Rapid evidence and gap map of virtual care solutions for youth and families to mitigate the impact of the COVID-19 pandemic on pain, mental health, and substance use

CIHR Knowledge Synthesis: COVID-19 in Mental Health and Substance Use
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English and French language knowledge mobilization output available at:
www.partneringforpain.com/portfolio/virtual-care
(1-page infographic, project video, interactive Evidence and Gap Map, and policy brief)

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Rapid evidence and gap map of virtual care solutions for youth and families to mitigate the impact of the COVID-19 pandemic on pain, mental health, and substance use

The COVID-19 pandemic is challenging the mental and physical health of everyone, but particularly our youth. These impacts will be long-lasting. The extreme and prolonged stress experienced by youth today will set the stage for their mental and physical health well into adulthood. To prevent this, youth need early intervention now.

One of the most common impacts of extreme stressors and traumatic events in youth is pain. Stress can manifest in physical pain, particularly early in development. Critical to the COVID-19 pandemic are emerging reports of increased pain (headaches, stomachaches) amongst Italian and Spanish youth when surveyed about the effects of quarantine. This finding parallels increases in new onset pain amongst youth following other traumatic experiences. When surveyed 5–8 months following Hurricane Katrina, 11–25% of youth reported new onset headaches, back, joint, and/or limb pain. Left untreated, these pains will likely become chronic. This is an urgent public health threat as chronic pain (pain lasting >3 months) already affects 1 in 5 Canadian youth, costs >$19 billion USD/year, and negatively impacts families. Given extreme and prolonged stress of COVID-19, coupled with social isolation and reduced access to care, prevalence rates will rise.

Chronic pain in youth is tied to mental health and substance use into adulthood. Youth with chronic pain experience PTSD, anxiety, depression, and insomnia at much higher rates than their peers with associated substance use (opioids, marijuana). Longitudinal studies provide compelling evidence that chronic pain in childhood heightens risk for internalizing mental health disorders (PTSD, anxiety, depression), opioid misuse, and chronic pain into adulthood. The undertreatment of pain is a major contributor to the opioid crisis. Youth are a part of this opioid crisis.

Early virtual treatment of pain in youth during the COVID-19 pandemic is critical to prevent mental health issues into adulthood. Overnight, virtual care has become imperative. Research focused on youth and evidence-based virtual delivery of clinics and resources are identified mental health priorities for the COVID-19 pandemic. Without adequate pain relief and access to care, youth experience deteriorated mental health and functioning, and are at risk for substance misuse. Poor access to care and mental health were identified amongst the Top 10 patient-oriented research priorities for youth with chronic pain in Canada. COVID-19 has exacerbated these concerns with closure of clinics and therapies. Evidence-based and emerging virtual treatments (apps, online modules, telehealth clinics) exist to improve pain and mental health in youth and their parents, but implementation is sparse. Our health system must be nimble to respond virtually to levels of individual need, while at reduced capacity.

Stepped care models ensure that youth with pre-existing and new onset pain during COVID-19 and their parents receive intervention tailored to their individual needs. Using a resiliency-based approach, interventions in the 5-step model increase in time and resource intensity to support the population (step 1) up to specialist care (step 5), and can include: educational material, peer support, self-directed, group, or individual treatment. Stepped care is endorsed by the Mental Health Commission of Canada, and is well-suited for addressing the expected surge of youth mental health needs post-disaster.

Evidence and gap maps (EGMs) provide a novel knowledge synthesis approach that can accelerate uptake of virtual stepped care solutions for youth. At this critical time, knowledge syntheses must enable rapid informed decision-making by key stakeholders (patients/families, healthcare providers, policymakers) and consider both existing evidence and newly developed interventions in response to COVID-19. EGMs are ideal as they provide an interactive visual overview of the breadth, availability, and quality of evidence, and have been created by our team. The EGM visual summary provides an accessible and usable synthesis of knowledge strengths and gaps to inform practice, policy, research, or investment. Systematically mapping evidence for virtual care solutions for pain, mental health, and substance use in youth with pre-existing and new onset pain across the stepped care model will enable
Objectives

(1) To identify recommendations for virtual care best practices for pain, mental health, substance use, and functioning for youth <18 years old with pre-existing and new onset pain, and their families (Phase 1 – reported herein).

