

A Community-Engaged Approach to Measuring Trust in Biomedical Research

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Background

Lack of trust toward research is one of the most commonly cited barriers to study participation, especially among groups underrepresented in research.^{1,2} Of 45 instruments for measuring trust, only two are related to biomedical research,³ and neither of the two includes the four trust areas most commonly identified by racial/ethnic minorities.^{4,5,6}

Objective

To understand elements of trust in research among underrepresented groups that may not be reflected in existing trust scales.

Methods

We conducted a series of 7 focus groups, taking a cross-cultural approach with three racial/ethnic groups. Participants were consented and completed a demographic survey and either the Hall or Mainous Trust Scale. Topics discussed included Research, Trust, Privacy/Confidentiality, and Research Participation. Transcripts of the focus groups will be blindly reviewed and excerpts will be coded for themes by two independent coders.

Results

Of the 58 participants, 80% were racial / ethnic minorities, 69% had no prior research participation, 39% had high school diploma or less level of education, and 33% had an annual household income of less than \$15,000. In preliminary thematic analysis, results show that trust in research varies based on the research institution's history, time spent by the researcher on enrollment, completeness of study information given, and recruitment appeal source (i.e., friend, doctor, respected community figure, flyer, radio, etc.).

Discussion

Perspectives on trust among racial/ethnic minorities and individuals with limited income differ from the majority population and may not be captured by existing trust measures. New or adapted measures of trust are needed to assess trust among these groups.

References

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1. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee:

understanding mistrust about research participation. *Journal of health care for the poor and underserved* 2010;21:879-97.

2. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health* 2014;104:e16-31.
3. Ozawa S, Sripad P. How do you measure trust in the health system? A systematic review of the literature. *SocSci Med* 2013;91:10-4.
4. Durant RW, Legedza AT, Marcantonio ER, Freeman MB, Landon BE. Different types of distrust in clinical research among whites and African Americans. *Journal of the National Medical Association* 2011;103:123-30. 5 Armstrong K, McMurphy S, Dean LT, et al. Differences in the patterns of health care system distrust between blacks and whites. *Journal of general internal medicine* 2008;23:827-33.

6 Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. Public health reports 2003;118:358.