

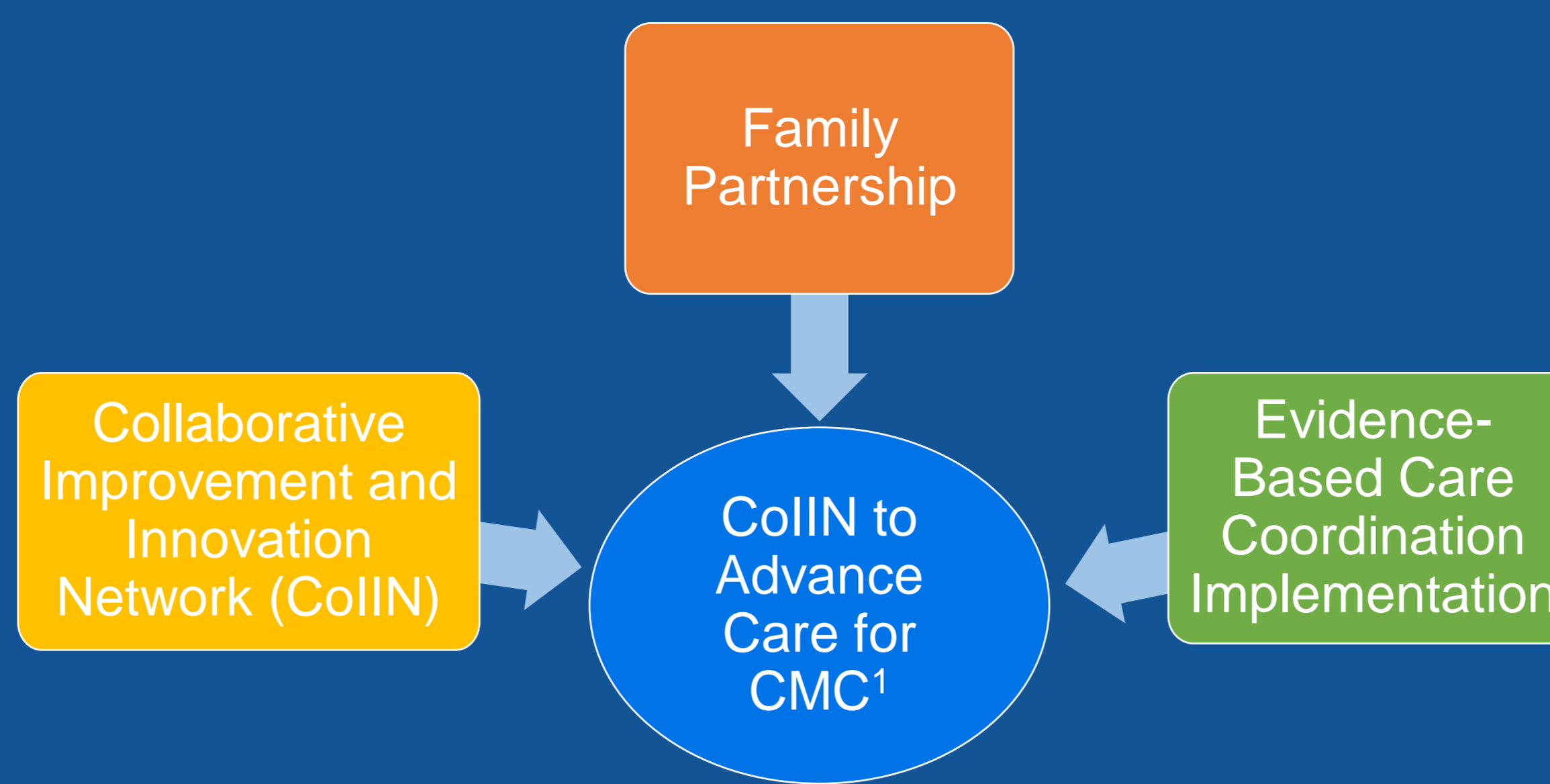
Family engagement model to support translation of evidence-based care coordination for children with medical complexity

14TH ANNUAL CONFERENCE

ON THE SCIENCE OF DISSEMINATION AND IMPLEMENTATION IN HEALTH



Rhonda Cady, PhD, RN, Gillette Children's Specialty Healthcare, St. Paul, MN
Tricia Brisbane, MA, Family Advisor, Gillette Children's Specialty Healthcare, St. Paul, MN