(2) To identify virtual care solutions to improve pain, mental health, substance use, and functioning for youth <18 years old with pre-existing and new onset pain, and their families (Phase 2 – reported herein).

(3) To create an evidence and gap map to guide multi-sectoral stakeholders regarding virtual stepped care solutions to improve pain, mental health, substance use, and functioning for youth <18 years old with pre-existing and new onset pain, and their families during the COVID-19 pandemic and beyond (Phase 2 – reported herein).

Methods and Results

This mixed-methods knowledge synthesis uses a phased approach to ensure findings are disseminated rapidly. Frameworks for rigorous conduct of rapid systematic, scoping reviews, and EGMs are followed, including: (1) identify research question; (2) identify relevant sources (e.g., eligibility and search); (3) screening and selection; (4) data extraction (e.g., outcomes, quality rating); (5) synthesis; and (6) consultation with stakeholders. The PRISMA Checklist guides quality reporting at each phase.

Phase 1 Methods

This rapid systematic review protocol is registered in PROSPERO: CRD42020184498.

1.1 Eligibility Criteria, Search Strategy, and Conduct

English language peer-reviewed scientific articles published in the last 10 years were identified for inclusion if they: (1) discussed children and adolescents aged <18 years reporting any type of chronic pain (i.e., pain lasting >3 months); (2) focused on any type of virtual care (e.g., telephone, telehealth, telemedicine, mhealth, ehealth, online, digital); and (3) reported on guidelines, best practices, considerations, and/or recommendations for virtual care. All article types were considered eligible (e.g., systematic reviews/meta-analyses, clinical practice guidelines, editorials, commentaries, qualitative studies); however, primary studies with the identified purpose of evaluating the effectiveness of virtual care were excluded (e.g., randomized controlled trials, nonrandomized treatment studies) as they are included in a subsequent scoping review mapping all virtual care solutions for pediatric chronic pain. The search strategy was developed in collaboration with a health information specialist team member. Database searches were conducted in Medline, CINAHL, Embase, PsycINFO, and Web of Science the week of May 25th, 2020.

1.2 Screening and Selection

Three research assistants or clinical research coordinators screened all abstracts and subsequent full-text studies for eligibility, in duplicate using Covidence. Disagreements were resolved by consultation with two of the project team members as needed.

1.3 Data Extraction and Synthesis

Data extraction was done independently by two team members with disagreements resolved through consensus. Extracted data included: author; publication year; article type; and type(s) of virtual care; key concepts, recommendations, or guidelines identified for virtual care and their relevance to level(s) of stepped care (steps 1-5). Stepped care levels were coded as:

- **Level 1:** self-guided (whole population online self-help [e.g., apps, educational websites])
- **Level 2:** peer-to-peer support (low needs [e.g., online real-time peer support])
- **Level 3:** minimal health professional involvement moderate needs (moderate needs [e.g.,

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real-time psychoeducational workshop, expert-assisted e-supports via app or website])

- **Level 4**: ongoing real-time health professional interaction (high needs [e.g., ongoing/intensive real-time individual or group programming])

- **Level 5**: real-time specialist health professional(s) interaction (complex needs [e.g., specialist consultation and care, tertiary clinic])

Our original review protocol indicated that identified studies would be coded for quality as assessed using AGREE II for guidelines\(^{47,48}\), however, this was not done as no specific guidelines were identified and the AGREE II tool was not deemed appropriate. Team members used meta-ethnographic techniques to synthesize concepts, recommendations, and guidelines that commonly occurred across articles\(^{49,50}\).

**Phase 1 Results**

**1.1 Study Selection**

Database searches identified 6334 records. Three additional articles known to the study authors published since the start of the COVID-19 pandemic were also included. After duplicates were removed, 4161 unique abstracts remained for review. Of these, 4101 were deemed not eligible. A total of 60 full texts were reviewed and 44 were excluded. Sixteen full texts met inclusion criteria. See Figure 1 for the PRISMA review flowchart, including reasons for full-text exclusion.

