



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

One Voice, One Vision in Palliative Care

EAPC Future Directions for Palliative Care Research

Professor Sonja Mcilpatrick

Outline

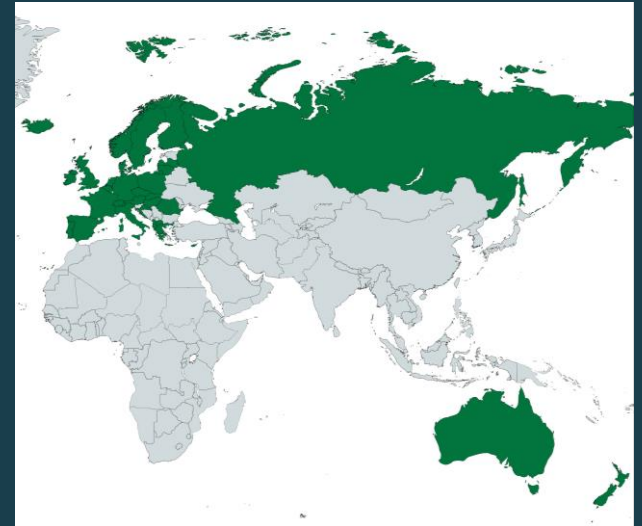


- What is the work of EAPC?
- Where have we come from?
 - European Declaration of Palliative care 2020
- What are EAPC Future directions for palliative care research?
 - Examples of funded research projects
- Final thoughts

European Association for Palliative Care (EAPC)

The EAPC is a membership organisation that aims to **advance, influence, promote and develop palliative care in Europe**. Currently the EAPC has **55 member associations** from **35 countries** and **individual members** from **48 countries** globally.

Members are engaged in palliative care from a range of perspectives; specialist clinical practice, education, policy and research.



The EAPC

Forum for those
throughout

Members are
a range of perspectives
practice, education, professional groups, policy and research.

As a member of
AIIHPC; IAPC, PCRS you
can sign in as a
member of the EAPC

The EAPC lobbies and advocates for the development of
palliative care through its activities and through its work in
developing the practice of palliative care



EAPC head office, projects team:



Dr Julie Ling
Chief Executive
Officer



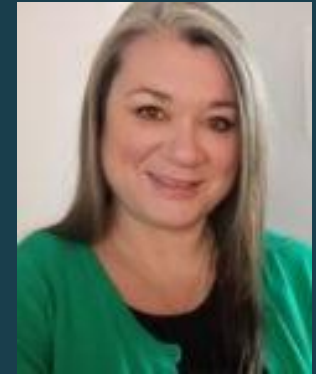
**Dr Cathy
Payne**
Research & Project
Manager



**Fódhla Ní
Chéileachair**
Project Officer



Carla Reigada
Project Officer



**Joanne
Brennan**
Communications
manager

EAPC Board

EAPC board from May 2019 to June 2023
Elected at the General Assembly,
Berlin, Germany



Pictured left to right: Natasha Pedersen, Gert Huysmans, Josep Porta sales, Danila Valenti, Daniela Mosoiu, Catherine Walshe, Christoph Ostgathe, Sébastien Moine, Sandra Martins Pereira, Sonja McIlfratrick Karl Bitschnau, Jeroen Hasselaar, Martin Loučka

President:

Christoph Ostgathe

(Germany)

Vice-Presidents:

Sébastien Moine

(France)

Sandra Martins Pereira

(Portugal)

Jeroen Hasselaar

(Netherlands)

Treasurer:

Catherine Walshe

(United Kingdom)

Secretary:

Gert Huysmans

(Belgium)

Board Members:

Daniela Mosoiu

(Romania)

Josep Porta Sales

(Spain)

Danila Valenti

(Italy)

Sonja McIlfratrick

(Northern Ireland)

Natasha Pedersen

(Norway)

Martin Loučka

(Czech Republic)

Karl Bitschnau

(Austria)

EAPC RESEARCH NETWORK CHAIR:

Augusto Caraceni

(Italy)

Our work:

EAPC TASK FORCES AND REFERENCE GROUPS:

The EAPC has a number of focused working groups called Task Forces and Reference Groups; we are indebted to the energy, effort and enthusiasm that are shown by the many people engaged in the work of these groups. We are mindful that they donate their time and expertise on a voluntary basis. There are currently xx active Reference Groups and xx active Task Forces.



