# Understanding youths' lived experience of digital mental health interventions through a photovoice approach

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## Abstract

Youth can face mental health challenges in the transition from adolescence to adulthood. Web-based programs, apps, and websites for mental health are increasingly developed for youth due to their consistent use of online and mobile technologies. These resources have several benefits including easy access to information, anonymity, and low cost. This study sought to develop an understanding of youth's experiences with web-based programs, apps, and websites for mental health. Nine participants between the ages of 15-21 with lived experience of a mental health concern from British Columbia and Ontario were recruited for this study. The photovoice method was used to aid participants in exploring their experiences with digital mental health interventions through photography. Group workshops and individual interviews allowed youth to reflect on their photographs.

Data analysis was conducted through open inductive coding applied to transcripts from workshops and interviews. Themes related to youths' digital mental health intervention use journeys were identified as (1) Searching for support, (2) Individual needs unmet, and (3) Finding relief. Photovoice provided a suitable research method for prioritizing youth lived expertise due to its flexible and adaptable approach. Mental health researchers and service providers should readily consider the experiences of youth when designing, selecting, and assessing digital mental health interventions as part of an integrative approach to mental health care.

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## Introduction

Digital mental health interventions, such as webbased programs, apps, and websites for mental health, are increasingly developed for youth due to the demographics' consistent use of online and mobile technologies (Rickwood, 2012). These interventions provide several benefits, including equity and ease of access to evidence-based resources, the immediacy of information and support, anonymity, low cost, and increased service capacity and efficiency. The ability of these interventions to overcome geographic barriers to service (Christie et al., 2019; Grist et al., 2017) was critical to mental health service delivery during the COVID-19 pandemic. The pandemic forced organizations to "broadened their use of virtual care and digital mental health interventions" (Kemp et al., 2021, p. 2).

Youth is considered the period from 12 to 25 years of age. This period can be difficult as they navigate social and developmental changes. Youth mental health is foundational for one's overall mental health (Malla et al., 2018; Patel et al., 2007). It is the peak period for the onset of mental health disorders, with 75% of mental health disorders presenting before age 25. Moreover, there is a strong relationship between mental health disorders and long-term health, developmental, social, and educational impacts on youth (Coughlan et al., 2013; Malla et al., 2018; Patel et al., 2007). Despite the prevalence of digital mental health interventions for youth, user uptake and adherence issues persist (Bevan Jones et al., 2020; Orlowski et al., 2015). These challenges are perhaps related to insufficient research to support the effectiveness of apps for youth with mental health disorders (Grist et al., 2017) and the limited evaluation of these interventions (Bevan Jones et al., 2020; Orlowski et al., 2015). Research has shown when youth participate in the development of these interventions it is often restricted to consultative and consumerist engagement (Orlowski et al., 2015).

Participatory design methods (e.g., co-design, participatory design, experience-based co-design, etc.) are increasingly used in the development of digital mental health interventions and services for youth (Antezana et al., 2015; Clarke et al., 2015; Nakarada-Kordic et al., 2017; Terp et al., 2016; Shepherd et al., 2015; Winsall et al., 2019). These methods typically involve youth with lived experience, their communities, and mental health professionals working collaboratively to share power, prioritize relationships, and design solutions (McKercher, 2020). Despite the proven effectiveness of participatory methods to elicit youth perspectives in developing mental health interventions and services (Hackett et al., 2018; Nakarada-Kordic et al., 2017; Terp et al., 2016), institutional and systemic barriers continue to prevent youth participation in research more generally. The tokenization of youth participants and the misrepresentation of youth experiences by researchers are often the results of a "lack of respect for young people's capacity to engage in the research process" (Teixeira et al., 2021, p. 145). By shifting to participatory methods prioritizing authentic engagement with youth, such as Youth Participatory Action Research (YPAR), the inclusion of youth expertise can hopefully help overcome systemic barriers to youth involvement in research.

As an adult whose mental health journey began in adolescence, I understand the detrimental impact of not having access to mental health services during that period can be. While discussions surrounding mental health are more prominent and acceptable in society than during my youth, the issues have in no way disappeared. Moreover, the stress and social isolation experienced by all during the pandemic had a significant effect on young people's mental health. In Canada, 67-70% of children and youth 6-18 years of age experienced a decline in one or more of the following mental health domains during the pandemic: depression, anxiety, irritability, attention, hyperactivity, and obsessions/compulsions (Cost et al., 2022). At the time of this report, Margaret Eaton, National CEO of the Canadian Mental Health Association issued an Open Letter to Prime Minster Trudeau, calling on the federal government to "create a dedicated and permanent funding stream" for community organizations delivering mental health services to youth and their families (Eaton, 2023). More than ever, youth and their families cannot access the mental health care they need. In Canada, 75% of children and youth cannot access healthcare for mental health, resulting in increased Emergency Department visits for mental health conditions (Act for Mental Health, 2023).

Digital mental health interventions provide an opportunity to reach youth and their families outside traditional clinical services and settings, however, more research is needed to understand how youth situate these interventions within their lived experience of mental health information and support-seeking practices. As digital mental health interventions can overcome accessibility barriers to mental health services and support, this research can help fill the gaps in understanding youths' lived experiences with those interventions through participatory approaches. The findings from this research will demonstrate that while the benefits of digital mental health interventions are notable, including anonymity, low cost, and overcoming geographic barriers, youth still have concerns with these platforms. These concerns contribute to youth discovering their mental health needs are often unmet by apps designed to appeal to the broadest user base. As the abundance of interventions can be difficult to navigate, clinicians and service providers are in a position to provide individualized recommendations for youth patients.

Furthermore, youth don't necessarily view digital mental health interventions as providing the most effective form of support. Limited access to other mental health services and support including therapy, which is often viewed more favourably, incentivizes the use of digital interventions which are quick and easy to access. In understanding youth's experiences with digital mental health interventions there is an opportunity for these interventions to be used more effectively as part of an integrated approach to mental health care, which may help with issues of limited access to mental health services and support for youth and their families.

## Literature review

# Digital mental health interventions

As the prevalence of digital mental health interventions for youth increases so does research into their design, development, and use. When it comes to designing digital mental health interventions, gamification methods have been investigated within the context of mHealth (e.g., mobile health) delivery. Christie et al. (2019) have explored the use of gamified features in designing mHealth interventions for mental health to increase user engagement among vulnerable populations. Authors noted that gamification methods were used to balance traditional therapy models with the attention spans of youth (Christie et al., 2019).

There is interest in exploring cultural adaptions to digital mental health interventions for youth. Lal et al. (2018) researched the cultural adaption of an eHealth (e.g., the use of information and communication technology to support the health sector) intervention designed to promote recovery and prevent relapses in youth receiving specialized services for first-episode psychosis. The research contributed to a gap in the literature about the process of adapting eHealth interventions and evaluations across a range of cultural, geographic, and healthcare settings (Lal et al., 2018).

Both Byron (2019) and Lucassen et al. (2018) examined LGBTQ+1 youth's unique needs concerning the adaptation and use of digital mental health interventions. Research by Lucassen et al. (2018) demonstrated how to refine a computerized CBT intervention for LGBTQ+ youth, due to the demographics increased risk for mental health concerns. Measures included integrating strategies to address stigma and mistreatment challenges within the scope of the intervention (Lucassen et al., 2018). Interestingly, Byron (2019) found that LGBTQ+ participants addressed the need for an app to be actively sought by users, which is often unlikely. Findings demonstrated a discrepancy between quantitative and qualitative data. While quantitative data indicated the favorability of app development amongst participants, qualitative data showed actual usage was low (Byron, 2019).

The complementary role of technology in supporting youth mental health services has been examined by Montague et al. (2015). In exploring how to harness youth's high technology use to better manage mental health problems, Montague et al. (2015) found that youth participants were already using technology as an informal complement to mental health treatment. Youth asserted that formal technology integration must have a clear benefit to their treatment, while not replacing face-to-face time with mental health professionals (Montague et al., 2015).

<sup>&</sup>lt;sup>1</sup> LGBTQ+ is an acronym for lesbian, gay, bisexual, transgender, and queer, with the + signifying those gender identities and sexual orientations not described by the other initials. It is one of several commonly used acronyms including LGBT+, LGBTIQ+, and LGBTQ2+.

When it comes to mental well-being prevention, digital mental health interventions are being investigated for their feasibility. Manicavasagar et al. (2014) evaluated the usefulness of online delivery for a positive psychology program intended as a preventative mental well-being measure for Australian youth. They noted that while the program reduced symptoms of psychopathy and increased well-being in youth, especially for those using the program for thirty minutes or longer each week, issues of adherence and age appropriateness need to be addressed (Manicavasagar et al., 2014).

In the wake of the COVID-19 pandemic and the increasing need for online delivery of youth mental health services, Kemp et al. (2021) undertook a national jurisdictional scan to better understand how digital mental health interventions are "selected, recommended, and used" across Canada (p. 1). The scan included academic and grey literature, stakeholder interviews, and a review of Twitter content. Researchers presented their concerns regarding the "sustainability of these digital mental health interventions as well as a need for services to be more informed by the experiences and preferences of youth" (Kemp et al., 2021, p. 2).

## Methods for engagement

Participatory research methods are increasingly used to engage youth in the design and development of mental health resources and services. The application of participatory methods in these contexts is intended to explore the possibilities and opportunities for engaging youth in research more generally. Often this is facilitated using co-design approaches where power is shared, and relationships are prioritized. Co-design processes often use creative methods, however, there is no single approach to follow, rather, "there are a series of patterns and principles that can be applied in different ways to different people" (McKercher, 2020, p. 15). These principles are usually applied to a process which moves from building facilitation conditions, aligning with stakeholders, discovery and design, testing and refinement, and implementation and learning. This process is not linear and may change and adapt depending on the context (McKercher, 2020).

The relational quality of co-design is particularly important in bridging gaps in understanding between participants with lived experiences of mental ill health and researchers. As in the case of Nakarada-Kordic et al. (2017) and Terp et al. (2016), co-design was used successfully to engage youth with complex mental health disorders. Nakarada-Kordic et al. (2017) found the creative methods used in co-design could successfully engage youth with psychosis, and Terp et al. (2016) explored how codesign can support and inspire participation in the development of mental health care for youth with schizophrenia. Interestingly, Nakarada-Kordic et al. (2017) noted that the flexibility of the co-design methodology allowed researchers to interact with participants in creative ways but more importantly, dispelled researcher misconceptions about the capacity of people experiencing psychosis to engage in research. Terp et al. (2016) suggested that a Community of Practice (CoP) can be beneficial to understand the physical and relational environment where participatory design occurs to support engagement and participation.

