

Holland Bloorview

Kids Rehabilitation Hospital

Guiding Family Engagement in Research:

A Framework from Holland Bloorview
Kids Rehabilitation Hospital

A framework to support authentic and meaningful partnerships among families, staff, and researchers to advance childhood disability research.



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For more information about the framework or our experience engaging families throughout the research process, please contact the Family Leadership Program or the BRI Operations team

familypartner@hollandbloorview.ca
brirequests@hollandbloorview.ca

*all italicized words are defined in the Glossary of Terms
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Introduction

Since 2013, Holland Bloorview Kids Rehabilitation Hospital (herein 'the hospital') and the Bloorview Research Institute (BRI) have grown a robust Family Engagement in Research (FER) program. This program has been designed to support **authentic and meaningful engagement of clients and families in the research process**. Through this initiative, clients and families are engaged as true partners, with their role extending beyond the traditional study participant.

The FER program is a partnership between the hospital and BRI, and sits within the hospital's longstanding Family Leadership Program. The FER program is co-led by the Director of Research Operations and the Manager of Client and Family-Centred Care, in collaboration with the Research Family Engagement Committee (RFEC). The program also benefits from a dedicated Co-ordinator of Family Engagement, who is responsible for engaging and recruiting family members, liaising with researchers and creating matches between family members and researchers for various projects.

The purpose of this User Guide (herein referred to as 'the Guide') is to:

- Provide an overview of the updated FER framework and guiding principles
- Describe family member roles in the framework
- Support use of the framework at both the individual and organizational levels

This Guide has been designed for all families, researchers, research staff and trainees seeking to use the Holland Bloorview Family Engagement in Research Framework.

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About the Family Engagement in Research Framework

At Holland Bloorview we understand that involving *families* as partners in research enhances the relevance, quality, impact and utility of research findings. To complement the expertise and knowledge researchers contribute, the family's lived experience can bring perspectives to the research process that would otherwise be absent in traditional research process. To see the full benefit of the family perspective in research, families should be involved in all aspects of the research process.

Developing and running the FER program for the past five years has produced many learnings, which have been used to refine and refresh our guiding framework. This updated framework was *co-created* with clients, families, staff, trainees, and researchers through a series of facilitated workshops. Existing patient/family partnership frameworks, current literature, *best practice*, and the experiences of our stakeholders guided the work.



The **objective** of this framework is to enable family engagement in all aspects of the research process from conceptualization (thinking about research) to dissemination (sharing) of results.

The framework is centered on client and family needs, and identifies five key stages within the research process where family members can leverage their lived experience expertise. These stages include: Think (Conceptualize), Plan, Do (Conduct), Share (*Disseminate*) and Use (*Implement*). By assuming one or more of the three roles, Family Advisor, Family Partner and/or Lived Experience Educator, families can ensure their perspectives are woven into the research process. Details about each of the stages and definitions of each role can be found below.

Through implementing this framework at Holland Bloorview, it is our **vision** that all research at Holland Bloorview will be informed and co-designed by families in collaboration with researchers and staff.

Guiding Principles

The FER framework is rooted in Holland Bloorview's five guiding principles for family engagement. These principles were informed by *SPOR*, *PCORI* and *INVOLVE* and *co-created* with clients, families, staff and researchers at Holland Bloorview.



Inclusiveness

Family engagement in research integrates a diversity of family perspectives



Support

Adequate support and flexibility are provided to all members of the research team to ensure that they can contribute fully



Co-develop

Stakeholders work together from the beginning to identify research problems and gaps, set priorities and implement solutions



Mutual respect

Acknowledge and value each other's expertise and experiential knowledge



Transparency

Goals and expectations for all research team members should be clearly identified and communicated

See [Appendix A](#) for examples of how the above principles can be operationalized.

Family Roles

The framework identifies 3 key roles that families can have throughout the research process.

Family Advisor: Provides advice or insight at a single point in time during the research process. Examples include reviewing a grant application, sitting on a panel, reviewing study material and providing feedback.