RESEARCH POPULATION & OBJECTIVES

Children with Medical Complexity (CMC)²

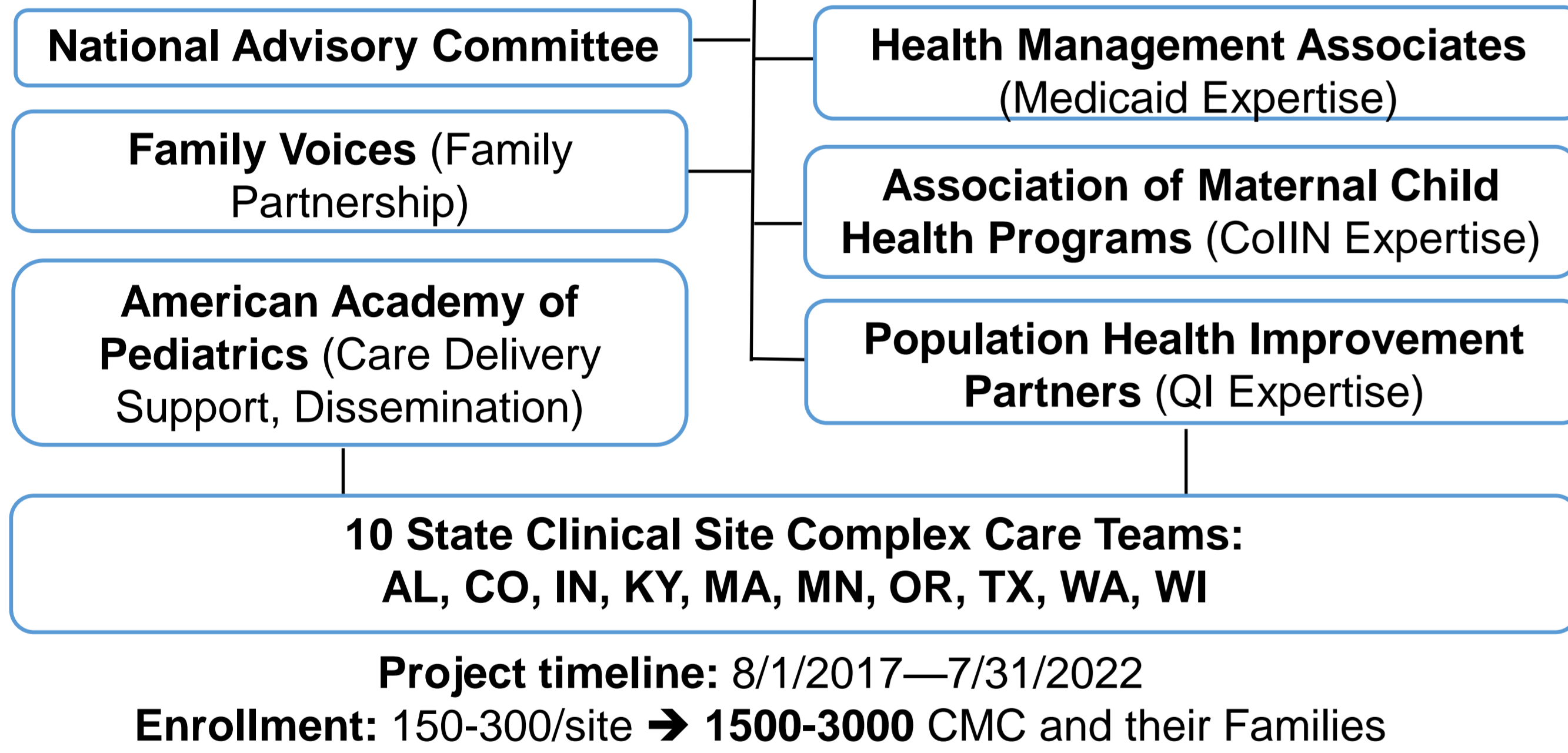
- Multiple complex chronic conditions
- Severe functional limitations
- Technology dependence (tracheostomy, feeding tube, ventral-peritoneal (VP) shunt)
- < 1% of US children but ~ 40% pediatric health resource utilization

Objectives

- Improve Quality of Life for Medically Complex Children
- Increase Well-Being of their Families