Experience-based co-design (EBCD) is another approach to participatory research gaining popularity in the field of mental health services. This "user-focused design process" prioritizes patients' experiences when designing products and services (Bate & Robert, 2006, p. 309; see also Mulvale et al., 2019). In applying the EBCD method to mental health and social service improvements for youth with mental health concerns, Mulvale et al. (2019) demonstrated how the elicitation techniques used in EBCD could foster "mutual understanding and collaborative ideas" amongst youth, their families, and service providers (p. 1). Additionally, Hackett et al.'s (2018) use of EBCD provided an example of engaging youth in the codesign of a prototype for a user-driven feedback questionnaire to improve the quality of mental health services for youth.

More recently, Mulvale et al. (2021) have explored EBCD's potential alignment with integrative dynamics (ID) processes as an approach to patient and family engagement in mental health. ID moves beyond traditional negotiation approaches, which can be emotionally charged, to help people with "opposing perspectives" work together by focusing on shared issues (Mulvale et al., 2021, p. 148). In a retrospective study of EBCD data to improve youth transitions from child to adult mental health services, authors found the EBCD approach aligned well with the ID model, and can be used to improve relations among youth, caregivers, and service providers (Mulvale et al., 2021). Huggett et al. (2017) and Shepherd et al. (2015) have described the use of participatory approaches in the development of digital mental health services. Huggett et al. (2017) highlighted a youth-adult partnership model in a system-level initiative as a potential replicable strategy for developing resources relevant to youth needs and preferences. The model was applied to the co-creation of a mobile app to help youth with mental health and substance use concerns. Participatory approaches have been used to address the specific needs of underserved Indigenous minority youth. Shepherd et al. (2015) employed co-design to improve engagement with a computerized CBT prototype for Maori youth by increasing the prototype's cultural relevance.

While steps towards youth engagement in research via participatory methods are promising, others have noted the depth of participation is often still limited. In exploring the broader issues related to the participatory engagement of youth in research, both Bevan Jones et al. (2020) and Orlowski et al. (2015) undertook systematic reviews on the use of participatory approaches in the design of digital mental health interventions for youth. Findings suggest there are persistent issues with user uptake and adherence, and perhaps relatedly, there is insufficient research to support the effectiveness of these interventions, a lack of research evaluating these interventions, and limited youth involvement in their development (Bevan Jones et al., 2020; Orlowski et al., 2015).

The systemic review of YPAR undertaken by Branquinho et al. (2020) underscores the lack of youth-focused participatory research. The review concentrated on YPAR programs with a focus on health and well-being to identify the general stages in their program strategy and make recommendations for future YPAR integrations. The authors argue YPAR for health intervention needs to move beyond the categories of design, implementation, and evaluation. They propose the following steps to be included in YPAR programs: raising awareness amongst stakeholders of the advantages of YPAR, including youth themselves; developing young people's research skills to promote equity; including youth at all stages of the research process; utilizing digital tools to motivate youth participation; counteract relation barriers between youth and adults; evaluate with quantitative and qualitative measures; leverage social media for dissemination of results; and replicate YPAR programs in adult spaces (Branquinho et al., 2020).

## Mental health service design

When developing and evaluating mental health service design for youth, quantitative methods are often employed. Bassilios et al. (2017) and Rickwood et al. (2019) used quantitative methods to evaluate youths' engagement and satisfaction with online mental health service platforms. Rickwood et al. (2019) developed a quantitative satisfaction questionnaire to evaluate an online mental health service platform. The authors note the measure designed for this study could be adapted for other online mental health services, as at the time of publication, there were no standardized service satisfaction measures currently available for youth in this context (Rickwood et al., 2019). In collecting quantitative data on two low-cost psychological services for youth in Australia, Bassilios et al.'s (2017) comparative analysis revealed the complementary nature of these two service offerings, and the gaps in service they fill for youth.

The collaborative methods employed by Stubbing et al. (2021) were intended to inform mental health service design for youth in New Zealand. Stubbing et al.'s (2021) use of the collaborative workshop methodology piloted by Calder-Dawe and Gavey (2019) was successful in eliciting participants' visions for an ideal mental health service for youth. This methodology empowers youth "to develop solutions to problems that affect them and to improve their [research] skills" (Stubbing et al., 2021, p. 5). Based on their findings, the authors argue for the inclusion of youth voices when designing services for young people (Stubbing et al., 2021). Finally, Burns and Birrell's (2014) review provides an informative description of Australia's innovative youth mental health system, which is informed by an evidence-based approach, advocacy, and the inclusion of youth in service design, development, and ongoing evaluation. While authors argue Australia's system is "enviable" in its potential to "substantially enhance the well-being of young people [and] to improve their engagement with mental health services," the challenge of ensuring young people receive timely, effective, evidencebased care still exists (Burns & Birrell, 2014, p. 303).

## **Ethical considerations**

As the inclusion of youth in participatory research becomes more expected, recommendations for ethical and authentic engagement practices are being called for. Bowler et al. (2021) argue for "conscious co-design" as a method for raising "adult researcher's self-awareness of their own role in co-design with young people" (p. 22). Their inclusion of Soep and Chávez's (2010) model of collegial pedagogy, where co-design is an experience of shared growth, is positioned as an approach to move towards more conscious practices when engaging youth in research. This model is presented as a map for guiding participation or as a "diagnostic tool" for evaluating "the nature of interaction in codesign projects with children and youth" (Bowler et al., 2021, p. 22).

Teixeira et al. (2021) provide recommendations for scholars conducting research with youth. Authors are keenly aware of the presence of adultism in academic research, and the barriers it can pose to authentic youth participation in research. Adultism is "a lack of pro-child social norms that includes negative attitudes about youth, laws that delegitimize youth, and youth internalizing these negative beliefs (Flasher, 1978; Kennedy, 2018, as cited in Teixeira et al., 2021, p. 143). It is noted that adultism is embedded in structural racism and that participatory methods are designed to decolonize knowledge production (Teixeira et al., 2021). YPAR methods are presented as a favourable approach to meaningful youth participation, however, risks of tokenization and inequitable participation will remain if researchers choose to ignore the systemic issues of ethics and power within academia (Teixeira et al., 2021).

In presenting their recommendations for more ethical and authentic participatory practice, Pierri (2018) addresses the paradox embedded in the notion of participation stemming from the "ethical complexities" of collaboration in the mental health sector, and "normative expectations" around participation in research (p. 26). Pierri (2018) suggests completely authentic participatory design is something to strive for, but perhaps unachievable. To promote ethical and authentic participatory practice, Pierri identifies and encourages two key trends in design practice, which are "an enhanced sensibility towards issues of power and agency in design, and a deep questioning of the role of design and designers" (Pierri, 2018, p. 35).

Within the expansion of digital mental health intervention offerings for youth, ethical considerations around user privacy and safety have become increasingly important. Several digital mental health interventions for youth have recently been developed with automated conversational agent platforms (e.g., chatbots). Kretzschmar et al. (2019) outline a framework for the minimum ethical standards for automated conversational agent platforms based on youth perspectives, including issues around privacy and confidentiality, efficacy, and safety. Such discussions are intended to add to the ethical debate around automated conversational agent platforms among app developers, practitioners, young people, and other stakeholders.

# Methods

## Participatory Action Research (PAR)

The research design is situated in participatory methods whereby the people directly affected by the issue under study are involved in the research: Participatory Action Research (PAR) and Youth Participatory Action Research (YPAR). The origins of PAR are traced to Action Research (AR) with its focus on aiding minorities in overcoming "exploitation and colonialism through their inclusion in self-study and research" (Lewin, 1946, as cited in Bowler et al., 2021, p. 16). Through its rejection of positivism, AR argues social perceptions guide behaviour. Understanding the meaning behind people's behaviour can influence their actions (Bowler et al., 2021). In practice, AR is less a research technique, but rather a collection of approaches committed to the "service of human flourishing" (Reason & Bradbury, 2008, p. 1, as cited in Bowler et al., 2021, p. 16).

PAR challenges traditional scholarly assumptions about expertise, acknowledging participants have expert knowledge due to their familiarity with the issues under study (Bowler et al., 2021; Cammarota & Fine, 2008; Rodríguez & Brown, 2009). As participants directly contribute to knowledge production, researchers utilizing PAR methods must abandon their "role of sole expert" if they hope to genuinely collaborate with participants (Rodríguez & Brown, 2009, p. 23). This undoing of the traditional participant and researcher roles is a crucial difference between PAR and other forms of research. Through PAR the researcher does not work alone, but rather as an individual, alongside participants in a collaborative and collective capacity (Cammarota & Fine, 2008).

To position participants as experts, PAR researchers provide people and communities with skills to facilitate change through research (Bowler et al., 2021; Rodríguez & Brown, 2009). Drawing on Freire's (2000) critical pedagogy, PAR emphasizes the development of participants' critical consciousness through research. Critical consciousness is composed of the practices of critical reflection, motivation, and action. Through research, critical consciousness manifests in "marginalized or oppressed people's analysis of societal inequalities to redress such inequalities" (Diemer et al., 2016, p. 216). By activating consciousness, participants can advocate for themselves to confront challenges directly impacting their lives and communities (Bowler et al., 2021; Freire, 2000; Rodríguez & Brown, 2009).

Although participatory research methods are increasingly used to engage youth in the development of digital mental health interventions, others have noted youth's involvement has largely been limited to consultative and consumerist engagement (Orlowski et al., 2015). These limits may be related to the disconnect between youth's mental health-seeking practices and ambivalence toward mental health apps (Byron, 2019; Trnka, 2016). While youth may recognize an interest in app-based interventions, they are not actively engaging with them (Byron, 2019). Therefore, it is imperative to position youth as experts when conducting research directly related to their lived experience of digital mental health interventions.

## Youth Participatory Action Research (YPAR)

In addition to PAR, this research integrates YPAR approaches due to its youth-focused orientation to inquiry, whereby youth are trained to identify, research, and analyse problems relevant to their lives and communities (Anyon et al., 2018; Cammarota & Fine, 2008; Ozer et al., 2020; Ozer, 2017; Ozer & Douglas, 2015). Rodríguez and Brown (2009) conceptualize YPAR with three key principles. First, YPAR is situated and inquiry-based as the research is focused on problems experienced by youth. Second, YPAR is participatory as youth are genuine collaborative partners in the research process. Lastly, YPAR is transformative and activist as the research aims to improve the lives of youth. This research employs YPAR due to its ability to initiate impacts at the individual, system, and institutional levels. At the individual level, YPAR supports positive youth development and empowerment through increased psychological autonomy, the importance of identity and purpose, and the role of responsibility in "helping to foster a sense of moral identity" (Ozer, 2017, p. 174). YPAR intervenes in settings and systems (e.g., schools and communities) shaping youth development. Lastly, YPAR disrupts traditional, institutional standards of inquiry by engaging youth as experts and co-researchers. As the lived experience of youth mental health has implications at the individual, system, and institution levels, YPAR is apt to leverage youth's expert knowledge to initiate change.

