

The Youth Wellness Quest: A Comprehensive Online Mental Health Literacy and Self-Advocacy Resource Developed by Youth for Youth

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Abstract

A lack of mental health literacy may impact youths' ability to advocate for themselves as they seek to access and navigate the mental healthcare system. Recognizing this, members of the National Youth Action Council at the Centre for Addiction and Mental Health in Toronto, ON, developed the Youth Wellness Quest resource. This health literacy resource informs youth of possible available services, increasing their capacity to make informed mental healthcare decisions. The youth-led process of creating this resource, from development to dissemination, is described within this paper, showcasing how youth can lead the development of tools designed for youth.

Introduction

In a recent survey of Canadian youth, 59% of respondents stated that they did not know where to go for help regarding mental health issues (Jing 2019). This is concerning, especially as youth – defined as those aged 15 to 29 years by Statistics Canada (2019) – have reported worse mental health than older Canadians (Garriguet 2021). Understanding the types of services available and how to access them is a key component of mental health literacy; poor mental health literacy can be a significant barrier for youth seeking help, many of whom prefer to be self-reliant and advocate for themselves (Bowers et al. 2013; Gulliver et al. 2010; Mehra et al. 2021). Most youth accessing the mental health system for the first time find

Key Points

- A youth team led the development and evaluative study of a mental health literacy resource for youth, along with its transformation into an engaging online resource.
- All activities were youth-led, with support from experienced researchers, a youth engagement coordinator, education specialists and web developers.
- This online youth-led resource is now an online platform, complemented by a brief downloadable version that provides youth with relevant information to better understand the mental healthcare system and service options, empowering youth to advocate for themselves and make informed decisions about their mental health and substance use care.

it difficult to navigate (James 2007; McGorry et al. 2013). Youth with higher levels of mental health literacy may access help earlier, leading to better outcomes (Kelly et al. 2007).

Youth Wellness Quest

Recognizing the issue noted above, members of the National Youth Action Council (NYAC) at the Centre for Addiction and Mental Health (CAMH) in Toronto, ON, developed the Youth Wellness Quest (YWQ) resource (www.youthwellnessquest.com). NYAC members are Canadian youth with lived experience of mental health and/or substance use difficulties who understand struggles with

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the mental healthcare system and who used their lived experience to develop YWQ. The YWQ tool is a health literacy and self-advocacy resource for youth seeking services for any type of mental health or substance use concern. It is composed of a guide (Figure 1) and a checklist (Figure 2). The guide helps youth identify the issues most important to them and explains how these may be addressed using youth-friendly language in an engaging, easy-to-navigate format (Figure 3). It lists potential types of services and treatment partners rather than specific treatment providers, guiding youth in how to find such services in their own communities. It suggests questions that youth may ask service providers to be well informed and engaged in the treatment process. Youth may document their needs and preferences on the checklist as part of developing their own treatment plan, potentially alongside their service providers. As the ultimate goal of YWQ is to move youth from the role of patient to partner in their own mental healthcare, the YWQ resource was developed by youth for youth.

In developing the YWQ, NYAC members conducted a study to understand youths' perspectives on a draft version, involving five focus groups and an online survey (Syan et al. 2021). Participants lived across Canada, were aged 14 to 26 years and had diverse gender identities, cultural backgrounds and sociodemographic characteristics. Study participants were asked about the resource's content, presentation, utility and ability to promote self-advocacy. Overall, youth evaluations

of the draft YWQ were positive, with some suggestions for content expansion. Participants suggested that the resource be available as both a comprehensive online version and a shorter print version for use with service providers in healthcare and mental health organizations, as well as educational institutions. A youth-led peer-reviewed journal article provides further details (Syan et al. 2021).

Funding Application

To develop an online version of the YWQ resource, a knowledge translation grant application was co-written by NYAC members, including the youth project lead, a youth advisor and allied researchers, then submitted to the Ontario SPOR SUPPORT Unit (OSSU). The youth project lead and youth advisor referenced the YWQ research project to frame the application. Through multiple team discussions, the youth lead and advisory team co-designed the knowledge translation plan, including the steps, the timeline, the youth leadership and engagement plan and the dissemination plan. While an allied researcher with grant-writing experience supported them and refined the final application for submission, youth contributed the core substance. OSSU funding was awarded to the team.

