

# Canadian Atlas of Palliative Care: Mapping the Present – Shaping the Future



**Presenters:**

Dr. José Pereira  
Jeffrey Moat, CM  
Dr. Leonie Herx  
Christopher Klinger, PhD

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# 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.

**Stay connected: [www.echopalliative.com](http://www.echopalliative.com)**

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.



# LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by CFPC and RCPSC.



Learn more about the course and topics covered by visiting

[www.pallium.ca/course/leap-core](http://www.pallium.ca/course/leap-core)

# Introductions

## Presenters:

### **Jeffrey B. Moat, CM**

Chief Executive Officer, Pallium Canada

### **Dr. José Pereira, MBChB, CCFP(PC), MSc, FCFP, PhD**

Professor, Faculty of Medicine, University of Navarra, Spain

Professor, Division of Palliative Care, Department of Family Medicine, McMaster University

Scientific Advisor and Co-Founder, Pallium Canada

### **Dr. Leonie Herx MD PhD CHE FCFP CCFP (PC)**

Clinical Professor, Cumming School of Medicine, University of Calgary

Section Chief, Pediatric Palliative Medicine, Alberta Health Services - Calgary Zone

Director, Rotary Flames House

Research Associate, Pallium Canada Atlas Project

### **Christopher A. Klinger, PhD**

Research Scientist, Pallium Canada

Assistant Professor (Part-Time), Dr. Joshua Shadd - Pallium Canada Research Hub, McMaster University

# 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.

# Conflict of Interest

## **Pallium Canada**

- Non-profit
- Partially funded through a contribution by Health Canada
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Pocketbook

## **Presenters:**

- Jeffrey B. Moat: FT employee of Pallium Canada
- Leonie Herx: Research Associate, Pallium Canada Atlas Project
- José Pereira: Scientific Advisor for Pallium Canada
- Christopher Klinger: Research Scientist, Pallium Canada

# The Atlas Approach: Overview & Role of Atlases



# Atlas Approach

- Atlases of palliative care map the status of palliative care in a country across several domains.
- Domains established by international collaboration led by Global Palliative Care Observatory at the University of Navarra in Spain (a WHO Collaboration Centre).
- Domains include:
  - Policy indicators
  - Service provision indicators
    - Palliative care units and hospices
    - Palliative care teams in hospitals and community
    - Palliative care integration in LTC, primary care, various specialties, etc.
  - Education indicators
  - Access to medications indicators
  - Professional activities

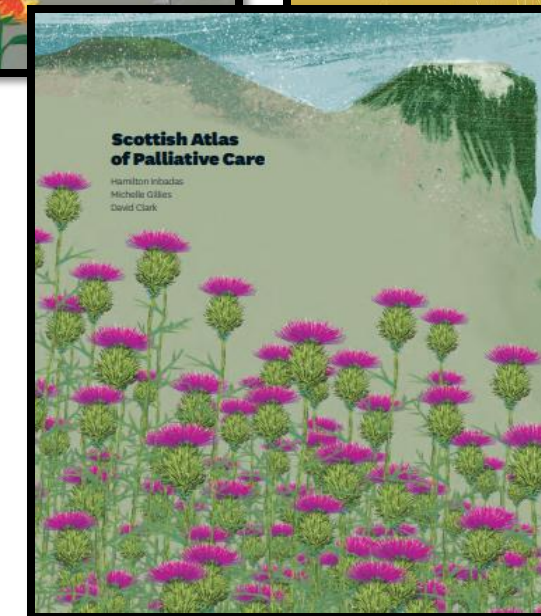
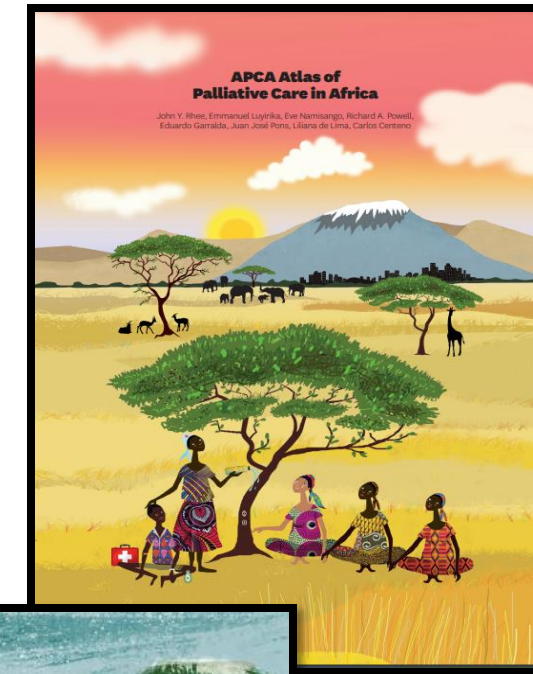
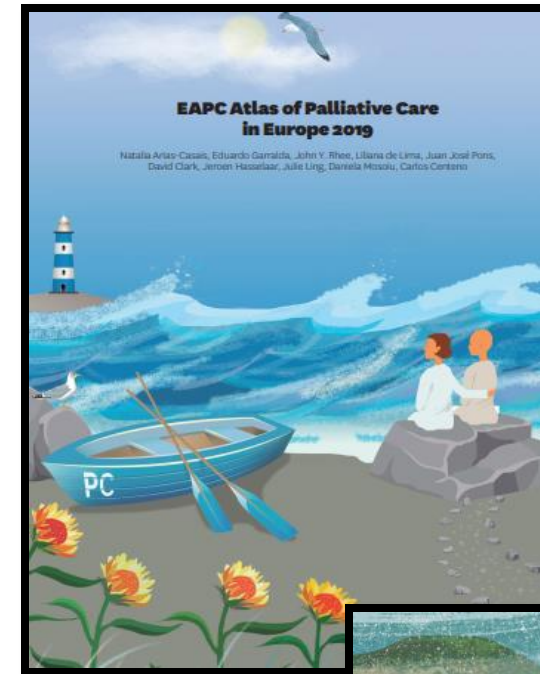


## WHO Palliative Care "House"

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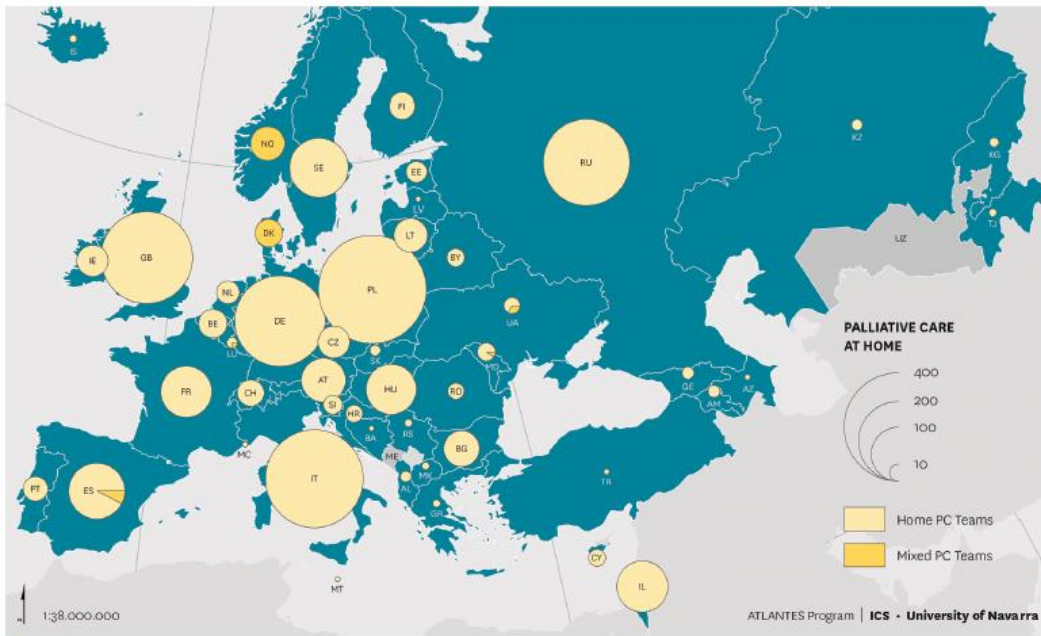
# Atlas Approach

- Several Atlases developed since 2007:
  - Africa 2017 & 2024 underway
  - Europe 2007, 2013, 2019
  - Latin America 2013, 2020 and 2024 underway
  - Middle East 2017
  - Scotland 2016
  - Asia (in progress)



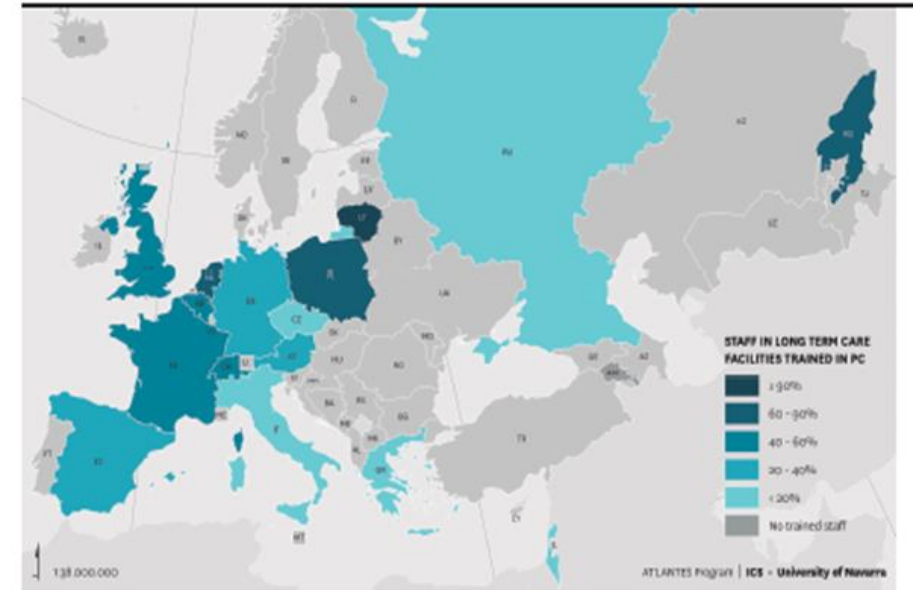
# Examples of Atlases

## Graphical presentations

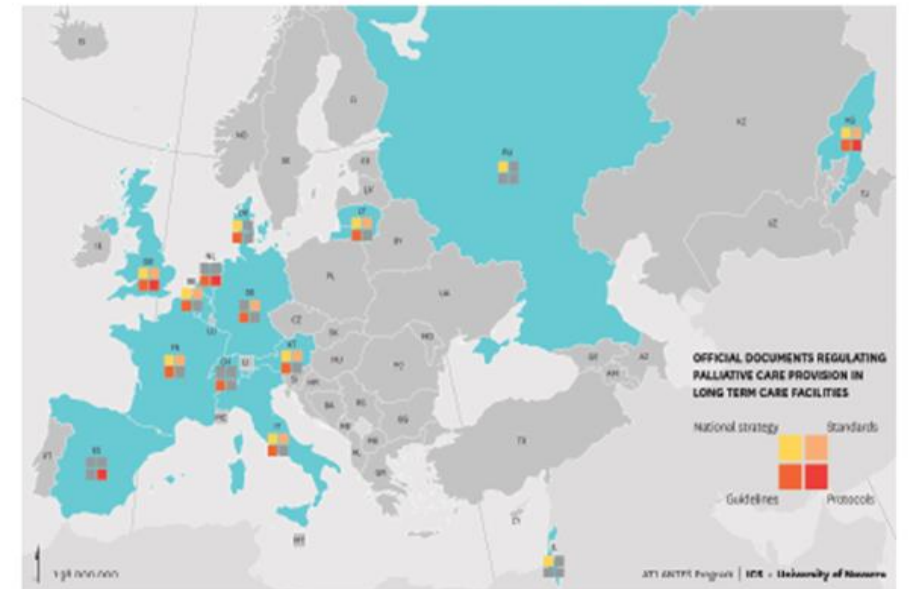


Map 1.5. Palliative Care at Home.

