

Guide for Researchers and Families Partnering in Pediatric Health Research 2024



Dear Family Leaders & CHEO Research Institute (RI) Staff,

The Patient and Family Engagement in Research (FER) movement continues to gain momentum nationwide. It has been foundational here at the RI for many years thanks to the trailblazing work of our former COO, Rhonda Correll, and the founding Family Leader Program Coordinator, Michelle Quinlan. The Family Leader Program continues to include the participation of 50+ family leaders and countless RI staff as we engage in research together.

As more research teams bring on family leaders in advisory and partnering roles, guidance and resources for their collaborations are needed. This guidebook aims to provide a central hub of resources that we think you will find helpful as you partner together. FER is an iterative process; as a result, we aim to add new documents, resources, and tools as best practices and further research discoveries emerge about this vital work.

This guidebook was co-created with two RI staff and three family leaders. Over many months, we came together to discuss what resources we found most helpful for family leaders and research staff. We now share our curated list with you.



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Additional Acknowledgments

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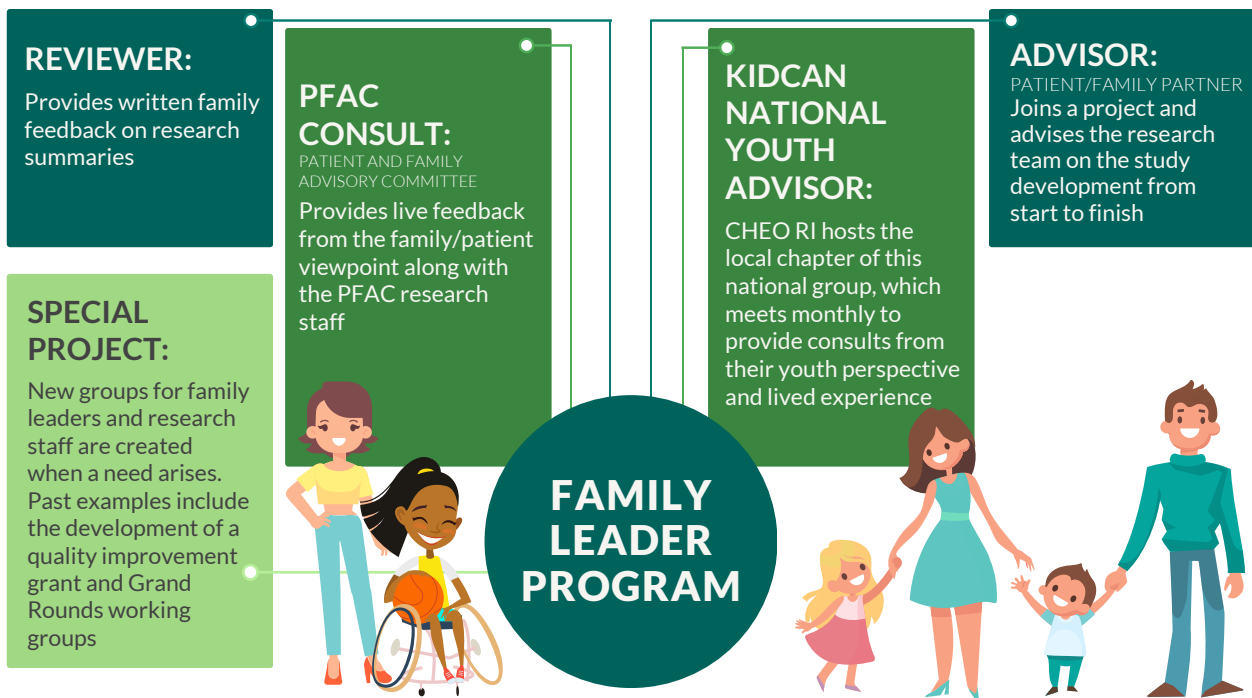
Introduction

We are so pleased that you are reviewing this guidebook. Our goal is to demystify the practice of engaging patients and families as partners in research. It can be challenging to know where to start, so we aim to break down each step clearly. The practice of engaging family and patient involvement in research goes by many names. Family members and patients involved are often referred to as partners in research, knowledge brokers, or lived experience users. Here at CHEO, we call them family leaders. A family leader is anyone with lived experience within the healthcare system as a patient, family member, caregiver, or community member.

