



# Palliative care development in Europe - identifying and addressing the gaps

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# Strengthening palliative care as part of Universal Health Coverage

WHA Resolution 67.19 (2014)

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY

WHA67.19

Agenda item 15.5

24 May 2014

## **Strengthening of palliative care as a component of comprehensive care throughout the life course**

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course;<sup>1</sup>

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council's Commission on Narcotic Drugs' resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes,<sup>2</sup> and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines;<sup>3</sup>

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

## National palliative care capacities around the world: Results from the World Health Organization Noncommunicable Disease Country Capacity Survey

**Results:** This survey reveals that (a) a minority (37%) of countries have an operational national policy for noncommunicable diseases that includes palliative care, (b) palliative care is least likely to have funding available compared with other core noncommunicable disease services, and (c) there is a large country-income gradient for palliative care funding, oral morphine availability, and integration of palliative care services at the primary levels of the health system.

**SIXTY-SEVENTH WORLD HEALTH ASSEMBLY**

**WHA67.23**

**Agenda item 15.7**

**24 May 2014**

**Health intervention and technology assessment  
in support of universal health coverage**

The Sixty-seventh World Health Assembly,

**Special Article**

# Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021



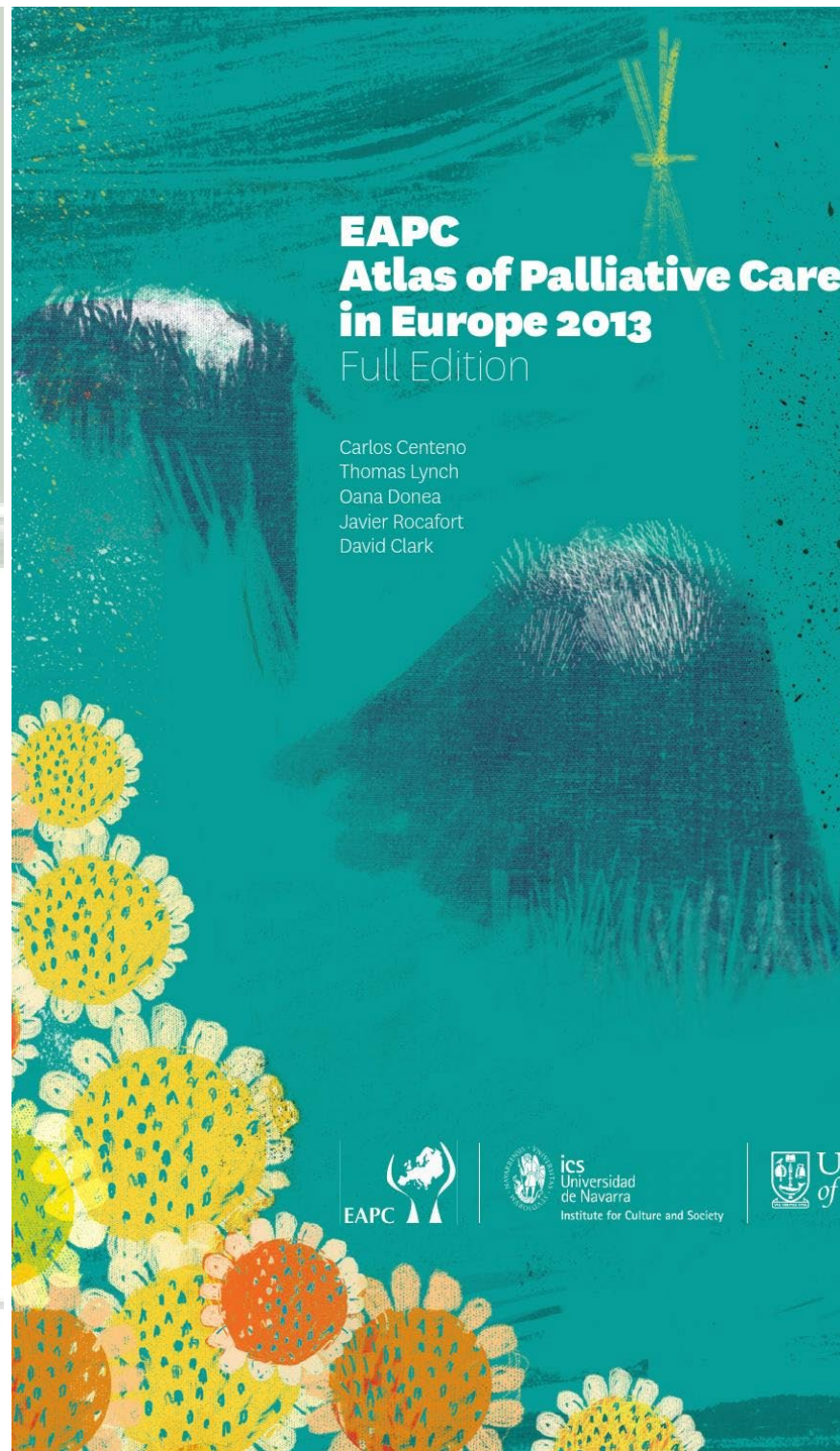
Eric A. Finkelstein, PhD, Afsan Bhadelia, PhD, Cynthia Goh, MBBS, Drishti Baid, BA, Ratna Singh, MA, Sushma Bhatnagar, MD, and Stephen R. Connor, PhD

