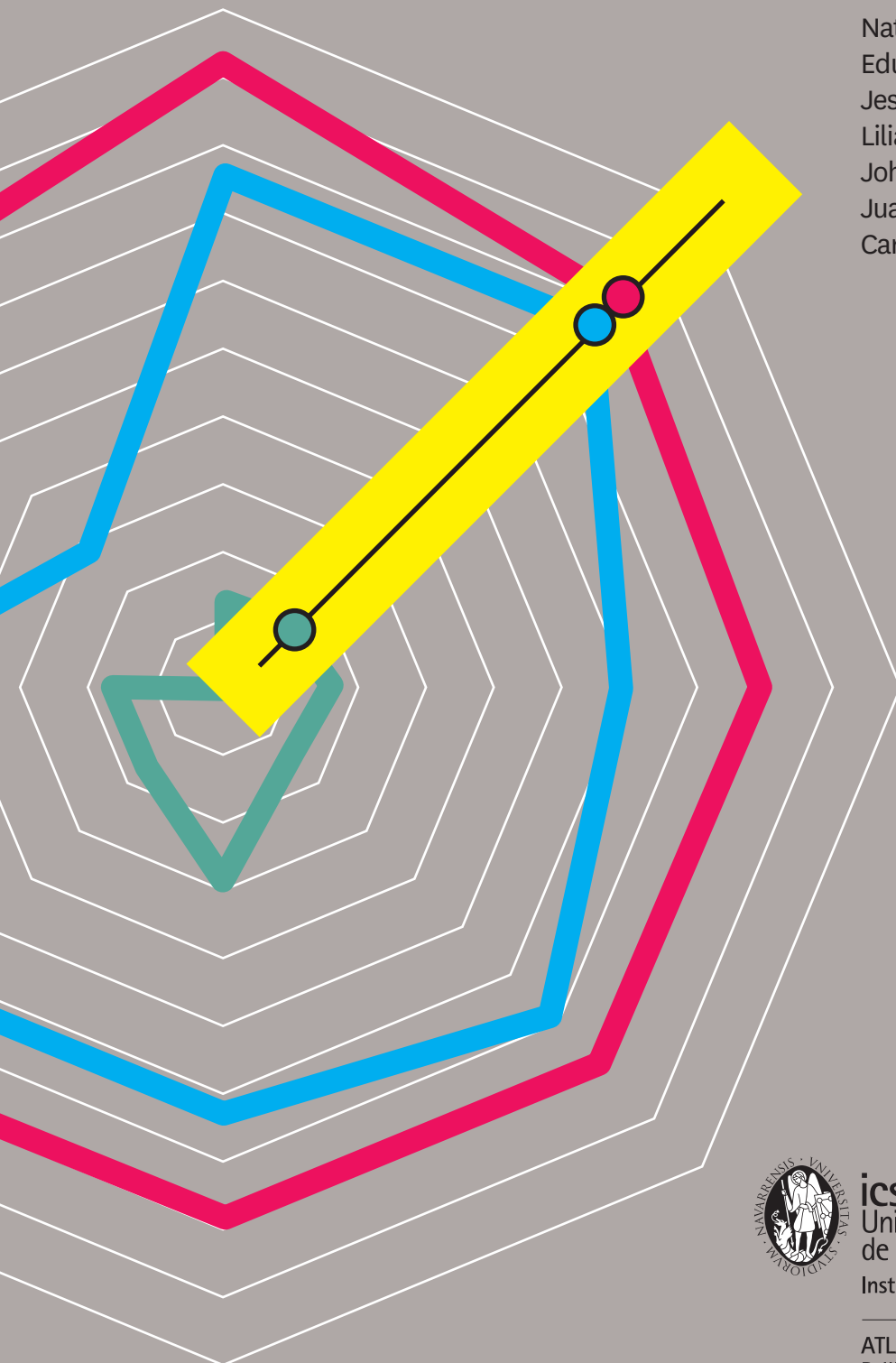




Brief Manual on Health Indicators Monitoring Global Palliative Care Development

Natalia Arias-Casais
Eduardo Garralda
Jesús López Fidalgo
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Presentation

Indicators to accurately track the development of palliative care are key to understanding the progress made in improving patients' access to good symptom management and care

Indicators to accurately track the development of palliative care at the national-level are needed (1,2) and important to accurately measure access to palliative care. According to the World Health Organisation (WHO) Public Health Strategy for palliative care, four domains are key to achieving this goal: inclusion of palliative care in national health policies, access to essential medicines for pain relief and palliative care, training of health professionals, and service provision (3).

Over the last decade, global, regional and national palliative care organizations have increasingly placed more resources and research into defining a set of indicators to monitor and report progress in palliative care development. As an example of this growing need, the 71st World Health Assembly approved the inclusion of a specific national-level palliative care indicator in the WHO's Impact Framework (Access to palliative care assessed by morphine-equivalent consumption of strong opioid analgesics (excluding methadone) per death from cancer). To date, neither palliative care research groups nor international organisations have agreed on which indicators best assess national palliative care development. However, indicators in the literature have traditionally assessed development using the WHO Public Health Strategy domains as a framework as well as expert sources for information (4) (5).

A recent systematic review by our group identified the most frequently used indicators in the last decade to assess palliative care development at the national level (5). A total of 165 indicators were extracted from 480 different formulations of various indicators.

«A recent systematic review by our group identified the 45 most frequently used indicators in the last decade assessing national-level palliative care development around the world»

One prominent indicator is “consumption of morphine per cancer death” (WHO, 2013), which received critiques that led to its amendment by changing its wording to “consumption of morphine per death” to include a wider population

of people in need of palliative care other than restricting the indicator to patients with cancer. This change also overcame the issues associated with having different types of cancer registries in different countries (6). Meanwhile, other relevant regional and global studies addressing the field of palliative care development used combinations of different sets of indicators (7-14). However, none of implemented a validated process for selection or for use of indicators in the studies.