Engaging family leaders in research is dynamic, with varying levels of involvement. The core aim of family engagement in research is to move beyond viewing patients or families as mere participants by including them as active members in the research design. Family leaders bring their lived experiences, perspectives, and expertise to the research process to guide the execution of projects.

At a Glance

Introduction	02
Rationale	03
Engagement at the CHEO RI	04
Evaluation	08
Partnering in Basic Science	09
Sharing Your Story	11
Glossary	12



Why is Patient Engagement Important?

There are many rationales for Family Engagement in Research, with CHEO RI's rationales being both ethical and pragmatic in nature. Engaging patients and families is crucial because they are the end users and ultimate interest holders of research outcomes. Since youth and families are most affected by the outcomes of research, researchers have an ethical responsibility to involve family leaders. Similarly, many family leaders feel a moral responsibility to engage in research to give back to the community and improve care for other children and families.

From a practical perspective, there is growing evidence that Family Engagement in Research improves study designs, study enrolment, and knowledge translation. Overall, partnering together in research is meaningful and beneficial for everyone involved.

Inclusive Voices

Equity, Diversity, Inclusion, and Indigeneity (EDII) are key considerations for the Family Leader Program. The strength of the patient and family voice lies in the diverse perspectives of lived experiences they bring to research. It is crucial for the program to reflect the varying needs and experiences within our communities. Our goal is to create an environment that is accessible for underserved identities. To achieve this, the Family Leader Program uses an EDII matrix to track intersectionality, guide recruitment, and ensure we are mitigating barriers to foster an inclusive collective voice.



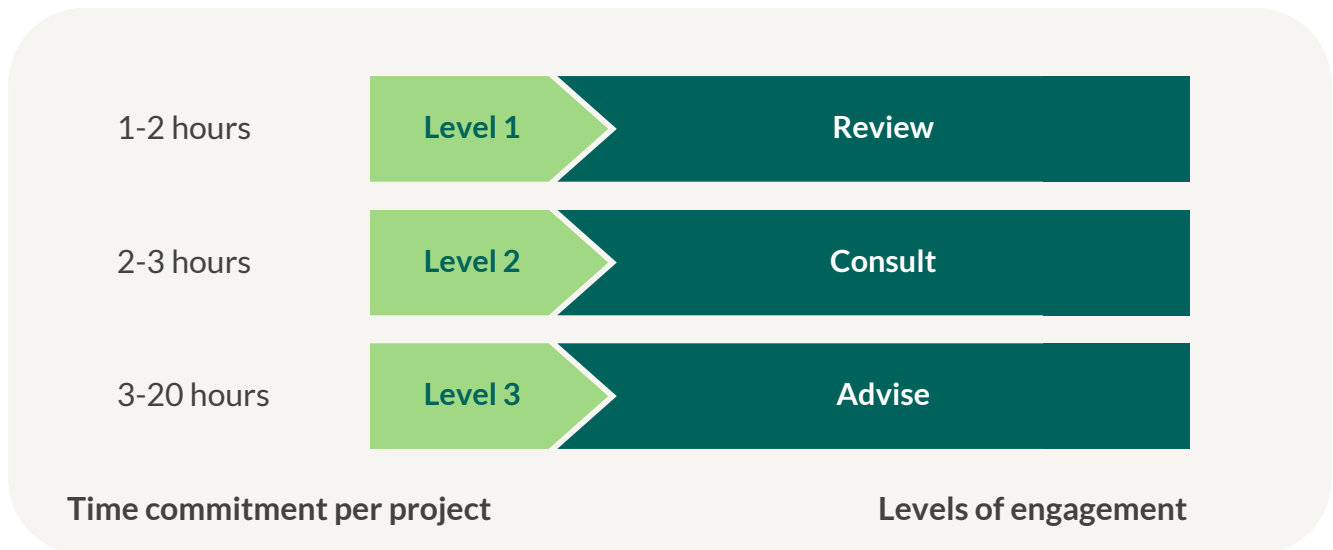
Additional Resources



- [McMaster FER Course](#)
- [McMasters' Supporting Equity-Centered Engagement Guide](#)
- [CHEO RI EDII Research Grant Guide](#)
- [Patient-Oriented Research Curriculum In Child Health \(PORCCH\) Modules](#)
- [Frequently Asked Questions - CHEO RI Family Leader Program](#)

Levels of Family Leader Engagement at the CHEO RI

There are varying levels of engagement at CHEO RI, each unique to the specific project or task. These levels of engagement can fluctuate over time. This infographic breaks down the approximate hours of commitment required from the family leader at each level of engagement achieved.