FIGURE 1.
Sample excerpt of the YWQ guide

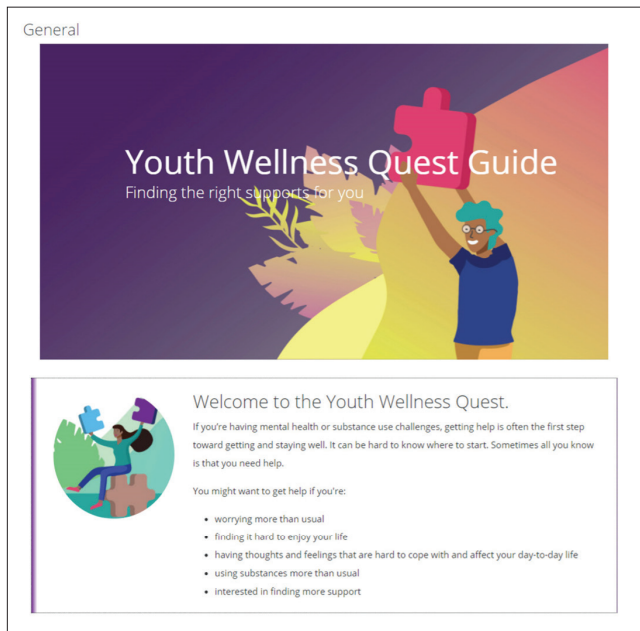
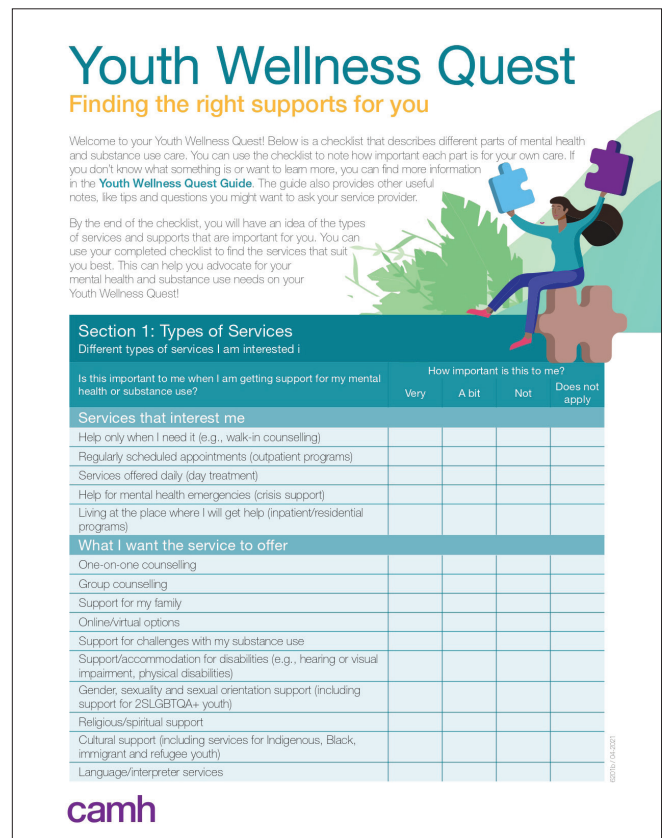


FIGURE 2.
Sample excerpt of the YWQ checklist



Project Execution

Funding was used to develop a comprehensive online version of the YWQ resource. Per study findings, this involved building an engaging and accessible youth-friendly resource for Canada-wide dissemination. The project was led by youth, using the McCain Model of Youth Engagement (Heffernan et al. 2017). One youth served as the primary lead, with six additional NYAC youth advisors supporting the project; these youth varied in the amount and type of lived experience they had, as well as in socio-economic and demographic backgrounds. Experienced researchers, a youth engagement coordinator, education specialists and web developers also provided support. The youth team was paid for their contributions.

The youth lead began by updating the content based on the research results, with input from the youth advisors. This included implementing suggestions to change some of the language and add information about services for historically marginalized populations. New sections were added, such as self-help, confidentiality and privacy. The finalized core content was adapted to an online educational software platform by adding links, click navigation, fillable fields, images, infographics and a short introductory video, making it engaging and easy to navigate. Some new content was added to increase online interactivity, such as worksheets and self-reflection activities. Through multiple virtual meetings and e-mail consultations with six youth advisors and other team members, the team enhanced the design, look and feel of the resource.

