

Pediatric Palliative Care: How Can You Play a Role?



Host: Holly Finn

Presenters: Kira Goodman & Dr. Dave Lysecki

Date: October 09th 2025

Territorial Honouring



The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



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Pallium Canada's award-winning suite of LEAP courseware transforms health care practice through interprofessional and evidence-based palliative care training:

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- Earn annual learning credits and a nationally recognized certification.
- Backed by evidence and best practices.
- Practical, case-based learning with real-life scenarios.

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Introductions

Host

Holly Finn

Senior Manager, Program Delivery
Pallium Canada

ECHO Support

Elias Cherfan

Program Manager, Support Desk
Pallium Canada

Presenters

Dr. Dave Lysecki

Pediatric Palliative Medicine Specialist, Medical
Director of Canada's Pediatric Palliative Care
Alliance

Kira Goodman

RN, BSCN, Project Director for Canada's
Pediatric Palliative Care Alliance

Welcome and Reminders

- For comments and introductions, please use the chat function!
- For questions, please use the Q&A function, these questions will be addressed at the end of the session.
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session.

Disclosure

Relationship with Financial Sponsors:

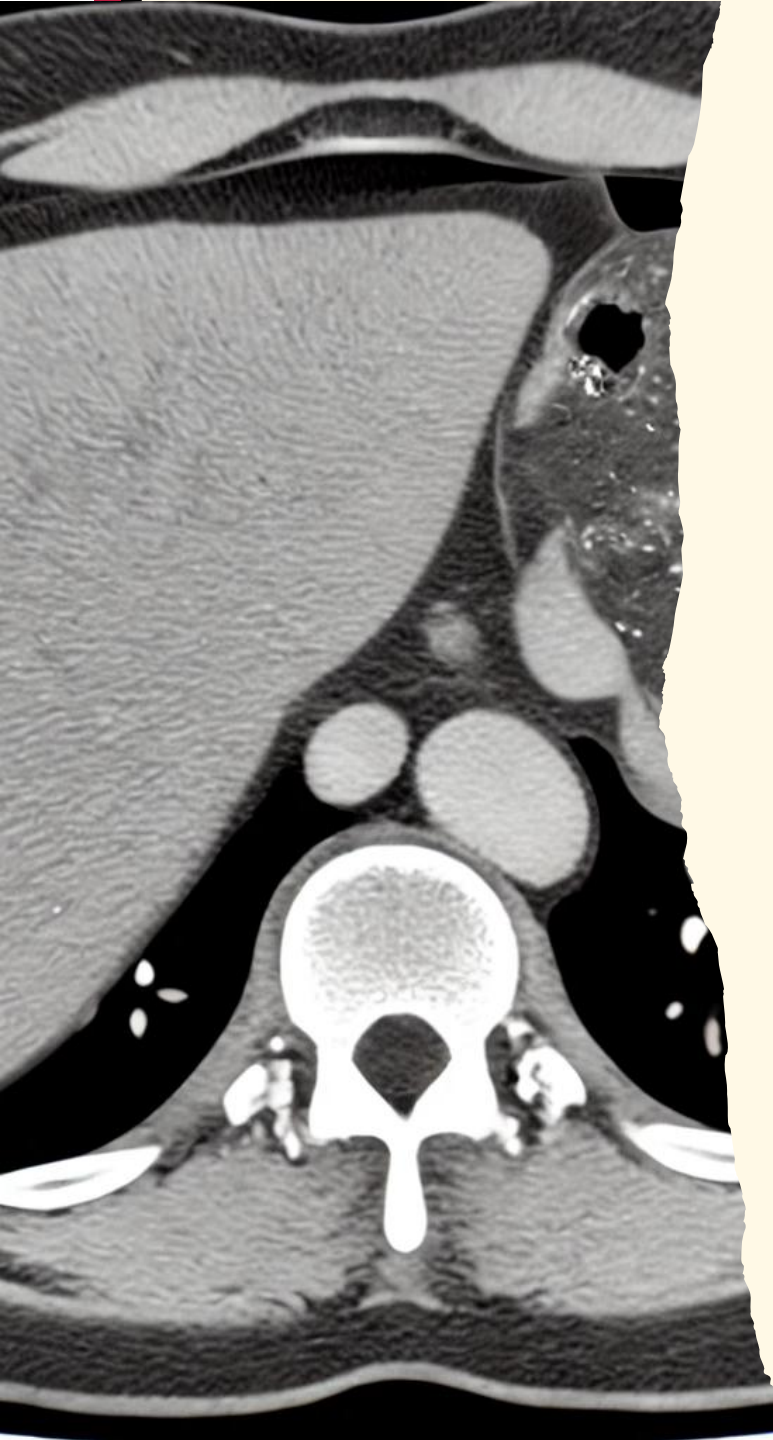
Pallium Canada

- National registered charitable organization
- Funded by Health Canada

Host/Presenter

- Holly Finn: Employed by Pallium Canada
- Dr. Dave Lysecki: Nothing to disclose
- Kira Goodman : Funded by Health Canada

Pediatric Palliative Care: How Can You Play a Role?



Case - Jerry

13y.o. with relapsed
metastatic
hepatoblastoma and
Trisomy 21

Loves “fishing, fishing,
and more fishing”

Friendly, but dysregulated
with pain 2° to traumatic
medical stress (since ICU
admission post-surgery
with delirium)





Case - Jerry

Port-a-Cath and a G-tube
with nutritional
supplementation

Methadone for bony pain,
mirtazapine for anxiety,
oral palliative
chemotherapy, and
infection prophylaxis
(Septra, fluconazole)



Case - Jerry

Jerry is from rural Ontario and has spent most of his last 2 years in Toronto.

Jerry and family would like to spend as much of his remaining days as possible at home by the lake