Task Forces (n=17)

LGBT+
Occupational Therapy
Palliative Sedation
Prisoners
Refugees & Migrants
Social Work
Volunteering
Wish to Hasten Death
ACP in Dementia
Bereavement
Children and Young People
Cost of Family Caregiving
Big Data in End-of-life Research
Healthcare Guidelines
Last Aid
Leadership
Palliative wound care

Reference Groups (n=8)

Aging and Palliative Care
Education and Training in Palliative Care
Family Carers
Intellectual Disability
Neurology
Primary Care
Public Health
Spiritual Care

New groups in 2021

Task Forces:

Innovation in nurse education

Knowledge transfer / Dissemination:



12th World Research Congress of the European Association for Palliative Care
Interactive Online Sessions
18 - 20 May 2022



EAPC 17th World Congress Online
"EXPLORING NEW DIMENSIONS"
Interactive Online Sessions
6 - 8 October 2021



11th World Research Congress Online
European Association for Palliative Care
One Voice, One Vision in Palliative Care
Interactive online sessions 7- 9 October 2020



EAPC 2019
16th World Congress of the European Association for Palliative Care
Global palliative care - shaping the future
23 - 25 May 2019 | Berlin, Germany



10th World Research Congress of the European Association for Palliative Care
24-26 May 2018, Bern, Switzerland



EAPC 2017
15th World Congress of the European Association for Palliative Care
Progressing Palliative Care
18 - 20 May 2017 | Madrid, Spain



9th World Research Congress of the European Association for Palliative Care
Dublin, Ireland 9 - 11 June 2016



8th World Research Congress of the European Association for Palliative Care
Lleida, Spain 5-7 June 2014



13th Congress of the European Association for Palliative Care
30.5 - 2.6.2013
PRAGUE - CZECH REPUBLIC



7th Research Congress of the European Association for Palliative Care
Trondheim, Norway 7 - 9 June, 2012



12th CONGRESS of the EUROPEAN ASSOCIATION for PALLIATIVE CARE
18th - 21st MAY 2011
Lisbon Congress Center
Portugal



6th Research Congress of the European Association for Palliative Care
SECC, Glasgow, United Kingdom, 10-12 June 2010
Abstract submissions deadline: 16 November 2009 www.eapcnet.org/research2010



11th CONGRESS OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE
7th - 10th MAY 2009
VIENNA AUSTRIA
Committed to People

Opportunities to disseminate/collaborate our dissemination tools.....



EAPC 18th World Congress
EAPC EQUITY AND DIVERSITY
15 - 17 June 2023
Rotterdam, The Netherlands



Home

EU-Funded Palliative Care Research

The European Association for Palliative Care (EAPC) is a core partner of many large European Union funded studies, with knowledge transfer and stakeholder engagement as a primary focus. As a forum for all of those either working, or with an interest in palliative care throughout Europe and beyond, EAPC can ensure identification, timely engagement and communication with all relevant stakeholders at all stages of the research. Our communication channels afford opportunities for wide dissemination and exploitation of key messages, and opportunities for synchronous and asynchronous knowledge exchange. Several EU projects have formed EAPC task forces to support dissemination activities. This includes stakeholder engagement, production of White Papers, Policy Documents or Tools for practice and the formulation of further research questions. Please contact info@eapcnet.eu if you have any questions



RN Junior Forum

- New to research in palliative care?
- Want to network with others and share experiences?
- Do you want to develop the skills to lead palliative care research in the future?



Email:
cathy.payne
@eapcnet.eu



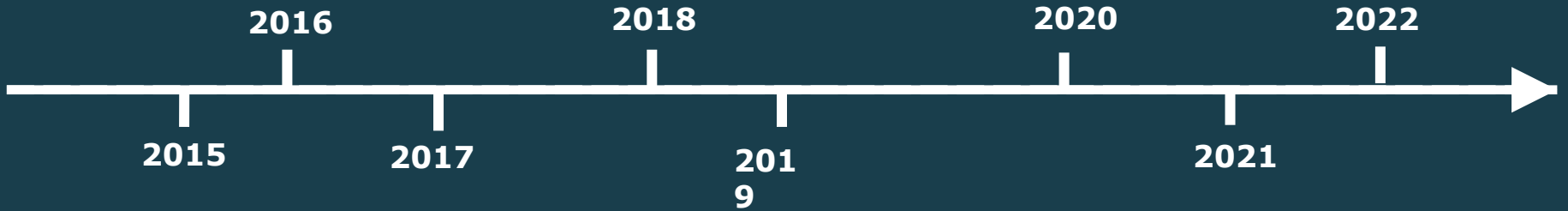
EAPC Webinar Series

Aim to increase awareness, knowledge and skills related to palliative care for health care workers, the public and volunteers. Our webinars are free to attend live with back catalogue for members.