The difference between PAR and YPAR is the implications for youth education and development. YPAR incorporates notions of *praxis*, or critical reflection and action. Praxis inspires educational and developmental outcomes by demonstrating the agency youth possess in instigating changes at individual and community levels. YPAR provides the opportunity for youth to understand and analyse how social constructions mediate their lived experience, and the influence of praxis encourages actions to construct realities better suited to their needs (Cammarota & Fine, 2008). Traditionally YPAR has been utilized to improve communities and schools but is increasingly used to evaluate or adapt health programs and services for youth (Ozer, 2017). The expanded breadth of YPAR applications is due to its promotion by institutions calling for innovation in the advancement of adolescent well-being through "youth engagement, empowerment, and equity" (Ozer, 2017, as cited in Teixeira et al., 2021, p. 143). Through the promotion of participatory approaches, including YPAR, opportunities for genuine youth participation in research are emerging (Teixeira et al., 2021).

Challenges in user uptake and adherence to online and mobile mental health interventions and the limitation of youth participation in research to mainly consultative engagement underscore criticism that research is generally adult-centred. Negative opinions of youth often translate to a lack of respect for their ability to contribute to the research process (Teixeira et al., 2021). To address issues related to youth mental health, participatory approaches, such as YPAR, which deconstruct assumptions about expertise, can be utilized by adults to learn from, and with youth, about issues challenging for adult researchers to understand (Ozer, 2017).

## Photovoice

In alignment with PAR and YPAR methodologies, photovoice was used as part of an iterative and collaborative data collection and analysis process. Photovoice is a participatory method where participants use photography to visually record and collect data about issues directly affecting themselves and their communities (Catalani & Minkler, 2010; Flicker et al., 2008; Wang, 2006; Wang & Redwood-Jones, 2001; Berkeley YPAR Hub, 2023). The goals of photovoice enable people to represent their daily reality, promote critical dialogue regarding community and individual concerns, and reach policymakers (Wang, 2006; Wang & Redwood-Jones, 2001). Participants take pictures that reflect their understanding of the world and are guided through a critical discussion of the imagery, culminating in action planning and dialogue with decision-makers (Flicker et al., 2008).

Based on critical education and feminist theory (Wang 2006; Wang & Redwood-Jones, 2001), photovoice was developed by Caroline C. Wang and Mary Ann Burris in 1992 in the Ford Foundation-supported Women's Reproductive Health and Development Program in Yunnan, China. Photovoice was used "as a way to bring daily life experiences of village women in Yunnan... into decision-making for regional development" (Photovoice Worldwide, 2021). As photovoice became practiced widely, it has continued to be used to address health, public health, health promotion, and community health issues (Catalani & Minkler, 2010; Flicker et al., 2008). Photovoice has been useful in engaging youth in research where they are directly affected by the issues under study. It has been used to understand environmental influences on at-risk youths' mental and emotional health (Bashore et al., 2017); engage youth in social change and civic engagement (Wilson et al., 2007); build trust with minority youth in the exploration of environmental health and health inequalities (Butsch Kovacic et al., 2014); engage youth in a community-based assessment of adolescent substance use (Brazg et al., 2011); develop methods to engage youth in the "problem identification, data analysis, and feedback stages of research" (Foster-Fishman et al., 2010, p. 67); and, to understand the relationship between mobility and social relations for Indigenous youth (Goodman et al., 2018).

This research followed several of Wang's (2006) characteristics of youth photovoice projects. Youth were involved in all aspects of the research including data collection and analysis. A colearning process was shared among the researcher, the youth, and community partners. The process was reflexive and iterative allowing for and enabling the development of critical consciousness amongst participants. Lastly, there were efforts to maintain "a balance among the goals of research, action, and evaluation" (Wang, 2006, p. 156).

### Recruitment

Ethics approval was obtained from the Ontario College of Art and Design University Research Ethics Board on August 15<sup>th</sup>, 2022. Following this approval process, the first phase of recruitment began. Recruitment criteria during this initial phase included youth ages 15-21 with a mental health concern (e.g., anxiety disorder, depression, psychosis, bipolar disorder, schizophrenia, etc.) living in Victoria, BC and surrounding communities including Esquimalt, Saanich, and Oak Bay. A form was provided to potential participants to identify the necessity for guardian consent for those under the age of 19, the general location where the participant resided, and whether they had access to a digital device with photographic capabilities (e.g., mobile phone, iPad, tablet, digital camera, etc.).

During the first recruitment phase, three youths were recruited from two youth-focused organizations in Victoria, BC. In addition to these two organizations, numerous organizations with connections to youth, including secondary and post-secondary groups, mental health support services, community-based services, and religious groups, were contacted to connect around recruitment for this project. Unfortunately, only a small number of organizations agreed to share the recruitment information with their youth through email or social media. These challenges to participant recruitment were attributed to several barriers. A level of hesitancy on the part of organizations was perceived when it came to sharing recruitment materials they were unaffiliated with. This hesitancy was often drawn out through additional bureaucracy as the approval process to share the materials required coordination among several individuals.

Due to limited success in recruiting youth in Victoria, BC, the research project was amended to expand participation to youth in British Columbia and Ontario. The facilitation of activities shifted online to accommodate this amendment, thus reducing accessibility constraints on participation. The Research Ethics Board approved these amendments on November 14th, 2022. Upon approval of the amendment, participants recruited up until this point were informed of these changes via email and issued a new consent form describing the changes to online facilitation. Participants were given the option to withdraw from the study if they were no longer comfortable participating. Of the three participants recruited at this time, one withdrew from participation.

#### **Barriers to recruitment**

Throughout the first phase of recruitment, there were barriers to connecting with youth outside of an organization's main point of contact, who was often an adult. A common concern amongst adults was the perceived busy schedules of the youth, with adults often declining to share the recruitment materials within their youth network. While the ongoing recurrence of this barrier was surprising, it is not uncommon for research focusing on youth, nor for research attempting to facilitate recruitment through communitylevel partnerships.

As noted by Checkoway and Richards-Schuster (2004), the presence of adultism is a key challenge to YPAR efforts. As stated previously, adultism is a term used to refer to the view of adult superiority over youth. This often manifests in adults believing they can make decisions on behalf of youth, "are more knowledgeable than youth," and consequently, lacking "respect for young people's capacity to engage in the research process" (Teixeira et al., 2021, p. 145). In the case of recruitment, the way this bias can manifest implicitly became particularly clear through my communications with adults. Organizations and youth groups I contacted were not research focused (e.g., mental health support, community centre programs, religiously affiliated youth groups, arts-based youth programs, etc.), however, there were still underlying assumptions about youth's ability to engage in research. The adults coordinating these groups presented barriers to recruitment access for research but also barriers to connecting youth to research directly affecting them. As these experiences demonstrate, even community-based organizations "inherently have power differentials in place between youth and adults," and thus taking research directly to youth would require "a fundamental rethinking of relationships and roles" (Bettencourt, 2018, as cited in Teixeira et al., 2021, p. 143).

Despite the frustrations with this recruitment barrier, it should be noted that "academic community partnerships are painstakingly hard, even for the well intentioned and committed adults partners" (Teixeira et al., 2021, p. 143). Within community organizations, resources and personnel are often stretched thin. Being asked to support externally led projects can be difficult and can take time and resources away from internal projects with limited, subsidized funding. Such concerns are further amplified given the historical context of academia's relationship with community partners. Traditionally, academia "treated community members as a means to an end as opposed to the beneficiaries and co-creators of knowledge" (Langhout & Thomas, 2010; Wallerstein & Duran, 2017, as cited in Teixeira et al., 2021, p. 143). Therefore, hesitancy in partnering with academic research, including, but not limited to, participant recruitment, is not unsurprising.

#### Photovoice participants

While the amendment increased the scope of recruitment, many of the same recruitment challenges continued. As already stated, these challenges generally concern issues of gatekeeping based on protecting youth's time and attention. Despite this challenge, the expanded inclusion criteria for participation did help recruitment and a total of nine participants were recruited and consented to participation at the commencement of data collection, with one participant dropping out within the course of the project for personal reasons and another dropping out by omission.

Inclusion criteria included youth between the ages of 15-21 living in British Columbia or Ontario with lived experience of a mental health concern (e.g., anxiety disorder, depression, psychosis, bipolar disorder, schizophrenia etc.); willing to participate in a photovoice project and take photographs; and, comfortable discussing their mental health journey. All participants had access to a digital device which they could use to take photographs (e.g., mobile phone, iPad, tablet, digital camera, etc.). Of the nine participants, two were between the ages of 15-18, and seven were between the ages of 19-21. In terms of location, three participants were based in British Columbia, while six were in Ontario.

## Mental health training

Due to the project's inclusion of youth with lived experience of mental health concerns, steps were taken to support participants if they experienced worsening mental health during research-related activities. This study focused on personal experiences, therefore, research activities such as picture-taking, workshops, and interviews had the potential to bring up memories related to previous, and current, experiences of mental health concerns. As a researcher using participatory approaches to support and empower youth in a co-learning process, it was imperative to learn the skills necessary to help youth who may be dealing with declining mental well-being. Further, it was important to be self-reflexive about my mental well-being, due to the nature of the research topics.

In preparation for conducting research, I completed Mental Health First Aid Supporting Youth (Virtual) Training on August 18<sup>th</sup>-19<sup>th</sup>, 2022. This course, offered by the Mental Health Commission of Canada, is designed to help members of the public deal with young people who may be showing signs of worsening mental well-being or crisis. The course provided training on recognizing the signs of declining mental health, initiating conversations with young people about their mental health, discussing services and supports for recovery, and assisting and identifying a mental health crisis (Mental Health Commission of Canada, 2022).

## Preparing youth for photovoice

An orientation and training session was held before data collection and analysis. Seven of the nine participants were in attendance for this virtual workshop. Two participants who were unable to attend completed virtual individual orientations in the days following. The orientation began with an overview of the project and the research process. A workshop engagement agreement was shared with participants and reviewed as a group. The agreement was designed to ensure an inclusive and supportive environment for sharing ideas and perspectives among the group.

