

Partnering for Pain: A Priority Setting Partnership to Identify Patient-Oriented Research Priorities for Pediatric Chronic Pain in Canada

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For which topic were research priorities identified?

pediatric chronic pain

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Chronic pain is increasingly recognized as a public health crisis in Canada owing to its high prevalence, life-long deleterious impact and economic burden. However, often lost in this discussion are the estimated 1-3 million Canadian children with chronic pain, who are substantially impaired across important life areas including school, family, friends, sleep, mental well-being and physical activity. Forty years ago, it was believed that children were less sensitive to pain, and minimal analgesics were given. It was only through the timely synergy of new science and public outcry that our understanding and treatment of pain in children improved. The field of pediatric pain has grown exponentially since that time, and, although researchers have identified knowledge gaps, the patient and family voice is largely lacking. Moreover, despite major efforts, treatments for pediatric chronic pain have limited evidence, health care providers receive little pain education, and most Canadian children cannot access adequate pain care. Thus, there is a dire need to ensure future research is relevant, meaningful and useful to those who need it every day.

What was the objective?

to collaboratively identify the top 10 research priorities in pediatric chronic pain

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: collecting research questions: survey: participants were asked to describe up to 5 priorities, 540 research priorities submitted. Step 2: data processing: out-of-scope submissions removed, remaining categorized, rewritten in PICO format, only those questions remained that were submitted by at least 2 people (at least 1 of whom a patient), 63 priorities remained. Step 3: interim ranking: via survey, participants were asked to rate each question, the 25 most highly ranked research questions from each of the 3 stakeholder groups selected. Step 4: final prioritization: workshop: small group discussions with nominal group technique, small group rankings

Which stakeholders took part?

Patients, families, clinicians. Survey: 215 participants (86 patients [40.0%], 56 family members [26.0%] and 73 clinicians [34.0%]). Interim ranking: 57 participants (19 patients [33%], 17 family members [30%] and 21 clinicians [37%]). Workshop: 20 participants (6 patients [30%], 6 family members [30%] and 8 clinicians [40%]).

How were stakeholders recruited?

The survey was promoted via social media (Twitter, Facebook, Instagram⁴⁵), at pediatric chronic pain programs and other pediatric care centres (postcards, posters, emails), through professional and patient organizations (newsletters, blog posts, emails) and via targeted emails to pediatric clinicians. Interim survey: Targeted email invitations were sent to 156 patients, family members and clinicians who were former research participants or were identified through pediatric chronic pain programs, patient partner organizations and steering committee member networks. Workshop: Potential participants were identified via steering committee networks and partner organizations.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 2 young adults with lived experience with pediatric chronic pain, 3 parents, 7 pediatric pain nursing, psychology or physician clinicians and/or researchers, and 1 adult chronic pain clinician. The members oversaw the process and were full collaborators: they co-designed, executed and evaluated all phases of the priority setting partnership.