflection; and**
- 2. To collaboratively facilitate with stakeholders, increased awareness of, and reflections on, the tensions, concerns, and other pertinent issues crucial to promoting and maintaining a ‘culture of trust and trustworthiness’ in collaborating CCTS institutions and networks engaged in biomedical research nationwide.**

OBJECTIVES

- 1. To facilitate an exploration of the concepts of trust and trustworthiness while discussing and affirming stakeholders’ understandings,**
- 2. To understand the need for reflection on issues of trust and trustworthiness in biomedical research,**
- 3. To discuss the implications of a “culture of trust and trustworthiness” in collaborating institutions,**
- 4. To formulate practical steps for promoting trust and trustworthiness among collaborating institutions and those volunteering for research,**
- 5. To discern benchmarks for assessing the adequacy of trustworthiness, and**
- 6. To propose effective actions for improving the engagement, recruitment, and retention of research participants in the collaborating CCTS institutions and nationally.**

TRUST AND TRUSTWORTHINESS IN GENETIC AND GENOMIC RESEARCH: BARRIERS TO PARTICIPATION

OVERVIEW OF FORUM SERIES (2 OF 2)

Schedule of Activities

- 9:30 am – 10:00 Meet and greet with coffee
- 10:00 am – 10:30 **Talk:** Epistemology and Ethics of Trust and Trustworthiness
Speaker: Stephen sodeke, PhD, MA
Activity: Build a Trust and Trustworthiness collage using Poll Everywhere
- 10:30 am – 11:00 **Activity:** Watch the video-clip “Blood Journey”
Examining mistrust and untrustworthiness as barriers to research participation
Facilitated discussion: Stephen Sodeke, PhD, MA
- 11:15 – 12:15 Current experiences with barriers to participation: the AGHI case:
Panel discussion
Moderator: Mariko Nakano, PhD
Speaker: Julie Schach and group
- 12:15 – 12:30 Break for working lunch
- 12:30 – 1:00 Future Bioethics Forum
Facilitated discussion: Stephen Sodeke, PhD, MA

SESSION 1

- **The epistemology of trust and trustworthiness: what do we know, and how do we know it?**
 - **Concepts of Trust Examined**
 - **Concepts of Trustworthiness Examined**
 - **Audience understandings of Trust and Trustworthiness documented using words collage**

THE EPISTEMOLOGY OF TRUST AND TRUSTWORTHINESS: WHAT DO WE KNOW, AND HOW DO WE KNOW IT?

• CONCEPTS OF TRUST EXAMINED

-- A relationship commenced or developed between two individual moral agents –trustor and trustee; willingness to be vulnerable.

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

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

1. Trustor's assumption of a 'participant stance' out of necessity rather than choice may increase vulnerability
2. Trustee's attitude of 'good will' or such expectations towards the trustor may be present, but not necessarily so (Baier 1986; O'Neil 2002a)
3. Reliance: an act of dependence based on the likely prediction of other's behavior not necessarily entailing 'good will' (Jones 1996)
4. Voluntariness in trust-given, not upon demand (Kingory 2015)
5. Honored and lead to feelings of gratitude or disproved and lead to feelings of betrayal (Holton 1994; Wright 2010)

• CONCEPTS 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' (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)

• QUESTION:

We know there are more! Do these propositions square with researcher and research personnel experiences?

TRUST AND TRUSTWORTHINESS COLLAGE

- **What is your understanding of trust and trustworthiness?**

ACTIVITY: Build a collage based upon your understandings. With Poll Everywhere as instructed, use your cell phone to send the **words that come to mind for you when you think about trust and trustworthiness.**

SESSION 2

- **Examining mistrust and untrustworthiness as barriers to research participation**

USPHS STUDY OF UNTREATED SYPHILIS AT TUSKEGEE (1932-1972)

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

Study:

600 black men (399 with syphilis, 201 without) were told they had “bad blood,” a local term used to describe syphilis, anemia, and fatigue.

Men were observed without treatment even when penicillin was available for treatment.



MR. HERMAN SHAW IN THE WHITE HOUSE, MAY 16, 1997



- *“The damage done by the Tuskegee Syphilis Study is much deeper than the wounds any of us may have suffered.”*
- *-- Mr. Herman Shaw, 16 May 1997*

Examining mistrust and untrustworthiness as barriers to research participation: One Example

- Watch the video-clip: “Blood Journey”

<http://www.nytimes.com/video/us/1247467672743/blood-journey.html>

- FACILITATED DISCUSSION

- What is particularly troubling to you about the Havasupai Case?
- What bioethical issue(s) loom large in the Case?
- What harm was done? Who was harmed?
- Which type of trust was betrayed? Personal, Institutional, or both?
- Can the behaviors of the researchers be justified?
- Was the informed consent signed sufficient justification for the removal, storage, and use of the blood specimen obtained from the Havasupai?
- Were any other ethical obligations violated?
- What can be done to ensure that these acts do not happen again?

