

Family engagement in child health research needed.

Kirsti Mardell¹, Crystal Shannon^{1,2}

¹Kids Brain Health Network; ²University of British Columbia, Okanagan

Background

- Family engagement in research is needed in order to bring communities such as parents of children living with neurodevelopmental disabilities a collaborative voice.
- Researchers and families may have different reasons for wanting to participate in pediatric research; however, their goals may still align when the commitment to foster better outcomes and positive change for child health is present.
- The authors formed a researcher-family partnership during the first cohort of the Family Engagement in Research (FER) Certificate of Completion, sponsored by Kids Brain Health Network in partnership with CanChild and McMaster University.
- Together, Kirsti and Crystal, developed a knowledge translation (KT) tool in the form of an infographic to heighten awareness of the importance of integrated research teams.

Aim

- The aim of the infographic is to illustrate the importance of family engagement in research for child health in a visually appealing manner that can be easily understood and disseminated.

Methods

- The authors met online during the FER course designed for graduate students and family members who share a joint interest for neurodevelopmental research.
- Kirsti and Crystal decided on an infographic as their project because they felt it would be a feasible project to complete within the course's allotted timeframe.
- Strategies included consistent, flexible communication via various methods including telephone calls, FaceTime, and email was required to create the KT tool.
- Mutual respect, commitment, and constant feedback and acknowledgement were essential.
- Strength-based division of tasks was key to the success of the project based on the partners' academic and parental lived experiences.



 

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

- To improve quality of outcomes in research for children and youth.
- To create more meaningful child health research.
- More inclusive representation makes stronger research studies.
- Leads to more appropriate child health interventions.
- 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

- Curran, J.A., Bishop, A., Chorney, J., MacEachern, L., & Mackay, R. (2018). Partnering with parents to advance child health research. *Healthcare Management Forum*, 31(2), 45-50.
- Canadian Institutes of Health Research. (2015). CIHR Jargon Buster. Retrieved from <http://www.cihr-irsc.gc.ca/e/48952.html>
- Gill, C., Ansermino, M.J., Sanatani, S., Mulpuri, K., & Doan, Q. (2014). Paediatric patient family engagement with clinical research at a tertiary care paediatric hospital. *Paediatric Child Health*, 9(10), 537-442.
- Gwara, M., Smith, S., Woods, C., Sheeren, E., & Woods, H. (2017). International children's advisory network: a multifaceted approach to patient engagement in pediatric clinical research. *Clinical Therapeutics*, 39(10), 1933-1938.
- Shen, S., Doyle-Thomas, K.A.R., Beesely, L., Karmali, A., Williams, L., Tanel, N., & McPherson, A. C. (2017). How and why should we engage parents as co-researcher in health research? A scoping review of current practices. *Health Expectations*, 20(1), 543-554.
- Woodgate, R.L., Zurba, M., & Tennent, P. (2018). Advancing patient engagement: youth and family participation in health research communities of practice. *Research Involvement and Engagement*, 4(1), 1-6.

CRYSTAL SHANNON & KIRSTI MARDELL COPYRIGHT © 2018.

Research Partners



Crystal Shannon & Kirsti Mardell

Dissemination

- The infographic is user-friendly and can be widely distributed to a variety of stakeholders using several platforms including: facebook groups and organizations or can be posted on related websites including the Kids Brain Health Network.

Next Steps

- Kirsti continues her mission to advocate for more supports and services for families and children living with neurodevelopmental differences to benefit her rural community, the Regional Municipality of Wood Buffalo in Alberta where resources are lacking. She continues to engage with health research whenever opportunities arise.
- Crystal is enrolled in the Interdisciplinary Graduate Studies program: Community Engagement, Social Change, and Equity theme at UBC Okanagan in Kelowna, British Columbia where she continues to engage families and community partners in child health research. Her doctoral pursuits are focused on the development and implementation of an online parent support intervention to help promote safe and active recreation for children living with autism spectrum disorders.

Lessons Learned

- Upon completion of the FER project, the authors reflected upon their collaborative process determining the following four recommendations:
 - 1) Constant communication needed throughout the entire project
 - 2) Flexibility necessary
 - 3) Establish short-term & long-term goals
 - 4) Equal partnership from start to finish