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CONGRESS**

October 18–21 octobre 2022

Palais des Congrès de Montréal

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada

Presented by: Alice Muirhead

Dr. Amy Montour

Lisa Vaughn

Sophie Pamak

CONFLICTS OF INTEREST DECLARATION



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- **Alice Muirhead**, First Nations, Inuit and Métis Lead, Person-Centred Perspective and Prevention, Canadian Partnership Against Cancer
- **Dr. Amy Montour**, Interim Chief & Medical Director of Hospital Based Medicine and the Co-Lead of the Indigenous Medicine Division at the Brant Community Healthcare System
- **Lisa Vaughn**, Manager of Community Wellness, Métis Nation of Alberta Métis Nation of Alberta as the Manager of Community Wellness; Citizen of the Métis Nation of Alberta and a PhD student at the University of Alberta in the Faculty of Nursing.
- **Sophie Pamak**, Manager of the Home and Community Care Program with the Department of Health and Social Development at the Nunatsiavut Government

LEARNING OBJECTIVES



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At the conclusion of this presentation, participants will be able to:

- Describe the factors which contribute to palliative and end-of-life care experiences for First Nations, Inuit and Métis
- Describe promising practices in palliative and end-of-life care for First Nations, Inuit and Métis



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CanMEDS COMPETENCY FRAMEWORK

- 6. Establishes an inclusive and culturally-safe practice environment
 - 6.1 Demonstrates humility and openness to patient's ideas and knowledge
 - 6.1 6.2 Seeks to understand and respects culturally-based health beliefs
 - 6.3 Explores how the patient's previous experiences, including adverse life events impact individual clinical encounters and interactions with the health system and incorporates this understanding in their provision of care



Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada

OCTOBER 21, 2022

Giving of thanks/acknowledgements

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- **Turtle Island Consulting Services Inc.**
- **First Nations, Inuit, Métis and non-Indigenous peer reviewers**

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Giving of thanks/acknowledgements

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- Anonymous Reviewers
- Marygalak Ashoona Bergin, BA (Psychology)
- Alexander Kmet, MD, CCFP (FPA) (PC)
- Laura McCormick, PSW
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- Shelly Cory, MA
- Jeffrey Moat, B. Comm, CM
- Amy Montour, BScN, MSc, MD, CCFP (PC)
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- Sophie Pamak, RN, CCHN(C)
- Elder Ella Paul
- Chrystal Toop, RSSW
- Elyse Tratt
- Lisa Vaughn, RN, MN
- Erica Williams

NOTHING about us
WITHOUT US

Thanks for sharing stories, experiences and wisdom with us!

Agenda

- The Canadian Partnership Against Cancer (the Partnership)
- *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada:*
 - Background
 - Palliative care and end-of-life care
 - Indigenous perspectives on palliative care and end-of-life care
 - Culture as medicine
 - Braiding Indigenous ways of knowing and biomedical approaches
 - Competencies and promising practices
- Discussion
- Questions and answers



The Partnership

- was created by the Government of Canada in 2006
- is the steward of the Canadian Strategy for Cancer Control (the Strategy)
- continues to support the work of the collective cancer community in achieving our shared 30-year goals:

A future in which people in Canada have equitable access to high-quality cancer care, fewer people get cancer, more people survive cancer and those living with the disease have a better quality of life.

- receives ongoing funding from Health Canada to continue supporting partners from across Canada.
- has been working with partners from across what is now called Canada **to advance action on the cancer care priorities of First Nations, Inuit and Métis Peoples, their families and communities;** and
- **supports self-determined, Peoples-specific solutions for sustainable system change across cancer care** that benefit all First Nations, Inuit and Métis Peoples, their families and communities.

For more information about the Partnership, visit www.partnershipagainstcancer.ca

How did we get here?



2017 – Bill C-277

Better access to palliative and end-of life services in community and home settings; structure to guide and support the implementation of high-quality palliative care services.



2019 Health Canada developed:

Framework on Palliative Care in Canada and Action Plan on Palliative Care



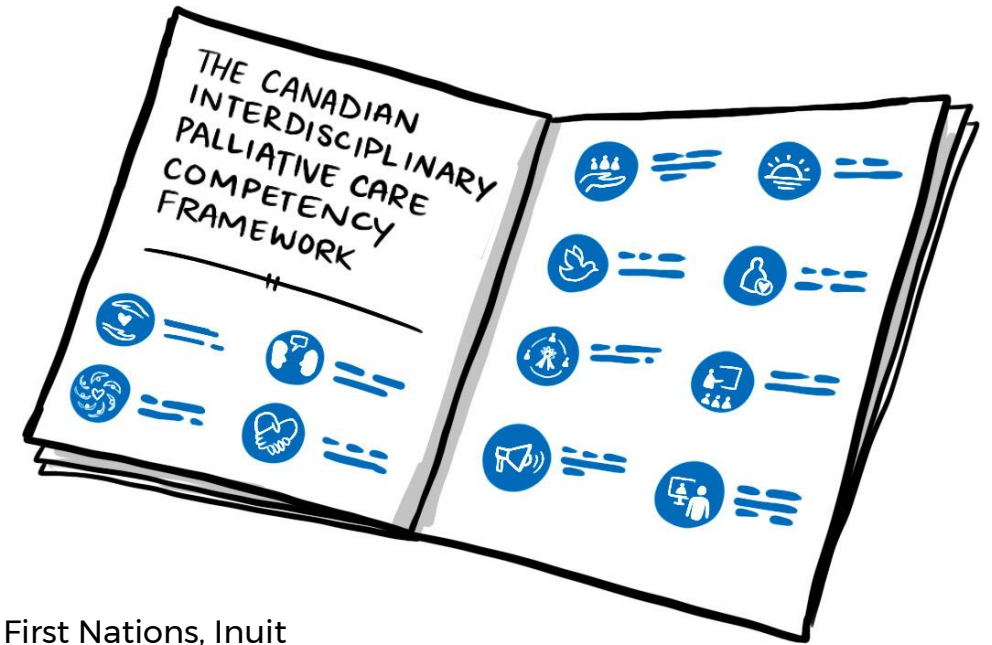
2019 The Partnership begins work on the *Canadian Inter-Disciplinary Palliative Care Competency Framework*



2020 The First Nations, Inuit and Métis Advisors provide guidance relative to the *Canadian Inter-Disciplinary Palliative Care Competency Framework*.



2021 The Partnership convenes First Nations, Inuit and Métis and non-Indigenous home and palliative care providers and organizations to discuss future opportunities.





