

Youth engagement in the YouthCan IMPACT trial

Joanna L. Henderson PhD CPsych, Lisa D. Hawke PhD, Jacqueline Relihan

■ Cite as: *CMAJ* 2018;190(Suppl 1):S10-S12. doi: 10.1503/cmaj.180328

CMAJ Podcasts: author interview at <https://soundcloud.com/cmajpodcasts/patient-oriented-research>

In Canada, some 20% of youth experience mental health and addiction disorders,¹ yet rapid access to developmentally sensitive, evidence-based care is limited. Youth and caregivers consider Ontario's system of care for mental health and addiction disorders in youth to be fragmented, underresourced and inefficient.² Our team is addressing these challenges by implementing and rigorously evaluating an integrated community-based collaborative care team (ICCT) model in Toronto, providing rapid access to youth-friendly, evidence-based services in a stepped-care manner.³

The YouthCan IMPACT project was funded by OSSU (the Ontario SPOR [Strategy for Patient-Oriented Research] SUPPORT [Support for People and Patient-Oriented Research and Trials] Unit) in 2015.³ Through cross-sectoral collaborations, the ICCT model provides stepped-care services with low-, mid- and high-intensity interventions for mental health and addiction disorders in co-located, community-based walk-in service hubs. A randomized controlled trial is systematically evaluating the effectiveness of this model, compared with hospital-based treatment as usual. Five hundred youth are being randomly assigned to usual treatment at one of five area hospitals or to ICCT services. Participants are assessed at intake, 6 months and 12 months to examine the effects on functioning, symptoms, continuity of care and other variables, including a robust economic analysis.³ The model reflects an international movement toward integrated youth service hubs and has been identified for provincial demonstration in additional communities by Ontario's Ministry of Health and Long-Term Care,⁴ pointing to the urgent need for strong data from randomized clinical trials.

Reflecting OSSU values and increasing calls to involve youth extensively in work conducted for and about them,⁵ which is expected to lead to better outcomes, youth engagement is a key tenet to YouthCan IMPACT. In the context of work with youth with mental health and addiction disorders, we refer to "youth with lived experience" rather than using the "patient" language of OSSU and SPOR. The youth engaged in our projects self-identify as having lived experience of challenges and service use related to mental health and addiction disorders, but they are not required to have been registered as "patients" of a formal medical establishment. Our approach to youth engagement has been documented in two manuscripts coauthored by youth team members,^{6,7} which highlight the importance of authentic engagement, clear expectations, flexibility and multiple levels of engagement that reflect the interests and availability of different youth.

KEY POINTS

- The YouthCan IMPACT project is evaluating community-based, integrated collaborative care teams through a collaborative co-development process that includes youth-serving agencies, researchers, youth, caregivers and other stakeholders.
- The youth engagement model includes high engagement for a small number of youth and more periodic engagement for a broader number of youth, ensuring that a broad range of youth voices are brought to the project.
- Youth have provided substantial contributions to both research and clinical aspects of the project, resulting in a more feasible, youth-friendly project with outcomes that are more relevant to the needs of youth today.
- It is important that researchers work with youth to ensure meaningful engagement and shared decision-making, while continually monitoring their engagement to ensure that the youth engaged are truly bringing the youth voice to the project.

The governance model of YouthCan IMPACT includes youth with lived experience as full members of the core decision-making body and working groups, ensuring that the youth voice is heard at all levels. Decisions are made by discussion, compromise and consensus. When youth suggestions cannot be integrated because of methodologic considerations, open and honest discussions ensure that the youth understand the reasoning and that any possible compromises are made. Since grant development, eight youth have been involved as casual staff at the Margaret and Wallace McCain Centre for Child, Youth & Family Mental Health, working across projects, including YouthCan IMPACT (two male and six female youth aged 19–26, with at least two youth on staff at any time). They receive an hourly wage funded in part by OSSU with support from other sources. They were recruited via regular institutional human resources processes, with circulation of the job posting to community partners.

To reach a broader and more representative group of youth, we have a youth advisory group currently consisting of 22 youth (age 16–24) whom we consult regularly for more extensive feedback; they receive an honorarium for their service. Youth advisory group members are continually recruited through our community partners and broad circulation of recruitment materials. Since 2016, youth have been supported by a youth engagement coordinator (0.8 full-time equivalent), funded by philanthropic

donors, to support their ongoing effective engagement in YouthCan IMPACT and other projects.

Youth have made substantial contributions to the design of the YouthCan IMPACT research and clinical service pathway. Notably, in a multidisciplinary research team including psychiatrists, psychologists, social workers, nurses and other mental health researchers, youth guided the selection of the primary outcome measure for the study. Whereas the research team's initial thoughts were to focus on symptoms of mental health and

with the community sites to ensure that the physical environment is attractive and youth-friendly; and the development of psychoeducational materials presenting youth-friendly information about the services available. Youth have been co-presenters at conferences and coauthors on peer-reviewed journal articles about this and other projects, reflecting their substantial contributions.^{3,6,7,9} As the YouthCan IMPACT project advances, youth will continue to be involved in all aspects, including extensive involvement in decisions made about the project.



addiction disorders, the youth expressed the importance of focusing on functioning instead. The primary outcome measure for the study is therefore the Columbia Impairment Scale,⁸ which considers youth functioning in various spheres of life. This is a key, study-transformative youth contribution that will make the study outcomes more relevant to the youth experience.