It has not been until recently that a solid base of knowledge existed upon which a greater consensus of the “best” indicators could be reached. We decided to conduct an international consensus process with the aim of identifying national-level indicators for comparative studies on the development of palliative care internationally with national experts, national associations or policymakers.

«We have identified the 25 best indicators to assess national-level palliative care development through an international panel of experts»

Through a modified RAND/UCLA Delphi process (15), we have identified the 25 best indicators to assess national-level palliative care development through an international panel of experts. Our study brought, for the first time, professionals with expertise in regional and global palliative care development from several countries and institutions to achieve consensus on how we should measure the development of palliative care internationally. The set of indicators shows high content validity and an excellent level of international agreement.

Using a consensus-based list of indicators improves upon existing studies on national-level palliative care indicators by providing a specific, evidence-based starting point on the development of palliative care, adding evidence to existence studies and allowing for replication. Furthermore, this allows for assessing national level progress and conducting comparative analysis and prospective studies. Tracking the indicators across time offers the opportunity to pool data data in a same repository that could be prospec-

Presentation

tively evaluated, allowing for trends in palliative care development at the international level.

The indicators presented here do not cover the whole spectrum of palliative care integration at different levels (for example, palliative care in primary care, in long term facilities, for children and other vulnerable populations, and in specific chronic conditions, etc.). The indicators included in the study miss these important areas of palliative care integration and continue to assess the issue, as it has traditionally been done, by focusing on the general development of palliative care and the implementation of palliative care services. An example of the need to identify new indicators on the integration of palliative care into the health system stems from the advice of experts in this study who highlighted the importance of addressing palliative care at the primary care level. For instance, the most highly-scored indicator within the services domain was the number of specialised home palliative care teams. This indicator speaks to the need for making palliative care accessible to those in need, and this can only be achieved, as stated in WHA67.19 (16) and the Astana Declaration (17), by strengthening the primary care provision of palliative care. In this light, a new process to identify and agree upon indicators addressing palliative care integration is necessary

to complete the picture of palliative care development at the international and national levels.

We would like to contribute to the ongoing discussion on the question of palliative care development assessment by presenting the first list containing the best indicators for the evaluation of the development of palliative care at the national-level, achieved through a consensus process. We present this brief manual to be used as a reference by researchers and stakeholders interested in assessing palliative care development and conducting comparative analysis.

«Tracking the indicators across the time offers the opportunity to pool data data in a same repository that could be prospectively evaluated, allowing for trends in palliative care development at the international level»

Some members of the research team at the University of Navarra: Jesús López, Juan José Pons, Carlos Centeno, Natalia Arias-Casais and Eduardo Garralda.





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Aims and objectives

Having a set of indicators would serve to evaluate the development of Palliative Care at a national level

GENERAL OBJECTIVES

The objective of this initiative is to present a set of national-level indicators to assess the development of palliative care in different countries and regions. The resulting indicators from a consensus process with an international panel comprised of professionals in palliative care with extensive experience in cross-national assessment of palliative care development, research and advocacy. Global and International palliative care associations have endorsed the indicators presented in this manual. Since indicators should be adjusted to the national and regional contexts, their implementation in such studies should be preceded by discussion on the feasibility of each indicator in their specific contexts.

«Indicators should be adjusted to the national and regional contexts. Implementation should be preceded by discussion on the feasibility of each indicator in their respective contexts»

SPECIFIC OBJECTIVES

- To provide a set of indicators that can be used for national-level evaluation of palliative care development globally.
- To present a consensus process amongst international experts on palliative care development to identify the best indicators to assess development on this field.
- To provide indicators to allow countries the evaluation of their current status, advancement and progress on improving access to palliative care in their countries.
- To present a standardised set of indicators to allow cross-national comparison and track global development of palliative care.
- To provide evidence based outcomes to be used for advocacy purposes, joining the efforts of advancing palliative care as part of the UHC globally.



Methods

A systematic review on the most frequently used indicators to assess national-level palliative care development was conducted and published. A panel of experts was selected following a strict selection criteria. Experts were invited to participate in a consensus process to rate the identified indicators.

Through a systematic review, the most frequently used national-level indicators assessing palliative care development for cross-national comparison in international studies during the last decade were identified ($n=38$). The indicators were categorized following the domains of the World Health Organisation Public Health Strategy for Palliative Care. A short document summarizing each indicator, its definition, questions used to address it in the survey, and references to previous studies referring to the indicator was compiled. An international panel of experts on palliative care development was selected according to the following criteria: a) demonstrated experience with national-level indicators for palliative care, b) demonstrated experience in palliative care development evaluation projects, and c) participation in palliative care networks or advocacy activities for at least four years. The group had experts from different backgrounds, affiliated to various national and international palliative care associations and living in different areas to ensure a broad geographical representation.

In a two-round modified RAND/UCLA Delphi process, experts narrowed down the list of indicators. In the first round, experts rated, on a 1 to 9 scale, indicators by three parameters: relevance, measurability, and feasibility. Relevance was defined as the degree to which the indicator is related to palliative care development at a national-level. Measurability was defined as the degree to which an indicator can be quantified or measured. Since this study was conducted in the framework of the next assessment of palliative care in Europe, in this case, feasibility was defined as the degree to which an indicator would be easily obtained or collected by palliative care experts in the WHO-European region. The average of each of the three parameters' medians was used to calculate a Global Score (GS). For the first round, a higher level of consensus was determined by the top tercile of possible scores ($GS \geq 7$). In the second round, each expert rated indicators fine-tuning the previous global score they gave knowing the rating of the group (1-9).