During the orientation, a significant amount of time was used to address ethical issues related to the research process and the use of images to create meaning. Ethical guidelines were shared with the participants before diving into a discussion of sample ethical scenarios related to picturetaking. Participants identified potential ethical issues from each scenario in the chat or aloud. As obtaining consent from photography subjects is a key ethical concern for this project, a photography release form was shared with participants, and the researcher articulated steps for obtaining consent in writing or recorded verbally. An image analysis activity prepared participants to use photography to represent their ideas, feelings, and emotions. Images were shown and participants were encouraged to discuss them aloud or in the chat. The following questions were used to prompt participant discussion: What do you see? What do you think it means? What does this make me wonder about? Following this activity, the orientation concluded with an introduction to the SHOWeD Analysis Template. The mnemonic SHOWeD has historically been a key component of photovoice research and was developed to allow participants to discuss and frame stories around their photographs. SHOWeD questions are as follows: What do you See here? What's really Happening here? How does this relate to Our lives? Why does this situation, concern, or strength exist? What can we Do about it? (Wang, 2006).

Following the orientation session each participant was given access to a Google folder shared between them and the researcher, which included copies of materials discussed during the orientation (e.g., Ethical Guidelines for Pictures, Photography Release Form, and a SHOWeD Analysis Template). In addition to project resources, a List of Mental Health Supports was provided to each participant which was tailored to their provincial regions and included links to online mental health resources, online chat support services, in-person mental health services, and immediate crisis line numbers.

# Photography discussion workshops

Following the orientation, participants undertook two weeks of data collection in which they took photographs related to the photography prompt: How do you experience web-based programs, apps, and websites for mental health? Participants were then invited to participate in two photography discussion and analysis workshops. The purpose of these workshops was to share and discuss the photographs, which elicited dialogue on participants' experiences with digital mental health interventions. The workshops encouraged the identification of themes related to their experiences through the presentation of photographs, which were then validated and expanded upon in group discussion. While the mnemonic SHOWeD was introduced in these workshops as a method for participants to frame their photographs, it was not particularly useful. Rather, participants were able to present their photographs and identify the connections between an image's visual components and their lived experiences without the SHOWeD framework to facilitate.

Attendance for the first workshop was low, with only three of the nine participants in attendance. As the workshop had been scheduled close to the winter holiday break for most participants, busy schedules contributed to low attendance. Following the first workshop, participants undertook the second round of data collection through photography. Due to the low attendance at the first workshop, it was decided that the participants would continue to explore the original photography prompt: How do you experience web-based programs, apps, and websites for mental health? Participants who attended the first workshop were encouraged to explore a new facet of the original photography prompt if they wished. Attendance at the second workshop, which was held two weeks after the first, was much higher with six participants attending, two of which attended the first workshop.

## Individual interviews

In addition to the photography discussion workshops, participants were invited to partake in individual interviews following the workshops. All nine participants agreed to participate in individual interviews at the commencement of the project, however, only six participants ended up participating. The purpose of the interview was to review preliminary project findings and to revisit the participant's photographs and associated quotes pulled from the transcripts by the researcher. During the review of findings, participants were asked the following: if the findings resonated with their experience of digital mental health interventions; the findings that felt most and least relevant to their experience; and if anything was missing from the findings based on their experiences of digital mental health interventions. Subsequently, participants had the opportunity to return to each photograph they presented throughout the project to revisit the associated quotes describing the photograph and add any additional comments they thought were necessary. Each interview lasted for between 45 minutes to one hour on average.

## Data collection and analysis

The research design incorporated several methods of iterative and collaborative data collection and analysis. Participants began this process through data collection (e.g., photography) and group analysis of this data for themes through discussion. Open inductive coding was applied to transcripts from these workshops, and subsequent interviews, by the researcher in multiple stages. Coding began with the first workshop, from which a code list was identified. These codes were categorized into themes related to participants' experiences with digital mental health interventions: (1) using digital mental health interventions; (2) searching for digital mental health interventions; (3) accessing digital mental health interventions; and (4) external factors affecting the use of digital mental health interventions. Initial codes were applied to transcripts from the second workshop and expanded upon. Frequently identified themes and codes were summarized in a preliminary summary of findings which were validated through individual interviews with the participants, with a subsequent final round of coding applied to the interview transcriptions.

# **Findings**

As noted by Kemp et al. (2021), while digital mental health interventions provided support for youth during the COVID-19 pandemic, there are concerns about their sustainability and longevity. Relatedly there are calls for more engagement with youth to improve the "integration of digital health with [mental health] organizations" and the "need for services to be more informed by the experiences and preferences of youth" (Kemp et al., 2021, p. 2-4). The findings from this research address the calls to engage youth in developing a more informed understanding of their experiences and preferences with digital mental health interventions. To showcase participants' experiences and preferences with digital mental health interventions, the findings are categorized by themes related to the youths' use journeys: (1) Searching for support, (2) Individual needs unmet, and (3) Finding relief.

## Searching for support

#### Motivations for use

Participants noted their motivations for using digital mental health interventions often stemmed from a desire for support during times when they wanted to be alone and avoid social contact. One participant mentioned they use apps when they can feel their mental health waning and want an escape:

I use them when things feel like they're really accumulating and I need to escape reality. It's not when I am at my worst, but when I am really tired and I don't want to do anything else, or I am not interested in doing work or going out with people, that's when I would use an app.

This sentiment of utilizing digital mental health interventions when one desires to be alone was shared by other participants. One participant suggested a digital mental health intervention can provide a level of connection when you don't feel prepared to talk to someone:

I was using apps mostly when I really needed the support. Sometimes you don't feel like talking to somebody, but you still want to feel an element of human connection. In some ways, an app can do that.

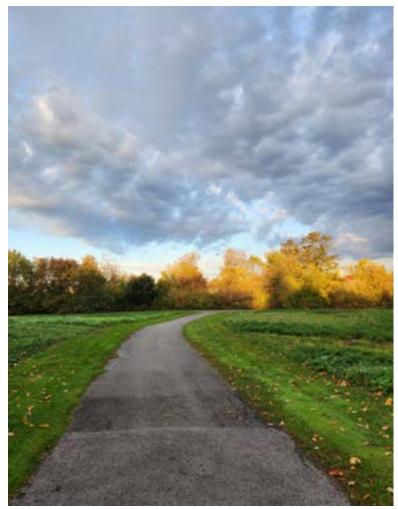


Figure 1. Participant photograph

Participants frequently acknowledged the ability to maintain anonymity as an added benefit of using digital mental health interventions, which may be related to their sometimes-isolating experiences of mental ill health. In a photograph presented by one participant (see Figure 1), the idea that one's mental health experience is an isolated one was articulated with the following:

Everyone keeps saying that life is a journey. At the same time people don't realize that a lot of the time, it's just you alone, walking by yourself. There are things you have to do alone for self-growth, including your [mental] health issues. I feel that this photograph represents that. It's a journey and you have to walk by yourself, but at the same time, it can be a pretty good journey. Sometimes there are downsides to walking alone, but at other times, you can enjoy the view and the scenery. There's hope for you.

This participant echoed others' socially isolating motivations for using digital mental health interventions. They further explained that digital mental health interventions provide them with stability in unstable moments when they preferred to be alone:

Apps help me take care of myself in the moments when I am feeling unstable. When I am feeling really done and desperate. I used apps in those situations, and I would say that I still prefer to use apps in those situations than talk to my therapist. When I am feeling down, I prefer to be alone, and if I want to be alone, there's no way I can talk. Once I'm feeling better I am more comfortable with my therapist than an app.

Interestingly, this participant often remarked they realized apps can only provide temporary relief from their mental health concerns, articulating a need for their therapist when they are feeling up to talking.

Several participants discussed the cost barriers that exist to accessing mental health services. For some, these barriers motivated their use of digital mental health interventions. One participant shared that their use of digital mental health interventions increased after graduating:

I used a lot of different mental health apps out of pure desperation after I graduated because I lost my health benefits and couldn't get access to affordable therapy. I would use them pretty much anytime I felt like I was in crisis. It felt like I was on autopilot during that time and would use them anytime I felt desperate.

A lack of health insurance to cover the costs of therapy was a concern repeated by other participants and a motivation for their use of digital mental health interventions. One participant noted that after covering bills including tuition, they wouldn't have been able to access therapy without health insurance: I think the appeal of apps is that they're not as expensive as therapy, because therapy is very expensive. If my insurance hadn't covered therapy, I don't think I would be able to spend that much [on therapy] after paying all my bills and tuition. Having insurance was one of the reasons why I approached therapy, but if I hadn't had my insurance plan, I probably would have stuck to apps.

The low-cost barriers associated with digital mental health interventions were an appealing feature for most participants. Relatedly, there was a strong preference for digital mental health interventions that were free to use.

#### Navigating privacy and paywalls

The preference for free digital mental health interventions may be associated with privacy concerns. Past experiences with unauthorized credit card charges and credit card fraud made participants wary of sharing such information with a digital mental health intervention. As one participant shared:

If [an app] is asking for my credit card, I am out. In the past, I have had people steal my credit cards. So as soon as [an app asks] I am like 'nope,' I don't trust them, I am gone.

Overall, most participants noted when an app asks for personal information, including credit card information, they are more hesitant to use it. These personal information requests can cause anxiety for participants, especially if they have experienced credit card fraud. One participant noted the contradiction this cost dynamic creates for users:

If [an app] takes my credit card even for a trial and then I see a big bill on my credit card [statement], that makes me worried and anxious. It is almost the opposite [of what the app should be doing].

While mental health apps are not unique in the presence of paywalls, participants were clear in their preference for free apps and their understanding of the inherent contradiction that emerges when an app focused on mental health causes anxiety with use.

#### An abundance of options

Participants noted there are many digital mental health interventions available to use and it can be challenging to narrow down options to find one beneficial for them. It isn't only online where participants are inundated with lists of apps to wade through, as one participant recounted their experience at a mental health crisis unit:

When I went to the mental health crisis unit at the hospital they gave me a list of like 50 apps and were like 'try it.' It wasn't helpful. When somebody's in crisis they don't need 50 app options, they need two, and to be told which two to pick.

Navigating through the options of digital mental health interventions can be difficult. Oftentimes participants found an app through recommendations by peers, doctors, or therapists. As one participant noted, recommendations from peers carry weight when deciding to try a digital mental health intervention:

My main exposure to apps and websites is hearing my peers talking about them. Someone tells you an app worked really well and then you try it because they spent time and effort looking into it.