**1.2 Study Characteristics**

Of the 16 articles meeting review inclusion criteria, 10 were scoping or systematic reviews/meta-analyses\(^{31,51–59}\), 3 were commentaries/editorials/opinion articles\(^{55,60,61}\), 2 were qualitative studies\(^{62,63}\), and one was a non-systematic literature review\(^{64}\). Articles addressed virtual care for a variety of chronic pain conditions of mixed etiology, including headaches, migraines, musculoskeletal pain, recurrent abdominal pain, chronic widespread pain/fibromyalgia, arthritis, post-concussion, sickle cell disease, and irritable bowel syndrome. Most articles addressed lower levels of the stepped care continuum. Types of virtual care discussed included apps, telephone support, virtual peer-to-peer, and web-based self-management with or without coach support.

**1.3 Synthesis of Results**

Meta-ethnography across the 16 articles identified four key themes, including opportunities to better leverage virtual care (theme 1), direct effective implementation of virtual care (theme 2), selection of virtual care platforms (theme 3), and gaps in need of further consideration when using virtual care (theme 4) to support youth with chronic pain and their families. Key points related to each theme are synthesized in a 1-page infographic [available for download: www.partneringforpain.com/portfolio/virtual-care].

1.3.a Leveraging virtual care. Virtual care for youth with chronic pain and their families: is acceptable, reasonable, and effective; is underutilized (especially for real-time symptom assessment and psychological treatment); and increases access to care (particularly in rural or remote areas).

1.3.b Implementing virtual care. Virtual care for youth with chronic pain and their families: should be freely available across all technologies (telephone, apps, websites, videoconference); needs to include training, terms of use, and guidelines for health professionals, youth and families; must use secure infrastructure (encrypted, password protected, authorized access); should be developmentally appropriate; must meet ethical standards of care; and should be transparent in communication (therapist vs. computer-generated messaging).

1.3.c Best platforms for virtual care. Virtual care platforms for youth with chronic pain and their families: need to be user-friendly and acceptable to youth and families; must be backed by science; should involve youth, families, and health professionals in their development; should be individualized or customizable; must be comprehensive in terms of pain management (address pharmacological,
psychological, and physical strategies); need to use multimedia content (videos, text, images); must meet accessibility standards; and should be able to integrate social and peer support.

1.3.d Identified gaps in virtual care. Virtual care for youth with chronic pain and their families: requires standardized practice guidelines for implementation and evaluation; must have evidence showing its effectiveness for all symptoms or concerns identified by youth and families; needs to include knowledge about its limitations and suitability for all aspects of care (such as physical exam); need to consider potential harms and impact on the therapeutic relationship; requires strategies to enhance engagement; and needs integration into clinical care pathways, face-to-face care, and the electronic medical record.

A thorough list of research priorities for virtual care for individuals with chronic pain during the COVID-19 pandemic are additionally outlined in one of the included articles\textsuperscript{25}.

**Phase 2 Methods**

A scoping review\textsuperscript{40,41,45} was conducted using three sources of information synthesized in the evidence and gap map (EGM)\textsuperscript{35,36}.

**2.1 Record Selection**

2.1.a Scientific and grey literature searches. The inclusion criteria from the Phase 1 scientific literature search were used, but restrictions related to article type (inclusion criteria #5) was changed to include only primary studies of any type evaluating virtual care interventions (randomized controlled trials [RCTs], nonrandomized trials, observational studies, mixed methods studies, qualitative studies, case reports, dissertations, and conference abstracts). A revised search strategy was developed in collaboration with a health information specialist team member. Database searches were conducted in Medline, CINAHL, Embase, PsycINFO, and Web of Science between June 9-18\textsuperscript{th}, 2020. Two project team members screened all abstracts and subsequent full-text studies for eligibility, in duplicate using EPPI-Reviewer\textsuperscript{70}. Disagreements were resolved by consultation with another project team members, as needed.

2.1.b Scientific and grey literature searches. The additional grey literature search occurred over 2-weeks in September-October 2020 of the app stores and the Google Search Engine. Posts were also made to the following professional listservs to further identify any relevant apps or websites (Society of Pediatric Psychology, Pediatric Pain, Pain in Child Health).