The data obtained was analysed by median and 95% confidence interval (CI) (17), Disagreement Index (DI), and Content Validity Index (I-CVI). DI was utilised following the RAND/UCLA Delphi method (18) based on the inter-percentile ranges, a commonly used statistical measure of dispersion of a distribution. A $DI \geq 1$ means disagreement among experts' ratings. I-CVI (19) focuses on the agreement of relevance of the indicator rather than the agreement per se. An I-CVI of 1 means unanimity in terms of relevance.

To define the final list of best indicators, more consensus was required narrowing down the list. Final consensus was defined as indicators scoring in the lower limit of the 95% CI ≥ 7 , and an I-CVI ≥ 0.30 . An I-CVI of 0.3 means that at least one of three experts evaluated that the indicator score was the highest.

Twenty-five indicators fulfilled the criteria and were thus selected as the best indicators after conclusion of the consensus process. This manual presents the information page of each of the 25 selected indicators. Each page depicts the profile of the indicator, showing its definition, questions to explore, references to previous studies and scores during the second round of the consensus process.

WORKING DEFINITIONS USED IN THIS PAPER

■ **Global Score:** Level of agreement to which one indicator shows palliative care development at the national level, **ranging from 1 to 9.**

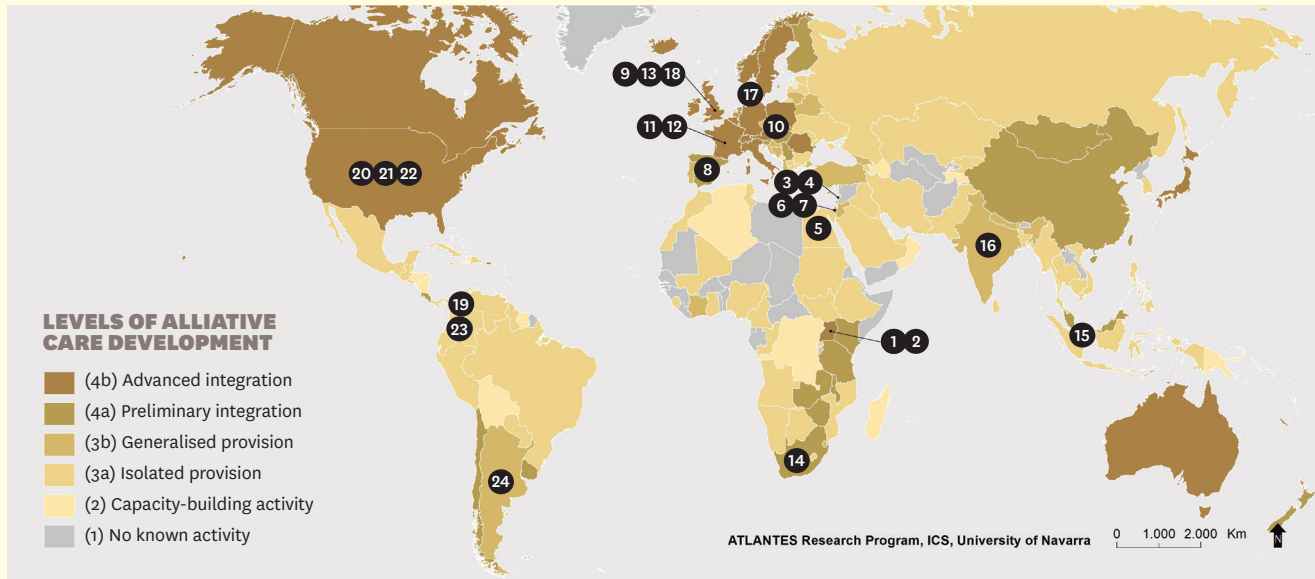
■ **Content Validity Index (I-CVI):** Level of the agreement on relevance per indicator. It shows how many experts rated it with the highest scores. An I-CVI = 1 means unanimity amongst experts rating high scores. An I-CVI of 0.3 means that at least 1/3 of the experts rated the highest score regarding its relevance, **ranging from 0 to 1.**

■ **Disagreement Index (DI):** Level of disagreement on a rated item based on inter-percentile ranges. It is a commonly used statistical measure to assess of dispersion of a distribution. A $DI \geq 1$ means disagreement among experts' ratings, while $DI \leq 1$ shows agreement amongst experts. $DI \leq 1$ score represent experts rating on the same range, the closer to zero, thus stronger the agreement. $DI \geq 1$ score show that experts scored in different ranges, with wider dispersion. Thus 1 marks the threshold to consider disagreement amongst experts, **ranging from 0 to 1.**

Acknowledgement: To Edgar Benitez for his support with the graphics and figures.