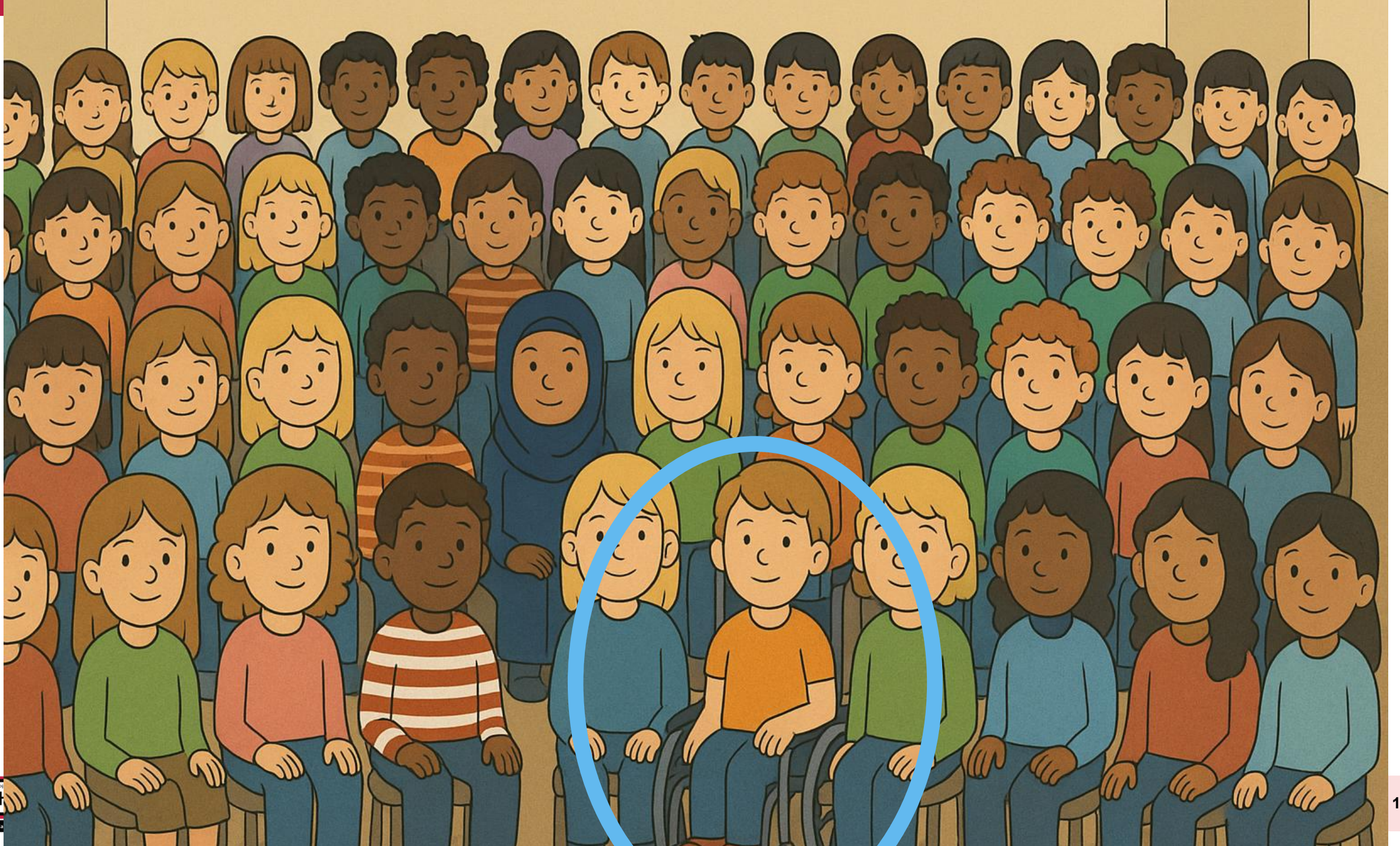


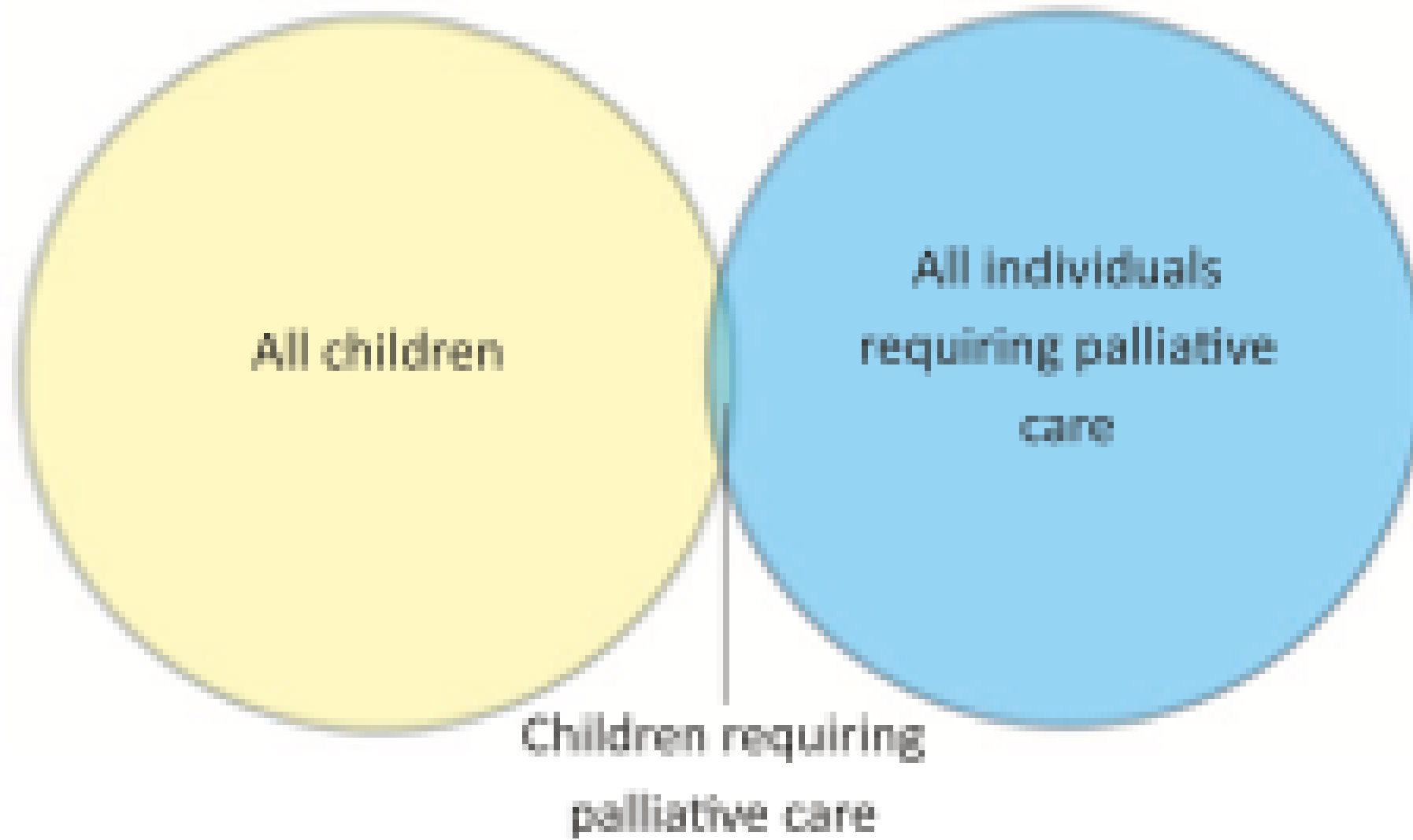
Houston, we have a *number* problem

Why is the number six so scared?
Because seven eight nine!

