
POSTER ABSTRACT

Nothing For Youth, Without Youth: Combining Evidence-Based and Youth Perspectives on Youth Engagement in Health Research

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Katherine Bailey¹, Brooke Allemang², Jeanna Pillainayagam⁵, Sarah Munce³,
Alene Toulany¹⁴

1: Temerty Faculty of Medicine, University Of Toronto, Toronto, Ontario, Canada

2: Office of Patient, Family, and Community Engagement, The Hospital for Sick Children, Toronto, Ontario, Canada

3: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada

4: Department of Adolescent Medicine, The Hospital for Sick Children, Toronto, Ontario, Canada

5: McMaster University, Hamilton, Ontario, Canada

Background: Youth engagement in health research, referring to the collaboration between researchers and youth to produce research, has been shown to enhance the relevance, applicability, and impact of interventions aimed at improving health outcomes. Despite its potential, many researchers feel ill-equipped to effectively implement youth engagement strategies within their own research contexts. Our synthesis aims to describe evidence-based and youth-generated barriers and recommendations for meaningful engagement of youth in health research.

Methods: Our synthesis was conducted in two phases, including a narrative review of the literature and formation of a Youth Advisory Council (YAC) to review the identified literature and provide their perspectives grounded in their lived experiences. The search terms 'youth engagement' and 'health research' were searched in various databases, including PubMed, PsycINFO, Web of Science, Google Scholar, and Scopus, as well as grey literature sources. Eleven youth from across Canada joined the YAC and participated in four virtual meetings, which focused on 1) a collaborative ideation session to conceptualize their contributions to the synthesis, 2) discussion centered on their reflections on the literature, 3) establishing focused working groups to contribute to specific components of the manuscript, and 4) reviewing the written materials produced by each working group and reaching consensus on how these would be displayed in the manuscript. Flexible youth engagement approaches were used, including leveraging a range of communication approaches, creating a terms of reference, and discussing strategies to foster inclusive spaces. Youth advisors were remunerated for their contributions.

Results: Barriers to youth engagement were organized into youth-level, researcher-level, organizational-level, and system-level. Youth-level barriers included mistrust in healthcare providers and/or researchers, time commitments to engage in research, difficulty navigating academic spaces, and previous discriminatory experiences. Researcher-level barriers included pre-existing beliefs about the utility of youth engagement, lack of confidence in engaging with youth, and competitive/inflexible "publish or perish" mindsets. Organizational barriers included inadequate infrastructure to support youth engagement, including funding or training opportunities, and strict research timelines that do not accommodate the flexibility needed for youth engagement.

System-level barriers included power dynamics between youth and adult researchers, as well as systemic discrimination and exclusion of marginalized identities from research. Recommendations for youth engagement were summarized into training opportunities, recruitment strategies, budgeting and incentives, research meetings and communication approaches, engaging youth from diverse backgrounds, evaluating engagement, and capacity development.

Conclusions: Researchers must foster an inclusive environment that promotes collaboration, trust, and safety to enable youth to meaningfully contribute to research endeavours. Future research should prioritize investigating the dynamics of power-sharing between researchers and youth and evaluating the impact of youth engagement on youth themselves.