*Lien Centre for Palliative Care, Duke-NUS Medical School, Singapore and Duke University Global Health Institute (E.A.F.), Durham, North Carolina, USA; Department of Global Health and Population, Harvard T.H. Chan School of Public Health, Boston (A.B.), Massachusetts, USA; Department of Palliative Medicine, National Cancer Centre, Singapore (C.G.); Singapore General Hospital, Singapore (D.B.); University of*



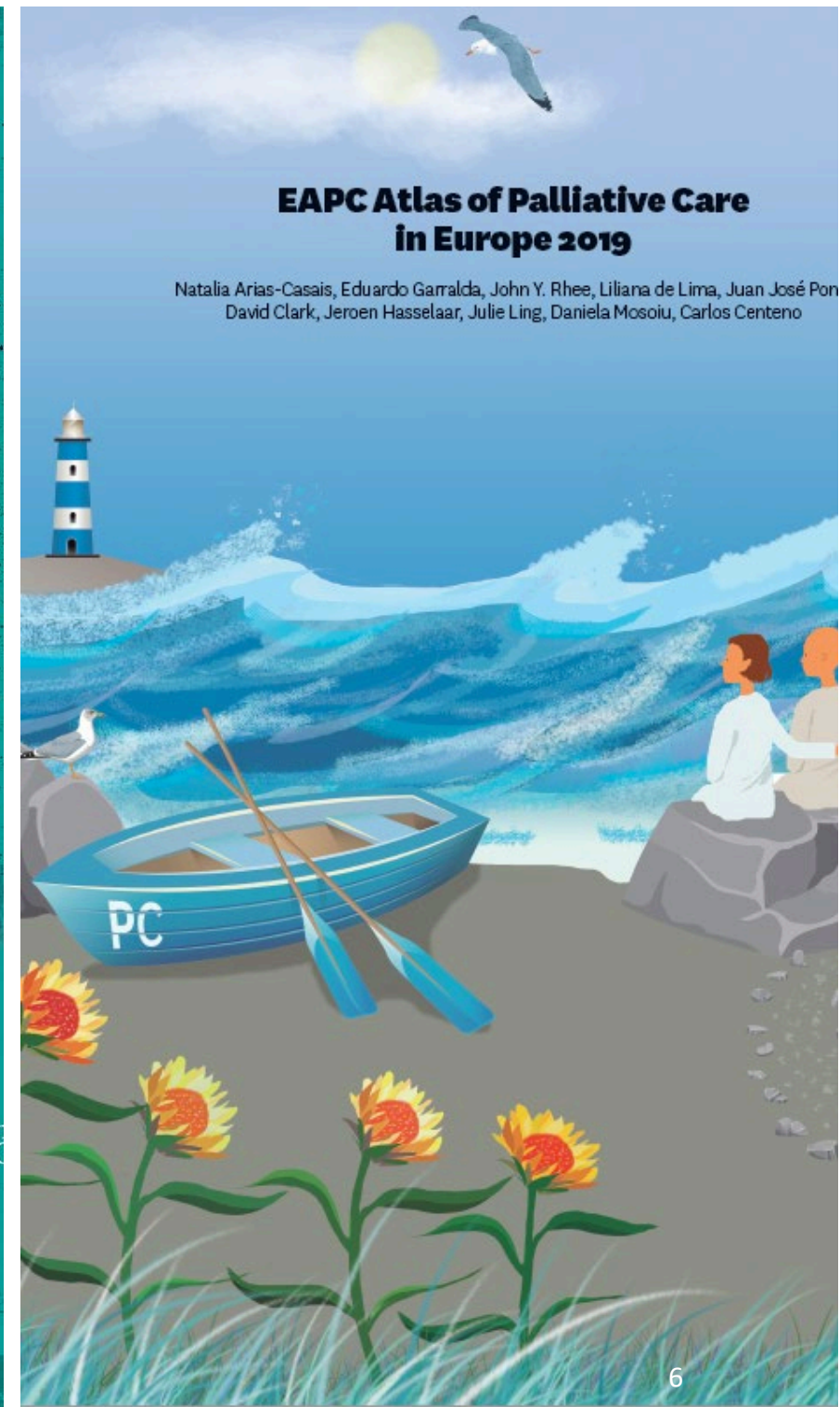
# EAPC **Atlas** of Palliative Care in Europe

