

Shared decision-making around the world: Informing an equitable, patient-oriented decision aid for in-person vs virtual care of pediatric chronic pain



Mica Gabrielle Marbil (1,2), Jenna Jessa (2,3), Justin Bonhomme (3), Tracy Wasylak (4,5), Prabjit Ajrawat (6), Zahra Alidina (6), Gillian Backlin (7), Javed Gill (7), Isabel Jordan (7), Vina Mohabir (8), Sabine Soltani (1), Fiona Campbell (9), Nivez Rasic (3,10), Katherine Wynne-Edwards (11), Krista Baerg (12), Diane Lorenzetti (13), Nicole MacKenzie (14,15), Melanie Noel (1,2,10), Tim Oberlander (16), Jennifer N. Stinson (8,17), Karine Toupin-April (18), Fiona Webster (19), Kathryn A. Birnie (1,3)

1 - Department of Psychology, University of Calgary; 2 - Alberta Children's Hospital Research Institute, University of Calgary; 3 - Department of Anesthesiology, Perioperative & Pain Medicine, University of Calgary; 4 - Strategic Clinical Networks, Alberta Health Services; 5 - Faculty of Nursing, University of Calgary; 6 - Patient and Family Partner, ON, Canada; 7 - Patient and Family Partner, BC, Canada; 8 - Child Health Evaluative Sciences, The Hospital for Sick Children; 9 - Department of Anesthesia and Pain Medicine, The Hospital for Sick Children, University of Toronto; 10 - Vi Riddell Children's Pain and Rehabilitation Centre, Alberta Children's Hospital; 11 - Patient and Family Partner, AB, Canada; 12 - Department of Pediatrics, University of Saskatchewan; 13 - Health Sciences Library & Department of Community Health Sciences, University of Calgary; 14 - Department of Psychology and Neuroscience, Dalhousie University; 15 - Centre for Pediatric Pain Research, IWK Health; 16 - Department of Pediatrics, University of British Columbia; 17 - Lawrence S. Bloomberg Faculty of Nursing, University of Toronto; 18 - School of Rehabilitation Sciences and Department of Pediatrics, University of Ottawa, and Children's Hospital of Eastern Ontario Research Institute, Institut du savoir Montfort; 19 - Arthur Labatt Family School of Nursing, Western University

Abstract

Background: Chronic pain (CP; i.e., pain >3 months) affects 20% of youth and is associated with several deleterious outcomes. While the COVID-19 pandemic required virtual delivery of health services, no current guidelines exist for virtual pediatric CP management. Little is known regarding virtual versus in-person treatment efficacy. Equity-seeking groups are disproportionately impacted by CP and face systemic barriers to virtual care. Reducing treatment disparities is a patient-identified priority. Youth with CP and their families must have a voice in treatment decisions. Shared decision-making (SDM) allows patients, families, and health professionals to decide on treatment collaboratively based on evidence and patient preferences. As part of a multi-phase project to promote SDM and develop a decision aid for in-person versus virtual pediatric CP management, this study examined decision-making practices for in-person versus virtual CP care.

General Methods: An electronic survey was distributed to health professionals from 102 pediatric CP clinics around the world. Participants reported on demographics, decision-making practices, perceptions of in-person versus virtual care, and patient and professional decision-making roles. Descriptive statistics were used to identify commonalities across current practices.

Results: Respondents ($N = 68$) most identified as women, not of colour, anesthesiologists, and from the United States. Types of virtual care most endorsed were video conference platforms, email with patients/families, and telephone consultation. Overall, virtual care constituted <25% of CP treatment. Families were commonly reported to have the largest role in decision-making. New referrals, patient demographics and location, and patient values/preferences most influenced in-person versus virtual care decisions. Most clinics did not evaluate their in-person versus virtual care treatment decisions.

Conclusions: New referrals, patient demographics, and patient preferences most impact virtual care decisions. Most clinics do not evaluate their in-person versus virtual care decisions, suggesting a lack of general treatment outcome assessment.

Keywords: shared decision-making, pediatric pain, virtual care

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Previously...

In Phase 1 of our project to develop a decision aid for in-person versus virtual care for pediatric chronic pain management, our systematic review revealed **insufficient evidence** comparing in-person versus virtual care for pediatric chronic pain. Only 2 studies were included, both of which had **mostly white samples** and inadequately represented ethnically diverse groups.



Our current work:

Most respondents were women (57%), female (54%), physicians (52%), and not of a racial or ethnic minority group (84%).

Virtual care constitutes <25% of overall pediatric chronic pain treatment, regardless of discipline.

The top 3 factors influencing virtual care decisions are:



Evidence was least commonly ranked among top 3 ($n = 13, 19.1%$).

Most clinics ($n = 56, 82.4%$) do not evaluate in-person vs virtual care decisions.

Those that did most often used **mixed method feedback (e.g., satisfaction surveys) or electronic health records** to evaluate decisions.



Equity, Diversity & Inclusion (EDI)

Our **national project team** includes youth, caregivers, and health professionals who are **diverse in race, gender, disability, and rurality** and who developed project methods together, allowing us to approach project outcomes from intersectional lens. **Research protocols and measures** have been developed with diverse members of the research team.

This phase involved **multinational engagement** with health professionals around the world to capture SDM practices. The next phase will have direct participation from youth and caregivers who identify as **being of racialized groups, and of complex medical needs or brain-based disabilities**.

Sex- & Gender-Based Analysis (SGBA+)

Sex and gender are not primary outcomes, as it is unclear if these impact virtual pediatric chronic pain management. However, we integrated **separate measures of sex and gender** in our demographic questionnaires.

As girls experience more severe pain (Dunn et al., 2011), and youth with chronic pain who do not identify as cisgender are underrepresented in research, **we will purposefully seek diverse representation among youth and caregivers in the next study phase** to ensure their perspectives are reflected in the resulting decision aid.

Next Steps...

In phase 3, we will **interview diverse youth with chronic pain, their caregivers, and healthcare professionals**, recruited through partner organizations, to determine critical features of the decision aid.

