



COMMENTARY

Recommendations for youth engagement in Canadian mental health research in the context of COVID-19

Brooke Allemang, MSW, RSW¹, Olivia Cullen, MSW, RSW¹, Kyleigh Schraeder, Ph.D., R.Psych.², Karina Pintson¹, Gina Dimitropoulos, MSW, PhD, RSW, RMFT^{1,3}

Abstract:

The COVID-19 pandemic has resulted in reduced access to in-person mental health services, and a shift to virtual platforms. Youth may be uniquely impacted by physical distancing requirements during the pandemic, including limited socialization opportunities, closures of educational institutions, a lack of meaningful extracurricular activities and adverse implications on key developmental milestones. Due to the potential impact of COVID-19 on youth well-being, the need to rapidly transform services to be accessible, and the potential risks associated with this rapid transformation, it is imperative that youth continue to be engaged in research and service development. Young people's perspectives, strengths and skills need to be considered to effectively adapt the delivery of mental health services. Continuing to center youth engagement in mental health research throughout the pandemic can ensure research questions, programs, and services align with the needs and preferences of youth. In this commentary, we pose three recommendations for conducting youth-engaged mental health research during the pandemic, including adapting youth engagement strategies when rapid decisions must be made, the use of tools for virtual engagement, and suggestions for evaluating youth engagement practices. These strategies and principles may be applicable to other scenarios where rapid research or system transformation would benefit from youth engagement, such as time-limited child research by trainees (e.g., dissertations) or natural disasters.

Key Words: *youth engagement; mental health; COVID-19; rapid research*

Résumé

La pandémie de la COVID-19 a entraîné un accès réduit aux services de santé mentale en personne, et une transition aux plateformes virtuelles. Les jeunes peuvent être particulièrement touchés par les consignes de distanciation physique durant la pandémie, notamment par les occasions limitées de socialisation, la fermeture des institutions éducatives, le manque d'activités parascolaires et les implications néfastes sur les principales étapes du développement. Étant donné l'impact potentiel de la COVID-19 sur le bien-être des jeunes, le besoin de transformer rapidement les services pour les rendre accessibles, et les risques potentiels associés à cette transformation rapide, il est impératif que les jeunes continuent de participer à la recherche et au développement des services. Les perspectives, les forces et les talents des jeunes gens doivent être pris en considération afin d'adapter efficacement la prestation des services de santé mentale. Continuer d'axer la participation des jeunes dans la recherche en santé mentale durant la pandémie peut faire en sorte que les questions, les programmes et les services de la recherche correspondent aux besoins et aux préférences des jeunes. Dans le présent

¹Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada

²Department of Pediatrics, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

³Mathison Centre for Mental Health Research & Education, Calgary, Alberta, Canada

Corresponding E-Mail: gdimit@ucalgary.ca

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commentaire, nous énonçons trois recommandations pour mener une recherche en santé mentale avec la participation des jeunes durant la pandémie, notamment adapter les stratégies de participation des jeunes lorsqu'il faut prendre des décisions rapidement, l'utilisation des outils de participation virtuelle, et des suggestions pour évaluer les pratiques de participation des jeunes. Ces stratégies et principes peuvent s'appliquer à d'autres scénarios quand la recherche rapide ou la transformation du système bénéficierait de la participation des jeunes, comme la recherche sur les enfants en temps limité par les stagiaires (p. ex., dissertation) ou des catastrophes naturelles.

Mots clés: participation des jeunes, santé mentale, COVID-19, recherche rapide

Background

Youth mental health service delivery has been affected by the rapid response of mental health systems to continue operations during COVID-19 (Young Minds, 2020). The global pandemic has led to reduced access to many non-essential services, including in-person outpatient mental health services, and a shift to virtual platforms (Ibrahim, 2020; Katapally & Kwabia, 2020; Smith & de Laplante, 2020). A recent Canadian commentary noted the COVID-19 pandemic has resulted in increased stress within households, with those who undergo quarantine being at risk for anxiety, depression, insomnia, and anger (Vigo et al., 2020). With closures of educational institutions and the need to maintain physical distancing, socialization is limited for young people. Pre-existing mood and anxiety disorders among youth may be exacerbated as a result of the pandemic with the loss of extracurricular activities and social interactions which typically provide structure and meaning (Courtney et al., 2020). While research on the impact of COVID-19 on intimate partner violence is scarce, community organizations reported a surge in cases related to interpersonal violence in the wake of the pandemic (Smith, 2020; Taub, 2020). In addition, stressors associated with caregiving, supervising educational activities and working from home amidst coping with economic and social losses may contribute to challenging family dynamics and increased risk of emotional consequences of COVID-19 on youth (Courtney et al., 2020). The aforementioned issues highlight the potential risks to youth well-being during lockdown. These factors may have important implications for how mental health services are delivered to youth and families, and how researchers engage youth in research during COVID-19.

