Guide for researchers and families partnering in pediatric health research

2023

CHEO RESEARCH INSTITUTE
INSTITUT DE RECHERCHE

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

Introduction

We are so pleased that you are reviewing this guidebook. We aim to demystify the practice of engaging patients and families as partners in research. Sometimes it can be hard to know where to start, so we aim to break down each step. The practice of engaging family and patient engagement in research has many names, which can add to the confusion. Family members and patients are often called 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 with the health care system as a patient, family member, caregiver, or community member.

Engaging family leaders in research is dynamic in nature with varying levels of engagement. The core aim of family engagement in research is moving beyond the patient or family as participants, to including them as active members of the research design. Family leaders bring their lived experiences, perspectives, and expertise to the research process and execution of the project.

REVIEWER: Provides written family feedback on research summaries

SPECIAL PROJECTS: New groups for family leaders and research staff are created when a need arises. Past examples include the development of a quality improvement grant and Grand Rounds working groups

PFAC CONSULTS:
PATIENT AND FAMILY ADVISORY COMMITTEE
Provides live feedback from the family/patient viewpoint along with the PFAC research staff

FAMILY LEADER PROGRAM

KIDCAN NATIONAL YOUTH ADVISORS: CHEO RI hosts the local chapter of this national group, which meets monthly to provide consults from their youth perspective and lived experience

ADVISOR:
PATIENT/FAMILY PARTNER
Joins a project and advises the research team on the study development from start to finish

Why is Patient Engagement Important?

There are many rationales for Family Engagement in Research. CHEO RI's rationales are both ethical and pragmatic in nature. Patient and family engagement is important because patients and families are the end users and the ultimate stakeholders. Since children, youth, and families are most affected by the outcomes of research, researchers have an ethical responsibility to engage with family leaders. Similarly, many family leaders describe a sense of moral responsibility to engage in research, and a desire to give back and improve care for other children and families in the community.

Pragmatically, growing evidence points towards improvements in study designs, enrolment, and knowledge translation when FER is part of the research process. In sum, partnering together in research is meaningful and beneficial to everyone engaged!

Inclusive Voices

Equity, Diversity, Inclusion, and Indigeneity (EDII) are important considerations for the Family Leader Program. The strength of the patient and family voice is that it brings a rich array of perspectives of lived experience to research. It is crucial for our program to reflect the varying needs and experiences within our communities. Creating an environment that is accessible for underserved identities is our intention. For this reason, the Family Leader Program uses an EDII matrix to track intersectionality, guide recruitment and ensure we are mitigating barriers, so that we can continue to foster an inclusive collective voice.

Additional Resources

- **McMaster FER Course:** https://www.canchild.ca/en/research-in-practice/family-engagement-in-research-course
- **McMasters' Supporting Equity-centered Engagement Guide:** https://ppe.mcmaster.ca/resources/equity-centred-engagement/
- **CHEO RI EDII Research Grant Guide**: Equity, Diversity, Inclusion, and Indigeneity (EDII): Grant-writing Guide for Researchers
- **Patient-Oriented Research Curriculum In Child Health (PORCCH) Modules:** https://porcch.ca/
- **Frequently Asked Questions - CHEO RI Family Leader Program:** https://www.cheoresearch.ca/for-patients-family/partner-in-research/

Levels of Family Leader Engagement at the CHEO RI

There are varying levels of engagement at the CHEO RI. Levels of engagement are unique to each project or task. There can be elements of various levels occurring over time. This infographic breaks down the hours of commitment of the family leader and the level of engagement reached.

Time commitment	Levels of engagement	
4-20 hours	Level 3	Advise
3-4 hours	Level 2	Consult
1-2 hours	Level 1	Review

Many researchers request family review when they are planning a new research study. This process includes opportunities for family leaders to read about the planned study and provide feedback, followed by a response from researchers back to family leaders addressing suggestions. This collaboration occurs at a single point in time and fits in the **review** level.

A team at the RI may present their project to the Research Patient Family Advisory Committee (RI PFAC) for a consultation, during a regularly scheduled meeting. The RI PFAC shares some general considerations and ideas for the next stage of the project. This fits in the **consult** level.

Lastly, researchers may include a family leader on their project team from the very beginning stages of planning a research study. Family leaders bring their lived experience to the subject area and their input influences the study design throughout the process. This engagement is at the **advise** level.