Panel of experts



REGION	N.	NAME	AFFILIATION	COUNTRY
AFRICA	1	Eve Namisango	African Palliative Care Association	Uganda
	2	Fatia Kiyange	African Palliative Care Association	Uganda
MIDDLE EAST	3	Hibah Osman	BALSAM Center	Lebanon
	4	Ibtihal Fadhil	Middle East Non Communicable Disease Alliance	Lebanon
	5	Sami Alsirafy	Kasr Al-Ainy School of Medicine, Cairo University	Egypt
	6	Michael Silberman	Middle East Cancer Consortium	Israel
	7	Ron Sabar	Middle East Cancer Consortium	Israel
EUROPE	8	Carlos Centeno	European Association of Palliative Care (University of Navarra)	Spain
	9	Richard Harding	Cicely Saunders Institute of Palliative Care King's College London	United Kingdom
	10	Martin Loucka	Center for Palliative Care	Czech Republic
	11	Marilène Filbet	Centre Hospitalier Universitaire de Lyon	France
	11	Sandrinne Bretonnière	French National Center for Palliative Care and End of Life	France
	13	Sheila Payne	Lancaster University (Past president of the European Association of Palliative Care)	United Kingdom
GLOBAL ORGANISATIONS	14	Julia Downing	International Children's Palliative Care Network	South Africa
	15	Trisha Suresh	The Economist Intelligence Unit	Singapore
	16	M.R. Rajagopal	Lancet Commission (Pallium India)	India
	17	Marilys Corbex	World Health Organisation	Denmark
	18	David Clark	End of life study group University of Glasgow (Worldwide Hospice and Palliative Care Alliance)	United Kingdom
	19	Liliana de Lima	International Association of Hospice and Palliative Care (Lancet Commission, Asociación Latinoamericana de Cuidados Paliativos)	United States, Colombia
	20	Eric Krakauer	World Health Organisation (Lancet Commission, Harvard University)	United States
LATIN AMERICA	21	Diederik Lohman	Human Rights Watch	United States
	22	Stephen R Connor	Worldwide Hospice and Palliative Care Alliance	United States
LATIN AMERICA	23	Tania Pastrana	Asociación Latinoamericana de Cuidados Paliativos	Colombia
	24	Roberto Wenk	Asociación Latinoamericana de Cuidados Paliativos	Argentina



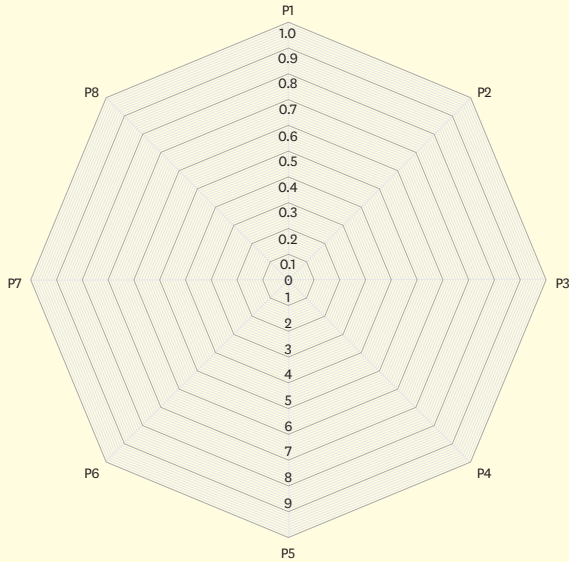
Indicators

DOMAIN	CODE	NAME
POLICY	P1	Designated human resource (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care
	P2	Existence of a current national palliative care plan, programme, policy or strategy
	P3	Existence of a specific palliative care national law
	P4	Existence of national standards and norms for the provision of palliative care services
	P5	Existence of systems of auditing, quality evaluation, improvement or assurance for palliative care services
	P6	Allocation of funds for palliative care activities in the national health budget by the Ministry of Health or equivalent government agency
	P7	Inclusion of palliative care services in the basic package of health services
	P8	Inclusion of palliative care in the list of health services provided at primary care level in the national health system
EDUCATION	E1	Existence of a process of official specialisation in Palliative Medicine for physicians, recognized by the competent authority
	E2	Medical schools including mandatory palliative care education in undergraduate curricula
	E3	Nursing schools including mandatory palliative care education in undergraduate curricula
	E4	Professorship in palliative care in medical schools
USE OF MEDICINES	M1	Opioid consumption –in morphine equivalence (ME) excluding methadone- per capita as reported to the INCB (year)
	M2	General availability of immediate-release oral morphine (liquid or tablet) at the primary care level
	M3	Requirement of specific licenses to prescribe opioids
	M4	Professionals legally allowed to prescribe opioids
SERVICE PROVISION	S1	Number of specialised home palliative care teams (estimate)
	S2	Number of inpatient palliative care units in hospitals (public and private) (estimate)
	S3	Number and type of palliative care programs for children (estimate)
	S4	Number of inpatient hospices
	S5	Number of specialised hospital palliative care support teams
	S6	Number of specialised palliative care services in the country per population
PROFESSIONAL ACTIVITY	V1	Existence of at least one national palliative care association
	V2	Existence of a national palliative care directory of services
	V3	Number of scientific articles on palliative care development in the past five years