Family Partner: Participates as an active member of the research team throughout the research process. Examples include *co-investigator*, *knowledge user*, *collaborator* or *content expert*.

Lived Experience Educator: Educates researchers, research staff and trainees throughout the research process through sharing lived experiences. Examples include sharing family stories at meetings or communicating research results as part of a workshop or presentation.

Examples of Family Engagement throughout the research process:

Family engagement is diverse and can take many different forms depending on the nature of the partnerships. There is no "one-size fits all" model for engagement and the table below is meant to provide some examples of how families can partner in the research process, but should not be considered an exhaustive list. Before entering into a partnership, the following should be thoughtfully considered by both the client/family and the research team:

- stage of the research
- research goals and objectives
- needs and strengths of the client or family partner and the research team.

The table below provides examples of what engagement could look like at different stages in the research process. It can be used as a guide to help family members and research teams discuss and define the unique role a client/family may play on a specific research team within a given context.

Family Leader Roles			
	Family Advisor	Family Partner	Lived Experience Educator
Think (Conceptualize) 	One or more family members advise/review research objectives and outcomes prior to grant submission.	Family members are engaged as a member of the research team at the time of proposal development.	Family members share their lived experience with a study team to help determine research foci or study objectives.
Plan 	Family members advise on logistics, data collection tools and approaches.	Family members contribute to <i>Research Ethics Board</i> (REB) application, with specific attention to recruitment materials, inclusion/exclusion criteria, consent forms, data collection tools (i.e. interview tools), <i>knowledge translation</i> planning.	Family members share their lived experience participating in research to inform how research may be conducted.
Do (Conduct) 	Family members advise on recruitment material or identify potential networks for recruitment.	Family members aid with study recruitment activities, data collection (i.e. attend focus groups, interviews; deliver/support interventions, etc.) <i>Family Co-Investigators</i> or <i>Knowledge Users</i> contribute unique perspectives to the interpretation of the data	Family members inform data collection materials and protocols based on their lived experience participating in research.
Share (Disseminate) 	Family members provide insights on where and how research results should be <i>disseminated</i> .	Family members contribute as a co-author on a manuscript, support the development of a knowledge translation plan, create <i>knowledge translation products</i> , present research findings.	Family member shares their lived experience to promote awareness of research findings.
Use (Implement) 	Family members consult on <i>implementation</i> planning strategies for research tools and technologies that are ready to be utilized in practice (e.g. clinic).	Family team members contribute to the creation of <i>implementation</i> plans and strategies for research tools and technologies that are ready to be utilized in practice (e.g. clinic).	Family members share their lived experience to amplify the impact of <i>implementation</i> efforts and research results.

Enablers of Family Engagement in Research

It is important to know what helps engagement between families and researchers be authentic and meaningful.

Within Holland Bloorview, enablers of successful engagement and partnership during the research process include:

1 A culture of co-creating with clients, families and alumni

A strong commitment from the hospital and its staff, including senior leadership, is required. At Holland Bloorview, our FER program sits within the hospital's longstanding Family Leadership Program. The FER program is co-led by the Director of Research Operations and the Manager of Client and Family-Centred Care. The VP of Research and the Senior Director of Client and Family Integrated Care are standing members of the RFEC. This demonstrates the FER program and its framework is embedded within the hospital's strong culture of co-creating with clients, families and alumni. Senior leadership recognizes the unique and valuable perspectives that all stakeholders bring to the research process.

2 Guidance and oversight

Successful *implementation* of family engagement requires guidance and oversight from an advisory body, such as a research family advisory. Holland Bloorview has created the Research Family Engagement Committee, which has a diverse membership of researchers, trainees, clients, families, administration and senior leadership.

3 Ethical guidelines for engaging with clients and families in research

It is critical that all members of a research team understand the ethical guidelines for partnering with clients and families to ensure equitable, inclusive and transparent engagement. To ensure ethical principles are being considered, understood and implemented as we promote and support family engagement at Holland Bloorview, two members of the Research Ethics Board, including the chair of the board, sit on the RFEC.

