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Solutions for Kids in Pain: Embedding and actioning patient partnership in a national knowledge mobilization network

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Abstract

Background Patient engagement is now often expected or required by funders for research projects, initiatives, or networks. Solutions for Kids in Pain (SKIP) is a national knowledge mobilization network in Canada that is on a mission to mobilize evidence-based solutions in children's pain through coordination and collaboration. SKIP began as a Networks of Centres of Excellence-Knowledge Mobilization (NCE-KM) network from 2019 to 2024 and continues as a university-based centre. SKIP was built on a foundation of engaging with patients (children and youth) and caregivers (parents) primarily guided by the Patients Included™ charter.

Main body This paper shares SKIP's leading approach to patient partnership during its time as a NCE-KM network. As required by its NCE funding, SKIP was hosted by an academic institution (Dalhousie University) and co-led by a knowledge user partner (Children's Healthcare Canada), with six hubs across Canada. Here, we demonstrate how SKIP integrated patient partners through its governance, management, committees, and KM activities. We also discuss patient partnership resources developed by SKIP to support its implementation of quality patient partnership practices. Three case examples show in detail how SKIP tailored and evolved its patient partnership approach to specific projects and context. These examples include SKIP's Patient and Caregiver Advisory Committee, a national Youth in Pain project, and integrating patient partners in the co-development of Canada's first national health standard for Pediatric Pain Management. Each case demonstrates foundational principles to SKIP's patient partnership including providing compensation and efforts to create safe and inclusive spaces.

Conclusion SKIP's commitment to patient partnership is actioned through integrating patient partners throughout all aspects of its work. We share insights gained from SKIP's patient partnership activities during its time as an NCE-KM network, including developed resources and practices. We encourage others to adopt and adapt our learnings and resources for their own work. As SKIP's NCE-KM funding and structure ends and the organization continues as a university-based centre, SKIP remains committed to developing and sharing leading patient partnership practices.

Keywords Patient engagement, Youth engagement, Patient and public involvement, Patient partnership, Knowledge mobilization, Patient and family partner, Patient research partner, Knowledge translation

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Plain English summary

Patient engagement is now often expected in research projects, initiatives, or networks. Solutions for Kids in Pain (SKIP) is a network in Canada whose purpose is to mobilize research findings into the hands of people who can use and benefit from it. SKIP's first five years from 2019 to 2024 were as a Network of Centres of Excellence-Knowledge Mobilization (NCE-KM) network. Although SKIP continues as a university-based centre, we are taking this opportunity as the NCE-KM funding and structure end to share SKIP's leading approach to patient partnership. We want others involved in research and knowledge mobilization activities, projects, and initiatives to use and benefit from what SKIP has learned. From its start, SKIP engaged with patients (children and youth) and caregivers to develop its mission and vision and build a partnership approach based on the Patients Included™ charter. Patient partners were included throughout SKIP's governance, management and committees, and in all of its activities. SKIP's foundational patient partnership principles include providing compensation, covering expenses, and creating a safe space, among others. We share three key examples of patient partnership during SKIP's time as an NCE-KM that highlight how partnership was tailored, what resources were created, and support structures in place, including: (1) SKIP's Patient and Caregiver Advisory Committee, (2) the Youth in Pain project, and (3) the national standard for Pediatric Pain Management. Dedicated staff, organizational capacity, and resources are required to integrate quality patient partnerships throughout an organization. Partnerships require ongoing commitments to remain positive, impactful, and sustainable.

Background

Patient engagement is becoming a critical approach, expected by many research funding organizations to be embedded within projects, initiatives, or networks [1–3]. Patient engagement (often referred to outside of Canada as consumer involvement [4] or patient and public involvement [5]) is defined as meaningful engagement with patients on research teams and throughout a project, including in governance [6]. Evidence is beginning to emerge about the benefits of patient engagement to research, including in knowledge mobilization [7, 8]. In this paper, we use the term 'patient' to include youth who have lived experiences relating to acute and/or chronic pain, and their families and caregivers (including parents).

In 2018, the Networks of Centres of Excellence program in Canada [9] launched a call for their Knowledge Mobilization (NCE-KM) initiative. Knowledge mobilization (KM) refers to a wide range of activities relating to the production and use of research results, including knowledge synthesis, dissemination, transfer, exchange, and co-creation or co-production by researchers and those who apply research results (that is, knowledge users), such as patients, parents, policymakers, and others [10]. The NCE-KM initiative provided competitive and dedicated funding to networks to support moving existing research knowledge into the hands of those who could put it into practice or use it.

Funded by the NCE-KM program from 2019 to 2024, Solutions for Kids in Pain (SKIP) is a national network on a mission to improve children's pain management by mobilizing evidence-based solutions through coordination and collaboration. SKIP's vision is healthier Canadians through better pain management for children.

Although SKIP's finite funding from the NCE-KM has come to a close, SKIP continues its national mission and vision as a university-based centre. From its inception, SKIP was built on a foundation of engagement with patients (children and youth) and caregivers (parents and/or family) as guided by the Patients Included™ charter, even though this was not required for NCE-KM funding [11]. SKIP's exclusive focus on KM in children's pain complements other pediatric and pain-related KM and research networks in Canada [12–15].

This article celebrates and shares SKIP's evolving best-practice approach to partnering with patients over its time as an NCE-KM network. We provide details about SKIP's patient partnership foundation and explore how and why SKIP evolved its language from patient engagement to patient partnership. We also discuss how SKIP deliberately and conscientiously increased diversity and inclusion of patient partners and share how SKIP tailored its patient partnership approach based on context and type of engagement. While SKIP's activities focused on KM, its patient partnership principles and learnings can be applied broadly across the research process. We share information and resources so that others can adapt and adopt what is most relevant to their context.

