Relationship of Trust and Research Engagement

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Background/Objective: Lack of trust is a major barrier to research participation and can lead to disparities in health outcomes. Scales that measure trust in healthcare organizations and biomedical research have never been synthesized into a single tool, nor has such a scale been used to assess attitudes regarding trust in a more focused community. This project aims to measure trust in medical researchers and healthcare institutions in Indiana.

Methods: A survey was created by combining previously validated trust scales (Shea et al., Mainous et al., and Hall et al.) along with questions about demographic backgrounds. Cognitive interviewing was conducted in three focus groups to finalize survey questions. The questionnaire was sent to participants recruited via email from the All IN for Health registry, a statewide database of volunteers interested in research participation.

Results: At the time of analysis, 481 participants had completed the survey. About half of respondents were age 60+, and almost three times more women participated than men. The majority had bachelor's degrees or higher (72.5%). About half of participants agree that healthcare organizations cover up their mistakes. Half disagreed that patients get the same medical treatment regardless of race/ethnicity. Almost one in five respondents (17.4%) believe that medical researchers conduct experiments on people without their knowledge.

Conclusion: Preliminary results suggest additional efforts may be needed to foster trust in healthcare research and organizations. Results may not be generalizable to the entire population due to differences in gender, race/ethnicity, and level of education across initial respondents. One limitation is that recruitment using the All IN for Health registry may have produced biased results. Further studies are needed to understand factors that may influence trust.

Scientific/Clinical/Policy Implications: Results may influence public outreach and research recruitment to gain trust from Indiana residents and enhance participation in medical research.