



**Harnessing Digital Technologies  
to Improve Pain Care in Children**  
SKIP AMA Highlights

Led by  
**Dr. Chitra Laloo and Dr. Jennifer Stinson**

July 20 - 24, 2020





# Highlights



**Dr. Jen Stinson**

**RN-EC, PhD, CPNP**

## **Solutions for Kids in Pain has put together a list of resources to help patients & families stay healthy while at home**

Many people's daily routines and wellness practices have been disrupted as a result of COVID-19. Resources of wellness are no longer as readily available given the cancellation of appointments, closures of clinics and fitness centres, and reduction in daily activity overall. More people are now turning to apps, websites and other digital resources to manage their pain while at home. With little direction as to which resources are evidence-based or useful, it can be challenging for patients and families to know where to look as well as the validity of those sources. The SickKids Pain Centre and SKIP recognize this need and developed a list of [Pain Management Apps and Online Resources](#) to help guide patients and families manage pain while at home. It includes useful health education websites, tools, apps, guidelines and support systems in the areas of:

- Symptom tracking
- Pain management
- Mindfulness
- Distraction
- Stress
- Mental health
- Health education



Report

# Highlights



**Dr. Chitra Laloo**

**BHSc, PhD**

## **iCanCope with Pain: A web and mobile pain self-management platform for adolescents and young adults with chronic pain**

### **Chronic pain in young people**

Chronic pain is common in young people aged 12-25 years. This pain can negatively impact all aspects of life. However, the developmental periods of adolescence and emerging adulthood also represent a critical window of opportunity to optimize and solidify positive health behaviours related to pain self-management. Empowering young people with self-management skills early in their disease trajectory can prevent future pain-related disability and impaired work productivity and improve quality of life.

### **Leveraging user-centred design to create *iCanCope***

*iCanCope* is a comprehensive pain self-management platform designed to empower young people and help them manage and live better with their painful condition. *iCanCope* was developed with extensive input from young people and healthcare providers. Interviews, focus groups, and design sessions were completed to better understand the self-management needs of this group and identify key requirements and design principles. Key features of the *iCanCope* platform are summarized in **Figure 1**. The platform aims to help youth feel empowered and independent in their pain management through improved knowledge, self-efficacy and coping skills.

*Post continued on next page*

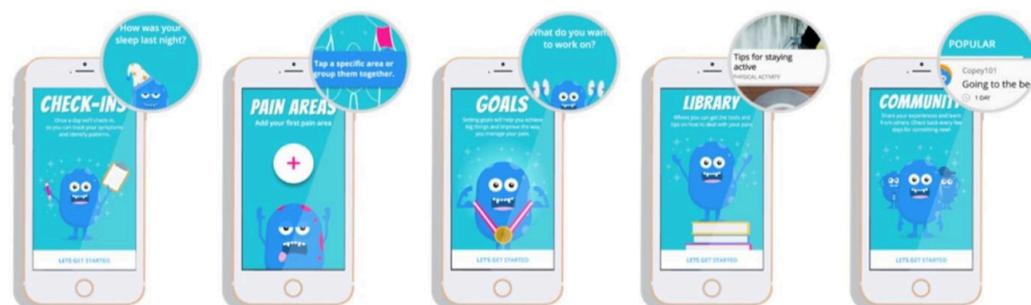


Figure 1. The *iCanCope* app (iOS/Android) empowers users to track their symptoms, set functional goals to improve daily function, learn evidence-based pain management strategies, and safely interact with peers living with a similar painful condition. Condition-specific versions of *iCanCope* are currently being evaluated through ongoing randomized controlled trials.

Follow Copey on Instagram @icancopepain!



# Highlights



## Dr. Chitra Laloo

BHSc, PhD

### Current platform status (Summer 2020)

The English-language *iCanCope* application has been developed and deployed on iOS and Android for Chronic Pain, Juvenile Idiopathic Arthritis, and Sickle Cell Disease at multiple sites across Canada (Ontario, Nova Scotia, Alberta, Saskatchewan, British Columbia) and the United States (Georgia, Connecticut, Washington). A Norwegian-language cultural adaptation (iOS, Android) for Chronic Pain has also been deployed in Norway. Versions for youth with Post-Operative Pain and young adults with Neurofibromatosis are currently under development. All versions of *iCanCope* are being rigorously evaluated through ongoing randomized controlled trials (RCTs) in order to determine feasibility and impact on health outcomes. Upon trial completion, *iCanCope* will be publicly released.