Main text

SKIP's foundation for patient engagement and partnership

With primary funding from the NCE-KM program, SKIP was established in 2019 with a mission to mobilize evidence-based solutions for children's pain management in Canada [16]. Unique to SKIP's NCE-KM funding requirements, SKIP was co-led by academic (CTC, KAB) and knowledge user (Children's Healthcare Canada; EG) partners [17]. Children's Healthcare

Canada is a national association with 48+ healthcare organization members, whose mission is to accelerate excellence and innovation in health systems caring for children and youth through purposeful partnerships [17]. SKIP's NCE-KM network was hosted at Dalhousie University from 2019 to 2024 and continues there as a university-based centre (2024-present). SKIP's central administration team is located at Dalhousie University, with six hubs located across Canada (IWK Health, Halifax; CHU Sainte-Justine, Montreal; Children's Healthcare Canada, Ottawa; The Hospital for Sick Children, Toronto; Stollery Children's Hospital, Edmonton; University of Calgary, Calgary). In addition to Children's Healthcare Canada's members, SKIP's hubs worked with more than 175 diverse sector partners and youth and caregivers to collaborate and co-produce interconnected KM activities.

Patient engagement was integral from the conception of SKIP and in its initial application to the NCE-KM program. Since then, SKIP's patient engagement approach has grown and evolved. Patient partners were involved in writing the original NCE-KM grant application in which patients were incorporated in its governance (as Board members), management, and committees, and as part of all KM activities (see Fig. 1). SKIP's four KM goals related to children's pain management are outlined in the organization's logic model, and include: (1) identifying and filling gaps; (2)

producing and promoting tools; (3) facilitating institutional change; and, (4) raising awareness and creating urgency.

These KM activities have included needs assessments, KM tools and resources, presentations, and media opportunities, among others. As much as possible, SKIP's activities are provided in English and French as Canada's official languages. SKIP's first needs assessment was done prior to its inception as a network, informing SKIP's NCE-KM application and subsequent KM activities to address the unique needs and barriers of patients and caregivers, researchers, and other knowledge users (i.e., health professionals, administrators, policymakers, educators) in accessing evidence-based solutions for children's pain [18]. SKIP invested in administrative team staff members with lived experience and whose roles were dedicated to patient engagement. Given SKIP's unique decentralized model with hubs located across Canada, patient engagement activities were guided by a unified approach, though were tailored based on purpose, location, resources, and/or expertise. Tailored approaches are discussed and illustrated in more detail below.

SKIP's language related to patient engagement evolved over its course as a NCE-KM network. Originally SKIP used the term 'patient engagement', ultimately shifting to the term 'patient partnership' to better reflect equal footing to and to recognize the value of the knowledge and expertise brought by patient partners. SKIP's patient partnership model was built on the Patients Included™

Governance and operations	Knowledge Mobilization Goals and Activities			
	Confirm knowledge user needs and organize current resources and evidence	Produce and promote knowledge mobilization tools	Facilitate institutional change	Increase awareness and foster a sense of urgency
<ul style="list-style-type: none"> • Board members • Staff • Patient and Caregiver Advisory Committee • Project advisory committees 	<ul style="list-style-type: none"> • Identify needs and gaps • Co-develop priorities and action plans • Inform needs assessments, evidence summaries, resource repositories, and environmental scans 	<ul style="list-style-type: none"> • Co-develop tools for patients, caregivers, health professionals, and policymakers <p>(e.g., conferences, blogs, booklets, toolkits, educational materials, infographics, learning modules, podcasts, policy roundtables, posters, videos, webinars, websites, digital events, pamphlets, fact sheets, conversational guides).</p>	<ul style="list-style-type: none"> • Member of national guideline development working group • Consult on adaptation and implementation of quality, equitable pediatric pain care • Identify pain champions 	<ul style="list-style-type: none"> • Co-develop and present in webinars and workshops • Media interviews • Lobby day on Parliament Hill • Panelists • Co-develop social media and public awareness campaigns

Fig. 1 Breadth of SKIP's Partnerships with Patients. This figure demonstrates different ways in which patient partners were engaged across all of SKIP's NCE-KM governance and operations, and its four KM goals and their associated activities

charter, which provides organizations with a means to demonstrate “...their commitment to incorporating the experience and insight of patients into their organisations by ensuring that they are neither excluded nor exploited” [11]. SKIP has continually been guided by the Patients Included™ Ethics Charter which means involving patients in all of its work and supporting those patients via providing needed accommodations, paying for expenses related to engagement, and offering compensation [19]. SKIP recognized that the tenants of the Patients Included™ charter represented a minimum standard for non-exploitive inclusion of patient partners and has evolved its own patient partnership practice beyond the initial charter requirements (more details below).

Patient partnership in SKIP's governance, committees and network team

Patient partnership is a foundational value for SKIP. During its time as an NCE-KM network and required incorporation as a not-for-profit, individuals who identified as patients or caregivers were members of SKIP's Board of Directors, committees, and staff. SKIP organizational roles directly related to patient partnership and their responsibilities are described in Table 1. One key organizational role was SKIP's Patient and Caregiver Advisory Committee (PCAC), discussed in more detail later in this paper as a case example. Regarding staffing, two staff members at the SKIP administrative centre were directly

involved in patient partnership work during SKIP's time as an NCE-KM network. A full time Engagement and Impact Coordinator facilitated patient partnership throughout the administrative centre's activities, supported patient partnership best practices and processes, and provided guidance to the SKIP hubs in their patient partnership work. A part-time Patient Partnership Advisor (IJ) brought her own lived expertise in rare disease, a lifetime of chronic pain, and as a parent of two disabled young adults with lived experience of pain, in addition to her own experience as a patient partner and in advising on quality patient partnership. The Patient Partnership Advisor role was dedicated to continuously improving patient partnership practice by supporting SKIP staff, hubs, and patient partners. All activities undertaken by SKIP's administrative centre included patient partners such as communications, reporting, branding, design, and implementing patient partnership activities.