## Chapter 7. Integration of Palliative Care In Long-Term Care Facilities In 18 European countries

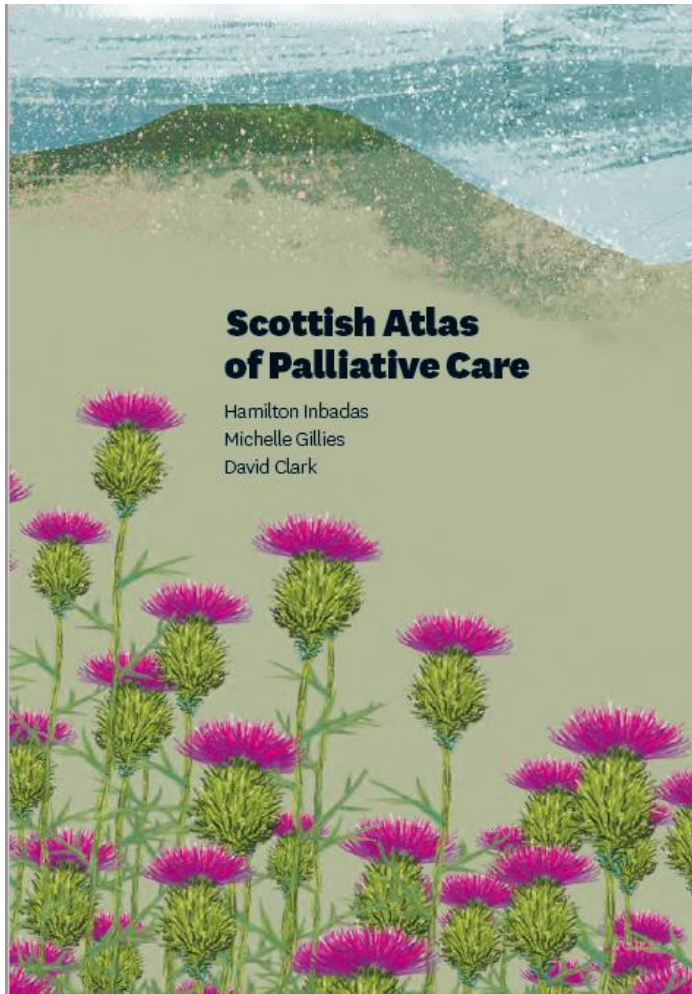


Map 7.1. Staff in Long Term Care Facilities trained in Palliative Care.



Map 7.2. Official documents regulating Palliative Care provision in Long Term Care Facilities.

# Scottish Atlas



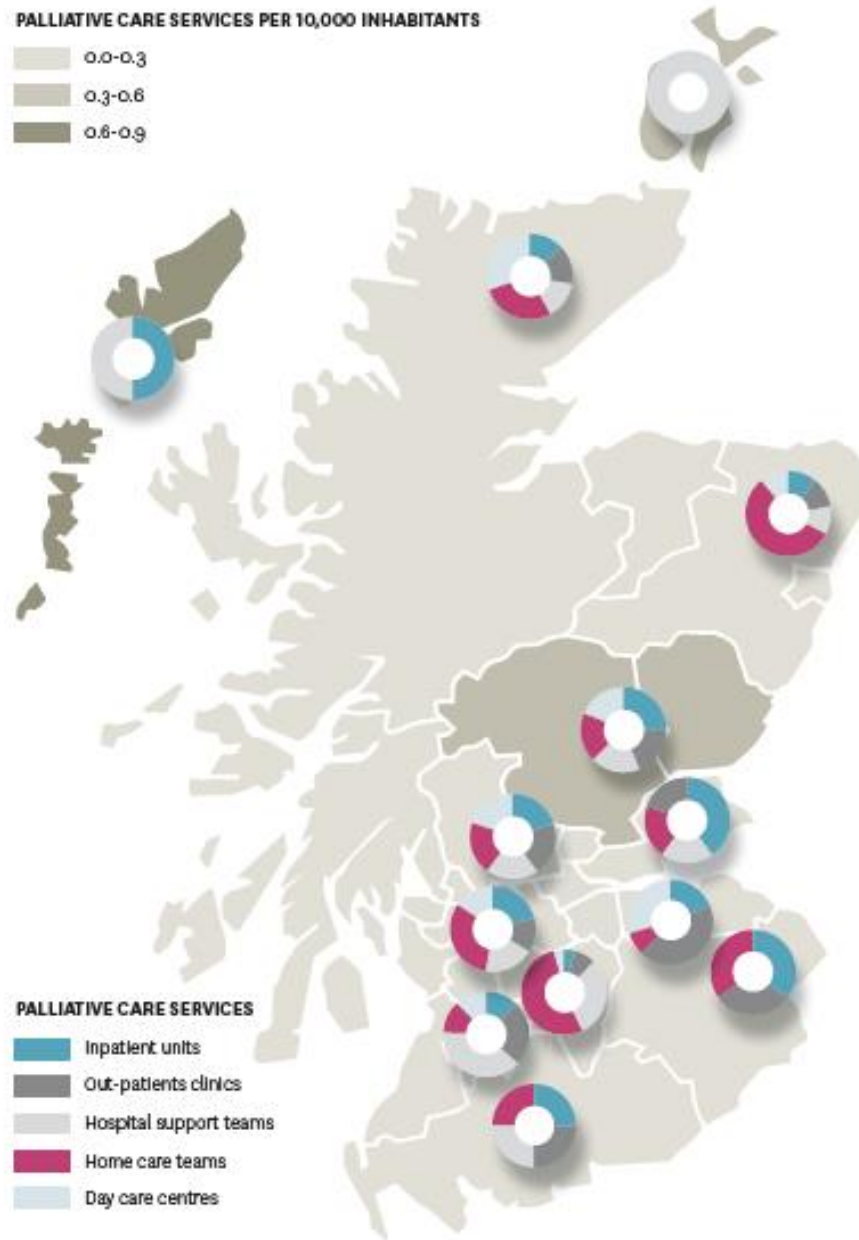
## Scottish Atlas of Palliative Care

Hamilton Inbadas  
Michelle Gillies  
David Clark

### PALLIATIVE CARE SERVICES PER 10,000 INHABITANTS



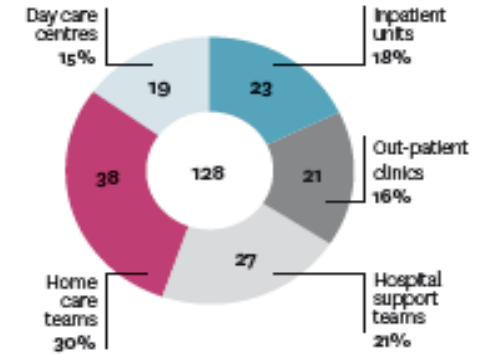
### PALLIATIVE CARE SERVICES



## 03. Specialist palliative care services in Scotland

### PALLIATIVE CARE SERVICES [2015]

SERVICE	NO	%
Inpatient units	23	18
Out-patient clinics	21	16
Hospital support teams	27	21
Home care teams	38	30
Day care centres	19	15
TOTAL	128	100



In addition to the numbers of services indicated above, Marie Curie Scotland, Macmillan Cancer Support and Children's Hospice Association Scotland (CHAS) provide palliative care services at the national level, often in collaboration with other palliative care services.

# Role of Atlases

- Facilitate integration of palliative care across health systems and access for patients
  - **Identify and highlight successes (to spread and scale-up) and gaps (to address)**
- Catalyze reflection and action by health systems leaders, policymakers, planners, and managers
- Raise awareness in special areas where further focus might be required
- Identify and describe **similarities** and **variations** across jurisdictions in the state of palliative care delivery

# Alignment to National Palliative Care Action Plans

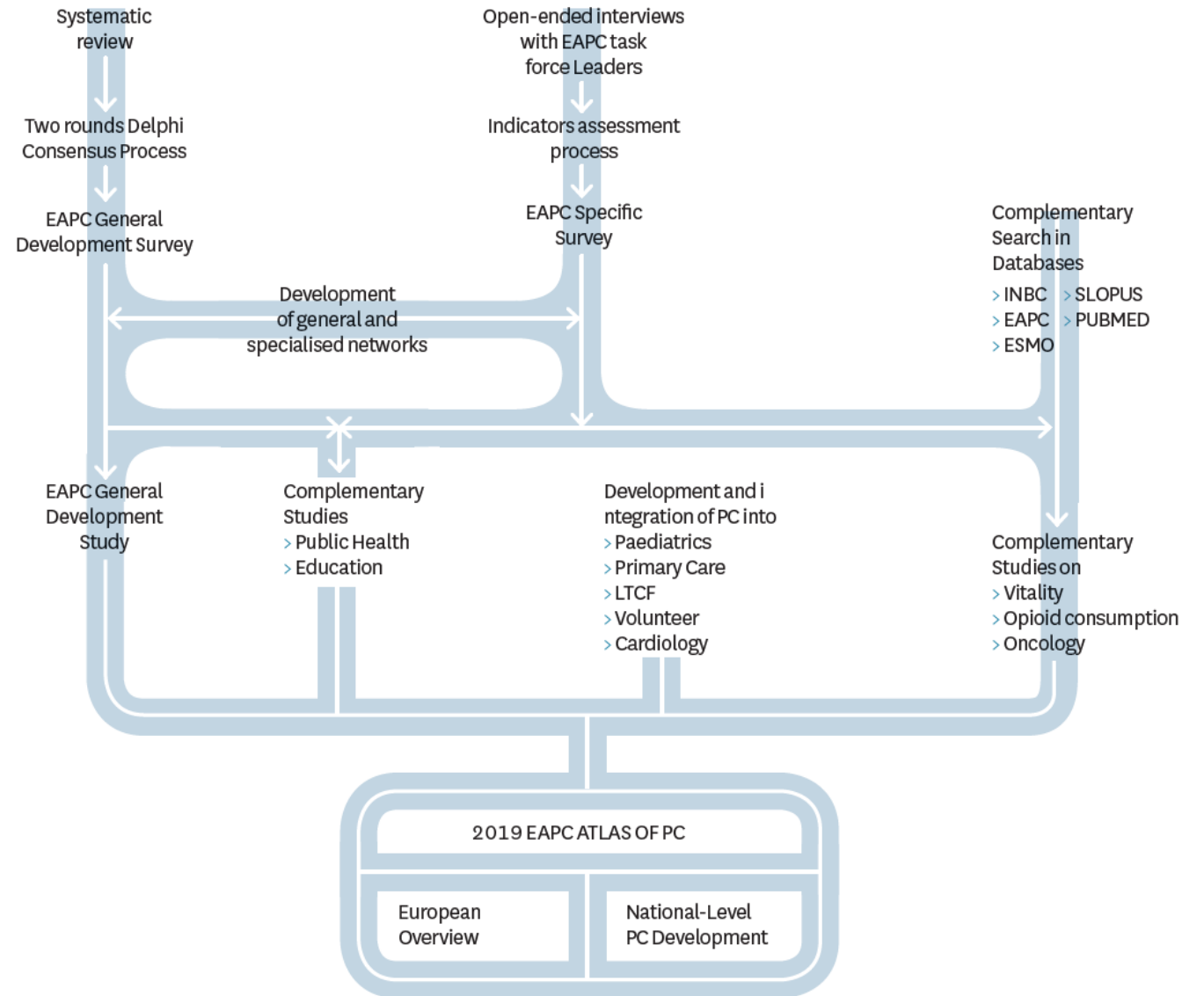
- Health Canada's Framework on Palliative Care:
  - for "... research and the collection of data on palliative care, and measures to facilitate equitable access to palliative care across Canada, with a closer look at underserved populations."
  - lists as a priority, "Map national and local palliative care services and supports to highlight what is available but not well known, and where gaps exist."

