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Background

To deliver care in a manner that improves patient outcomes, we must understand the diversity of patient priorities and treatment experiences in the real world. However, there is lack of consensus across different stakeholders on how to meaningfully incorporate patient priorities in healthcare research, from comparative effectiveness research to outcomes and value assessment, to inform decision-making.

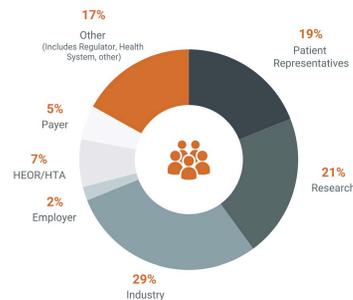
Objective

To drive consensus across stakeholders on what matters most to patients in their health care and explore how to measure value from the patient perspective.

Methods

- IVI hosted a PCORI-funded Methods Summit, held virtually over 3 days in Oct.-Nov. 2021, convening different stakeholder groups to discuss priority patient inputs, methods, and research needed to more fully capture patient perspectives to inform healthcare research.
 - 22-member multi-stakeholder steering committee guided program design.
 - Day 1 was a public meeting with overview and perspectives from 3 panels representing patients, payers, and methods experts.
 - Day 2 utilized small-group discussions for specific issues identified from Day 1.
 - Day 3 involved work with experts to synthesize findings and develop key principles to incorporate patient perspectives in healthcare decision-making.
- >170 stakeholders (Figure 1) representing patients, employers, researchers, payers, manufacturers, and health systems participated, including 25 patient organizations, as well as national and federal partners including Centers for Medicare and Medicaid Services, FDA, and National Quality Forum.

Figure 1. Profile of IVI Methods Summit Participants



Findings

All stakeholder groups agreed that much of what currently gets measured in healthcare research and delivery does not fully reflect patient experiences and priorities in seeking care. **Key themes** identified included:

- Patients and caregivers are at the center of managing healthcare but often left out of data reporting and value determination process.
- Patients bear significant burden in evidence generation but are not empowered or resourced to do this essential work.
- Claims data are inadequate for assessing value, with additional data needed to capture what happens at home, at work, and in the community during daily living.

Key principles were produced to offer guidance and specific steps to incorporate patient and family perspectives into healthcare decision-making and to inform action by IVI, PCORI, and others to engage patient communities to measure patient-important impacts and develop methods to incorporate patient perspectives. Key principles fell into two domains:

Elevate Visibility and Policy Support for Patient-Centered Impacts as an Essential Element in Assessing Value and Facilitating Access

- Prioritize and define patient-centered impacts and research questions as early as possible in CER and value assessment
- Share data collected as part of CER or value assessment back with patients in a timely and actionable manner
- Include and fairly compensate patient leadership, perspectives, and expertise in PCOR/CER and value assessment
- Establish standards and accountability to increase transparency into how patient inputs are considered and incorporated in decision-making

Incorporate Patient Impacts and Perspectives in Regulatory and Payer Decision-Making by Improving Measures and Methods

- Create measures and methods to capture costs and burdens to patients/families as a result of health or healthcare
- Identify purpose of measurement within CER or value assessments for specific decision contexts and address tension between condition-specific and cross-cutting measures by investing in both areas of measurement development
- Increase transparency in data collection and management, with sharing of patient-centered data as a "public good"
- Standardize measures of health-related social needs that address patient-centered outcomes and health disparities
- Invest in decision analytic methods and workforce training to support research, patient, regulatory, and payer communities in collecting, interpreting, and incorporating patient-important impacts into decision-making

Conclusion

The PCORI-Funded IVI Summit 2021 generated insights that provided different stakeholders with guidance and specific steps to ensure healthcare research more fully captures patient priorities and leads to more patient-centered care.

Reference

Innovation and Value Initiative. 2021 Annual Methods Summit: Designing Equitable Measures and Methods for Patient Priorities in Healthcare Value Assessment. <https://www.thevalueinitiative.org/2021-methods-summit/>