Enhancing Systems of Care for Children with Medical Complexity
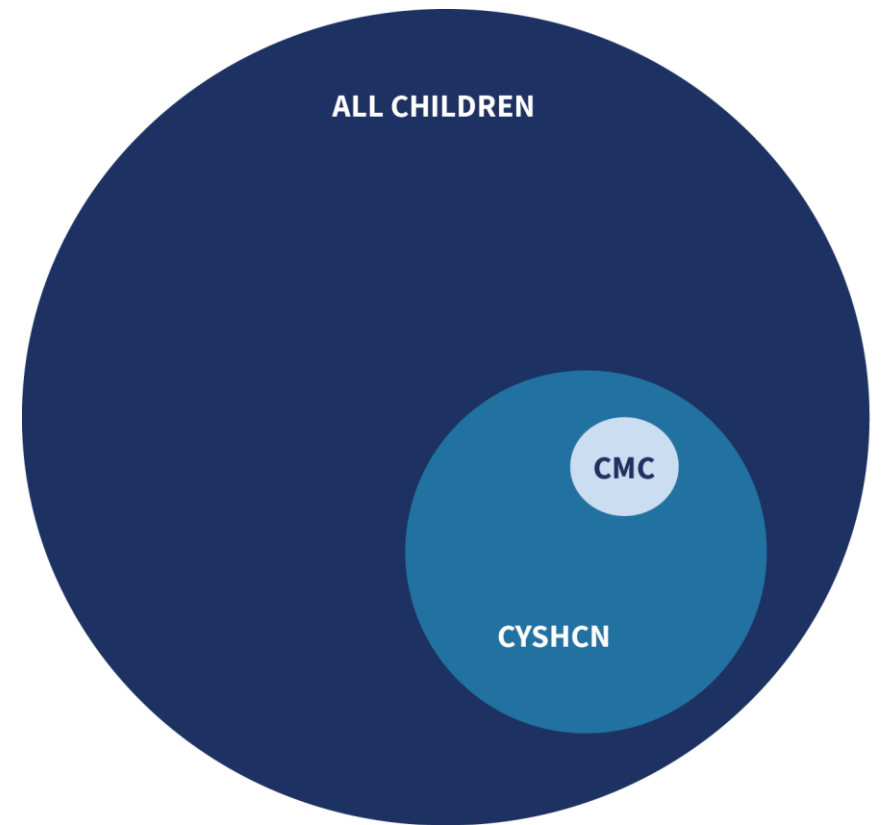
Participatory Design of a Multi-Site Evaluation

Elizabeth Cope*, Sarah Hoyt, Maria Mutka, LaToshia Rouse, Richard Antonelli, Jeffrey Schiff
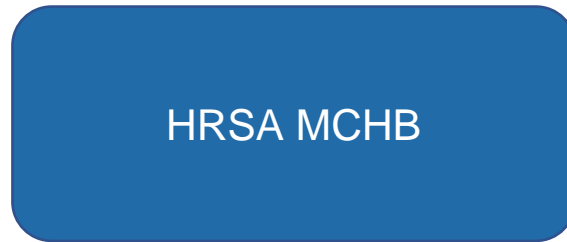
Why are we talking about this?

- Children with medical complexity (< 5%)
  - Intensive hospital / community-based service need
  - Reliance on technology, polypharmacy, home care / congregate care
  - Risk of frequent & prolonged hospitalizations → high service utilization
  - Elevated need for care coordination
- Needs not well met by existing models of care
- Caregivers → stress, depression / anxiety, sleep deprivation, financial hardships, social isolation

ALL CHILDREN

CMC

CYSHCN

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Enhancing Systems of Care for Children with Medical Complexity Initiative

Funding

Operations

Oversight

HRSA MCHB

Coordinating Center (CC)

AH BCH FV UCSF AAP PAF

Advisory Committee

- Evaluate models of care
- Offer training & TA
- Foster external collaboration
- Promote uptake & sustainability