Hearing recommendations from trusted sources can be the impetus for trying an app. For another participant, recommendations from their doctor and therapist resulted in a positive experience with a CBT app for insomnia:

My therapist when I was in college first showed this app to me. Then my doctor recommended it, so I thought maybe I should give it a try if multiple people are recommending it to me. I started using it and liked it. I've been using it [on-and-off] for over two years now.

Recommendations from trusted individuals are a method for navigating the abundance of digital mental health intervention options. Individuals with an understanding of a young person's specific mental health concerns may be in an important position to advise on whether a particular digital mental health intervention will prove to be beneficial.

### Individual needs unmet

#### Limitations of apps

In addition to difficulty selecting a digital mental health intervention amongst the abundance of options, participants noted the features provided by the interventions they try are limited. One participant explained most digital mental health interventions are similar to each other, focusing on productivity, time management, or preventing symptoms, rather than providing long-term guidance:

Most of the websites [or apps] I found were very similar to each other. They were focused on productivity, time management, and preventing symptoms, rather than explaining [the symptoms] and how you can take care of yourself long-term.

Others noted it is important not to mistake lots of app features with an increased likelihood it will provide support. As one participant explained, when apps provide a broad range of features, they are left overwhelmed trying to navigate through which features work best for them:

If [an app's features] are too broad then you lose that individual focus. In the past, I have tried apps that focus on so many things. There's too much and it's overwhelming.

While there is no limit to the number of mental health apps and related digital interventions, the apps themselves are often restricted by their generalized approaches to mental health with broad feature offerings. By trying to provide as many features as possible participants can be left overwhelmed as they seek out support for their individual needs.

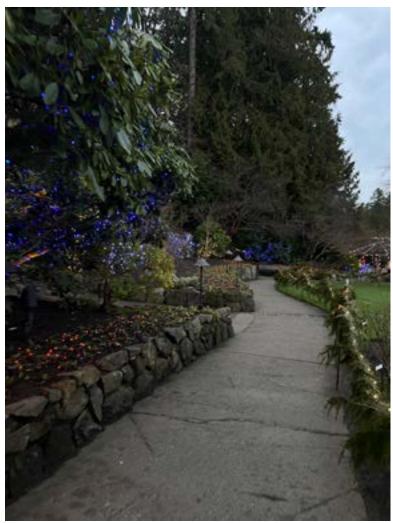


Figure 2. Participant photograph

#### Discouraged by the process

Due to the limited support participants receive from digital mental health interventions, it was not uncommon for participants to express discouragement and disappointment with their experiences. One participant articulated this sentiment when describing their creative intentions for one of their photographs (see Figure 2):

The picture is of a very dark path. I don't want to sound overly depressing, but you don't know when you're gonna find the right app that works for you. If you do find the right app or website it can [still] feel like you're going into a dark tunnel, you're blind and you can't really see anything. That's what my experience with apps and websites to help promote mental health feels like.



Figure 3. Participant photograph

For this participant, such experiences create a roadblock to obtaining support through digital mental health interventions. Committing time to find an app, only to find it doesn't work is a discouraging process. As the same participant explained further:

I think a lot of people, myself included, feel their needs aren't met by mental health apps. They've reached a roadblock where they wonder if they really want to spend their time and energy looking for something that might not have a [positive] return. I think that's why a lot of people find themselves jumping between [different] apps and websites, or not using any at all.

This experience of compounding roadblocks to finding mental health support through digital interventions was addressed by more than one participant. Through a photograph (see Figure 3), one participant related their experience of ADHD symptoms to their experiences with digital mental health interventions:

This is an image of me in a moving vehicle with a blurred background, and very moody tones. I took it on a rainy day. I am grayed out and shadowy, but you can kind of see that I am making a weird face. At that point, I was in the car for 30 minutes and I get fidgety and uncomfortable in cars due to my ADHD. It enamoured a similar mood whenever I am searching or accessing online [mental health] treatment because it takes forever to find the correct provider, or look at a website and figure out whether or not it's legit, or if you have to pay 1000s of dollars to use it.

For this participant, there are several factors which can become roadblocks to finding mental health support online. The length of time it takes to find support, trying to decipher the legitimacy of the support provider, and navigating paywalls can all lead to potential roadblocks to using digital mental health interventions.



Figure 4. Participant photograph

## **Finding relief**

#### Benefits of specialized apps

Despite the potential roadblocks to accessing support for mental health through web-based programs, apps, and websites, several participants did note positive experiences, particularly when it came to using apps or platforms tailored to address specific concerns. One participant who has been using a CBT-based app for insomnia for two years used the image of holding hands (see Figure 4) to articulate the beneficial relationship the app has provided:

I have had a lot of different experiences with mental health apps. One of them in particular was made to help with insomnia, which I found really helpful. That app worked with me rather than against me, which I represented with two people holding hands.

Recommendations from their therapist and doctor guided this participant to try the app. By focusing on a specific concern and using an app designed to address that concern, the participant had a much different experience than when they were using apps to deal with their depression and anxiety. This participant went on to clarify:

Before with my depression and anxiety, I couldn't find any apps to help, and it was really hard. When we figured out my issue with insomnia we found a CBT app for insomnia that finally stuck. It was super helpful and rewarding.

Specialized apps can provide a positive experience that more generalized apps do not. One participant who received their ADHD diagnosis through a new online platform recalled the overall benefit this app has had on their life:

I've recently used an online platform for mental health. It's really helped me and it's actually given me my life back. You've probably seen it on TikTok everywhere. It's called Talk with Frida. It's a relatively new [platform], and I got my ADHD diagnosis through them. It's been a literal lifesaver. Until this experience, I had never had a welcoming experience with an online mental health provider.

These experiences demonstrate the benefit of a more specialized app. While the apps themselves may not specifically address a mental health concern, apps that address intersecting concerns which may affect one's overall mental health can still provide a significant benefit.



Figure 5. Participant photograph

#### Positive use patterns and practices

A positive experience with digital mental health interventions may not be entirely due to the intervention itself, but rather experiencing the positive benefits despite the limitations of the app. One participant used a photograph (see Figure 5) to describe the experience of overcoming difficulties with an app after seeing the positive benefits it provided in their life:

When you first look at the photograph there is a grassy bit, then there are dark dead trees, and then it goes on to the sky. It's like when an app starts out good and you get hyped up thinking this is going to fix everything. Then you have some difficulties with the app, and it starts to feel like the complete opposite. But if you keep at it, and keep trying, you'll be able to enjoy it or experience some positive effects. It's not perfect, but I know it's helping me, even if it's just a little bit.

While an app might not provide dramatic changes to one's mental health, small, visible benefits can be encouraging. After experiencing benefits from a digital mental health intervention, the same participant described the way they integrated an app into their daily routine as part of a preventative approach to mental health:

I try to [use an app] as part of my morning routine. After I exercise I do a five-minute breathing activity. In the beginning, it was hard to focus, but once I saw how much better it made my day and how much calmer I felt, I wanted to keep doing it. Now I hopefully don't get to the point where I'm so overwhelmed.

Participants were aware that even these small instances of support from digital mental health interventions can potentially provide long-term support if you find something that works. One participant who enjoyed using the apps for journaling distinguished using an app for immediate support and using it as part of creating good mental health habits:

Sometimes you're having a bad day and you need something to blur out what you've been going through. On the other hand, I find it nice to have [an app] that will get me into journaling and writing about my life. It can help prevent incidents that lead me to feel like I have no other resort. It's good to have that distinction. Do you want to use this app for the long term and build good habits to reduce your mental duress, or do you want to use this app when you need it during those hard times?

While participants were aware that digital mental health interventions most likely would not be able to address all their mental health concerns, it was clear they saw the potential of these interventions to provide aspects of support in a more holistic approach to their mental health. More than one participant noted apps could supplement the support of other mental health services when immediate access is an issue:

The apps do have a place when you're on a holiday [and can't access mental health services]. When there's a gap in service, the apps can be more beneficial.

I feel apps might work better when you cannot access a therapist. But at the same time, if you're looking for long-term care, it still makes more sense to me to have in-person therapy.

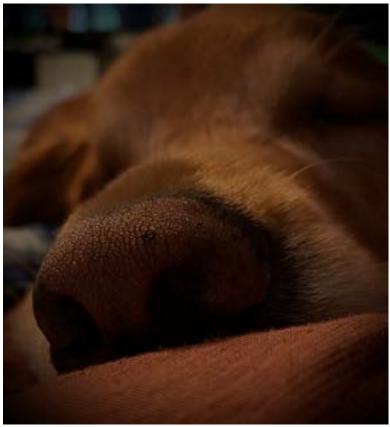


Figure 6. Participant photograph

The benefits of therapy, as opposed to digital mental health interventions, were frequently mentioned by participants. Before revealing their positive experience with a therapist, one participant used a photograph (see Figure 6) to describe the hopelessness they experienced with mental health apps:

This is my service dog, who helps a lot and is usually quite close to me. Right now he's sleeping on the floor beside me. When I took this picture I was playing with settings. I noticed it was all dark around the outside, but there was some light reflecting on his nose. It reminded me of the apps where some things work, but then the majority of it is just hopelessness.

For this participant, their experience with digital mental health interventions was just discouraging as their experiences with in-person mental health services until they found their therapist:

A lot of the [in-person] resources that I went to were similar to the apps that I tried to use, in that they weren't helpful. I just felt more judged walking out. It wasn't until I sought out my own therapist and was able to connect through the therapeutic relationship that I found help.

The limitations of apps to provide long-term support as opposed to therapy was an issue addressed by others. For one participant their experience with therapy provided a new perspective on those limitations:

Initially I was satisfied with the apps, but then I tried therapy. After talking to my therapist about a few of my issues I realized the apps are not really treatment, irrespective of what options they might give to control your symptoms. The apps help control the symptoms but not why you're experiencing them.

Therapy is one-way participants are seeking out support for their mental health beyond web-based programs, apps, and websites for mental health. However, it should be reiterated, the cost of therapy can be a significant roadblock to access for those without the financial means or extended health insurance.

#### Other methods to support mental health

At times when participants are experiencing heightened mental distress a mental health app isn't always their first choice, rather turning to Netflix, YouTube or other sources of media can provide immediate relief. More than one participant described using other sources of media to distract themselves and relax:

If I'm feeling super stressed out, I'm less likely to use apps, I'm more likely to watch Netflix, where I can get comfortable, relax, and watch something.

