"Building Blocks" of Partnerships: Considerations for Trainees Preparing to Engage Families in Research

Family engagement in research (FER) moves boundaries by giving families a voice in research, but many trainees do not know where to start developing skills in engaging families in research!

These blocks are yours to build with – take what you need, in the order that works for your project and learning, to take steps toward developing practices for meaningfully engaging families in research!

General Recommendations

- Family members' help can be used in ALL research phases, not just when determining relevant research questions or disseminating knowledge!
- Do not let the amount of 'extra' FERwork discourage you! It's ok to start small with 'JUST' ONE family member.
- The personal experiences of a family member may not necessarily generalize to the whole target group of your research. Choose wisely!



Determine your questions and aims

- How can the inclusion of family partners uncover questions related to your objectives?
- What type of family member are you interested in (e.g., child, parent, sibling)?
- How will family partners be involved?

Search for partners

Consider reaching out to:

- Family groups and research organizations
 - E.g., Solutions for Kids in Pain, CanChild
 - E.g., your provincial Supporting Patient Oriented Research [SPOR] group
- Clinical or school settings (e.g., care teams at hospitals, school boards)
- Social Media (e.g., advertising via CanChild on *Twitter)*

Trainee Mentorship in Developing Family Partnerships

Seek mentorship opportunities:

- Research supervisors
- Formal training programs
 - E.g., Family Engagement in Research (CanChild/McMaster University)
 - E.g., Patient Oriented Research Curriculum in Child Health (PORCCH; Child-Bright Network)
- Experts in your field
 - Seek researchers in your field who are champions in FER!
- Your trainee groups and research organizations
 - Your trainee peers may have expertise in FER and can offer advice

Collaboration

 Communicate about expectations and preferences **EARLY AND OFTEN.** Consider using the Involvement Matrix.



- Family partners may have competing demands and their situation or availability can change suddenly.
 - Build flexibility into your plans: things will often take longer than you think.
 - Consider that your schedule may need to be outside your typical working hours.

Managing Expectations

- Families do not want to spend time sharing ideas that cannot happen!
 - Be clear about the givens and realities of the project (e.g., compensation, project priorities)
 - **Discuss** what makes it valuable for them to participate and try to accommodate for that. Think outside the box!

https://www.kcrutrecht.nl/involvement-matrix/

https://researchgate.net/publication/328224558 Early career researchers' perspective es and roles in patient-oriented research https://www.canchild.ca/en/research-in-practice/family-engagement https://journals.sagepub.com/doi/abs/10.1177/0840470417744568?journalCode=hm

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