Background

- This knowledge product is the result of a **July 2021 virtual roundtable discussion**.
- *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada* focuses on **sharing the challenges and resiliencies in accessing timely and culturally congruent palliative and end-of-life care for First Nations, Inuit and Métis Peoples**.

Specifically,

- Readers are welcomed to **adapt, scale and reference** strategies, programs and resources that support Indigenous approaches to palliative and end-of-life care.

Background – continued



Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada...

- is a **comprehensive foundational resource**; and
- **bridges the history of Indigenous Peoples in Canada with a pathway and set of resources for empowering both Indigenous and non-Indigenous Peoples to grow and develop community-based palliative and end-of-life care services.**

Palliative care and end-of-life care

Palliative care...

- **relieving symptoms** (pain and discomfort) and
- **improving the quality of life** for people with life-limiting illnesses.
- **End-of-life care focuses on meeting the goals of people** within their last hours, days, weeks or months of life; includes supporting their **families through the life-limiting illness and after death**; and is **part of palliative care**.
- For many First Nations, Inuit and Métis Peoples, their families and communities, **dying and death are not just about biomedical and physical processes. It is about an individual's transition to the spirit world—a social and spiritual event to be honoured and celebrated as a collective.**

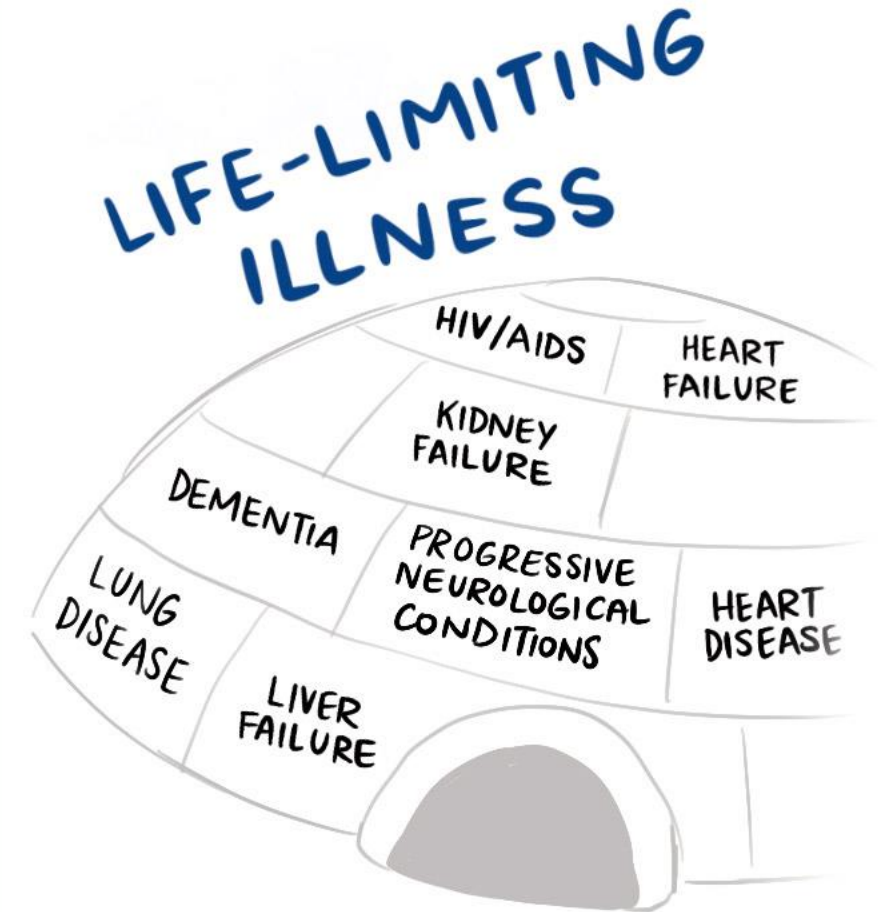


Palliative care and end-of-life care – continued

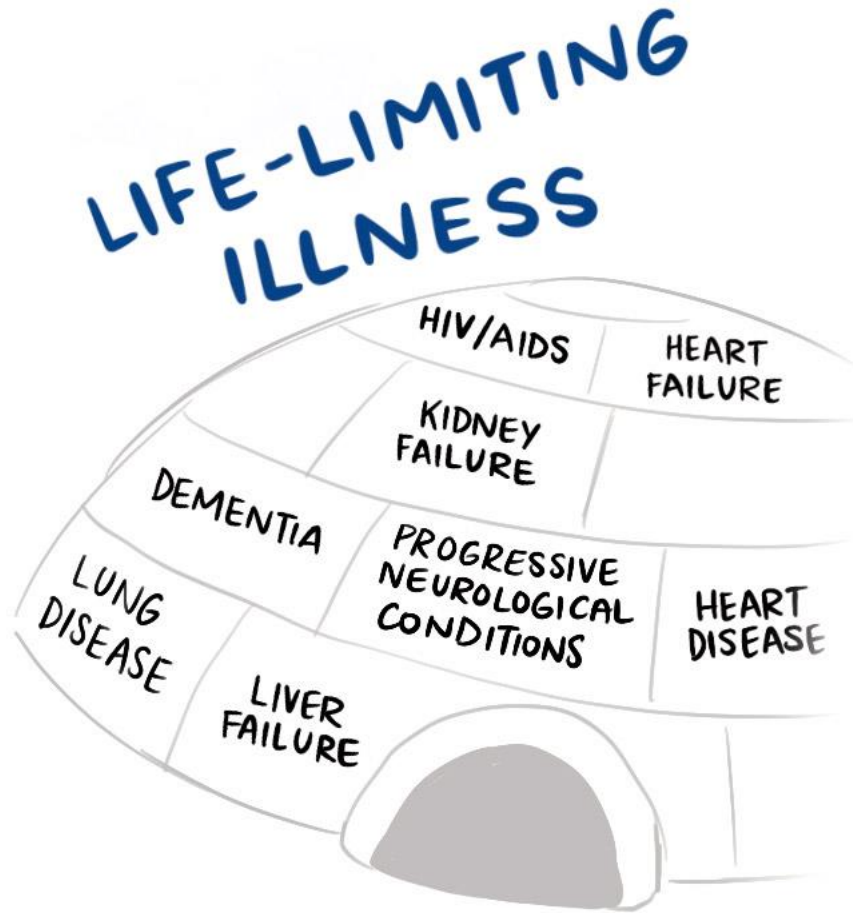
Life-limiting illnesses

- are complex, progressive chronic diseases ranging from cancer to organ diseases and failure; and
- in the case of end-of-life care, death is imminent—with a life expectancy of one year or less.

