Partnering with Youth and Parents for the Greatest Impact of Top Patient-Oriented Priorities in Pediatric Chronic Pain Research, Care and Policy

Kathryn A. Birnie, Carley Ouellette^{P}, Justina Marianayagam^{P}, Fiona Campbell, Christine Lamontagne, Paula Forgeron, Jennifer Stinson and the Partnering For Pain Priority Setting Partnership Team

Abstract

Our original patient-oriented research project identified the top 10 priorities for pediatric chronic pain research and care in Canada from the perspective of people with lived experience (patients), their family members and healthcare professionals through a modified James Lind Alliance Priority Setting Partnership. We undertook subsequent knowledge translation activities with youth, families, healthcare professionals, decision makers and researchers to (1) generate awareness and interest in the top 10 priorities and our partnership process, (2) facilitate collaborative dialogue and open innovation and (3) integrate and adopt the top 10 priorities into stakeholder activities. This paper describes our knowledge translation activities, outcomes and impact.

Introduction

Chronic pain affects 11–38% of children and adolescents (King et al. 2011) or approximately one to three million youth in Canada, and costs C$40 billion annually (Health Canada 2021). Youth with chronic pain experience poor quality of life and impairment in physical, sleep, social, family- and school-related functioning (Eccleston et al. 2021; Forgeron et al. 2010; Groenewald et al. 2020; Lewandowski et al. 2010; Valrie et al. 2013). Pediatric pain researchers have identified priorities for future research (Caes et al. 2016; Liossi et al. 2017), but prior to our work, the patient and family voice was largely absent from guiding what research should be prioritized to improve chronic pain for youth in Canada and their families.

Our original patient-oriented research (POR) project sought to identify the top 10 priorities for pediatric chronic pain research and care in Canada from the perspective of people with lived experience (patients), family members and healthcare professionals (Birnie et al. 2018; Birnie et al. 2019). We modelled our methods to identify the top priorities after the internationally established James Lind Alliance Research Priority Setting Partnership (James Lind Alliance Priority Setting Partnerships 2018). The James Lind Alliance methodology is recognized for its equitable and rigorous approach to identify what matters most to people who need to use the research in their everyday lives (Manafò et al. 2018). We have previously published on our partnership (Birnie et al. 2018) and our national multistage engagement process to reach the final top 10 list, which was completed in December 2018 (Birnie et al. 2019).

Key Points

- Partnership with youth with chronic pain and parents led to a greater impact of knowledge translation activities.
- A focus on knowledge translation and patient partnership enabled our work to move beyond knowledge sharing to behaviour and policy change.
- Challenges in patient engagement and knowledge translation were overcome through inclusion of multiple youth and parent partners.

P = Patient partner.

BOX 1.
Top 10 patient-oriented research priorities in pediatric chronic pain in Canada

1 What treatments or strategies effectively prevent acute pain from becoming chronic in children and adolescents?

2 What is the impact of living with chronic pain on children's and adolescents' academic performance and educational attainment, and what strategies best support vocational planning for children and adolescents with chronic pain?

3 What physical and psychological treatments are effective for improving pain and function in children and adolescents with chronic pain (e.g., functional outcomes including quality of life, depression, fatigue, sleep, acceptance, concentration, resilience, coping and self management)?

4 What strategies improve access and delivery of evidence-based treatments, and coordination of care for all Canadian children and adolescents with chronic pain and their families with a view to reduce disparities?

5 What strategies effectively increase healthcare providers' training, knowledge, recognition, beliefs, attitudes and communication about the validity and risk of chronic pain in children and adolescents, and its evidence-based treatments?

6 What strategies effectively increase governmental and healthcare organizational financial support for evidence-based pediatric chronic pain care in Canada?

7 What strategies for educating school personnel about pediatric chronic pain effectively increase their awareness, understanding and recognition of the validity, impact and treatment of pediatric chronic pain?

8 What interventions are effective for managing acute pain flares in children and adolescents with chronic pain?

9 What is the interaction between chronic pain and mental health symptoms in children and adolescents, and when and how can co-occurring chronic pain and mental health symptoms be most effectively diagnosed and treated?

10 When are treatments for chronic pain in children and adolescents most effective (e.g., after medical investigation is complete, during variation by type of treatment modality or with the readiness of the child/adolescent or family to engage in treatment)?

Source: Birnie et al. 2019.