As the levels rise, so do the time commitment and collaboration.

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/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

Research funding reviews have been the backbone of the Family Leader Program. They serve as a great introductory step into collaborating with a family leader. The review level doesn't require a large time commitment from a family leader. It's also something they can complete from home and at a time that works best for them. This flexibility makes the review level a favourite among our family leaders and was often referred to as 'Parents in Pyjamas' when the program began.

Review Writing Process

Check out RI family leader, Ellen Song, and Research Manager, Katie O'Hearn's discussion on the **review writing process** from their unique perspectives. Their recording of **Research Growth Awards 101** explains the process line by line of our largest internal grant competition.

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 one of the family leaders on the Research PFAC. During these meetings, research teams come and present their projects and the advisory group provides live feedback during the call. Azam described a recent 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
Priority Setting Partnerships

How does a JLA PSP work?

1. Create a Steering Group
2. Gather evidence uncertainties
3. Summarising the responses gathered
4. Evidence checking
5. Interim Priority setting
6. Workshop
7. Publish and promote Top 10 research priorities

James Lind Alliance and Priority Setting Partnerships

RI Researcher Nicole Obeid and other CHEO staff participated in a priority setting exercise about eating disorders, by narrowing down priority areas and questions with the help of patients, parents, research staff and community members. 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, playing 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?
- **CHILD-BRIGHT**: Guidelines for Patient-Partner Compensation and Recognition
- **Building successful partnerships:** A conversation guide for researchers and patient/family partners
- **Memorandum of understanding:** Template
- **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?

Evaluation is an essential ingredient to sustainable, productive, and mutually respectful family partnerships. While research outputs such as successfully recruiting participants to a study or producing a peer-reviewed article may signal some types of success, understanding how family partnerships impact the research process, research teams, and patient and family partners is key to benchmarking, improving, and developing evidence for patient and family engagement in research.

Here are a few tools for evaluation:

Volume 24 Number 3 June 2021

Health Expectations

An International Journal of Public Participation in Health Care and Health Policy

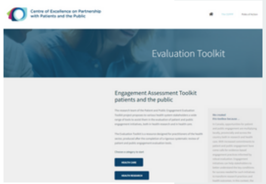
Patient Engagement In Research Scale (PEIRS)
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8235891/

PUBLIC AND PATIENT ENGAGEMENT EVALUATION TOOL

VERSION 1.0 (JUNE 2015)

McMaster University

Public And Patient Engagement Evaluation Tool (PPEET)
https://www.iap2usa.org/resources/Documents/Research/Evaluation+Tool+-+PublicandPatientEngagementEvaluationTool.pdf



Centre of Excellence on Partnership with Patients and the Public

Evaluation Toolkit

Engagement Assessment Toolkit patients and the public

A full repository of evaluation tools currently available patient engagement in research and health care can be found here:
https://ceppp.ca/en/evaluation-toolkit/

Tools and Resources | Contact | English | Français

Engage with Impact Toolkit

Evaluating the impact of patient, family and caregiver engagement in health systems

The *Engage with Impact Toolkit* was designed to help organizations evaluate the impact of their patient, family and caregiver engagement programs and activities. On this site you will learn more about what the Engage with Impact Toolkit is and how it can be used.

The Toolkit has been developed for a wide range of users. This includes Ontario Health Teams, health and health care service organizations, and government agencies. As key partners in patient engagement, we also expect patient, family and caregiver partners, and their organizations and networks, to be key users of this resource.

We plan to update and tailor the Toolkit as we gather additional feedback, so we encourage you to check this website frequently. We also welcome your feedback on the *Engage with Impact Toolkit* and how it is being used. Please feel free to contact us.

Toolkit Modules

To develop a comprehensive evaluation strategy for patient engagement in research, we recommend using the Engage with Impact Toolkit.
https://www.evaluateengagement.ca/

Glossary of Terms

Research Growth Awards (RGA)
This research funding competition happens twice a year. Family Leader reviews are required.

Research Coordinator Award (RCA)
This research funding competition happens once a year. It allows a coordinator to plan out their own research project. 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 Lead Coordinator
This staff member of the Office of Research Support 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 is an Ontario-funded support program that 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.

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.

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