Ensuring Equity and Inclusion in Virtual Care Best Practices for Diverse Populations of Youth with Chronic Pain

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Abstract

Poor access to care is a top patient-oriented research priority for youth with chronic pain in Canada, and the COVID-19 pandemic has exacerbated these concerns. Our patient-oriented project team engaged with marginalized and racialized youth with chronic pain (Black youth with sickle cell disease, Indigenous youth and youth with complex medical needs) and their families to ensure that best practice recommendations for virtual care are inclusive and equitable. Input provided through virtual round-table discussions improved recommendations for leveraging, implementing and selecting best platforms for virtual care for youth with chronic pain and identified new gaps for future research, practice and policy change.

Key Points

- Partnership is key to equitable, diverse and inclusive engagement, particularly when engaging with populations or population groups that are marginalized.
- Virtual activities both facilitated and hindered equitable, diverse, inclusive and accessible engagement.
- Patient engagement offered an opportunity to critically expand on and refine learnings from the scientific literature – in this case, on a rapidly emerging widespread need for virtual care for pain during the COVID-19 pandemic.

Introduction

The COVID-19 pandemic necessitated a rapid and wide-scale pivot to virtual care across all areas of health, including for youth living with chronic pain (Bokolo 2020; D'Alessandro et al. 2020; Eccleston et al. 2020). Poor access to care is a top patient-oriented research priority for youth with chronic pain in Canada (Birnie et al. 2019), and the COVID-19 pandemic has exacerbated these concerns with the closure of clinics and therapies (Cohen et al. 2020; Eccleston et al. 2020; Killackey et al. 2021; Shanthanna et al. 2020). Early treatment of pain in youth is critical to prevent persisting pain, mental health and substance use issues into adulthood (Groenewald et al. 2019; Kashikar-Zuck et al. 2014; Murray et al. 2019; Walker et al. 2010, 2012), and the COVID-19 pandemic has only reinforced that necessity. In 2020, members of our team received a Canadian Institutes of Health Research (CIHR) rapid COVID-19 Knowledge Synthesis Grant to review existing scientific literature to identify recommendations for best practices for virtual care for youth with chronic pain and their families (Birnie et al. 2021a). The 16 scientific articles included in our scoping review highlighted a range of recommendations related to leveraging and implementing virtual care, selecting best virtual care platforms and identifying limitations and considerations for remaining research priorities for pediatric chronic pain. These articles also underscore the immense potential for harnessing virtual care to address

P = Patient partner.

this growing population. These themes were summarized in a one-page infographic available in English and in French (https://partneringforpain.com/) (Birnie et al. 2021a). This review was intended to guide healthcare professionals and decision makers in evidence-informed practice and policy.

However, in undertaking this scoping review, our team recognized the omission of diverse populations or population groups in the included studies that identified best practices for virtual care for youth with chronic pain. In general, pain services and research disproportionately exclude individuals who are marginalized, such as people who are Indigenous, Black or Persons of Colour, or people who cannot communicate verbally, among others, despite being vulnerable to a higher prevalence of chronic pain and less likely to be able to access virtual care (e.g., poorer Internet access; Craig et al. 2019; Crawford and Serhal 2020; Latimer et al. 2018). According to the International Association for the Study of Pain, populations can be considered vulnerable due to (i) physical, psychological and/or verbal impairments, (ii) social circumstances or (iii) shortcomings in healthcare and are at risk of being under-assessed and undertreated for pain (IASP n.d.). It is imperative that recommendations for virtual care include the perspectives of diverse and vulnerable pain populations that are underrepresented in existing clinical care and scientific literature. Evidence-based and emerging virtual treatments exist for pediatric pain generally (Birnie et al. 2021b), but implementation and access are sparse.

Project Objectives and Overview

The aim of our project was to engage with diverse youth with chronic pain and their families to ensure that recommendations for best practices for virtual care are inclusive and equitable. We engaged Black youth with sickle cell disease, Indigenous youth (including all of First Nations [status and non-status], Métis and Inuit) and youth with complex medical needs (including youth with brain-based developmental disabilities), their parents/caregivers and healthcare professionals in collaborative dialogue regarding recommendations for virtual care for chronic pain identified in our original scoping review (Birnie et al. 2021a). These populations were specifically selected because they are susceptible to inequities in pain care (Craig et al. 2019) and healthcare access (Kuo et al. 2014), experience stigmatization (Jenerette and Brewer 2010; Wakefield et al. 2017) and systemic barriers (i.e., systemic racism; Anastas et al. 2020; Latimer et al. 2018; Wylie et al. 2019) or may be impacted by socio-economic factors that further exacerbate existing inequities (Ambrose 2020), all of which can ultimately impact virtual care delivery. Virtual care is here to stay, and we must ensure that it meets the needs of diverse youth and their families. Creating space for patient and family voices to direct decisions regarding virtual care best practices in Canada is both timely, given the COVID-19 pandemic, and long overdue, given their integral role as partners in virtual care.