See Box 1. Since then, our national team of youth with lived experience, parents, healthcare professionals and researchers have been working in partnership to ensure these top 10 priorities are being mobilized for the greatest impact.

Patient Partnership

Our approach to patient engagement recognizes and values the expertise of lived and living experience of youth with chronic pain and their family members. Youth and parent partners were engaged equally as members of the project team (Birnie et al. 2018), including as members of the steering committee overseeing the Priority Setting Partnership (Birnie et al. 2019). They were also responsible for co-producing and mobilizing all knowledge translation activities. Youth and parent partners were identified through known relationships to project team members (e.g., former patients and family members), as well as through postings to patient engagement registries (e.g., Saskatchewan Centre for Patient-Oriented Research). Youth and parent partners were diverse in race, geography/rurality, type of chronic pain and experience of chronic pain care. Youth and parent partners identified important areas of representation to ensure that diverse participants from underrepresented groups engaged in the priority setting partnership (e.g., age, sex and gender, chronic pain experience, geography/rurality, family member relationship, family system, healthcare setting and discipline of healthcare professionals). Youth and parent partners were co-authors on resulting publications, co-facilitators and co-presenters. Youth partner experiences with the project (Birnie et al. 2018), as well as evaluation of our patient engagement process (Birnie et al. 2019), have been previously reported.

Knowledge Translation Goals and Activities

With support from the Ontario SPOR (Strategy for Patient-Oriented Research) SUPPORT Unit EMPOWER award, our team set out three primary knowledge translation goals to act on the top 10 patient-oriented priorities for pediatric chronic pain research and care in Canada. Together, we undertook diverse activities aligned with our goals to reach various key audiences including patients and families, healthcare professionals, researchers, research funders, decision makers and policy makers.

First goal: To generate awareness about and interest in the top 10 priorities in pediatric chronic pain and the partnership process undertaken to identify these priorities

Activities

We co-created a suite of materials outlining the top 10 priorities. Three key outputs included (1) a one-page infographic available in English and in French outlining the priority-setting methodology and results to enable quick communication; (2) a brief video taken at the final priority-setting consensus meeting that includes interviews with youth, parents and healthcare professionals engaged in the priority-setting activities and outlines the top 10 list; and (3) a co-developed patient journey map that graphically outlines one family's lived experience with chronic pain from early childhood to late adolescence, including highlights. The patient journey map is intended to meaningfully articulate the lived experience impact of the top 10 priorities. A "Partnering For Pain" logo and website were created to further facilitate communication and awareness through brand recognition and centralized access to outputs (https://partneringforpain.com/portfolio/top-10-priorities-for-pain/). Additional activities to generate awareness about the top 10 priorities include articles written for the Canadian Institutes of Health Research (CIHR) Institute of Musculoskeletal Health and Arthritis (Birnie 2019) targeting researchers and health research funders and in *RELIEF* – a publication by the International Association for the Study of Pain (Sukel 2020) – targeting the public, and a podcast episode with Pain BC's (2020) *Pain Waves* targeting healthcare professionals and the public.

Impact

Increased awareness and interest in the top 10 priorities in pediatric chronic pain and the partnership process is reflected through widely reached key audiences who have read, listened to and attended the knowledge translation activities. In 2020, the Partnering For Pain Priority Setting Partnership received the Pain Awareness Award from the Canadian Pain Society, as well as a CIHR Institute of Human Development Child Youth Health Video Prize (https://partneringforpain.com/portfolio/top-10-priorities-for-pain/).

Second goal: To facilitate collaborative dialogue among patients, families, researchers, healthcare professionals and decision makers to address the top 10 priorities in pediatric chronic pain