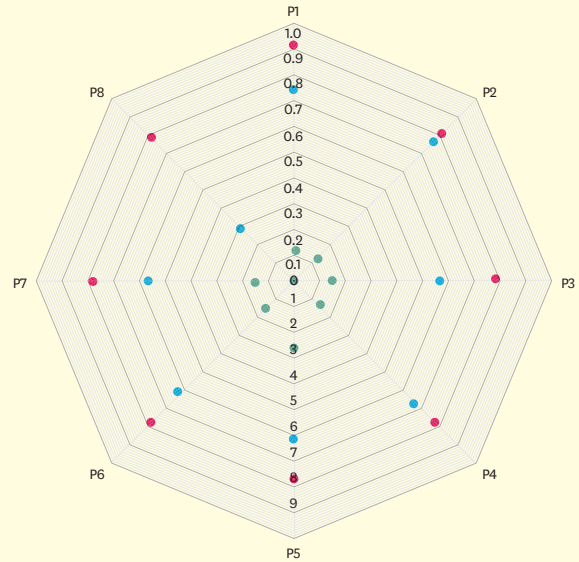
How to read the charts

1. Range



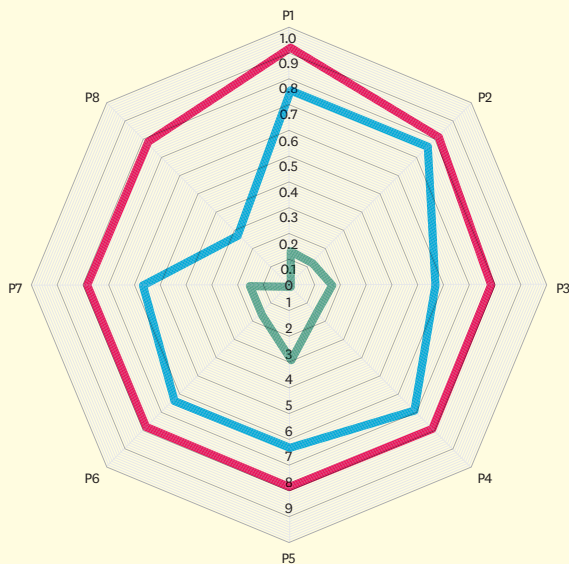
Each thematic block has as many vertices as indicators. Different geometric forms are generated on top of these vertices derived from three scales: the Content Validity Index (score 0 to 1), Disagreement Index (score 0 to 1), and the Global Scale (score 1 to 9).

2. Scores



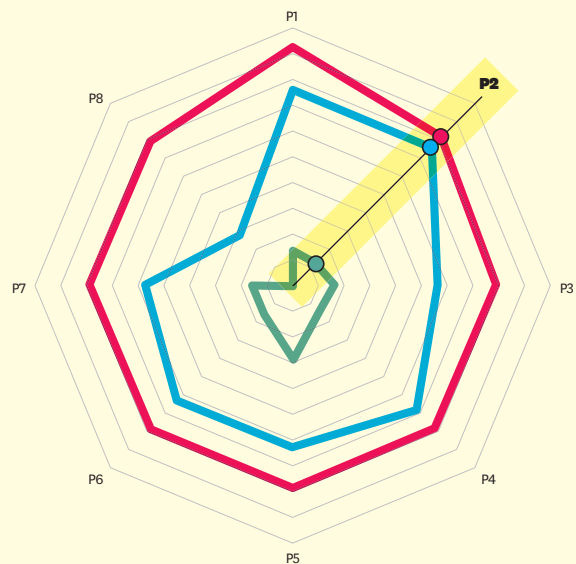
On this figure, the scores from the Content Validity Index are placed in green, the Disagreement Index in blue, and the Global Score in magenta.

3. Theme Figure



The lines for the Content Validity Index, Disagreement Index, and Global Score are connected and the three superimposed figures are generated.

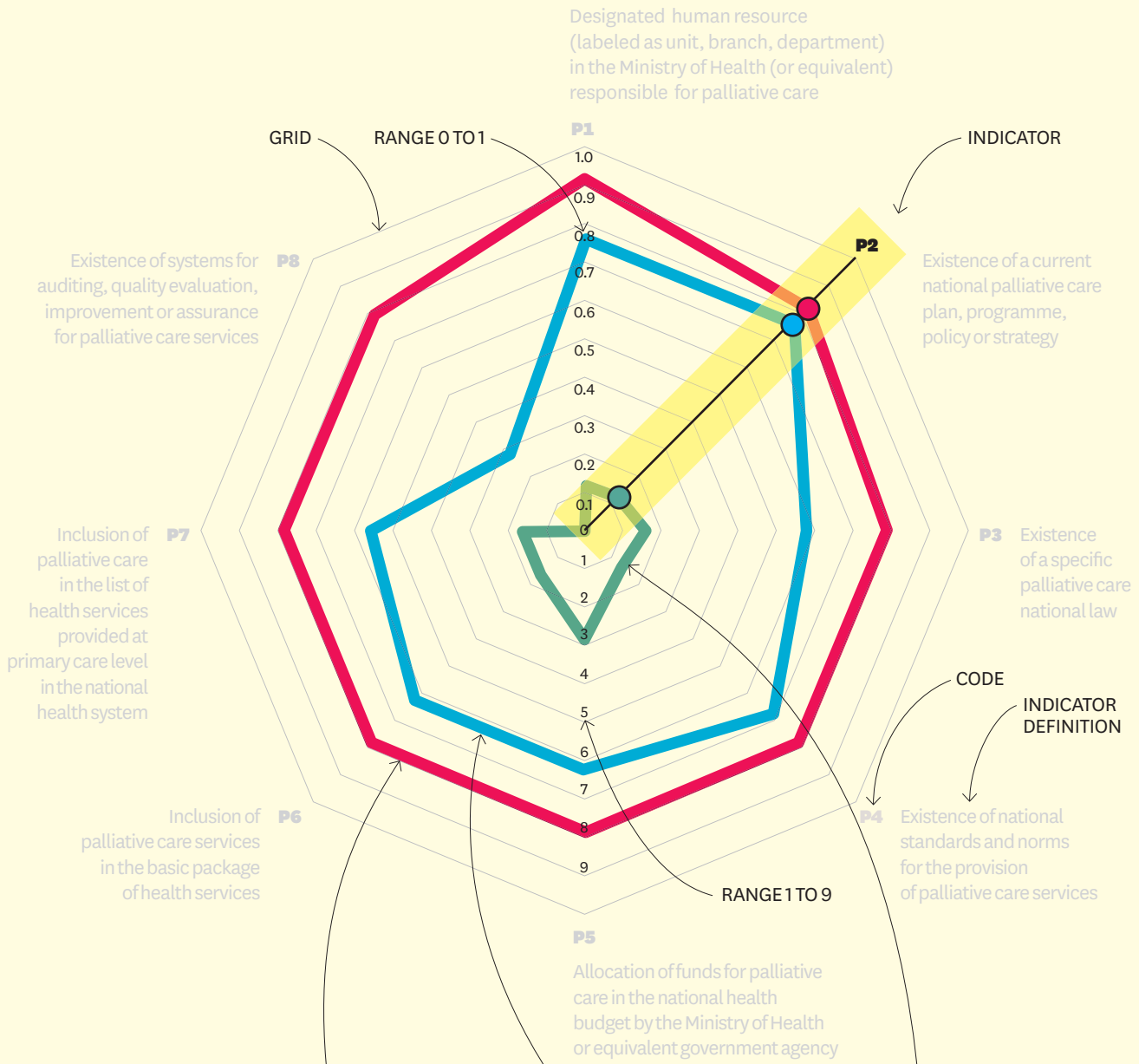
4. Single indicator



The result of the particular indicator is highlighted with a yellow band.