YouTube, Netflix, and Disney+, any of those when I'm having a harder time and I need something for long-term distraction, but even with TikTok I can get sucked in for three hours when I don't want to think about what I am watching. While consuming media can help participants relax in the moment, others noted the benefits of exercise for their mental health long-term. Participants easily drew connections between feeling better and exercising. Two participants described when they were working out more, they experienced benefits to their overall mental health:

Last year, I used to work out a lot and go for walks and I found that helps my mental health. It's those things I did in real life that were more effective than apps.

Before when I was working out, I felt healthier. It felt like everything I was experiencing I could let it out with aggression. I was playing sports and I never had the need for [mental health] apps.

Not only did mental health apps provide limited benefits as opposed to exercising, but staying active meant those participants did not find the need for the apps. When it comes to immediate relief and long-term preventive measures, participants are seeking out methods to support their mental health beyond the resources available to them through their mobile phones or computers.

### Discussion

Mental health is an increasingly serious concern for youth and their families throughout Canada and the world. The pandemic exacerbated pre-existing issues and required organizations providing mental health support to pivot to the digital delivery of mental health services quickly. It is therefore more important than ever to understand how youth are, or are not, supported by digital mental health interventions (Kemp et al., 2021). Their experiences with digital interventions can provide insights and recommendations into the future of digital delivery of mental health services. The study findings are important as concerns surrounding youth mental health are at an inflection point (Eaton, 2023). In analysing these findings, I situate participants' lived expertise and experiences with digital mental health interventions within and extending from established literature. Then, I will discuss photovoice as a methodological approach to investigating issues related to youth mental health.

# Lived expertise in digital mental health interventions

Youth are turning to digital mental health interventions to find support for their mental health concerns. The experience of using digital interventions for support is happening during a foundational time for one's overall mental health. The peak onset of mental health disorders occurs during adolescence, which has implications for youth's future mental health journeys (Kretzschmar et al., 2019; Malla et al., 2018; Patel et al., 2007). The shift to digital delivery of mental health support by service providers during the COVID-19 pandemic was significant (Kemp et al., 2021), however, the pandemic as a motivating factor for using digital interventions was not discussed by participants. Rarely did the topic of the pandemic come up in discussions with the group, nor did individual interviews. This may tell us that the shift to digital delivery was more of a transformational challenge for the mental health system and not youth. The findings suggest that youth are already using digital interventions for youth-initiated mental health support and expect those interventions to help.

While there is limited research investigating youth's motivations for seeking mental health support through digital interventions, findings from this research align with established literature and current statistics on mental health service access more generally. As participants noted, the ability to maintain anonymity was a motivation for their use of digital mental health interventions, which correlated with not feeling ready to speak to someone directly about their mental health concerns. The desire for anonymity emphasized concerns regarding online privacy noted by most participants. As Kretzschmar et al. (2019) have noted, trust and confidentially concerns are common barriers to seeking mental health support. When discussing personal, sensitive information, sharing anonymously online may be a more desirable way to disclose mental health concerns if talking to a clinician in person feels daunting (Kretzschmar et al., 2019). Therefore, it is entirely understandable why concerns around maintaining privacy were of the utmost importance for participants.

Barriers to mental health support are not always related to the apps themselves. As several participants mentioned digital interventions were used to support their mental health when other services were unavailable. Cost barriers to therapy were addressed by multiple participants, including whether one has access to health insurance with mental health coverage. Such findings are supported by recent Canadian statics showing three in four children and youth cannot access the mental health support they need because it is not available or funded by public health coverage (Eaton, 2023). While most participants found varying degrees of support through digital mental health interventions, services such as therapy were seen as providing the most benefit. As this research suggests, youth aren't necessarily turning to digital mental health interventions because they think they will provide the most support for them. Rather limited access to other forms of support, which they view as being more beneficial, means digital interventions are the easiest to access.

Ambivalence towards digital interventions may not be due to a limited desire to use apps for mental health support, but rather the limitations of apps to address specific, individual concerns. As Byron (2019) suggested, LGBTQ+ youths' ambivalence toward apps may have been due to youth not finding apps to be particularly useful individually. While this may be the case, particularly for LGBTQ+ youth in their use of more universally designed interventions (Byron, 2019), the findings here suggest generalized, or more 'universal' interventions, do not meet the needs of non-LGBTQ+ identifying youth as well. It could be inferred that the disappointment participants felt from their experiences using digital interventions was due in part to the ambivalence between their desire to use digital interventions and finding the individualized support of apps limiting.

The findings align with established research on the potential benefits of refining digital mental health interventions to provide more specialized support. For youth who recalled positive experiences with digital interventions, there was often an element of specialization within the intervention which could be correlated with the positive outcome. It was clear from the participants that apps and online platforms that were designed to address a specific concern such as insomnia or ADHD, provided a clear benefit to their lives. Such findings align with other research demonstrating the potential benefits of adapting e-therapy models to address the concerns of marginalized populations. Research by Lucassen et al. (2018) demonstrated findings that LGBTQ+ young people are interested in using digital mental health interventions, but interventions need to be tailored to LGBTQ+ youth and their needs and preferences.

Lucassen et al. (2018) noted while digital mental health interventions are an important tool to address the mental health concerns of youth, these interventions are often "designed for a general population" (p. 14). Just as LGBTQ+ youth need digital interventions which provide content and strategies relevant to their lived experiences (Lucassen et al., 2018), other lived experiences, including additional health concerns such as insomnia and ADHD, may intersect with one's mental health. Even for participants who did not mention the implications of an intersecting experience on their mental health, the generalized approach offered by more mainstream interventions was a drawback and roadblock to finding digital support.

When digital mental health interventions work, youth can see the benefits for themselves. Whether participants found relief through specialized apps or those with more generalized features, they noted that consistent, preventative use did provide some relief. As demonstrated by Manicavasagar et al. (2014) digital mental health interventions can reduce symptoms of psychopathy and increase the well-being of youth when used preventatively. However, issues of adherence need to be addressed for these preventative measures to provide the most benefit (Bevan Jones et al., 2020; Orlowski et al., 2015; Manicavasagar et al., 2014). As the findings show, demonstrated benefits can be useful in establishing a routine involving digital interventions to support mental health. What is clear from the experiences described by participants, is that the benefits from preventative use were tied to interventions that aligned with their personal preferences and needs.

Many participants were already using digital interventions to manage their mental health concerns, which aligns with established research by Montague et al. (2015). Interestingly, it wasn't only digital mental health interventions that youth used to manage their concerns, but consumption of media appeared to play a part in supporting their mental health. In addition, multiple participants were clear in their assertions of the considerable benefits they experienced from non-digital support, in particular therapy. This is consistent with findings that youth are interested in "using technology as an adjunct to more traditional treatments," if it does not replace face-to-face care (Montague et al., 2015, p. 5-6). Participants' opinions further align with research showing youth perceived digital interventions as less effective than traditional therapy (Montague et al., 2015, p. 6). At least four participants noted the positive benefits individual therapy provided them.

The findings are supported by research demonstrating that when it comes to integrating digital mental health interventions into mental health support practices, youth are already using digital interventions as a means of client-initiated care (Montague et al., 2015). Only one participant noted that they used an app recommended by a clinician or therapist. Interestingly, this experience was perceived as being especially positive for the participant. Most participants articulated levels of discouragement with the process of searching for digital interventions, which they did on their own as part of youth-initiated self-care. This may suggest clinicians and service providers can be important resources in helping youth navigate the abundance of digital mental health interventions to find resources that work for them as an individual.

# Discussing mental health through photography

Photovoice has been used to investigate health, public health, health promotion, and community health issues, however, there has been limited facilitation of the photovoice methodology in the investigation of youth mental health issues, specifically youth's use of digital mental health interventions. Methodological findings from this research suggest that photovoice is apt to investigate topics related to mental health research and interventions. This is due to its flexibility as "it can be altered to fit diverse partnerships, community contexts, participant characteristics, and research or intervention interests" (Catalani & Minkler, 2010, p. 448). The flexibility offered by photovoice was leveraged by both the researcher and the participants in the investigation of youths' experiences with digital mental health interventions. Youth used photovoice to discuss sensitive topics related to their lived experiences using digital mental health interventions and draw connections between their experiences and others. These discussions focused on their use of digital mental health interventions and how they situate interventions within a larger discussion of their experiences with mental ill health.

It is important to note that the insightful discussions that emerged during workshops and interviews were not tied to a reliance on the SHOWeD questions. During the first workshop, it became clear that the SHOWeD framework was not useful for participants. Rather than ask participants to journal answers to the SHOWeD questions and then share them aloud, facilitation shifted with participants being asked to briefly describe their photograph aloud, at which point the researcher would ask a few follow-up questions specifically related to their photograph. From these followup questions, a discussion would arise, with other participants often joining in to share their related personal experiences and reflections.

Difficulty facilitating discussion through the SHOWeD framework may have been due to the sensitive nature of the research topic and the project's timeline. As described by Bashore et al. (2017) in their use of photovoice to investigate the environmental influences on at-risk youths' mental and emotional health, the SHOWeD framework can be challenging for discussing sensitive topics. Their research found not all participants "were able to articulate a thoughtful response to the SHOWeD questions" (Bashore e al., 2017, p. 472), however as comfort levels with SHOWeD increased over time, participants provided more thoughtful reflections. While a longer project timeline can allow for increased comfort with the SHOWeD technique, I would argue as a participatory method, researchers facilitating photovoice should be mindful of participants' challenges with the method and leverage the flexibility of photovoice to adapt their process.

### Limitations

The intersecting challenges of time and resources were the most significant limitations of this research. The challenge of working as a sole researcher had implications for the recruitment process, which needed to overcome several hurdles and resulted in a low sample size. Recruitment delays resulted in timeline shifts, which meant holding workshops near the end of the year when participants were busy with end-of-school term activities resulting in low attendance at the first workshop. Due to the shortened project timeline, only two group discussion workshops were facilitated. Additional workshops could have fostered increased engagement and provided new topics for discussion amongst the participants.

Organizations with ties to mental health support services appeared to garner the most interest from potential participants, which may have affected group dynamics in terms of participants' willingness to discuss topics related to mental health. While nine participants were recruited there was lower attendance in research activities, with seven participating in workshops, and six agreeing to individual interviews. Demographic information about race, Indigenous status, income, gender identity, and sexuality were not accounted for, which limits the understanding of these factors in the digital mental health intervention use practices of participants.