# The Atlas Approach: Methods

# Overall methods

- Multiple steps of development
- Multiple information and data sources
  - Literature searches
  - Review of reports
  - Surveys and interviews of key informants (2 to 10 per country; depending on country size and population)
  - Informants are formal or informal palliative care leaders recognized by peers

## Methodology Flowchart





# Core Research Team

Organization	Name(s)	Role(s)
Pallium Canada	Dr. Leonie Herx Jeffrey Moat, CM Julia Moat, BA	Co-Investigator and Ontario Lead Co-Investigator Research Assistant
McMaster University	Dr. José Pereira Michelle Howard, PhD Christopher Klinger, PhD Dr. Derelie (Dee) Mangin Dr. Denise Marshall	Principal Investigator Local Principal Investigator Co-Investigator and Project Lead Co-Investigator Co-Investigator
OntarioTech University	Brenda Gamble, PhD	Local Principal Investigator
University of Navarra, Spain	Dr. Carlos Centeno and the ATLANTES Global Observatory of Palliative Care	Local Principal Investigator
Canadian Society of Palliative Care Physicians	Dr. David Henderson	Co-Investigator
Lakeridge Health	Dr. Edward Osborne	Collaborator

# Canadian Atlas - Methods Used

- **Largely using same methods as international Atlases:**
  - Publicly-available data
  - Surveys
  - Interviews with key informants
  - Domains align with international Atlases

# Methods Used (continued)

- Nine domains aligned with international Atlases
- Most indicators/elements derived from international work and adapted for Canada
- National, provincial/territorial, and regional levels
- Highlighting Focussed Populations and Community Engagement
- Concurrent process for Indigenous Peoples, following Ownership, Control, Access, and Possession (OCAP) principles

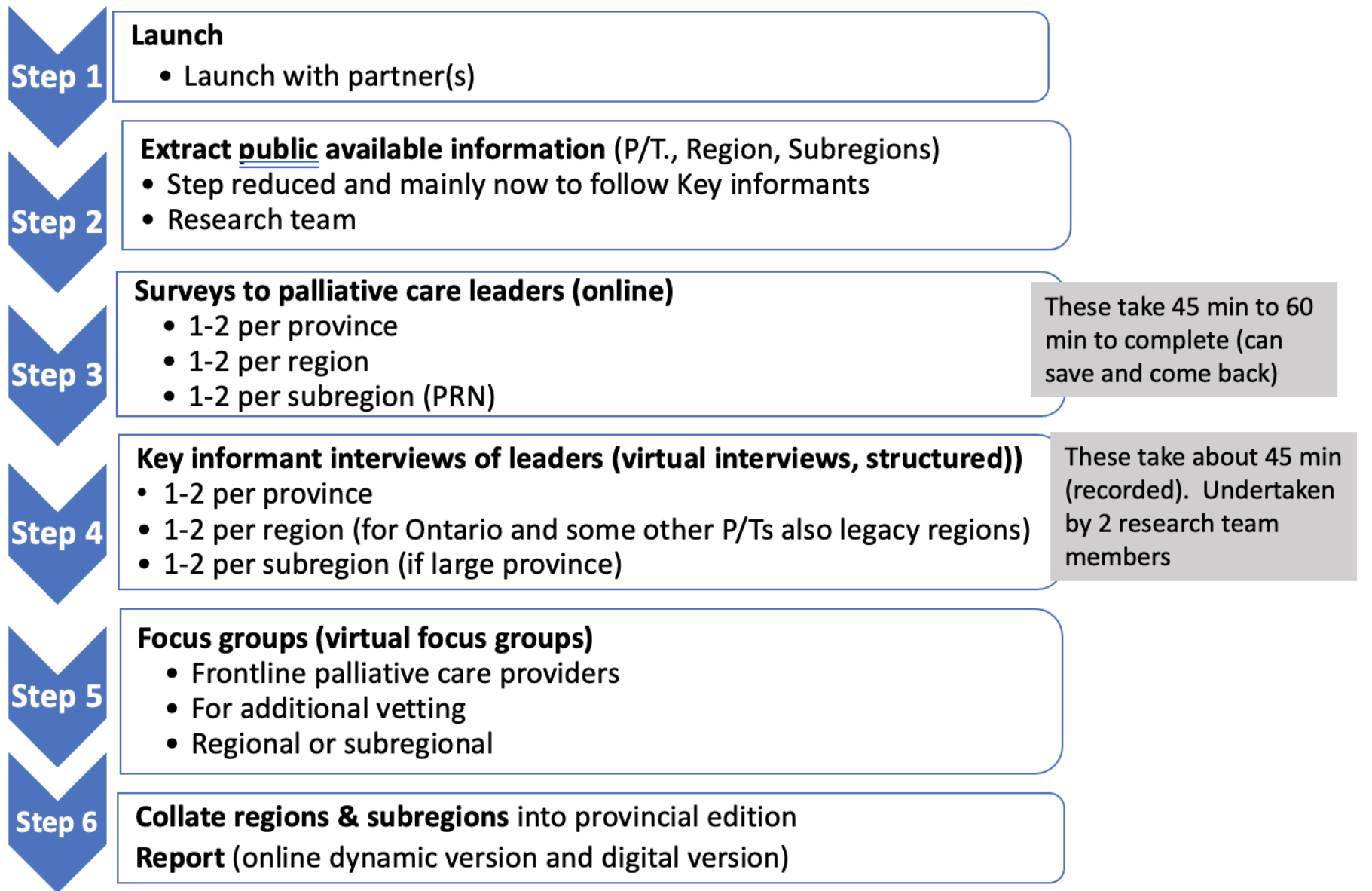
Domain	Elements	Level
<b>1. Demographics (D)</b>	D1: Population Density, D2: Total Area, D3: Hospitals and Classification, D4: Primary Care Involvement, D5: Death per Year (and Causes), D6: Organization of Health Services, D7: Population Profile (including Indigenous Peoples and Focused Populations)	D1-D4 and D6-D7: R, PT, F D5: PT, F
<b>2. Policy (P)</b>	P1: Designated Palliative Care Office, P2: Palliative Care Policy, P3: Palliative Care Legislation, P4: Standards/Norms of Practice, P5: Monitoring Systems, P6: Designated Funding, P7: Palliative Care Billing Codes, P8: Advance Care Planning Legislation	P1-P2, P4-P6 and P8: R, PT, F P3 and P7: PT, F
<b>3. Services (S)</b>	S1: Acute Care: Palliative Care Units, Specialist Teams and Integration of Services S2: Community Services: Community-Based Teams, Home Care and Hospice Services, etc.	S1: R, PT S2: R, PT
<b>4. System Performance (PF)</b>	Indicators mainly taken from provincial and territorial reports alongside various stakeholder organizations; Leverage of partner organizations toward the Canadian Atlas project	PF: R, PT
<b>5. Education (E)</b>	E1/E2: Palliative Care (Sub-)Specialty for Physicians and/or Nurses, E3: Palliative Care in Medical Schools, E4: Education in Residency, E5: Palliative Care in Nursing Schools, E6: Academic Palliative Care Positions/Chairs, E7: Palliative Care Research, E8: Continuing Education	E1-E2: F E3-E7: R, PT E8: R, PT, F
<b>6. Professional Activities (A)</b>	A1: Palliative Care Association, A2: Palliative Care Directory, A3: Palliative Care Conference(s), A4: Quality Improvement Activities, A5: Research Funding, A6: Palliative Care Publications	A1, A5: PT, F A2-A3: R, PT, F A4: R, PT A6: F
<b>7. Focused Populations (FP)</b>	FP1: Pediatric Palliative Care, FP2: Pediatric Palliative Care Unit(s), FP3: Palliative Care for LGBTQ2SIA+, FP4: Palliative Care for the Homeless and Marginally Housed, FP5: Prison Populations, FP6: Immigrants and Refugees, FP7: Informal Caregivers	FP1-FP4: R, PT FP5-FP6: PT, F FP7: R, PT, F
<b>8. Community Engagement (C)</b>	C1: Volunteer Program(s), C2: Volunteer Training, C3: Compassionate Communities, C4: Compassionate Community Activities, C5: Caregiver Education and Support	C1-C5: R, PT
<b>9. Other Activities (O)</b>	O: Other Resources and Programs	O: R, PT, F

# Canadian Atlas – Methods Used

- **Unique to Canadian Atlas:**

- Our reality: Variations across P/Ts and across their regions and subregions, therefore multiple levels
  - Country-wide (Federal)
  - Provinces & Territories
  - Regions and subregions
- Surveys and key informants
  - Federal (4 to 8 leaders)
  - P/T level: 2 to 3 leaders/managers
  - Regions: 2 to 3 leaders/managers
  - Subregions: 2 to 3 leaders/managers
- Front-line workforce input (focus groups, including LEAP facilitators)
- Highlighting focused populations
- Requiring separate Atlas for Indigenous populations

# Methods: Steps



# Canadian Atlas of Palliative Care: Progress to Date

- Started work in 2019. Research team from several institutions:
  - McMaster University, OntarioTech University, Nova Scotia, University of Navarra, etc.
  - Established project team, national network and partnerships
  - 2020: Tailored domains and indicators to the Canadian context
    - Done by Research team plus international experts;
- REB (McMaster) approval: Pilot Study, then Ontario, then BC and Alberta, next country-wide
- Started piloting in 2 regions and their sub-regions (selected on basis of presence of urban, rural and remote regions for testing)
  - ➔ • Central East (CE) Region, ON
  - Hamilton-Niagara-Haldimand-Brant (HNHB) Region, ON

# Canadian Atlas of Palliative Care

- Funding received:
  - AB Edition (Alberta Health Services/Government of Alberta)
  - BC Edition (Order of St John of Jerusalem, YP Heung Foundation)
  - ON Edition (PSI Foundation) versions of the Canadian Atlas, mapping support from Esri Canada
- Atlases Currently Underway:
  - Alberta Edition: Launched and Surveys completed. Interviews/Focus Groups underway.
    - In collaboration with Division of Palliative Care, University of Calgary
  - British Columbia Edition: Launched and 3/5 regional Surveys completed. Further interviews to follow.
    - In collaboration with BC Centre for Palliative Care
  - Ontario Edition: Launched Phase 1 - Surveys underway. Interviews to follow.
  - Quebec Edition: Education mapping in collaboration with RQSPAL