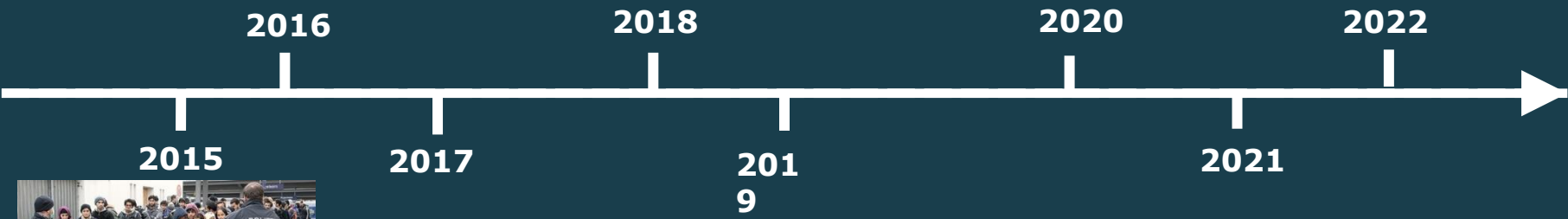
Dissemination tools	URL	Followers/members
Twitter 	https://twitter.com/EAPCvzw	9,301
EAPC Blog 	https://eapcnet.wordpress.com/	17,972
YouTube 	https://www.youtube.com/channel/UCoYvLZTrAFUj3Zwg9KLvL7A	127
Facebook 	https://www.facebook.com/EAPC.Vzw	8,177
Instagram 	https://www.instagram.com/eapc.vzw	858
LinkedIn 	https://www.linkedin.com/groups/3958468/	4,459
MailChimp 	https://www.eapcnet.eu/	11,018
Research Gate 	www.researchgate.net/profile/Cathy-Payne-2 https://www.researchgate.net/profile/Julie-Ling	

2014-2022

So much as happened ...



2014-2022



2014-2022



2016

2018

2020

2022

2015

2017

2019

2021



2014-2022



2016

2018

2020

2022

2015

2017

2019

2021



2014-2022



2016



2018

2020

2022

2015



2017



2019

2021



2014-2022



2016



2018

2020

2022

2015



2017



2019



2021



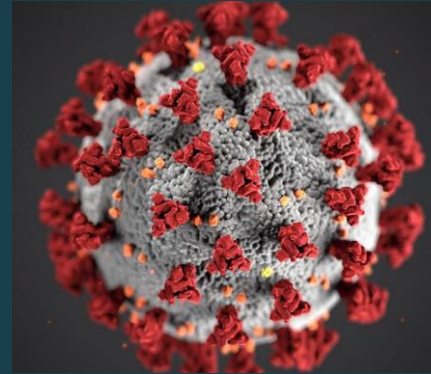
2014-2022



2016



2018



2020

2022

2015



2017



201



2021

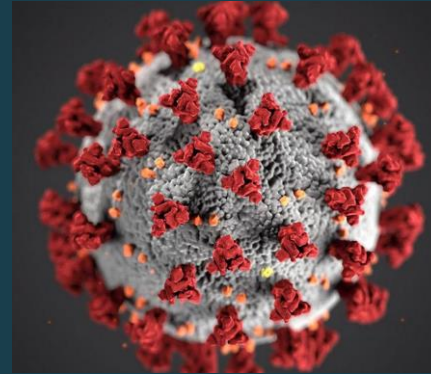
2014-2022



2016



2018



2020

2022

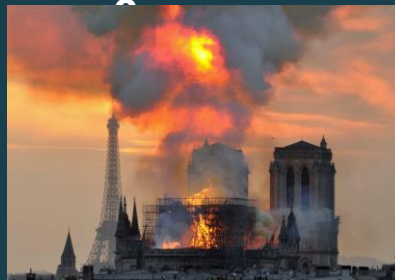
2015



2017



2019



2021



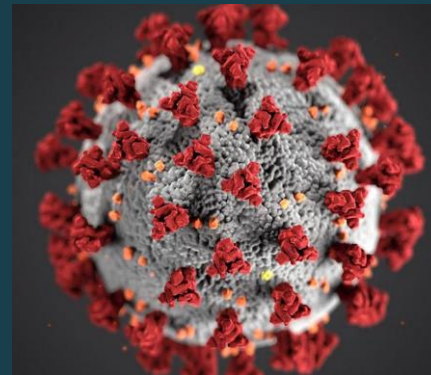
2014-2022



2016



2018



2020



2022

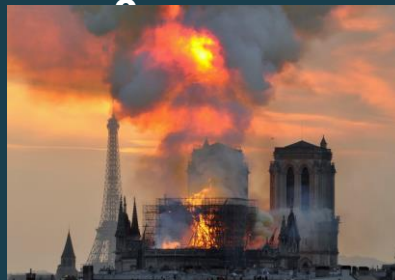
2015



2017



2019



2021



2014-2022 Palliative Care



2014-2022 Palliative Care

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



2014-2022 Palliative Care

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



2014

2016

2018

2020

2022

2015

2017

2019

2021



2014-2022 Palliative Care

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



Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104-116
© The Author(s) 2015, Article reuse Guidelines:
<https://doi.org/10.1177/0269216315616524>

