A Novel Stakeholder Engagement Approach for Patient Centered Outcomes Research

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Background
The engagement of patients and other stakeholders is a critical element in the design of patient-centered outcomes research (PCOR) studies. However, methodology for scalable engagement in research management particularly activities such as operationalization of principles and setting of priorities is not well-developed.

Study Design
PCORI engagement principles were applied to the development of network policies and determination of research priorities in three conditions:

- Weight management/obesity, Heart failure, Kawasaki disease

Objectives:
A. Operationalize a comprehensive stakeholder engagement program
   - Utilize PCORI Engagement Framework (See Fig 1)
B. Enable meaningful participation in creation of stakeholder-engaged research vision
   - Stakeholder advisory boards involved in planning and development the governance activities and refining policies.
C. Assess engagement strategies at scale
   - Stakeholder research prioritization expert panels that set research priorities using an online, modified Delphi method, a deliberative, iterative approach to attaining consensus with discussion and statistical feedback (See Fig 2)
   - Assessment will conducted in future

Setting

- 14 clinical sites
- 30 million patients

Conclusions
An efficient way to engage large numbers of representative stakeholders in research is a necessary first step to assure the public of trustworthy use of data networks for health research. This paper describes a comprehensive approach to engagement in PCOR research management that can inform ongoing development of rigorous methodologies.

Implications for Policy or Practice: This study provides insights on advantages, challenges, and lessons learned related to meaningful participation of patients, and interaction among diverse stakeholders who might not typically work together. These findings may be helpful for other researchers and practitioners interested in research networks and patient-centered outcomes research.

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