How to read the charts



METRICS

Global Score: Degree to which one indicator reflects palliative care development at the national-level.

Range: 1 to 9.

Content Validity Index (I-CVI): Level of agreement of the top relevance per indicator. The I-CVI reflects coherence among experts rating the indicator. An I-CVI of 1 indicates 100% unanimity among experts, rating that indicator at the highest score. An I-CVI of 0.3 means at least one-third of the experts rated that indicator at the highest score.

Range: 0 to 1.

Disagreement Index (DI): Level of disagreement on a rated item based on inter-percentile ranges. It is a commonly used statistical measure to assess the dispersion of a distribution. A DI ≥ 1 means high-agreement among experts' ratings, while DI ≤ 1 shows low-agreement among experts.

Range: 0 to 1.

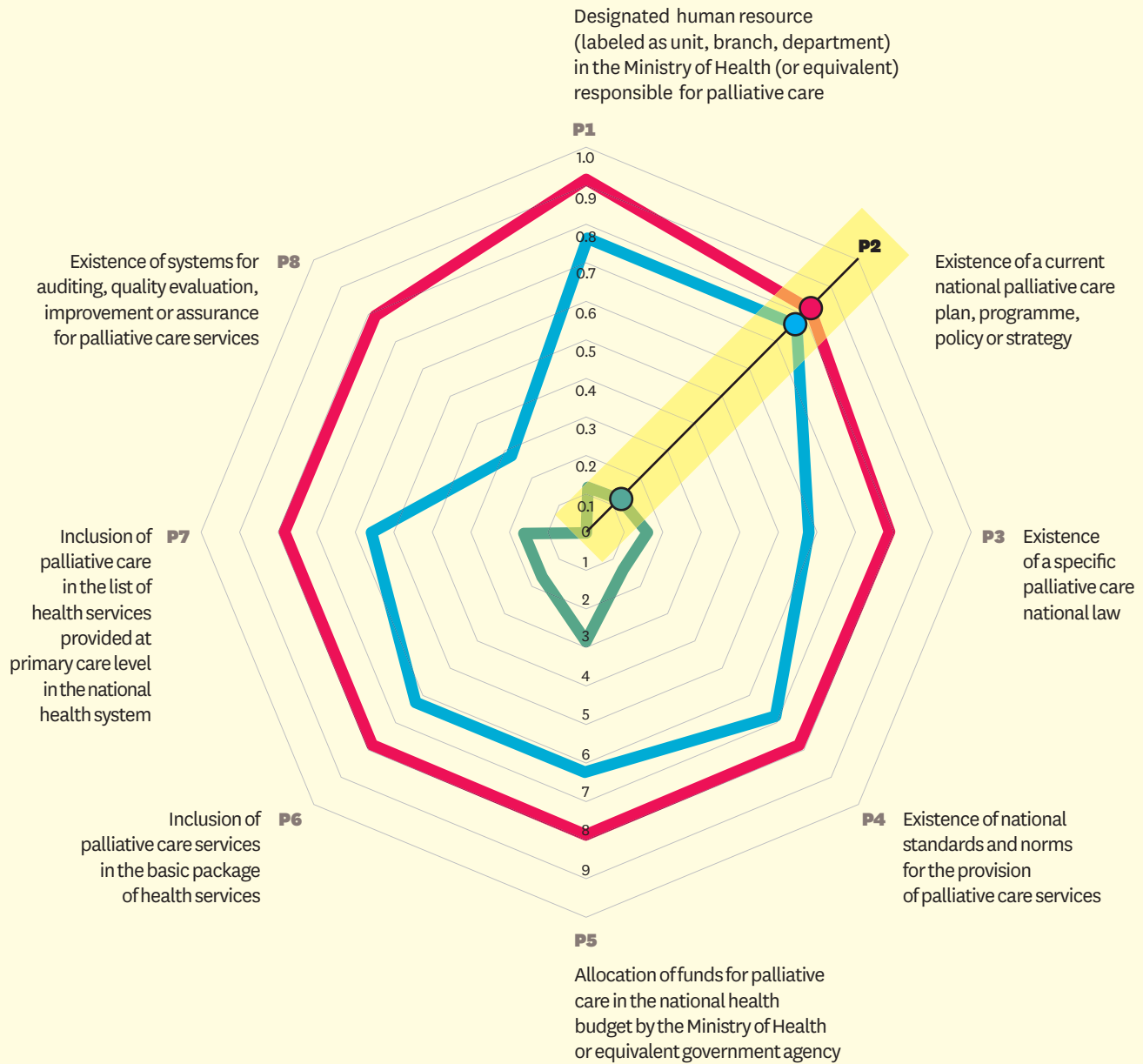


P

**Policy
Indicators**



At a glance



METRICS

Global Score: Degree to which one indicator reflects palliative care development at the national-level.

Range: 1 to 9.