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FOUNDATION



# Partnerships/Supporters

## Partner Organizations:



Canadian Hospice Palliative Care Association  
Association canadienne de soins palliatifs

CSPCP  
Canadian Society of  
Palliative Care Physicians



SCMSP  
Société canadienne des  
médecins de soins palliatifs



CANADIAN PARTNERSHIP  
AGAINST CANCER  
PARTENARIAT CANADIEN  
CONTRE LE CANCER



Canadian Palliative Care  
Nursing Association  
Association Canadienne des  
Soins Infirmiers Palliatifs

## Provincial/Territorial Hospice Palliative Care Associations:

- Alberta Hospice Palliative Care Association
- Association québécois de soins palliatifs
- Hospice PEI
- Hospice Yukon
- Hospice Palliative Care Ontario
- Newfoundland and Labrador Palliative Care Association
- Nova Scotia Hospice Palliative Care Association
- Palliative Care Manitoba

## Supporters:

- Canadian Association of Social Workers
- Department of Health and Social Services, Northwest Territories
- McMaster University, Department of Family Medicine
- Ontario Palliative Care Network
- Réseau québécois de recherche en soins palliatifs

## Focused Populations:

- Canadian Network of Palliative Care for Children
- Egale
- Office of the Correctional Investigator
- Palliative Education and Care for the Homeless

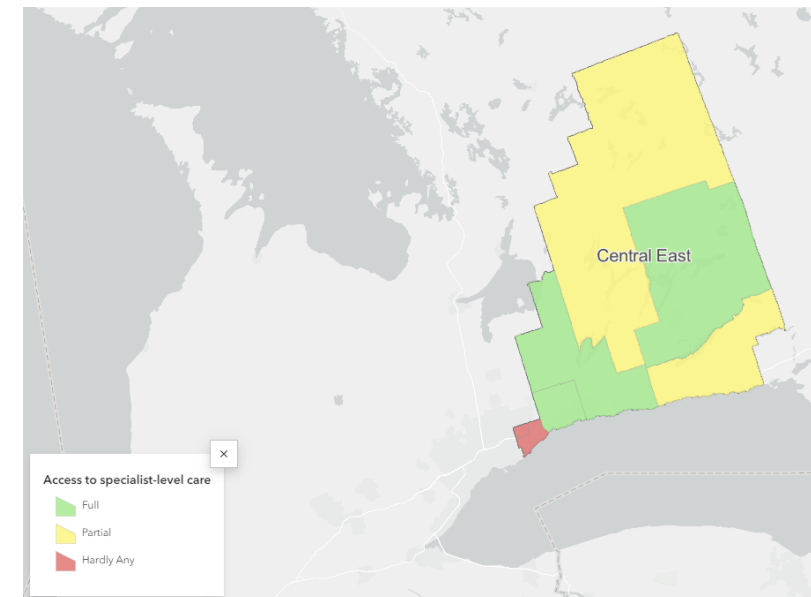
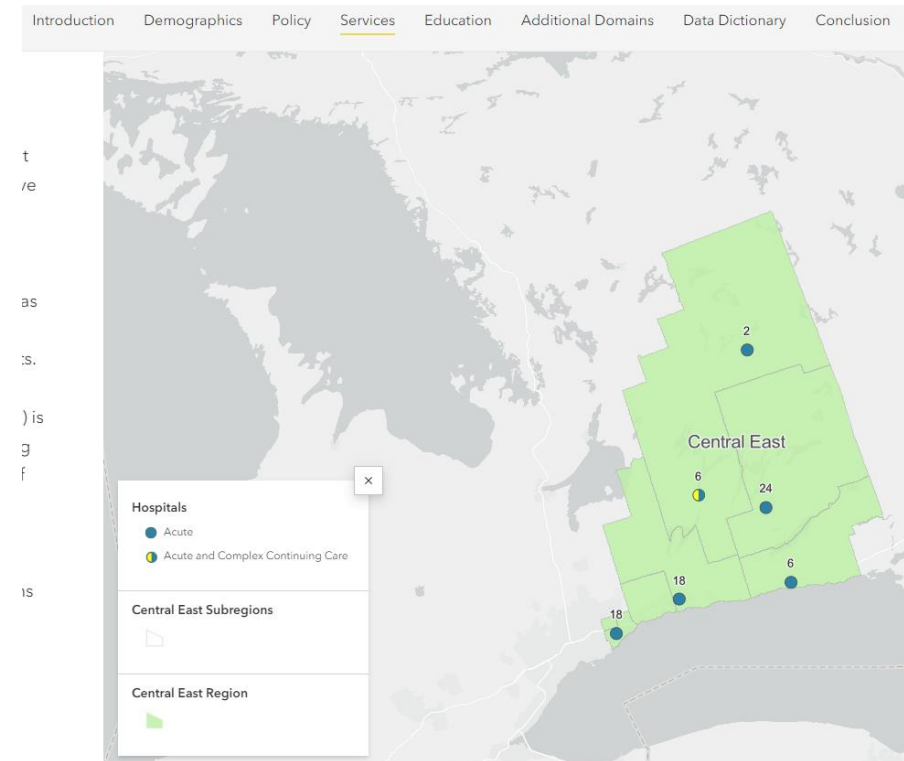
...and additional Collaborators from British Columbia, Ontario, and Québec.



# Example of Atlas: Central East Region (Pilot)

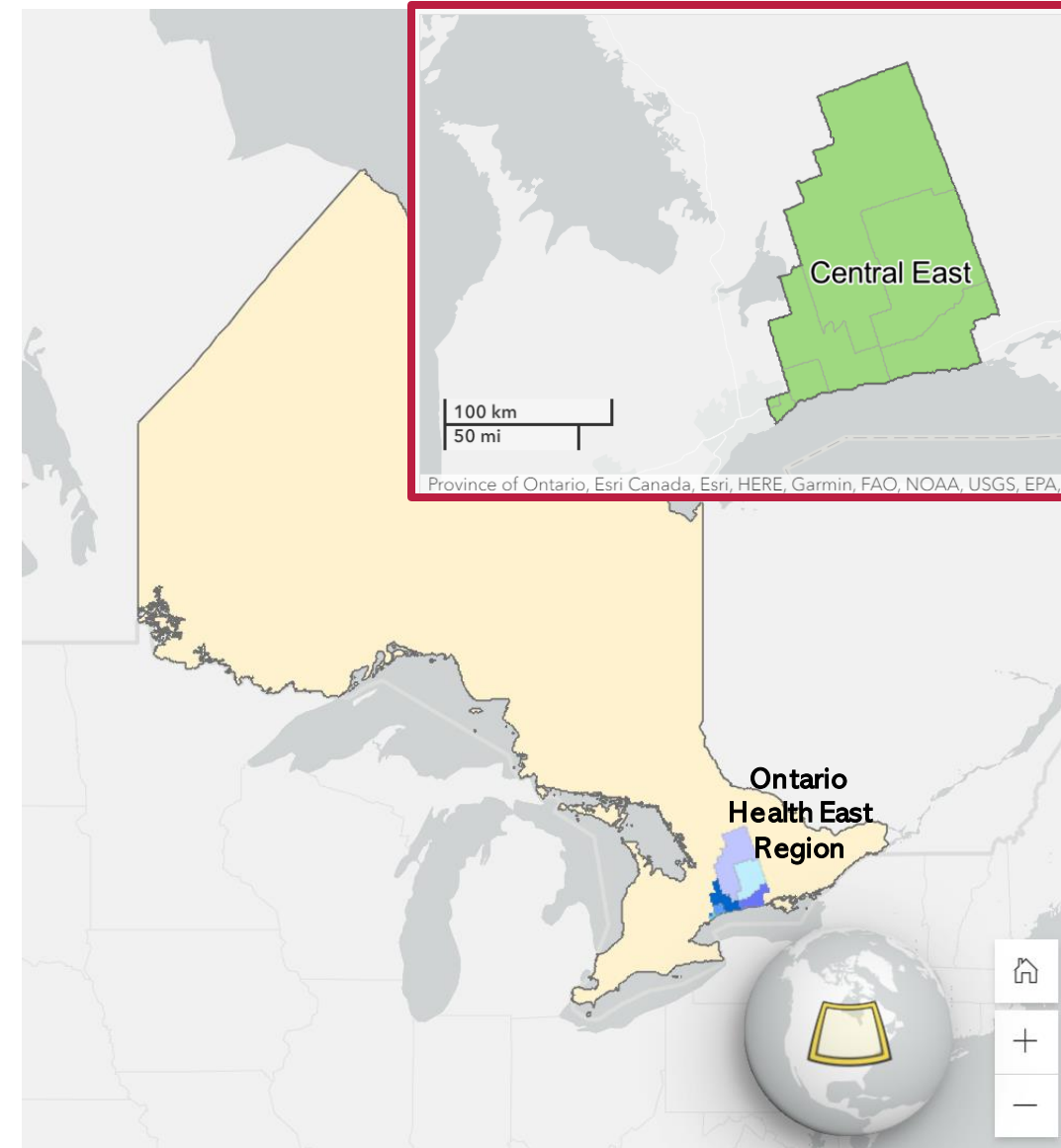
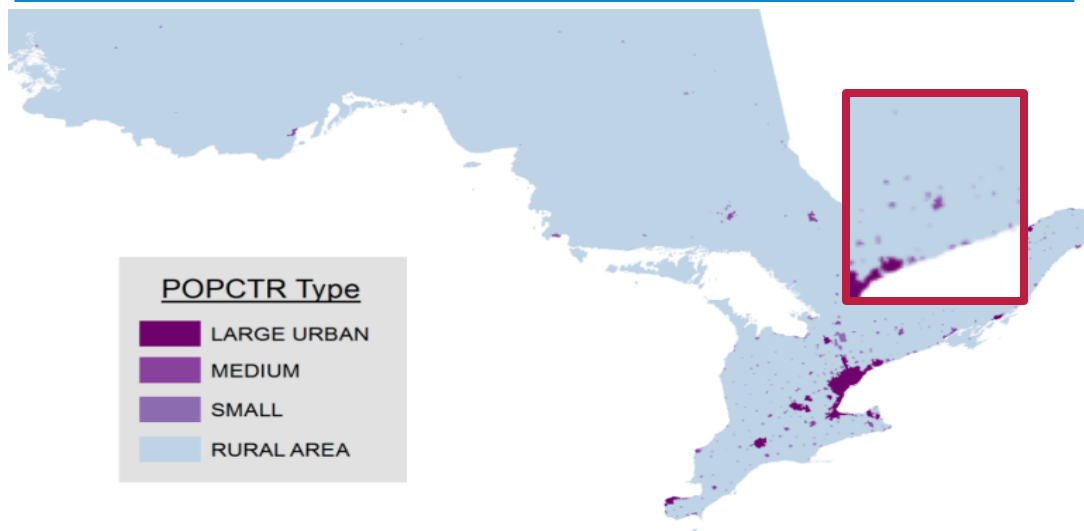
# Display

- Results reported by Domain via Story Map
- Dashboards utilized to provide overview
- Maps, icons, colour coding, tables and graphs to display details/results
- Color coding
  - e.g., Full, partial or no presence
- Comparison to some standards in some domains
  - e.g., Adequacy of palliative care beds (Catalonia Formula)