Affinity Groups

Family Partners   Measure & Eval

Workgroups

FP   M & E   Equity
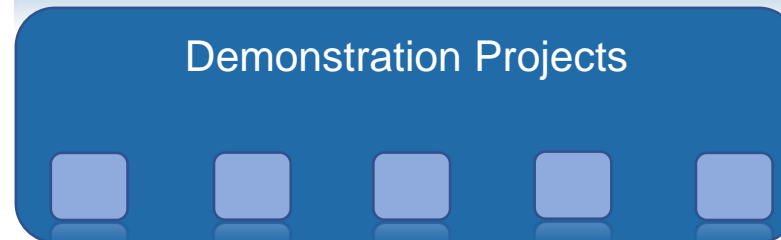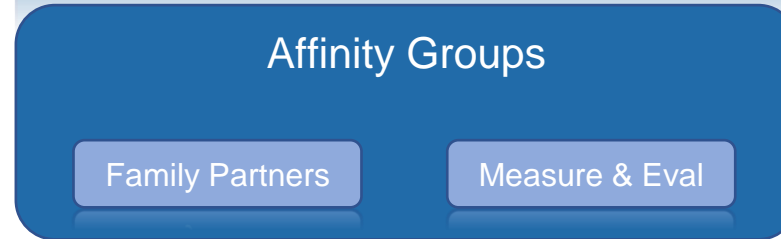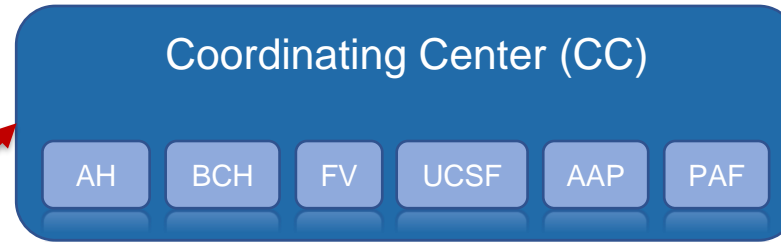
CC Partner Orgs:
AH: AcademyHealth
BCH: Boston Children's Hospital
FV: Family Voices
UCSF: Univ of CA, San Francisco
AAP: American Academy of Pediatrics
PAF: Patient Advocate Foundation

Demonstration Projects
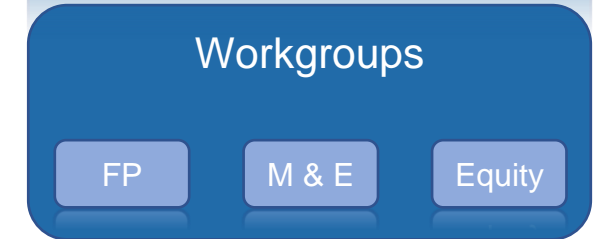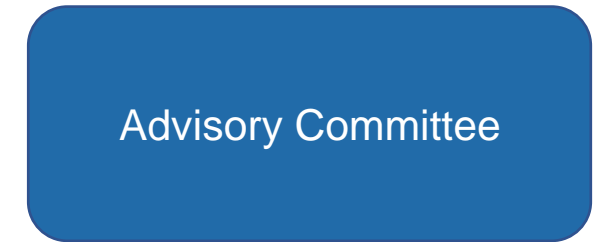
Testing models of care to:
- Enhance access
- Use innovative technologies
- Use equity-informed approaches

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Balancing Evaluation Priorities

Important to Patients / Families

Family Burden

Inform the Field for Uptake & Spread

Important to Sites (QI / Learning)