Processes and resources to support patient partnership

A number of processes and resources were created over time to support patient partnership activities across the SKIP network. One of the PCAC's first activities was developing a patient partner *compensation guidance document* applicable to all SKIP-led and funded activities [20]. In practice, there was some variability in compensation amounts across KM activities due to policies and practices in place within SKIP hub institutions and

Table 1 SKIP organizational roles and responsibilities directly related to patient partnership

Role title	Responsibilities related to patient partnership/engagement
Patient Partnership Advisor	<ul style="list-style-type: none"> -Direct contact for PCAC and individual patient partners working with SKIP -Provide expertise on Patients Included™ principles and requirements -Liaise between the wider SKIP Network, partners, and PCAC -Advocate for equity, diversity and inclusion (EDI) across SKIP activities, including during the formation of new initiatives and opportunities -Develop and update resources to support full scope of patient partnerships, including recruitment, onboarding and registration materials -Advise and mediate emergent issues, obstacles, or concerns from SKIP staff and/or patient partners related to collaboration and other patient partnership activities -Support onboarding and initial contact with patient partners engaging in SKIP activities -Support all SKIP staff with relationship-building and maintenance with patient partners, including participating in regular check-ins with patient partners
Engagement and Impact coordinator	<ul style="list-style-type: none"> -Maintain and align patient partnership resources with SKIP administrative requirements -Maintain and update patient partnership database -Establish and update administrative financial requirements for patient partnership compensation payments and honoraria -Support Knowledge Brokers with outreach, relationship-building, and collaboration with patient partners
Knowledge Broker	<ul style="list-style-type: none"> -Develop, update, and support dissemination of patient partnership opportunities, utilizing SKIP's Patient Partnership Opportunity template -Ensure patient partnership opportunities are integrated into novel initiatives and activities -Provide briefing and onboarding to patient partners to orient them to participation in novel initiatives or collaborative activities -Support SKIP Administrative Centre staff with onboarding of patient partners for financial compensation and/or honoraria -Provide and organize regular check-ins with patient partners to ensure sufficient support provided and/or concerns addressed

partner organizations. Despite this, a commitment to offering compensation was upheld across all of SKIP's KM activities. SKIP advocated with other organizations and partners when compensation practices or amounts were lower than those in SKIP's guidance document. SKIP's compensation guidance document has been accessed numerous times via SKIP's website, and has been cited by other organizations as directly informing their own compensation guidance documents [21, 22].

Another key SKIP patient partnership resource was a *patient partner database* used to identify and communicate with patient partners about KM opportunities. The database was initially populated with individuals with whom SKIP had already partnered. At that time, no demographic information was collected, and patient partners were only asked to indicate their interest in types of KM opportunities (e.g., tool and resource development, workshops, advocacy opportunities, media engagements, etc.). Realizing the limited diversity in existing patient partner perspectives, SKIP began to intentionally recruit greater diversity in patient partners with regards to age, race, ethnicity, sex, gender identity, sexual orientation, disability, rurality, geographical location, pain and/or healthcare experiences. New patient partners could sign up directly for the database, and information was shared broadly about new KM opportunities. SKIP's patient partner database was housed in SimplyCast, an online customer relationship management (CRM) platform focused on communication and engagement solutions.

Following consultation with Dalhousie University's Research Ethics Board (REB), it was determined that SKIP's activities are not considered research and fall within Article 2.5 of the Tri-Council Policy Statement (TPCS2 2022) and therefore would be exempt from the requirement of REB approval [23]. However, all information collected related to patient partners—including information stored in the patient partner database—were treated as confidential.

Legend: Table 2 shares a number of resources that were developed (often by and with the Patient and Caregiver Advisory Committee) to facilitate patient partnership work at SKIP. It may be helpful for other organizations committed to patient partnership to develop similar types of documents tailored to their organization and organizational structure. Documents can be accessed by contacting the corresponding author.

Patient partnership in SKIP's KM activities

Some flexibility implementing patient partnership in all of SKIP's KM activities was needed depending on its purpose, resources, and who was engaged (including patient partners). Despite this, fundamental principles for

patient partnership remained similar and guided by the Patients Included™ Ethics Charter (see Fig. 2) [19].

Each of SKIP's hubs included a Knowledge Broker who was supported in their patient partnership work by the Patient Partnership Advisor. The Patient Partnership Advisor was available to coach, onboard and provide tools to create an equitable experience for patient partners involved in SKIP work at the hubs. In some cases, SKIP tools, resources, and practices were integrated into the hubs' non-SKIP patient partnership practices in KM and research.

During its time as an NCE-KM network, SKIP developed offered a consultation service called 'Jump in with SKIP' for any Canadian-based researcher looking for guidance incorporating patient partners and effective KM into their research to help ensure its greatest impact. 'Jump in with SKIP' provided mentorship in patient partnership and access to >100 patient partners in SKIP's patient partner database (see one example here [24]). The 'Jump in with SKIP' service could be accessed by completing a brief online survey linked from SKIP's website or via email to anyone within the SKIP network. Interested parties were connected with SKIP's Associate Scientific Director (KAB) and/or SKIP Knowledge Brokers for support.

Demonstrating SKIP's patient partnership in action

While the above part of this paper shares SKIP's general approach and developed resources for patient partnership, there is also value in illustrating SKIP's approach to patient partnership in action during its time as an NCE-KM network. Here we highlight SKIP's leadership in patient partnership through three national project examples (see Fig. 3). These were chosen to showcase both the breadth and impact of quality patient partnership.