We invite all of you to expand the scope of palliative and end-of-life care to include *death in crisis*.



Palliative care and end-of-life care – continued



Life-limiting illnesses – cancer diagnosis

- Cancer remains the leading cause of death in Canada.
- An estimated two in five Canadians will be diagnosed with cancer in their lifetime and one in four will die from cancer.

Compared to non-Indigenous populations in Canada,

- Cancer rates for First Nations, Inuit and Métis...

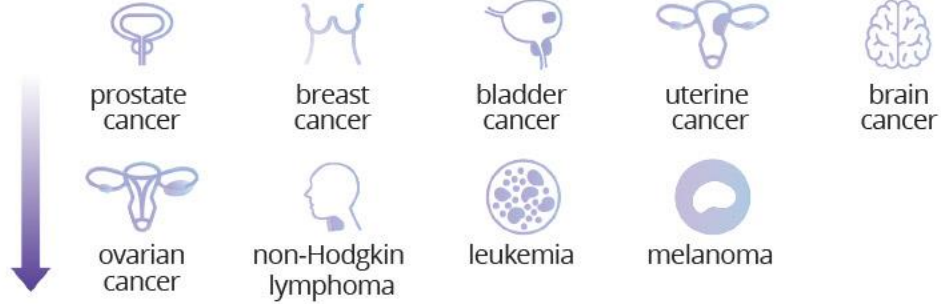
Incidence

Compared to the non-Indigenous population,

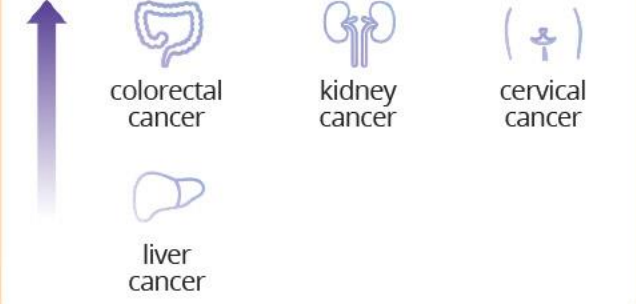
First Nations adults have a



Lower incidence of



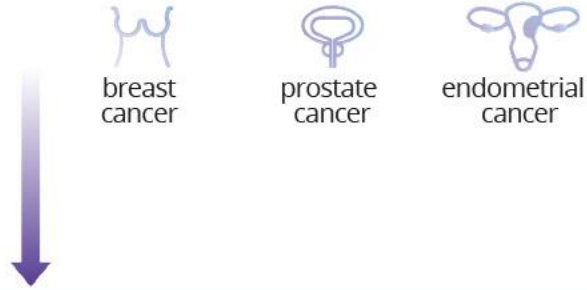
Higher incidence of



Inuit adults have a



Lower incidence of



Higher incidence of



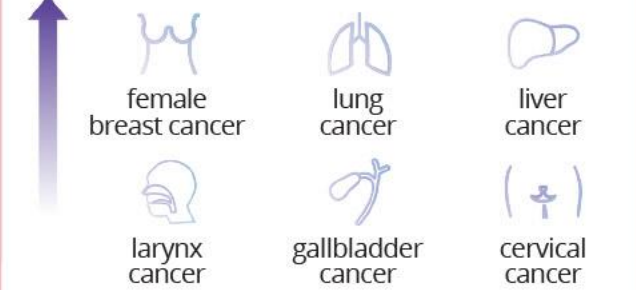
Métis adults have a



Lower incidence of



Higher incidence of



Indigenous perspectives on palliative care and end-of-life care

Why are Indigenous approaches to palliative and end-of-life care important?

- In Canada, **Indigenous Peoples (First Nations, Métis and Inuit) are the fastest growing populations.**
- Many Indigenous Peoples and communities across Canada commonly **hold perspectives and understandings of health, helping, dying and death that differ from other ethnic groups.**
- **Health-care services in Canada are generally based on non-Indigenous biomedical values**, which can lead to inequities in service delivery and health outcomes for Indigenous Peoples.

Indigenous perspectives on palliative care and end-of-life care – continued

Why are Indigenous approaches to palliative and end-of-life care important?

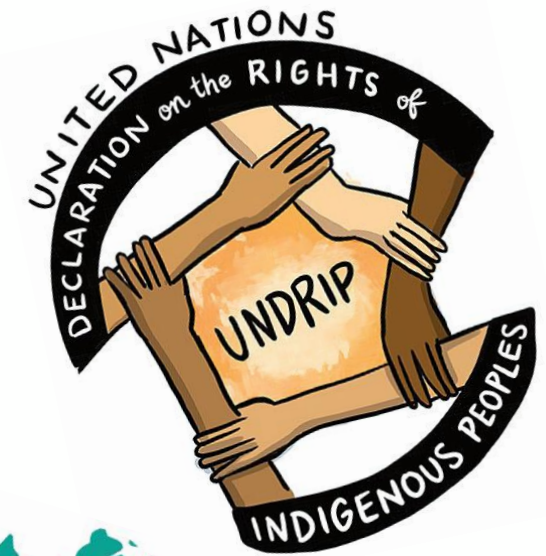
- An **increasing number of Indigenous communities across Canada are caring for more citizens** who are aging and/or diagnosed with complex, chronic and/or life-limiting illnesses.
- The majority of Indigenous Peoples with life-limiting illnesses **prefer to receive palliative and end-of-life care at home where family, friends, community and cultural practices surround them.**