### Conclusion

Digital mental health interventions are increasingly selected by youth as part of youth-initiated self-care. While the benefits of anonymity and low cost are notable, youth themselves are identifying concerns with these platforms which often fail to meet their individual needs. Adherence issues to digital mental health interventions may be less attributed to a general ambivalence towards these interventions, but rather finding their needs unmet by apps designed to attract the broadest user base. As the abundance of interventions can be daunting and discouraging to navigate, clinicians and service providers are apt to provide recommendations tailored to patients' mental health concerns.

When youth choose to use a digital mental health intervention it isn't necessarily because they think it will provide the most support. Often limited access to other forms of support such as therapy, which they view as more beneficial, means digital interventions are the quickest and easiest to access. It is therefore important that digital mental health interventions are not provided as an alternative option to therapy, but rather used in conjunction with a more integrated approach to mental health care. However, for an integrated approach to be successful steps need to be taken to make sure mental health care is made available to all through public health coverage.

#### References

- Act for Mental Health. (2023). Parents. Act for Mental Health. <u>https://www.actformentalhealth.ca/parents/</u>
- Antezana, G., Bidargaddi, N., Blake, V., Schrader, G., Kaambwa, B., Quinn, S., Orlowski, S., Winsall, M., & Battersby, M. (2015). Development of an Online Well-Being Intervention for Young People: An Evaluation Protocol. JMIR Research Protocols, 4(2), e4098. <u>https://doi. org/10.2196/resprot.4098</u>
- Anyon, Y., Bender, K., Kennedy, H., & DeChants, J. (2018). A Systematic Review of Youth Participatory Action Research (YPAR) in the United States: Methodologies, Youth Outcomes, and Future Directions. *Health Education* & Behavior, 45(6), 865-878. <u>https://doi. org/10.1177/1090198118769357</u>
- Bashore, L., Alexander, G. K., Jackson, D. L., & Mauch, P. (2017). Improving health in at-risk youth through Photovoice. *Journal of Child Health Care*, 21(4), 463–475. <u>https://doi.org/10.1177/1367493517734391</u>
- Bassilios, B., Telford, N., Rickwood, D., Spittal, M. J., & Pirkis, J. (2017). Complementary primary mental health programs for young people in Australia: Access to Allied Psychological Services (ATAPS) and headspace. International Journal of Mental Health Systems, 11, 1-11. https://doi.org/10.1186/s13033-017-0125-7

- Bate, P., & Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. BMJ quality & safety, 15(5), 307-310. http://dx.doi.org/10.1136/qshc.2005.016527
- Bettencourt, G. M. (2020). Embracing problems, processes, and contact zones: Using youth participatory action research to challenge adultism. Action Research, 18(2), 153-170. <u>https://doi-org.ocadu.idm.oclc.</u> org/10.1177/1476750318789475
- Bevan Jones, R., Stallard, P., Agha, S. S., Rice, S., Werner-Seidler, A., Stasiak, K., Kahn, J., Simpson, S. A., Alvarez-Jimenez, M., Rice, F., Evans, R., & Merry, S. (2020). Practitioner review: Co-design of digital mental health technologies with children and young people. Journal of Child Psychology and Psychiatry, 61(8), 928–940. <u>https://doi.</u> org/10.1111/jcpp.13258
- Berkeley YPAR Hub. (2023). Investigating a Problem. Berkeley YPAR Hub. <u>https://yparhub.berkeley.</u> <u>edu/investigating-problem</u>
- Bowler, L., Wang, K., Lopatovska, I., & Rosin, M. (2021). The Meaning of "Participation" in Co-Design with Children and Youth: Relationships, Roles, and Interactions. Proceedings of the Association for Information Science and Technology, 58(1), 13–24. <u>https://doi. org/10.1002/pra2.432</u>

- Branquinho, C., Tomé, G., Grothausen, T., & Gaspar de Matos, M. (2020). Community-based Youth Participatory Action Research studies with a focus on youth health and well-being: A systematic review. Journal of community psychology, 48(5), 1301–1315. <u>https://doi. org/10.1002/jcop.22320</u>
- Brazg, T., Bekemeier, B., Spigner, C., & Huebner, C. E. (2011). Our Community in Focus: The Use of Photovoice for Youth-Driven Substance Abuse Assessment and Health Promotion. *Health Promotion Practice*, 12(4), 502–511. <u>https://doi. org/10.1177/1524839909358659</u>
- Burns, J., & Birrell, E. (2014). Enhancing early engagement with mental health services by young people. Psychology research and behavior management, 7, 303–312. <u>https://doi. org/10.2147/PRBM.S49151</u>

Butsch Kovacic, M., Stigler, S., Smith, A., Kidd, A., & Vaughn, L. M. (2014). Beginning a Partnership with PhotoVoice to Explore Environmental Health and Health Inequities in Minority Communities. International Journal of Environmental Research and Public Health, 11(11), 11132–11151. <u>https://doi.org/10.3390/</u> ijerph111111132

Byron, P. (2019). 'Apps are cool but generally pretty pointless': LGBTIQ+ young people's mental health app ambivalence. *Media International Australia*, 171(1), 51–65. <u>https://doi. org/10.1177/1329878X19844034</u> Calder-Dawe, O., & Gavey, N. (2019). Feminism, Foucault, and Freire: A dynamic approach to sociocultural research. *Qualitative Psychology*, 6(3), 216–231. <u>https://doi. org/10.1037/qup0000106</u>

- Cammarota, J., & Fine, M. (2008). Youth Participatory Action Research: A Pedagogy for Transformational Resistance. In J. Cammarota & M. Fine (Eds.), Revolutionizing Education: Youth Participatory Action Research in Motion (pp. 1-11). Taylor & Francis Group.
- Catalani, C., & Minkler, M. (2010). Photovoice: A Review of the Literature in Health and Public Health. Health Education & Behavior, 37(3), 424– 451. <u>https://doi.org/10.1177/1090198109342084</u>
- Checkoway, B., & Richards-Schuster, K. (2004). Youth participation in evaluation and research as a way of lifting new voices. *Children*, Youth and Environments, 14(2), 84-98. <u>http://www. jstor.org/stable/10.7721/chilyoutenvi.14.2.0084</u>
- Christie, G. I., Shepherd, M., Merry, S. N., Hopkins, S., Knightly, S., & Stasiak, K. (2019). Gamifying CBT to deliver emotional health treatment to young people on smartphones. *Internet interventions*, 18, 100286. <u>https://doi. org/10.1016/j.invent.2019.100286</u>

- Clarke, J., Vatiliotis, V., Verge, C. F., Holmes-Walker, J., Campbell, L. V., Wilhelm, K., & Proudfoot, J. (2015). A mobile phone and web-based intervention for improving mental wellbeing in young people with type 1 diabetes: Design of a randomized controlled trial. JMIR Research Protocols, 4(2), e4032. <u>https://doi. org/10.2196/resprot.4032</u>
- Cost, K. T., Crosbie, J., Anagnostou, E., Birken, C. S., Charach, A., Monga, S., Kelley, E., Nicolson, R., Maguire, J. L., Burton, C. L., Schachar, R. J., Arnold, P. D., & Korczak, D. J. (2022). Mostly worse, occasionally better: Impact of COVID-19 pandemic on the mental health of Canadian children and adolescents. *European Child &* Adolescent Psychiatry, 31(4), 671–684. <u>https://</u> doi.org/10.1007/s00787-021-01744-3
- Coughlan, H., Cannon, M., Shiers, D., Power, P., Barry, C., Bates, T., Birchwood, M., Buckley, S., Chambers, D., Davidson, S., Duffy, M., Gavin, B., Healy, C., Healy, C., Keeley, H., Maher, M., Tanti, C., & McGorry, P. (2013). Towards a new paradigm of care: The International Declaration on Youth Mental Health. Early Intervention in Psychiatry, 7(2), 103–108. <u>https://doi. org/10.1111/eip.12048</u>
- Diemer, M., Rapa, L., Voight, A., & Mcwhirter, E. (2016). Critical Consciousness: A Developmental Approach to Addressing Marginalization and Oppression. Child Development Perspectives, 10(4), 216-221. <u>https://doi. org/10.1111/cdep.12193</u>

Eaton, M. (2023, February 28). Open letter to Prime Minister Trudeau: There's a mental health crisis for children and youth and they need your help. CMHA National. <u>https://cmha.ca/news/letterto-pm-trudeau-copying-ministers-bennettduclos-and-freeland/</u>

Flasher, J. (1978) Adultism. Adolescence, 13(51), 517.

- Flicker, S., Maley, O., Ridgley, A., Biscope, S., Lombardo, C., & Skinner, H. (2008). PAR: Using technology and participatory action research to engage youth in health promotion. Action Research, 6(3), 285–303. <u>https://doi. org/10.1177/1476750307083711</u>
- Foster-Fishman, P. G., Law, K. M., Lichty, L. F., & Aoun, C. (2010). Youth ReACT for Social Change: A Method for Youth Participatory Action Research. American Journal of Community Psychology, 46(1-2), 67–83. <u>https://doi. org/10.1007/s10464-010-9316-y</u>
- Freire, P. (2000). Pedagogy of the oppressed (M.B Ramos, Trans., 30th anniversary. ed.). New York: Continuum. (Original work published 1968)
- Goodman, A., Snyder, M., & Wilson, K. (2018). Exploring Indigenous youth perspectives of mobility and social relationships: A Photovoice approach. The Canadian Geographer / Le Géographe Canadien, 62(3), 314–325. <u>https:// doi.org/10.1111/cag.12460</u>

- Grist, R., Porter, J., & Stallard, P. (2017). Mental Health Mobile Apps for Preadolescents and Adolescents: A Systematic Review. Journal of Medical Internet Research, 19(5), e176. <u>https://</u> doi.org/10.2196/jmir.7332
- Hackett, C. L., Mulvale, G., & Miatello, A. (2018). Codesigning for quality: Creating a user-driven tool to improve quality in youth mental health services. Health Expectations: An International Journal of Public Participation in Health Care and Health Policy, 21(6), 1013–1023. <u>https://doi. org/10.1111/hex.12694</u>
- Huggett, D., Flynn, A., Jaouich, A., Taylor-Gates, M., & Davidson, S. (2017). Engaging Youth in a Mental Health System Improvement Initiative in Ontario: Developing the Be Safe Resource. Canadian Journal of Community Mental Health, 36(2), 121–131. <u>https://doi. org/10.7870/cjcmh-2017-019</u>
- Kemp, J., Chorney, J., Kassam, I., MacDonald, J., MacDonald, T., Wozney, L., & Strudwick, G. (2021). Learning About the Current State of Digital Mental Health Interventions for Canadian Youth to Inform Future Decision-Making: Mixed Methods Study. Journal of Medical Internet Research, 23(10), e30491. <u>http://dx.doi.org/10.2196/30491</u>
- Kennedy, H. (2018) How adults change from facilitating youth participatory action research: Process and outcomes. *Children and Youth Services Review*, 94, 298–305. <u>https://doi. org/10.1016/j.childyouth.2018.10.010</u>