Review Level

At the review level, researchers request feedback from family leaders. The family leader then reads a summary of the proposed research study and provides written feedback through a form, which researchers directly address. Requests for reviews can happen at any time of the year and require a commitment from the family leader only at this one time point to complete the review.

Consult Level

At the consult level, research teams present their project to the Patient Family Advisory Committee (PFAC), which consists of family leaders and researchers. The advisory committee then provides general considerations and ideas. Family leaders who join the PFAC commit to participating in regularly scheduled meetings once a month, as well as reviewing material in preparation for these consults.

Advise Level

At the advise level, researchers request for a family leader to be part of their research team from the very start of their project. Family leaders influence the study design with their lived experience and continuously provide their unique perspective throughout the research process, helping shape the study from its inception. Research projects can vary in duration.

As the level of engagement increases from review to advise, the time commitment and depth of collaboration also increase.

Review Level

Family Leader, Ellen Song acted as a reviewer for a research funding competition.



"I was very pleased to see Dr. Pohl and her team incorporate my review feedback into their research protocol. Given our closeness to these medical complexities, it is encouraging to know that the research team valued my perspective and lived experiences, and included the patient and family voice throughout their application. I am happy my feedback was appreciated and led to a positive change in how the study was conducted."



"Feedback from family leaders like Ellen Song brings a new perspective and leads to meaningful improvements to the research protocol."

-Dr. Daniela Pohl
Clinical Investigator

Internal research grant reviews have been the backbone of the Family Leader Program, serving as an excellent introductory step into collaborating with a family leader. The review level does not require a significant time commitment from family leaders. It is also quite flexible as reviews can be completed from anywhere, at one's own convenience within a two-week period. This flexibility makes the review level a favorite among our family leaders. It was originally coined 'Parents in Pyjamas' when the program began.

Review Writing Process

In [Writing Reviews 101](#), we made a tip sheet for family leaders writing research reviews.

New! An updated recording of [Research Summaries & Family Review 101](#) explains line by line the process of our largest internal grant competition.

New! [The Research Growth Awards Process](#), a visual guide to each step.

[People with Lived Experience in Peer Review](#)

[Guide for Patient Reviewers](#)

Consult Level

Here at the CHEO RI, consult work is usually carried out through the Research Patient Family Advisory Committee. In some ways, it is similar to a review, since researchers submit a short summary of their studies in advance. Yet, one key difference is the consultation is done during a virtual meeting, which includes many family leaders from diverse backgrounds and a variety of research staff—this collective creates the perfect environment for research teams to visit. The consultation level is sure to include an exchange of ideas, comments, and feedback. Sometimes new questions and directions for the project emerge.

Azam Ishmael is a Research PFAC alumni. During these meetings, research teams come and present their projects and the advisory group provides live feedback during the call. Azam described a visit from Dr. Waleed Alqurashi, “Dr. Alqurashi came and consulted with the group, sharing both the study he was undertaking and the methodology behind it. After explaining to us the challenges he was encountering and what he was hoping to accomplish, the group was able to share its feedback and brainstorm ideas on how we could help draw from our experience. It was also great to see that some of our feedback was incorporated into the study and hear how the study was going.”



The CHEO RI is often involved with priority-setting partnerships, most recently in areas related to concussions, hospital admissions, and eating disorders. This work allows for consultation with patients and families at the very beginning: the research question!



James Lind Alliance and Priority-Setting Partnerships

RI Researcher Nicole Obeid and other CHEO staff participated in a priority-setting exercise on eating disorders. They worked with patients, parents, research staff, and community members to identify and narrow down key priority areas and questions. Take a look at how they partnered with patients and families on this project. Are you curious about how one of these exercises works? This infographic details each step. Some family leaders became advisors and co-authors due to their high levels of partnership.



Listen to our podcast! - [Family Engagement in Research Roadmap: Experiences of a Team at CHEO](#)

Advise Level

The advise level requires more time and reaches high levels of engagement since a family leader joins the research team for the entire length of the study. Family leaders provide their viewpoints from lived experience, which fosters a research design that is more patient- and family-oriented.



Family Leader Lisa Wadden acted as an advisor with Dr. Katz on a respirology study.