In a youth advisory group meeting of 13 youth, including two youth facilitators, youth identified the values they wanted upheld by researchers and community staff. This discussion led to the development of posters presenting YouthCan IMPACT values, displayed in researchers' offices and clinical sites to remind team members continually of project values (available at www.youthcanimpact.com/about-youthcan).

Other youth contributions include the development of a recommended mobile apps list for the community service pathway; co-development of the study website; group training of the research assistants to ensure that recruitment and assessment are conducted in a youth-appropriate, validating manner; work

Youth engagement has not been without challenges. Notably, it is important to monitor engagement continually to ensure that youth are truly bringing the youth voice to the project. Regularly bringing new youth onto the team broadens the youth voice and ensures that voices represent young people today. It can be challenging to ensure that the youth advisory group has diverse membership and that a strong youth facilitator is available to facilitate meetings. In addition, it is important for researchers to work with the youth to ensure that engagement is meaningful to them and collective decision-making remains at the forefront.

The YouthCan IMPACT experience has pointed to the value that engagement of youth with lived experience can bring to research and service design initiatives, making the research and service context more relevant to youth. Much of the knowledge gained about youth engagement applies not only to clinical research, but also to youth-relevant research as a whole (Hawke and colleagues have outlined practical recommendations on engaging youth in diverse research projects⁶). With YouthCan IMPACT as one example

of successful engagement, researchers and system planners are encouraged to engage youth to make their work more feasible, youth-friendly¹⁰ and appropriate to the young people their projects are targeting. The results of this youth-engaged study will guide the ongoing development of community-based integrated service hub models in Ontario and beyond.

References

1. Boyle MH, Georgiades K. Disorders of childhood and adolescence. In: Cairney J, Streiner D, editors. *Mental disorders in Canada: an epidemiological perspective*. Toronto: University of Toronto Press; 2009.
2. Kozloff N, Cheung AH, Ross LE, et al. Factors influencing service use among homeless youths with co-occurring disorders. *Psychiatr Serv* 2013;64:925-8.
3. Henderson JL, Cheung A, Cleverley K, et al. Integrated collaborative care teams to enhance service delivery to youth with mental health and substance use challenges: protocol for a pragmatic randomised controlled trial. *BMJ Open* 2017;7:e014080.
4. Ontario providing faster access to mental health services for thousands of people [press release]. Toronto: Ontario Ministry of Health and Long-Term Care; 2017.
5. Bell E. Young persons in research: a call for the engagement of youth in mental health research. *Am J Bioeth* 2015;15:28-30.
6. Hawke LD, Relihan J, Miller J, et al. Engaging youth in research planning, design and execution: practical recommendations for researchers. *Health Expect* 2018 June 1 [Epub ahead of print]. doi:10.1111/hex.12795.
7. Heffernan OS, Herzog TM, Schiralli JE, et al. Implementation of a youth-adult partnership model in youth mental health systems research: challenges and successes. *Health Expect* 2017;20:1183-8.
8. Bird HR, Shaffer D, Fisher P, et al. The Columbia Impairment Scale (CIS): pilot findings on a measure of global impairment for children and adolescents. *Int J Methods Psychiatr Res* 1993;3:167-76.
9. Rong J, Cleverley K, Relihan J, et al. Youth engagement in the design of services and research for youth mental health and addictions services: innovative projects and key youth contributions [presentation]. *Proceedings from the 31st Annual Research & Policy Conference: Child, Adolescence & Young Adult Behavioral Health symposium*; 2018 Mar. 6; Tampa (FL).
10. Hawke LD, Cleverley K, Settapani C, et al. Youth friendliness in mental health and addiction services: protocol for a scoping review. *BMJ Open* 2017;7:e017555.

More information on this project is available at www.ossu.ca/IMPACTAwards.

Competing interests: Joanna Henderson reports a grant from OSSU (the Ontario SPOR [Strategy for Patient-Oriented Research] SUPPORT [Support for People and Patient-Oriented Research and Trials] Unit). No other competing interests were declared.

This article was solicited and has been peer reviewed.

Affiliations: Margaret and Wallace McCain Centre for Child, Youth & Family Mental Health (Henderson, Hawke, Relihan), Centre for Addiction and Mental Health; Department of Psychiatry (Henderson, Hawke), University of Toronto, Toronto, Ont.

Contributors: All authors contributed to the conception and design of the work, drafted the manuscript, revised it critically for important intellectual content, gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

Funding: The study discussed in this article is being conducted with the financial support of OSSU, and also has been made possible through a financial contribution from the Margaret and Wallace McCain Centre for Child, Youth & Family Mental Health at the Centre for Addiction and Mental Health. The funders will play no role in the design of the study or the collection, analysis and interpretation of the data.

Acknowledgements: The authors thank Peter Szatmari, as well as the Margaret and Wallace McCain Centre for Child, Youth & Family Mental Health youth engagement facilitators, Youth Advisory Group members and youth engagement coordinator (Karleigh Darnay) for their contributions to the project. The authors also thank the YouthCan IMPACT research and clinical teams for being advocates for strong youth engagement throughout the course of this project.

Correspondence to: Joanna Henderson, joanna.henderson@camh.ca