RESEARCH COLLABORATIVE

Center for Innovation in Social Work and Health at Boston University



10 State Clinical Site Complex Care Teams:
AL, CO, IN, KY, MA, MN, OR, TX, WA, WI

Project timeline: 8/1/2017—7/31/2022

Enrollment: 150-300/site → 1500-3000 CMC and their Families

PRINCIPAL FINDINGS

Family Engagement in Systems Assessment Tool (FESAT)⁴



Four Domains of Family Engagement in Systems⁵

Representation

- Reflect diversity of the community (race, ethnicity, language, income, education level and geography)
- Partner with family-led and community-based organizations

Transparency

- Provide access to relevant knowledge
- Practice partnership in all parts of the process

Impact

- Identify what has changed and what the organization or system of care is doing differently because families were involved

Commitment

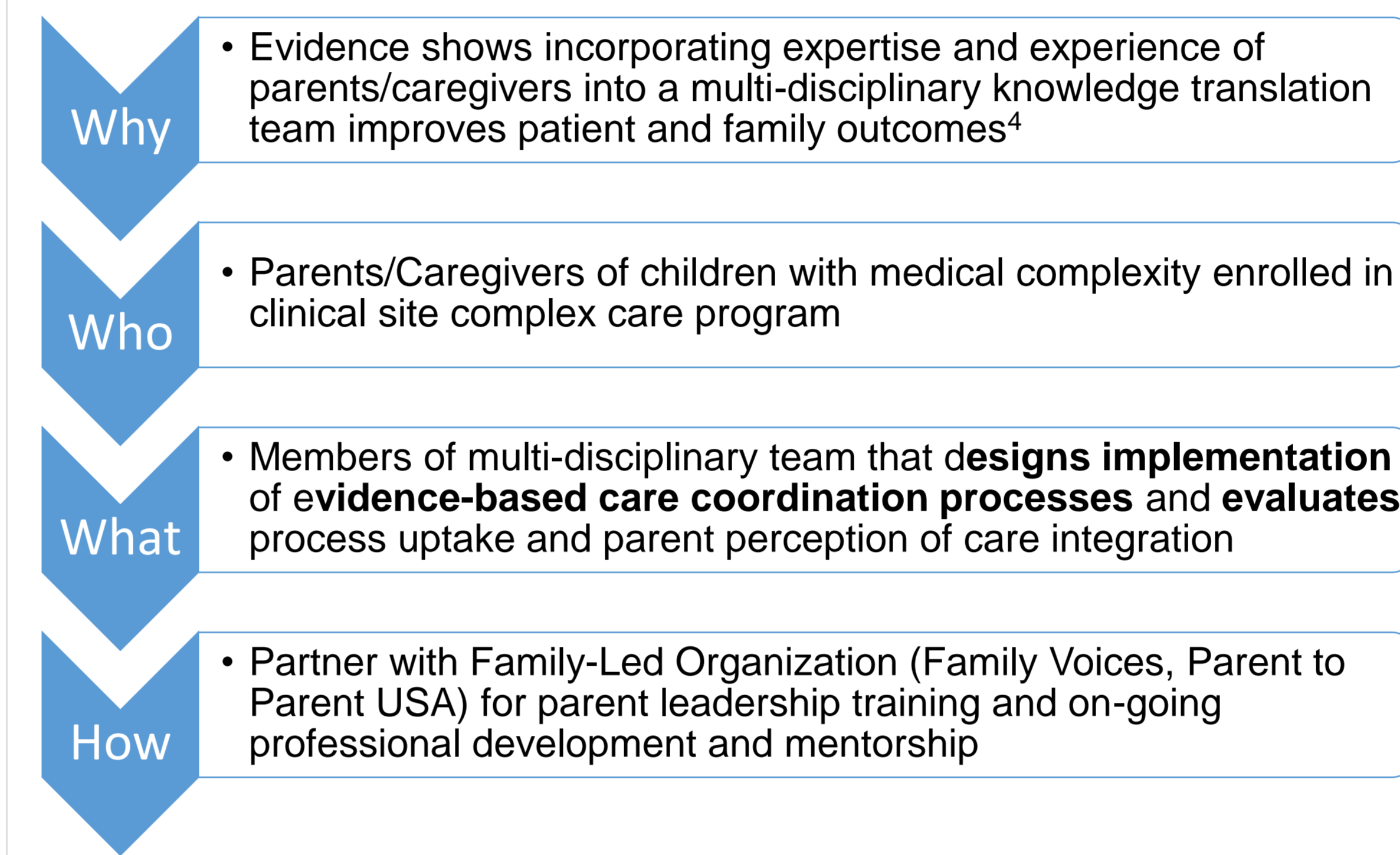
- Promote engagement as a core value
- Establish engagement at all levels, in all systems of care

