

Engaging families as partners in health research: a novel KMb tool

Background: Involving clients and families as partners in research enhances the relevance, quality, impact and utilization of health research. Family engagement programs across the sector of paediatric rehabilitation have demonstrated how lived experience can inform organizational decision-making related to the shaping of programs and services. As a class project for a Family Engagement in Research (FER) course, researchers and Peer Navigators, all whom are parents of children with neurodevelopmental disabilities, created a knowledge mobilization (KMb) tool to increase client and family awareness of research offerings and engagement opportunities within a Children's Treatment Centre setting.

Objective: The objective of this project was to design an interactive tool for clients, caregivers and parents to become more aware of research projects and their role in becoming a family research partner.

Method: Content for the tool was retrieved from best practices identified through a review of KMb tools that support families as partners in health research. Feedback was collected from the Family Engagement Team to identify barriers that clients and families face when accessing research engagement opportunities at Grandview Kids and abroad. An environmental scan of the Kids Brain Health Network and CanChild FER course student project library was completed to identify previously published KMb tools that aim support FER. A client and family onboarding process to research engagement was drafted and tested with the family engagement team to stimulate common pathways a family may follow at Grandview Kids. The KMb tool was presented to various knowledge users for further feedback in design and usability.

Outcomes: A KMb tool that resembled a road map of the journey to becoming a family research partner was created to increase the availability to information about family engagement in research (e.g. what is research, what are the rights of a family research partner, what are the different roles of the family partner). The tool was designed to be customizable with the intent that other organizations could adapt the tool to reflect unique internal processes.

Next steps: Grandview Kids will continue to implement a clear pathway for clients and families to engage with internal and external research opportunities.