

# Canuck Place Children's Hospice Family Engagement Coalition

## Introduction

Many governing bodies across Canada, and the world, recognize patient-partner participation as necessary at all levels of healthcare and a best practice priority for quality improvement and patient experience. This past year, Canuck Place Children's Hospice (CPCH) invested in developing a comprehensive Family Engagement Framework to provide guiding principles for partnering with families. CPCH is the only pediatric palliative care provider for BC and the Yukon and we are **committed to integrate the perspective and participation** of children, youth, and families to improve CPCH care and services.

## Objective

The Family Engagement Coalition (FEC) was established **to co-develop and propose** a Family Engagement Framework for CPCH. Patient and family partner engagement is an explicit action of person and family-centred care and is paramount to pediatric palliative care. By providing opportunities for engagement to occur at all levels **CPCH models "doing with"** families in our care.

## Description

Almost half of the FEC was comprised of patient/family members, **representing diversity in lived experiences, demographics, cultures, and needs**. Each member contributed to the co-development and proposed recommendations of best-practice engagement with the children, youth, and families of CPCH. Family partners were engaged in presenting, writing, co-facilitating, and ongoing dialogue during monthly virtual meetings over the course of a year. The remaining members of the FEC was comprised of CPCH staff, including clinical care, donor relations, communications, and external partners from the healthcare sector.

## Outcome

The drafted **Family Engagement Framework**, both a document and a tool for practice, was envisioned and co-created by the collaborative work of the FEC. The Framework was approved by the FEC and sent to CPCH Senior Leaders and the CPCH Board for approval. **This tool provides training and resource opportunities** for CPCH staff on how to engage with the families we care for, a process for providing engagement opportunities to families, and ongoing evaluation of engagement for continuous improvement. The next step includes **operationalizing the framework across the organization** in collaboration with families, the Family Advisory Committee, and Family Engagement Advisors.



The FEC was formed. Almost half of the group are family members from across BC, representing diversity in lived experiences, demographics, cultures, and needs.

### June 2022 - March 2023

The FEC met regularly to brainstorm, discuss ideas, and create the main categories for the Framework, using an evidence-based trauma and resiliency-informed principal approach.