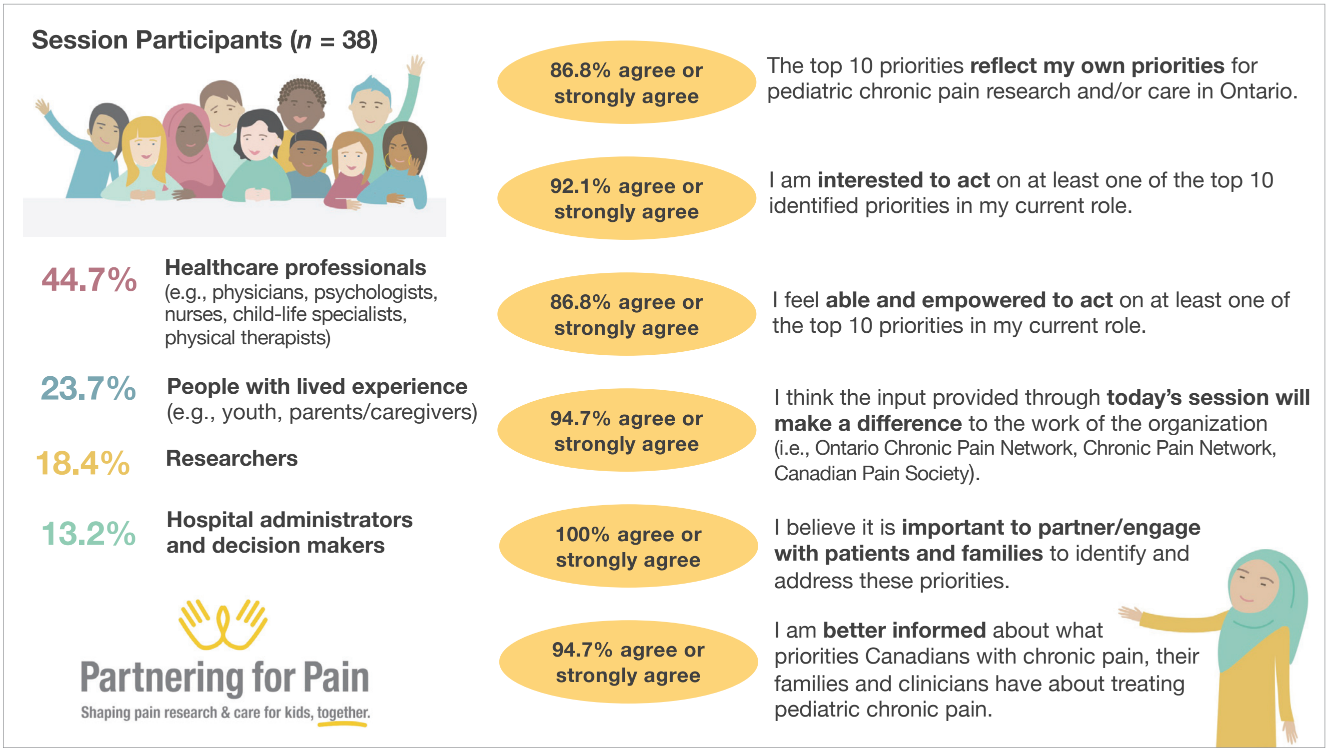
Activities

Research team members and youth and parent partners co-developed and co-facilitated round-table discussions of the top 10 priorities with multidisciplinary groups of healthcare professionals and researchers at the Ontario Chronic Pain Network annual meeting, the Chronic Pain Network (CIHR-funded SPOR) and the Canadian Pain Society annual meeting.

Impact

Evaluation from the round-table dialogue sessions about the top 10 priorities are shown in Figure 1.

FIGURE 1.
Evaluation from the round-table dialogue sessions about the top 10 priorities in pediatric chronic pain



Session Participants (*n* = 38)

44.7%	**Healthcare professionals** (e.g., physicians, psychologists, nurses, child-life specialists, physical therapists)
23.7%	**People with lived experience** (e.g., youth, parents/caregivers)
18.4%	**Researchers**
13.2%	**Hospital administrators and decision makers**

86.8% agree or strongly agree	The top 10 priorities **reflect my own priorities** for pediatric chronic pain research and/or care in Ontario.
92.1% agree or strongly agree	I am **interested to act** on at least one of the top 10 identified priorities in my current role.
86.8% agree or strongly agree	I feel **able and empowered to act** on at least one of the top 10 priorities in my current role.
94.7% agree or strongly agree	I think the input provided through **today's session will make a difference** to the work of the organization (i.e., Ontario Chronic Pain Network, Chronic Pain Network, Canadian Pain Society).
100% agree or strongly agree	I believe it is **important to partner/engage with patients and families** to identify and address these priorities.
94.7% agree or strongly agree	I am **better informed** about what priorities Canadians with chronic pain, their families and clinicians have about treating pediatric chronic pain.

Source: Image reprinted with permission from Partnering for Pain.

