

Strategies for Equitable and Meaningful Youth

Engagement: A Reflection on the Youth Engagement in Research (YER) Project

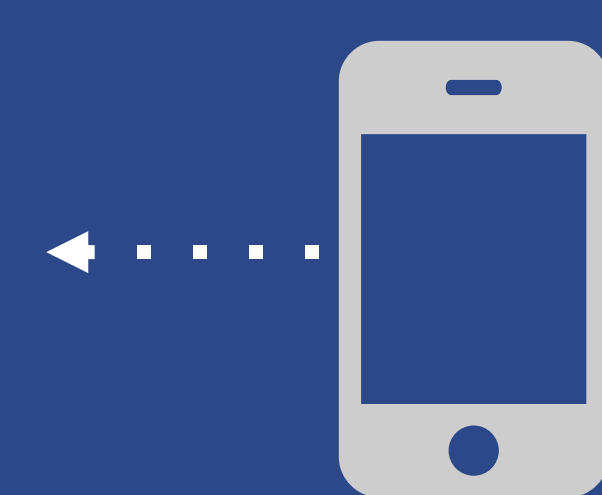
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Background: When research is accessible, **everyone** benefits! When those with lived experience partner within research they build skills that help them be stronger advocates within their own healthcare and wider community at large.

Patient Partnership:

- By its very nature, the Patient-Oriented Research (POR) approach allows for a more equitable research project because it engages patients as partners and allows research to focus on priorities that are important to patients.
- Specific to the YER Project, which these reflections are drawn from, patient partners were involved as co-investigators from the very beginning. It was 3 youth with cerebral palsy who proposed that there were no training/educational opportunities for youth with neurodisabilities to learn about engaging in research.
- Patient Co-Investigators were involved with everything from grant and ethic proposals, to writing semi-structured interview guides and hosting a 2-day symposium, to learning and assisting in qualitative coding. Co-Investigators were also involved in the research paper draft, submission, and corrections. Those of us with lived experience are also actively involved in the dissemination of our project and future next steps.

With clear and flexible methods of communication, equitable and accessible research is possible!



Scan this QR Code to access the YER Linktree (research paper and resources).

Implications On...

Practice:

- Including patient partners, not just youth, with lived experience allows researchers and clinicians to see beyond just a disorder/disability to a person.
- Researchers will gain a stronger understanding of disability culture and lived experience.

Organizational/System

Leadership:

- Patient-Oriented Research allows researchers and those with disabilities/health conditions to push back against the ableist foundations present in academia and research.

Transition from Pediatrics to Adult Healthcare System:

- Skills learned from partnering in research allow youth with disabilities to become stronger advocates in their own healthcare, which ideally leads to better health outcomes as they transition between the pediatric and adult healthcare systems.

