



Invitation for Engagement for Provincial Pediatric Advance Care Planning Project

Opportunity:

Canuck Place Children's Hospice (CPCH) is seeking adolescents/youths/young adults managing a serious illness¹ in British Columbia who are open to sharing their experience with Pediatric Advance Care Planning² (pACP). In addition, we hope to have representation of the following:

- You may also be a person who identifies as Indigenous or represents diverse cultural or social backgrounds in British Columbia
- You may also be a person with neurological developmental diversity and a serious illness
- You may also be living with a condition with an uncertain future
- You may have experience receiving pediatric palliative care

For participation, you need access to a computer and knowledge of the Zoom platform, as well as be able to commit to a two-hour virtual session.

This opportunity will invite you to share your ***lived experience surrounding pACP*** facilitated by Young Adult Engagement Advisor with lived experience and a counsellor from CPCH with a practice focus on supporting the adolescent/youth/young adult voice.

Goals of the opportunity are:

- To explore, listen and understand the experiences, issues and needs of adolescents/youths/young adults surrounding pACP.
- To develop an understanding of how best to have these conversations with you.
- To integrate your unique perspective and expertise of living with a serious illness.

Dates for the session are:

- Monday October 23rd 4pm-6:00pm PST
- Thursday October 26th 4pm-6:00pm PST

The sessions will be facilitated virtually and 2 hours in length.

Your perspective will inform the provincial process of pACP and enhance care for people your age as we continue to work on this initiative. Compensation for time and reimbursement for any necessary expenses is supported for this engagement session and aligns with engagement standards (\$25/hour).

The facilitator(s) will be speaking in English, therefore if you require interpretation, services are available, please let us know.

¹ ***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.

² ***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.

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



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 adolescents/youths/young adults across BC come with a variety of experiences and all voices are valued. CPCH will provide a safe, confidential and supportive online space for you to share your experience of pACP through:

- Allowing for the expression of feelings without fear of judgment
- Providing peer support through young adult engagement advisor facilitation and CPCH counsellor
- Offering an opportunity to meet adolescents/youths/young adults across BC who receive/have received, pediatric advance care planning services.
- Maintaining a safe space that does not identify individuals which adolescent/youth/young adults 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 adolescents/youths/young adults who represent different experiences, care populations and demographics. If interested in participating in this opportunity or you wish to learn more about this engagement session, please contact familyexperience@canuckplace.org by Wednesday October 20th, 2023. We look forward to hearing from you – your voice matters!

If you are a family member interested in this opportunity and sharing your perspective of supporting your child/youth/young adult with a serious illness or a sibling of a child/youth/young adult with a serious illness, please see our family partner engagement opportunity or our sibling engagement opportunity <https://www.canuckplace.org/resource-hub/family-engagement-opportunities/>.

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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