

National Reproductive and Perinatal Loss Think Tank Report

FROM SILOS TO COLLECTIVE ACTION



On June 11, 2025, over 100 participants from across Canada gathered virtually for the first session of the National Think Tank on Reproductive and Infant Loss, and perinatal palliative care. This initiative brought together healthcare providers, researchers, grief care advocates, people with lived experience, and community leaders to examine the current gaps and possibilities across systems related to pregnancy loss, infant death, and perinatal palliative care. This Think Tank was convened with the overarching goals of supporting national collaboration, knowledge sharing, and co-creation of solutions that are informed by empathy and grounded in practice.

Participant Demographics

Over 200 individuals registered for the National Think Tank, representing a wide array of backgrounds and professions. The majority of the 100+ participants who attended and actively engaged in the event were from Ontario (88), with additional representation from Nova Scotia, British Columbia, Alberta, New Brunswick, Quebec, and other provinces and territories. Notably, 39% of registrants identified as people with lived experience of reproductive or infant loss.

Objectives

- To identify systemic gaps and pressure points in care, opportunities for capacity building, and access to resources for those impacted by reproductive and infant loss.
- To build a shared understanding of what's currently working, what needs improvement, and where the biggest gaps exist.
- To spark a national network of collective action across roles, disciplines, and regions.

Activity 1:

EMPATHY MAPPING - ONE FAMILY'S JOURNEY

Participants were led through an empathy mapping exercise reflecting on a family's journey, including confirmation of early pregnancy, diagnosis, decision-making, labour, birth and death, and life after loss.

Through each stage of the journey, participants shared:

- What the family might be thinking and feeling
- What care and resources should be provided at each stage

Using the Menti platform, participants submitted anonymous reflections in real time. These responses were displayed on screen and gathered as part of the data set.

EMPATHY MAPPING AND CARE REFLECTION RESULTS BY PHASE

Confirmation of early pregnancy

Top feelings

Fear, anxiety, excitement, hope, and cautious optimism

Top Care Needs identified:

- Access to emotional validation and counseling
- Peer support groups (especially for pregnancy after loss)
- Early prenatal care and reassurance

Diagnosis

Top feelings

Anger, grief, shock, sadness, devastation

Top Care Needs identified:

- Empathy and compassion in communication
- Time to process information
- Clear, non-judgmental discussion of options
- Emotional and psychological support

Decision Making

Top feelings

Grief and love intertwined. Fear, sadness, and resilience

Top Care Needs identified:

- Birth planning tailored to their hopes and goals
- Readily available mental health and emotional support
- Compassionate presence and peer connection

Labour, birth, and death

Top feelings

Deep love, profound sadness, grief, some joy and relief in shared time

Top Care Needs identified:

- Gentle, compassionate care from staff
- Time, space, and stillness to be with the baby
- Recognition of the significance of the moment

Life after loss

Top feelings

Grief, sadness, isolation, guilt, ongoing adjustment

Top Care Needs identified:

- Long term grief support and peer connections
- Validation and normalization of grief responses
- Invitations to talk about their child and continued remembrance

Immediately after death

Top feelings

Overwhelming grief, heartbreak, disbelief

Top Care Needs identified:

- Time and space to say goodbye
- Support for arranging ritual, ceremony, funeral
- Consistent, compassionate acknowledgment of the loss

Activity 2:

BREAKOUT GROUPS

Next, participants moved into breakout groups focused on three themes:

- Care
- Literacy and Capacity
- Resources and Services

Each group was asked: What is working well? What exists but needs improvement? Where do gaps exist? Facilitators documented the conversations through shared whiteboards and written notes.

CARE		
Working well	Needs Improvement	Gaps
<ul style="list-style-type: none">• Compassionate Care workshops (PAIL), serious illness guides• Social media reducing stigma and connecting grieving families• Growing palliative care referrals and understanding	<ul style="list-style-type: none">• Earlier intervention before 20 weeks (outside of ERs)• More culturally-informed, LGBTQ2S+-affirming care• Consistent education for HCPs and team-based approaches	<ul style="list-style-type: none">• Fragmented services and follow-up care• Lack of inclusive policies for grief leave, support for dads/siblings/grandparents• Minimal postpartum mental health support
LITERACY AND CAPACITY		
<ul style="list-style-type: none">• E-learning and trauma-informed care offerings (e.g., from PAIL)	<ul style="list-style-type: none">• Knowledge translation from research to practice• Inconsistency in training access by region or role	<ul style="list-style-type: none">• Rural/remote areas lack trained providers• Standardized info lacking; many orgs duplicating efforts in silos• Limited infrastructure (e.g., designated space for stillbirths)
RESOURCES AND SERVICES		
<ul style="list-style-type: none">• Peer support increasing• Some blended in-person/online supports available• Bereavement carts and integrated tools in some hospitals	<ul style="list-style-type: none">• Supports vary drastically by region• Lack of Indigenous-led and culturally safe programs• Limited early pregnancy loss clinics	<ul style="list-style-type: none">• Families often travel long distances for care• Internet access limits virtual grief care in rural zones• Fertility loss services still underrepresented

Additional insights from participants included:

“Leave policies that include reproductive loss”
“Being met with presence”
“Support for dads and siblings too, not just moms”
“Care for rainbow babies and families”
“Validation, connection, acknowledgement”
“Staff education needs to be consistent across units”
“Training should include cultural safety and trauma-informed care”
“Lack of comfort navigating grief”
“Travel required to access care”
“Bereavement resources inconsistent”
“Time to spend with families is often a challenge”
“More understanding of compound grief”
“Access to options for leaves of absence”
“More integration of peer and professional supports”
“Duplication of services due to lack of coordination”
“Stillbirth care delivered next to families with healthy babies – need separate space”

What we heard

EVALUATION OF THE THINKTANK EXPERIENCE

96% of participants found the webinar relevant to their role or context
82% of participants found value in the empathy mapping exercise
96% of participants found some value in the breakout room discussions

Participants also noted they had hoped for more conversation, more time to hear about projects that others were engaged in, and opportunities to learn from others who do similar work by sharing experiences and strategies.

Informing the Path Forward

NEXT STEPS

- **Further engagement and consultation to ensure representation from all provinces**
- **National environmental scan to document current state of care and support available**
- **Offer a quarterly community of practice to allow for connection, networking, and resource sharing**

Parents, practitioners, and professionals guided our focus as we continue to move towards a pan-Canadian approach to the care and support of families who experience reproductive loss, pregnancy and infant loss, and perinatal palliative care.