

Researching What Matters to Improve Chronic Pain Care in Canada: A Priority-Setting Partnership Process to Support Patient-Oriented Research

Poulin et al. (2018)

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For which topic were research priorities identified?

chronic pain

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Chronic pain affects more than 6 million Canadians. Patients need to be involved in setting research priorities to ensure a focus on areas important to those who will be most impacted by the results.

What was the objective?

to identify chronic pain research priorities in Canada, primarily from the perspective of people with lived experience of chronic pain and those who care for them, with input from clinicians, decision makers, and researchers

What was the outcome?

a ranking list of 14 research questions

How long did the research prioritization take?

September 2015 - October 2016

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: generating research questions: five town hall meetings, survey, 74 interviews and structured questions on Facebook to gather ideas about important research questions about chronic pain in Canada, town hall meetings to generate research questions, survey with series of 45 questions to elicit research questions: a total of 1481 survey responses containing 690 suggestions for research priorities, in total 5250 submissions including comments, questions, and personal stories, list of questions reduced to 199 items. Step 2: Delphi: Delphi round 1: survey with 199 items, participants were asked to rate importance of each question, any question that received greater than 50% of the participants endorsing it as being a high priority was then included in round 2, resulting in list of 38 questions. Step 3: comparing list of priorities with interviews from Indigenous chronic pain research priorities. Step 4: Delphi round 2: participants were asked to re-rate questions, resulting in list of 23 questions. Step 5: Delphi round 3: panel of ten clinicians and ten patients rated the questions, steering group reviewed results, final 14 questions were then categorized in 4 categories

Which stakeholders took part?

People with lived experience of chronic pain (e.G., patients, caregivers, and family members), clinicians, researchers, and decision makers with an interest in chronic pain. Survey: 1481 participants. Delphi round 1: 45 participants. Delphi round 2: 58 participants. Delphi round 3: 20 participants: 10 patients and 10 clinicians.

How were stakeholders recruited?

The survey was distributed widely through a snowball technique to all of the contacts of the steering committee and patient advisory group. To increase dissemination of the project and increase participation, participants and patient group representatives leveraged Twitter to extend message and embedded links to the website and video on YouTube.

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 patient advisory board and a steering group. The patient advisory board consisted of 6 patient representatives from various chronic pain associations. The steering group consisted of 4 clinician-scientists and 3 patients. The members were responsible for any major decisions about the study, taking into account the input from the patient advisory group.