

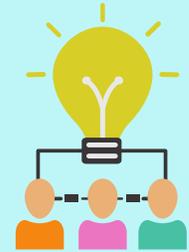
Family Engagement in Research: A Conversation Guide



What is Family Engagement in Research (FER)?

Family Engagement in Research (FER) is a term used to describe a specific kind of research that:

- ✓ Recognizes families as key partners in designing, planning, and carrying out a research project;
- ✓ Provides an opportunity for family partners and researchers to each benefit from being part of the leadership team of a research project;
- ✓ Values all perspectives from families and researchers;
- ✓ Emphasizes collaborative work to add value to research being done with families;
- ✓ Relies on meaningful conversations about what the partnership will look like; and
- ✓ Empowers everyone to be able to participate in impactful research.



Instructions for Using the Guide



Researchers and family partners in research: This tool can guide a conversation around roles and expectations throughout a research project, from start to finish.

Families are encouraged to participate in any and all stages of the research process
Researchers can support family partners' skill development and engagement in each stage



 ***Stages:** 1) Plan 2) Recruit 3) Do the study 4) Analyze 5) Disseminate 6) Evaluate

- This conversation is intended to be revisited at each stage and throughout the project as needed
- Often, these stages can take place concurrently and/or out of order
- Discussing expectations can maximize family partner input and add value for everyone!



*From the Ontario Brain Institute's "Ways Community Members Can Participate in the Stages of Research"

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Stage 1: Plan the Study

- What perspective do you already bring to this study as a family/parent?
- Are there any perspectives that are missing? If so, will we recruit more family partners? How?
- What would a really successful project look like?
- What time commitment are families and researchers willing to put into this project?
- What are the expectations for the researchers? This project?
- Who will be involved in later stages? How?
- Who will be responsible for scheduling regular check-in meetings?
- Is the study design for this population realistic and doable?
- How will we plan for barriers or hiccups?
- What do family partners already know about ethics? How can we fill in any gaps in ethical training (e.g. ethics training)?
- What is our dissemination plan?



Your Conversation:



Examples

- Co-design a set of skills or perspective matrix to ensure all necessary perspectives are included in research team (e.g. different disability types, provinces, lived experience perspectives)
- Co-design terms of reference for research team with two researcher and family partner co-leads to clarify commitments



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Stage 2: Recruit & Retain Participants

- How would family partners like to contribute at this stage?
- Is the method of recruitment of this population suitable?
- What do we think of this method of advertising? Is this attractive to the population of interest?
- Do we feel these areas of recruitment are realistic and sufficient?
- Who is responsible for distributing recruitment materials? How?
- Do family partners have any specific networks or connections to help with recruitment?

Your Conversation:



Examples

- Co-develop study recruitment materials
- Family partners provide access to closed family Facebook groups
- Consult family partners on what variation in perspectives would look like and how to identify these diverse perspectives (e.g. identify rural and Northern Canadian participants)



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Stage 3: Do the Study

- How are we working together to collect data?
- What are our thoughts on the data collection methods for this population (e.g. family partner feedback on interview guide or feedback on survey instrument used)?
- Are family partners comfortable collecting data for this study (e.g. interviews, leading focus groups etc.)?
- What are we doing to help family partners feel more comfortable with their role in data collection?



Your Conversation:



Examples

- Family partners provide input and revisions to study interview guide for participants
- One family partner is interested in helping with interviewing families—family partner takes ethics training and conducts interviews with family participants

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Stage 4: Analyze the Results

- Do family partners need any training for their role in analysing results?
- From a family partner perspective of lived experience, do the results make sense?
- Are we incorporating both researcher and family perspectives into these results?
- What have we missed in these results?

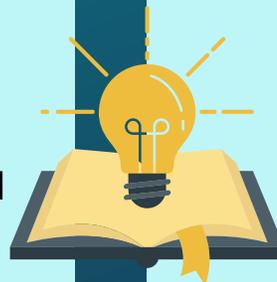


Your Conversation:



Examples

- Family partners review literature discovered during searches, identify relevant documents that are missing but that are relevant and important to families.
- Themes and findings from interviews are discussed with family partners and additional context on significance of key themes identified is provided (e.g. why a specific program is not available in a city)



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Stage 5: Disseminate the Results



- How can family partners advise on the dissemination plan?
- How can family partners help with disseminating study results to knowledge users? What are the best avenues for dissemination?
- What are the key messages from this study?
- How can we make our findings more accessible to the different knowledge users?
- If you were a parent interested to learn about a study like this, how would you find information about it? Where would you look? How could we get our results there?

Examples

- Family partners help identify key knowledge users and the information that should be included in the final report (e.g. providing a plain language summary of information)
- Develop a Knowledge to Action Policy Dialogue together with researchers and family partners to deliver in a virtual environment



Your Conversation:



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Stage 6: Evaluate the Study

- How do the family partners and researchers perceive that the study went?
- Did our roles match our expectations?
- What went well? What did not go well? What suggestions do we have for future studies?
- How can we enhance the experience of family partners?



Your Conversation:



Examples

- Researchers host a post-study meeting with family partners (questions sent out in advance) to brainstorm and reflect on what went well and lessons to improve our approach
- Co-develop a summary document of lessons learned by both researchers and family partners