

RESENTER: **Mairead Green** 

**BACKGROUND:** Family engagement in research is growing in popularity, yet many institutions struggle to achieve the cultural shift necessary to make this practice successful. Engagement in research can provide patient-oriented research goals, increase accessibility of research to patients, and increase participation and retention rates in studies. Here we describe how CHEO Research Institute has been able to create an environment where patient perspectives in research are not only respected but expected.

### METHODS

2018

020

Family engagement added to CHEO RI Strategic Plan

Program structured around Holland Bloorview's model but adapted to acute care setting

Recruitment of Family Leaders (FL)

FLs provide feedback on an internal grant twice a year

Families reviewing research via REDCap survey

Expansion of program to include different levels of engagement

FLs participate in a Research Patient and Family Advisory Council

2022

FL reviews now required for all major internal awards

FLs acting as advisors on a research project

**RESEARCH INSTITUTE** 

**INSTITUT DE RECHERCHE** 



SPECIAL

2.

3.

The process has been iterative. After each cycle of a grant completion, or PFAC term, we seek feedback from our stakeholders and make changes to our program. This co-creation of FER has been a central strength of our program.

## Embedding Family Engagement in Research (FER) Into Your Institution Lessons learned by CHEO Research Institute (RI) **ADVISOR:** KIDCAN PFAC



# **Offer flexibility for patient partners**

• The partner chooses whether to be involved in reviewing, consulting or advising.

• Some engage on many projects, all with differing levels of engagement.

# **Create different types of roles**

#### • Over time our program has come to **include** several roles.

• Often family leaders start out as reviewers while they orient themselves to the world of research and develop confidence as family leaders and as experts in their own experience.

## Seek feedback and make changes!



As we reflect on our progress and practices over the last 4 years, we attribute our advancement to these key elements:

-Buy-in and presence from the executive level

-Ensuring FER was detailed in the strategic plan

-Moving from advocacy to policy by embedding family review in our internal grants completions

- Building awareness of FER into the everyday workflow through the Start Smart Program

-Co-creating a flexible engagement program that allows family leaders to work remotely and on their own schedule

-Fostering an environment of continuous learning by revising practices each grant cycle

-Offering professional learning and leadership opportunities for our family leaders



#### **INCREMENTAL CHANGE Number of Volunteers**



Check out our research guidebook and family leader page!



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Children's Healthcare Canada

Santé des enfants Canada