### Key findings to date

- Pilot RCT in adolescents with chronic arthritis pain demonstrated preliminary effectiveness in reducing pain intensity, surpassing minimally important clinical difference threshold (>1 point on 0-10 NRS). See: <https://tinyurl.com/icancopeJIAtrial>
- Pilot RCT in adolescents with chronic pain found that most users exhibited moderate-to-high adherence to daily symptom tracking over 2 months. See: <https://tinyurl.com/icancopeEMA>
- Successful integration of Apple ResearchKit to support remote paediatric eConsent. See protocol: <https://tinyurl.com/icancopeResearchkit>



# Highlights



**Dr. Jen Stinson**  
**RN-EC, PhD, CPNP**

## The need for virtual chronic pain care and lessons learned from a successful pivot at SickKids

During the COVID-19 pandemic, and similar to other natural disasters, youth are reporting new onset pains (e.g., headaches, back, joint, and/or limb pain). Without treatment, these pains will become chronic (pain lasting >3 months), a problem already affecting **1 in 5 Canadian youth** that is associated with devastating impacts on youth and families. Pain is one of the first warning signs of a cascade of mental health issues (e.g., depression, anxiety, post-traumatic stress disorder) that can persist into adulthood and far exceed rates of peers without pain.

Early interventions can reduce chronic pain progression, severity, disability, mental health issues and healthcare costs, yet many youth do not receive this care.

The **optimal treatment model** for pediatric chronic pain is an interdisciplinary **“3-Ps” approach** (pharmacological, physical, psychological). The most severely affected youth are seen in tertiary care clinics, while the majority are managed by community providers, or go unmanaged.

Youth with chronic pain and their families are facing many additional challenges during the COVID-19 pandemic. Most ambulatory chronic pain clinics halted care or pivoted to telehealth at reduced capacity. Many community-based therapists (e.g. psychologists) who are critical for effective 3P care stopped providing care, and school closures have halted critical counselling services. These changes can delay assessment and treatment, and dramatically disrupt the daily routines critical for chronic pain self-management.

The [Chronic Pain Program](#) at the Hospital for Sick Children (SickKids) in Toronto is the largest pediatric pain program in Canada. It is staffed by a multidisciplinary team comprised of an anesthesiologist, advanced practice nurse, psychologist, physiotherapist, psychiatrist, occupational therapist, rehabilitation therapy assistant, patient care information coordinator, and data analyst.

*Post continued on next page*



# Highlights



## Dr. Jen Stinson

**RN-EC, PhD, CPNP**

In 2019, SickKids developed a *Virtual Care Steering Committee* with a mandate to provide guidance and oversight in advancing the implementation and scaling of virtual care across the hospital. The COVID-19 pandemic accelerated the need to move ambulatory in-person visits with the pediatric chronic pain clinic to a virtual care model.

When the first Ontario cases of COVID-19 were identified in January 2020, a *Patient and Family High Risk Screening Alert* was issued. This alert was the impetus for the Chronic Pain Clinic's Advanced Practice Nurse to be appointed as the *COVID-19 Team Champion*. **Within 24 hours** of the hospital decision to cancel all non-urgent in-patient and ambulatory visits, the *Pain Team Champion* led the creation of a plan to transition nearly all new and follow-up appointments and individual treatment sessions (psychology, physical therapy, occupational therapy, psychiatry and medication check-ins) from in-person to virtual care. **This plan was implemented, evaluated, and modified over the course of two weeks.**

Rapid transition to virtual care:

- Weekly in-person case rounds shifted to virtual meetings using Zoom™ software.
- Leveraged GuestLink™ software (Ontario Telemedicine Network), which allows the patient and healthcare team to connect from anywhere, including their homes.
  - GuestLink™ was chosen over Zoom for Healthcare™ because of prior team experience and because it was designed to meet requirements of the Personal Health Information Protection Act (PHIPA), S.O. 2004, and Regulation 329/04
  - Each appointment is assigned an encrypted, password-protected video conference link. The host can lock the videoconference once it has started to prevent unwanted individuals from joining the session
- Emails sent to patients to outline new processes and to provide education around privacy and confidentiality.