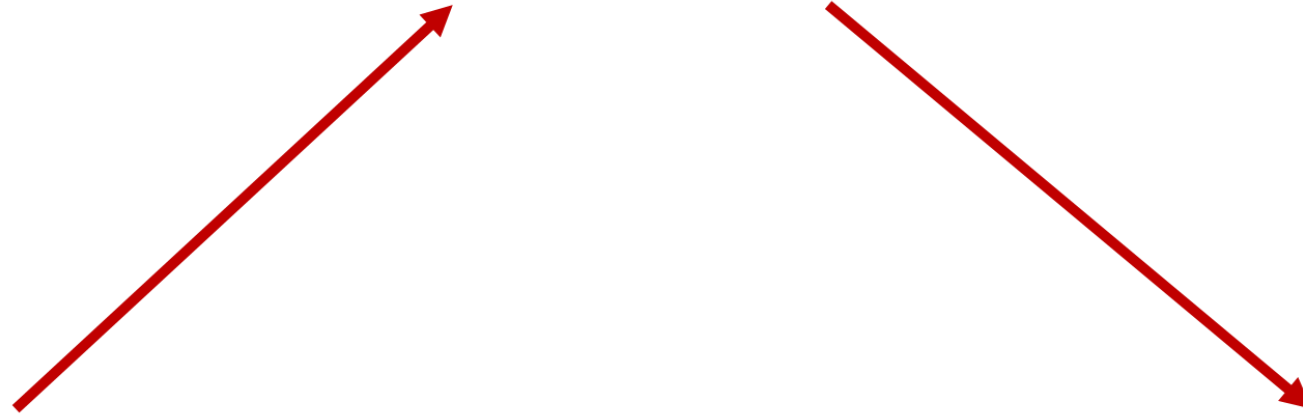








Family Health Teams

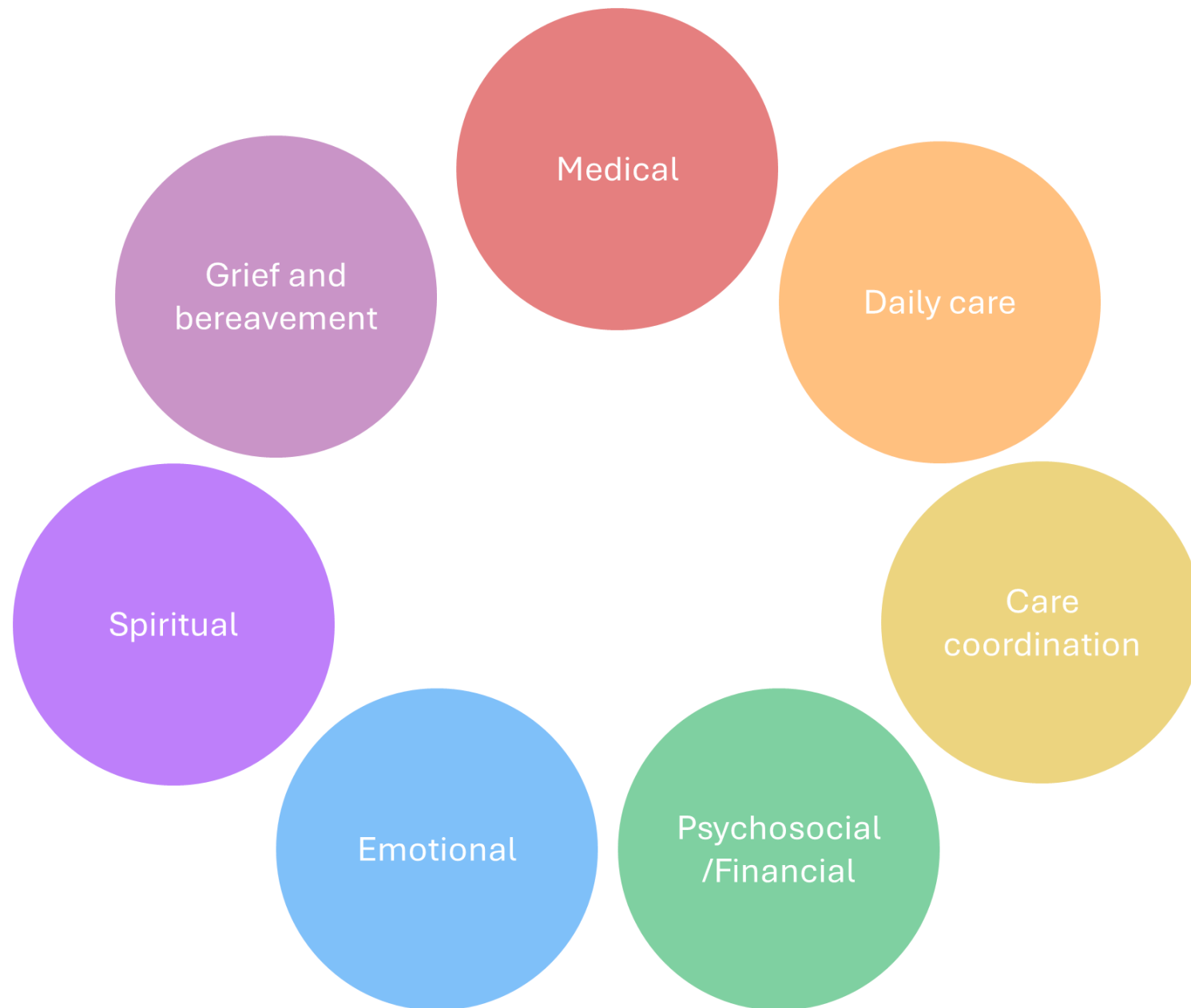


Palliative Care

Pediatrics

Palliative Care = (pro)Active care

- Health maintenance – nutrition, antibiotic prophylaxis, constipation
- Chemo – CBCs, Fever mgmt. plan
- Central line – access, flushes
- Mental Health support: Counselling, anxiety, PTSD, mirtazapine
- Pain management – methadone, escalation?
- In-home care – nursing, physician visits, OT/PT
- 24/7 on call support
- Care coordination
- Death planning – pronouncement, funeral planning, organ donation
- Sibling support
- Parent support – social, financial, grief
- Staff Support