SAGE
journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch^{1,2}, Carlo Leget³, Patrick Bahr¹, Christof Müller-Busch^{4,5}, John Ellershaw⁶, Franco de Conno⁷, Paul Vanden Berghe⁸, and on behalf of the board members of the EAPC



The Economist Intelligence Unit

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by
LCN
foundation

2014-2022 Palliative Care

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



Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104-116
© The Author(s) 2015, Article Reuse Guidelines
<https://doi.org/10.1177/02692163151561624>

SAGE
journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch^{1,2}, Carlo Leget³, Patrick Bahr¹, Christof Müller-Busch^{4,5}, John Ellershaw⁶, Franco de Conno⁷, Paul Vanden Berghe⁸, and on behalf of the board members of the EAPC

2014

2016

2018

2020

2022

2015

2017

2019

2021

The Economist Intelligence Unit

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by
LCN
foundation

THE LANCET

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report

"Serious health-related suffering is a massive, appalling oversight in global health that must be remedied. Palliative care and pain relief are some of the most neglected dimensions of global health today."

Commissioned by The Lancet

2014-2022 Palliative Care

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



Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104-116
© The Author(s) 2015, Article Reuse Guidelines
<https://doi.org/10.1177/0269216315616524>

SAGE
journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch^{1,2}, Carlo Leget³, Patrick Bahr¹, Christof Müller-Busch^{4,5}, John Ellershaw⁶, Franco de Conno⁷, Paul Vanden Berghe⁸, and on behalf of the board members of the EAPC



2014

2016

2018

2020

2022

2015

2017

2019

2021

The Economist Intelligence Unit

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by
LCN
foundation

THE LANCET

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report

"Serious health-related suffering is a massive, appalling oversight in global health that must be remedied. Palliative care and pain relief are some of the most neglected dimensions of global health today."

2014-2022 Palliative Care

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



Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104-116
© The Author(s) 2015, Article Reuse Guidelines
<https://doi.org/10.1177/0269216315616524>

SAGE
journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch^{1,2}, Carlo Leget³, Patrick Bahr¹, Christof Müller-Busch^{4,5}, John Ellershaw⁶, Franco de Conno⁷, Paul Vanden Berghe⁸, and on behalf of the board members of the EAPC



2014

2016

2018

2020

2022

2015

2017

2019

2021

The Economist Intelligence Unit

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by
LCN
foundation

THE LANCET

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report

"Serious health-related suffering is a massive, appalling oversight in global health that must be remedied. Palliative care and pain relief are some of the most neglected dimensions of global health today."

EAPC Atlas of Palliative Care in Europe 2019

Natalia Arino-Casas, Eduardo Soriano, John Y. Pines, Liliana de Lima, Juan José Pons, David Clark, Jeremy Haselbar, Julie Ling, Daniela Moroni, Carlos Cornejo

PC

2014-2022 Palliative Care

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



Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104-116
© The Author(s) 2015, Article Reuse Guidelines
<https://doi.org/10.1177/0269216315616524>

SAGE
journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch^{1,2}, Carlo Leget³, Patrick Bahr¹, Christof Müller-Busch^{4,5}, John Ellershaw⁶, Franco de Conno⁷, Paul Vanden Berghe⁸, and on behalf of the board members of the EAPC



2014

2016

2018

2020

2022

2015

2017

2019

2021

The Economist Intelligence Unit

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by
LCN
foundation

THE LANCET

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report

"Serious health-related suffering is a massive, appalling oversight in global health that must be remedied. Palliative care and pain relief are some of the most neglected dimensions of global health today."

EAPC Atlas of Palliative Care in Europe 2019

Natalia Arino-Casas, Eduardo Soriano, John Y. Pines, Liliana de Lima, Juan José Pons, David Clark, Jeremy Haselbar, Julie Ling, Daniela Moroni, Carlos Cornejo

2014-2022 Palliative Care

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



Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104-116
© The Author(s) 2015, Article Reuse Guidelines
<https://doi.org/10.1177/02692163151616524>

SAGE
journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch^{1,2}, Carlo Leget³, Patrick Bahr¹, Christof Müller-Busch^{4,5}, John Ellershaw⁶, Franco de Conno⁷, Paul Vanden Berghe⁸, and on behalf of the board members of the EAPC



2014

2016

2018

2020

2022

2015

2017

2019

2021

The Economist Intelligence Unit

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by
LCN
foundation

THE LANCET

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report

"Serious health-related suffering is a massive, appalling oversight in global health that must be remedied. Palliative care and pain relief are some of the most neglected dimensions of global health today."