- Kretzschmar, K., Tyroll, H., Pavarini, G., Manzini, A., Singh, I., & NeurOx Young People's Advisory Group. (2019). Can Your Phone Be Your Therapist? Young People's Ethical Perspectives on the Use of Fully Automated Conversational Agents (Chatbots) in Mental Health Support. Biomedical Informatics Insights, 11, 1178222619829083. <u>https://doi. org/10.1177/1178222619829083</u>
- Lal, S., Gleeson, J., Malla, A., Rivard, L., Joober, R., Chandrasena, R., & Alvarez-Jimenez, M. (2018). Cultural and Contextual Adaptation of an eHealth Intervention for Youth Receiving Services for First-Episode Psychosis: Adaptation Framework and Protocol for Horyzons-Canada Phase 1. JMIR Research Protocols, 7(4), e8810. <u>https://doi. org/10.2196/resprot.8810</u>
- Langhout, R. D., & Thomas, E. (2010). Imagining participatory action research in collaboration with children: An introduction. *American journal of community psychology*, 46, 60–66.
- Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues*, 2(4), 34-46. <u>https://doi-org.ocadu.idm.oclc.</u> org/10.1111/j.1540-4560.1946.tb02295.x
- Lucassen, M., Samra, R., Iacovides, I., Fleming, T., Shepherd, M., Stasiak, K., & Wallace, L. (2018). How LGBT+ Young People Use the Internet in Relation to Their Mental Health and Envisage the Use of e-Therapy: Exploratory Study. JMIR serious games, 6(4), e11249. <u>https://doi. org/10.2196/11249</u>

- Manicavasagar, V., Horswood, D., Burckhardt, R., Lum, A., Hadzi-Pavlovic, D., & Parker, G. (2014). Feasibility and effectiveness of a web-based positive psychology program for youth mental health: Randomized controlled trial. *Journal of Medical Internet Research*, 16(6), e140. <u>https:// doi.org/10.2196/jmir.3176</u>
- Malla, A., Shah, J., Iyer, S., Boksa, P., Joober, R., Andersson, N., Lal, S., & Fuhrer, R. (2018). Youth Mental Health Should Be a Top Priority for Health Care in Canada. *Canadian Journal of Psychiatry. Revue Canadienne* De Psychiatrie, 63(4), 216–222. <u>https://doi.</u> org/10.1177/0706743718758968
- McKercher, K. A. (2020). Beyond Sticky Notes: Co-design for real: mindsets, methods and movements. Sydney, Australia: Beyond Sticky Notes.
- Mental Health Commission of Canada. (2022). MHFA Supporting Youth (Virtual). Mental Health Commission of Canada. <u>https://</u> <u>mentalhealthcommission.ca/training/</u> <u>mhfa/youth-virtual/</u>
- Montague, A. E., Varcin, K. J., Simmons, M. B., & Parker, A. G. (2015). Putting Technology Into Youth Mental Health Practice: Young People's Perspectives. SAGE Open, 5(2), 2158244015581019. <u>https://doi. org/10.1177/2158244015581019</u>

- Mulvale, G., Green, J., Miatello, A., Cassidy, A. E., & Martens, T. (2021). Finding harmony within dissonance: Engaging patients, family/ caregivers and service providers in research to fundamentally restructure relationships through integrative dynamics. *Health Expectations*, 24(S1), 147–160. <u>https://doi. org/10.1111/hex.13063</u>
- Mulvale, G., Moll, S., Miatello, A., Murray-Leung, L., Rogerson, K., & Sassi, R. B. (2019). Codesigning Services for Youth With Mental Health Issues: Novel Elicitation Approaches. International Journal of Qualitative Methods, 18, 1609406918816244. <u>https://doi. org/10.1177/1609406918816244</u>
- Nakarada-Kordic, I., Hayes, N., Reay, S. D., Corbet, C., & Chan, A. (2017). Co-designing for mental health: Creative methods to engage young people experiencing psychosis. *Design for Health*, 1(2), 229–244. <u>https://doi.org/10.1080/2</u> <u>4735132.2017.1386954</u>
- Orlowski, S. K., Lawn, S., Venning, A., Winsall, M., Jones, G. M., Wyld, K., Damarell, R. A., Antezana, G., Schrader, G., Smith, D., Collin, P., & Bidargaddi, N. (2015). Participatory Research as One Piece of the Puzzle: A Systematic Review of Consumer Involvement in Design of Technology-Based Youth Mental Health and Well-Being Interventions. JMIR Human Factors, 2(2), e4361. <u>https://doi.org/10.2196/ humanfactors.4361</u>

- Ozer, E. J., Abraczinskas, M., Duarte, C., Mathur, R., Ballard, P. J., Gibbs, L., Olivas, E. T., Bewa, M. J., & Afifi, R. (2020). Youth Participatory Approaches and Health Equity: Conceptualization and Integrative Review. American Journal of Community Psychology, 66(3-4), 267–278. <u>https://doi. org/10.1002/ajcp.12451</u>
- Ozer, E. J. (2017). Youth-Led Participatory Action Research: Overview and Potential for Enhancing Adolescent Development. *Child* Development Perspectives, 11(3), 173–177. <u>https://</u> doi.org/10.1111/cdep.12228
- Ozer, E., & Douglas, L. (2015). Assessing the Key Processes of Youth-Led Participatory Research: Psychometric Analysis and Application of an Observational Rating Scale. Youth & Society, 47(1), 29–50. <u>https://doi.org/10.1177/0044118X12468011</u>
- Patel, V., Flisher, A. J., Hetrick, S., & McGorry, P. (2007). Mental health of young people: A global public-health challenge. *Lancet*, 369(9569), 1302–1313. <u>https://doi.org/10.1016/S0140-6736(07)60368-7</u>
- Photovoice Worldwide. (2021). What is Photovoice? Photovoice Worldwide. <u>https://photovoiceworldwide.com/</u><u>what-is-photovoice/</u>
- Pierri, P. (2018). Participatory design practices in mental health in the UK: Rebutting the optimism. Design Issues, 34(4), 25-36.

Reason, P., & Bradbury, H. (2008). Introduction. In P. Reason & H. Bradbury (Eds.), The SAGE handbook of action research: Participative inquiry and practice (2nd ed., pp. 1-10), SAGE Publications. <u>http://dx.doi.</u> org/10.4135/9781848607934

- Rickwood, D., Wallace, A., Kennedy, V., O'Sullivan, S., Telford, N., & Leicester, S. (2019). Young People's Satisfaction With the Online Mental Health Service eheadspace: Development and Implementation of a Service Satisfaction Measure. JMIR Mental Health, 6(4), e12169. https://doi.org/10.2196/12169
- Rickwood, D. (2012). Entering the E-Spectrum: An Examination of New Interventions for Youth Mental Health. Youth Studies Australia, 31(4), 18–27.
- Rodríguez, L. F., & Brown, T. M. (2009). From voice to agency: Guiding principles for participatory action research with youth. New directions for youth development, 2009(123), 19–34. <u>https:// doi-org.ocadu.idm.oclc.org/10.1002/yd.312</u>
- Shepherd, M., Fleming, T., Lucassen, M., Stasiak, K., Lambie, I., & Merry, S. N. (2015). The design and relevance of a computerized gamified depression therapy program for indigenous māori adolescents. JMIR Serious Games, 3(1), e3804. <u>https://doi.org/10.2196/games.3804</u>
- Soep, E., & Chávez, V. (2010). Drop that knowledge: Youth Radio stories. University of California Press.

- Stubbing, J., & Gibson, K. (2021). Can We Build "Somewhere That You Want to Go"? Conducting Collaborative Mental Health Service Design with New Zealand's Young People. International Journal of Environmental Research and Public Health, 18(19), 9983. <u>https://doi.org/10.3390/ijerph18199983</u>
- Teixeira, S., Augsberger, A., Richards-Schuster, K., & Sprague Martinez, L. (2021). Participatory Research Approaches with Youth: Ethics, Engagement, and Meaningful Action. American Journal of Community Psychology, 68(1–2), 142–153. https://doi.org/10.1002/ajcp.12501
- Terp, M., Laursen, B. S., Jørgensen, R., Mainz, J., & Bjørnes, C. D. (2016). A room for design: Through participatory design young adults with schizophrenia become strong collaborators. International Journal of Mental Health Nursing, 25(6), 496–506. <u>https://doi. org/10.1111/inm.12231</u>
- Trnka, S. H. (2016). Digital Care: Agency and Temporality in Young People's Use of Health Apps. Engaging Science, Technology, and Society, 2, 248–265. <u>https://doi. org/10.17351/ests2016.119</u>
- Wallerstein, N., & Duran, B. (2017). Theoretical, historical and practice roots of CBPR. In:
  Wallerstein, N., Duran, B., Oetzel, J. G.
  & Minkler, M. (Eds.), Community based participatory research for health: Advancing social and health equity (pp. 17–30). Jossey-Bass.

- Wang, C. C. (2006). Youth Participation in Photovoice as a Strategy for Community Change. Journal of Community Practice, 14(1–2), 147–161. <u>https://doi.org/10.1300/J125v14n01\_09</u>
- Wang, C. C., & Redwood-Jones, Y. A. (2001). Photovoice Ethics: Perspectives from Flint Photovoice. Health Education & Behavior, 28(5), 560–572. <u>https://doi. org/10.1177/109019810102800504</u>
- Wilson, N., Dasho, S., Martin, A. C., Wallerstein, N., Wang, C. C., & Minkler, M. (2007). Engaging Young Adolescents in Social Action Through Photovoice: The Youth Empowerment Strategies (YES!) Project. The Journal of Early Adolescence, 27(2), 241–261. <u>https://doi. org/10.1177/0272431606294834</u>
- Winsall, M., Orlowski, S., Vogl, G., Blake, V., Nicholas, M., Antezana, G., Schrader, G., & Bidargaddi, N. (2019). Designing Online Interventions in Consideration of Young People's Concepts of Well-Being: Exploratory Qualitative Study. JMIR Human Factors, 6(1), e10106. <u>https://doi.org/10.2196/10106</u>