

# Ensuring equity and inclusion in virtual care best practices for youth with pain and medical complexity

## PRESENTERS



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## INTRO:

- Although youth with medical complexity often experience pain, their perspectives were not represented in the available scientific literature

## AIM:

- The goal of this knowledge translation activity was to ensure that virtual care recommendations for pediatric chronic pain are equitable and inclusive of youth with medical complexity and their families.

## METHODS:



# The COVID-19 pandemic necessitated a rapid and large-scale shift to virtual care

We conducted a rapid systematic review in May 2020 to identify best practices for virtual care for youth with chronic pain and their families.

This knowledge synthesis was summarized in a 1-page infographic (available at <http://www.partneringforpain.com/portfolio/virtual-care>) and highlighted recommendations for leveraging and implementing virtual care, selecting platforms, and knowledge gaps

## What we know about Virtual Care for youth with chronic pain and their families:

<h3>Leveraging Virtual Care</h3> <ul style="list-style-type: none"> <li>- is acceptable, reasonable and effective</li> <li>- ensures better access to care (particularly rural or remote areas)</li> <li>- is under-utilized (especially for real-time symptom assessment and psychological treatment)</li> </ul>	<h3>Implementing Virtual Care</h3> <ul style="list-style-type: none"> <li>- should be freely available across all technologies (including telephone, apps, websites, video-conference)</li> <li>- needs to include training, terms of use, and guidelines for health professionals, youth and families</li> <li>- must use secure infrastructure (encrypted, password protected, authorized access)</li> <li>- should be developmentally appropriate</li> <li>- must meet ethical standards of care</li> <li>- should be transparent in communication (therapist vs. computer-generated messaging)</li> </ul>	<h3>Best Platforms for Virtual Care</h3> <ul style="list-style-type: none"> <li>- need to be user-friendly and acceptable to youth and families</li> <li>- must be backed by science</li> <li>- should involve youth, families, and health professionals in their development</li> <li>- should be individualized or customizable</li> <li>- must be comprehensive in terms of pain management (provide pharmacological, psychological, and physical strategies)</li> <li>- need to use multimedia content (videos, text, images)</li> <li>- must meet accessibility standards</li> <li>- should be able to integrate social and peer support</li> </ul>	<h3>Identified Gaps in Virtual Care</h3> <ul style="list-style-type: none"> <li>- requires standardized practice guidelines for implementation and evaluation</li> <li>- must have evidence showing its effectiveness for all concerns identified by youth and families</li> <li>- needs to include knowledge about its limitations and suitability for all aspects of care (such as physical exam)</li> <li>- need to consider potential harms and impact on the therapeutic relationship</li> <li>- requires strategies to enhance engagement</li> <li>- needs integration into clinical care pathways, face-to-face care, and electronic medical record</li> </ul>
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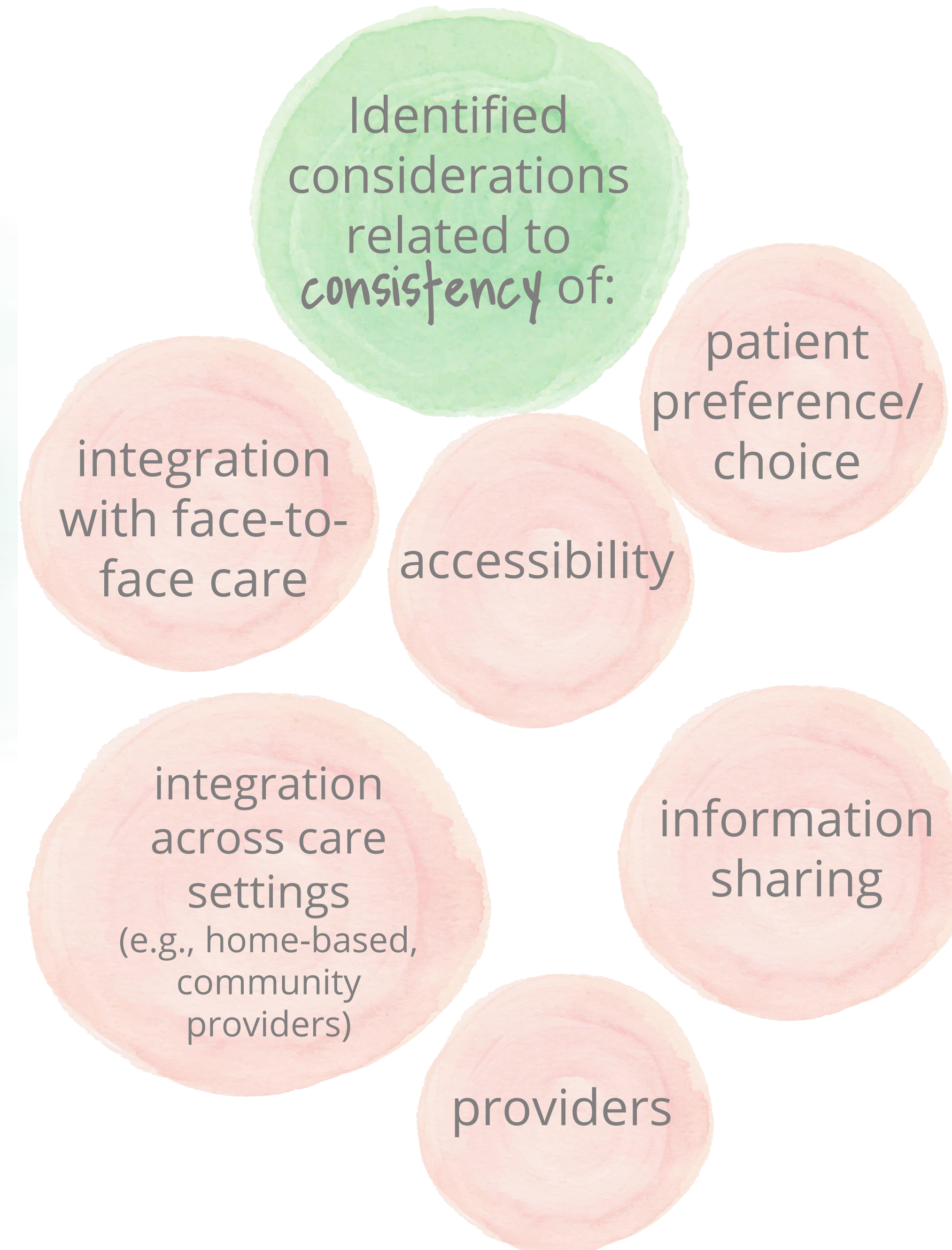
“ Yes, we need virtual care, but I need a person to help me manage all of this stuff and to help my child navigate this system. ”  
Parent

