

BALANCING POWER DYNAMICS IN FAMILY ENGAGED RESEARCH

Supporting researchers in implementing strategies to balance power dynamics in family engaged research

Facilitators



Creating a safe environment



Establishing clear communication channels



Clarifying roles & expectations at the outset



Building partnerships on respective expertise



Discussing compensation with family partners



Providing resources and support for family partners

Barriers



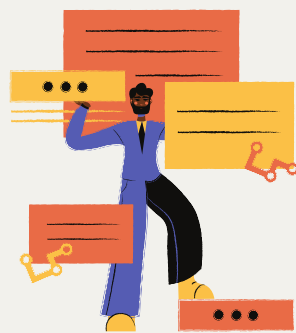
Rushing into the partnership



Keeping information from family partner



Assuming that partners have similar expectations



Imposing your ideas



Assuming that family partners can offer free time



Assuming that families understand the research process

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Researchers' checklist

Create a safe environment

- ☐ Put time and effort into building the relationship: sharing experiences, personal interests
- ☐ Introduce members of the team using stories, instead of academic titles
- ☐ Be aware of and respect family partner's vulnerability
- ☐ Create an environment in which everyone feels comfortable sharing their knowledge, opinion and concerns
- ☐ Approach families with empathy, non-judgement and humility

Establish clear communication channels

- ☐ Develop a culture of mutual respect
- ☐ Discuss motivations for involvement of family partners
- ☐ Use transparent and honest communication
- ☐ Ensure that everyone is comfortable with the communication methods used
- ☐ Ensure that a team member checks in with those who are quiet
- ☐ Use a visual map of the project
- ☐ Plan face-to-face communications and meetings (in-person or virtual)

Clarify roles & expectations

- ☐ Clarify and discuss roles, expectations, objectives and related time commitments from the beginning and on a regular basis
- ☐ Build-in debriefing time
- ☐ Share decision making
- ☐ Maintain flexible and adaptable roles
- ☐ Develop terms of reference (can be revisited during the project)
- ☐ Develop a formal agreement outlining discussed roles and responsibilities

Build partnership on respective expertise

- ☐ Recognize various types of involvement
- ☐ Appreciate the experiential knowledge of patient/family partners
- ☐ Discuss the skills and interests of the partners
- ☐ Discuss the level of technical complexity and time required to complete the different tasks

Discuss compensation with partners

- ☐ Discuss the preferred type of compensation/acknowledgement with family partners (e.g., financial, training, co-authorship)
- ☐ Cover expenses related to involvement in addition to compensating families for their time
- ☐ Ensure that compensation is equitable
- ☐ Develop a mutual agreement of what is an appropriate compensation at the beginning of the collaboration

Provide resources and support for family partner

- ☐ Build in time to answer questions
- ☐ Provide the tools/resources required to understand the research process
- ☐ Provide background information on the research project
- ☐ Provide administrative support
- ☐ Discuss other possible barriers and provide resources to overcome them: scientific language, transportation, schedule...

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