Young people's unique perspectives, strengths and skills need to be considered to effectively adapt the delivery of mental health services in light of the pandemic, especially

given the potential implications of COVID-19 on youth mental health. There are risks associated with rapidly transformed services being misaligned with the needs of service users, including treatment disengagement and/or worsening mental health. Youth engagement (YE) in mental health research is a critical component of participatory research methodologies, where decision-making is shared between researchers and participants. We propose YE in mental health research remain a priority throughout COVID-19 to ensure research questions, programs and services align with the needs of those with lived experience.

Meaningful YE during COVID-19 should consider the level of engagement that is feasible when rapid decisions must be made and when social distancing measures are in place. Several frameworks, guidelines and models have been developed to operationalize YE practices in mental health research (Darnay et al., 2019; Heffernan et al., 2017; Henderson, Hawke, & Relihan, 2018; Iyer, Boksa, & Joerber, 2019). The principles of valuing youth's experiential knowledge, engaging in reciprocal learning and respecting the diversity of their opinions are critical to fostering an environment of meaningful YE (Hawke et al., 2018). We propose, however, that adaptations to existing YE frameworks are needed when social distancing practices are imposed, and rapid decisions must be made. In the context of COVID-19, new pressures are being placed on mental health researchers to identify innovative solutions for working with families. Rapid response funding initiatives may present challenges for researchers wishing to engage youth in mental health research (e.g., time to recruit youth partners). In this commentary, we pose recommendations for adapting YE strategies in response to COVID-19, the use of tools for virtual engagement, and suggestions for evaluating YE practices during the pandemic.

Recommendation #1: Adapt YE strategies when rapid decisions must be made during the pandemic

When the mental health system requires that rapid changes are needed in response to the pandemic, YE processes require adaptation. YE is defined as “the meaningful participation, and sustained involvement, of a young person in an activity, with a focus outside of him or herself” (Centre of Excellence for Youth Engagement, n.d., p. 1), with opportunities for decision-making, growth and leadership. YE typically takes place over an extended period of time, allowing for relationship-building and development of trust on an ongoing basis (Children and Youth Planning Table, n.d.). It may be difficult, however, to form meaningful and sustained partnerships with youth unknown to research teams when decisions must be made rapidly. The feasibility of recruiting, training and mentoring youth who have not been involved in research in the context of rapid response grant projects should be considered. In order to address these barriers, we suggest leveraging connections with pre-existing advisory council members, or community or tertiary care organizations with whom youth already have long-term or continuous relationships. Once youth partners are identified, asking them about their availability and preferred methods for providing input on research projects and priorities (i.e., virtual group meetings, one-on-one phone calls, online surveys) is strongly recommended. Given that timelines for youth involvement in rapid response research projects may differ from traditional engagement opportunities, having transparent dialogue with youth partners from the outset about the specific phases in which feedback will be sought and the phases in which *they* would like to provide their input is imperative. For example, opportunities for large group meetings may be limited in the early stages of grant writing with tight deadlines, however, more sustained and consistent engagement may take place as the project evolves and moves into different stages. Thus, providing youth the option to complete online surveys/polls when group meetings are not possible is suggested. Lastly, we have found it helpful in our own research to openly acknowledge the challenges associated with YE practices when rapid decisions are needed, and the tensions we feel with reduced opportunities for in-person engagement. These efforts may serve to enhance transparency, honesty and trust among researchers and youth partners. Mobilizing youth with diverse experiences remains essential even when requiring rapid meaningful engagement or establishing new advisory

groups under these circumstances. We recommend careful consideration be given to how youth participate, collaborate and share their voices in meaningful ways. Further details about traditional YE practices and additional considerations during COVID-19 are presented in Table 1.