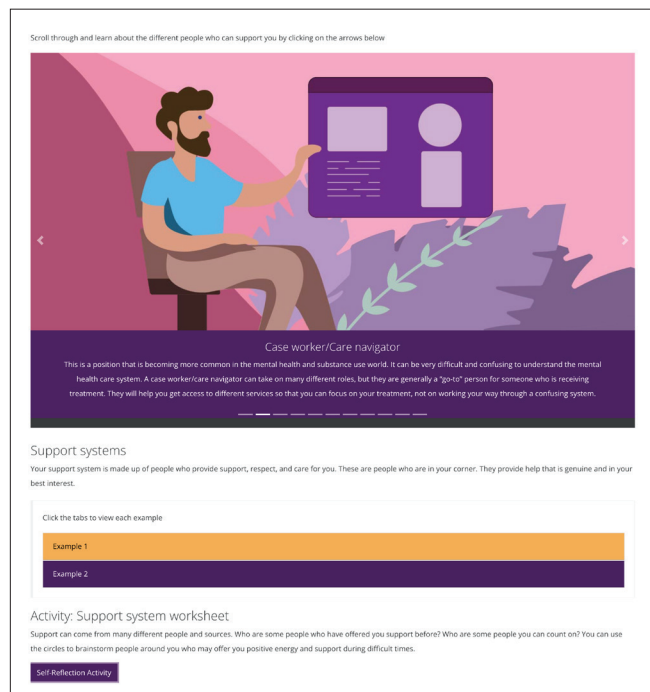
Once the web designers programmed the content, the same youth team pilot-tested the draft resource to identify optimizations. Revisions were made accordingly. Pilot testing and revision continued iteratively with the youth team until a launch-ready version was established. The final resource is freely accessible at www.youthwellnessquest.com. To complement the online version, the youth team developed a brief print version available for free download on the platform and for purchase in bulk for a cost-recovery fee at the CAMH store.

Dissemination and Knowledge Translation

The online YWQ resource was launched on May 13, 2021. According to the dissemination plan, the youth lead created multiple social media advertisements and shared them repeatedly through the NYAC mailing list and the NYAC and CAMH Twitter and Facebook accounts. As of August 13, 2021, three posts in the Facebook NYAC community group, four NYAC Twitter posts and five paid Instagram and Facebook advertisements targeting youth and other family members together garnered 1,626,707 views and generated 539 website hits.

Furthermore, the YWQ resource was circulated through existing networks of youth-serving organizations and community stakeholders, including healthcare professionals, through a newsletter and several presentations. The introductory video

FIGURE 3.
Sample excerpt of the YWQ guide website



was uploaded onto YouTube (CAMH 2021), generating over 200 views. A landing page was created for the resource on the Centre for Innovation in Campus Mental Health website (Centre for Innovation in Campus Mental Health 2021). Through the sum of these dissemination activities, the online YWQ resource received 989 visits in its first three months. Future dissemination plans include the development of a French-language version and leveraging opportunities to insert the YWQ resource into the Canadian youth wellness landscape. The effectiveness of the tool and these dissemination practices will be evaluated over time.

Challenges and Mitigating Strategies

With a strong youth engagement infrastructure in place, the team has previously worked through engagement challenges and developed effective mitigating strategies that were applied during this project (Hawke et al. 2018; Heffernan et al. 2017; Syan et al. 2021). However, this was a relatively long-term project, initially beginning in 2015 at the idea stage and achieving implementation in 2021. As a youth-led project, limited dedicated project hours and youth turnover slowed progress. In 2019, the team, therefore, hired a new dedicated project lead with sufficient hours to move the project forward to completion. Another challenge was regarding the inherent mobility of youth, who are at a life stage characterized by change in educational and occupational status. It was unclear whether the same young people would be available throughout

the writing and publication process for the current manuscript or whether career progress would interfere with staffing continuity. This challenge was mitigated by ensuring that additional youth were engaged for flexibility and ongoing youth leadership despite individual mobility. No other major challenges regarding engagement were encountered. Although the COVID-19 pandemic has led to many organizations pivoting how their teams operate, this project already engaged with youth through online platforms. Thus, this project has continuously involved youth – albeit only those with Internet access – throughout its progression.

Some challenges were technical in nature – that is, creating an online resource with intuitive click navigation and engaging materials within the limitations of the online software. These challenges were discussed among the project team, including web designers, to develop solutions. However, at a draft development stage, the team realized that the resource was optimized for desktop usage, not the mobile usage that was expected to be the main means of access for youth. In team meetings, this challenge was discussed, and progressive refinements were identified until a version was established with acceptable mobile functionality.