Third goal: To engage pediatric pain researchers, healthcare professionals, government decision makers and healthcare and patient organizations to integrate and adopt the top 10 priorities in pediatric chronic pain research, clinical practice, policy and advocacy

Activities

Knowledge translation activities also focused on enabling action on the top 10 priorities. Following consultation with the Ontario SPOR SUPPORT Unit, our team created an Evidence and Gap Map, which mapped existing evidence from systematic review and clinical practice guidelines for any treatment for pediatric chronic pain to the top 10 priorities (Birnie et al. 2020). Evidence and Gap Maps provide visual summaries of the scope and quality of available evidence to enable informed decisions for policy makers (Saran 2020; Snilstveit et al. 2017). A research team member and youth partner evaluated whether each scientific article included in the Evidence and Gap Map addressed each of the top 10 priorities. This work identified POR priority areas with sufficient and high-quality evidence for immediate action by healthcare professionals, decision makers and policy makers (i.e., psychological interventions for pediatric chronic pain), as well as areas needing further evidence for prioritization by health research funders and researchers (e.g., strategies for educating school personnel about pediatric chronic pain).

Co-presentations with youth and parent partners of the top 10 priorities and our partnership process included posters, webinars and talks targeting researchers (e.g., Canadian Pain Society, International Association for the Study of Pain, International Symposium on Pediatric Pain, Chronic Pain Network), healthcare professionals and families (Children's Healthcare Canada, Pediatric Pain Project ECHO, Alberta SPOR SUPPORT Unit Patient Engagement platform) and decision makers and policy makers (Canadian Academy of Health Sciences). Two youth partners were also highly engaged in additional activities targeting policy makers as members of the External Advisory of Health Canada's Canadian Pain Task Force and as part of a lobby day on Parliament Hill in Ottawa, ON, in partnership with Solutions for Kids in Pain (SKIP)– a Networks of Centres of Excellence knowledge mobilization network focused on pediatric pain.

Impact

A great success for our knowledge translation activities was the integration of the top 10 priorities and patient partnership approach into the following: reports from Health Canada's Canadian Pain Task Force (Canadian Pain Task Force 2019), the Canadian Academy of Health Sciences' development of a national strategy for chronic pain (CAHS 2018) and a recent Lancet Child & Adolescent Health Commission in Paediatric Pain (Eccleston et al. 2021). These documents guide priorities and recommend actions for transformative change to improve pain care for youth and their families in Canada and around the world. Following completion of the Priority Setting Partnership, the Partnering For Pain POR program was developed at the University of Calgary, led by Katie Birnie, which seeks to action all of the identified top 10 priorities.

Key Messages and Implications

The OSSU EMPOWER award and patient partnership enabled the creation of novel, creative and accessible knowledge translation activities and outputs to better reach different audiences beyond other pediatric pain researchers (i.e., the public, patients and families, healthcare professionals, decision makers and policy makers). A focus on knowledge translation and patient partnership enabled our work to move beyond knowledge sharing to behaviour change.

Challenges included some turnover of youth and parent partners due to the length of the project, as well as the high level of engagement required. This was overcome through inclusion of multiple youth and parent partners to decrease potential burden and create flexibility over type and amount of engagement. Additional challenges included the geographical location of project team members across the country, thereby requiring various methods – including virtual team meetings, phone calls and use of an online discuss forum – to build strong relationships and meaningful connections between team members. Lastly, having one main project lead and contact for youth and parent partners helped to mitigate any potential dual relationships and power differentials for youth partners who were former pediatric patients of healthcare professional team members.

All project and knowledge translation activities were undertaken in partnership with youth with lived experience and parents. It is our belief that patient partnership achieved greater reach and impact of the top 10 priorities by powerfully combining lived experience with rigorous scientific methodology. Our patient partners took the projects' findings to new conversations and new audiences, particularly with decision makers and policy makers. Lived experience narratives are a powerful knowledge translation tool that supports developing policies, shared decision making, strategies and research in healthcare through increased awareness of patient experiences (Park et al. 2021; Rose et al. 2016). Collaboration and advocacy by team members who are also researchers was needed to overcome challenges for youth and parent partners, including securing compensation for invited presentations with external partner organizations.

The national scale and scope of this project's high-quality and meaningful patient partnership serves as a key exemplar to other researchers, thus enabling more researchers as well as youth and families to engage in patient partnerships, particularly in the areas of child health and pain. HQ

Acknowledgements

The authors would like to express gratitude to Garry Salisbury, formerly from the Ontario Ministry of Health and Long-Term Care; PainBC; Sandy Smeenk from the ILC Foundation; and SKIP for their partnership in this work. Lastly, the authors thank Eddy Nason (formerly Ontario SPOR SUPPORT Unit) and John Lavis (McMaster University) for their guidance via the OSSU EMPOWER award regarding the Evidence and Gap Map methodology and Julie Drury for her recommendations regarding effective knowledge translation for this project.