Content Validity Index (I-CVI): Level of agreement of the top relevance per indicator. The I-CVI reflects coherence among experts rating the indicator. An I-CVI of 1 indicates 100% unanimity among experts, rating that indicator at the highest score. An I-CVI of 0.3 means at least one-third of the experts rated that indicator at the highest score.

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Range: 0 to 1.

P1

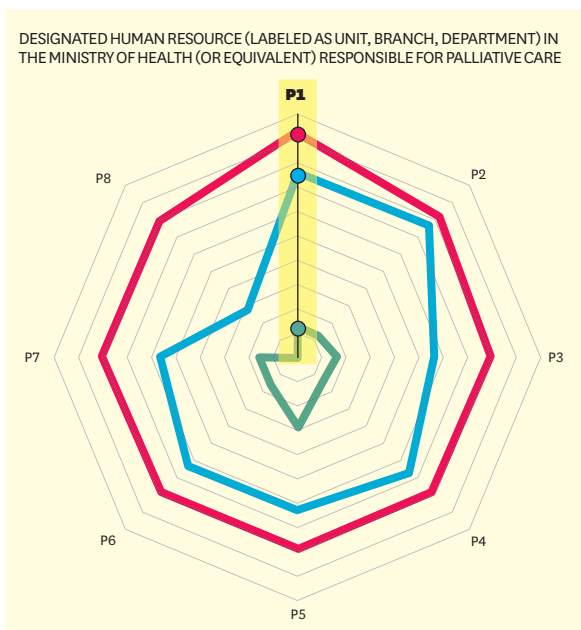
Designated human resource (labeled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care



Global Score (median/max, CI 95%) **9/9 (8-9)**

Content Validity Index (agreement on relevance) **0.76**

Disagreement Index **0.13**



DEFINITION

Existence of a current designated person, desk, unit, branch, or department within the Ministry of Health or equivalent government agency with responsibility for overseeing palliative care activities, development, and/or growth in the country with an accompanying budget.

QUESTIONS TO EXPLORE

- 1 Designated human resources (or desk, unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care. Categories: Yes, No, I do not know.
- 2 What type of role does this position entail? Categories: Political role, Technical role, Scientific and advisory role, I do not know, Other (please explain).
- 3 What percentage of this person's time is dedicated to palliative care? Categories: Less than 10%, Between 10% and 50%, More than 50%, Full time, I do not know.

ADDITIONAL INFORMATION

■ Existence of a current designated person, desk, unit, branch, or department within the Ministry of Health or equivalent government agency with responsibility for palliative care. A responsible person, desk, unit, branch, or department should be assigned in the government to oversee palliative care activities, development, and/or growth in the country with an accompanying budget.

■ Wording for this indicator was derived from the WHO: "Is there a unit/branch/department in the MOH or equivalent with responsibility for NCDs and their risk factors?" The consulted document can be found here: WHO. Assessing National Capacity for the Prevention and Control of Non-Communicable Diseases, Global Survey, 2015. Link: <http://apps.who.int/iris/bitstream/10665/246223/1/9789241565363-eng.pdf?ua=1>

■ We have adjusted the wording to include components that we felt were important from the APCA Atlas of Palliative Care in Africa, 2017.

P2

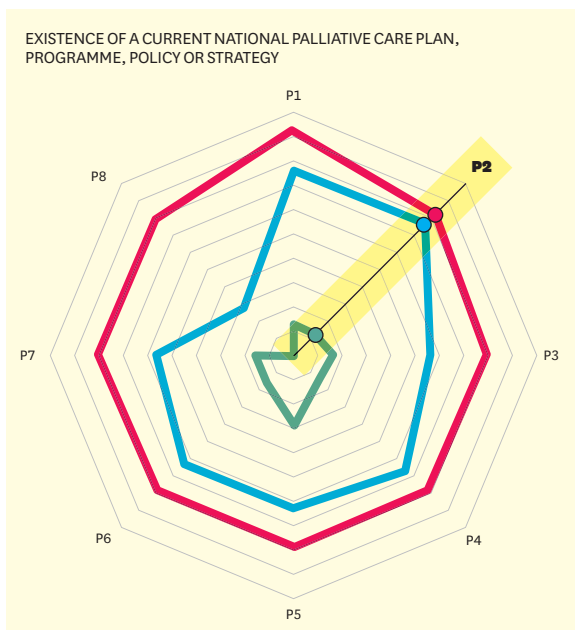
Existence of a current national palliative care plan, programme, policy or strategy



Global Score (median/max, CI 95%) **8/9(8-9)**

Content Validity Index (agreement on relevance) **0.76**

Disagreement Index **0.13**



DEFINITION

National plan or programme refers to regulatory and official publications that are applicable to the whole country (these could be in the form of laws or other official documents). These publications are usually endorsed by the national health authority and contain norms and standards for the development of palliative care, regulations relating to its service provision and in some cases guidelines for palliative care research. It should: Have national scope, be designed to integrate palliative care in health care services, count with an assigned budget and a responsible person.

QUESTIONS TO EXPLORE

1 Which form of national palliative care plan (or programme, strategy) is/are available in your country?
Options: Stand-alone national palliative care plan (or programme, strategy), National cancer plan (or programme, strategy) with a section for palliative care, National Non-communicable Diseases plan (or programme, strategy) with a section for palliative care, National Human Immunodeficiency Virus (HIV) plan (or programme, strategy) with a section for palliative care, There is no national palliative care plan (or programme, strategy) available in my country, nor is there a section of palliative care included into other, strategies (Cancer, HIV, Non-communicable diseases).