Recommendation #2: Use tools for engaging youth using virtual platforms

While best practice guidelines suggest using in-person methods for engaging youth in research, some of these strategies may require alternative delivery formats, including virtual meetings or videoconferencing, during the pandemic. There are well-documented benefits associated with leveraging technology for YE: greater accessibility for youth, the ability to bring together youth from diverse geographic locations, less financial strain associated with travel, and flexibility in the timing of meetings (Children and Youth Planning Table, n.d.; Guan & Subrahmanyam, 2009; James et al., 2017; Meenagh, 2015; Wurtele & Kenny, 2016). Youth may be more willing to engage in research virtually during the pandemic, given the sense of belonging this forum may provide at a time when social isolation is common.

There are unique challenges for researchers and youth using virtual platforms in the context of a pandemic. For example, it may be difficult for youth to find private spaces to share their personal perspectives about their mental health journeys. Ethical challenges or risks to youth safety may surface when asking youth to share their stories online with researchers and/or other youth they have never met in person. Privacy and security of data captured using online or virtual platforms may be a concern. As such, protocols are needed to ensure youth who become distressed while involved in a virtual meeting are able to access timely and appropriate supports. Additionally, given the overarching sentiments of uncertainty and anxiety amongst Canadians during the pandemic, researchers should be prepared to encounter and facilitate challenging conversations amongst youth and their colleagues online.

Another issue in doing YE using virtual platforms is achieving equitable and fair representation. The pandemic has shown there continues to be a digital divide and unequal access to internet/technology, and so certain youth voices may be missing. Capturing a diversity of perspectives using online methods may be particularly challenging for underserved youth, including those without access to reliable

Table 1. Considerations for Youth Engagement During COVID-19

Recommendation	Traditional Youth Engagement Strategies	Additional Considerations During COVID-19
<p>#1. Adapt youth engagement strategies when rapid decisions must be made during the pandemic</p>	<ul style="list-style-type: none"> • Advertise & provide incentives for youth participation (compensation, honoraria, research training, reference letters, volunteer hours, etc.) • Hold public educational webinars about mental health research, participatory methods, community engagement to generate interest in research 	<ul style="list-style-type: none"> • Leverage pre-existing connections with community organizations and/or existing youth advisory councils • Ask youth about their interest and availability in being involved in research during this challenging time including time commitment • Consult with youth about their preferences for providing input on research priorities during the pandemic (i.e., virtual group meetings, one-on-one telephone calls, online surveys, email feedback, etc.) • Have transparent dialogue with youth partners & set realistic expectations, timelines for involvement (i.e., opportunities for group meetings may be limited due to time constraints, feedback may be sought at specific phases of the research) • Provide resources to support youth in light of potential added stress of the pandemic (i.e., mental health resources) • Provide additional compensation (as appropriate/possible) to youth given increased burden during pandemic and potential inability to maintain other part-time employment due to social distancing policies • Openly acknowledge the challenges associated with the need for rapid decisions • Provide youth partners the option to complete online surveys, polls, or questionnaires to provide feedback when short timelines make group meetings infeasible • Create infographics to be shared on social media for recruitment purposes highlighting the importance of public participation in research when rapid decisions must be made about research priorities or program development during pandemic
<p>#2. Use tools for engaging youth using virtual platforms</p>	<ul style="list-style-type: none"> • Assign rotating youth facilitators & notetakers for virtual meetings to increase engagement & accountability • Utilize breakout rooms when using virtual platforms for group meetings to stimulate greater depth of dialogue • Use whiteboard function to allow for universal participation/commenting on specific questions during group meetings • Use polling function when anonymity and quick responses required to specific questions in group meetings 	<ul style="list-style-type: none"> • Encourage “video-on” mentality during virtual engagement group meetings to ensure safety where possible, with consideration of individual circumstances/preferences • Utilize activities which foster youth interactions & use ice breaker activities during group meetings to enhance feelings of connection during pandemic • Use shared platforms (i.e., Google Drive, Dropbox) to allow youth partners to share their comments on materials on their own time given competing priorities and time commitments during pandemic • Use smartphone messaging applications like WhatsApp or Slack to allow for asynchronous communication between researchers and youth