Contributors: Thomas Lynch, Juan Narberá, Luis María Pérez, Anthony Greenwood, Emma Booth, David Ford, Amelia Gardiner, Liliana de Lima



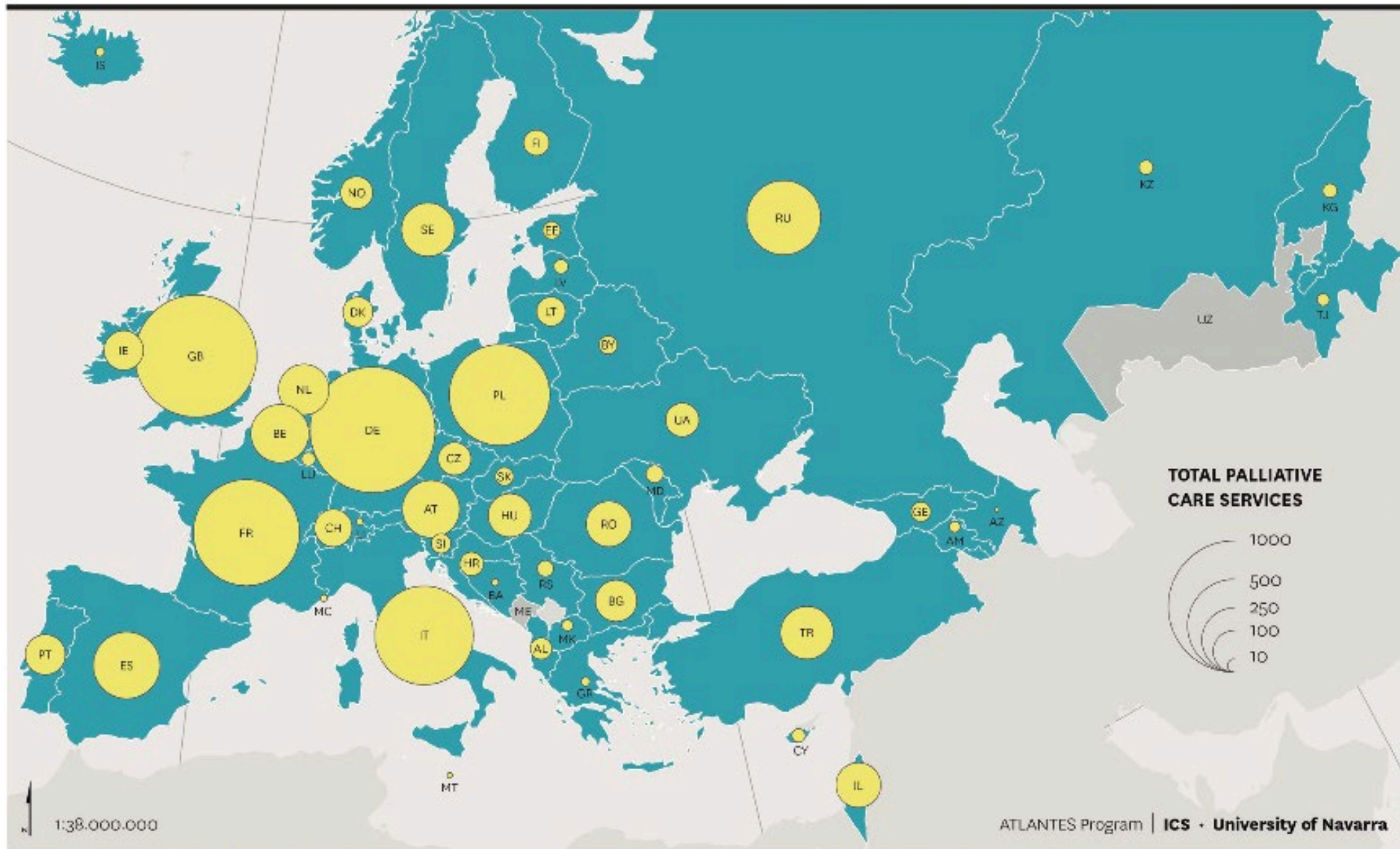
# EAPC **Atlas of Palliative Care** in Europe 2013 Full Edition