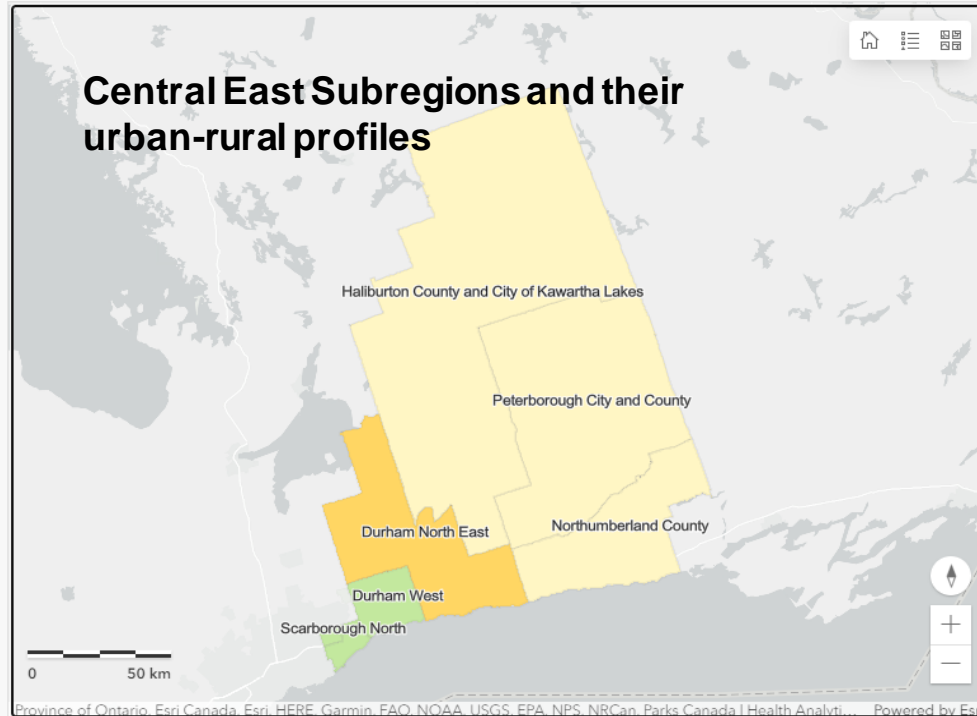


# Demographics of Central East region

Overall description:	Mixed urban, small communities, rural
Area:	16,673 km <sup>2</sup>
Population:	1.5 million
Population density:	89.78 people/ km <sup>2</sup>
Sub-regions	6



# Demographics of Central East region

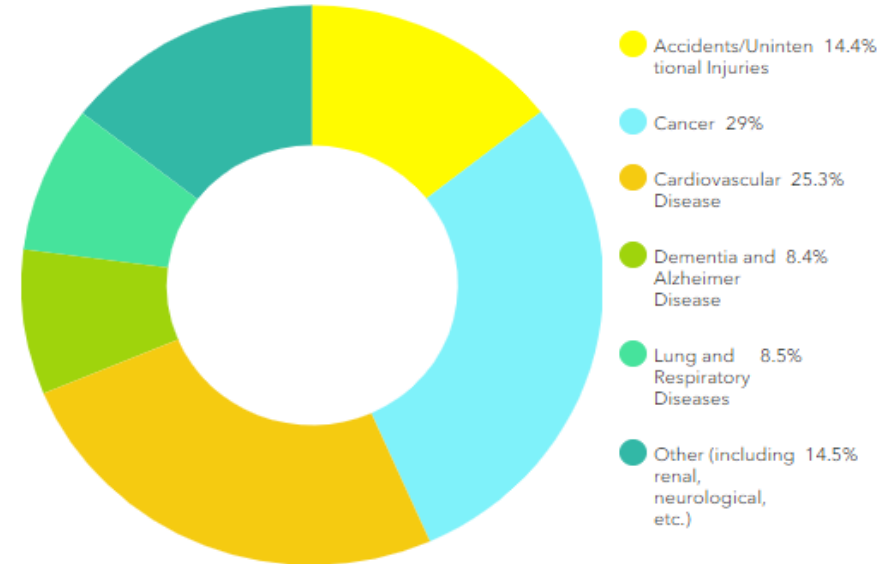


## Central East Subregions

- Medium Urban Population Centre
- Rural Area
- Small Urban Population Centre

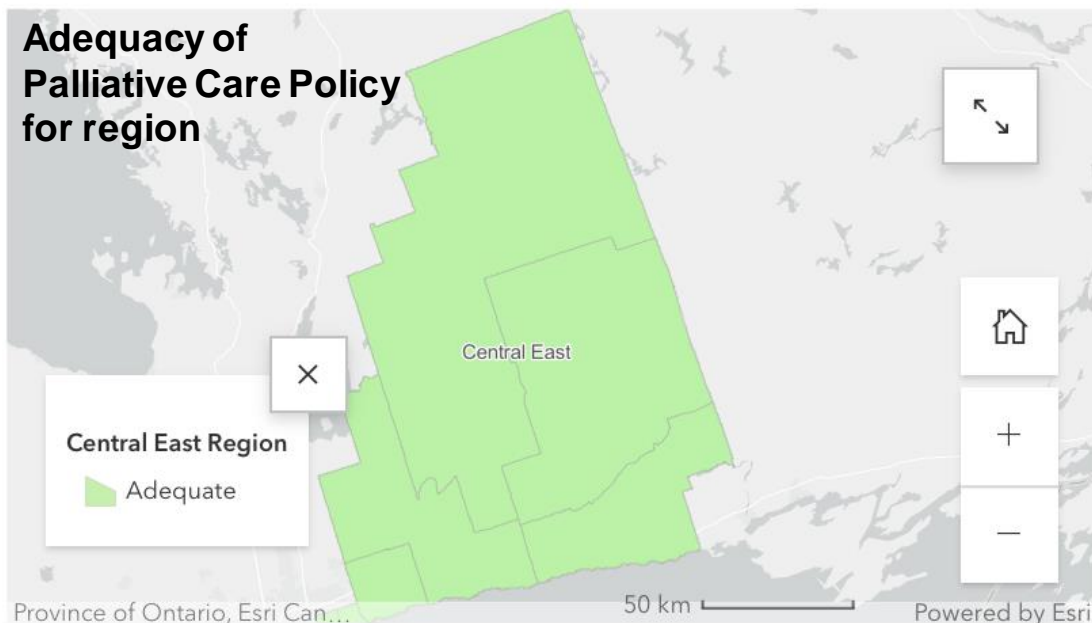
Age Range	Population Size	Percentage
0-19	348,700	23%
20-64	931,595	60%
65-74	150,900	9%
75+	119,720	8%

## Number of deaths per year and causes of death



Region Name	Population	Population Den...
Peterborough City and County	134920	32
Haliburton County and City of Kawartha Lakes	90260	11.4
Northumberland County	71200	40.3
Durham North East	287800	132.5
Durham West	320400	713.4
Scarborough North	176615	4165.5
Scarborough South	417060	3015.6

## Policy: Existence of palliative care policy



### Context

\*The region had a relatively active palliative care network until provincial rearrangement occurred in 2019. New leadership structures for palliative care under development at a provincial level.

\*\*"Law" here refers to a law that specifically mentions access to "palliative care". In this region, the provincial law that calls for the integration of palliative care in long-term care (LTC) facilities applies.

Indicator	Present	Comments
Designated office/secretariat/program responsible for palliative care	Yes	Large region level (OH East) + provincial
An active palliative care strategic plan	Yes	At provincial level
Law to ensure palliative care access	Partial. For LTC*	Provincial law for LTC only
Law related to ACP	Yes	Provincial level
Standards and norms for palliative care	Yes	Yes
Compassionate care benefits	Yes	Federal level

## Policy: Formal and active strategy to integrate palliative care



### Context

The region had a relatively active palliative care network until provincial rearrangement occurred in 2019. New leadership structures for palliative care under development at a provincial level.

Indicator: Formal and active strategy to integrate palliative care into	Present	Comments
Home and community care	<b>No*</b>	No regional-level strategy. High-level provincial strategy
In-patient and outpatient hospital services (cancer and non-cancer)	<b>No*</b>	High-level provincial strategy
LTC facilities	<b>Partial</b>	No region-wide strategy. Present in some individual LTC homes
Paramedic/emergency services	<b>Yes</b>	N/A

\*Provincial-level Palliative Care Services Strategic Plan (2019) in place.

## Specialist Level Palliative Care Services: Palliative Care Units (PCUs)

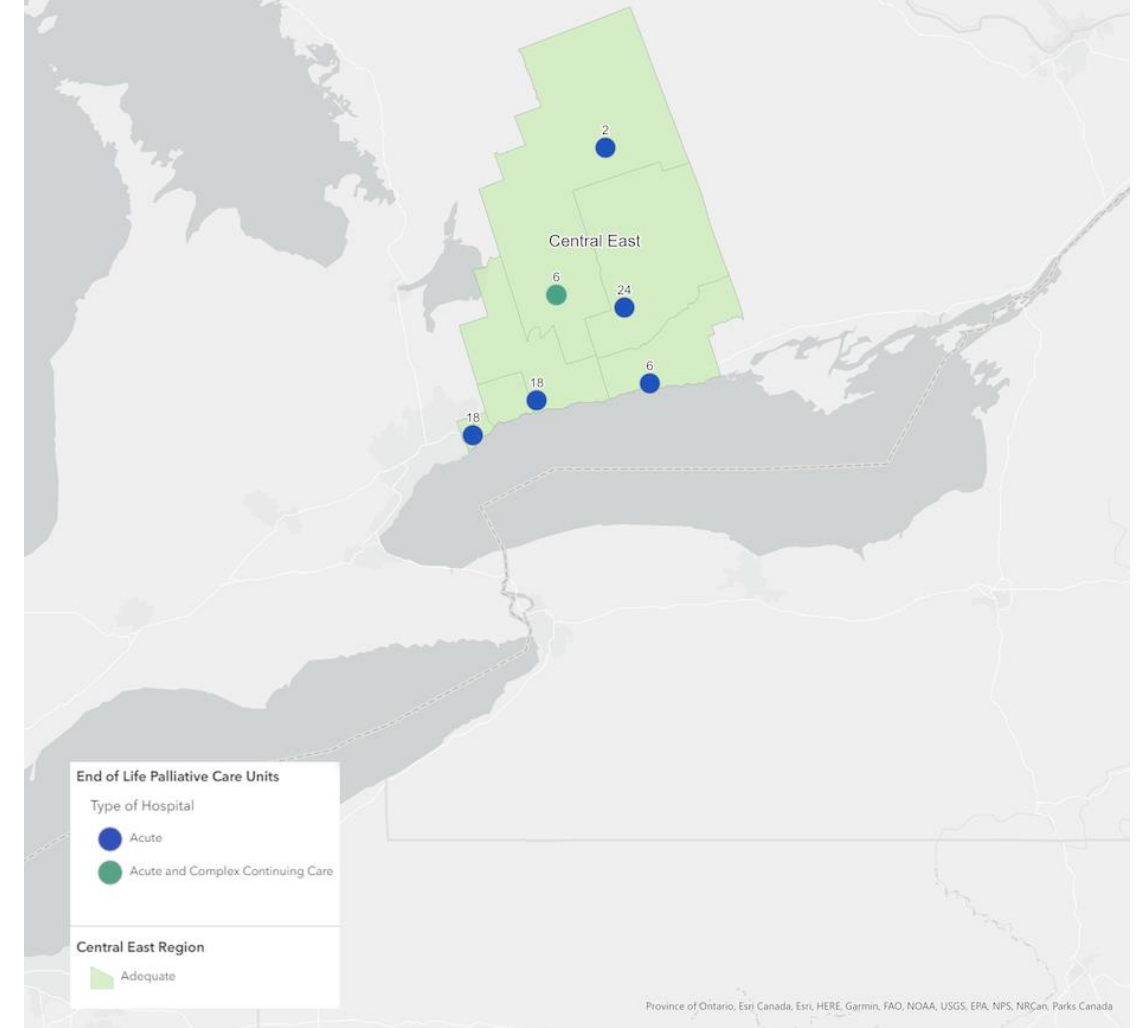
PCU Information	
Total number of PCUs in region	<b>6</b>
Total number of PCU beds in region	<b>74</b>
Are number of PCU beds in region adequate?***	Adequate*
Unit profiles	All are EOL units**
Location	Acute hospital: 5 Continuing care: 1

### Context

\* Total number of PCU beds are more than adequate, but they are mostly *End-of-life* units. Therefore, some patients with hospice-level or continuing-care type care being cared for in the PCUs. By Catalonia Formula, region requires about 30 to 40 beds

\*\*End-of-Life (EOL) PCU units: PCU that mainly cares for patients in the terminal phase; alive discharge rate <20%, short length of stay (median 8 days). No Acute PCUs that care mainly care for patients across illness trajectory and with alive discharge rates of >30%.