EAPC Atlas of Palliative Care in Europe 2019

Natalia Arino-Casas, Eduardo Sorribás, John Y. Pines, Liliana de Lima, Juan José Pons, David Clark, Jeremy Haselbar, Julie Ling, Daniela Moros, Carlos Cornejo

World Health Organization

QUALITY HEALTH SERVICES AND PALLIATIVE CARE
Practical approaches and resources to support policy, strategy and practice

2014-2022 Palliative Care

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY

Agenda item 15.5

WHA67.19

24 May 2014

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



2014

Palliative Medicine
Volume 30, Issue 2, February 2016, Pages 104-116
© The Author(s) 2015, Article Reuse Guidelines
<https://doi.org/10.1177/02692163151616524>

SAGE
journals

Review Article

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch^{1,2}, Carlo Leget³, Patrick Bahr¹, Christof Müller-Busch^{4,5}, John Ellershaw⁶, Franco de Conno⁷, Paul Vanden Berghe⁸, and on behalf of the board members of the EAPC

2016



2018



2020

Cross-sector Partnerships to build capacity for Palliative Care Research

2022

2015

The Economist Intelligence Unit

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit

Commissioned by
LCN
foundation

2017

THE LANCET

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report

"Serious health-related suffering is a massive, appalling oversight in global health that must be remedied. Palliative care and pain relief are some of the most neglected dimensions of global health today."

2019

EAPC Atlas of Palliative Care in Europe 2019

Natalia Arino-Casas, Eduardo Sorribas, John Y. Pines, Liliana de Lima, Juan José Pons, David Clark, Jeremy Haselbar, Julie Ling, Daniela Moros, Carlos Cornejo

2021

World Health Organization

QUALITY HEALTH SERVICES AND PALLIATIVE CARE
Practical approaches and resources to support policy, strategy and practice

European Declaration Palliative Care 2020



- Launched in October 2015
- Developed during the EU Projects
EURO IMACT & IMPACT
- Supported by the EAPC, INTERDEM,
AGE Platform Europe and EUGMS

Definition Declaration

- are statement(s) of intent or summaries of the desirable situation to which participants intend to work and to which they would like to encourage others to work*
- they highlight matters of concern**
- call others to action**
- they are a window on the priorities emerging in the field**

http://www.thewhpca.org/images/resources/advocacy/advocacy_toolkit_05april.pdf
Inbadas H et al., J Pain Symptom Manage. 2016 Sep; 52(3)

Definition nowadays



2014 European Declaration on Palliative Care

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and treatment of other problems, physical, psychosocial and spiritual"
[World Health Organization].

Definition nowadays

Original Article

Redefining Palliative Care—A New Consensus-Based Definition



Lukas Radbruch, MD, Liliana De Lima, MHA, Felicia Knaul, MD, Roberto Wenk, MD, Zipporah Ali, MD, Sushma Bhatnagar, MD, Charmaine Blanchard, MD, Eduardo Bruera, MD, PhD, Rosa Buitrago, BSc, MCPH, Claudia Burla, MD, PhD, Mary Callaway, MME, Esther Cege Munyoro, MD, Carlos Centeno, MD, Jim Cleary, MD, Stephen Connor, PhD, Odontuya Davaasuren, MD, Julia Downing, PhD, Kathleen Foley, MD, PhD, Cynthia Goh, MD, Wendy Gomez-Garcia, MD, Richard Harding, PhD, Quach T. Khan, MD, Phillippe Larkin, PhD, Mhoira Leng, MD, PhD, Emmanuel Luyirika, PhD, Joan Marston, BSc, Sebastien Moine, MD, Hibah Osman, MD, PhD, Katherine Pettus, PhD, Christina Puchalski, MD, M.R. Rajagopal, MD, Dingle Spence, MD, Odette Spruijt, MBChB, Dip Obs, Chitra Venkateswaran, MD, Bee Wee, MD, PhD, Roger Woodruff, MD, Jinsun Yong, PhD, and Tania Pastrana, MD, PhD

Definition nowadays

754 *Journal of Pain and Symptom Management*

Vol. 60 No. 4 October 2020

Original Article

Redefining Palliative Care—A New Consensus-Based Definition




Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

Definition nowadays

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and treatment of other problems, physical, psychosocial and spiritual" [WHO 2002].





