When and How Are We Engaging Stakeholders in Health Care Research?

Stakeholder engagement in research refers to the involvement of patients, doctors, payers, and other decisionmakers, from the early stages of setting priorities and forming research questions through the final stages of implementing and disseminating results. Many advocates for patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) see collaboration between researchers and stakeholders as the best way to generate evidence that is relevant, responsive, and trustworthy, and thus likely to be put into practice. The goal of CER is to help people choose the most effective treatments for their individual needs; the use of PCOR can enhance the impact of CER.

To establish a baseline understanding of the frequency and nature of reported stakeholder engagement, a team from RAND, Tufts University, and Brown University systematically reviewed more than 2,000 abstracts and 70 articles published since 2003. The team enlisted seven stakeholders—including two patients—to assist with the design, conduct, interpretation, and dissemination of the review.

The study found significant variation in terms of both how and what researchers report about stakeholder engagement (see the figure):

Frequency of Stakeholder Engagement, by Stage of Research

![Frequency of Stakeholder Engagement Chart]

Who is engaged?
■ Patients and health care providers were the most frequent collaborators.
■ Policymakers and other researchers collaborated infrequently, or about 20 percent of the time.
■ Payers, product makers, and purchasers collaborated rarely, or less than 10 percent of the time.

When are they engaged?
■ Stakeholders were most frequently engaged in the earlier stages of research, when priorities are determined and evidence is generated.
■ Engagement was least frequent in syntheses of previous research, simulation studies, guideline development, and dissemination of findings.

The research team developed a 7-Item Stakeholder Engagement Reporting Questionnaire to encourage more uniform reporting on collaboration with stakeholders. The team recommends additional studies to evaluate the impact of engagement on the relevance, transparency, and adoption of research, as well as new tools and training opportunities to improve engagement methods throughout the life cycle of a research project.