*Post continued on next page*



# Highlights



## Dr. Jen Stinson

**RN-EC, PhD, CPNP**

Key enablers to rapid transition to virtual care:

- Early appointment of a clinician from the Chronic Pain Team as COVID-19 Team Champion
- Robust and dedicated 24/7 IT support
- Institutional mandate to deliver virtual care
- Leveraging Ontario Telemedicine Network (OTN) and existing educational materials around security and privacy (see: <https://support.otn.ca/en/members/privacy-toolkit>)
- Team commitment to principles of innovation and flexibility and cohesive working style
- Constant emphasis on goal to empower children and families to engage in self-management strategies

Details of the SickKids pivot to virtual chronic pain care are provided in this [open access Case Report](#) from the Canadian Journal of Pain by D'Alessandro and colleagues.



# Highlights



**Dr. Chitra Laloo**

**BHSc, PhD**

## Teens taking charge: A web-based self-management program for adolescents with juvenile arthritis pain

Juvenile idiopathic arthritis (JIA) is a serious and potentially debilitating pediatric illness that affects about 1 in 1000 children. Pain is one of the most common and distressing symptoms of JIA. Improved disease self-management early in the disease trajectory may help to improve health outcomes, including pain.

[\*Teens Taking Charge\*](#) is a web-based self-management program for 12-18 year olds with JIA that was created through a phased approach:

- **Phase 1:** Needs assessment found that adolescents articulated a universal need for more JIA-specific knowledge, self-management strategies, and meaningful social support.
- **Phase 2:** Prototype website developed and underwent iterative cycles of usability testing to ensure ease of use and understanding of the program.
- **Phase 3:** Pilot feasibility randomized controlled trial (RCT) completed with 46 adolescents with JIA and their caregivers and found high acceptability, user satisfaction, and compliance.

Our lab recently completed a full-scale RCT to evaluate the effectiveness of *Teens Taking Charge* in reducing symptoms and improving health-related quality of life (HRQL) in adolescents with JIA compared with a web-based education control condition.

*Post continued on next page*



# Highlights



## Dr. Chitra Laloo

BHSc, PhD

### Outcomes of Full Scale RCT

- N=333 adolescents and N=306 caregivers enrolled from 11 Canadian pediatric rheumatology centers.
- Intervention group completed website modules addressing cognitive behavioral coping skills, stress management, and other self-management topics, while also receiving monthly telephone calls from a trained health coach.
- Education control group reviewed public JIA educational websites and received monthly calls from a coach to discuss their own best efforts at managing JIA
- Outcome assessment occurred at baseline, 12 weeks (post-treatment), and at 6- and 12- months post-randomization.
- Significant overall reductions in pain intensity ( $P=.02$ ) and pain interference ( $P=.007$ ) were observed for intervention participants compared with control, after adjusting for baseline levels.
- Significant overall improvement in HRQL related to problems with pain ( $P=.02$ ) and problems with daily activities ( $P=.01$ ). There was also a significant difference in the intervention group over time ( $P=.008$ ) for HRQL related to treatment problems, with the intervention group participants demonstrating improved HRQL by 12 months compared with education control group participants.

The results of this RCT suggest that the *Teens Taking Charge* intervention is effective at reducing both pain intensity and pain interference, as well as improving HRQL in adolescents with JIA, compared with education control. These effects are sustained for up to 12 months following program completion.



# Highlights



**Dr. Jen Stinson**

**RN-EC, PhD, CPNP**

## Digital Health Interventions to support procedural pain management

### Background

Distraction is a commonly used psychological intervention to support procedural pain management in children and adolescents. A Cochrane review identified evidence (very low- to low quality) supporting the efficacy of distraction in reducing children's needle-related pain or distress, or both (see: [Birnie et al, 2018](#)). More recently, a meta-analysis of digital technology distraction (e.g. virtual reality; VR) for pediatric acute pain found evidence of modest pain and distress reduction for procedural pain (see [Gates et al, 2020](#)).

### Virtual reality research in the iOUCH Pain Lab

Subcutaneous port accesses with needles are amongst the most painful and distressing treatment-related experiences for youth with cancer. VR has potential to offer immersive distraction to youth with cancer undergoing these procedures. In partnership with *KindVR*, our lab developed an underwater-themed VR program for this group.

Usability study was completed to assess program acceptability and safety in the pediatric oncology setting. Two iterative cycles of usability testing with n=11 youth with cancer (11±2.95 years; 27% female) were completed. Youth used the intervention during port access while thinking aloud and answering questions about acceptability under observation by the research team and their clinician.

The VR program was reported as highly acceptable and easy to use. No safety issues were identified. Software refinements were made after cycle 1 to add more distracting elements (e.g. games, music) and optional notifications about the status of the port access. No further design changes were needed after cycle 2.

Next steps: we will examine effectiveness of the VR intervention in reducing pain and distress during port access through a larger clinical trial.