Diagnosis

Nursing and
personal care

Funeral planning

End of Life Care

Treatment

Parent support

Financial
programmes

Advanced
symptom mgt

Health
Maintenance

Sibling support

Employment

Accessible
housing

Prognostication

Spiritual support

School

Transportation

Symptom
management

Grief support

Family health
care

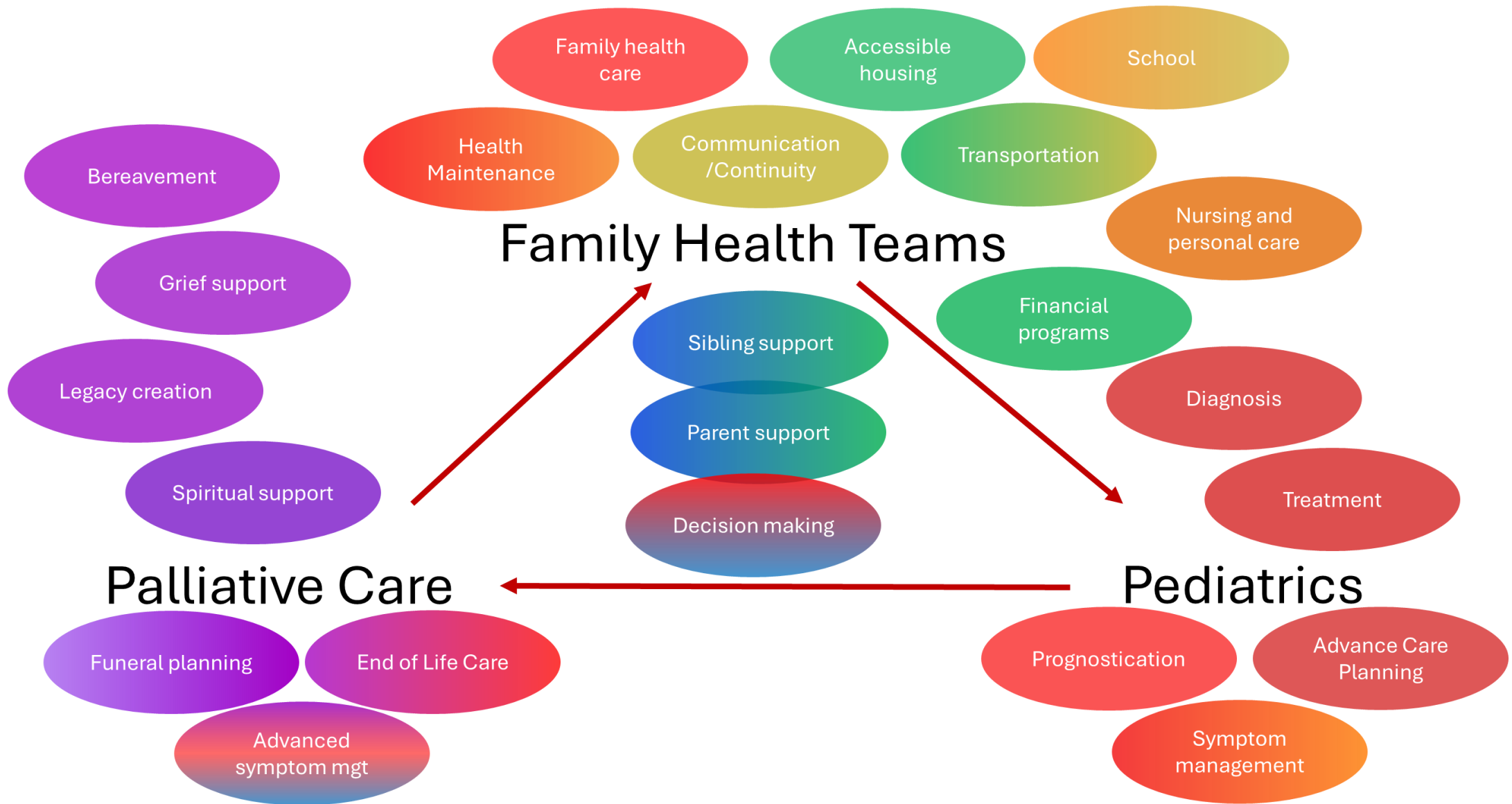
Decision making

Advance Care
Planning

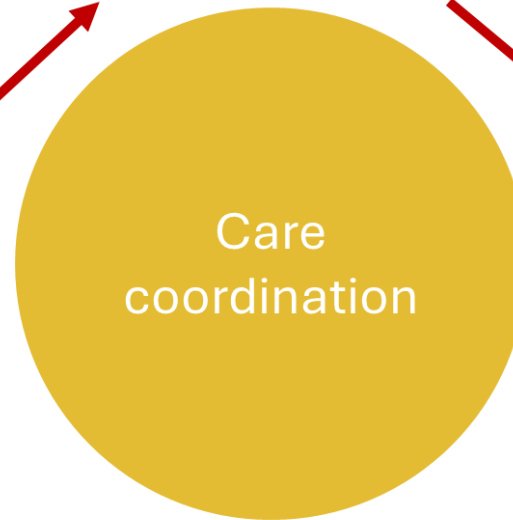
Bereavement

Communication
/Continuity

Legacy creation



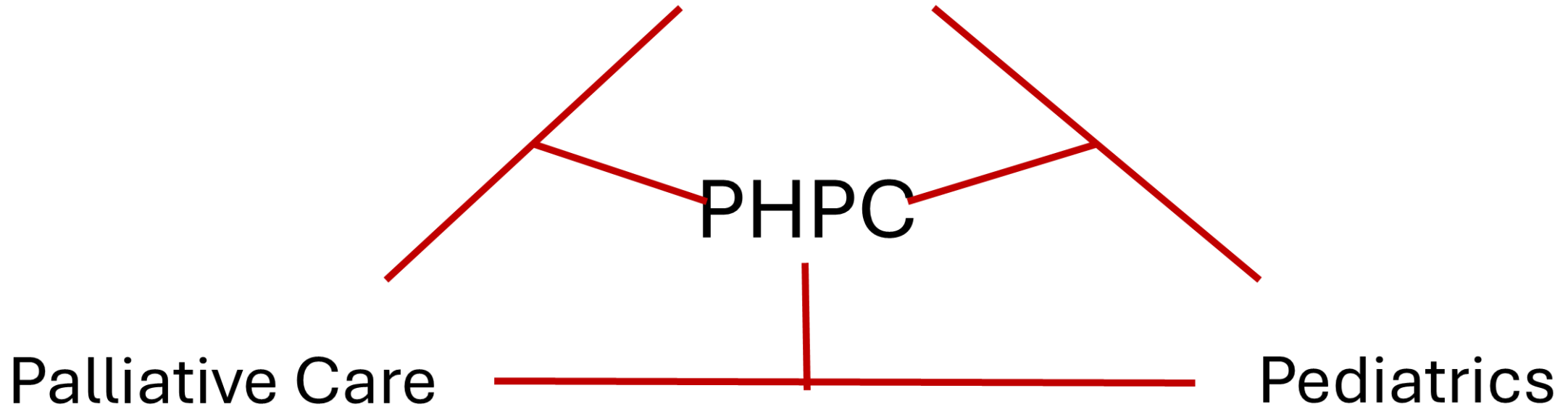
Family Health Teams

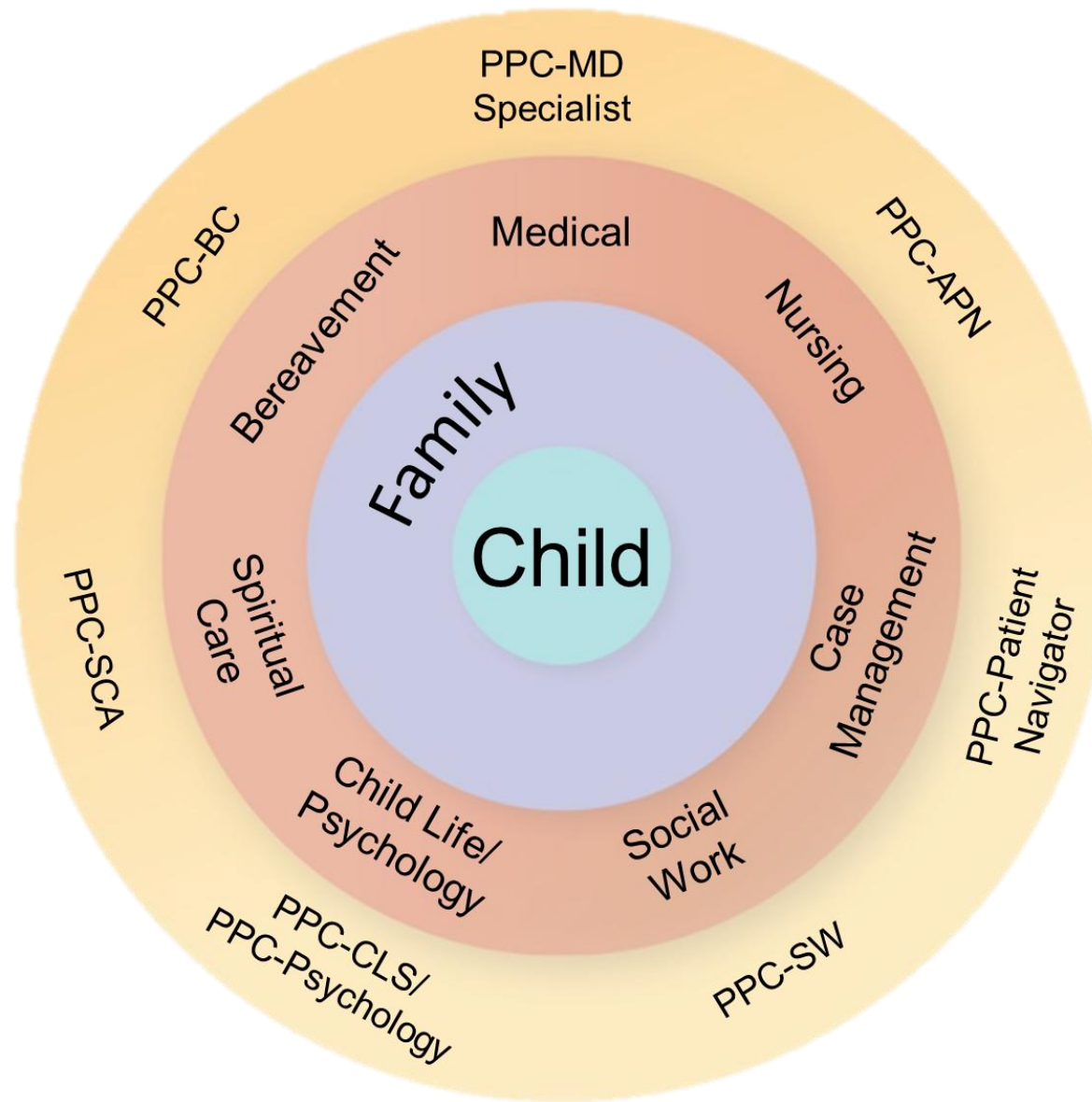


Palliative Care

Pediatrics

Family Health Teams



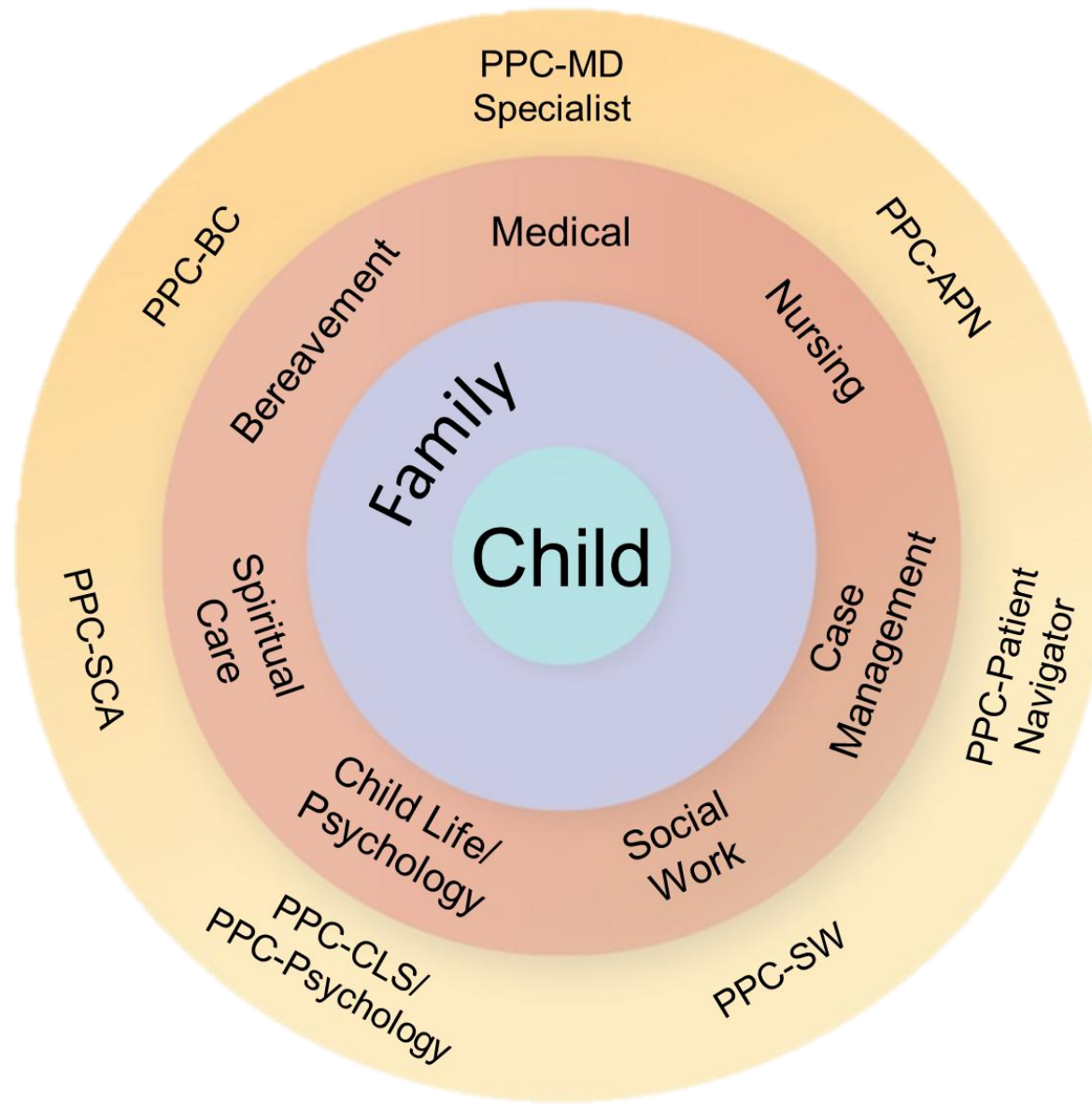


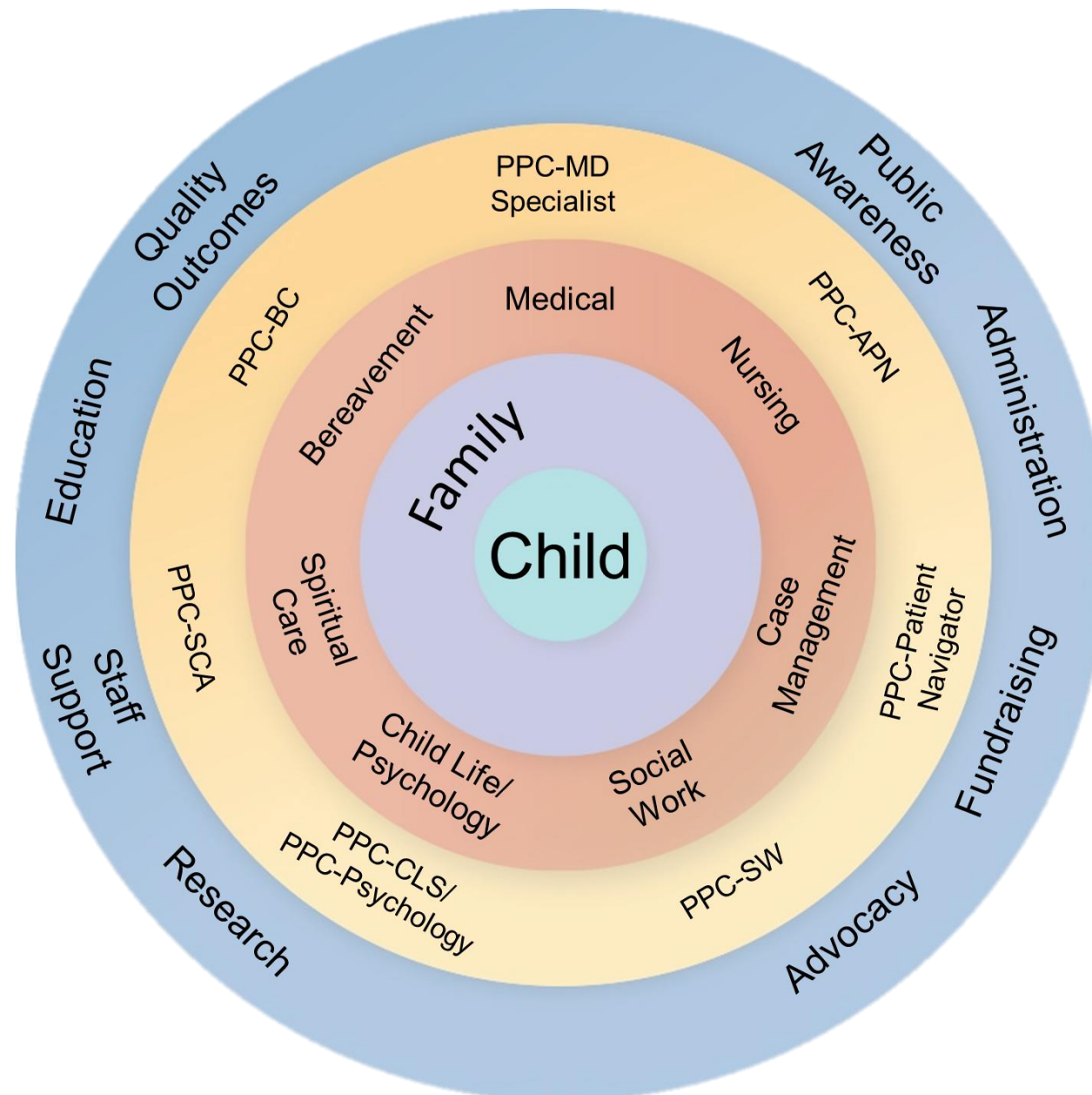
Palliative Care = (pro)Active care