Apps were sourced through the two major smartphone operating systems: iOS (iTunes App Store) and Android (Google Play Store). The iTunes App Store was searched by a clinical research coordinator for any app with the keyword “pain” in the title under the categories of “Health & Fitness”, “Lifestyle”, and “Medical”. The Google Play Store was searched with the keyword “pain” in the search tool function with no imposed restrictions related to store subcategories. Apps were included if they primarily addressed chronic pain, if the primary goal of the app was to provide education, tools, or advice related to managing pain and/or mental health and/or substance use, and if youth/adolescent were intended users. This latter inclusion criteria was determined by screening the app titles and descriptions for words such as “child”, “pediatric”, “kid”, “teen”, “youth”, “young” and “adolescent”, screening whether the app publisher was a pediatric focused organization, look at any specified ages for the apps intended user, and screening for the general presentation of the app (e.g., app presentation depicting age-neutral images). E-books were excluded; defined as an app that did not provide any additional content or functionality beyond a textbook. All identified apps in the searches were included for subsequent screening by a clinical research coordinator with consultation provided by a project team member, as needed.

Relevant websites were searched by a clinical research coordinator using the Advanced Google Search engine with search term combinations drawn from the scientific literature search strategy. The first 10
pages of each search query was screened for relevance. A snowball-sampling method was also implemented such that any new sites found while searching relevant sites were followed up for possible eligibility and inclusion. Websites were included if they were published by a pediatric-oriented organization, the website dealt with chronic pain, the primary intended user was youth, adolescent or child, and the website provide information, resources and tools for self-help/management of chronic pain. Additionally, the website needed to be last updated in the last 3 years. Websites were excluded if they provided an article only introducing the concept of chronic pain or listing available in-person services. Only eligible websites were recorded with consultation from a project team member, as needed.

2.1. Call for emerging innovations. The above searches may miss virtual care practices that have rapidly emerged in response to the COVID-19 pandemic and/or are currently under empirical study. We conducted a call for demonstrated and emerging virtual care innovations that support mental health, substance use, and functioning in youth reporting pain in partnership with the Canadian Foundation for Healthcare Improvement (CFHI) and Solutions for Kids in Pain (SKIP) using methodology from CFHI. The call for virtual care innovations was launched in partnership with SKIP and CFHI in early August 2020 and will remain open until September 30, 2020. More details available here: https://www.kidsinpain.ca/call-for-innovations.

Eligible applications could come from healthcare organizations (public or private), the community, government, or social service sectors. Eligible applications had to be based in Canada and/or have a current Canadian site as stipulated by CFHI’s focus on the Canadian health system. Applicants completed an online written application. This included a description of the virtual care innovation, its application to date with youth reporting pain and their families, its focus on addressing mental health, substance use, and/or functioning, any completed or ongoing evaluation, involvement of youth/families in its development or design, and needed tools, personnel, technology, and estimated cost for implementation. The call was distributed via email to pediatric chronic pain programs in North America, listservs (Society of Pediatric Psychology, Pediatric Pain, Pain in Child Health), patient organizations (PainBC), and partners (Solutions for Kids in Pain [SKIP], CFHI).

All applications were reviewed by an independent Merit Review Panel developed by SKIP and CFHI. The Merit Review Panel was comprised of 16 individuals, including youth with lived experience with chronic pain, parents/caregivers, clinical and policy experts in prevention and/or management of pediatric chronic pain or virtual care, and experts in quality improvement or health service implementation. All applications were adjudicated based on four criteria related to: (1) innovation and partnership with children/youth, families, care partners, and others; (2) evaluation and impact; (3) potential for successful spread; and (4) potential for long term success/sustainability of the innovation.