She played an active role in planning the recruitment strategies. Given her lived experience, Lisa had many community connections which she used to help bring awareness about the study from a specific patient population. She gave feedback on key locations for study posters, focusing on areas other families who would be eligible for the study would most likely visit.

“It was very rewarding to see the enthusiasm of other parents and to eventually see them share posts when their children got the call to come in for a sleep study as part of Dr. Katz’s research.”

Additional Resources



- Compensation Primer: [Starting the Conversation](#)
- CHEO RI: [Guidelines for Recognizing Family Leader- Advisors](#)
- The Change Foundation: [Should money come into it?](#)
- [Current Guidelines for Patient-Partner Compensation and Recognition](#)
- Building successful partnerships: [A Conversation Guide for Researchers and Patient/Family Partners](#)
- [Memorandum of Understanding: Sample](#)
- Family Engagement in Research Initial Meeting Guide
 - [For Research Partners](#)
 - [For Family Partners](#)
- Can-SOLVE CKD Network: [Roles and Skills for Patient Partners in Research](#)

Should Family Partnerships Be Evaluated? If So, How?

While research outputs, such as successfully recruiting study participants or publishing a peer-reviewed article, may indicate certain types of success, understanding the impact of family partnerships on the research process, research teams, and patient and family partners is key. This understanding allows for benchmarking, improvement, and the development of evidence to support patient and family engagement in research.

Tools for Evaluation

- 1** The [PEIRS-22](#) is designed to be completed by patient and family partners and has been shortened to include the most essential elements. [The tool and related resources are found here.](#)
- 2** [This 2024 article](#), *Measuring the Impact of Patient Engagement in Health Research: An Exploratory Study Using Multiple Survey Tools*, compares the most commonly used evaluation tools.



Additional Resources

- [Guidance on Authorship with Patient Partners](#)
- [Holland Bloorview's Simulations to Promote Authentic and Meaningful Partnerships in Childhood Disability Research](#)
- [Youth Engagement Guidebook for Researchers](#)



Partnering in Basic Science

Here are some tips for effectively integrating a family partner into your team, inspired by the Berman Lab:

1

Evaluate Team Readiness: Ensure your team is prepared to provide the necessary time, compensation, and openness for meaningful collaboration with a family partner.

2

Start Early: Ideally, involve patient/family partners from the outset, even before applying for grant funding. Seek insights from other lab-based teams who have experience in this area. [Reach out to the RI Family Engagement in Research Facilitator](#), kcourtney@cheo.on.ca if you need help with this step.

3

Co-Create a Team Charter or MOU: Develop a memorandum of understanding (MOU) that outlines the partnership's specifics, including reasons for partnering, timelines, and specific tasks. Treat these documents as living documents, updating them as the project progresses. Here is our [Sample MOU](#) to help you get started.

4

Establish Roles/Duties and Expectations: Establish and explain the roles of every research team member during early stages, including the patient/family partner's role within the research team, specific responsibilities, areas where collaboration is needed, and the extent of their participation. Develop clear expectations and ensure patient/family partners are aware of the specifics (ex. written or verbal contributions, time commitment, and confidentiality).

5

Informal Group Meetings: Set agendas collaboratively and encourage team members to share personal interests and hobbies at the first meeting. This allows group members to connect on a human level, beyond the titles and outside the lab. Discuss the project in non-technical language and avoid acronyms to ensure clarity and inclusiveness. Provide a list of defined acronyms for future meetings.

6

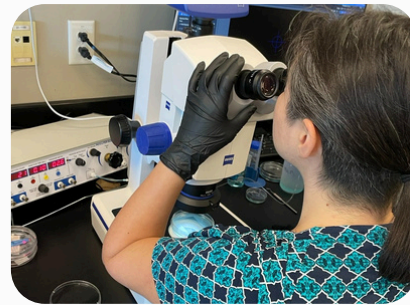
Offer Training Opportunities: Provide optional training for all team members, such as [CIHR FER](#) and [Porcch Modules](#). Discuss with each team member what meaningful engagement looks like and any personal goals they hope to achieve during the process.

7

Plan a Lab Visit: If possible, arrange for patient/family partners to visit the lab. This helps them better understand and visualize the work better. Demonstrate aspects of the research and allow for hands-on exploration.

8

Designate a Point Person: Assign a team member as the main contact for family advisors to address updates, concerns, and questions.