Site Burden

Relevant to Policy for Sustainability

Evaluation Design & Launch Plan
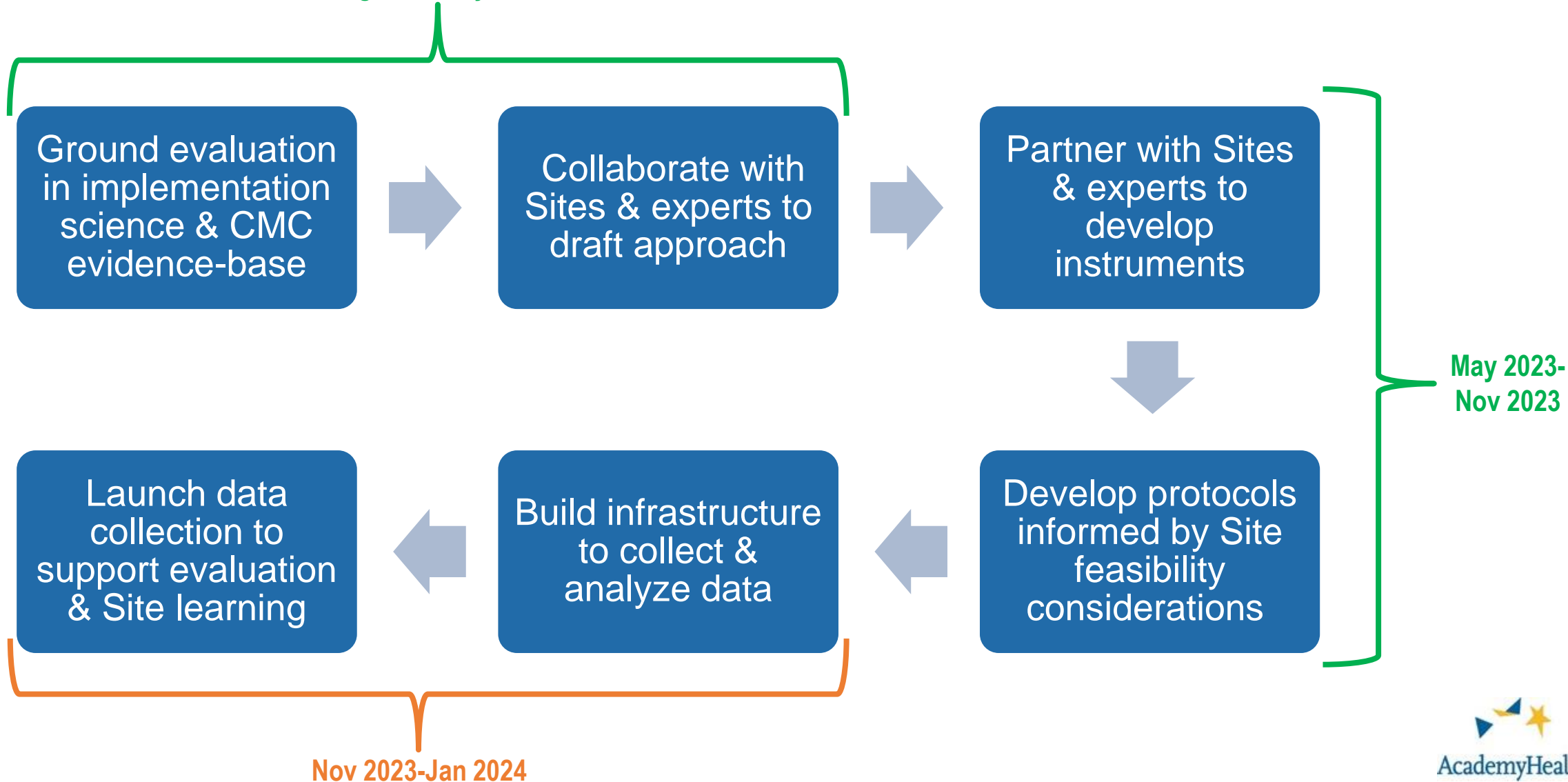
Engagement Framework

Intensity (→)	Gather Information	Discuss	Engage	Partner
Reach (←)	**Broader**	**Moderate**	**Narrower**	**Most Narrow**
Engagement Mechanisms	- Rank-order sorting - Rating scales - Open comments	- Working Session - Town Hall	- Deliberative Dialogue	- Integrated CC Team: AH, BCH, FV, UCSF, AAP
Mix (→)	**Single Stakeholder Groups**		**Multi-Stakeholder Groups**	