Patient and caregiver advisory committee (PCAC)

At the inception of SKIP as a NCE-KM network in 2019, its original PCAC consisted of two youth and two co-chairs (DPR, IJ). Over time, the PCAC grew. At the conclusion of SKIP's time as an NCE-KM in 2024, the PCAC's membership totalled eight diverse members with both youth and caregiver perspectives of unique intersectionalities from across Canada. Included in the membership was one patient partner co-chair (KS) who was supported by the Patient Partnership Advisor (IJ) and the Engagement and Impact Coordinator. Recruitment of these committee members was supported by the PCAC Member Application forms (see Table 2).

The PCAC's role was to build meaningful partnerships with patients and caregivers and ensure alignment of SKIP's governance and KM activities with the Patients Included™ Ethics Charter [19]. In addition to

Table 2 Patient partnership resources created by SKIP

Resource name	Why the resource was developed and its description
Patient Partner Opportunity Template (see Additional File 1)	Created as a template for knowledge brokers and others, as applicable, to advertise and promote opportunities for patient partners to engage with SKIP activities. The template requests that the opportunity is described in approachable language, and that it provides all relevant information for patient partners about the available opportunity for partnership with SKIP. The template prompts those who will post the opportunity (or reach out to a specific patient partner) to provide context and key standardized details related to the opportunity and the kind of engagement requested (i.e., activity details and what to expect, project title, background about the project, how much time will it take?, what would I asked to be do?, is it suitable for a beginner?, can it be done from home?, who are my contact persons?, compensation)
Equity, Diversity and Inclusion (EDI) Based Patient Partner Application Questions	Developed to collect additional information about and from patient partners who applied to partnership opportunities at SKIP, as a way to focus on equity, diversity and inclusion in these open calls. For example, information was collected on race, gender, identity, disability, etc., and the questionnaire was worded to be inclusive, provided an explanation as to why such demographic information was being collected, and if helpful, a SKIP staff member would be available to help potential patient partners fill out the form
Compensation Guide for Patient Partners	Developed as a practical document to help patient partners understand more potential choices with respect to accepting compensation from SKIP. The document explains the difference between paying expenses and providing compensation, different options for these and estimated timeline for reimbursement or payment. Potential forms and information that may be requested are also explained
Compensation Guide for Knowledge brokers	Developed as a practical document to help SKIP's knowledge brokers understand more about how to implement SKIP's Compensation Guide for Patient Partners. The document explains the difference between paying expenses and providing compensation, provides some resources that may be helpful, shares a flow chart of steps related to expense and compensation payment along with information associated with each step
PCAC Member and Patient Partner Recruiting Forms	These application surveys were created the Patient Partner Advisor initially to support the recruitment of members for the PCAC and then later adapted (with input from the PCAC) for recruitment for patient partners. In addition to asking about basic personal and contact information, the surveys prompted applicants to voluntarily provide demographic data related to EDI, including age, gender identity, First Nations status, racial background, and disability status. The language in the survey was intentionally used to be inclusive of equity-seeking communities in order to encourage their participation. The survey was shared via both SimplyCast and Qualtrics and supported the creation of a PCAC with diverse representation and more diverse patient partners
Onboarding Form and Conversation Guide	Created as an intake form to collect the information required from patient partners to facilitate expense and compensation payment. Information collected includes the partnership opportunity and compensation amount, patient partner personal information (including preferred name, pronouns, address, email address), communication preferences, accessibility needs, type of compensation and frequency of payment, and other required payment information
Onboarding Slide Deck Template	This slide deck was initially created to onboard PCAC members and then was used to create a template for other partnership opportunities. The intention was to have an opportunity to orient new patient partners to SKIP, show them how their opportunity fit into SKIP's work, and provide details on how their patient partnership opportunity would be conducted. There was also an opportunity for the patient partner to ask questions of SKIP staff during this onboarding process
Terms of Reference for Committees with Patient Partners (see Additional Files 2 & 3)	These terms of reference documents were developed to support clarify of scope, responsibilities, and structure of committees within SKIP and SKIP initiatives that involved patient partners. These documents are described in more details below pertaining to: (1) SKIP's Patient and Caregiver Advisory Committee; and (2) SKIP's Youth in Pain project National Advisory Group

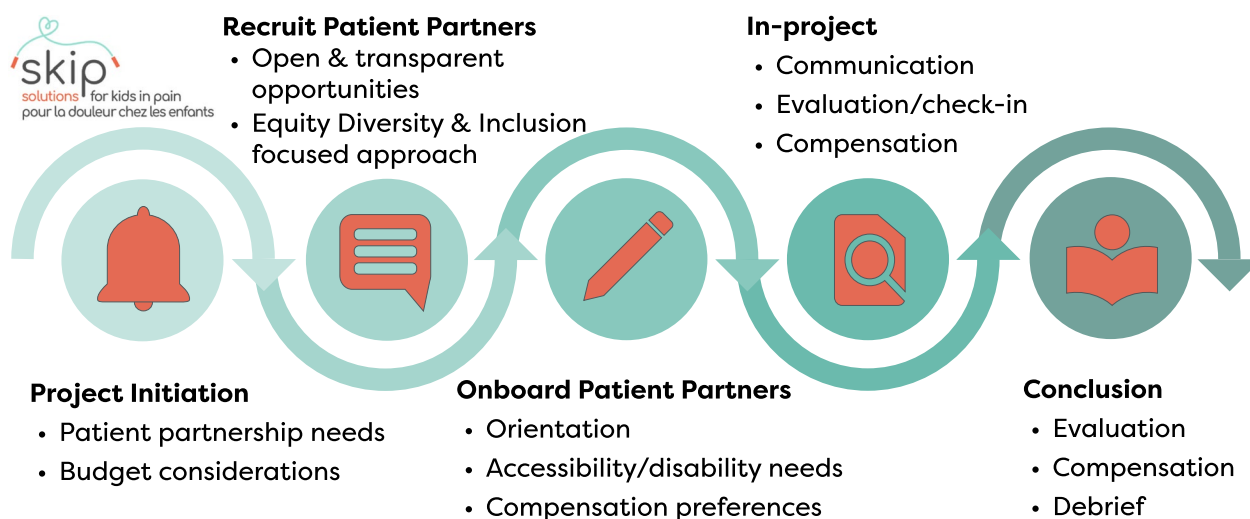


Fig. 2 SKIP's Patient Partnership Practice: A non-comprehensive workflow. The basic workflow followed by SKIP to engage patient partners throughout its project activities from start to end. Some approaches and activities related to each part of the workflow are highlighted