- **Home care nursing** – regular visits, pain assessment, daily care support
- **Family Health Team / Primary Care** – Parent/Sibling support, home visits, 24/7 support, pronouncement, funeral planning
- **Pediatrics** – Nutrition, Constipation, CBCs, fever management, Port-a-cath care
- **Palliative Care** – Methadone
- **PPC (Virtual)** – Counselling, Mirtazapine, 24/7 backup, staff support
- **Pediatric Onc (Virtual)** - Chemotherapy

Palliative Care = (pro)Active care

- 17y.o. with cerebral palsy, severe scoliosis, recurrent aspiration pneumonia
- 12y.o. with Duchenne's muscular dystrophy and ASD
- 4y.o. with new diagnosis of Batten syndrome
- 1 week old, 24wk GA infant, with intraventricular hemorrhage
- 6mo old with infantile spasms
- 21-week fetus with Trisomy 18







Canada's
**pediatric
palliative
care** alliance

The Grant:

Health Canada funded Roger Neilson Children's Hospice with \$1.2 million over 27 months.

Our Core Deliverables

- 1) A bilingual resource hub
- 2) Building a network for practitioners
- 3) A shared vision of high quality pediatric palliative care

The Overarching Vision:

A future where every Canadian child with a serious illness has access to high-quality pediatric palliative care, regardless of location, background, or circumstance.

Key Players:

- Health Canada: Funder.
- Roger Neilson Children's Hospice: Project Lead and supporter.
- Project team: Day-to-day operations.
- Other Key Collaborators: Healthcare Professionals, Families and Organizations across Canada

Population Distribution in Canada

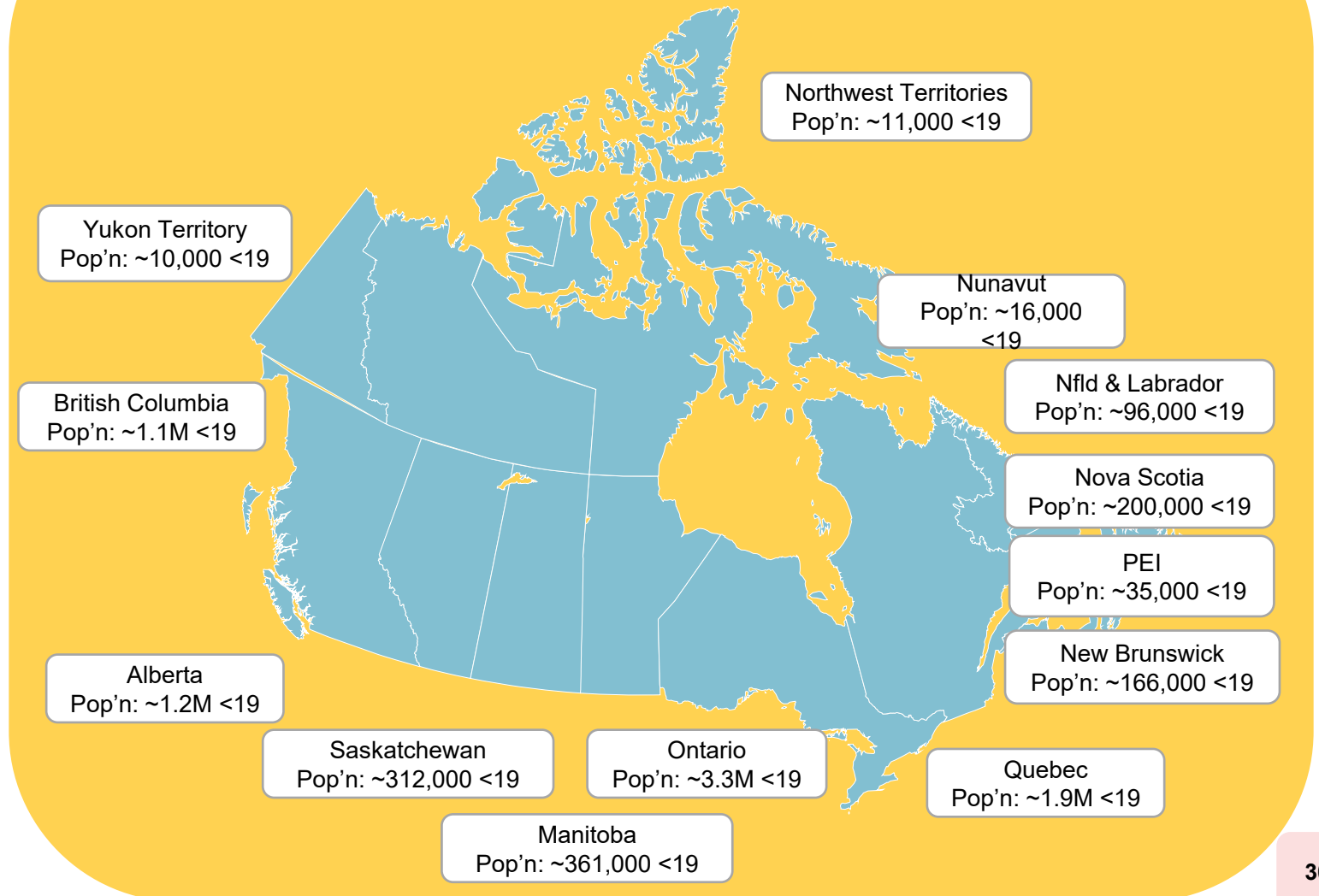
Total Number of Canadians (all ages)