continued

Table 1. Continued		
Recommendation	Traditional Youth Engagement Strategies	Additional Considerations During COVID-19
	<ul style="list-style-type: none"> • Chat box can be utilized when feedback needed from many participants simultaneously during group meetings • Send out materials to youth partners in advance via email to allow for reflection and brainstorming prior to group meetings 	<ul style="list-style-type: none"> • Utilize other social media platforms (i.e., Instagram, Facebook) which allow for asynchronous engagement, communication, and information sharing; youth can take turns monitoring and facilitating discussions/videos/posts on these platforms • Consider subsidies for shared tablets/computers to reduce participation barriers • To alleviate burden on youth during a challenging time, provide greater opportunities for open-ended survey/email feedback as opposed to several group meetings depending on preferences of youth • Ensure that youth with delays, disabilities, or chronic conditions that require accommodations to participate are provided with what they need
#3. Measure the impact of rapid youth engagement	<ul style="list-style-type: none"> • Encourage youth to complete pre- and post-engagement questionnaires with option for anonymous responses about process of engagement, youth satisfaction, project outcomes • Ask youth how they would like to provide feedback (i.e., verbally, visually, virtually) – involve them in the process 	<ul style="list-style-type: none"> • Modify existing tools (i.e., PPEET*) based on feedback from youth for virtual and rapid engagement by including context-specific questions about the pandemic (i.e., How has the pandemic impacted the process of engagement in research for you?) • Use open-ended questions to allow youth to offer insights on engagement processes during the pandemic given no gold standard tools exists for evaluation in this context • Compare youth satisfaction with engagement process in research projects pre- and post-pandemic • Compare number of youth engaged in research process in pre- and post-pandemic projects, length of youth involvement, specific tasks youth involved in and outcomes • Compare incentives for pre- and post-pandemic projects and youth satisfaction with, or value (does incentive raise levels of participation?) in these projects
*PPEET = Patient and Public Engagement Evaluation Tool		

internet, cell phones or computers. This means researchers may be missing the voices of some youth, or may obtain perspectives that are not representative of the population at large. Efforts to creatively recruit and hear the perspectives of youth, particularly those who may be low-income or experiencing homelessness should be considered, for example: subsidies for shared laptops/internet, recorders for youth to share their stories, honoraria for youth who have lost income during the pandemic, or socially distanced in-person gatherings where appropriate. Additionally, we recommend researchers budget for equipment related to YE using digital platforms.

Finally, given restrictions on in-person meetings during the pandemic, special precautions could be taken by researchers and youth to foster connection with each other during online engagement activities. We will present some recommendations based on our experiences having shifted all in-person consultations with youth partners to virtual meetings since the pandemic. Icebreaker activities, clear articulation of goals for engagement, timelines, and roles should be established early on in collaboration with youth. Leveraging extended functionality on video-chatting platforms like breakout rooms, polling and the whiteboard function can afford youth opportunities for sharing verbally and using

text. In our experience, using activities which allow youth to interact with one another (i.e., small group discussions in breakout rooms) enhances feelings of connection among participants. Giving youth the option to offer feedback on resources and materials outside of virtual meeting times using shared platforms (i.e., Dropbox) should competing priorities impede their ability to attend group consultations is also suggested. Asynchronous communication between researchers and youth partners may also take place through platforms like Slack, Telegram, WhatsApp, Discord or Wire. Indeed smartphone messaging applications have been shown to be particularly effective for engaging with young and digitally fluent populations in research (Chen & Neo, 2019). Providing opportunities for ongoing involvement, mentorship and community-building activities beyond the “rapid” engagement phase may incentivize ongoing involvement with rapid response projects, given opportunities for networking and collaboration are valued by youth partners (Heffernan et al., 2017).

Recommendation #3: Measure the impact of rapid YE

Evaluation of rapid YE may need to be modified during the pandemic. Generally, evaluating engagement and research outcomes takes time and expertise of researchers to account for different evaluation methods (surveys, interviews, etc.). Within participatory research methods, it is important to consider not only the outcomes of the research, but the process and experience of engaging in the research, which can be especially meaningful for the youth involved. Evaluating YE in research can help to ensure consistency in the way that engagement principles are implemented, can provide feedback on what is or is not working, and hold researchers accountable to youth partners, funders, and the larger community who may benefit from research (Boivin et al., 2018).

