

Preface

The 'Youth in Pain: Solutions for Effective Opioid Use' project is a nationwide initiative led by [Solutions for Kids in Pain \(SKIP\)](#) to improve safe, effective, equitable, and evidence-based use of opioids for pain in youth in Canada. Lasting through March 2024, this project will co-develop resources, mobilize evidence, build capacity, and launch a national awareness campaign related to opioid use for acute and chronic pain in youth. This project is supported by Health Canada's Substance Use and Addictions Program (SUAP).

Purpose of the 'Youth in Pain' (YIP) National Advisory Group Terms of Reference (TOR)

This Terms of Reference (TOR) document outlines the roles and responsibilities of the National Advisory Group (AG) for the 'Youth in Pain' (YIP) project, including guidelines for how the AG operates, its mandate, duration, and meeting frequency.

Amendments to this TOR, if required, will be made in consultation with the SKIP YIP team and the AG members.

1. Definitions

The Advisory Group (AG)	The National Advisory Group (AG) for the 'Youth in Pain' project, which includes all members, co-members, and ex-officio/observing members.
National Advisory Group (AG) Members	The National Advisory Group for the 'Youth in Pain' (YIP) project is composed of members drawn from a broad range of organizational partners, healthcare professionals, parents/caregivers, policy leaders, and individuals with lived experience in this area. The AG members reflect a range of opinions, experiences, and expertise and represent a balanced diversity of perspectives and interests on the topic.
Ex-officio/observing Advisory Group members	The YIP project Advisory Group will include several observing/ex-officio members. These members are volunteer participants, and do not share the same obligations as noted below for official members. Their votes will be considered during consensus-based decision-making or votes by the AG. These members are

	fully bound by the Ground Rules of Engagement of the Advisory Group (see Section 6 below), including the Privacy and Confidentiality policies (Section 6b).
SKIP 'Youth in Pain' (YIP) Team	The YIP project is supported via scientific leadership from SKIP's Associate Scientific Director and a nationally-focused Knowledge Broker and a project coordinator, who are the project's primary points of contact. The YIP project activities are undertaken by all of SKIP's 5 hubs (Western, Central, Eastern, Children's Healthcare Canada, and Francophone), which include Hub Leads and Knowledge Brokers. The project is also supported via SKIP's Administrative Centre, including SKIP's Managing Director, a Patient Partnership Advisor, a Communications Specialist, and other operations staff. For more information see: https://kidsinpain.ca/locations/
SKIP Leadership Team	The SKIP Leadership Team supports the vision, direction, and oversees the execution of the YIP project. This includes Dr. Katie Birnie, PhD, RPsych, SKIP's Associate Scientific Director, Dr. Christine Chambers, SKIP's Scientific Director, and Emily Gruenwoldt, SKIP's Knowledge User Director. For more information, visit https://kidsinpain.ca/leadership/
SKIP Board of Directors	SKIP's Board of Directors supports the YIP project's vision, direction, and provides advisory input into the deliverables and integration of this project alongside the rest of SKIP's activities. For more information on SKIP's Board of Directors, including a full roster, please see https://kidsinpain.ca/directors/
Project Term	Begins August 2022 (backdated); ends March 2024
Consensus-based approach	In a consensus-based approach, participants are expected to openly discuss ideas, perspectives, and viewpoints; seek to develop common ground; and narrow areas of disagreement to the best of their ability. Differing viewpoints and opinions will be recorded and noted in Advisory Group meeting notes.

Youth	This project uses a broad definition of “youth”, focusing on the experiences of children, adolescents, and emerging adults from birth to 25 years old.
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2. Mandate

Four deliverables have been identified under the National Advisory Group (AG)’s mandate, to be completed by the end of the ‘Youth in Pain’ project term (March 2024):

1. Strategically support the development and dissemination of resources and system-level strategies for safe, effective, equitable and evidence based use of opioids for acute and chronic pain to benefit youth, parents/caregivers, healthcare professionals, and decision-makers.
2. Update and expand an Opioid and Pain in Youth resource toolkit.
3. Co-create a national public awareness social media campaign to reduce stigma and promote evidence-based use of opioids for acute and chronic pain in youth.
4. Provide guidance, input, and advise on the other activities of the YIP project led by the SKIP Hubs, including during invited presentations at monthly AG meetings (e.g., the Online Pediatric Pain Curriculum educational modules; educational opioid-focused tools developed for acute and chronic pain management; the Indigenous community engagement initiative, etc.)

3. Advisory Group Composition & Membership

The Advisory Group has been assembled with a strong commitment to equity and diversity in representation on this issue. This includes subject matter experts, patient and caregiver partners with lived experience, community leaders and advocates, and subject matter experts. At present, there are expected to be 16 AG members, with two of those participating in the capacity of “ex-officio” or “observing”.

4. Meeting Frequency and Attendance Expectations

The AG meets once a month, virtually for ~2 hours. Meetings will be held for the term of the ‘Youth in Pain’ project (March 2024).

Advisory Group members are expected to make their best efforts to attend these meetings, and support the Project Coordinator to find appropriate times to set their schedule (e.g., completing Doodle polls, e-mailing regarding availability, confirming dates and times that work, accepting meeting invites, etc.).

It is expected that individual AG members and/or their co-members attend at least half of the sessions through March 2024.

