

## Team develops scale to rebalance burden of initiating trust in science

April 27 2023



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A Vanderbilt University Medical Center-led team has developed a scale to measure trustworthiness in biomedical research among minority populations—a landmark tool for researchers to use to improve their



own trustworthiness, and thus participation in research.

The Perceptions of Research Trustworthiness (PoRT), described in an original investigation published in *JAMA Network Open*, is a groundbreaking tool designed as an on-going gauge of perception of trust and distrust in biomedical research, said team leader Consuelo H. Wilkins, MD, MSCI, Senior Vice President and senior associate dean for Health Equity and Inclusive Excellence and professor of Medicine at Vanderbilt University Medical Center (VUMC).

By focusing on the trustworthiness of research and the investigators, the burden of 'trust' is moved from the participant to the researcher—a rebalancing of the historical approach to trust in science, Wilkins said.

Usually, the onus of trusting the process is placed on the participant, who is perceived to have at least a latent trust in science.

However, the culture and experiences of historically marginalized and minoritized racial and ethnic groups foster a deep-rooted distrust of science and biomedical research. Wilkins is ardently pushing for the research institution to take on the burden of being trustworthy—and measuring their success in earning and maintaining trust.

"The critical message of this validation of PoRT is about how are we as researchers being trustworthy? So often we put the burden on the research volunteer, the patient, the community to be trusting of us. We're not asking, 'Are we worthy of their trust?' They have valid reasons to not trust researchers and institutions. We have to change how we communicate and act with cultural humility and acknowledge past exploitations while clearly illustrating the benefit of participating in their community and society. The hard work of 'trust' is on us," Wilkins said.

The research team wants PoRT to be used in projects across the country



to measure and understand how trust influences outcomes, especially behaviors and willingness to participate.

"This is a process; the work is ongoing because you have to peel back the layers to identify what is fueling trust or distrust in individual populations. We tend to place all minority and marginalized groups in one bucket when it comes to understanding the rationale for trust and mistrust. However, one of our studies shows that Black Americans had lower levels of trust in biomedical research compared to White Americans, and factors contributing to differing trust levels varied by group. This points to the need for tailored or targeted strategies in approaching different populations to improve trust in the biomedical research processes," said Jennifer Cunningham-Erves, Ph.D., MPH, associate professor in Meharry Medical College's Department of Internal Medicine.

The development and validation of PoRT took many years. Yet, being able to measure and gauge trustworthiness is vital to recruiting study participants who are representative of the population. This tool is a way for researchers to put commitments to equitable studies into action by actively improving themselves before launching the study.

"The journey to measure <u>abstract concepts</u> such as 'trustworthiness,' along with the multidimensional relationship between '<u>trust</u>' and 'distrust' is exciting and challenging. We've had confidence that researchers can behave in a more trustworthy manner even as people along the way said it can't be proved or reliably measured. I found that emboldening," said Sarah Stallings, Ph.D., research assistant professor in the genetic medicine division at VUMC.

**More information:** Sarah C. Stallings et al, Development and Validation of the Perceptions of Research Trustworthiness Scale to Measure Trust Among Minoritized Racial and Ethnic Groups in



## Biomedical Research in the US, *JAMA Network Open* (2022). DOI: 10.1001/jamanetworkopen.2022.48812

## Provided by Vanderbilt University Medical Center

Citation: Team develops scale to rebalance burden of initiating trust in science (2023, April 27) retrieved 21 June 2024 from <a href="https://phys.org/news/2023-04-team-scale-rebalance-burden-science.html">https://phys.org/news/2023-04-team-scale-rebalance-burden-science.html</a>

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