

An Approach to Capture Divergent Stakeholder Views on Future Research Needs

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Stakeholder involvement in identifying and prioritizing future research needs is a core principle of PCORI's mission and mandate. Yet, the evidence base for how to capture stakeholder inputs in the knowledge development process is surprisingly underdeveloped. The usual way stakeholders are involved is through a small panel where knowledgeable individuals are recruited either as scientific experts, experienced clinicians, informed patients, or as advocates to represent or speak to the views of the larger community. An alternative approach is to survey a large panel of stakeholders so that diverse opinions can be better reflected in the final set of rankings or priority listings as has been done in the UK (Entwistle et al, 2008). There is no evidence to date about which approach is optimal. Given the wide range of diseases and disorders today that are characterized by divergent stakeholder opinion, research is needed to assess the relative merits of these two approaches. We will address this need by developing a better understanding of how stakeholders value future research using autism as an indicator condition. Utility theory holds that utility for a future research investment is derived from its attributes (Lancaster, 1991). Attributes can be measured by discrete choice experiments administered as a survey as done to model community preferences for health services. Using discrete choice experiments to model preferences for future research needs as proposed in this application is novel. Autism is an instructive context for methods development because of a wide diversity of stakeholder opinion, but the methods developed here can be readily applied to other disease conditions. The proposed study will be carried out in relation to three aims:

Aim 1: To compare attributes and utilities for future research from small and large panels of stakeholders, Aim 2: To compare priorities for future research generated by the small and large panel utility models estimated in Aim 1, and Aim 3: To explore stakeholder satisfaction with the small and large panel approaches. The proposed study responds to PCORI's interest in methods development, transparency, credibility, and access. Findings will advance the Institute's mission to promote a rigorous stakeholder-driven process for informed health care decision-making and health care delivery.

RELEVANCE

The proposed research can contribute to PCORI's mission to support informed health care decision-making that improves health care delivery and outcomes by providing evidence on methods to elicit stakeholder preferences for future research that provide insight into the heuristics of future research choices and their variation within stakeholder communities.