Carlos Centeno  
Thomas Lynch  
Oana Donea  
Javier Rocafort  
David Clark



# EAPC Atlas of Palliative Care in Europe 2019

Natalia Arias-Casais, Eduardo Garralda, John Y. Rhee, Liliana de Lima, Juan José Pon, David Clark, Jeroen Hasselaar, Julie Ling, Daniela Mosoiu, Carlos Centeno



**Map 1.2.** Total Palliative Care Services.

### What is palliative care?

It is a **special care** for people with life-threatening illness and their families.

It improves the **quality of life**.

It **relieves** pain and physical, psychosocial and spiritual suffering.



It **benefits health systems**, which can save money by using resources better.

It can be given in homes, health centres, hospitals and hospices.

It can be done by many **health professionals and volunteers**.

### Palliative care for everyone who needs it

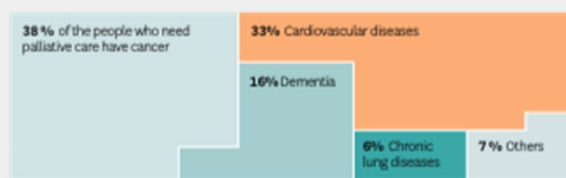
- For the entire disease trajectory: from the beginning and alongside the disease.
- For people with cancer and other diseases.
- For all countries, regardless of their income level.
- For adults and also for children.

### Who needs it?

**4.4 million** People who need palliative care dying each year in Europe

**4.9 million** People who will need palliative care by 2030

### People with many types of diseases need palliative care



### Are we ready for the challenge?

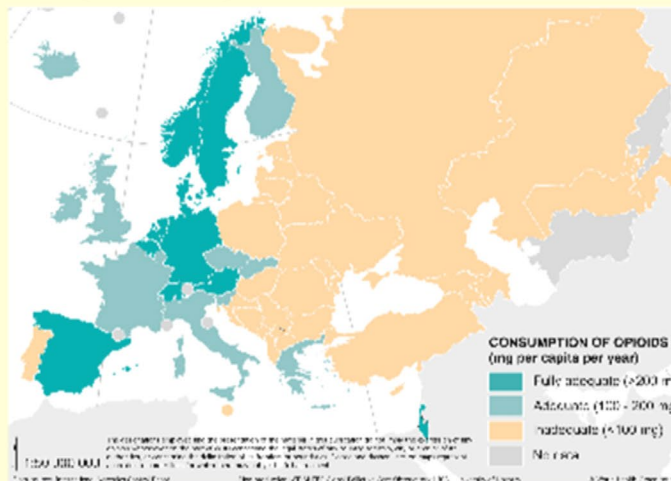


**65%** of the European population **has no access** to palliative care services.

**46%** of European countries **have no process** for specialization for doctors in palliative care

**83%** of European countries **do not teach** palliative care to all future doctors.

### Consumption of main opioids



### What are the barriers?

- Excessively restrictive regulations for opioid pain relief.
- Future health professionals are not taught about palliative care
- No specialization for palliative care professionals.
- Poor public and professional awareness of how palliative care can help.
- Cultural and social barriers.

### What can countries do?

- Policies**  
Revise laws and processes to improve access to opioid pain relief.
- Education**  
Promote palliative care education for all health professionals.
- Primary health care**  
Provide palliative care through primary health care centres and homes.

