Engaging patients, families, subject matter experts, and health system leaders in research study design results in findings that:

- are more relevant and meaningful to families,
- can be acted on over the long-term by health care providers, and
- are trustworthy to scientists.

**PROJECT HIGHLIGHTS**

**Results of advisory group engagement**

**How we worked with the group:**
- Working sessions and town hall discussions
- Small-group breakdowns
- Open comment periods
- Ranking, sorting, and rating scale tools

**Approach:** edits to big picture research questions

**Survey:** decreased questions from 115 to 39; edits to more than 50% of survey questions

**Interviews:** edits to all interview scripts and approaches

**Priority areas for survey & interviews**

- Access to care
- Care coordination
- Engagement in care
- Compassionate care*
- Culture & respect*
- Family flourishing & wellbeing*

*Topics particularly emphasized by patients and families

**Example of how a question changed:**

- **Original Survey Questions**
  - During the last 12 months, how often did you feel discriminated against (i.e., you were treated differently or the child's care was affected) by the child's care team?

- **Revised Survey Questions**
  - During the last 12 months, did you feel that members of the health care team were biased against you and/or the child (treated you unfairly)?

**PATIENT/COMMUNITY IMPACT**

Engaging patients/caregivers and health system leaders in the research planning process resulted in data collection tools more likely to measure what matters when figuring out if these interventions worked or not.

Data collected for the evaluation will be used to determine how effective interventions were in:

- Improving care access & coordination
- Improving family experience & outcomes

**CONCLUSIONS**

The planning for this evaluation provides a real-world example of how patient/family engagement can be put into practice to meet the goals of diverse stakeholders.

The participatory design was accomplished through thoughtful and repeated engagement of patients/families, health system leaders, and experts throughout the creation of data collection tools.

This approach resulted in data collection tools that:

1. Measure what matters most to those most affected by the interventions (i.e., patients/families and those who deliver care)
2. Do not create unnecessary burden on patients/families or those delivering care by trying to ask too many questions

**RECOMMENDATIONS**

1. Including patients/families and health system leaders in research design is key to producing trustworthy, relevant findings.
2. Relationship-building is essential for engaging diverse stakeholders in research over time.
3. Combining 11 small groups, and large group feedback opportunities ensures the richest level of input is received.
4. Engaging in an empathetic way, promoting belonging, and fostering an "all teach, all learn" culture provide benefits.

**CONTACT INFORMATION**

Sarah Hoyt
Senior Manager, Health Systems Improvement
Sarah.Hoyt@academyhealth.org

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling $3.5 million. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.