2.2 Data Collection and Quality Ratings

2.2.a Patient and Parent Project Advisory Group. A group of 5 youth with lived experience with mixed etiology chronic pain and 3 parent/caregiver advisors from across Canada was convened for two 1-hour advisory group meetings in August 2020 to identify and prioritize components of virtual solutions to be coded and identified on the EGM. Advisory group members were identified through an open public call for advisors posted on social media and shared via partner organizations (e.g., SKIP) as well as the team’s own networks. All advisors were compensated for their time ($30/hour). This advisory group sessions were co-designed and co-led by project youth and parent partners, along with a project team member. A written summary was provided from session 1 and the start of session 2 to confirm the research teams understanding of the advisory groups’ ideas and priorities.

2.2.b Data Coding and Quality Ratings. Three team members independently coded all records for the following information: data source (scientific literature, grey literature, or call for innovations); type of
study; level of scientific evidence (critically low, low, moderate, high); technology platform; relevance to level of stepped care (steps 1-5)\textsuperscript{33}; components of virtual care solution identified by the Project Advisory Group and for pediatric chronic pain treatment studies\textsuperscript{65}, including symptom tracking, medications, psychological strategies, physical and lifestyle strategies, social/family components, health professional communication, school resources, emergency/crisis strategies, user experience, integration with the health record, intended user, type of pain or diagnosis; user age (children, adolescents); and language. All records were independently assessed for quality using the Mixed Methods Appraisal Tool (MMAT-v2018) appropriate across study types\textsuperscript{66,67}. Apps, websites, and emerging innovations with no evaluation were given the lowest quality rating.

**Phase 2 Results**

### 2.1 Record Selection

See Figure 2 for the PRISMA review flowchart, including reasons for full-text exclusion.

#### 2.1.a Scientific literature search

The scientific database searches identified 6305 records. After duplicates were removed, 4031 unique abstracts remained for review. Of these, 3715 were deemed not eligible. Of the remaining 316 records reviewed in full-text, 211 were excluded.

#### 2.1.c Grey literature search

The app stores searches identified 305 records that were all reviewed in full. Of these, 249 were excluded. Sixteen eligible websites were identified and included.

#### 2.1.c Call for emerging innovations

The call identified 8 eligible demonstrated and/or emerging innovations in virtual care to support youth living with chronic pain across Canada. All are integrated into the EGM.

### 2.2 Evidence and Gap Map (EGM)

The completed interactive EGM is available at [www.partneringforpain.com/portfolio/virtual-care](http://www.partneringforpain.com/portfolio/virtual-care). In total 185 records are included in the EGM, including 105 scientific records, 56 apps, 16 websites, and 8 innovations. A brief video introducing the EGM is also available on the website in English and a subtitled French language version.

Data from the scoping review were visually synthesized in an EGM using EPPI-Mapper\textsuperscript{70} with accompanying narrative. Rows of the EGM list 5 levels of the stepped care model and columns components of treatment, and other relevant data coding. Each cell shows the number and quality of evidence for virtual care solutions on that combination of stepped care level and intervention component. The EGM identifies areas with high quality evidence-based virtual care solutions (for immediate scale and spread) and areas where few or no solutions exist (for targeted virtual care development and research/policy prioritization)\textsuperscript{35–38}.

#### 2.2.a Where there is evidence

A number of key points are identified with existing evidence. Most virtual care solutions were applicable to youth across childhood and adolescence with any chronic pain condition (chronic primary pain, headache/migraine, abdominal pain, rheumatological conditions, sickle cell disease). There are over 100 self-guided apps and websites accessible and relevant to all youth with existing or new onset pain and their families that offer symptom tracking and pharmacological, psychological, and/or physical and lifestyle pain management strategies (level 1 of stepped care). Apps report the most customizability of available virtual care solutions for individual users. Psychological strategies are numerous (mostly levels 1 and 3 of stepped care). Their focus is primarily on pain education, relaxation, and behavioural pain management strategies (e.g., goal setting, gradual return to activity).

The highest quality of evidence is available for internet-delivered psychological interventions for youth and their parents with minimal health professional involvement (level 3 of stepped care).
2.2. Where there are evidence gaps. A number of key areas lacking evidence are easily identified. Most self-guided apps and websites lack rigorous scientific evidence (considered critically low or low quality of evidence). Virtual care solutions are lacking at higher levels of stepped care, with little ongoing individual or group therapies led by a health professional, or specialist/tertiary care (levels 4 and 5). Virtual care solutions are rarely integrated into an electronic medical record or rarely have the ability to communicate or share information with health professionals. Only a moderate number of virtual care solutions engage parents, with very little peer support or content offered to siblings of youth with pain. There is a general dearth of solutions addressing areas identified as important to youth and families, including medication side effects and tracking, sleep, diet, substance use, school resources, information for teachers, and dealing with acute pain flares or crises (e.g., suicidality). Less than 5% of virtual care solutions addressed issues of web content accessibility.