More information is available in the *EAPC Atlas of Palliative Care in Europe*. <https://bit.ly/2FoPpox>

More information is available at [www.euro.who.int/en/palliativecare](http://www.euro.who.int/en/palliativecare)



# Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years

Natalia Arias-Casais<sup>1</sup> , Jesús López-Fidalgo<sup>1,2</sup> , Eduardo Garralda<sup>1,3</sup>, Juan José Pons<sup>1,4</sup>, John Y Rhee<sup>5</sup> , Radbruch Lukas<sup>6,7</sup>, Liliana de Lima<sup>7</sup> and Carlos Centeno<sup>1,3</sup>

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## Abstract

**Background:** Service provision is a key domain to assess national-level palliative care development. Three editions of the European Association for Palliative Care (EAPC) Atlas of Palliative Care monitored the changes in service provision across Europe since 2005

The economics of healthy and active ageing series

## HEALTH AND SOCIAL CARE NEAR THE END OF LIFE

Can policies reduce costs and improve outcomes?

Charles Normand

Peter May

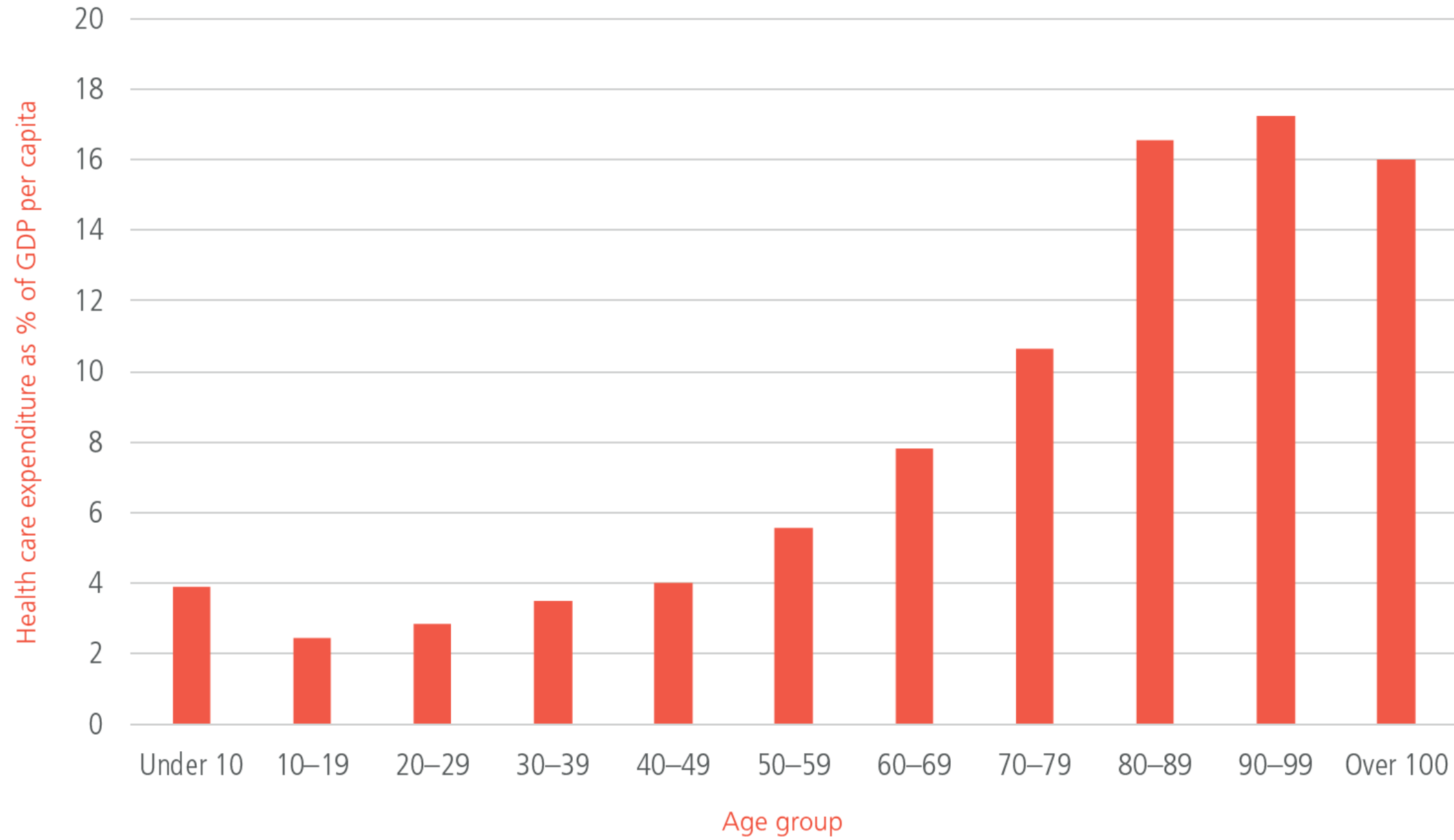
Bridget Johnston

Jonathan Cylus

WHO 2021

- Number of deaths each year increasing
- End of life care ↑ spending on health & social care (hospital care is the largest component)
- Expenditure can be managed & outcomes improved by:
  - Data on number of expected deaths