Funding

This work was funded by an EMPOWER Award from the Ontario SPOR SUPPORT Unit and a Patient-Oriented Research Catalyst Grant from CIHR.

References

Birnie, K.A. 2019. Partnering For Pain: A Priority Setting Partnership to Establish Patient-Oriented Research Priorities in Pediatric Chronic Pain. Canadian Institutes of Health Research. Retrieved October 18, 2021. <https://cihr-irsc.gc.ca/e/51558.html>.

Birnie, K.A., K. Dib and C. Ouellette. 2018, October. Co-Building a New Landscape in Pediatric Chronic Pain Research: Patient Partner and Researcher Perspectives on Meaningful Patient Engagement. *Pediatric Pain Letter* 20(3): 21–27. Retrieved October 18, 2021. <http://ppl.childpain.org/issues/v20n3_2018/v20n3_birnie.pdf>.

Birnie, K.A., K. Dib, C. Ouellette, M.A. Dib, K. Nelson, D. Pahtayken et al. 2019. Partnering For Pain: A Priority Setting Partnership to Identify Patient-Oriented Research Priorities for Pediatric Chronic Pain in Canada. *CMAJ Open* 7(4): E654–64. doi:10.9778/cmajo.20190060.

Birnie, K.A., C. Ouellette, T. Do Amaral and J.N. Stinson. 2020. Mapping the Evidence and Gaps of Interventions for Pediatric Chronic Pain to Inform Policy, Research, and Practice: A Systematic Review and Quality Assessment of Systematic Reviews. *Canadian Journal of Pain* 4(1): 129–48. doi:10.1080/24740527.2020.1757384.

Caes, L., K.E. Boerner, C.T. Chambers, M. Campbell-Yeo, J. Stinson, K.A. Birnie et al. 2016. A Comprehensive Categorical and Bibliometric Analysis of Published Research Articles on Pediatric Pain from 1975 to 2010: *PAIN* 157(2): 302–13. doi:10.1097/j.pain.0000000000000403.

Canadian Academy of Health Sciences (CAHS). 2018, November 22. *CAHS Major Forum 2018: Chronic Pain Summary Report Arising from Forum*. Retrieved October 18, 2021. <https://cahs-acss.ca/wp-content/uploads/2018/11/Forum-2018-Proceedings-Report.pdf>.

Canadian Pain Task Force. 2019, June. *Chronic Pain in Canada: Laying a Foundation for Action*. Health Canada. Retrieved October 18, 2021. <https://www.canada.ca/content/dam/hc-sc/documents/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2019/canadian-pain-task-force-June-2019-report-en.pdf>.

Eccleston, C., E. Fisher, R.F. Howard, R. Slater, P. Forgeron, T.M. Palermo et al. 2021. Delivering Transformative Action in Paediatric Pain: A *Lancet* Child & Adolescent Health Commission. *The Lancet Child and Adolescent Health* 5(1): 47–87. doi:10.1016/S2352-4642(20)30277-7.

Forgeron, P.A., S. King, J.N. Stinson, P.J. McGrath, A.J. MacDonald and C.T. Chambers. 2010. Social Functioning and Peer Relationships in Children and Adolescents with Chronic Pain: A Systematic Review. *Pain Research and Management* 15(1): 27–41. doi:10.1155/2010/820407.

Groenewald, C.B., S.W. Tham and T.M. Palermo. 2020. Impaired School Functioning in Children with Chronic Pain: A National Perspective. *The Clinical Journal of Pain* 36(9): 693–99. doi:10.1097/AJP.0000000000000850.

Health Canada. 2021, May. *An Action Plan for Pain in Canada*. Retrieved October 18, 2021. <https://www.canada.ca/content/dam/hc-sc/documents/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2021-rapport/report-rapport-2021-eng.pdf>.

James Lind Alliance Priority Setting Partnerships. 2018. JLA Guidebook. Retrieved December 1, 2018. <https://www.jla.nihr.ac.uk/jla-guidebook/>.