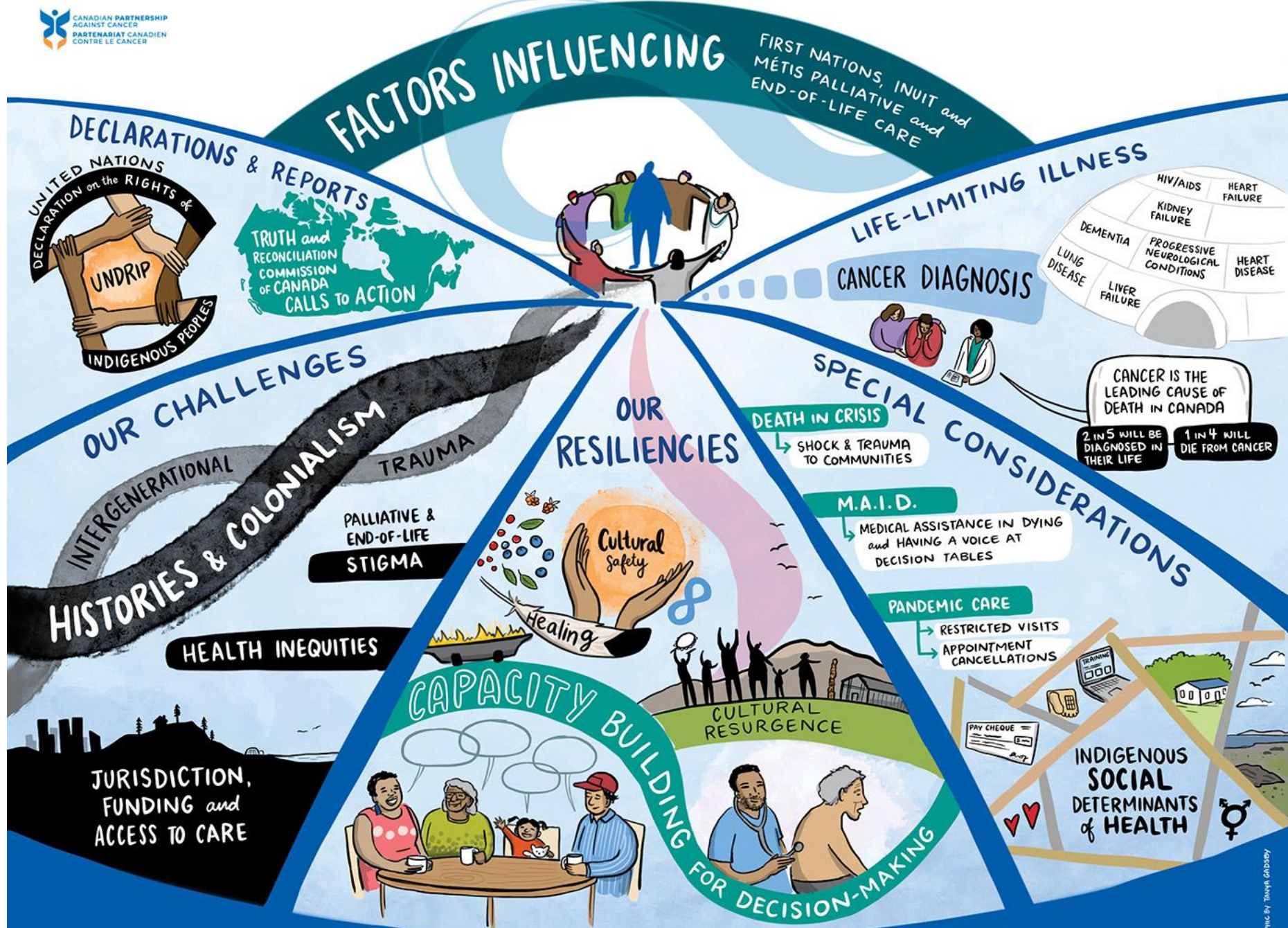


Indigenous perspectives on palliative care and end-of-life care – continued

In relation to palliative and end-of-life care:

- *United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)* and the *(Truth and Reconciliation) TRC calls to action* shine a light on the **importance of understanding the historical, social, cultural and political landscape that shape relationships between Indigenous Peoples and institutions such as the health-care system in Canada.**
- Self-determination is a central dimension to *UNDRIP* and Indigenous social determinants of health.
- It is the ability for Indigenous Peoples to decide for themselves what their life and death should look like.





Indigenous perspectives on palliative care and end-of-life care – continued



Challenges and resiliencies – historical factors

- Colonization
- Intergenerational trauma
- Health inequities

Health inequities, the historical effects of colonization and the residential school system in Canada are interrelated.

Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – jurisdictional factors

- The **Government of Canada (federal order of government)** has responsibility for **Indigenous Peoples**.
- The **delivery of health-care services in Canada** is primarily a **provincial/territorial responsibility**.
- In Canada, **palliative and end-of-life care** are **typically hospital-based and provincially/territorially-organized**.



Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – jurisdictional factors (barriers)

- **undefined roles and responsibilities**
- **lack of coordination** among service across orders of government
- **gaps in jurisdictional responsibility for funding** between orders of governments
- **challenges in navigating between political and jurisdictional boundaries**
- **inadequate availability of sustainable funding**
- **inequitable access to cultural supports/resources, medications, supplies and home care** in many rural, remote and northern communities
- **inequities between First Nations, Inuit and Métis populations**

Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – jurisdictional factors (opportunities)

- **growing recognition of Indigenous title and rights** in Canada
- **enhancing partnerships and collaborations** across orders of government
- **growing recognition of and respect** for the integrity of local Indigenous primary care systems (for example, traditional systems of care, home-based or community-based)

Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – cross-cultural factors

- Indigenous resilience and cultural resurgence:
 - connecting or reconnecting to land, people, place and Indigenous spirituality
 - revitalizing traditional livelihoods, Indigenous languages and community engagement



Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – cross-cultural factors

- Indigenous healing, helping and cultural safety
- Culturally safer practices are actions in colonized spaces (for example, biomedical health-care settings) where Indigenous Peoples, their families and communities feel
 - **respected**
 - **included**
 - **welcomed**
 - **comfortable being themselves and expressing all aspects of who they are**



Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – capacity building factors

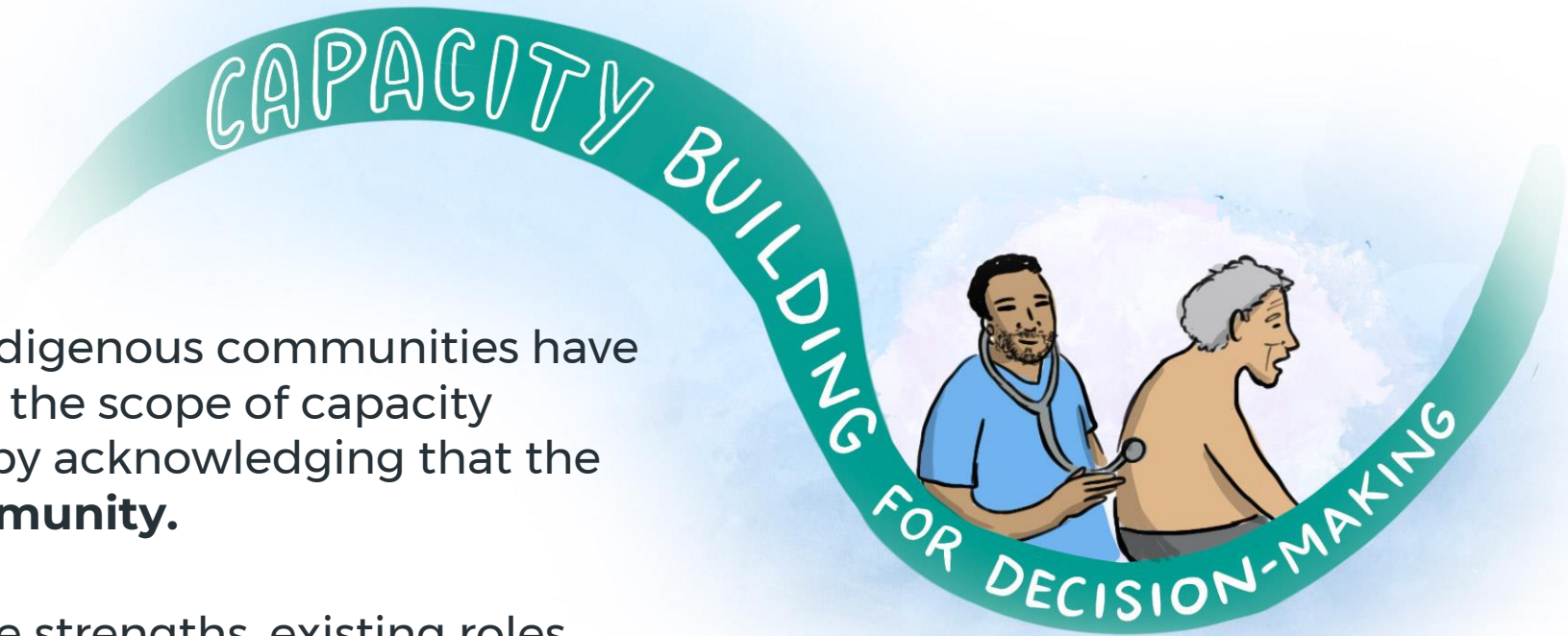
- Knowledge, skills and abilities empower Indigenous Peoples to participate in any or all aspects of decision-making in their communities, regions, provinces/territories and the country as a whole.
- For some Indigenous communities, capacity building has been hampered by many challenges.



Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – capacity building factors

- Despite barriers, many Indigenous communities have and continue to broaden the scope of capacity building and availability by acknowledging that the **answers are in the community.**
- There is recognition of the strengths, existing roles and capabilities of families and communities; for example, Elders, Knowledge Carriers, Indigenous healers and helpers, community leaders, families and friends.



Indigenous perspectives on palliative care and end-of-life care – continued

Challenges and resiliencies – resource factors

- The most important factors influencing the health of populations are life circumstances, often referred to as **social determinants of health**.
- Examples of social determinants of health are
 - income and socio-economic status
 - labour force participation
 - education and literacy
 - connection to land, geography and physical environments (includes infrastructure)



Indigenous perspectives on palliative care and end-of-life care – continued

DEATH IN CRISIS

↳ SHOCK & TRAUMA
TO COMMUNITIES

M.A.I.D.

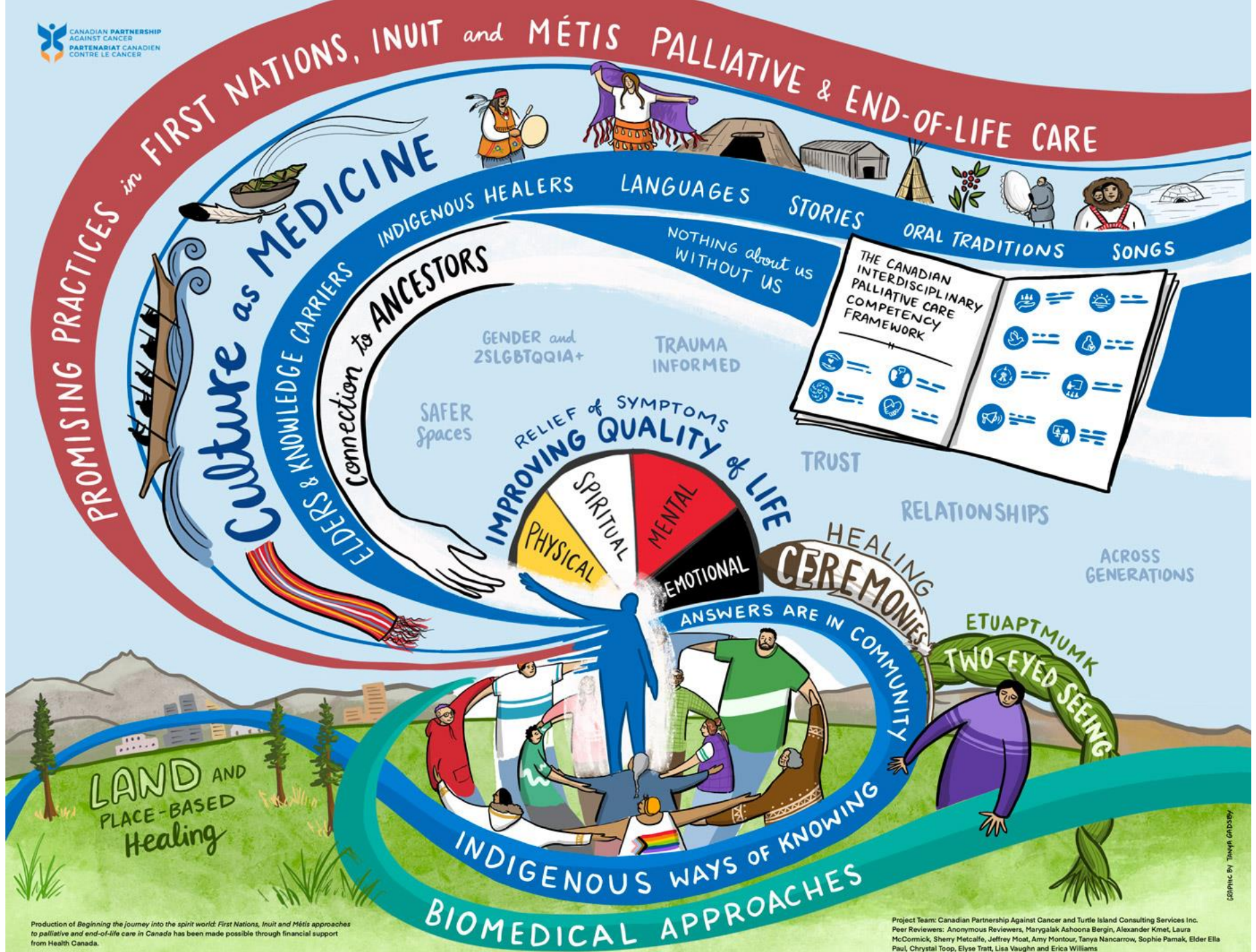
↳ MEDICAL ASSISTANCE IN DYING
and HAVING A VOICE AT
DECISION TABLES

PANDEMIC CARE

↳ RESTRICTED VISITS
↳ APPOINTMENT
CANCELLATIONS

Special considerations

- Indigenous social determinants of health
- Death in crisis
- Medical assistance in dying (MAID)
- Pandemic care



Culture as medicine

- **A holistic concept of health and wellness** (the balance of the mind, body, emotions and spirit) is an integral part of having a strong cultural identity.
- When culture is a core component to healing and helping, there are opportunities for programs, policies and broader strategies to **honour relationships to land, people and place; Indigenous spirituality and the role of community.**



Culture as medicine – continued

- Indigenous healing and helping ways of knowing are often linked to land and place.
- **Culturally safer palliative and end-of-life care provide a welcoming space for Indigenous Peoples** to connect or re-connect with their identities by being on the land and in community, speaking traditional language(s) and practicing culture.



