Youth engagement in the YouthCan IMPACT trial

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In Canada, some 20% of youth experience mental health and addiction disorders, 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. 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.

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. 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. 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, 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, 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, which highlight the importance of authentic engagement, clear expectations, flexibility and multiple levels of engagement that reflect the interests and availability of different youth.

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 involved as casual staff at various positions, including youth engagement coordinator (0.8 full-time equivalent), funded by philanthropic...
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 projects). 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
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.

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

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