King, S., C.T. Chambers, A. Huguet, R.C. MacNevin, P.J. McGrath, L. Parker et al. 2011. The Epidemiology of Chronic Pain in Children and Adolescents Revisited: A Systematic Review. *PAIN* 152(12): 2729–38. doi:10.1016/j.pain.2011.07.016.

Lewandowski, A.S., T.M. Palermo, J. Stinson, S. Handley and C.T. Chambers. 2010. Systematic Review of Family Functioning in Families of Children and Adolescents with Chronic Pain. *The Journal of Pain* 11(11): 1027–38. doi:10.1016/j.jpain.2010.04.005.

Liossi, C., A.-K. Anderson, R.F. Howard, On behalf of NIHR CRN-C CSG in Pain and Palliative Care. 2017. Development of Research Priorities in Paediatric Pain and Palliative Care. *British Journal of Pain* 11(1): 9–15. doi:10.1177/2049463716668906.

Manafò, E., L. Petermann, V. Vandall-Walker and P. Mason-Lai. 2018. Patient and Public Engagement in Priority Setting: A Systematic Rapid Review of the Literature. *PLoS ONE* 13(3): e0193579. doi:10.1371/journal.pone.0193579.

Pain BC. 2020. How Two Canadian Initiatives Are Advancing Children's Pain Research and Practice. *Pain Waves*. Retrieved February 29, 2020. <https://poddtoppen.se/podcast/1169792513/pain-waves/how-two-canadian-initiatives-are-advancing-childrens-pain-research-and-practice>.

Park, E., M. Forhan and C.A. Jones. 2021. The Use of Digital Storytelling of Patients' Stories as an Approach to Translating Knowledge: A Scoping Review. *Research Involvement and Engagement* 7(1): 58. doi:10.1186/s40900-021-00305-x.

Rose, R., S. Chakraborty, P. Mason-Lai, W. Brocke, S.A. Page and D. Cawthorpe. 2016. The Storied Mind: A Meta-Narrative Review Exploring the Capacity of Stories to Foster Humanism in Health Care. *Journal of Hospital Administration* 5(1): 52. doi:10.5430/jha.v5n1p52.

Saran, A. 2020. Evidence and Gap Maps. *Campbell Systematic Reviews* 16(1): e1075. doi:10.1002/cl2.1075.

Snilstveit, B., R. Bhatia, K. Rankin and B. Leach. 2017, February. *3ie Evidence Gap Maps: A Starting Point for Strategic Evidence Production and Use*. Working Paper 28. International Initiative for Impact Evaluation. Retrieved June 9, 2018. <https://www.3ieimpact.org/sites/default/files/2019-01/wp28-egm.pdf>.

Sukel, K. 2020, July 8. Managing Pain in Kids: What We Know and What We Don't Know [Previously accessed]. *Relief: Pain Research News, Insights, and Ideas.*

Valrie, C.R., M.H. Bromberg, T. Palermo and L.E. Schanberg. 2013. A Systematic Review of Sleep in Pediatric Pain Populations. *Journal of Developmental and Behavioral Pediatrics* 34(2): 120–28. doi:10.1097/DBP.0b013e31827d5848.

About the authors

Kathryn A. Birnie, PhD, RPsych, is an assistant professor in the Department of Anesthesiology, Perioperative and Pain Medicine at the University of Calgary; the Alberta Children's Hospital Research Institute; and the Hotchkiss Brain Institute. She is also the associate scientific director of SKIP. Kathryn is a clinical psychologist and lead for the Partnering For Pain patient-oriented research program in Calgary, AB, and the traditional territories of the people of the Treaty 7 Region in Southern Alberta and Métis Nation of Alberta, Region 3. She can be contacted at kathryn.birnie@ucalgary.ca.

Carley Ouellette, RN, MSc, is a registered nurse at Hamilton Health Sciences and a PhD student at School of Nursing, McMaster University. Carley is a person with lived experience and an active patient partner engaged in multiple projects. She works clinically as an emergency department nurse and is in her first year of doctoral studies at McMaster University in Hamilton, ON.

Justina Marianayagam, BHSc, is currently completing her MD at the Northern Ontario School of Medicine in Thunder Bay, ON. Justina is a person with lived experience.