THE ETHICS AND EPISTEMOLOGY OF TRUST AND TRUSTWORTHINESS: WHAT DO WE KNOW, HOW DO WE KNOW IT, AND WHAT OUGHT WE TO DO?

- **Why do we need trust and trustworthiness in biomedical research?**
 - trust is important, it allows us to form relationships with people and to depend on them
 - trust, even when warranted, is risky and dangerous (Stanford Encyclopedia of Philosophy, 2015)
 - lack of trust can jeopardise 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; Slegers et al. 2015)
 - researchers should concentrate on building trust relationship with participants and communities (Marshall and Rotimi 2001; Faden 2005)
- **Do researcher experiences support these assertions?**
 - “If people really distrusted biomedical research, then a decrease in biomedical research involving humans should be observed, not an increase” (O’Neil 2002a, b)
- **Is trust as important as we are led to believe? Can there be ambivalent trust? What are your thoughts?**

SESSION 3

- **Current experiences with barriers to participation: the AGHI case:**

Panel discussion

- **Moderator: Mariko Nakano, PhD**
- **Speaker: Julie Schach and group**



SESSION 4

- **Future Bioethics Forum**
Facilitated Discussion

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Helpful References (1 of 2)

- Baier, A. 1986. Trust and Antitrust. *Ethics* 96(2): 231–260.
- Corbie-Smith, G., S.B. Thomas, M.V. Williams, and S. Moody-Ayers. 1999. Attitudes and beliefs of african americans toward participation in medical research. *Journal of General Internal Medicine* 14(9): 537–546.
- Faden, R. R., A. C. Mastroianni, and J. P. Kahn. 2005. Beyond Belmont: trust, openness, and the work of the advisory Committee on human radiation experiments. *Belmont revisited: ethical principles for research with human subjects*. J. F. Childress, e. M. Meslin and H. T. Shapiro. Washington DC, Georgetown university press: pp. 41–54.
- Jones, K. 1996. Trust as an affective attitude. *Ethics* 107(1): 4–25.
- Jones, k. 2012. “Trustworthiness”. *Ethics* 123(1): 61–85.
- Kass, N.E., J. Sugarman, R. Faden, and M. Schoch-spana. 1996. Trust: the fragile foundation of contemporary biomedical Research. *The Hastings Center Report* 26(5): 25–29.
- Kerasidou, A., and M. Parker. 2014. Does research need bioethicists? *Ethics and science collaboration in biomedical research*. *Research Ethics* 10(4): 214–226.
- Kerasidou, A. 2017. Trust me I’m a researcher!: The Role of Trust in biomedical research. *Med. Health Care and Philos* 20:43-50.
- Kingori, P. 2015. The ‘empty choice’: A sociological examination of choosing medical research participation in resource-limited sub-Saharan Africa. *Current Sociology* 63: 763–778.
- Marshall, P.A., And C. Rotimi. 2001. Ethical challenges in community-Based research. *The American journal of the Medical Sciences* 322(5): 241–245.

Helpful References (2 of 2)

- Mastroianni, a.C. 2008. Sustaining public trust: Falling short in the protection of human research participants. *Hastings center Report* 38(3): 8–9.
- Mayer, R.C., J.H. Davis, and F.D. Schoorman. 1995. An integrative model of organizational trust. *Academy of Management Review* 20(3): 709–734.
- Rousseau, D.M., S.B. Sitkin, R.S. Burt, and C. Camerer. 1998. Not so Different after all: A cross-discipline view of trust. *Academy of Management review* 23(3): 393–404.
- Slegers, C., D. Zion, D. Glass, H. Kelsall, L. Fritschi, N. Brown, and B. Loff. 2015. Why do people participate in epidemiological research?. *Journal of bioethical inquiry* 12(2): 227–237.
- Sugarman, J., N. E. Kass, S. N. Goodman, P. Perentesis, P. Fernandes and R. R. Faden. 1998. What patients say about medical research. *IRB: Ethics and Human Research* 20(4): 1–7.
- O’neill, O. 2002a. *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press.
- O’neill, O. 2002b. *A question of trust*. Cambridge: Cambridge University Press.
- Walker, M.U. 2006. *Moral repair: Reconstructing moral relations after wrongdoing*. Cambridge: Cambridge university press.
- Wright, S. 2010. Trust and trustworthiness. *Philosophia* 38(3): 615–627.
- Yarborough, M., K. Fryer-Edwards, G. Geller, and R. R. Sharp. 2009. Transforming the culture of biomedical research from compliance to trustworthiness: Insights from nonmedical sectors. *Academic Medicine* 84(4): 472–477.
- Yarborough, M., And R.R. Sharp. 2002. Restoring and preserving trust in biomedical research. *Academic Medicine* 77: 8–14.