  - Appropriate treatment - balance between disease treatment vs. managing symptoms at the end of life
- Patient & family experience improved by skilled and careful assessment of needs & can reduce costs of care
- Need to assure palliative care does not shorten life and in some cases may extend it

Figure 1: Per person health care expenditures, 2016, in selected EU countries by age group as percentage of per person GDP



Source: Data from the European Commission Ageing Working Group (not published).


EAPC update

## White Paper on standards and norms for hospice and palliative care in Europe: part 1

*Recommendations from the European Association for Palliative Care*

Original Article

## Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care (EAPC): A Delphi study

Sheila Payne<sup>1</sup> , Andrew Harding<sup>1</sup>, Tom Williams<sup>1</sup>, Julie Ling<sup>2</sup> and Christoph Ostgathe<sup>3</sup>, on behalf of the Board of Directors of the European Association for Palliative Care



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2022, Vol. 36(4) 680–697  
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Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe : part 2. *Eur J Palliat Care*. 2010;17(1):22–33.

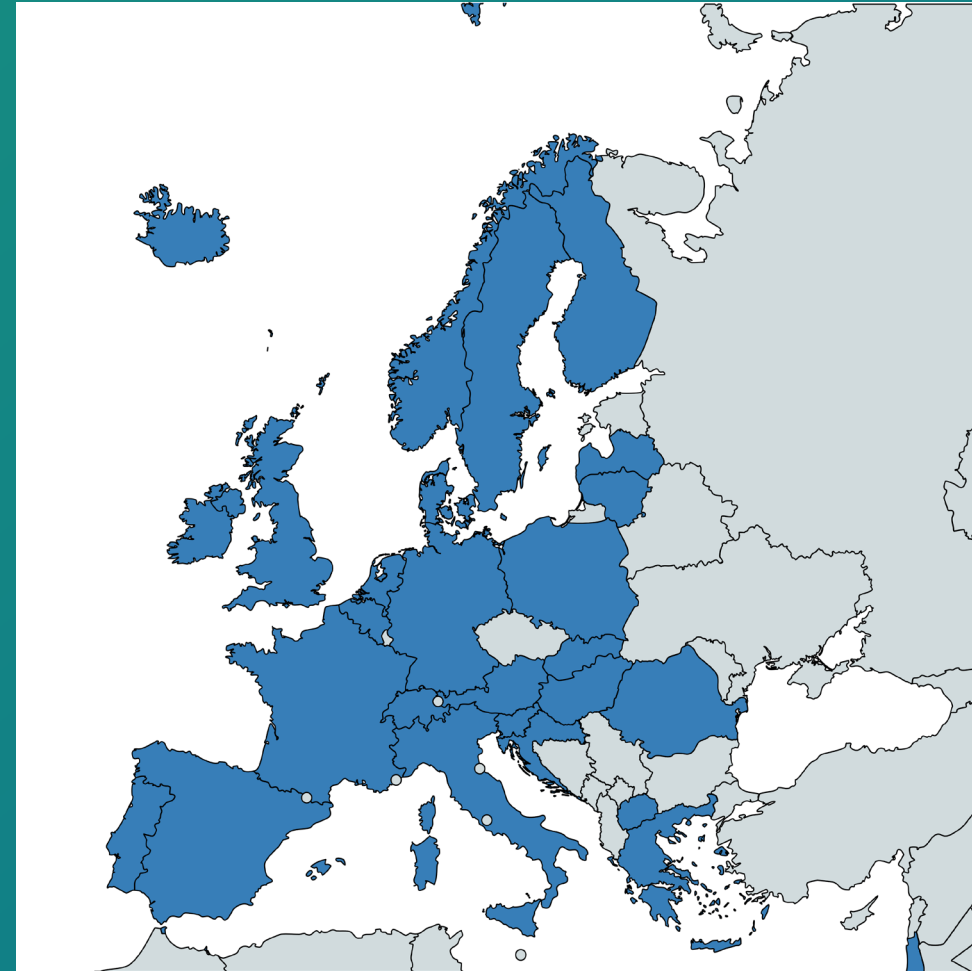
Payne s. (2022) revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care: A Delphi Study. *Palliative Medicine* 36(4)680-697

