

BUILDING SUCCESSFUL PARTNERSHIPS:

A CONVERSATION GUIDE FOR RESEARCHERS AND PATIENT/FAMILY PARTNERS*

What: This conversation guide is intended to facilitate communication between researchers and patient/family partners*.

Who: The guide can be used by both researchers and patient/family partners*. There is a researcher version and patient/family partner* version.

Why: We hope that this guide will help to build stronger relationships between researchers and patient/family partners* and lead to more equal partnerships.

When: The guide was written to be used when initiating a new partnership. However, we encourage researchers and patient/family partners* to revisit these conversations throughout the partnership in order to re-evaluate understanding of the partnership, personal expertise, goals, responsibilities, commitments, and barriers to engagement.

How: Structure your conversation using the five stages outlined in the guide. Use the sample phrases and key topics provided, or add your own based on the details of your research partnership. Apply the *"tips for communication and relationship-building"* to enhance self-awareness, trust, respect, mutual understanding, and reciprocity.

*In addition to patients and families, the term "partner" can also refer to caregivers or member of the public.

This conversation guide was created by Lin Li and Carlyne Osterhues as part of the **Family Engagement in Research Certificate of Completion Program** offered by **McMaster University and Kids Brain Health Network**.

Key topics were informed by course content and discussions in the Family Engagement in Research Certificate of Completion Program.

The flow of the conversation guide was based on the Serious Illness Conversations Guide attributed to © 2015 Ariadne Labs: A Joint Center for Health Systems Innovation (www.ariadnelabs.org) and Dana-Farber Cancer Institute. Revised December 2019. Licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License, <http://creativecommons.org/licenses/by-nc-sa/4.0/>.



CONVERSATION GUIDE: PATIENT/FAMILY PARTNER VERSION

	STAGES OF THE CONVERSATION	SAMPLE PHRASES
Introduce	Introduce the purpose of the research and partnership.	"I understand that this research is about_____." "I am interested in being involved in this project because_____."
Identify	Identify assumptions and understanding of patient/family engagement in research.	"I believe that being a patient/family research partner means_____." "My understanding of patient/family engagement in research is that_____." "I believe that the benefits of patient/family engagement are_____."
Share	Share personal strengths and expertise , for example: <i>Lived experience</i> <i>Prior research experience</i> <i>Memberships and groups</i> <i>Hobbies/interests</i> <i>Other strengths and skills</i>	"I have lived experience with [<i>condition</i>] for [<i>time period</i>]." OR "I have lived experience parenting a child with [<i>condition</i>] for [<i>time period</i>]." "I have daily, lived experience coping with_____." "I have been involved in other research projects on_____." "My involvement in previous research includes the following roles..." (e.g. consulting, reviewing proposals, recruitment, data collection, dissemination, etc.) "The tools/medical therapies that I have experience with are_____." "I am a member of...[<i>relevant groups, e.g. advocacy groups</i>]" "I have skills in [<i>writing, presenting, advocating, connecting with other parents, etc.</i>]"
Explore	Explore key topics , for example: <i>Goals for the partnership</i> <i>Roles & responsibilities</i> <i>Timeline and time commitment</i> <i>Knowledge gaps</i> <i>Potential barriers</i>	"My goal for this partnership is_____." "The desired outcome for this partnership is_____." "My role is to share my experience on a personal level dealing with _____ in order to further research and improve the quality of life for others." "The roles that I am comfortable with include_____." (e.g. recruitment, data collection, reviewing proposals, dissemination) "My time commitment to this project is_____." "My barriers are..." (e.g. time, transportation, finances) "I would like additional training in_____."
Close	Close the conversation: Summarize conversation Discuss next steps Ask about follow-up	"This is my understanding of what we discussed today: _____." "The next steps for this project are_____." "I can expect to hear from you in [<i>time frame</i>] and on a regular basis (e.g. monthly)."

CONVERSATION GUIDE: RESEARCHER VERSION

	STAGES OF THE CONVERSATION	SAMPLE PHRASES
Introduce	Introduce the purpose of the research and partnership.	<p>"I'd like to talk to you about the possibility of being a family research partner on our research project that aims to_____."</p> <p>"Being a family research partner means_____."</p> <p>"We would like to partner with families on this research because_____."</p>
Assess	Assess assumptions and understanding of patient/family engagement in research.	<p>"What is your current understanding about family engagement in research?"</p> <p>"What does being a family research partner mean to you?"</p>
Ask	<p>Ask about the patient/family partner's personal strengths and expertise, for example:</p> <ul style="list-style-type: none"> <i>Lived experience</i> <i>Prior research experience</i> <i>Memberships and groups</i> <i>Hobbies/interests</i> <i>Other strengths and skills</i> 	<p>"Can you tell me about your lived experience with [research topic]?" (e.g. being a parent, managing care and therapies, etc.)</p> <p>"What has your experience been with conducting, partnering, or participating in research?"</p> <p>"What strengths and skills do you bring to a research project?" (e.g. writing, presenting, advocating, networking, etc.)</p>
Explore	<p>Explore key topics, for example:</p> <ul style="list-style-type: none"> <i>Goals for the partnership</i> <i>Roles & responsibilities</i> <i>Timeline and time commitment</i> <i>Knowledge gaps</i> <i>Potential barriers</i> 	<p>"What do you hope to achieve or gain from this partnership?"</p> <p>"How would you like to be involved in this project?" (i.e. roles, timeline, time commitment)</p> <p>"What training and education would you need/prefer to be involved?"</p> <p>"What are potential barriers to your involvement?"</p> <p>"How can we support your participation in this work?"</p>
Close	<p>Close the conversation:</p> <ul style="list-style-type: none"> Summarize conversation Discuss next steps Commit to follow-up 	<p>"Here's what I heard you say: _____."</p> <p>"What is your understanding of what we talked about today?"</p> <p>"The next steps of this project are _____."</p> <p>"I will update you in [time frame] and on a regular basis (e.g. monthly)."</p>

TIPS FOR COMMUNICATION AND RELATIONSHIP-BUILDING

FOR RESEARCHERS AND PATIENT/FAMILY PARTNERS



SELF-AWARENESS

Ask yourself:

- What are my strengths and areas of expertise? What can I contribute to this relationship?
- What are my areas of improvement? Where do I lack knowledge? How does this impact the relationship?
- What are my assumptions about myself and the other person?

TRUST

- Ask open-ended questions.
- Create connection by sharing a short personal story.
- Be honest and authentic.
- Disclose any personal agendas.

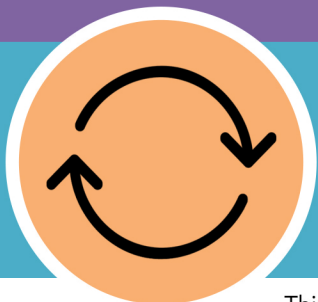


RESPECT

- Listen and pay attention to body language.
- Verbally and non-verbally acknowledge the other person (e.g. nodding, making eye contact)
- Respect each other's beliefs and celebrate differences.
- Value each other's time. Do not appear rushed, but communicate in a timely, efficient manner.
- Value yourself, your skills, knowledge, and lived experiences.

MUTUAL UNDERSTANDING

- State your goals and ask about the other person's goals for the partnership.
- Summarize conversations to confirm understanding ("This is what I heard you say").
- Check in frequently and ask for feedback.



RECIPROCITY

- Consider what each person is gaining from the partnership.
- Ensure that there is mutual benefit.
- Each person should determine how they will benefit from the partnership. What one person considers to be a benefit may not actually be one for another person.