4 Current, evidence-based *best practices*, guiding principles and research

FER is a relatively new concept within the research community and so it is important that *evidence-based practices*, guiding principles and research be constantly reviewed and applied, as appropriate. The members of the RFEC remain up to date with the latest literature on family engagement through journal clubs and utilize and implement learnings in their work.

5 Constant and rigorous monitoring and evaluation

The FER program monitors and tracks all engagement activities and consistently seeks feedback from research teams and families. Beyond day-to-day and annual tracking, the FER commissions periodic external reviews of the program to identify opportunities for change or improvement and understand the benefits of client and family engagement in research. This work aims to promote ongoing and enhanced engagement between clients, families and researchers.

6 Communication and consultation with the research community

Proactive and continuous communication of the framework, the latest research, and engagement successes ensures all stakeholders are adequately informed of *best practices* to promote successful partnerships. The FER and RFEC partner with our internal communication team to share and promote family engagement work and activities across the hospital and externally.



About Holland Bloorview Kids Rehabilitation Hospital and the Bloorview Research Institute

- Canada's largest paediatric rehabilitation hospital
- Ontario's only paediatric inpatient rehabilitation hospital
- Serve kids and youth with disabilities, injuries, and complex care needs
- Academic health science centre, fully affiliated with the University of Toronto
- Embedded research institute dedicated to conducting applied clinical research in the field of childhood disability
- Leaders in research, teaching, and client and family-centred care
- The BRI is internationally recognized for its leadership in the field of childhood disability research.
- The overall objectives of the BRI is to advance knowledge and understanding; improve the lives of children with disabilities; and transform the future of childhood disability research.
- The BRI brings together a multi-disciplinary team of scientists who partner with clinical staff, clients, and families to generate clinically-linked and applied pediatric rehabilitation research.

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Appendix A

Researchers and family members are strongly encouraged to embody the five guiding principles in their engagement approaches in the following ways:

Principles	Staff & Researcher	Family Member
<p>Inclusiveness</p> 	<ul style="list-style-type: none"> • Seek out representation from multiple and diverse families, both currently receiving services and alumni • Schedule meetings around school pick-up and drop-off times • Offer choice to participate virtually • Engage the entire project team in the responsibility to engage/ reach out to underrepresented groups • Demonstrate cultural safety and sensitivity • Use accessible language during team meetings and communication; avoid jargon and explain acronyms as they come up 	<ul style="list-style-type: none"> • Share perspectives that are inclusive of the broad family experience and needs, while rooted in your lived experience • Share preferred mode of communication • Introduce yourself to all members of the research team • Ask for clarification if you do not fully understand something shared or to spell out an acronym • Where you feel comfortable, share your pronouns and how you would like to be addressed
<p>Co-Develop</p> 	<ul style="list-style-type: none"> • Engage families as early as possible in the research process - ideally at the priority setting or grant writing stage • Work with all families towards common and mutually agreed upon goals and objectives • Commit to designing and conducting research and improvement initiatives that are reflective of all team members' contributions • Ensure decision making is shared and consensus among all members of the project team is sought • Acknowledge family's roles as appropriate in all publications, presentations and products resulting from the partnership 	<ul style="list-style-type: none"> • Actively participate in all aspects of the partnership • Share your ideas, thoughts, and questions with the entire team and project leads • Offer to co-develop aspects of the research process, where applicable and feasible