Knowledge Translation Goals and Activities

With support through an EMPOWER (Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach) award from the Ontario SPOR (Strategy for Patient-Oriented Research) SUPPORT Unit (OSSU), our team set three primary knowledge translation goals:

1. to facilitate collaborative dialogue regarding recommendations for virtual care for diverse chronic pain populations – specifically Black youth with sickle cell disease, Indigenous youth and youth with complex medical needs – and their families;

2. to engage diverse stakeholders and rights holders in contributing to recommendations for virtual care best practices in pediatric chronic pain; and

3. to share findings related to identified recommendations for virtual care with relevant stakeholder and rights holder groups and explore how these recommendations may be tailored to best address the needs of diverse chronic pain populations.

Knowledge translation goals were achieved through co-facilitation of virtual interactive round-table discussions and engagement conducted separately with each group (Black youth with sickle cell disease, Indigenous youth and youth with complex medical needs, including youth with a brain-based developmental disability) and stakeholder or Indigenous rights holder type (youth, parents/caregivers). Each session was tailored based on conversations with relevant patient partners and partner organizations, with some conducted in groups and others via individual interviews.

Patient Partner Roles

Our team used the term "patient partner" according to the CIHR definition to refer to individuals with personal experience of a health issue (i.e., chronic pain during childhood) and informal caregivers, including family and friends (CIHR 2018). Our team included nine patient partners with lived experience relevant to one of the three population groups of interest, as well as pediatric pain researchers, healthcare professionals and partner organization collaborators (Complex Care for Kids Ontario [CCKO], CHILD-BRIGHT Network – National Youth Advisory Panel [NYAP], Sickle Cell Awareness Group of Ontario [SCAGO], Network Environments for Indigenous Health Research [NEIHR] National Coordinating Centre and Solutions for Kids in Pain [SKIP]).

Patient partners were included as equal members of the research team, and partnership was sustained through regular virtual meetings and e-mail communication altogether, and separate communication was maintained for each population group of interest as well. This structure enabled continuity as well as flexibility for each population group to design and carry out engagement in ways that increased accessibility and equity for patient partners and community members. Interactive round-table discussions were co-designed for each population group in collaboration with patient partners and relevant partner organizations. Patient partners were centrally involved in facilitating all the round-table discussion sessions, including how engagement created a safe space for open dialogue and selecting questions for session evaluation. At each interactive round-table discussion, research and health professional team members were also present to provide a brief overview of the previously completed scoping review (Birnie et al. 2021a). Patient partners also contributed to synthesis and presentation of what we learned, including infographics and co-presentation of project findings.

The team's collaborative approach was reflected by a parent/caregiver patient partner:

> Among the many things I appreciated was that we – the three parents – had quite a bit of choice about how and how much we would be involved … More importantly, we were encouraged to provide suggestions about every aspect of the sessions and saw all of them taken up and applied. For instance, we recommended that there be two sessions rather than one (with the same group of participants), since that would give participants a chance to reflect over the course of a week on what they had heard and said and perhaps make it easier for the less-quick-to-speak parents to contribute more to the discussion. We also provided suggestions on the recruiting materials, the land acknowledgement, the "ice-breaker" and the questions or prompts themselves. And the "wrap-up" session was a chance not only to review the process but to add our own further thoughts.

Feedback from patient partners reflected the team's success in achieving meaningful, inclusive, accessible and collaborative partnership. As shared by a youth patient partner:

> First and foremost, I would like to thank the team for allowing me to partake in this project through co-facilitating and sharing my story along with the other youth. I was impressed by their eagerness to learn from me and each other participant about their experiences. Their genuine interest in creating a fruitful and accessible discussion for all made this process comfortable and enjoyable from start to finish. I really appreciated that accessibility was always prioritized. They thought of everything, from time zones to content format. The team was very approachable and a pleasure to work with.

Project Outcomes

Interactive round-table discussions were held via Zoom from November 2020 to January 2021. In total, 11 Black youth with sickle cell disease and seven parents/caregivers, two Indigenous youth with chronic pain and one parent/caregiver, and three youth with complex medical needs and four parents/caregivers were engaged.

Each virtual engagement session was evaluated using four questions adapted from the Patient and Public Engagement and Evaluation Tool module for one-time engagement activities (Abelson et al. 2016; Abelson and The PPEET Research-Practice Collaborative 2018). Of the 11 round-table discussion participants who completed the post-session evaluations, all agreed that they felt that their views were heard, that the goals of the sessions and questions presented were clear and that the engagement initiative was a good use of their time. All but one (91%) agreed that they were confident that the input provided through the engagement initiative would be used.

