Youth Engagement in Research Partnerships

Exploring Training Needs of Youth with Neurodevelopmental Disabilities

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BACKGROUND

What is Patient-Oriented Research?

A "continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes" according to the Canadian Institutes of Health Research.[1]

What are the gaps?

- Few training programs exist in Canada; none are tailored for youth with neurodevelopmental disabilities (NDD).
- A need for training opportunities was expressed by youth with NDD at a CP-NET Stakeholder Meeting.

RESEARCH QUESTIONS

1 What are the training needs for youth with NDD to enhance their knowledge, confidence, and skills, as research partners?

2 What are the benefits and challenges of engaging in an integrated knowledge translation (iKT) research approach?

METHODS

Study Design

Phase I: Focus Groups & Interviews: Youth with NDD (age 18-25) are consulted about barriers, facilitators and training needs in POR.

Phase II: Virtual Symposium (September 15 & 25, 2021): Youth & researchers from NDD networks discuss delivery methods & prioritize training topics.

Phase III: Training Material Development: Co-development of POR training opportunities *with* and *for* youth and researchers.

Qualitative Content Analysis[2]

PRELIMINARY RESULTS

Demographic

Table 1. Focus Group & Interview

		n	%
Youth (18-25)*		7	100%
	ASD	1	25%
	CP	2	25%
	ADHD	3	38%
	ASD & ADHD	1	13%
Gender	Male	2	25%
	Female	3	38%
	Other	2	25%

Table 2. Virtual Symposium

		n	%
Total Participant		17	100%
Youth (18-25)		10	59%
	ASD	1	6%
	CP	4	24%
	ADHD	3	18%
	ASD & ADHD	1	6%
	CP & ASD	1	6%
Researchers		7	41%
Gender			
	Male	5	29%
	Female	11	65%
	Other	1	6%

Note
ADHD: Attention Deficit Hyperactivity Disorder
ASD: Autism Spectrum Disorder
CP: Cerebral Palsy

*9 youth interviewed, 2 removed due to not fitting eligibility criteria (age and NDD)

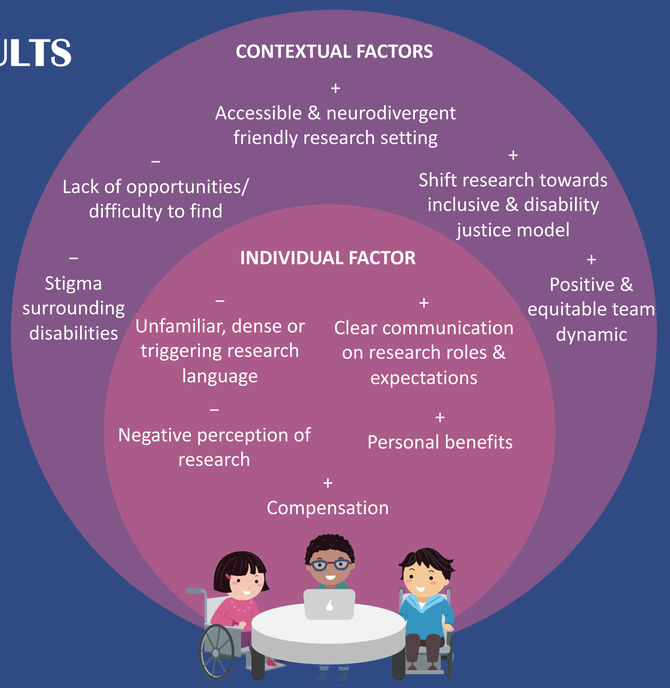

Figure 1. Individual and contextual barriers (-) and facilitators (+) in POR based on qualitative content analysis.

Prioritized Training Needs (Topics)

1. Communication training between youth & researchers
2. Research roles & responsibility
3. Finding research partnership opportunities

Potential Training Formats

- Video(s) with a person speaking to you
- Whiteboard animations with voiceover
- Infographic, PDF, Checklists
- Mentorship, Personal Check-Ins
- Online Interactive Modules
- Quizzes, activities, and reflections
- Simulations (e.g., scenarios + solutions)

Figure 2. Prioritized training needs and potential training formats based on virtual symposium discussions.

Scan the QR code to visit our study website or enter this link: tinyurl.com/CanChildYER

iKT Approach

Co-Investigators: 4 youth with lived experience, 1 parent with lived experience, and 5 researchers.

Various Communication Methods: monthly team meetings, email, individual check ins between student investigator and partners before each study phase.

Engagement Tools: Involvement Matrix[3] during individual check ins; Public and Patient Engagement Evaluation Tool[4] administered at the end of each phase.

Contribution from patient co-investigators throughout the research process:

Preparation
Co-designed protocol
Shaped focus group and interview questions
Filmed recruitment videos
Provided feedback on ethics and grant application

Execution
Recruited participants
Conducted focus groups and interviews
Co-hosted and facilitated the virtual symposium
Collaboratively analyzed qualitative data (coding)

Knowledge Translation
Co-developed prototypes of training opportunities
Co-presented findings at research conferences
Manuscript preparation

POTENTIAL IMPACT

Creating POR training opportunities for youth with NDD could bring more lived experience perspectives onto research teams, which ensure that research outcomes are more *meaningful* and *relevant* to youth with NDD.

REFERENCES

1. Government of Canada, 2019. Strategy for Patient-Oriented Research - Patient Engagement Framework. [online] Canadian Institutes of Health Research. Available at: https://cihr-irsc.gc.ca/e/48413.html
2. Hsieh, H.-F., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, 15(9), 1277–1288. https://doi.org/10.1177/1049732305276687
3. Smits, D.-W., van Meeteren, K., Klem, M., Alsem, M., & Ketelaar, M. (2020). Designing a tool to support patient and public involvement in research projects: The Involvement Matrix. *Research Involvement and Engagement*, 6(1), 30. https://doi.org/10.1186/s40900-020-00188-4
4. Abelson, J., Tripp, L., Kandasamy, S., Burrows, K., & on behalf of the PPEET Implementation Study Team. (2019). Supporting the evaluation of public and patient engagement in health system organizations: Results from an implementation research study. *Health Expectations*, 22(5), 1132–1143. https://doi.org/10.1111/hex.12949