*Post continued on next page*



# Highlights



**Dr. Jen Stinson**

**RN-EC, PhD, CPNP**

## **MEDiPORT Robot**

The interactive MEDiPORT robot was programmed to deliver psychological strategies to decrease pain and distress during port access in the pediatric oncology setting. A pilot feasibility RCT was completed in 4-9 year olds with cancer. Participants were randomized to the MEDiPORT cognitive-behavioural arm or active distraction (robot singing and dancing).

A total of 40 children were randomized. Most (85%) eligible children participated and none withdrew. Technical difficulties were more common in the cognitive-behavioral arm. Completion times for the study and needle insertion were acceptable and >96% of outcome measure items were completed. Overall, MEDiPORT and the study were acceptable to participants. There was no difference in reported pain between study arms, however distress during the procedure was less pronounced in the active distraction arm.

The MEDiPORT study appears feasible to implement as an adequately-powered effectiveness trial following modifications to the intervention and study protocol.

Learn more about MEDiPORT [here](#).



# Highlights



**Dr. Chitra Laloo**

**BHSc, PhD**

## Paediatric Project ECHO

### **What is *Paediatric Project ECHO: Managing Pain for Youth and Children?***

- A free online medical education and mentorship program for healthcare professionals with an interest in paediatric pain
- Funded by the Ontario Ministry of Health and based at The Hospital for Sick Children
- Designed to expand knowledge and build capacity using a combination of highly interactive videoconferencing, educational presentations, and hands-on workshops to build a supportive virtual community of practice.
- Offers community-based healthcare professionals with access to specialty training, mentorship, and support to deliver best-practice pain care to their patients.
- Quick program overview: [https://youtu.be/z\\_N1Qu1FUAs](https://youtu.be/z_N1Qu1FUAs)

### **Why join *Paediatric Project ECHO?***

- Convenient online environment to share and discuss best practices for managing paediatric acute and chronic pain with interprofessional colleagues across Ontario
- Online eLearning modules on paediatric pain are launching in Fall 2020. These modules have been carefully crafted by our specialist teams and are a supplementary tool to the ECHO sessions. They use interactive case-based learning to teach healthcare providers about paediatric:
  - Headaches
  - Chronic widespread pain
  - Abdominal pain, and
  - Procedural Pain

*Post continued on next page*



# Highlights



## Dr. Chitra Laloo

**BHSc, PhD**

### Why join *Paediatric Project ECHO*?

- Convenient online environment to share and discuss best practices for managing paediatric acute and chronic pain with interprofessional colleagues across Ontario
- Online eLearning modules on paediatric pain are launching in Fall 2020. These modules have been carefully crafted by our specialist teams and are a supplementary tool to the ECHO sessions. They use interactive case-based learning to teach healthcare providers about paediatric:
  - Headaches
  - Chronic widespread pain
  - Abdominal pain, and
  - Procedural Pain

### How is *Paediatric Project ECHO* being evaluated?

- Mixed methods research study is underway to evaluate program feasibility (participation levels, acceptability) and impacts (provider knowledge, self-efficacy, practice change).

### How can I learn more and get involved?

- Program info: <https://sickkids.echoontario.ca>
- Free registration: <https://tinyurl.com/paedECHO>
  - New pain cycle begins September 2020



# Resource Appendix

- [SKIP Pain Management Apps and Online Resources](#)
- [Pilot RCT in adolescents with chronic arthritis pain: Key Findings](#)
- [Pilot RCT in adolescents with chronic pain: Key Findings](#)
- [Successful integration of Apple ResearchKit to support remote paediatric eConsent](#)
- [Chronic Pain Program](#)
- [Leveraging Ontario Telemedicine Network \(OTN\) Privacy Toolkit](#)
- [SickKids Virtual Care Pivot: Open Access Case Report](#)
- [Teens Taking Charge Website](#)
- [Teens Taking Charge: Randomized Controlled Trial of a Web-based Self-Management Program with Telephone Support for Adolescents with Juvenile Idiopathic Arthritis](#)
- [Psychological interventions for needle-related procedural pain and distress in children and adolescents](#)
- [Digital Technology Distraction for Acute Pain in Children](#)
- [MEDiPORT Robot \(Youtube Video\)](#)
- [Paediatric Project ECHO Program Overview \(Youtube Video\)](#)
- [Paediatric Project ECHO: Learn More](#)
- [Paediatric Project ECHO: Get Involved \(Free Registration\)](#)