

Building capacity for families as partners in research: A Family Engagement in Research Certificate Program



Andrea Cross¹⁻³, Donna Thomson^{2,4}, Connie Putterman^{2,4}, Dayle McCauley¹, Patty Solomon³, Jan Willem Gorter¹⁻⁵

¹CanChild, McMaster University; ²Kids Brain Health Network; ³School of Rehabilitation Science, McMaster University; ⁴CHILD-BRIGHT; ⁵Department of Pediatrics, McMaster University

BACKGROUND

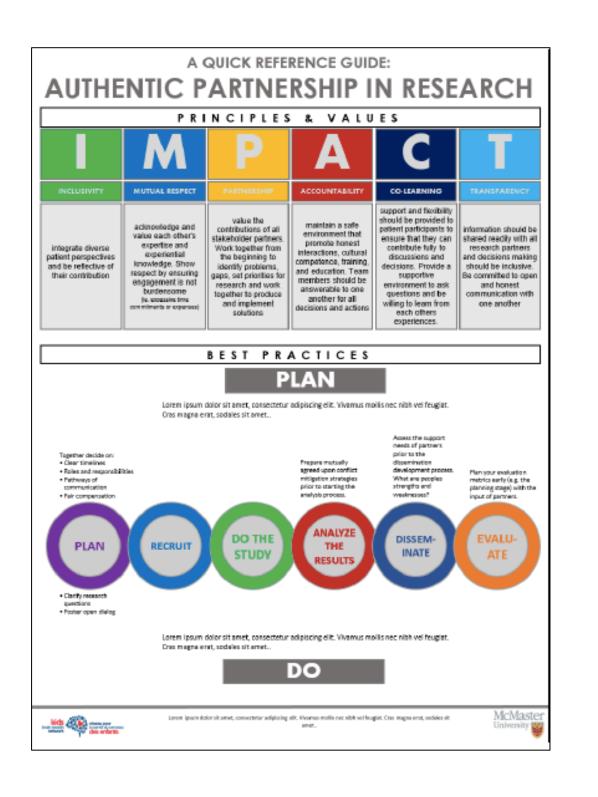
- Despite the perceived value of family engagement in research (FER), adoption among the research community has been limited by lack of clarity on how to do so effectively.
- Recognizing the need for training, Kids Brain Health Network in partnership with CanChild and McMaster University recently launched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

COURSE DESCRIPTION

Course Format

- The course brings parents of children with neurodevelopmental disabilities together with graduate student research trainees in a 10-week online course.
- The course was co-designed and co-instructed by parents and researchers.
- A Knowledge Translation (KT) project on FER is completed by pairs of research trainees and parents as part of the requirements of the course.

Project Examples



kid net	McMaster University
	FAMILY ENGAGEMENT IN CHILD HEALTH RESEARCH NEEDED
	WHAT IS FAMILY ENGAGEMENT IN RESEARCH?
	Definition: Family engagement is used interchangeably with Patient Engagement. Therefore, it is defined in Canada's Strategy for Patient-Orientated Research (SPOR) as being an act of meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. This brings affected communities a collaborative voice.
	REASONS FOR RESEARCHERS
	1. To improve quality of outcomes in research for children and youth. 2. To create more meaningful child health research. 3. More inclusive representation makes stronger research studies. 4. Leads to more appropriate child health interventions. 5. To address family-centred priorities to create positive changes in policy making and health practices.
	BENEFITS FOR FAMILIES
*	Increase parents' awareness of child health challenges. Increase confidence and creates empowerment. Builds connections and community. To sustain and enhance the quality of pediatric health care. Those who stand to benefit most are the end users.
	REFERENCES

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

COURSE FEEDBACK



"A fabulous opportunity in a warm, welcoming, and non-judgmental environment to understand and explore family engagement in research. Being able to have oneon-one conversations with my research partner gave me insight that is difficult to find in the community." - Parent

"I had zero experience regarding family engagement and research before taking this course, so it was very helpful for me to take this course. It really helped elevate my level of appreciation for family engagement in research. For anyone who is interested in family engagement in research I would definitely recommend it. It was really well designed." - Graduate Student Research Trainee



Key Themes

High levels of satisfaction (8.7/10)



Partnering on a KT project was a highlight of the course



KBHN and McMaster partnership was important to students



Gained confidence and competence in family engagement in research

- By bringing families and trainees together we have created a community for knowledge sharing and exchange.
- By the end of the certificate, students have an advanced understanding of family engagement, and are ready to partner on integrated research teams.
- Relationships have formed between trainees and researchers and many groups have shared that they plan to continue working together after the completion of the course.

ACKNOWLEDGEMENTS

We would like to thank the first cohorts of 36 students for their involvement, contributions, and dedication to this course. We would also like to thank Kids Brain Health Network for their financial support.

CONTACT INFORMATION

For more information contact: Andrea Cross (crossac@mcmaster.ca)