Suggestions made during the round-table discussions revealed additions or modifications to the best practices for virtual care for youth with chronic pain and their families not identified in the previous scoping review (Birnie et al. 2021a):

- *Leveraging virtual care:* (1) It may be an opportunity to increase positive healthcare experiences, reducing stigma, bias and discrimination in the healthcare system, thereby encouraging those in the 2SLGBTQ+ (Two-Spirit, Lesbian, Gay, Bisexual, Trans, Queer+) and BIPOC (Black, Indigenous and People of Colour) communities to access healthcare. (2) It will allow patients and families to access care in their own environment. (3) It will provide more opportunity for culturally inclusive practices (e.g., Indigenous youth may smudge in their own environments before an appointment).
- *Improving implementation of virtual care:* (1) Clinical environments should be arranged to support virtual care (e.g., limited distractions, private environment). (2) Appointment time and duration should be respected as much as possible by healthcare professionals, patients and families with consideration given to building trust and connection.
- *Selecting best platforms for virtual care:* (1) The virtual care platform should facilitate virtual medical education, teaching and demonstration for patients, families and caregivers (e.g., how to flush a line). (2) It should allow patients, families and caregivers to easily access and manage health information. (3) It should be able to

FIGURE 1.
Best practices for virtual care for diverse youth with chronic pain and their families (English-language version)

Virtual Care has never been more important.

We identified best practices for virtual care for youth with chronic pain from past research.

We learned that more work is needed to ensure that virtual care is equitable, inclusive, and accessible.

Next, we listened to diverse youth living with pain, their families, and healthcare professionals.

Black youth with sickle cell disease

Indigenous youth

youth with complex medical needs and brain-based developmental disabilities

parents and caregivers

healthcare professionals

Best practices for virtual care
for youth with pain and their families

Leveraging for Access and Care

- can increase healthcare access in home or community *(rural or remote areas)*
- less travel and associated costs
- under-used *(e.g. for real-time symptom assessment, psychological treatment)*
- can increase positive healthcare experiences, reducing stigma, bias, and discrimination
- opportunity for culturally inclusive practice *(e.g. in a youth's own space)*
- acceptable, reasonable and effective

Improving Implementation

- freely available *(e.g., across telephone, apps, websites, videoconference)*
- training, terms of use, and guidelines for all users
- secure, encrypted, password protected platform
- developmentally appropriate for youth's abilities
- meet ethical standards of care
- transparent communication *(e.g., real vs. automated)*
- appointment time and duration honoured by all users
- clinical environments that are private with limited distraction

Selecting Best Platforms

- backed by science, user-friendly and acceptable to all users
- provide technical support
- involve all users in development of virtual care platform
- meet accessibility standards and is customizable
- use multimedia content
- integrate peer support
- facilitate medical education for families
- access and manage health information
- coordinate care with multiple healthcare professionals in one visit

Our knowledge and momentum is building
but there is still work to be done...

- standardized guidelines for implementation and evaluation
- confirm effectiveness for concerns identified by youth
- increasing equity *(e.g., access to Internet and technology)*
- how to integrate all aspects of care *(e.g., physical exam or manual therapies)*
- strategies to build and maintain the therapeutic relationship
- strategies to enhance engagement
- integration into electronic medical record
- shared decision-making between families and healthcare professionals *(for in-person vs. virtual care)*

View our **evidence & gap map** for the full range of virtual care solutions at partneringforpain.com/portfolio/virtual-care

Want to learn more? Please contact:
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accommodate care with multiple healthcare professionals in one visit.

- *Identfying gaps in virtual care:* (1) Solutions are required to increase equity across Canada (e.g., reliable access to the Internet and technology required for virtual care). (2) Decisions for the type of care (virtual vs. in-person) should be made in collaboration with patients and families.

These findings are being integrated into a policy brief and revised infographic (see Figures 1 and 2 for the English- and French-language versions, respectively). These are shared on our project website: www.partneringforpain.com/portfolio/virtual-care. We have previously shared a poster about our project at the CHILD-BRIGHT virtual symposium, which was co-presented by patient partners. Members of our team have also been invited to engage with national decision makers and policy makers, such as Canada Health Infoway and Health Canada, working to improve virtual care.

FIGURE 2.
Best practices for virtual care for diverse youth with chronic pain and their families (French-language version)

Les soins virtuels n'ont jamais été aussi importants.

Nous avons identifié les meilleures pratiques en matière de soins virtuels pour les jeunes vivant avec la douleur chronique, en nous appuyant sur les recherches antérieures.

