

Family Engagement Fundamentals

As a Patient and Family Engagement Sub Platform with RareKids-CAN, we offer information sessions and resources that highlight key concepts when engaging with youth, families and individuals in pediatric rare disease clinical trials research. Explore a few ideas here with the following links. Curious to learn more? Email rkengage@mcmaster.ca

Meaningful Engagement

Articles & Links of Interest:

[What constitutes meaningful engagement for patients and families as partners on research teams?](#) (Black et al., 2018)

[An empirically based conceptual framework for fostering meaningful patient engagement in research](#) (Hamilton et al., 2018)

[Ethical Considerations for Partnering in Patient-Oriented Research](#) Alberta SPOR SUPPORT UNIT

[Overcoming barriers to implementation of patient engagement in clinical trials: feasibility testing of an embedded study](#) (Castonguay, et al., 2025)

[Clinical Trials Ontario](#)

[Patient-Oriented Research Level of Engagement Tool & Indigenous Research Level of Engagement Tool](#)

[Ways Community Members Can Participate In the Stages of Research](#)

[Involvement Matrix](#)

Training and Education Supports:

[CanChild's Family Engagement in Research Course](#)

[PORCCH modules: Patient-Oriented Research Curriculum in Child Health](#)