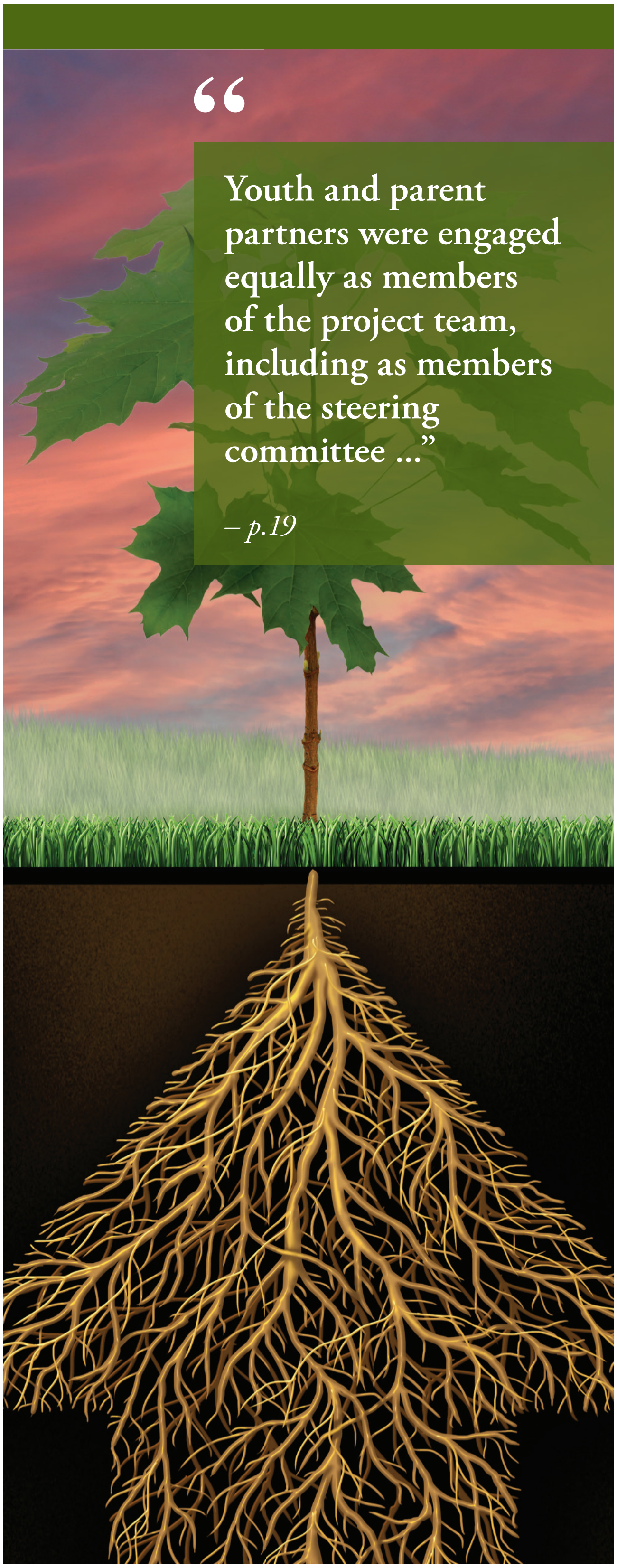
Fiona Campbell, MD, FRCA, is a professor at the University of Toronto and the medical director of the Chronic Pain Clinic at The Hospital for Sick Children in Toronto, ON.

Christine Lamontagne, MDCM, FRCPC, is the director of Chronic Pain Services at Children's Hospital of Eastern Ontario in Ottawa, ON.

Paula Forgeron, PhD, RN, is a professor at the University of Ottawa in Ottawa, ON. Before joining the university, Paula had a diverse clinical career with direct care experience in pediatric and adult emergency care and neonatal intensive care, as well as a position as the clinical nurse specialist on a pediatric complex pain team.

Jennifer Stinson, PhD, RN, is a senior scientist at The Hospital for Sick Children and a professor at the University of Toronto in Toronto, ON. Jennifer is a nurse practitioner and nurse clinician scientist.

The **Partnering For Pain: A Priority Setting Partnership** team includes **Katherine Dib**, **Mary Anne Dib**, **Esther Fleurimond**, **Isabel Jordan**, **Kimberly Nelson**, **Dallyne Pahtayken**, **Dolores Pahtayken** and **Adam Val Bonzil** (patient partners) and **Krista Baerg**, **Fiona Campbell**, **Jill Chorney**, **Melanie Noel** and **Patricia Poulin** (healthcare professionals and research collaborators).



> "Youth and parent partners were engaged equally as members of the project team, including as members of the steering committee ..."
>
> *– p.19*