Culture as medicine – continued

Relationships to land, people and place

- Indigenous identity
- Land and place-based healing and helping
- Indigenous languages
- Community engagement and partnerships



Culture as medicine – continued

Indigenous spirituality and connections with ancestors

For many First Nations, Inuit and Métis Peoples, their families and their communities, **dying and death are not just about biomedical and physical processes. It is about an individual's journey to the spirit world—a social and spiritual event to be honoured and celebrated as a collective.**

This journey includes

- **spirit and spirituality**
- **role of ancestors**—promising practice: spiritual assessment
- **role of healing ceremonies, teachings, practices and medicine**



Culture as medicine – continued



The answers are in the community

- Relational healing and helping practices in palliative and end-of-life care facilitate healthy ways to experience grief, loss and bereavement.

- **Role of Elders and Knowledge Carriers**

Promising practice: Elder and Knowledge Carrier engagement

- **Role of Indigenous healers and helpers**

Promising practice: Indigenous end-of-life guides

Culture as medicine – continued

The answers are in the community

Role of community leaders

- Strong local leaders in First Nations, Inuit and Métis communities can serve as catalysts for transformative change

Role of families and friends

- The process of connecting or reconnecting to family and friends is part of healing family structures and attachments that may have been disrupted or lost due to the effects of colonization and intergenerational trauma

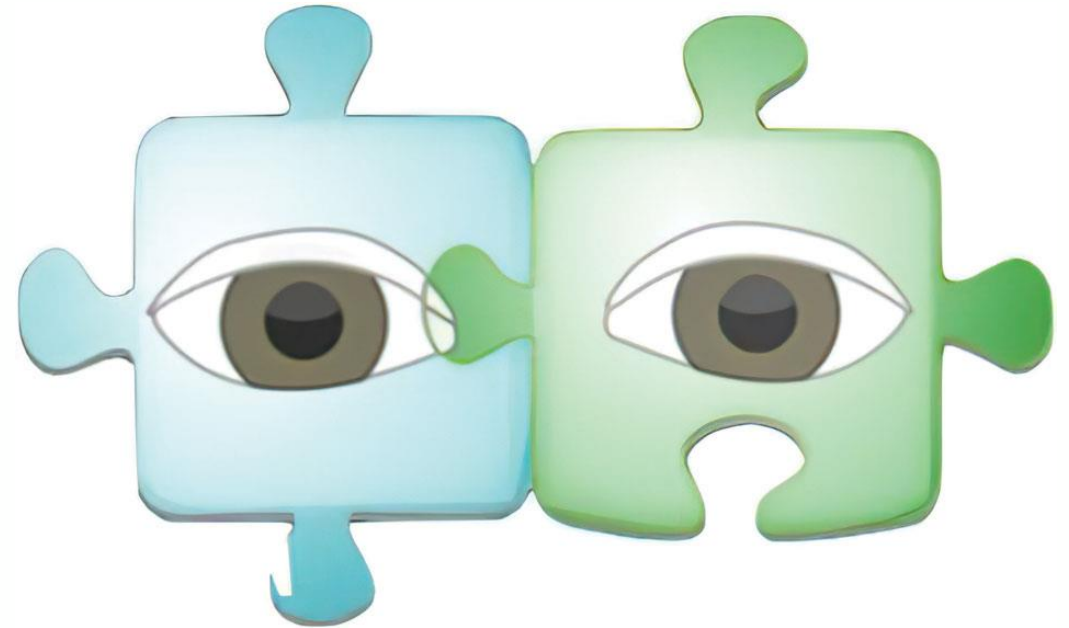
Nothing about us without us

- Local engagement and consultation with Indigenous Peoples and communities is required when developing and implementing palliative and end-of-life care programs