Youth's Experience of Engagement

Youth led this project and were involved in every step. The co-lead authors of this paper are two of these youth (AS and JYL). One was engaged from the very early days of the conceptualization of the YWQ resource in 2015, and both have been engaged since the research stage. The project enabled them to contribute their knowledge and skills, develop their capabilities, enhance their understanding of the Canadian healthcare system and learn about online resource development. They consider the opportunity to collaborate with other youth to have been an “incredible experience.” They emphasize that engaging youth with a range of experience in accessing care, advocating for themselves and navigating the healthcare system has made this resource more effective and tailored to its intended audience. Knowing this resource is now available for youth nationally, hopefully helping many, makes them “happy” and “proud.”

Research Team's Experience of Youth Engagement

Given the youth leadership through the resource development and research project, the entire team felt that youth leadership during knowledge translation was essential. They, therefore, continued to support the YWQ youth team in leading

the resource development. The researchers recognize that the engaged youth team was very familiar with the YWQ resource and with using online tools, making them the clear choice for design leadership. The researchers feel that the quality of the resource and its engaging, youth-centred content and design highlight the importance of ensuring youth leadership in all stages of a youth-oriented project like this one.

Youth led this project and were involved in every step.

Conclusion

The idea to develop the YWQ resource came from the lived experience of help-seeking youth, who described the mental health system as overwhelming and non-linear. Using a youth-led design, the team developed a unique Canadian health literacy and self-advocacy resource for help-seeking youth. The OSSU funding enabled us to pursue a youth-led knowledge-to-action process in which an online platform was developed, making the resource widely and freely accessible to youth.

In the past decade, there has been an increasing interest in the use of the Internet for mental health promotion and information dissemination (Clarke et al. 2015). Accessing mental health information online may offer youth increased privacy and anonymity (Clarke et al. 2015), which are major concerns for help-seeking youth (Williams and Chapman 2011). Online platforms may also provide minority and rural/remote populations with a cost-effective and accessible means of accessing services (Barak and Grohol 2011). Online platforms have been particularly important during the COVID-19 pandemic (WHO 2020), which has both negatively impacted the mental health of youth and led to services and resources moving online (Cielo et al. 2021; Hawke et al. 2020). Developing this online resource and complementary print materials allows us to reach a broad range of youth during this time of service disruption and help youth identify the types of services they wish to access.

Engaging youth service users in a project allows for a unique “insider” expertise that can lead to more effective and optimized designs of youth-focused services and resources (Gibbs et al. 2020). The value of youth engagement and leadership was experienced through all phases of the YWQ project, from defining the central need to disseminating the resource. Based on this positive experience, the authors call upon researchers, resource developers and service designers to engage youth for their expertise in developing youth-friendly resources that are developmentally appropriate and relevant to their intended audiences. **HQ**

References

Barak, A. and J.M. Grohol. 2011. Current and Future Trends in Internet-Supported Mental Health Interventions. *Journal of Technology in Human Services* 29(3): 155–96. doi:10.1080/15228835.2011.616939.

Bowers, H., I. Manion, D. Papadopoulos and E. Gauvreau. 2013. Stigma in School-Based Mental Health: Perceptions of Young People and Service Providers. *Child and Adolescent Mental Health* 18(3):165–70. doi:10.1111/j.1475-3588.2012.00673.x.