Curriculum development and Education nowadays

Curriculum development and Education nowadays

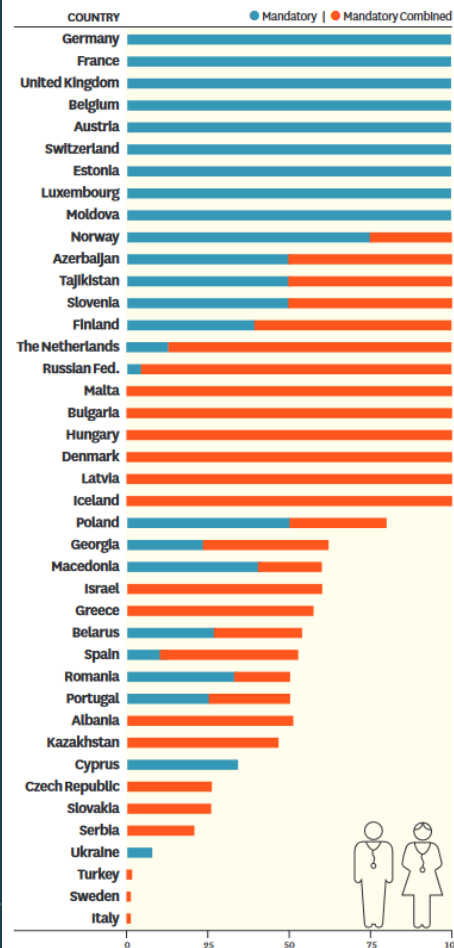


2014 European Declaration on Palliative Care

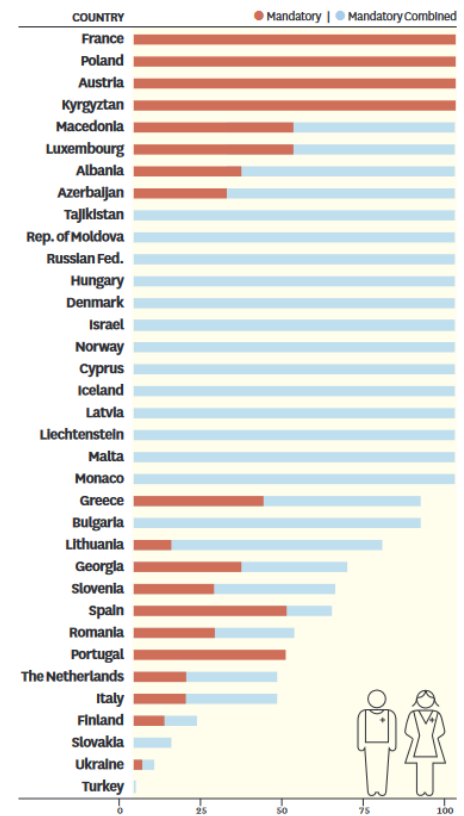
7. Invest in **curriculum development and education** in palliative care across all disciplines of health and social care at undergraduate and post-graduate level, and **establish palliative care as a specialty**.

Curriculum development and Education nowadays

PC TEACHING IN MEDICAL SCHOOLS



PC TEACHING IN NURSING SCHOOLS



Arias-Casais N et al. EAPC Atlas of Palliative Care in Europe 2019. Vilvoorde: EAPC Press; 2019.

Curriculum development and Education nowadays



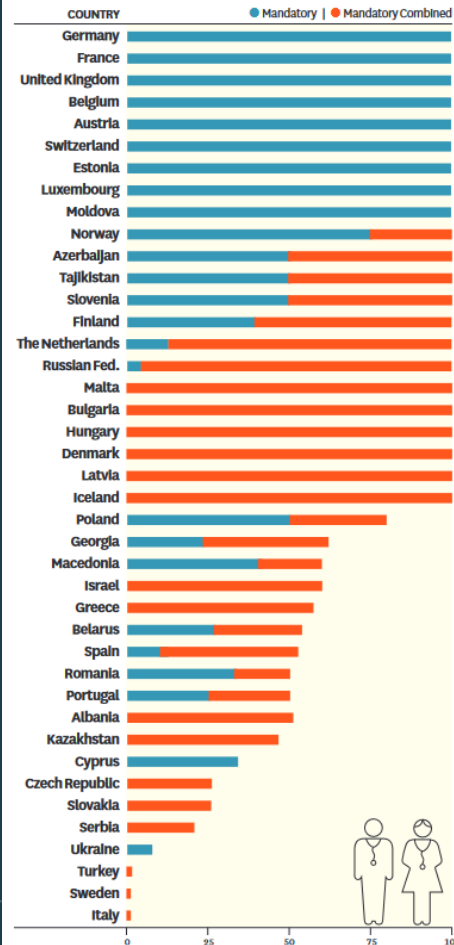
Co-funded by the Erasmus+ Programme of the European Union