YE in mental health research has been measured in various ways. Darnay et al. (2019) produced a YE guidebook, which recommends multiple evaluation methods, including quantitative and qualitative methods. Evaluation tools may need to be adapted for an online or blended (online/offline) setting. For example, the Public and Patient Engagement Evaluation Tool (PPEET; Abelson, Wilson, Shields, Schneider & Boesveld, 2016; Abelson, Humphrey, Syrowatka, Bidonde, & Judd, 2018) is a series of questionnaires used to evaluate patient and public engagement in health systems and research. Hamilton et al.’s (2018) Patient Engagement In Research Scale (PEIRS) is another

example of an instrument which was co-designed with patient partners to assess the quality of patient engagement in research projects. Tools like PPEET or PEIRS can be useful in rapid research where it may not be feasible to develop new evaluation tools. For instance, when asking if youth partners had the necessary resources to participate, these instruments can identify possible technological barriers, and research teams could hope to proactively support with reducing technological barriers. Questions specific to the pandemic can also be integrated into existing evaluation tools. Given the importance of ensuring evaluation of research and participation, having readily available and accessible tools that can be adapted in the face of rapid research is essential. While some research teams are collaborating with patients to develop and validate tools which assess stakeholder engagement in research (Abelson, Tripp, Kandasamy, Burrows, & PPEET Implementation Study Team, 2019; Goodman, Ackermann, Bowen, & Thompson, 2019; Hamilton et al., 2018), Boivin et al. (2018) note patients and the public are rarely involved in the design of evaluation tools or reporting of results. Scholars have argued evaluation of YE should not be considered separate and youth should be actively involved in this aspect, just as they are in the rest of the research (Boivin et al., 2018). To ensure effective evaluation is encompassed within rapid research, we recommend integrating multiple forms of evidence, including quantitative and qualitative data, and ensuring youth are part of this process.

Specifically, we propose the need to compare youth satisfaction, experience of engagement, the number of youth partners involved, the methods used for engagement, the phases in which youth are involved in research and the timeline for engagement in pre- versus post-pandemic research projects. We also acknowledge the importance of developing best practice guidelines for evaluating virtual and rapid engagement initiatives in collaboration with youth. This paper is positioned as a call to action for researchers, funders and mental health providers to leverage their connections with young people and think critically about how our work and the burden on youth partners are changing in light of the pandemic. The use of open-ended questions, in particular, is suggested in order to better understand what engagement means and how it is operationalized during the pandemic from the youth perspective. This will serve as a preliminary step in determining how to tailor and adapt existing tools for virtual or rapid engagement processes as well as evaluation processes. Finally, we need to continue to seek input

from youth on whether YE methods should change within different phases of the pandemic. Given there have been different responses across Canada to the pandemic, we might also need to respond to regional and provincial differences in restrictions made on youth that could result in varying YE strategies.

Discussion

Due to the potential impact of COVID-19 on youth mental health, the need to rapidly transform services to be accessible in different ways, and the potential risks associated with this rapid transformation, it is imperative that youth remain engaged in research and service development. Continuing to center YE in mental health research throughout the pandemic can ensure research questions, programs, and services align with the needs of youth.

We have highlighted three recommendations for YE in research in the context of the COVID-19 pandemic. We recommend careful consideration be given to how youth can participate and engage in the research process, even when rapid system transformation is needed. Asking youth about their interest and availability to contribute to research during these unprecedented, uncertain and challenging times is a critical first step in this process. In our experience, youth were especially interested in being involved in research over the summer months during the pandemic out of a desire to give back to other youth and find a sense of purpose. We acknowledge, however, this may change and look different across provinces with increasing demands and competing priorities with schools and workplaces opening up. We recommend researchers attend to the risks/benefits of virtual platforms and consider how youth can be involved beyond rapid engagement at the beginning of research. The utility of different tools and methods for obtaining input from youth (including synchronous and asynchronous methods) should be explored. Finally, we recommend researchers continue to measure the impact of rapid YE by comparing pre- and post-pandemic engagement processes and incorporating the youth perspective when developing evaluation procedures.

This pandemic has illustrated the need to be adaptable, flexible, and prepared throughout the research process. While our recommendations are presented specifically in terms of COVID-19, these strategies and principles are applicable to other scenarios. For example, global and environmental disasters such as floods or fires, or time-limited dissertation research may require researchers to move rapidly.

Understanding the risks and benefits of utilizing virtual platforms for YE in research may be important for engaging geographically diverse or underserved young people. Future directions in YE could include bringing together youth, researchers, clinicians and funders to share lessons learned about rapid research and consider how to collectively advance the field in Canada.

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Conflicts of Interest

The authors have no financial relationships to disclose.

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