

Submission Id: 5191

Title

Trustworthiness and goodwill (not awareness and education) are the key to equitable recruitment and retention

Priority 1 (Research Category)

Clinical trial

Presenters

Christy Ledford, PhD, FACH, Hailie Hayes, BS, Samantha Jones, PhD, Brittney Walker, JD, MPA, Lauren Cafferty, MA, Samantha Kench, BS

Abstract

Context: Of the multiple abuses in the Tuskegee Syphilis Study, the denial of penicillin once it became available was a direct violation of the equipoise principle – the state of uncertainty that no trial arm offers greater harm or benefit than any other arm. Although we generally discuss equipoise among researchers and clinicians, it is increasingly important to understand how patients perceive equipoise in trials. Historically marginalized communities can view research studies with skepticism if they perceive experimental treatments as proven, yet participants risk being relegated to the control arm. Research is needed to better understand how individuals’ perceptions of research processes influences their participation in clinical research.

Objective: To explore community perceptions of clinical research and researchers, with a particular focus on community members’ understanding and expectations of research purposes and design.

Study design and analysis: Phenomenological inquiry with maximum variation sampling.

Population studied: Community members who have consented into clinical research or blood donation (including consent into research use). Data analysis followed the Sort and Sift, Think and Shift process.

Results: We completed 17 interviews (76% women; 29% Black/African American). Overall, participants identify trust and relationship with the research team rather than cognitive or scientific principles as critical to research recruitment and retention. Community members trust researchers to be content experts, but they are skeptical about researcher intentions, due to a long history of research abuses in the nation. Community members expect researchers to be trustworthy and to have goodwill toward people in their community. Participants voiced skepticism associated with long, informational

documents associated with research studies. Motivations to participate in research were personal relevance of the study topic and compensation provided.

Conclusion: To facilitate equitable research, researchers should move away from technical scientific language in recruitment and consent (e.g., handing participants legal paperwork for consent) and instead facilitate personal conversations of what studies look like for participants. To accomplish this ethically, researchers must foster trusting relationships early. More research is needed to explore these concepts quantitatively, using source credibility scales that capture the tri-dimensional construct.