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

**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:**
Gillian Backlin (she/her) Patient Partner CHILD-BRIGHT NYAP Member

Isabel Jordan (she/her) Patient/Parent Partner

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.

**FINDINGS:**
Youth, parents/caregivers, and health professionals commented on the benefits and challenges of virtual care.

**STUDY TEAM:**
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**What we know about Virtual Care for youth with chronic pain and their families:**

**Leveraging Virtual Care**
- Is acceptable, reasonable and effective
- Ensures better access to care (particularly rural or remote areas)
- Is under-utilized (especially for tele-health visits)

**Implementing Virtual Care**
- Should be freely available across all technologies (including telephone, apps, web-based, video-conference)
- Needs to include training, terms of use, and guidelines for health professionals, youth, and families
- Must be secure (infrastructure encrypted, password protected, authorized access)
- Should be developmentally appropriate
- Must meet ethical standards of care
- Should be transparent in communication (therapist vs. computer-generated messaging)

**Best Platforms for Virtual Care**
- 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
- Need to use multimedia content (e.g., photos, text, images)
- Must meet accessibility standards
- Should be able to integrate social and peer support

**Identified Gaps in Virtual Care**
- Requires standardized practice guidelines for implementation and evaluation
- Must have evidence showing cost-effectiveness for all concerns identified by youth and families
- Needs to include knowledge about its limitations and suitability for all aspects of care
- Needs to consider potential harms and impact on the therapeutic relationship
- Requires strategies to enhance engagement
- Needs integration into clinical care pathways

**SESSION:**
Session asked about individuals’ experiences with virtual care and their feedback on the identified best practices for virtual care for youth.