We are committed to inclusiveness and accessibility. We will strive to support other ways for members to participate in the Advisory Group activities as much as possible, such as providing written feedback on agenda items/items presented to the group, accessing recorded AG meetings, setting up smaller group meetings for discussing AG issues.

5. AG Members' Roles and Responsibilities

SKIP's 'Youth in Pain' Team:

- Circulates meeting agendas to AG members ahead of each meeting;
- Provides meeting minutes to AG members following each meeting;
- Communicates identified action items and establishes deadlines;
- Ensures the AG is on track to complete its deliverables by end of term;
- Coordinates consultation and input from the AG members via email;
- Coordinates invited AG meeting guests and presenters;
- Follows up on AG members' input;
- Regularly provides progress updates from the SKIP Youth in Pain team and the wider SKIP network, as relevant.

YIP AG Members:

- Provide their availability to assist the scheduling of monthly meetings;
- Attend at least half of scheduled monthly AG meetings;
- Provide consultation and input into project deliverables (see Section 2 above) and other items tabled for feedback at meetings and/or asynchronously via e-mail;
- Vote on decisions brought forward to the AG, using a consensus-based approach;

- Support gathering and assessment of existing resources for opioid prescribing for pain in youth;
- Identify priority areas where additional resources/tools related to opioid use for pain in youth are needed;
- Identify opportunities for new project partners for effective dissemination and impact of YIP activities;
- Support the evaluation of the YIP project, including filling out surveys and/or assessments related to AG operations;
- Advise on the development and testing of key messages for use in the National Awareness Campaign.

6. Ground Rules of Engagement for the Advisory Group

a. Safety, Respect, Inclusivity, Accessibility:

- Like all activities run by SKIP, the ‘Youth in Pain’ project is committed to making the Advisory Group a **safe, inclusive, equitable, and non-judgmental space** for its members.
- All members have **the right to “pass” on activities/questions that make them uncomfortable**, and do not have to provide a rationale for doing so. All voices and opinions during Advisory Group sessions are to be respected.
- Advisory Group members are expected to understand that this project, and the AG itself, is **focused on systemic challenges, not individual or personal ones**. Members are expected to avoid commentary on individual decisions regarding opioid treatment decisions, the non-medical use of opioids, or opioid prescribing choices made by others.
- An important goal of the YIP project is the de-stigmatization of opioid use, in both medical and non-medical contexts. In this sense, we expect AG members to **respectfully engage with each other and invited guests**, who may represent differing opinions or lived experiences with opioid use and stewardship in both medical and non-medical contexts.
 - We ask that AG members make efforts to **use non-stigmatizing language as it relates to opioid use**, as outlined in [this document from Health Canada](#).
- Across all project activities with AG involvement, equal value will be given to the opinions and experiences of medical professionals and those with

lived/patient experiences. **The Advisory Group is designed to be an open space for shaping the priorities for safe, equitable, effective use of opioids in youth in medical contexts.**

b. Privacy and Confidentiality:

All AG meetings will be recorded, and meeting minutes will be shared amongst members. However, there is a reasonable expectation of confidentiality and privacy at all AG sessions. Members, guests, and SKIP staff are expected to maintain the confidentiality of AG discussions and not share them outside of direct individuals involved in the YIP project or its deliverables. Any directly identifying information involving AG members or other parties is to be treated as private and confidential, and not shared to outside individuals without permission from the AG as a whole.

7. Feedback Sessions and AG Check-Ins

SKIP's YIP Team will schedule at least two or more opportunities for the AG to provide feedback on the project's progress and members' experiences. These feedback sessions may be conducted either directly via 1:1 sessions with SKIP YIP Team members and/or with the larger AG group to facilitate communal input. These check-ins will be offered both as a way for the AG members to reflect on their experience, provide feedback on the management and coordination of the YIP project as a whole, and to determine if continued AG membership is a good fit for them.

These sessions may be recorded and/or transcribed for testimonial/evaluation purposes, but only after explicit AG member consent is obtained by participants.

8. Decision-Making Processes

There will be several issues and items brought before the Advisory Group that will require decision-making or direct input from its members (e.g., content development for resources, priorities for awareness campaign deliverables, etc.). While making these decisions, the Advisory Group will operate using a consensus-based approach, with members providing advice and input to the SKIP 'Youth in Pain' Team. Voting is not mandatory from members or co-members.

9. Compensation

Advisory Group members will be offered honoraria for their participation in the group, amounting to a total of \$2,000 CAD, paid in four installments across the

project term. These payments are optional and can be declined by participating members for any reason, including conflicts of interest or their home institution's policies. Payments will be disbursed either via direct deposit/electronic funds transfer (EFT) or mailed via cheque, depending on member preference. AG co-members and ex-officio members are, by default, expected to participate as unpaid participants unless other arrangements are made explicitly with SKIP's YIP Team for alternative remuneration options.

10. Conflicts of Interest

AG members must promptly report any existing or emerging conflict(s) of interest (perceived or actual) to the SKIP 'Youth in Pain' Team.

The SKIP YIP Team must communicate all reported conflict(s) of interest with the SKIP Executive Team and/or SKIP's Board of Directors.

The AG chair may deny or remove a member if deemed necessary to avoid, neutralize, or mitigate an actual, perceived, or potential conflict of interest.

If an AG member fails to promptly disclose the existence of, or potential for, conflict(s) of interest, SKIP's YIP Team may, in its sole discretion, remove the member.