Overall Conclusions

The rapid availability of best evidence to inform virtual care to support youth with existing and new onset pain, mental health, and substance use is critical. Phase 1 of this project identifies best practices for implementation of virtual care for this population, as well as key areas in needed of further new knowledge generation. Phase 2 of this project offers a novel knowledge synthesis tool (an interactive Evidence and Gap Map), mapping all of the virtual care solutions currently available to support youth living with chronic pain and their families across a stepped care continuum. The information is available in a useable format to enable efficient and effective use by multi-stakeholder audiences. This work is timely in its approach to integrate stepped care models for virtual pain and mental health care, as recommended by the Mental Health Commission of Canada and the newest report from the Government of Canada’s Canadian Pain Task Force.

There is an opportunity for researchers, health funders, health systems decision-makers and policymakers to rapidly: (1) identify areas with high quality evidence-based virtual care solutions for immediate scale and spread across communities, primary care, and the health system; (2) identify areas where few or no solutions exist for targeted virtual care development and research/policy prioritization; (3) partner directly with youth and their families to ensure that best practices for virtual care selection and implementation are integrated into policy at local, provincial, and national levels; and (4) act quickly to enable prevention, early intervention, and treatment of pain in youth and their families during this phase of the COVID-19 pandemic and beyond.

All existing and knowledge mobilization outputs from this project will continue to be posted at www.partneringforpain.com/portfolio/virtual-care. Scientific publications from these two knowledge syntheses are forthcoming, with additional knowledge mobilization efforts addressing all knowledge user audiences, including patients and families, health professionals, administrators/decision-makers, and policy makers. Through these efforts, our team will continue to provide more in-depth discussion and implications of these findings. Additional funded work already underway by our team includes community-based collaborative dialogues with racialized and vulnerable pediatric chronic pain populations regarding best practices for virtual care (i.e., Indigenous youth, Black youth with sickle cell disease, children with complex medical needs, and their families), and integration of identified virtual care solutions in the EGM as part of a Kids Pain Portal being developed within the Government of Canada-funded Wellness Together Canada stepped care mental health platform.
Figure 1. Phase 1 – PRISMA Flow Diagram

Records identified through database searching (n = 6334) → Additional records identified through other sources (n = 3) → Records after duplicates removed (n = 4161) → Records screened (n = 4161) → Records excluded (n = 4101) → Full-text articles assessed for eligibility (n = 60) → Full-text articles excluded, with reasons (n = 44)
- Not chronic pain (n=14)
- Not virtual care (n=10)
- Primarily focused on adults (n=9)
- Primarily evaluating an intervention (n=4)
- Other (n=7) (e.g., review protocol or abstract)

Studies included in qualitative synthesis (n = 16)
Figure 1. Phase 2 – PRISMA Flow Diagram

- Records identified through scientific database searching (n = 6305)
- Apps identified through grey literature search (App stores) (n = 305)
- Websites identified through grey literature search (websites) (n = 16)
- Innovations identified through CFHI/SKIP (n = 8)

Records after duplicates removed (n = 4031)

Records screened (n = 4031)

Records excluded (n = 3715)

Full-text articles, apps, websites, and innovations assessed for eligibility (n = 645)

Records included in qualitative synthesis (n = 185)

Records included in the Evidence and Gap Map (n = 185)

105 scientific records + 56 apps + 16 websites + 8 innovations

Full-text excluded, with reasons (n = 460)

- Scientific records (n = 211)
  - 87 = adult focused
  - 80 = not virtual care
  - 29 = not primary study
  - 15 = not chronic pain

- Apps (n = 249)
  - 211 = not chronic pain
  - 38 = adult focused
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