“ I don't believe that virtual care, like good virtual care, can exist without a good virtual platform. And I'm not just talking about like whether you decide to use zoom or whatever you use in your office. It's more like can I have my lab results electronically? Do you have my lab results electronically? Do I have to send you my login information? And I think that's something that's being left out of a lot of conversations. ”  
Youth

“ It should be a lot easier for physicians to jump on a call together or see you together. And I and I wish that you know, they could start thinking of ways to use virtual care to deliver that. ”  
Youth

## FINDINGS:

- Youth, parents/ caregivers, and health professionals commented on the benefits and challenges of virtual care



## STUDY TEAM:

- Gillian Backlin, CHILD-BRIGHT NYAP Member, Patient Partner
- Isabel Jordan BSc, Patient/Parent Partner
- Laesa Kim, Patient Partner
- Justina Marianayagam BSc, Patient Partner, Northern Ontario School of Medicine
- Corinne Lalonde BA MA, CHILD-BRIGHT NYAP Member
- Frank Gavin, CHILD-BRIGHT, Parent Partner
- Dr. Tiegahn Killackey RN PhD, The Hospital for Sick Children/University of Toronto
- Dr. Tim Oberlander MD FRCPC, BC Children's Hospital, University of British Columbia
- Dr. Hal Siden MD MSc FRCPC, BC Children's Hospital, University of British Columbia
- Dr. Jennifer Stinson RN PhD, The Hospital for Sick Children/University of Toronto
- Dr. Kathryn Birnie PhD RPsych, University of Calgary, Alberta Children's Hospital