## What has happened in Europe in last decade?

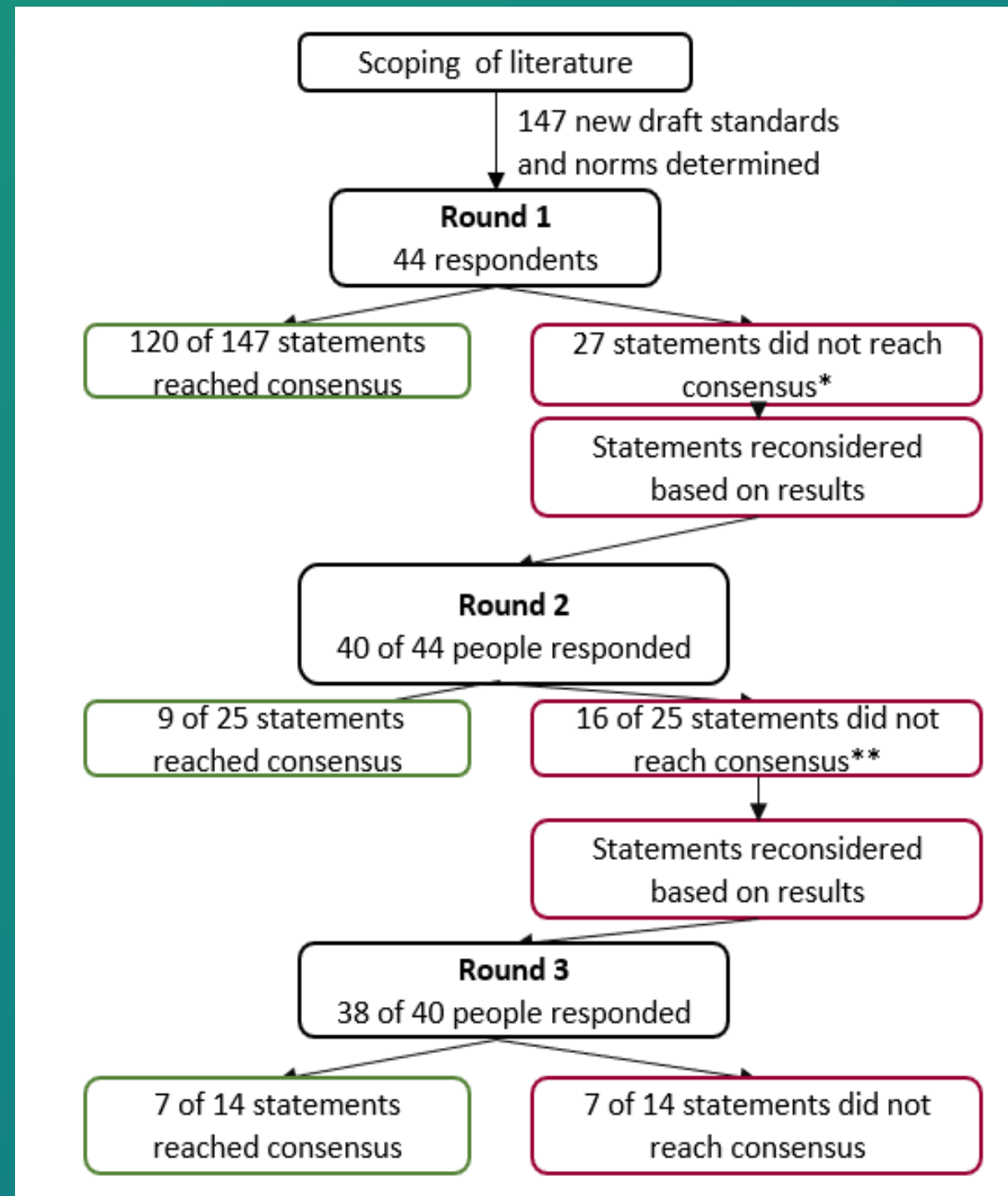
- Evidence of rapid service development in some European countries (EAPC Atlas 2019)
- Emergence of new specialisations in palliative medicine
- Increasing recognitions of specific needs of different groups
- Increase in specialist education and professional development
- The Lancet Commission (2017) proposed the concept of 'health-related suffering'
- IAHPC (2020) proposed a new consensus based definition based on concept of 'health-related suffering'

30 organisations (44 individuals)  
from 27 European countries responded.