### Location of PCUs, the number of beds in each, the type of hospital the PCU is in and the adequacy of the number of PCU beds across the whole region



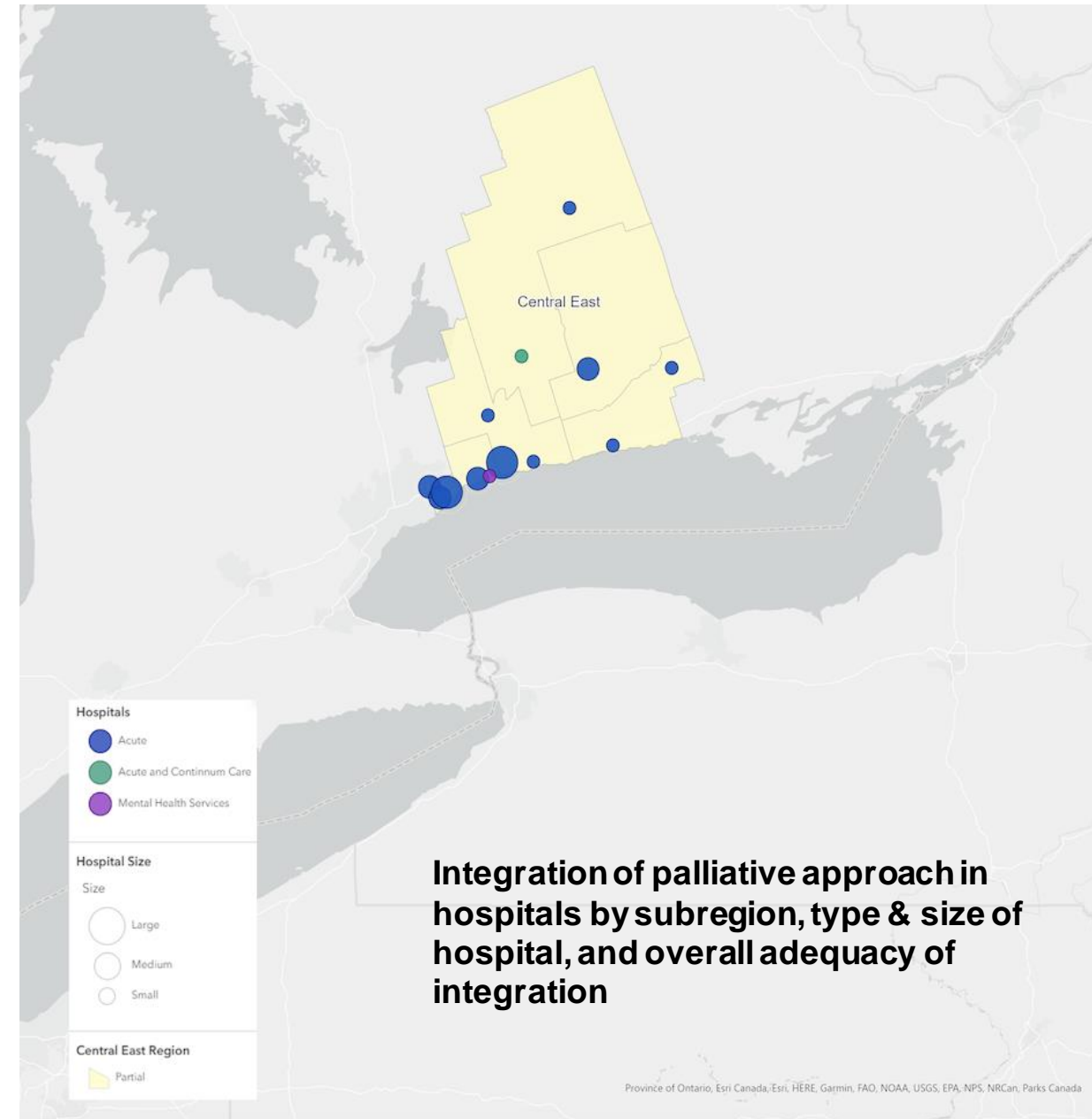
# Hospitals: Integration of the palliative care approach across services (inpatient units and outpatient clinics)

More information	
Integration of Palliative Care Approach* in hospital inpatient units and outpatient services across whole region	Mainly absent**
Formal strategy in place to integrate palliative care in all services across hospitals in region	Limited

## Context

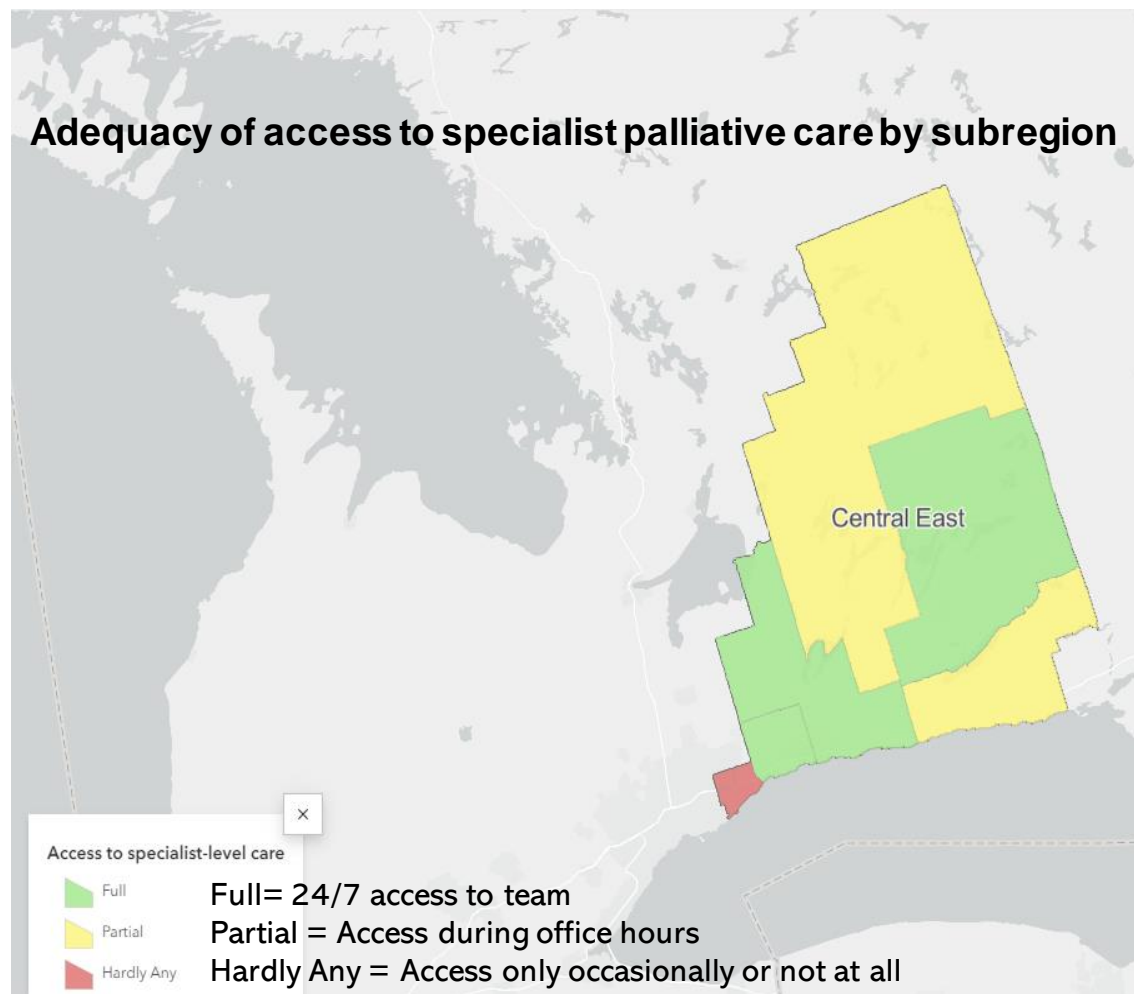
\*Integration of palliative care approach means that the majority of staff (>50%) are trained on the palliative care approach and the service refers to the specialist palliative care team, and in a timely manner.

\*\*The Lakeridge Oshawa Hospital had embarked on a process to train staff in medical units on the palliative care approach but this was stopped in 2019 to focus on implementation of a new electronic medical record (EMR).





## Community: Access to specialist palliative care teams



### Context

Teams of varying compositions

Some regions have two or more different community specialist palliative care teams (palliative care physicians, nurse practitioners and/or nurse consultation teams. Some collaboration between them.

The region as a **Pain and Symptom Management Consultation Team**. Mainly nurses with palliative care training. Provide some consultation support to family physicians and some long-term care homes in region and provide education in region, mainly to home care nursing staff.

The region has a **Nurse Practitioner Team** that provides MRP and/or Consultation support services.

**Community-based palliative care physicians** (some full time and others part-time palliative care and part-time family medicine) in several of the subregions and their communities.

These teams largely remunerated by Fee-for-Service.

Mostly use a *Takeover* model in which the palliative care physicians take over care from the patients' attending physicians (or when no family physician available). In some cases, less often, provide consultation support to family physicians and primary care teams.