Braiding Indigenous ways of knowing and biomedical approaches

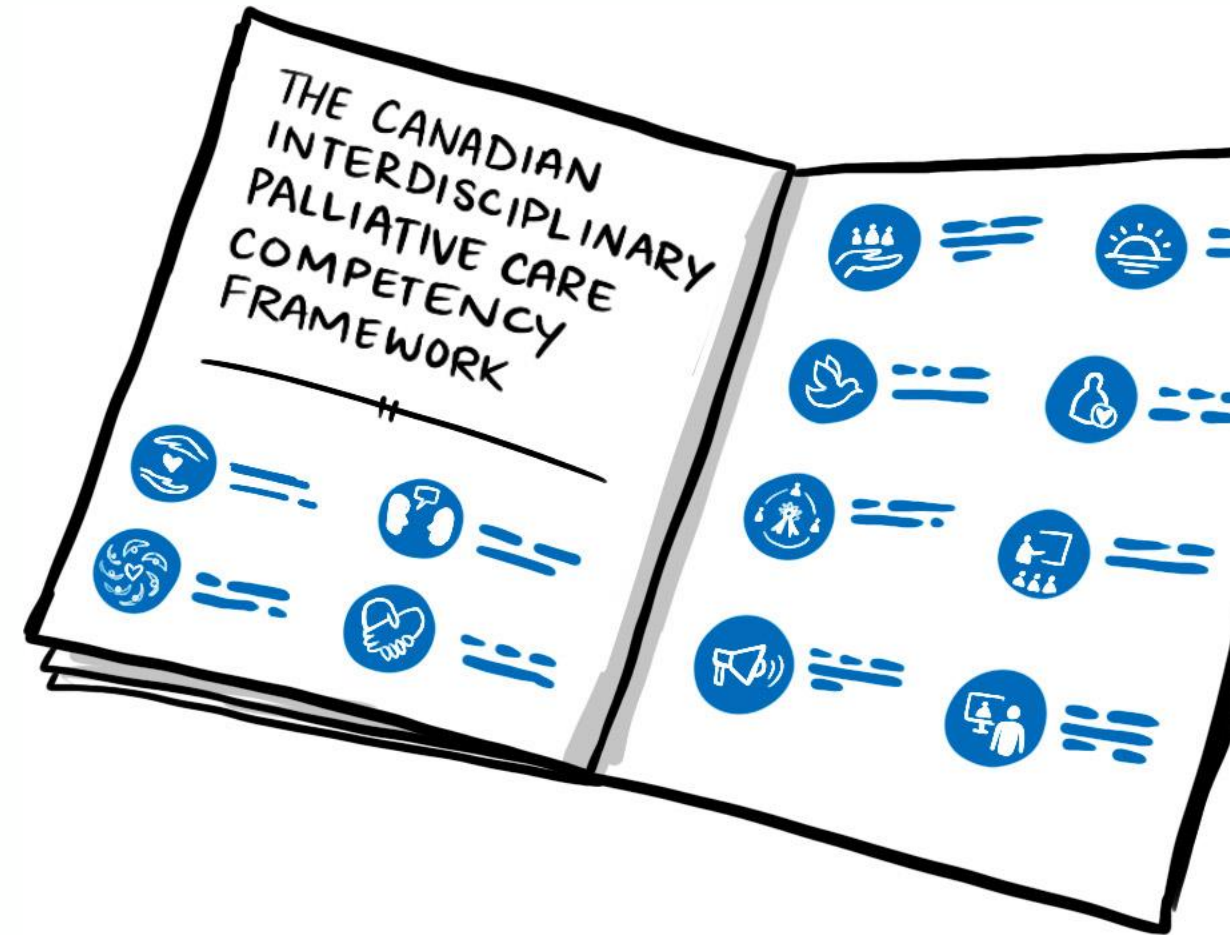
- The concept of braiding is based on the 2016 work of Drs. Gloria Snively and Wanosts'a7 Lorna Williams, *Knowing home: Braiding Indigenous science with Western science*
 - Etuaptmumk/two-eyed seeing
 - care across the generations
 - gender- and 2SLGBTQQA+-informed care
 - trauma-informed care
 - resilience-informed care
 - relationships and allyship



Etuaptmumk/two-eyed seeing. Image credit: Collaborative work by the research team of the Canada Research Chair in Integrative Science and Mi'kmaw Elders in Unama'ki/Cape Breton.

Competencies and promising practices

The Partnership developed a palliative care competency framework that outlines a clear and common vision of the **minimum national standards** that people (e.g., health-care providers) need to demonstrate to deliver high-quality, safer and ethical palliative and end-of-life care programs and services in Canada.



Competencies and promising practices – continued

There are **12 national palliative and end-of-life care competencies in Canada:**

1. Principles of palliative approach to care

- Promising practice: The Medicine Wheel

2. Cultural safety and humility

- Promising practice: Canadian Virtual Hospice—Indigenous cultural safety training: Advanced illness, palliative care and grief
- Promising practice: Saint Elizabeth Health @YourSideColleague® Essential Learning

3. Communication

- Promising practice: Culture-infused helping

4. Optimizing comfort and quality of life

- Promising practice: Yukon Hospital Corporation—First Nations Health Program



Competencies and promising practices – continued

5. Care planning and collaborative practice

- Promising practice: Canadian Virtual Hospice—*Coming full circle: Planning for your care workbook*

6. Last days and hours

- Promising practice: First Nations Health Authority and Douglas College [Indigenous end-of-life guide](#) course.

7. Loss, grief and bereavement

8. Self-care

- Promising practice: The “self is always first in the circle”

9. Professional and ethical practice

- Promising practice: *Traditional Native code of ethics*



Competencies and promising practices – continued

10. Education, evaluation, quality improvement and research

- Promising practice: Exchange of competencies (Inuit)
- Promising practice: Palliative Care ECHO Project by Pallium Canada
- Promising practice: Lakehead University—Improving end-of-life care in First Nations communities

11. Advocacy

12. Virtual care

- Promising practice: MBTelehealth (Manitoba)
- Promising practice: First Nations Health Authority (British Columbia)



Concluding remarks

The road we travel is equal in importance to the destination we seek. There are no shortcuts. When it comes to truth and reconciliation we are forced to go the distance.

-The Honourable Mr. Justice Murray Sinclair (former Chair of the Truth and Reconciliation Commission of Canada)

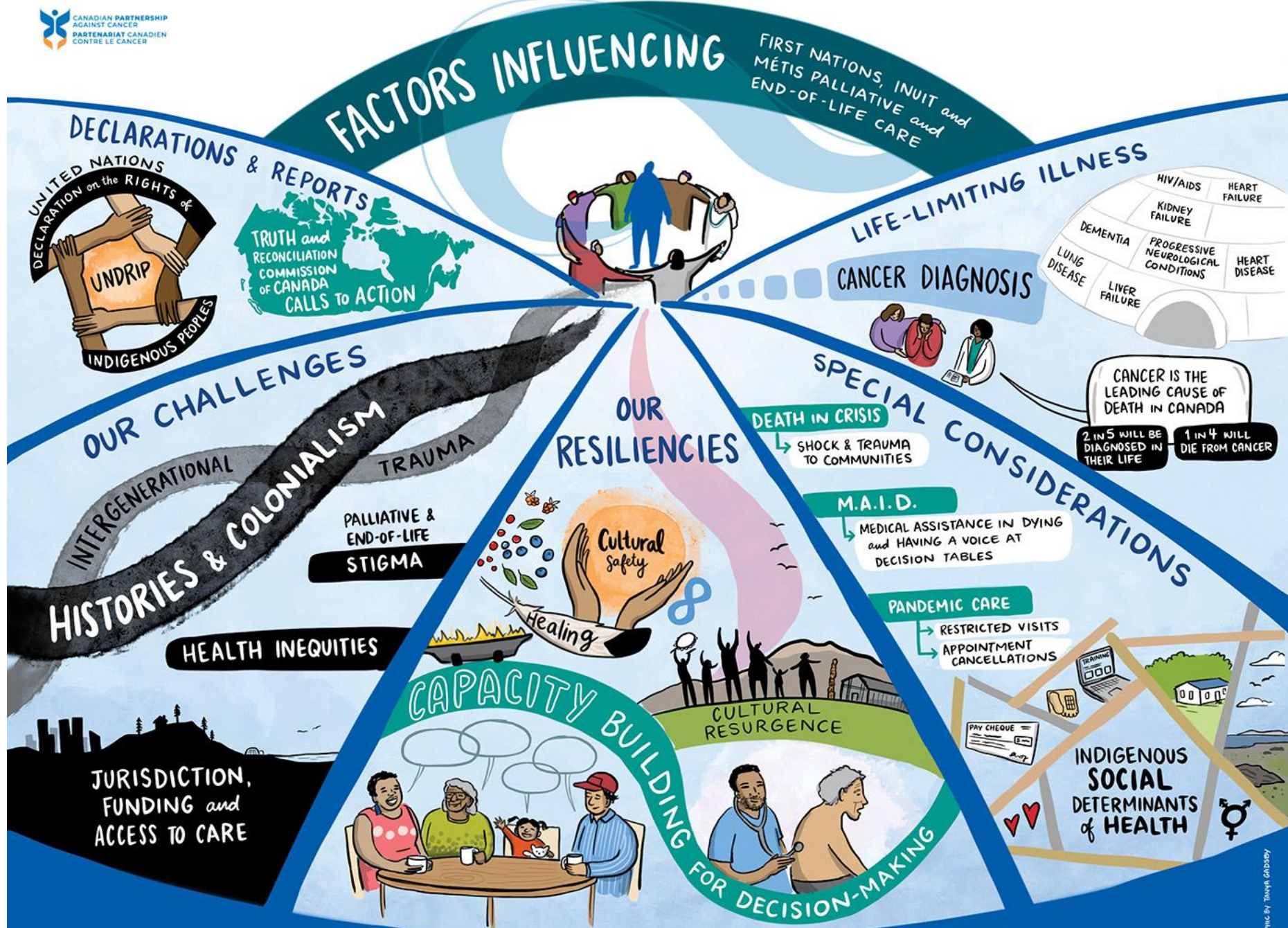
- The Partnership is committed to **advancing truth and reconciliation which includes achieving health equity for First Nations, Inuit and Métis Peoples.**

