

Background

- Despite the perceived value of family engagement in research (FER), adoption among the research community has been limited by lack of clarity on how to do so effectively.
- Recognizing the need for training, Kids Brain Health Network recently launched a **“Family Engagement in Research Certificate Program”** in partnership with McMaster.

“The course brings parents of children with neurodevelopmental disabilities together with graduate student research trainees to gain knowledge and understanding of FER, and build a cohort of future enlightened and engaged partners.”

Methods

- The course was co-designed and is now being delivered by both experienced parents and researchers.
- Using a before-after follow-up study design, we are conducting a pilot evaluation to explore the feasibility of the program, and the impact of the program on participants’ knowledge, attitudes, and self-confidence in FER.

Course Description

Course Format

- 10-week online course, which involves synchronous and asynchronous discussions, review of written materials and case studies, as well as collaborative group exercises.
- All students are required to complete structured weekly learning activities to critically reflect on the readings and apply new knowledge, as well as complete a course project.
- For the course projects, research trainees and parents are partnered together. The aim of the project is to create a Knowledge Translation (KT) tool on a topic related to family engagement in research.
- The first cohort of 18 students is in progress, with a second cohort planned for Winter 2019. Data collection is in progress.

Course Schedule

Week	Topic
1	Family Engagement in Research: What do we really mean?
2	Family Engagement in Research: Why is it important?
3	Building an integrated research team: How can we find each other?
4	Building an integrated research team: How can we work together?
5	Roles and responsibilities of families and researchers
6	Ethics of family engagement in research
7	Barriers and facilitators to family engagement
8	Family engagement tools & resources
9	Evaluation of family engagement activities
10	Course Projects & Presentations

Impact

- By bringing families and trainees together we have created a community for knowledge sharing and exchange.
- Friendships have formed between trainees and researchers and many groups have shared that they plan to continue working together after the completion of the course.
- Each group has created a KT tool on family engagement in research that will be shared outside of the course.

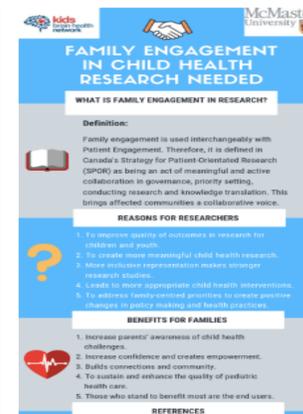
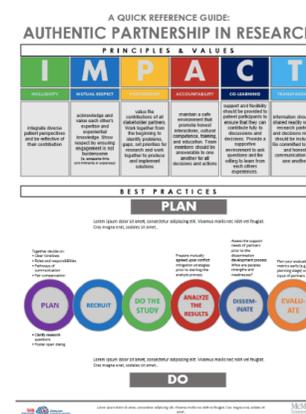
Acknowledgements

- We would like to thank the first cohort of 18 students for their involvement, contributions, and dedication to this course.
- We would like to thank Kids Brain Health Network (KBHN) for their financial support.

Course Feedback – Highlights & Example Course Projects

“The content is extremely interesting and well thought-out. Excellent readings.”
 – Parent

“I very much enjoyed being paired with a family leader. Discussing the course with them has been very insightful.”
 – Research Trainee



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