

BACKGROUND

Children with medical complexity (CMC) are children who have **multiple serious, chronic health conditions**, including **limitations affecting daily functioning** and **high health care service needs and use**.

CMC and their families often struggle to navigate the health care system; lacking assistance needed to coordinate care among multiple providers.

The *Enhancing Systems of Care for Children with Medical Complexity* coordinating center serves five demonstration sites testing **new ways of organizing care delivery for CMC (interventions)**.

OBJECTIVE

Evaluations of health care interventions should include patients/caregivers and health system leaders/clinicians in the planning process. This ensures the things that matter most to the people most affected are being looked at when figuring out if the interventions work or not.

Accordingly, this project had the following objectives:

1. Include the people most affected by the health interventions in the design of the data collection tools, and
2. Create data collection tools that, when used, will tell us if the health interventions made care better or not.

PROJECT DESIGN

Advisory groups were created to support planning for an evaluation of 5 demonstration sites – gathering **53 patients/families and experts** to provide 3 perspectives:

1. Research expertise – subject matter experts
2. Clinical expertise – health system leaders
3. Lived expertise – patients and families



DEMOGRAPHICS

The evaluation will look at new ways of organizing care delivery for CMC at **five sites in four states**:

- Florida
- Georgia
- Montana
- Texas



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 breakouts
- 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?
- If you felt discriminated against (i.e., you were treated differently or the child's care was affected) by the child's care team, what do you feel was the reason(s)?

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/the child **unfairly**)?
- **Against whom** did you feel that members of the health care team were biased?
- Do you feel that this bias **affected the child's care**?
- Why do you think the care team members were biased against you and/or the child? (Select all that apply)

PATIENT/COMMUNITY IMPACT

Engaging patients/caregivers and health system leaders/clinicians 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**.

Evaluation data collection begins in 2024. 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.

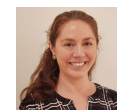
This approach resulted in data collection tools that:

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 1:1, small group, 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 benefit.

CONTACT INFORMATION



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