the compensation guidance document, the PCAC developed a plain language Terms of Reference document (see Additional File 2) that was finalized with support from a plain language writing specialist. The Terms of Reference included core values for the PCAC (respect, belonging, equity, fun), the functions of the PCAC, expectations of members, and responsibilities of the SKIP team. PCAC members were offered compensation for their role, meeting individually with the Patient Partnership Advisor to determine preferences around compensation, including the option to decline compensation.

PCAC meetings were held virtually 3–6 times per year. Meetings were designed to create a safe environment for members where openness and honesty were encouraged. The PCAC meeting approach evolved as patient partnership did at SKIP. For example, with an increase in members, efforts were made to ensure the Committee's final composition included a higher ratio of youth to caregiver members to reduce power differentials. Meetings were scheduled according to the members' availability across time zones, including weekends. Members were asked at each meeting about any accessibility needs to facilitate their participation, Zoom's automated closed caption functions were enabled, members were welcome to have their cameras on or off, and members could contribute verbally or via the platform's chat function. If members could not attend a meeting, they could provide feedback and insights to the Patient Partnership Advisor separately.

Initially, the PCAC co-chairs (DPR and IJ, appointed by SKIP leadership) developed meeting agendas in collaboration with a SKIP administrative centre staff member.

As the PCAC expanded, one co-chair (KS) was appointed with the intention to add another co-chair once the committee was more established (which did not happen due to timing). From this point the meeting agendas were developed collaboratively by the PCAC co-chair and Patient Partnership Advisor, and the latter supported the co-chair's facilitating of meetings. The Engagement and Impact Coordinator provided administrative support by scheduling meetings and taking meeting minutes. Meeting materials were usually sent out by the Engagement and Impact Coordinator or by the Patient Partnership Advisor, and at least 1 week in advance to provide members time to review.

In June 2023, a priority setting workshop was undertaken with the PCAC, to identify continued patient partnership priorities for SKIP as its NCE-KM funding was ending in 2024 and it explored organization sustainability options (later confirmed in its current state as a university-based centre in 2024). A consultant (DPR), was engaged to co-design the agenda with the Patient Partnership Advisor and PCAC co-chair, to facilitate the workshop, and to develop a workshop report. The consultant was one of SKIP's original PCAC co-chairs, has lived experience of pain herself, and has worked for over a decade to help organizations develop patient partnership in research activities and resources. The virtual workshop was hosted over two 1.5-h sessions (in the same week, 1 day apart) to accommodate potentially reduced energy and availability given PCAC members' accessibility requirements. The interactive workshops resulted in several PCAC-ideated potential actions for the PCAC and