- Centre for Addiction and Mental Health (CAMH). 2021, May 5. *The Youth Wellness Quest: Finding the Right Supports for You* [Video]. Youtube. Retrieved March 11, 2022. <<https://www.youtube.com/watch?v=wYMeEfCE3Q>>.
- Centre for Innovation in Campus Mental Health. 2021. Youth Wellness Quest – Finding the Right Supports for You. Retrieved December 12, 2021. <<https://campusmentalhealth.ca/resource/youth-wellness-quest-finding-the-right-supports-for-you/>>.
- Cielo, F., R. Ulberg and D. Di Giacomo. 2021. Psychological Impact of the COVID-19 Outbreak on Mental Health Outcomes among Youth: A Rapid Narrative Review. *International Journal of Environmental Research and Public Health* 18(11): 6067. doi:10.3390/ijerph18116067.
- Clarke, A.M., T. Kuosmanen and M.M. Barry. 2015. A Systematic Review of Online Youth Mental Health Promotion and Prevention Interventions. *Journal of Youth and Adolescence* 44(1): 90–113. doi:10.1007/s10964-014-0165-0.
- Garriguet, D. 2021, February 1. Chapter 1: Health of Youth in Canada. *Portrait of Youth in Canada: Data Report*. Statistics Canada. Retrieved March 18, 2022. <<https://www150.statcan.gc.ca/n1/pub/42-28-0001/2021001/article/00001-eng.htm>>.
- Gibbs, L., M. Kornbluh, K. Marinkovic, S. Bell and E.J. Ozer. 2020. Using Technology to Scale Up Youth-Led Participatory Action Research: A Systematic Review. *Journal of Adolescent Health* 67(2): S14–23. doi:10.1016/j.jadohealth.2019.10.019.
- Gulliver, A., K.M. Griffiths and H. Christensen. 2010. Perceived Barriers and Facilitators to Mental Health Help-Seeking in Young People: A Systematic Review. *BMC Psychiatry* 10(1): 113. doi:10.1186/1471-244X-10-113.
- Hawke, L.D., S.P. Barbic, A. Voineskos, P. Szatmari, K. Cleverley, E. Hayes et al. 2020. Impacts of COVID-19 on Youth Mental Health, Substance Use, and Well-Being: A Rapid Survey of Clinical and Community Samples: Répercussions de la COVID-19 sur la santé mentale, l'utilisation de substances et le bien-être des adolescents: un sondage rapide d'échantillons cliniques et communautaires. *The Canadian Journal of Psychiatry* 65(10): 701–09. doi:10.1177/0706743720940562.
- Hawke, L.D., J. Relihan, J. Miller, E. McCann, J. Rong, K. Darnay et al. 2018. Engaging Youth in Research Planning, Design and Execution: Practical Recommendations for Researchers. *Health Expectations* 21(6): 944–49. doi:10.1111/hex.12795.
- Heffernan, O.S., T.M. Herzog, J.E. Schiralli, L.D. Hawke, G. Chaim and J.L. Henderson. 2017. Implementation of a Youth-Adult Partnership Model in Youth Mental Health Systems Research: Challenges and Successes. *Health Expectations* 20(6): 1183–88. doi:10.1111/hex.12554.
- James, A.M. 2007. Principles of Youth Participation in Mental Health Services. *The Medical Journal of Australia* 187(S7): S57–60. doi:10.5694/j.1326-5377.2007.tb01339.x.
- Jing, J. 2019, August. *Analysis of Youth Mental Wellness Survey*. Youth Mental Health Canada. Retrieved December 12, 2021. <<https://ymhc.ngo/wp-content/uploads/2020/03/analysis-of-youth-mental-wellness-survey-v3.pdf>>.
- Kelly C.M., A.F. Jorm and A. Wright. 2007. Improving Mental Health Literacy as a Strategy to Facilitate Early Intervention for Mental Disorders. *The Medical Journal of Australia* 187(S7): S26–30. doi:10.5694/j.1326-5377.2007.tb01332.x.
- McGorry, P., T. Bates and M. Birchwood. 2013. Designing Youth Mental Health Services for the 21st Century: Examples from Australia, Ireland and the UK. *The British Journal of Psychiatry* 202(S54): S30–35. doi:10.1192/bjp.bp.112.119214.
- Mehra, K., L.D. Hawke, P. Watson, N.Y. Sheikhan, E. Leroux and J. Henderson. 2021. Youth Perspectives on Seeking Psychotherapy: A Concurrent Mixed Methods Study. *Journal of the Canadian Academy of Child and Adolescent Psychiatry* 30(3): 165–76.
- Statistics Canada. 2019, May 8. A Portrait of Canadian Youth: March 2019 Updates. Retrieved November 18, 2021. <<https://www150.statcan.gc.ca/n1/pub/11-631-x/11-631-x2019003-eng.htm>>.
- Syan, A., J.Y.Y. Lam, C.G.L. Huang, M.S.M. Smith, K. Darnay, L.D. Hawke et al. 2021. The Wellness Quest: A Health Literacy and Self-Advocacy Tool Developed by Youth for Youth Mental Health. *Health Expectations* 24(2): 659–69. doi:10.1111/hex.13214.
- Williams, K. A. and M.V. Chapman. 2011. Comparing Health and Mental Health Needs, Service Use, and Barriers to Services among Sexual Minority Youths and Their Peers. *Health & Social Work* 36(3): 197–206. doi:10.1093/hsw/36.3.197.
- World Health Organization (WHO). 2020, October 5. The Impact of COVID-19 on Mental, Neurological and Substance Use Services: Results of a Rapid Assessment. Retrieved November 23, 2021. <<https://www.who.int/publications/i/item/978924012455>>.

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