Principles	Staff & Researcher	Family Member
<p>Transparency</p> 	<ul style="list-style-type: none"> • Work as a group to define and clarify each family member's role based on project needs and individual preferences • Ask family directly when, how and why they want to be engaged • Builds trust by articulating expectations of all partners clearly and early on • Encourage all members of the project team to disclose conflicts of interest • Ensure relevant material is readily shared with all members of the project team • Communicate throughout the project, ensuring all members of the team are aware of progress, especially during waiting periods 	<ul style="list-style-type: none"> • Share any barriers to your participation and collaborate on how to enhance your ability to participate • Ask what you can expect from your participation in the research process and how the team hopes you can contribute
<p>Support</p> 	<ul style="list-style-type: none"> • Provide education, orientation and training on client and family partnership to all members of the project team • Provide new family partners with mentors to support their role as family partner, where appropriate • Ensure relevant material is readily shared with all members of the project team • Provide compensation to client and family partners as appropriate, including childcare, meals, parking/transit, honorariums and endorsement letters • Seek support and engage Family Leadership Program staff team as necessary to support partnerships 	<ul style="list-style-type: none"> • Follow up to inquire what types of information, orientation and support can set you up for success in the partnership and engagement opportunity
<p>Mutual Respect</p> 	<ul style="list-style-type: none"> • Create a trusting environment conducive to co learning and promote open and honest interactions • Engage the client and family as equal members of the team- their role on the team as experts in lived experience • Ensure everyone has the opportunity to meaningfully contribute • Ensure all requests are reasonable and meaningful • Give all partners adequate time to respond • Respond in a timely and consistent manner to all partners • Look for and articulate strengths and unique insights that come from the client and family's lived experiences 	<ul style="list-style-type: none"> • Contribute towards creating an open and transparent working environment that is conducive to partnership and <i>co-design</i> • Respond in a timely and consistent manner to all partners • Respect and appreciate the different kinds of expertise and experience that researchers, staff, and families bring to the conversation

Glossary of Terms

Best Practice: a procedure or approach that has been demonstrated by research and experience to be most effective and has been widely adopted as the superior approach.

Co-design/co-create: Working together with others to produce something meaningful.

Co-investigator: an individual working in partnership with the Principal Investigator in the management, development and/or execution of a research project.

Collaborator: A research team member who is expected to actively participate in the proposed activities but not lead/direct them.

Content expert: A research team member with extensive knowledge or experience in a particular topic or area of research, who can provide information and expertise that gives the content authenticity and credibility.

Dissemination: sharing knowledge with a specific target audience in a way that is effective, and meaningful to them. Dissemination goals can be to provide target audiences with knowledge, raise their awareness on a topic, or increase their ability to use and apply knowledge. Examples of dissemination activities include publications, summaries, and presentations.

Evidence Based Practice: the combination of clinical expertise, patient/client values, and the best research evidence into the decision making process for patient care.

Family member: A person or people who has/have direct lived or care experience, including clients, parents, siblings and caregivers.

INVOLVE: A national advisory group in the UK, funded by the Department of Health, that promotes public involvement in health and social care research. <https://www.invo.org.uk/about-involve/>

Implementation: using strategies to help apply and use evidence within a setting (e.g. hospital) and change practice. Examples of implementation include introducing a change to the school curriculum across the province or creating a practice change in a health care clinic.

Knowledge translation: involves a range of activities to support and enhance the understanding and use of evidence (e.g. research, experiential). Activities include gathering and reviewing, sharing, and using knowledge to improve the health of individuals.

Knowledge translation products: Products that are informed by and present evidence in formats that are concise, easy to understand and actionable. The goal of knowledge translation products is to address gaps and increase the use of evidence. Examples of products include clinical practice guidelines and handbooks.

Knowledge user: A research team member who is able to use the knowledge generated through research in order to make informed decisions about health policies, programs and/or practices. Examples of knowledge users include clinicians, policy maker, educator, decision maker, health care administrator, community leader, patient/client, family member.

PCORI: Patient Centered Outcomes Research Institute <https://www.pcori.org/>

Research Ethics Board (REB): An independent committee established by a hospital or institution to provide independent, multidisciplinary ethics review of research involving humans. The REB has the authority to approve, reject, request modifications to, or terminate any proposed or ongoing research.

SPOR: Canada's Strategy for Patient Orientated Research <https://cihr-irsc.gc.ca/e/41204.html>