Engagement Touchpoints (Nov 2022 – Nov 2023)

Group	Size (N)	Working Sessions (N)	Town Halls (N)	Deliberative Dialogues (N)	Asynchronous Review (N)
Demonstration Site (DS) Representatives					
Measurement & Evaluation Affinity Group (SME)	13	3	2	2	6
Family Partnership Affinity Group (ExE)	13		2	2	2
External Advisors (Subject matter experts, experts by experience, State & Federal policymakers)					
Advisory Committee	31		1	2	2
Measurement & Evaluation Workgroup	12	2	2	2	5
Family Partnership Workgroup	12		2	2	2
Equity Workgroup	12		2	2	2

Results of Engagement

Approach: Refinement of overarching research questions & frameworks

Protocols: integration of data collection infrastructure, timing, elements; alignment of incentives

Survey: reduction from 115 to 39 survey items; revisions to over half of final metrics and survey questions

Interviews: refinements to interview guides and protocols

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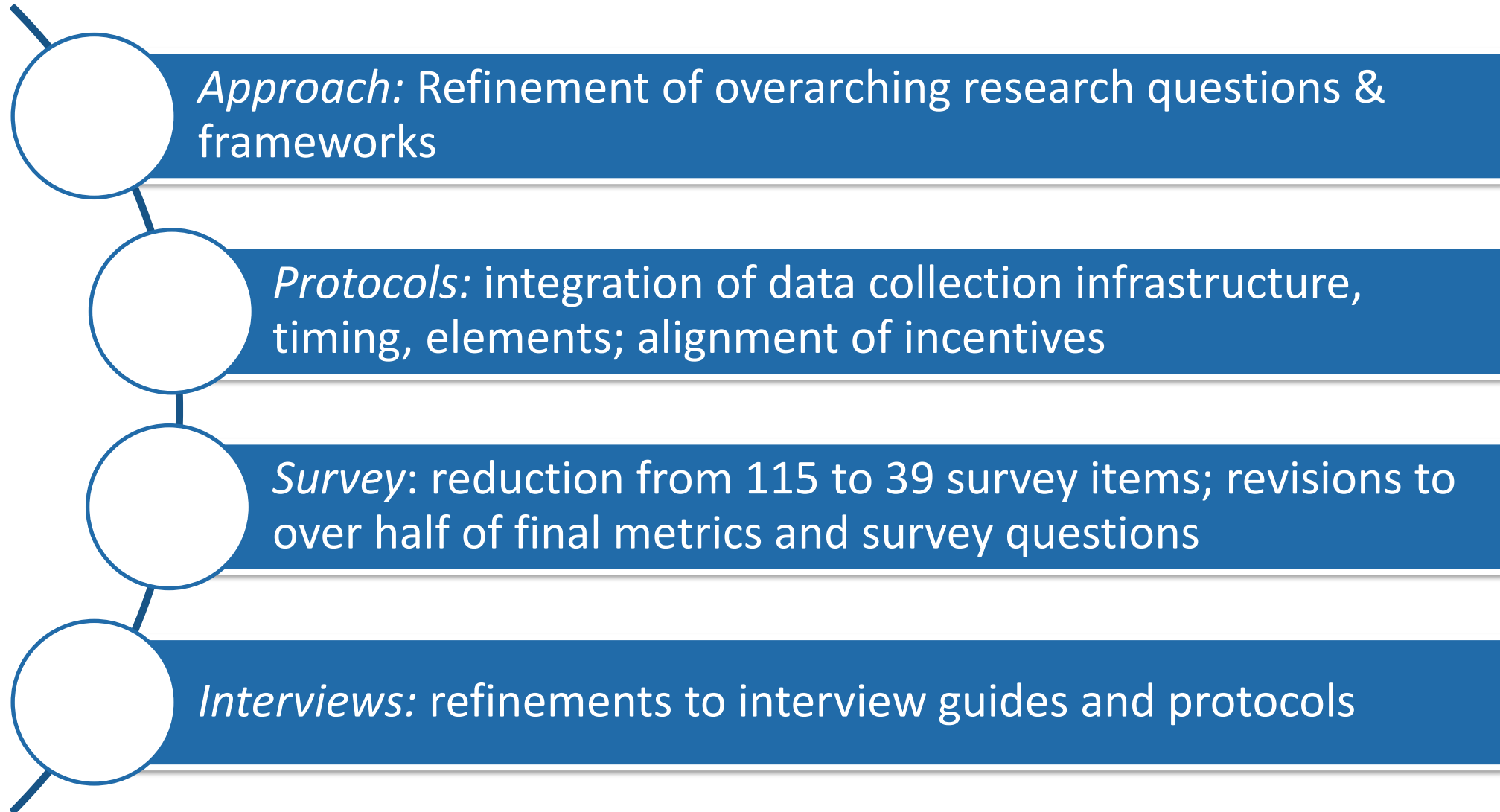
Evaluation Approach