Palliative Care Standardized Curriculum Translating International Recommendations into Undergraduate Palliative Care Curriculum (EDUPALL)

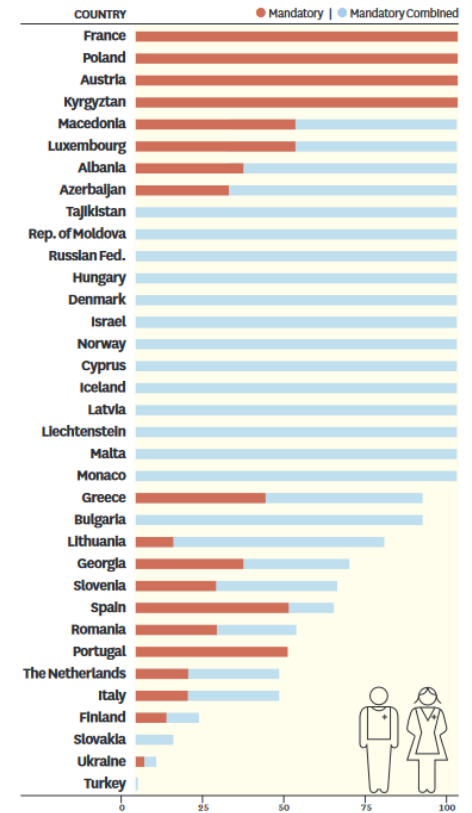
Erasmus+ Project Strategic partnership Ref. no.: 2017-1-RO01-KA203-037382

UNDERGRADUATE TRAINING

PC TEACHING IN MEDICAL SCHOOLS



PC TEACHING IN NURSING SCHOOLS



Arias-Casais N et al. EAPC Atlas of Palliative Care in Europe 2019. Vilvoorde: EAPC Press; 2019.

The background features a network diagram with several nodes (small grey circles) connected by thin white lines. The nodes are scattered across the frame, with some having multiple connections, creating a web-like structure. The overall aesthetic is clean and modern, typical of a professional presentation.

Early Integration nowadays

Early Integration nowadays



2014 European Declaration on Palliative Care

Palliative care is required from **early in the disease** course, can be delivered alongside potentially curative treatment, and continues to include **end-of-life or terminal care**.

3. Develop or redraft **palliative care-specific policies** to include referral criteria that allow patients and their family timely access to palliative care consistent with their level of need, regardless of diagnosis, age, prognosis, estimated life expectancy or care setting.

Early Integration nowadays

Received: 31 January 2022 | Revised: 3 July 2022 | Accepted: 28 July 2022

DOI: 10.1111/ecc.13680

ORIGINAL ARTICLE

European Journal of Cancer Care WILEY

Referral of patients with cancer to palliative care: Attitudes, practices and work-related experiences among Swedish physicians

Karin Adolfsson^{1,2} | Ulrika Kreicbergs^{3,4} | Charlotte Bratthäll⁵ |
Erik Holmberg^{1,6} | Thomas Björk-Eriksson^{1,6} | Margaretha Stenmarker^{7,8,9}

Results: The vast majority of the 130 physicians (99.2%) stated that PC was beneficial for the patient [...]. Still, only 27.6% of the participants introduced PC at an early stage of non-curable disease.

Early Integration nowadays

Received: 31 January 2022 | Revised: 3 July 2022 | Accepted: 28 July 2022

DOI: 10.1111/ecc.13680

ORIGINAL ARTICLE

European Journal of Cancer Care WILEY

Referral of patients with cancer to palliative care: Attitudes, practices and work-related experiences among Swedish physicians

Karin Adolfsson^{1,2} | Ulrika Kreicbergs^{3,4} | Charlotte Brattthäll⁵ | Erik Holmberg^{1,6} | Thomas Björk-Eriksson^{1,6} | Margaretha Stenmarker^{7,8,9}

Results: The vast majority of the 130 physicians (99.2%) stated that PC was beneficial for the patient) [...]. Still, only 27.6% of the participants introduced PC at an early stage of non-curable disease.

Conclusion: While rates of PC referral in our cohort are high compared with other [...] cohorts, timing of PC referral suggests referral patterns that are reactive to clinical decline rather than proactive as per national recommendations.



Contents lists available at [ScienceDirect](#)

Gynecologic Oncology Reports

journal homepage: www.elsevier.com/locate/gynor

Gynecologic Oncology Reports 43 (2022) 101053

Patterns of palliative care referral in platinum resistant ovarian cancer demonstrate reactive rather than proactive approach

Jennifer G. Haag^a, Alexzandra D. Adler^a, Jeanelle Sheeder^a, Lindsay W. Brubaker^{b,*}, Carolyn Lefkowitz^b

Public Awareness nowadays



2014 European Declaration on Palliative Care

8. Promote public awareness through **community level approaches**: education of the **public** and training of **family carers and volunteers**.