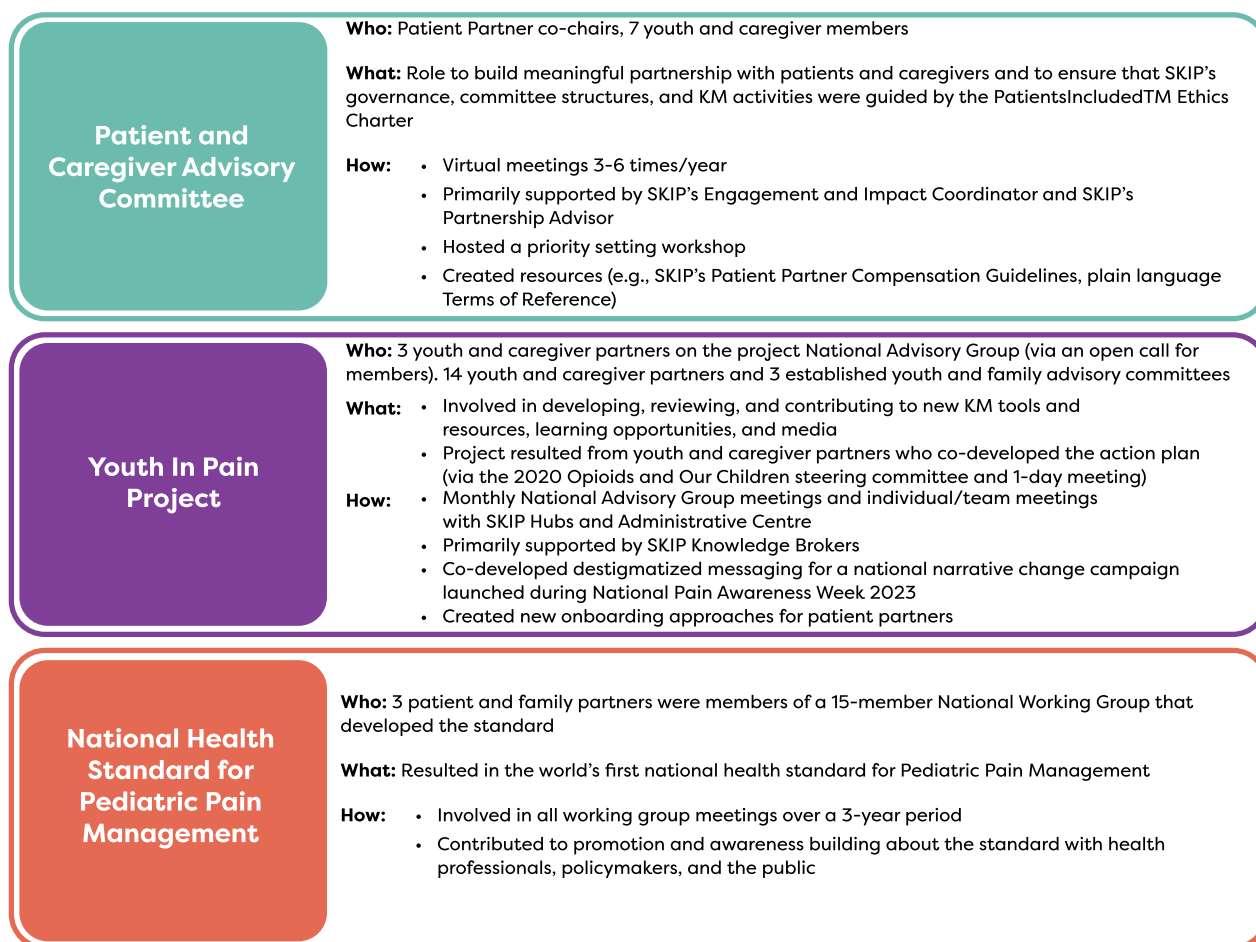


Fig. 3 Examples of Patient Partnerships at SKIP. The figure shows how patient partnership at SKIP was tailored to three national projects. For each project, the number of patient partners engaged, the ways in which they were engaged, and the supports provided to them are shared

SKIP. SKIP's Scientific Director (CC) and Associate Scientific Director (KAB) attended part of the first meeting to answer any questions and to be transparent that moving any identified priorities forward would be dependent on alignment with SKIP's evolving sustainability plan beyond the NCE-KM funding period. The workshop was a powerful way to engage the PCAC in a bottom-up, patient partner-led exercise as opposed to having priorities imposed in a top-down manner. As SKIP has transitioned to its current phase as a university-based centre, the ideas from the workshop have been shared with SKIP's leadership and Board as a potential driver for future patient partnership strategies.

Evaluation has been important to understand PCAC members' experiences. The PCAC concluded its activities with the natural ending of SKIP's NCE-KM funding. The Patient Partner Advisor (IJ) undertook an exit evaluation of PCAC members using the Patient

Engagement in Research Scale (PEIRS-22) [25]. PCAC members expressed that SKIP had created a safe environment, staff showed commitment and patience in their work, compensation was appreciated, and relationships were built. Main areas of improvement noted were the speed with which compensation was issued, meeting minute formatting, and more opportunities for engagement (through more meetings or other opportunities at SKIP). Seven of eight PCAC members were also interviewed to understand what went well and what needed improvement related to their experiences. Interviews were conducted by an administrative centre staff member who did not directly work with the PCAC to encourage safety. Responses were anonymized before being shared with the Patient Partnership Advisor.

The PCAC made influential and sustained contributions to SKIP and beyond, in part via resources that shared best practices in patient partnership. In addition to the above-mentioned plain language Terms of Reference document and SKIP's Compensation Guide for

Patient Partners [20], more resources are described in Table 2.

Youth in pain: solutions for effective opioid use

The Youth in Pain project effectively illustrates how SKIP involved patient partners throughout the arc of a project from initial idea generation to action and sustained impact. This project was the culmination of a co-developed action plan and shared evidence-based solutions for the medical use of opioids to address short- and long-term pain in youth [26]. Patient partners collaborated in all activities from start to finish, either as members of committees or advisory groups, and/or in developing all KM documents, tools, and resources. Steps were taken to ensure partnership was meaningful and sustained throughout, with patient partners contributing to all phases of KM and project development. Patient partners were offered compensation as per SKIP's guidelines [20], and were supported throughout, including being provided direct support from SKIP's knowledge brokers and administrative centre staff.

In February 2020, SKIP and the Canadian Foundation for Healthcare Improvement (now Healthcare Excellence Canada) co-hosted a national scoping meeting focused on effective and safe use of opioids for pain in children [27]. The Steering Committee that planned the 1-day meeting included patient and caregiver partners and undertook pre-meeting activities such as an environmental scan of existing initiatives, resources, and invested knowledge users; and, a rapid literature review. Patient and caregiver partners were among the 29 knowledge users who participated in the meeting with representatives from pan-Canadian health organizations, health professionals, researchers, regulatory and policy officers, and knowledge brokers. From this meeting the Steering Committee co-developed an action plan of priorities and required activities and resources to support safe, effective, and equitable prescribing and use of opioids for pain in children. SKIP then applied and received funding from Health Canada's Substance Use and Addictions Program (SUAP) to carry out the action plan (August 2022 to March 2024) called "Youth in Pain: Solutions for Effective Opioid Use" [26].

The project was guided by a National Advisory Group composed of a range of organizational partners, health professionals, patient and caregiver partners, policy leaders, and individuals with lived experience in pediatric pain. The National Advisory Group members reflected a broad range of opinions, experiences, and expertise representing a balanced diversity of perspectives and interests on the topic. At the time, youth perspectives were not sufficiently represented in SKIP's patient partnership database. Therefore, SKIP organized an open call

for patient and caregiver members of the National Advisory Group, with guidance from SKIP's Patient Partnership Advisor, to support engaging new individuals and to integrate youth perspectives. The open call resulted in 17 expressions of interest. A short-list of individuals was created based on eligibility criteria of relevance to the project (i.e., experience as an individual or as a caregiver of an individual with pain during childhood who used opioids for pain management) and considerations of diversity (e.g., geographical location, age, ethnicity). These individuals met virtually with the lead knowledge broker (RF) for the project to confirm their interest and fit for the planned activities. Ultimately, three individuals (two youth and one parent) joined the National Advisory Group. A terms of reference document, based on that of the PCAC, was co-developed for and with input from the National Advisory Group (see Additional File 3). In an effort to create a safe, nonjudgmental space for its members, a specific section of the terms of reference set ground rules for engagement focused on safety, respect, inclusivity, accessibility, privacy, and confidentiality. Additional content addressed the National Advisory Group mandate, member roles and responsibilities, conflicts of interest, compensation, and consensus-based decision-making. All of the National Advisory Group members were invited to complete an adapted version of the Patient Engagement in Research Scale (PEIRS-22) to report on their engagement experiences [25].

