



Invitation for Engagement for Provincial Pediatric Advance Care Planning Project

Opportunity:

Canuck Place Children's Hospice (CPCH) is seeking patient and family member partner(s) open to sharing their lived/living experience with pediatric advance care planning¹ (pACP) for an infant, child or youth (0-19 years of age) with a serious illness² to improve these important conversations.

In addition, we hope to have representation at the session of family members of any combination of the following:

- You can provide the perspective of a family living and managing pediatric serious illness within the BC pediatric healthcare system
- You are a person who identifies as Indigenous or represents diverse cultural and social backgrounds in British Columbia
- You are a person who represents pediatric families that support children with neurological developmental diversity and a serious illness
- You have experience supporting a child who is fragile with an uncertain healthcare journey
- You have experience receiving pediatric palliative care

For participation, a person needs to have access to a computer, familiarity with the use of the Zoom platform and be able to commit to a two-hour virtual session.

This opportunity will invite family partner(s) to share their ***lived/living experience surrounding pediatric advance care planning*** facilitated by Family Engagement Advisors from CPCH.

Goals of the opportunity are:

- To explore, listen and understand the experiences, issues and needs of children and families surrounding pediatric advance care planning
- To develop an understanding of how best to have these conversations with you.
- To recognize, acknowledge and integrate the unique perspective and expertise of the child and family.

Dates for the virtual sessions are:

- Tuesday, October 17th 5pm-7:00pm
- Tuesday October 24th 11am - 1pm

The facilitator(s) will be speaking in English, therefore if you require interpretation, services are available, please let us know. Compensation for time and reimbursement for any necessary expenses is supported for this engagement session and aligns with engagement standards (\$25/hour).

¹ **Pediatric advance care planning** (pACP) are ongoing conversations between children, their families and their healthcare providers to explore and understand the values, beliefs and wishes of the child and family. This conversation supports shared decision-making when a child's health condition is fragile and/or future planning for the care of the child if their health condition were to worsen.

² **Serious illness**: condition that impacts life and daily functioning with unknowns about the future and/or condition that can be difficult to manage in symptoms, treatments or family stress.

This engagement opportunity aligns with the values and principles of the Canuck Place Family Engagement Framework, co-designed by the Family Coalition.



Your perspective will inform the provincial pACP process, working groups and family engagement opportunities as we continue to work on this initiative.

Background

CPCH along with Child Health BC, Children's and Women's Indigenous Health, Perinatal Services BC and BC Children's Hospital are working together for a provincial approach to pACP. This is a **two-year** Ministry of Health priority project. The goal of the project is to improve the delivery of pACP services for children/youth/young adults with a serious illness and their families throughout British Columbia.

What we aim to support when participating:

We recognize families across BC come with a variety of experiences and all voices are valued. Canuck Place will provide a safe and supportive online space for families to share their experience of pediatric advance care planning through:

- Allowing for the expression of feelings without fear of judgment
- Providing peer support through family engagement advisor facilitation
- Offering an opportunity to meet families across BC who receive/have received, experienced pediatric advance care planning services.
- Maintaining a safe space that does not identify individuals which families can share as much as they chose to about their experiences
- Offering opportunity to debrief and access follow-up support if identified following the session.

We hope to engage family partners that represent different experiences, care populations and demographics. Therefore, the selection process for this opportunity will attempt to ensure broad representation, diversity and inclusion of the many different family situations.

If interested in participating in this opportunity or you wish to learn more about this engagement session, please contact familyexperience@canuckplace.org by Wednesday 11th October 2023.

We look forward to hearing from you- your voice matters!

If you are a adolescent/youth/young adult interested in this opportunity and sharing your perspective living with a serious illness, please see our adolescent/youth/young adult engagement opportunity.

If you are a sibling of a child/youth/young adult with lived/living experience of a serious illness and pACP, please see our sibling engagement opportunity.

Family Engagement at CPCH

Children and family are at the centre of the care provided at CPCH. We respond to the voices of our patients and families, and collaborate on improving care by working directly with families. This past year, CPCH, through the Family Engagement Coalition, invested in developing a comprehensive Family Engagement Framework to provide guiding principles, goals, opportunities, and processes to support our commitment to collaborative work with families. Partnering with families and acknowledging their living and lived experiences are vital and valuable components to improving our program services. The vision for the framework is to ensure consistent, safe, and respectful engagement with children, youth, and families at CPCH, to fully represent the diverse perspectives and promote continual improvement of pediatric palliative care and services.

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