## Community: primary palliative care provided by family physicians and primary care clinics

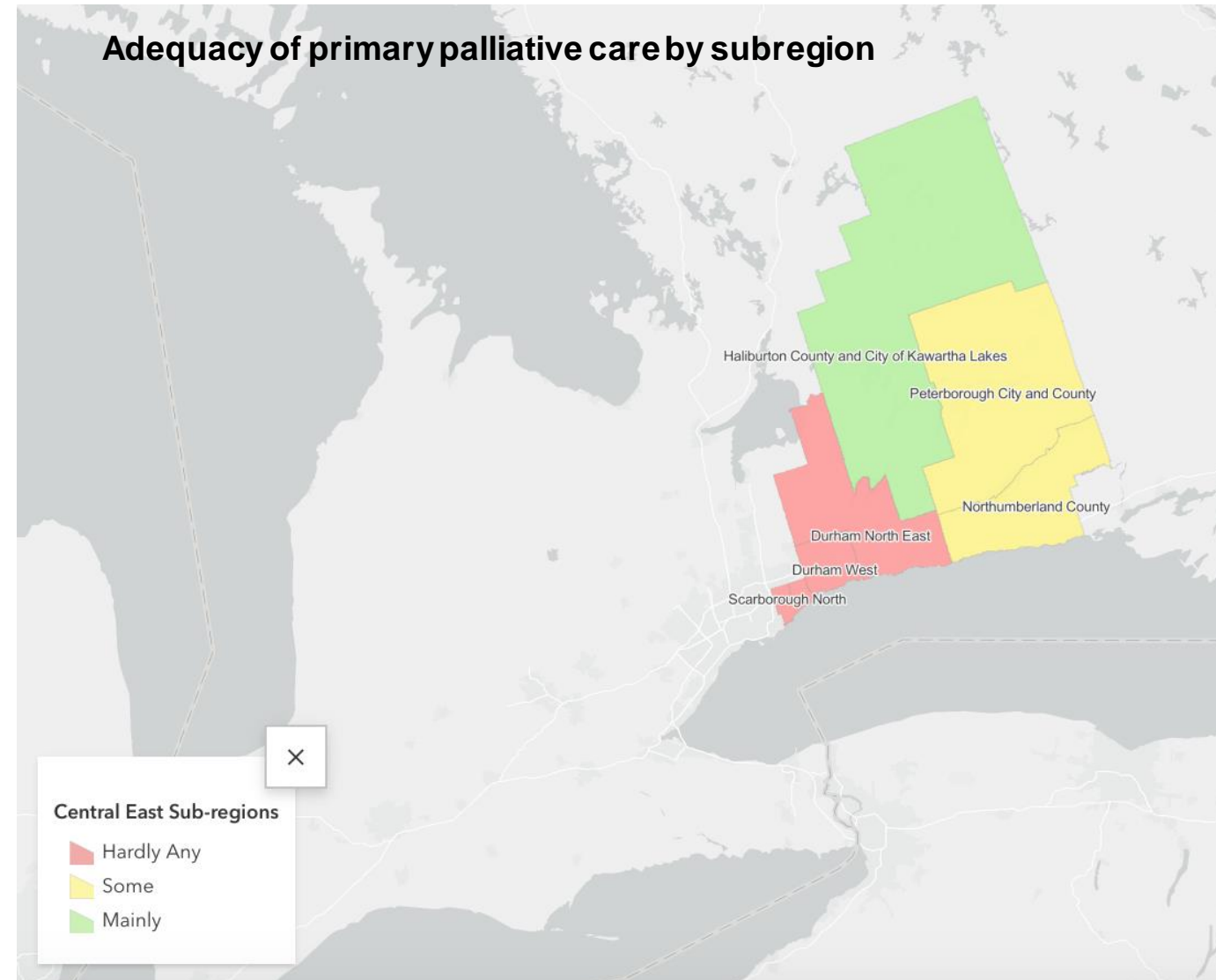
### Context

In the more urbanized parts of the region, primary palliative care (especially end-of-life care) is largely provided by palliative care physicians, who largely become most responsible clinicians of the patients. Most family physicians, including family health teams and other patient roster clinics, do not provide home visits and after-hours coverage to their patients with palliative care needs. This is provided by palliative care clinicians.

Rural based family physicians tend to provide primary level palliative care in most cases. In some communities, local family physicians with palliative care training may provide support or take over end-of-life care.

*Primary palliative care* is also referred to as the palliative care approach; clinicians who are not palliative care specialists but possess core palliative care skills to initiate palliative care early and care for patients with non-complex needs. It should include after-hours coverage and home visits.

### Adequacy of primary palliative care by subregion



# Hospice Residences

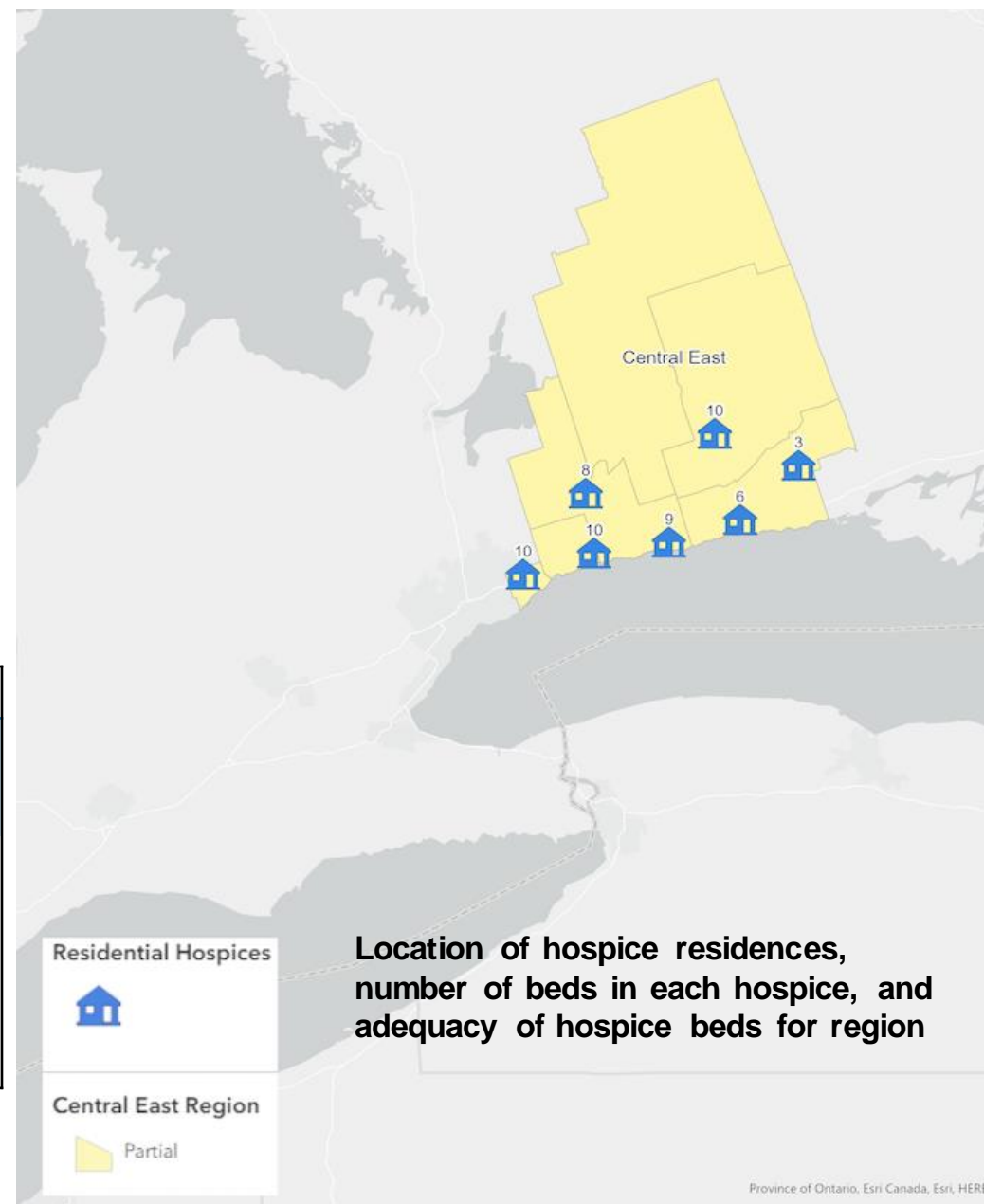
<b>More information</b>	
Total number of hospices in region	<b>7</b>
Total number of hospice residence beds in region	<b>56*</b>
Are number of hospice residence beds in region adequate?*	<b>Inadequate</b>

## Context

**\*Catalonia Formula.:** 10 in-patient palliative care beds/100 000 inhabitants of which 2 are PCUs and 8 are hospice-type or continuing care beds. Therefore, region requires about 110-120 hospice & continuing care beds.

## HIGHLIGHTS

- Two additional hospices are being built with capital funding from government and community through fund-raising. This will add about 8+8 additional beds when completed.
- One of the hospices has a room for children requiring palliative care (pediatrics palliative care)
- Three of the five hospices also provide community palliative care services (e.g. Grief and bereavement support, counselling, day hospice programs, hospice at home support, volunteer services).



# Community Hospice Services

**Total number of community hospice programs in region:** **5**

**Overall access in region:** **Partial**

*Hospice Community services include services such as Grief and Bereavement support, Counseling, Day hospice programs, Hospice in the home, Volunteer support.*

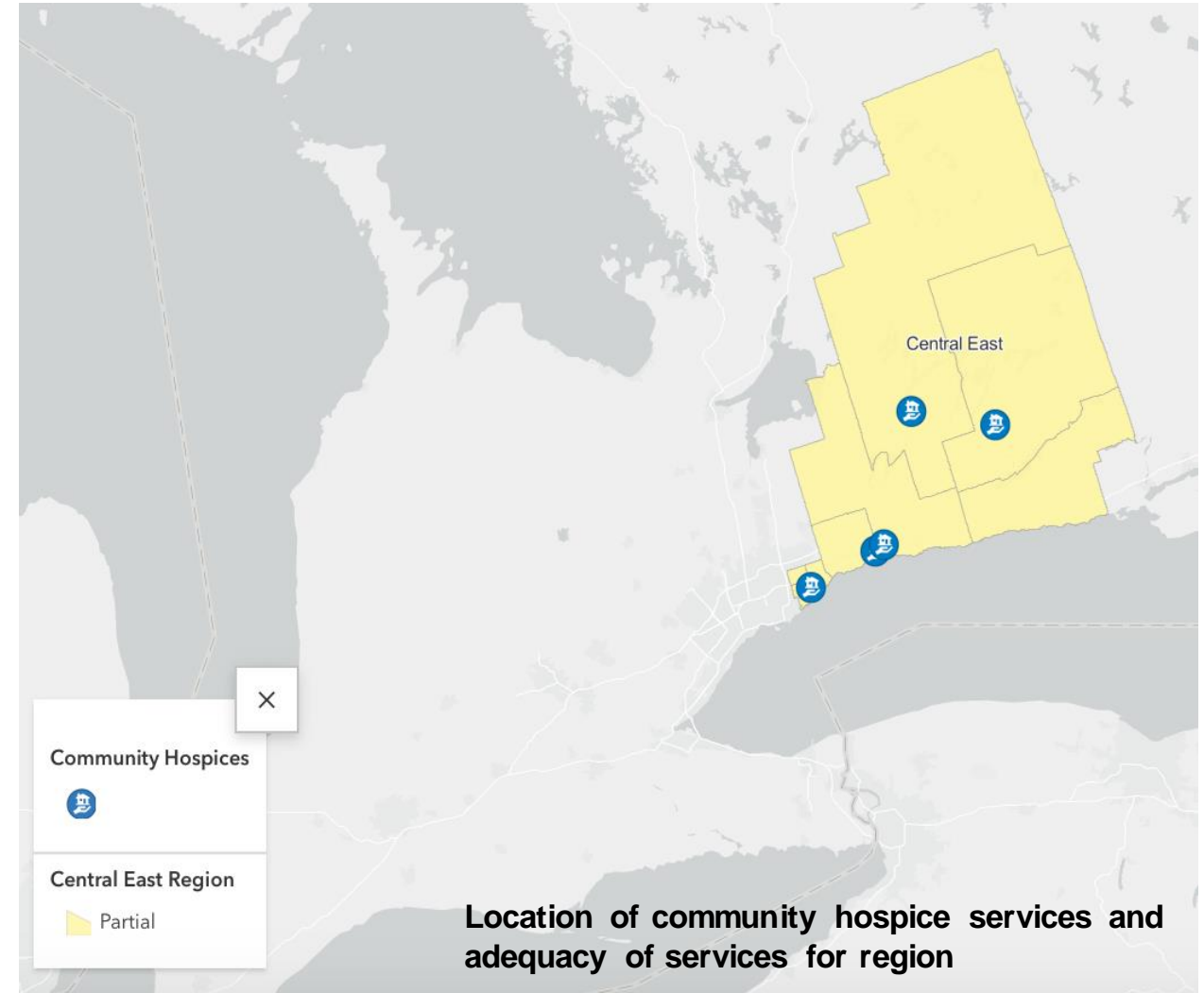
## Context

Three of the five Community Hospice Programs are delivered from hospice residences. The others do not include hospice residences

Most services are underfunded and understaffed. Long wait times in some cases for patients and families to access community services. Many communities unable to start community hospice services because of lack of funding.