Nous avons compris qu'il faut poursuivre le travail pour faire en sorte que les soins virtuels soient équitables, inclusifs et accessibles.

Nous avons ensuite écouté le point de vue de divers jeunes souffrant de douleur chronique, de leur famille et de professionnels de la santé :

Jeunes noirs ayant l'anémie falciforme

Jeunes Autochtones

Jeunes ayant des besoins complexes et des troubles du développement d'origine cérébrale

Parents et aidants

Professionnels de la santé

Pratiques exemplaires en soins virtuels
pour les jeunes souffrant de douleur chronique et leur famille.

La mobilisation pour l'accès aux soins :

- accroître l'accès aux soins à domicile ou dans la communauté *(régions rurales ou éloignées)*;
- diminuer les besoins en transports et les coûts qui y sont rattachés;
- accroître l'accès aux soins sous-utilisés *(en particulier pour l'évaluation des symptômes en temps réel et le traitement psychologique)*;
- accroître les expériences de soins de santé positives, réduire la stigmatisation, les préjugés et la discrimination;
- favoriser les pratiques culturellement inclusives *(ex. dans un lieu réservé aux jeunes)*;
- donner accès à des soins acceptables, raisonnables et efficaces.

Améliorer la mise en œuvre :

- services offerts gratuitement sur toutes les plateformes technologiques *(téléphone, applications, sites Web, visioconférence);*
- formation, conditions d'utilisation et lignes directrices pour tous les utilisateurs;
- services sécuritaires *(chiffrement, protection par mots de passe)*;
- adaptés au développement des capacités des jeunes;
- conformes aux normes de soins éthiques;
- communication transparente *(communications réelles plutôt que communications automatisées)*;
- respect de l'heure et la durée des rendez-vous par tous les utilisateurs;
- environnement clinique privé avec distraction limitée.

Choix des meilleures plateformes :

- fondées sur les connaissances, conviviales et adaptées aux utilisateurs;
- offrir du soutien technique;
- impliquer tous les utilisateurs dans le développement de plateforme de soins virtuels;
- conformes aux normes d'accessibilité et adaptables;
- utilisation de contenu multimédia;
- intégrant du soutien par les pairs;
- facilitant l'éducation médicale des familles;
- accès et gestion de l'information sur la santé;
- coordination des soins avec différents professionnels de la santé en une seule visite.

Nos connaissances s'améliorent et nous sommes sur une bonne lancée...
mais il y a encore du travail à faire...

- lignes directrices uniformisées concernant la mise en œuvre et l'évaluation;
- confirmer l'efficacité pour les préoccupations soulevées par les jeunes;
- accroître l'équité *(ex. accès à Internet et aux technologies)*;
- intégration de tous les types de soins *(ex. examen physique ou thérapies manuelles)*;
- stratégies pour établir et maintenir les relations thérapeutiques;
- stratégies pour favoriser l'engagement;
- intégration aux dossiers médicaux informatisés;
- prise de décision partagée par les familles et les professionnels de la santé *(pour le choix des soins en personne ou des soins virtuels)*.

Consultez notre carte **« des données probantes et des lacunes »** pour voir l'ensemble des solutions de soins virtuels à : partneringforpain.com/portfolio/virtual-care.

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#PartenairesPourLaDouleur

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Key Messages and Implications

An important reflection from our team is that partnership is key to equitable, diverse and inclusive engagement, particularly when engaging with populations or population groups who are marginalized (Craig et al. 2019). Strong partnership is created when each person can contribute their unique expertise and see their expertise both used and respected. Specifically, our team worked closely to empower patient partners to co-design and lead facilitation of engagement sessions to ensure that participants felt safe and respected. Contributions from patient partners led to the expansion of round-table discussions to two sessions instead of one for each group and also resulted in more clearly worded questions to guide the conversation. Working with each partner organization was critical for effectively reaching out and engaging with each population group. There was a need to be flexible within the engagement process to meet the different needs of each population group and address emerging challenges, such as shifting from group to individual and family-based engagement with Indigenous youth with chronic pain and their families.

Our interactive round-table discussion sessions were conducted using Zoom. Virtual activities both facilitated and hindered equitable, diverse, inclusive and accessible engagement. For example, going virtual made it more possible to engage with people across the country, but it likely limited our ability to reach those with poorer access to the Internet and communities where in-person community-based engagement is valued (e.g., with Indigenous communities).

The round-table discussion sessions provided new insights to improve equity and accessibility of best practices for virtual care. Patient engagement offered an opportunity to critically expand on and refine learnings from the scientific literature, in this case on a rapidly emerging widespread need for virtual care for pain during the COVID-19 pandemic.

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