Beyond the National Advisory Group, 14 patient partners were engaged throughout the project's activities, including in developing, reviewing, and contributing to newly developed KM tools and resources (e.g., conversation guides, handouts, toolkits, articles, videos, messaging for national public awareness campaign), learning opportunities (e.g., interactive online educational modules, webinars, presentations), and media (e.g., radio, television). An additional 75 youth and caregivers were engaged across 3 existing youth and caregiver advisory committees to provide feedback on specific KM tools led by SKIP's hub in Edmonton. The project drew from other existing patient partnership documents within SKIP including the Patient Partner Opportunity Template and equity, diversity and inclusion-based Patient Partner Application Questions, and compensation guidance documents. All patient partners were compensated as per SKIP's compensation guidelines [20] except when SKIP's Edmonton hub engaged established local institution youth and caregiver advisory committees. In this case honoraria were provided in line with local institutional policies (e.g., gift cards for food).

SKIP recognized that stigma and stigmatization were critical features of this project which focused on a charged societal issue. Intentional time and care were

taken by the SKIP team, particularly the project's knowledge broker (RF), to develop relationships with patient and caregiver partners. These efforts included both individual and group onboarding and separate meetings as needed throughout the project. Early in the project, the knowledge broker created time with a patient partner member of the National Advisory Group to have a discussion and listen to their thoughts around the topic of opioids and pain, including the importance of education and stigma. With permission, this unstructured interview was recorded and transcribed, and later integrated into an online article that helped raise awareness on the project's priorities and a number of its deliverables [28].

Based on the positive experience from the unstructured interview for SKIP and the patient partner, the project team organized other opportunities for storytelling called sharing sessions which were focused on this topic. Across the project, two separate stigma sharing sessions were done with three patient partners. For safety reasons these sessions were attended by at least two SKIP team members and patient partners had 60–90 min of unstructured time to share their experiences, life stories, and/or priorities for action. These sessions were critical to build trust and for SKIP to demonstrate its investment and interest in patient partner experiences and contributions beyond use for a predetermined deliverable or publicity event.

SKIP learned about the best ways for it to onboard patient partners in this project. The onboarding experience was streamlined to ensure ease of approach and a minimum burden of bureaucracy for partners, and to be consistent and flexible in ensuring that honoraria was provided to all those who contributed. During the onboarding of a patient partner, SKIP learned about a document that a family had produced that was especially useful for pain management in the patient partner's own healthcare journey undergoing surgery. SKIP has since collaborated with the family and the patient partner to adapt this document for broader audiences. To learn more about this document and ensure being aligned with the family's vision for it, the project's knowledge broker hosted an hour-long discussion to explore how the mother-daughter duo wrote and developed its content, and asked them about their potential openness to adapting it for more general use with families in Canada. Regular check-ins with the family took place to ensure SKIP's tool development plan was acceptable, meaningful, and aligned with their expectations. The family reviewed the final draft and had a check-in with SKIP before it was published [26]. This is an example of SKIP's flexible approach to partnership and in co-creating a patient partner-driven knowledge product.

Recognizing that patient partners' experiences might have been different from others on the National Advisory

Group, SKIP offered dedicated, private feedback sessions to close out the project and to gather their input and reflections. During one of these calls, a patient partner reflected that the experience was “extremely positive” and that the space created in the Advisory Group was “extremely respectful”—that it was a “receptive” and “non-hierarchical” space that “warmly welcomed” them and their perspectives and contributions (these comments were used with permission from this patient partner).

Lastly, SKIP has continued relationships and work from this project into other work. From the open call for the patient partners for the National Advisory Group, SKIP opened calls to the public for other partnership opportunities related to specific project deliverables. SKIP short-listed candidates based on their survey responses and did a brief interview to ensure fit. Mutual introductions were made to SKIP team members prior to the collaborations beginning, so that the patient partners felt a sense of continuity. In some cases, the project's knowledge broker participated in collaborative sessions with the new patient partners and knowledge brokers from other SKIP hubs leading specific KM tool development to ensure patient partner comfort. These partners found their engagements extremely meaningful, and they have maintained connection with project team members (e.g., knowledge brokers and administrative centre staff) via text/email following their contributions to these specific deliverables. These partner-team connections have proven durable, with those patient partners engaged in follow-up opportunities to share their stories and perspectives in other events, such as webinars, talks, and/or articles.

National health standard for pediatric pain management

Developing a national health standard for pediatric pain management was part of SKIP's initial application as an NCE-KM in 2019. This came to fruition in 2023, when SKIP, in partnership with the Health Standards Organization, published the world's first national health standard for Pediatric Pain Management [29]. The standard guides quality, equitable pain management for children (from birth to 19 years less one day) and their families in all hospital settings. It outlines 34 criteria for health care leaders and teams. The standard is a huge step towards more equitable, consistent and evidence-based pain management for children and their families across Canada.

Three patient and family partners were integral to developing the standard and in continuing efforts to build awareness about the standard. They were members of the national working group and participated in all meetings over a 3-year period, receiving compensation for their work. Patient and family partners shared

their expertise equally and alongside multidisciplinary health professionals (medicine, nursing, psychology, child life, physical therapy), hospital administrators, and policy/health standard experts on the working group to co-develop and review the structure and content of the final published health standard. Their contributions were critical to emphasizing the person-centered, equitable approach to pain management promoted throughout the standard's criteria. The resulting standard was one where children and families are centered as equal members of their health team. The standard recognizes the lived experience patients have as experts with respect to their own pain and the importance of acknowledging and taking into account that expertise [30, 31].