FUNDAMENTAL STUDY DESIGN COMPONENTS

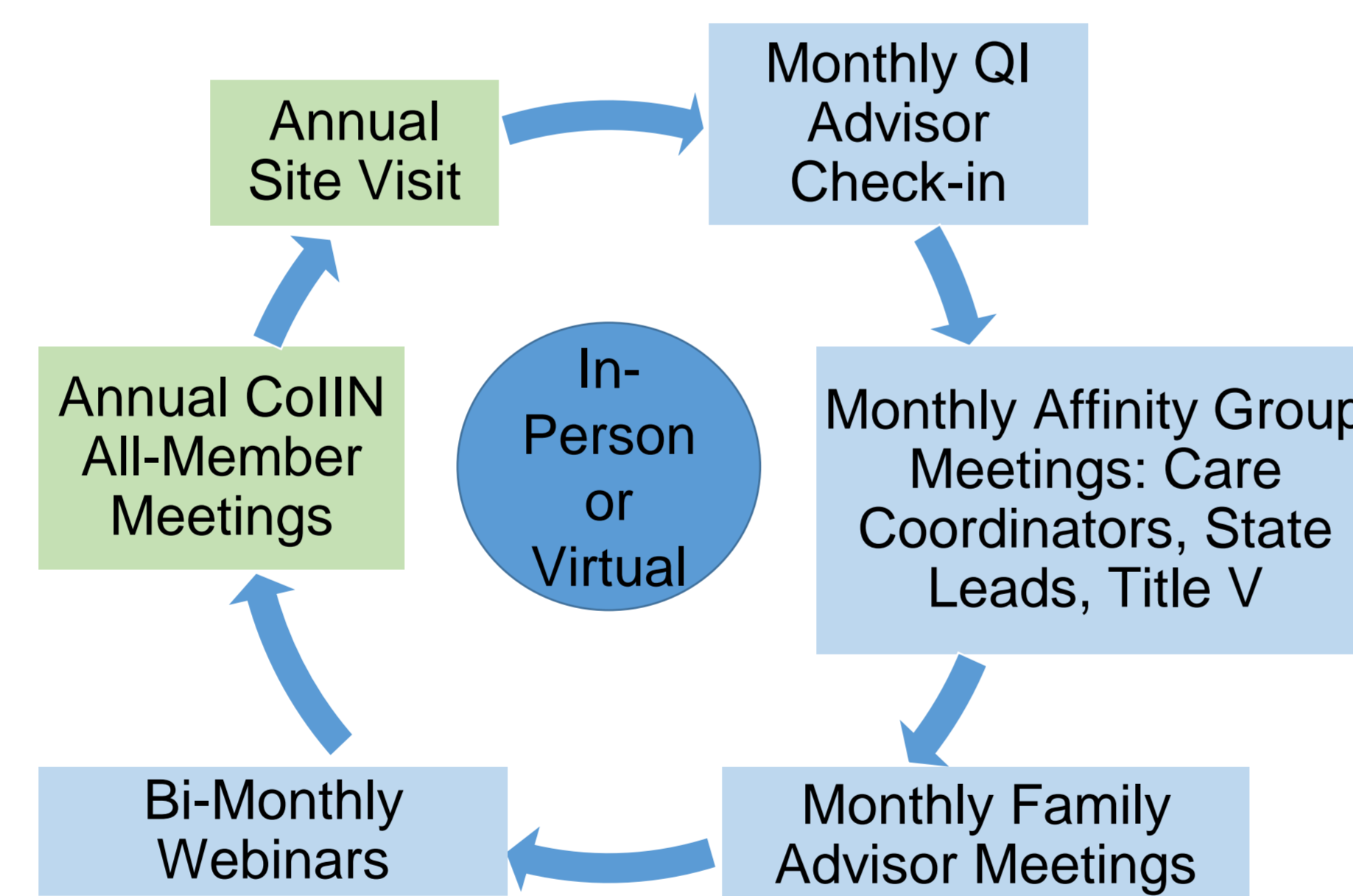
Collaborative Improvement and Innovation Network (CoIIN)³ Methodology