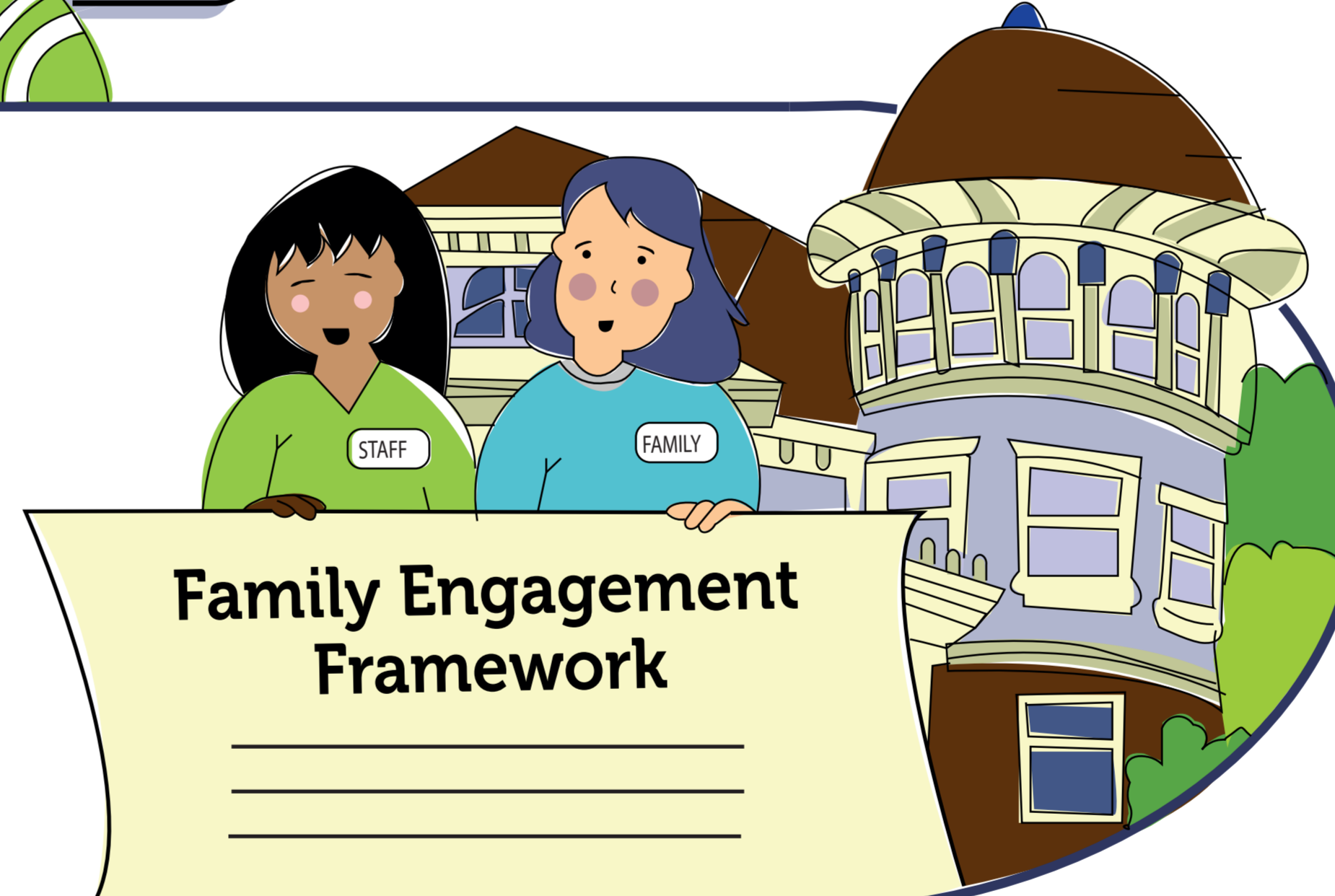


### March 2023 - June 2023

The FEC formed small groups to organize our collective ideas, worked through each category of the Framework in-depth, and created a first draft.

### September 2023

The final version of the Framework was approved. The goal is to ensure consistent, safe, and respectful engagement with children, youth, and families at CPCH.



## EMBRACING CHILD AND FAMILY-CENTRED CARE



## Significance

This FEC's initiative displays an example of what patient partnership can look like at a high-level planning, designing, and decision-making processes within our healthcare system. It provided an opportunity for families to collaborate and lead, and to inform and influence policy level structures within the systems that serve them.

Further, **the FEC's work occurred using an evidence-based, trauma and resilience-informed principal approach, to ensure a safe and brave space for both the group itself and the Framework**. FEC members benefitted greatly from this approach of authentic connection, shared vulnerability, and creating mutual purpose.

Collectively, this FEC hopes to see more trauma and resilience-informed care across all areas of healthcare planning and delivery within Canada. After sharing the Framework with both CPCH clinicians and families, we sent a survey to get their feedback and insights.

*"The understanding and knowledge I have acquired will allow me to be more effective in my role with colleagues, donors, government, and family partners. Specifically, I plan to incorporate learnings from the framework with my team, sharing insights to drive greater understanding of the FEC". - CPCH Leader*

*"On a larger scale I hope the FEC Framework will be seen and implemented in more hospital and community-like settings, on engaging with families in pediatric medicine." - CPCH Family*

*"I didn't expect the Framework to be such a large undertaking and outcome. I think we created something really special and all-encompassing." - CPCH Family*

## Contributors

- Laesa Kim [BCCHR, Parent Partner]
- Bev Pomeroy [Fraser Health, Parent Partner]
- Diana Salcedo [Parent Partner]
- Sara Rodrigues [Canuck Place, Parent Partner]
- Dana Warburton [Canuck Place, Parent Partner]
- Lisa Pratt [Canuck Place]
- Nadine Lusney [Canuck Place, Clinician]
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And all remaining members of the FEC.