41.3M

Total Number of Canadians Under 19

8.6M

Canadians Under 19 Years of Age in 2024 by Province



Distribution of Children's Hospices in Canada

Total Number of Hospices in
Canada

8

There are 4 additional hospices
in their advocacy stages:

Ontario – 2

Nova Scotia – 1

Quebec – 1

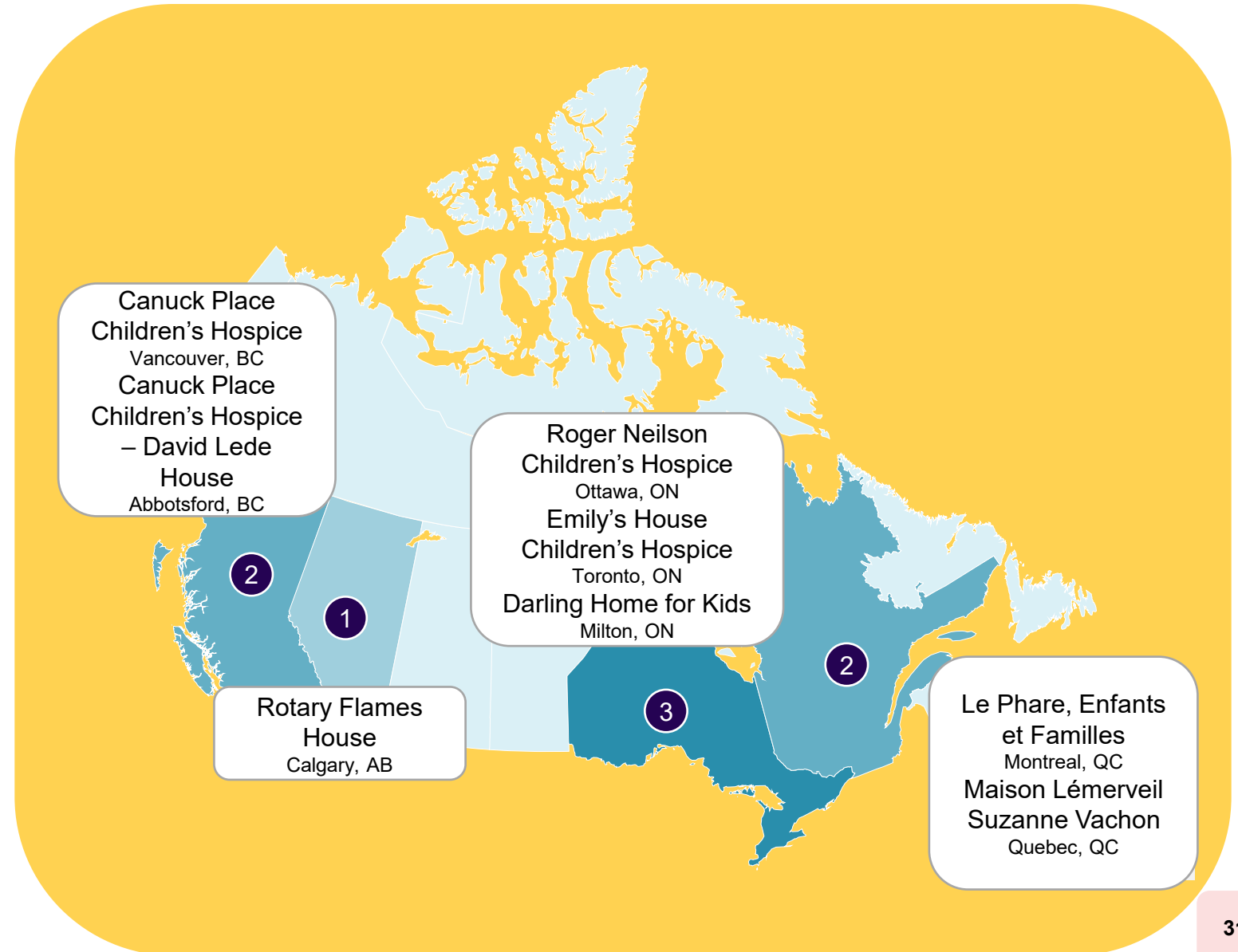
With 8.6M people <19 in Canada
we have

7 Hospices

Compared with

15.7M people <19 in the UK
there are

50+ Hospices



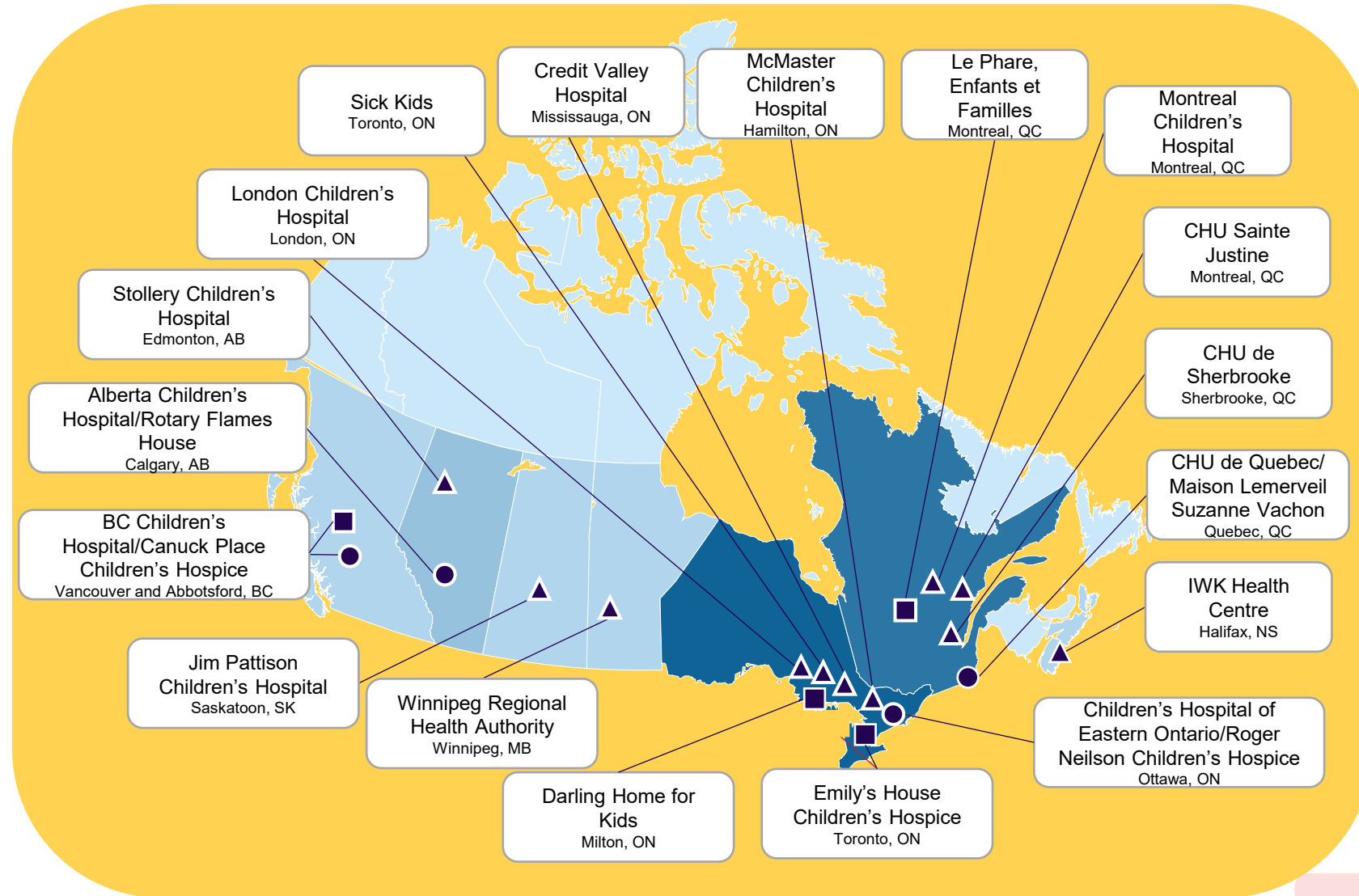
Distribution of Children's Hospices and Pediatric Palliative Care Teams in Canada