Public Awareness nowadays

RESEARCH ARTICLE

Open Access

Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study



Sonja McIlfatrick^{1*}, Paul Slater¹, Esther Beck¹, Olufikayo Bamidele², Sharon McCloskey³, Karen Carr¹, Deborah Muldrew¹, Lisa Hanna-Trainor¹ and Felicity Hasson¹

Results: A total of 1201 participants completed the survey (58.3% female, mean age 61 years) and 25 took part in interviews. A fifth of participants (20.1%) had previously heard about palliative care and had an accurate understanding of the term. Being female, higher educated, married, and older, increased respondents' levels of awareness. The three most commonly held misconceptions included: Palliative care is exclusively for people who are in the last 6 months of life (55.4% answered incorrectly); A goal of palliative care is to address any psychological issues brought up by serious illness (42.2% answered incorrectly); and a goal of palliative care is to improve a person's ability to participate in daily activities (39.6% answered incorrectly). Talking about palliative and end of life care was advocated but societal taboos restricted this occurring with exposure limited to personal experience.

Public Awareness nowadays

RESEARCH ARTICLE

Open Access

Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study



Sonja McIlfatrick^{1*}, Paul Slater¹, Esther Beck¹, Olufikayo Bamidele², Sharon McCloskey³, Karen Carr¹, Deborah Muldrew¹, Lisa Hanna-Trainor¹ and Felicity Hasson¹

Results: A total of 1201 participants completed the survey (58.3% female, mean age 61 years) and 25 took part in interviews. A fifth of participants (20.1%) had previously heard about palliative care and had an accurate understanding of the term. Being female, higher educated, married, and older, increased respondents' levels of awareness. The three most commonly held misconceptions included: Palliative care is exclusively for people who are in the last 6 months of life (55.4% answered incorrectly); A goal of palliative care is to address any psychological issues brought up by serious illness (42.2% answered incorrectly); and a goal of palliative care is to improve a person's ability to participate in daily activities (39.6% answered incorrectly). Talking about palliative and end of life care was advocated but societal taboos restricted this occurring with exposure limited to personal experience.


Public Awareness nowadays

RESEARCH ARTICLE

Open Access

Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study



Sonja McIlfatrick^{1*}, Paul Slater¹, Esther Beck¹, Olufikayo Bamidele², Sharon McCloskey³, Karen Carr¹, Deborah Muldrew¹, Lisa Hanna-Trainor¹ and Felicity Hasson¹

Results: A total of 1201 participants completed the survey (58.3% female, mean age 61 years) and 25 took part in interviews. A fifth of participants (20.1%) had previously heard about palliative care and had an accurate understanding of the term. Being female, higher educated, married, and older, increased respondents' levels of awareness. The three most commonly held misconceptions included: Palliative care is exclusively for people who are in the last 6 months of life (55.4% answered incorrectly); A goal of palliative care is to address any psychological issues brought up by serious illness (42.2% answered incorrectly); and a goal of palliative care is to improve a person's ability to participate in daily activities (39.6% answered incorrectly). Talking about palliative and end of life care was advocated but societal taboos restricted this occurring with exposure limited to personal experience.

Nowadays - take home messages

- PC has partially evolved over the last 8 years
- Aims of the European declaration still not achieved
- All ten points are as true and essential as they were in 2014
- Charters are tools to advocate and lobby for palliative care, but they are not enough ...
- Practical tools for implementation are urgently needed
- More research needed to address these aspects
- What types of research being undertaken?

Horizon 2020 framework programme

DIAdIC Duration 60 months Commenced 1.1.19	Evaluation of Dyadic Psychoeducational Interventions for People with Advanced Cancer and their Informal Caregivers (DIAdIC): An international randomized controlled trial
MyPal Duration 42 months Commenced 1.1.19	MyPal: Fostering Palliative Care of Adults and Children with Cancer through Advanced Patient Reported Outcome Systems
PalliativeSedation Duration 60 months 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

EU4Health programme

INTERACT-EUROPE Duration 18 months Commenced 1.6.22	Innovative collaboration for Inter-specialty cancer training across Europe
smartCARE Duration 24 months Commencing tbc	smart Card Application improving cancer survivors quality of life

EU4health

HORIZON-HLTH-2021-DISEASE-04

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

Final Thoughts - observations

- Palliative care research is developing –review of EU funded projects.
- Need to have research informing palliative care practice & informed by palliative care practice
- Challenges & opportunities do exist
- Collaboration, capacity building and continued investment vital for palliative care research