Patient and family partners have been integral to spreading awareness about the standard amongst the public, patients and caregivers, health professionals, and policymakers through presentations, articles, town halls, government briefings, and media [30–32]. Patient and family partners involved in developing the standard have shared what being involved meant to them and how they viewed their impact in its development. For example, one individual hopes that the standard will help patients, families and health professionals to develop a plan to manage pain, and lead to more consistent care, no matter where that care is delivered in Canada [33]. The standard also includes guidance on working with children who are non-verbal or who communicate in different ways. Another patient partner felt that a key part is that the standard addresses that trauma may be present, it encourages empathy from and listening by health professionals, and it should encourage discussions about pain management alternatives.

Key insights on patient partnership

We set out to share SKIP's learnings during its time as an NCE-KM, integrating extensive patient partnership on a national scale with varied partners and across diverse KM activities. Key facilitators and challenges related to this work are shared in an effort to support others in designing and carrying out quality patient partnership within their own work.

Facilitators

Dedicated resources are required to set up and structure processes for meaningful patient partnership. Human resources dedicated to supporting patient partners and staff, building partnerships, and financial resources are needed. SKIP leadership committed to providing the resources required to successfully enable patient partnership and brought prior extensive experience engaging in quality patient partnership in research and KM with children, youth, and families. An Engagement and

Impact Coordinator and a Patient Partnership Advisor were these human resources for SKIP; however, SKIP worked intentionally to build capacity amongst all of its network members (i.e., SKIP hub leads, knowledge brokers, administrative centre staff) for increased quality patient partnership (see Table 1). SKIP budgeted to support diverse patient partners through offering them compensation, to pay their expenses related to being engaged, and to support their engagement in other ways (e.g., through paying for a course, etc.). Time needs to be built into any project or initiative to allow as much flexibility as possible to respond to the people and needs within a project. For instance, building relationships with patient partners, developing a safe environment and trust within a group, and recruiting for diverse voices, all take an investment of time and likely will follow a trajectory different to the original project timelines. A diverse range of lived experiences and expertise in patient and caregiver partners is also important to increase the relevance and impact of any projects, initiatives and their outputs and outcomes. Working with diverse partners including patient organizations supported SKIP's ability to engage in broader and more diverse patient partnership, and to leverage additional sources of funding. SKIP's integral engagement with diverse patient partners supports its ability to engage effectively with policymakers, including in federal government, as they are often interested in hearing directly from people with lived experience.

As SKIP strengthened and established its processes and procedures, it gained visibility, respect and a reputation for this work. Positive patient partnership experiences travel quickly by word of mouth. SKIP became viewed as a highly credible organization with respect to partnership which aided recruitment of new patient and family partners.

Challenges

There are a number of challenges in this work and many of these are related to the structures in which SKIP operated. For example, with respect to compensating PCAC members, there were comments about how long processing could take—which was mainly due to institutional processes and timing. While the SKIP administrative centre and network used the PCAC's compensation guidance, SKIP's hubs were located at different institutions which often have their own compensation guidance and their own processing approaches (and sometimes challenges). With respect to applying an equity, diversity, inclusion, and accessibility lens to building its patient and caregiver partner database, a balance needed to be struck between asking more questions of potential patient and caregiver partners with being mindful of what might feel unsafe or intrusive. SKIP evolved in understanding

about how and what questions to ask when finding new patient partners. Expertise and input from SKIP's Patient Partnership Advisor and PCAC guided its improved recruitment of patient partners from equity-deserving communities. SKIP experienced staff turnover throughout its lifetime which can be challenging when needing to build trusting and stable relationships with patient and caregiver partners. Although SKIP had a robust evaluation framework for its KM activities, in SKIP's efforts to evaluate diverse patient partnerships ranging across the spectrum of partnership and activities, it was difficult to use one consistent evaluation approach. Tailored evaluation approaches provide richer information on partnership experiences, but do lead to more complexity in evaluation and potentially difficulty in comparing evaluations. Finally, although SKIP has prioritized providing its resources and tools in both English and French, as Canada's two official languages, we recognize that there are many other languages used by people living in Canada. Translating and adapting these resources would require additional funding and time, and is a future opportunity for expansion and increased accessibility.

Conclusions

Over its 5-year lifespan as an NCE-KM network (2019–2024), SKIP committed to and wove patient partnership throughout all aspects of its work. Patient partners were critical to its governance, committees, and staff, and contributed in diverse ways to a broad range of KM activities at SKIP's administrative centre and at SKIP's hubs. We share here the evolution of and insights from SKIP's patient partnership activities, including a number of resources for others to make their own. SKIP's commitment to learning and continuous improvement was a key factor to quality patient partnership. We hope others learn from this important patient partnership work. As SKIP continues as a university-based centre beyond its NCE funding, it remains committed to developing, actioning, and sharing quality patient partnership practices and resources as a leading example for others.

Abbreviations

EDI	Equity, diversity, and inclusion
KM	Knowledge mobilization
PCAC	Patient and Caregiver Advisory Committee
PE	Patient engagement
PEIRS	Patient Engagement in Research Scale
SKIP	Solutions for Kids in Pain
SUAP	Substance Use and Addictions Program (Health Canada)

Supplementary Information

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Supplementary Material 1.
 Supplementary Material 2.
 Supplementary Material 3.
 Supplementary Material 4: Peer review reports & author comments.

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Author contributions

DPR, CTC and KAB led conception of the work, DPR convened the writing group and discussions (CTC, IJ, KS, RF, LT, KAB). DPR led writing the manuscript. All authors contributed to the design, analysis of the work and in writing and revising the manuscript. All authors read and approved the final manuscript.

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Not applicable.

Consent for publication

The individuals whose quotations are used above provided consent to do so as noted in the text.

Competing interests

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Peer Review

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