Legend

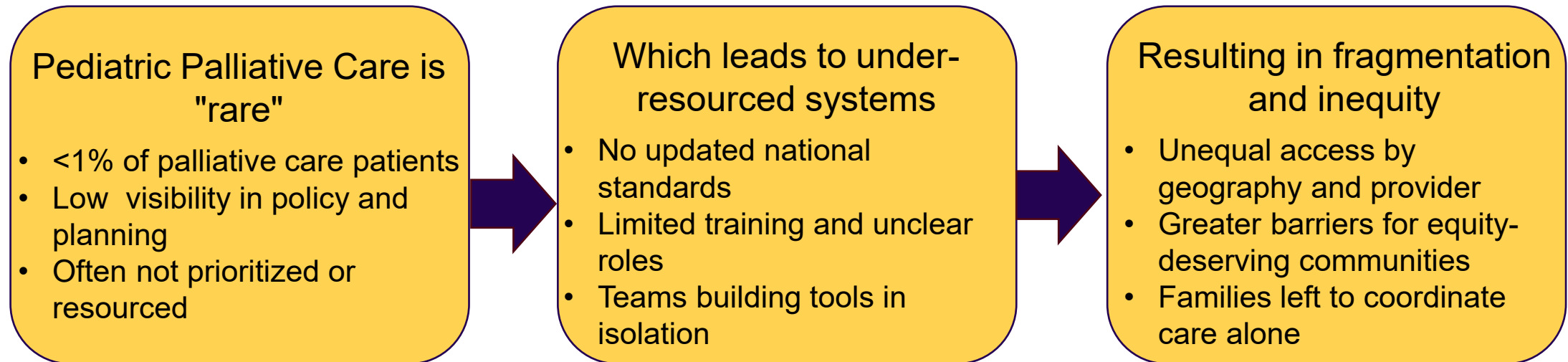
- ▲ Hospital or Community-Based Team
- Children's Hospice
- Combined Hospice and Hospital-Based Program

Total Number of Hospices and Teams in Canada

18



From Rarity to Inequity: Why PPC Needs National Coordination



Mending the Gaps: What the Evidence Tells Us

Challenges across the literature:

- Unclear roles and responsibilities between providers
- Shortage of specialized and generalist PPC expertise
- Fragmented systems and poor care coordination

Recommendations to strengthen PPC:

- Consistent education + national practice standards
- Better access: 24/7 supports, regional networks, care coordinators
- Increased awareness to shift PPC from "end-of-life only" to quality-of-life-focused care

From Evidence to Action

WHAT THE REVIEW FOUND

Unclear roles & care coordination

Gaps in generalist training

Fragmented systems

Lack of 24/7 access & rural support

PPC introduced too late

No national standards

HOW THE ALLIANCE IS RESPONDING

Core Care Pathway to define stages, roles & expectations

Resource Hub with tools for all providers, not just PPC teams

Communities of Practice + network mapping across regions

Resource Hub with tools for all providers + network mapping

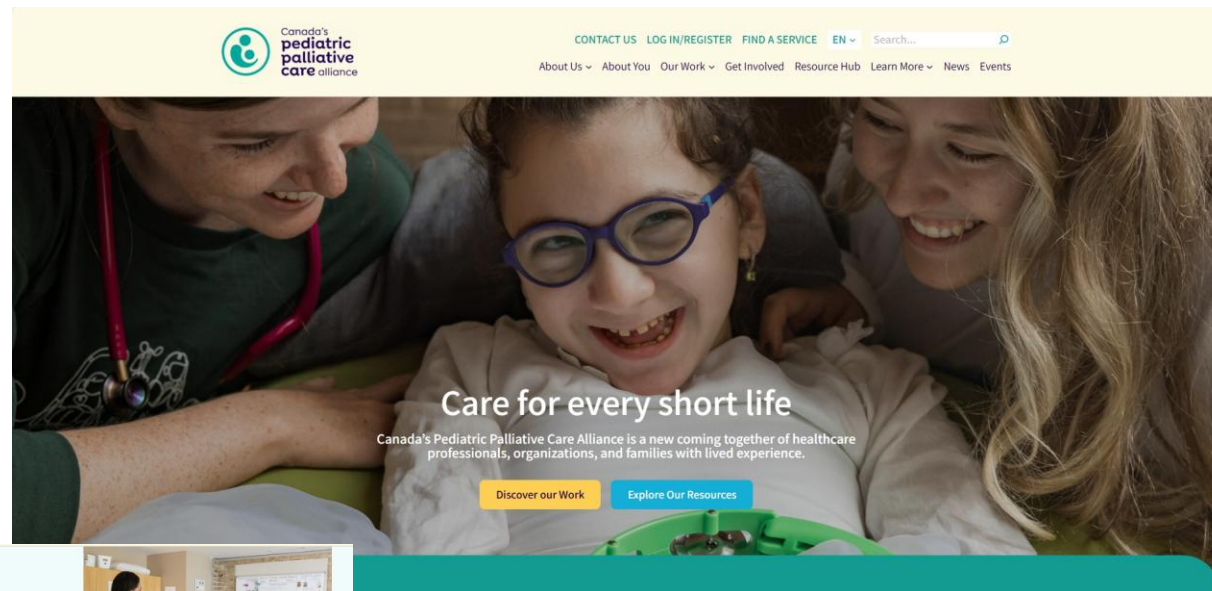
Education, awareness tools

Contributing Pediatric Voice to National Standard of Canada

Priorities for the Year Ahead

(through March 31, 2026) – and laying groundwork beyond

- **Launch Resource Hub (TODAY!):** bilingual, virtual platform with tools, resources & training
- **Launch Canadian Core Care Pathway for Pediatric Palliative Care** (co-developed with providers & families)
- **Map & referral pathways** to connect people with local services and supports
- **Grow Communities of Practice & asynchronous forum** for collaboration & knowledge sharing
- **Stay grounded & responsive** by continuing to listen to families and providers
- **Expand visibility** through major conferences & webinars



Specialty Teams

Click on a province to explore teams in your region.




Q & A



Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat

Thank You



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