"As I think back to our visit to the Berman Lab, there was so much that I learned that day, not only about the project itself and its purpose but also about the research team and the people behind it. I'm really excited about the potential of this project. It was an enlightening experience that made me feel part of the project. Not only did I better understand what the project was about, but I also felt the research team was approachable and open to questions and discussion."

- Madleen Zapata, Family Advisor

Additional Resources

- Our friends at the Ottawa General Hospital have just created a [helpful hub for pre-clinical partnering](#).
- [Informing Involvement Around Animal Research](#)
- [Promoting Patient Engagement in Early Phase Clinical Trials - Policy Brief](#)

Psychosocial Elements of Partnering in Research

Partnering with family leaders is more than a transaction. It's a collaboration that draws on the lived experiences of persons navigating the healthcare system. Often Family Leaders engage for deeply personal reasons.



Family leaders often have important perspectives to share on their care and treatment. Collaborating in a trauma-informed environment means acknowledging that the family leader may have experienced psychological trauma related to their healthcare experiences, and ensuring that they are not subjected to reliving this trauma through one's behaviours or interactions with them. Partnering in research and sharing these experiences can sometimes be distressing for family leaders. It is vital that the researchers working with them take steps to ensure they feel supported and protected. This also includes accepting and welcoming emotional experiences during meetings, where family leaders are often required to use their lived experiences to contribute to the discussion.

These resources touch on the psychosocial elements of partnering in research, which include important findings on trauma-informed care:

- [Emotion Plays an Important Role for Engaging in Research Partnerships](#)
- [Trauma-Informed Care Guide](#)

Sharing your Story

Sue Robins, a Patient Engagement Consultant has developed a number of tools to support families as well as health staff. Here are a few of our favourites!

- [Sharing Your Story](#) by Sue Robins
- [Giving a Talk](#) by Sue Robins

While partnering in research, you may be asked to share your or your child's story. Whether it be for a team meeting, a media interview, a committee, or a conference, this can be exhausting and traumatic. To support you in doing so, CHEO parents have developed a resource that offers guidance on [Sharing Your Story](#). It can be empowering to understand your triggers and plan out in advance what you are comfortable sharing. The resource mentioned above includes a guided tool to help you prepare for the event, as well as reflect on it afterwards.

Glossary of Terms

Research Growth Awards (RGA)

This research funding competition happens twice a year. Family leader reviews are required.

Research Institute Patient Family Advisory Committee (RI PFAC)

The PFAC serves as a subset of the larger Family Leader Program. The PFAC includes 5 RI staff and 7 family leaders, meeting 10 times a year to provide live consults.

Family Leader Program (FLP)

This is the RI's family engagement in research program. It currently has over 50 active members. These family leaders review, advise, and consult on scientific research.

Research Ethics Board (REB)

This board serves as an integral part of the research process. This board oversees the ethical and legal elements of proposed projects. The REB often appoints a family leader.

Letter of Intent (LOI)

A letter of intent is often used as the first step of a research funding competition and provides a snapshot of the project. At this stage, a panel can provide feedback on the strength of the application and whether it should move forward.

Family Engagement in Research (FER)

This general term is often used to describe activities or programs that include the involvement of patient and family voices within research processes.

Family Engagement in Research Facilitator

This Office of Research Support staff member oversees the Family Leader Program and seeks to embed meaningful FER into all aspects of research at the RI.

Ontario Child Health Support Unit (OCHSU)

This Ontario-funded support program aims to foster FER at CHEO, SickKids, and beyond.

Patient-Oriented Research (POR)

Patient-oriented research is about engaging patients, their caregivers, and families as partners in the research process. This partnering helps to ensure that studies focus on patient-identified priorities, which ultimately is intended to lead to better patient outcomes.

The Canadian Institutes of Health Research (CIHR)

A federal agency responsible for funding health and medical research in Canada.

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A federal agency responsible for funding health and medical research in Canada.

Canada's Strategy for Patient-Oriented Research (SPOR)

A strategy which supports hospitals and agencies aiming to advance their patient engagement efforts and increase their research in areas that keep the patient and family at the centre.

Person With Lived Experience (PWLE)

A person who, as a patient or family member, has knowledge based on their own identity, history, and perspective, beyond any professional or educational experience with the health care system. At CHEO, we refer to a PWLE as a Family Leader.



This guidebook has been developed in partnership and with support from the Ontario Child Health Support Unit (OCHSU).