## HIGHLIGHTS

- Communities across the subregions are working towards establishing community hospice programs. Most services are delivered through fundraising and charity, representing community mobilization.



## Long term care: Integration of palliative care approach

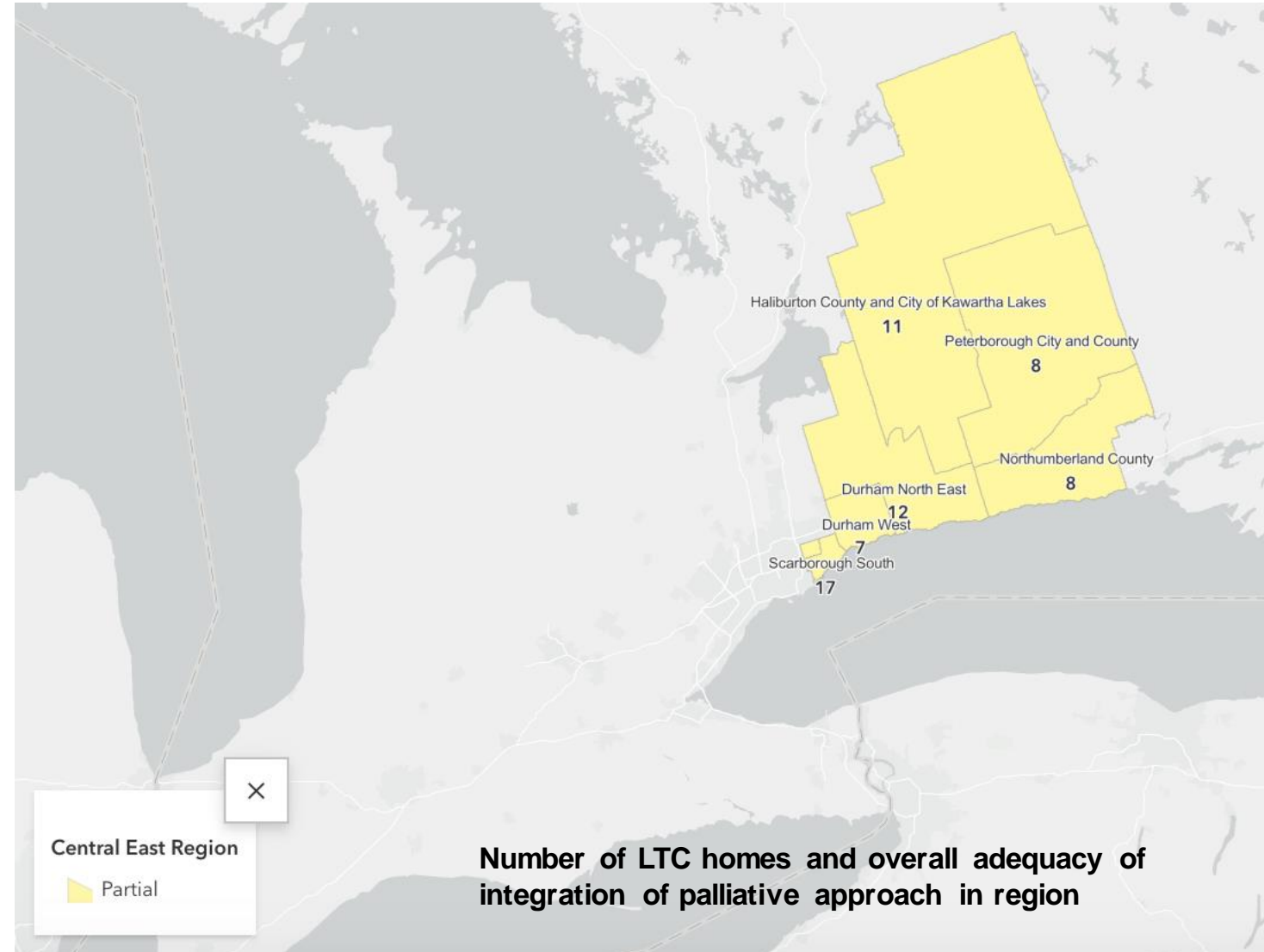
Total number of LTCs in region: **63**

Integration of palliative approach in region: **Partial**

### Context

The Central East Region has seen challenges with integration of palliative care into the long-term care (LTC) sector

There have been challenges with transition of care to and from the hospital because physician teams often do not go to LTC. Symptom management options differ, e.g., few pain pumps are utilized in LTC facilities.



# Focused populations: Pediatric palliative care

## Context

Pediatric palliative care is recognized as a gap in the Central East Region and services are largely lacking with the exception of:

- Hospice Peterborough has a pediatric strategy with community partners. It has a Child and Family Life Specialist and can provide a pediatric palliative care bed if needed.
- Community Care City of Kawartha Lakes is providing grief and bereavement services for pediatric populations.



Pediatric Palliative Care	Yes/No
Formal strategy for pediatric palliative care	Yes
Residential pediatric hospice(s)	No
Outpatient palliative care program(s) for pediatric populations	No
Respite pediatric palliative care (hospice or hospital setting)	Yes
24/7 access to specialist pediatric palliative care team	No
Education program(s) for pediatric palliative care	No

## Focused populations: Others

Population	Formal strategy	Programs and/or initiatives
LGBTQ2SIA+*	No	No
Homeless and Marginally Housed	No	Yes
Prisoners	No	Yes
Recent Immigrants and Refugees	No	No

### Context

#### LGBTQ2SIA+

- Seen as a gap for the region

#### Homeless and Marginally Housed

- Services supported through specific hospitals and community services.

#### Prisoners

- Haley House (10 beds) is a halfway house in Peterborough for individuals coming out of federal prison with palliative care or significant health concerns.

#### Recent immigrants and Refugees

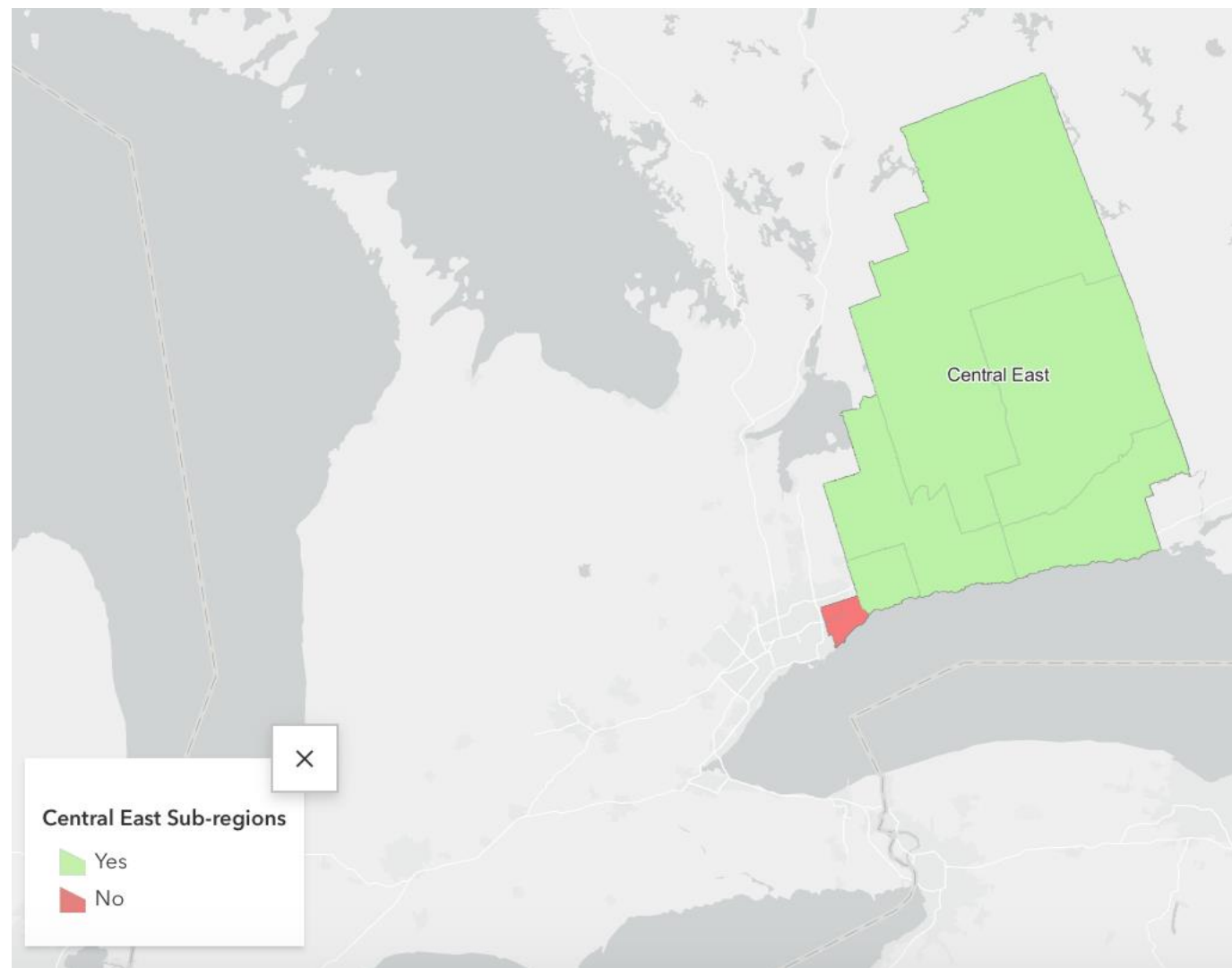
- Seen as gap for the region

## Provision of palliative care by paramedic emergency medical services (EMS):

### Context

Paramedic services that provide palliative care have spread across the Central East Region, with the exception of Scarborough

EMS integration for most of the region is not seamless but a great addition.





# The Road Ahead

- Upcoming Atlas releases
  - Ontario - early Summer
  - British Columbia - early Summer
  - Alberta - early Summer
- Execute communication plan
- Future Atlas priorities
  - First Nations, Inuit and Métis
  - Remaining provinces
  - Canada (National)

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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