Family Partnership



CoIIN Implementation: Cross-Sharing and Collaboration

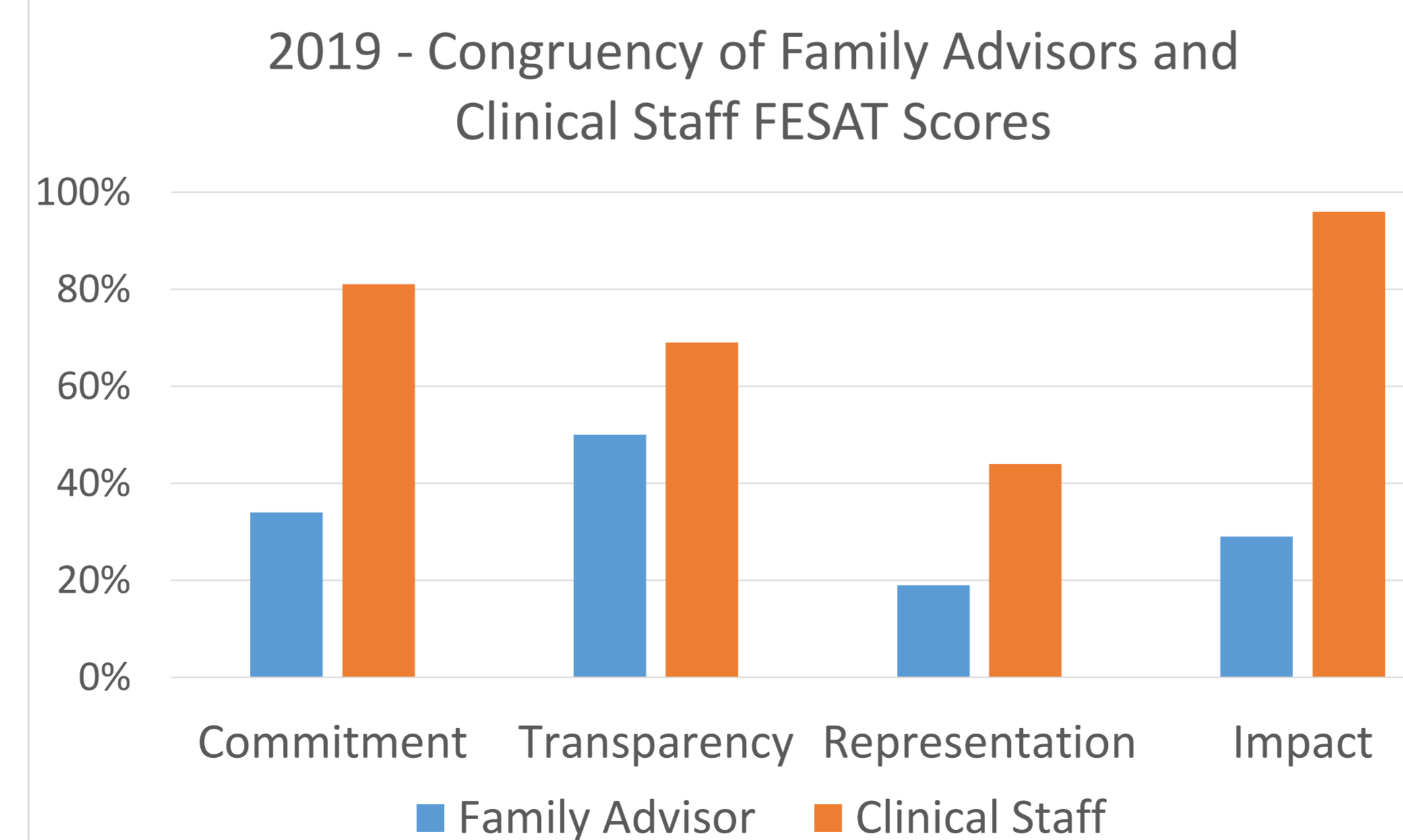


Gillette's Multi-Disciplinary Knowledge Translation Team

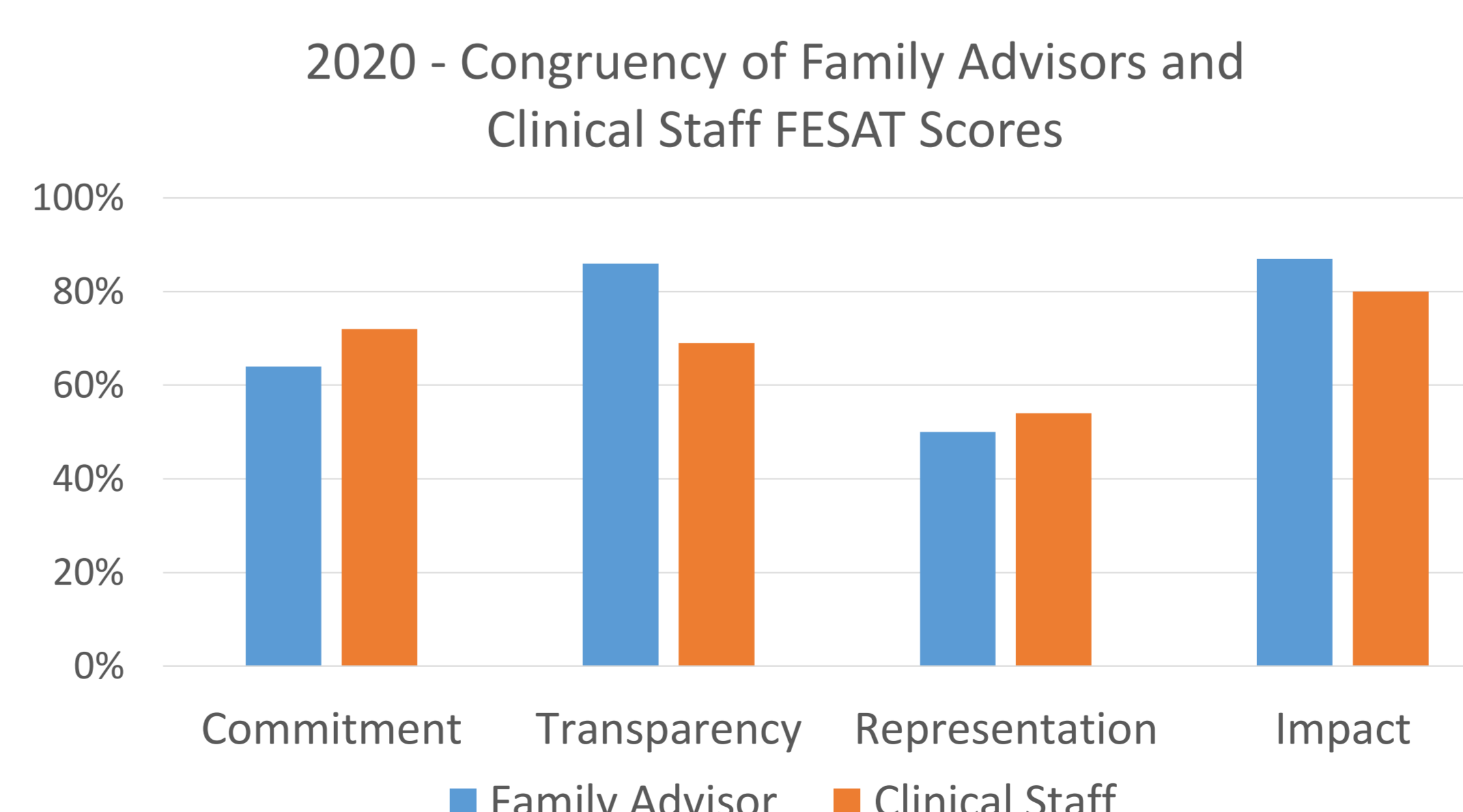
- Ground rules for equal inclusion and voice of all members
- Team members trained on process improvement and evidence-based care coordination processes⁵
- All team members paid, including family advisors



Used the evidence-based FESAT⁴ to assess engagement domains in our multi-disciplinary team



How can we do better? Develop Action Plan for each FESAT⁴ Domain



IMPLICATIONS FOR POLICY AND PRACTICE

Building Essential Allies⁶



- Building *Essential Allies*⁶ is a structured approach that requires support, resources and work
- Institute for Patient-and Family Centered Care resources provide expert guidance