**Response rate:**  
58% organisations  
82% countries



# Flow chart of Delphi process



## The 13 new areas reached consensus

- Geriatric Palliative Care, Dementia Palliative Care, Neonatal Palliative Care, Perinatal Palliative Care
- Delivery of perinatal palliative care
- Access to information, websites for services
- A process to support to exchange of information across caregivers, disciplines and settings
- Digital medical records
- Unrestricted opening hours for friends / family of dying patients
- Access to opioids, other essential medicines and specialist equipment in all settings where palliative care is provided



## Seven items did not reach consensus:

- Specific occupational roles which were not regarded as essential to the multidisciplinary team - occupational therapist, speech therapist, complementary therapist, lymphoedema therapist, trainer and librarian.
- Population size that a volunteer team should serve.
- 4 statements were removed as participants pointed out they were repetitious or confusing

- High overall consensus with original EAPC standards & norms (2009).
- Emergence of new areas of specialisation attest to the needs of patients across the life course and regardless of diagnosis.
- Strong endorsement of EAPC & WHO definitions, despite alternative global definitions being proposed.
- Recognition of integration, communication and digital technologies, and advance care planning.

## Limitations

- Survey questionnaire only available in English
- Data collection during pandemic (Round 1 November 2020; Round 2 January 2021; Round 3 March 2021)
- Response rate reasonable for online survey, limited attrition over three rounds
- Does not include the views of patients and families.

# EU Commitment to palliative care research



# Horizon 2020 framework programme

|   |   |
|---|---|
| <b>DIAdIC</b><br>Duration 60 months<br>Commenced 1.1.19             | Evaluation of Dyadic Psychoeducational Interventions for People with Advanced Cancer and their Informal Caregivers (DIAdIC): An international randomized controlled trial |
| <b>MyPal</b><br>Duration 42 months<br>Commenced 1.1.19              | MyPal: Fostering Palliative Care of Adults and Children with Cancer through Advanced Patient Reported Outcome Systems   |
| <b>PalliativeSedation</b><br>Duration 60 months<br>Commenced 1.1.19 | The use of proportional palliative sedation for the relief of refractory symptoms: an international multicenter study   |



Horizon2020  
European Union Funding  
for Research & Innovation

# ERASMUS + Programme

## **NursEduPal@Euro**

Duration 36 months

Commenced 27.11.20

Palliative Care Core Competencies and novel European matrix for educating bachelor-degree nurses

## **RESPACC**

Duration 24 months

Commenced 1.12.20

Research for palliative care clinicians



Co-funded by the  
Erasmus+ Programme  
of the European Union

# HORIZON-HLTH-2021-DISEASE-04

|   |  |
|---|--|
| <b>PAINLESS</b><br>Duration 60 months<br>Commenced 1.6.22     | Pain relief in palliative care of cancer using home-based neuromodulation and predictive biomarkers  |
| <b>EU NAVIGATE</b><br>Duration 60 months<br>Commencing 1.9.22 | Implementation and evaluation of a Navigation Intervention for People with Cancer in Old Age and their Family Caregivers: an international pragmatic randomized controlled trial |
| <b>INSPIRE</b><br>Duration 48 months<br>Commencing 1.9.22     | INtegrated Short-term Palliative REhabilitation to improve quality of life and equitable care access in incurable cancer   |
| <b>MyPath</b><br>Duration 60 months<br>Commencing 1.9.22      | Developing and implementing innovative Patient-Centred Care Pathways for cancer patients   |
| <b>PAL-CYCLES</b><br>Duration 60 months<br>Commencing 1.9.22  | PALliative Care Yields Cancer wellbEing Support (PAL-CYCLES)   |

# EU4Health programme

|  |  |
|--|--|
| <b>INTERACT-EUROPE</b><br>Duration 18 months<br>Commenced 1.6.22 | Innovative collaboration for Inter-specialty cancer training across Europe |
| <b>smartCARE</b><br>Duration 24 months<br>Commencing tbc         | Smart Card Application improving cancer survivors quality of life          |



Final thoughts...