	Implementation Context	Implementation Process	Implementation Outcomes
Research Questions	• What are the barriers and facilitators of site implementation strategies?	• How did sites prepare for and support implementation efforts?	• How did the interventions impact outcomes relevant to CMC and their families?
Data Sources	• In-depth Interviews	• Site Reporting • In-depth Interviews	• Survey • In-depth Interviews
Relevant Frameworks	• Exploration, Preparation, Implementation, Sustainment (EPIS) [From RE-AIM to EPIS] • Consolidated Framework for Implementation Research (CFIR)		
Protocol Integration	• Annual survey with local site-specific modules, administered by sites • Interviews in PY2 & PY5, administered by CC, incentives determined by CC family partners • Site reporting tools integrated with CC technical assistance activities		

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Example: Rank-Order Feedback Tool

Patient Family Experience of Care (PFE) & Care Coordination (CC)

Tier 1 Measures

Subdomain	Subdomain Topics	Importance to Measure: Rank topics in each subdomain (where 1=most important)	Site Plans to Measure This Topic (regardless of inclusion in the CC Evaluation)	Additional Comments / Considerations
Access to Information	Timely access to information about patient's care	2	yes	Instead of "patient's care", might prioritize "patient's health status."
	Patient/family questions are answered	4	yes	
	Information communicated in a way the patient understood	1	yes	
	Appropriate information communicated	3	yes	
Care Coordination - Team-Based Communication	The patient/family is a key center of the care team	1	yes	
	The care team has a centralized care coordinator	2	no	Our care model does not have a "centralized" care coordinator per se.

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Sample Question Transformation

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)

Family Survey Items

TOPIC AREA (# ITEMS IN SURVEY)	
BACKGROUND	
Respondent Details (4)	Insurance Coverage (4)*
Demographics (4)*	Condition Severity (7)*
MODEL QUALITY / OUTCOMES	
Access to Care (13)	Compassionate Care (2)
Care Coordination (3)	Culture & Respect (5)
Engagement in Care (8)	Family Flourishing / Wellbeing (5)

*To be collected from medical records

Family/Caregiver Interviews: Storytelling-based

Background & Coordination
Background: What do typical, great, and bad days look like? How was your most recent visit to the provider?
Experience & Care Coordination: understanding experiences related to interacting with providers & arranging for care with providers

Decisions, QoL, Compassion/Culture
Shared decision-making: How decisions are made & how it works when families and providers disagree
Health-related quality of life: What the site does & can/should do to help with QoL
Compassion & culture: focus on discrimination, trust, and support

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Key Takeaways

- This project offers a real-world use case for operationalizing participatory implementation evaluation design to meet complex competing needs

- Relationship-building is essential in longitudinal engagement

- Targeted and mixed engagement opportunities are both needed to ensure breadth & depth of input

- Collective empathy-building, promoting belonging and "all teach, all learn" culture provide benefit

- Logistical supports to facilitate engagement are critical (timing, level-setting, plain language, etc.)

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