Organizational leadership support for equal and paid family advisors

Parent/caregiver readiness to serve and training as a family advisor

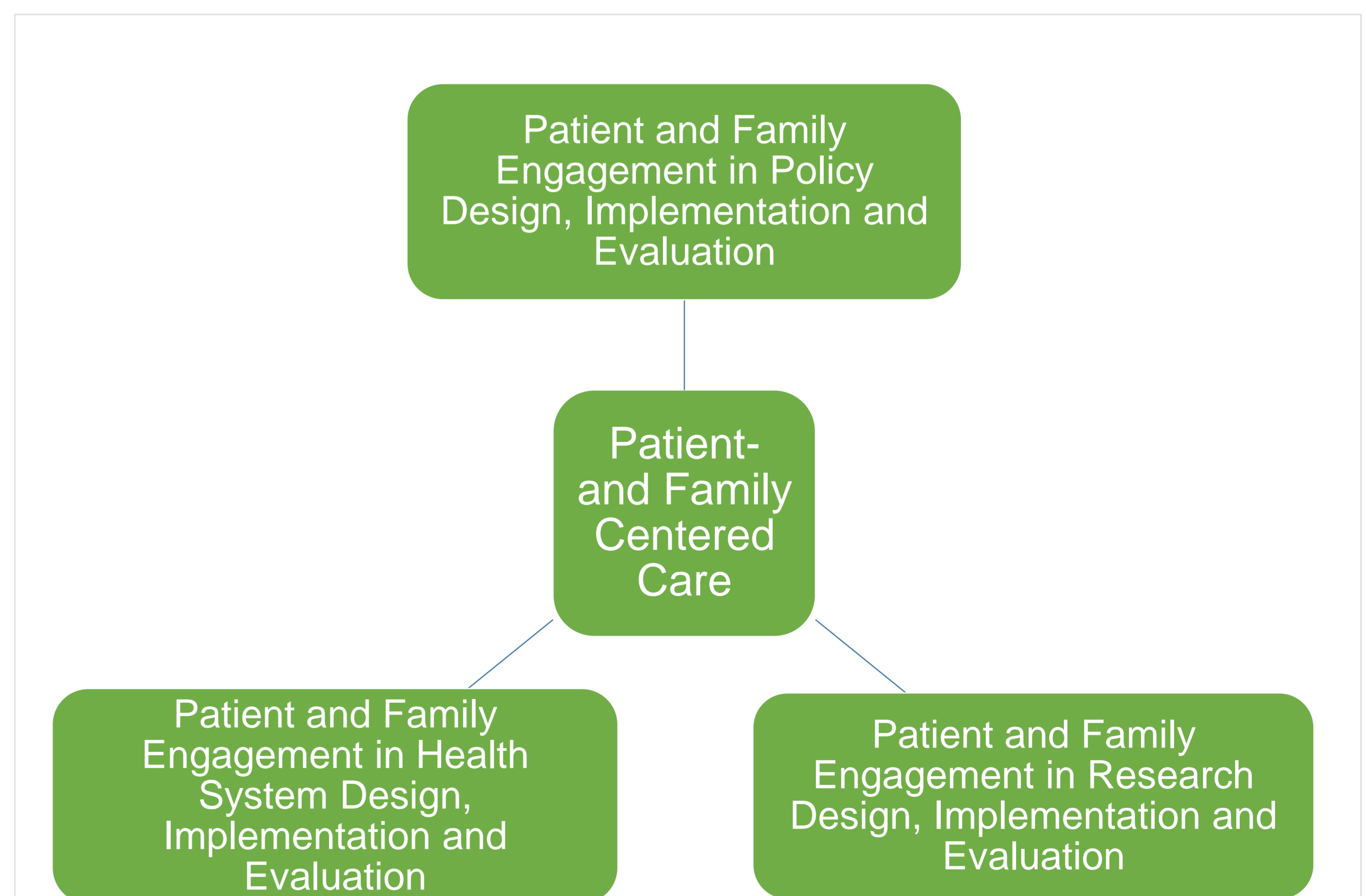
Clinical staff readiness to serve and training on working with family advisors

Ground rules for equitable participation established/enforced

Conflicts will happen; address immediately, openly and equitably

Conduct assessment of engagement and build action plans to address deficiencies

CONCLUSION



ACKNOWLEDGEMENTS

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CONTACT INFORMATION

Rhonda Cady: rhondagcady@gillettechildrens.com or 651-229-1713
Tricia Brisbane: tkbrisbine@gmail.com