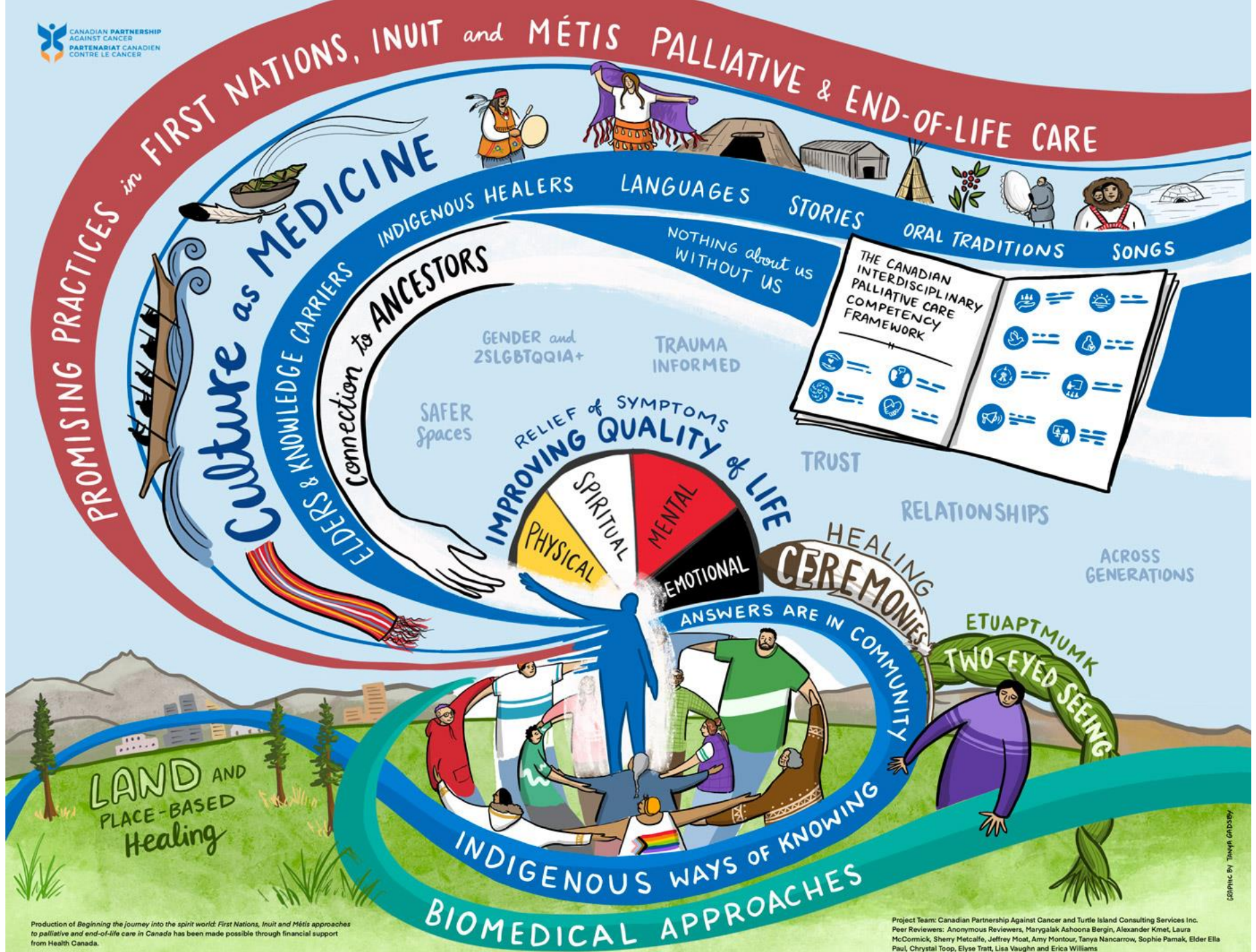


Concluding remarks – continued

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada

- **responds to recommendations from the July 2021 virtual roundtable discussion** with First Nations, Inuit and Métis Elders, Knowledge Carriers, community health professionals and researchers who have experience and knowledge of Indigenous approaches to palliative and end-of-life care; and
- **highlights factors that influence First Nations, Inuit and Métis palliative and end-of-life care and promising practices in First Nations, Inuit and Métis palliative and end-of-life care.**





Questions and Answers

To view the *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada* knowledge products, visit:

- [Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada \(EN\)](#)
 - [Factors influencing First Nations, Inuit and Métis palliative and end-of-life care infographic \(EN\)](#)
 - [Promising practices infographic \(EN\)](#)
- [Commencement du voyage dans le monde des esprits : Approches des Premières Nations, des Inuits et des Métis en matière de soins palliatifs et de fin de vie au Canada \(FR\)](#)

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