2 Has this plan (programme or strategy) been implemented?
Options: Yes, No, I do not know.

3 Has this plan (or programme, strategy) been officially evaluated (audited)?
Options: Yes, No, I do not know.

ADDITIONAL INFORMATION

■ Palliative care Stand-alone national programme: A stand-alone national plan or programme is defined as a specific palliative care plan or programme separate from a palliative care component within a broader programme, such as prevention and control of non-communicable diseases, a national cancer control, or HIV programme.

■ Palliative care section within a national Cancer/Non Communicable Diseases (NCDs)/HIV programme: A specific palliative care plan or programme or a palliative care component within a broader programme for prevention and control of cancer/NCDs/HIV

■ Wording and additional information for this indicator has been adapted from the ALCP Palliative Care Indicators, 2013; and the APCA Atlas of Palliative Care in Africa, 2017.

P3

Existence of a specific palliative care national law

DEFINITION

This indicator measures the existence of national legislation specific to palliative care.

QUESTIONS TO EXPLORE

- Which of the following national legislation is/are available in your country to regulate palliative care provision?
Options: National and general laws on Health Care, Public Health or Social Care with reference to palliative care, National laws on palliative care or specific to palliative care, National Legislation or decrees relating to certain features of palliative care, National Legislation on end of life issues with reference to palliative care, None of the above, I do not know.
- Please provide a link and/or a reference to the above mentioned.

ADDITIONAL INFORMATION

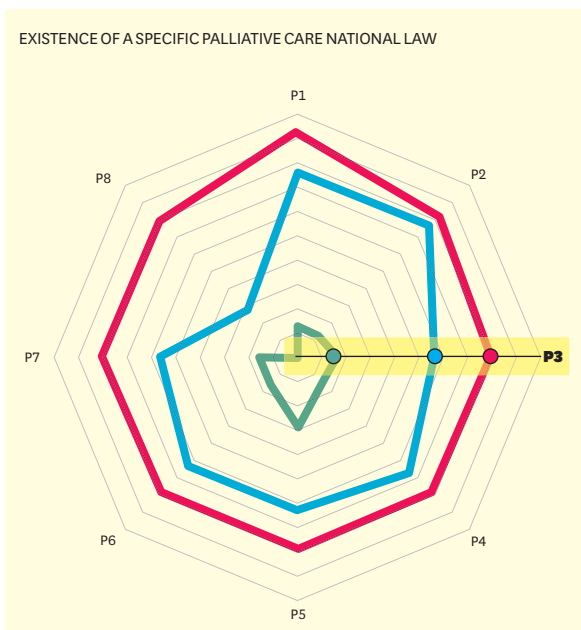
- National health care laws, public health laws and social care laws are the highest level of legislation in a country.
- General and national laws are unrestricted as to time, apply to all persons and has national validity.
- Specific legislation or governmental decrees relating to certain features of palliative care include, but are not limited to: regulation of provision, organisation, accessibility, information, transport, dependency, family allowance, etc. In some of the legislation, there is a reference to palliative care as a human right, or where medical students are required by law to take a palliative care course.
- Legislation on end of life issues with references to palliative care includes, but is no limited to: living wills, euthanasia, rights and duties of the patient at the end of life.
- Wording for this indicator has been adapted from: Woitha et al. Policy on palliative care in the WHO European region: an overview of progress since the Council of Europe's (2003) recommendation 24, 2016, European Journal of Public Health.



Global Score (median/max, CI 95%) **8/9 (7-8)**

Content Validity Index (agreement on relevance) **0.57**

Disagreement Index **0.16**



P4

Existence of national standards and norms for the provision of palliative care services

DEFINITION

Official documents that list the criteria and requirements that palliative care services should meet in order to have the required accreditation and to ensure appropriate palliative care for patients. Such documents, in form of norms, serve as guide to the development, equipment and configuration of services set to achieve adequate structural quality.

ADDITIONAL INFORMATION

■ The following article was used to define this indicator: Radbruch et al. White paper on standards and norms for hospice and palliative care in Europe: part 1 and 2. Recommendations from the European Association for Palliative Care. European Journal of Palliative Care, 2010.

QUESTIONS TO EXPLORE

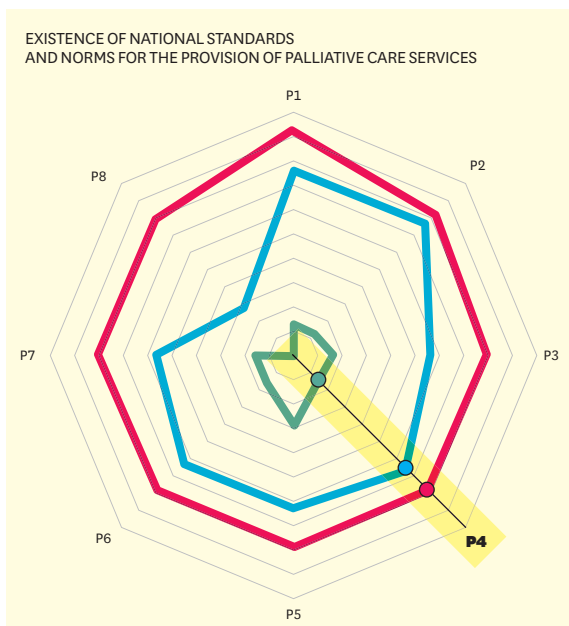
- 1 Existence of published national standards and norms for the provision of palliative care services. Options: Yes, No, I do not know.
- 2 Provide a link and/or a reference to such documents.



Global Score (median/max, CI 95%) **8/9 (8-9)**

Content Validity Index (agreement on relevance) **0.71**

Disagreement Index **0.13**



P5

Allocation of funds for palliative care in the national health budget by the Ministry of Health or equivalent government agency

DEFINITION

Ministry of Health or equivalent government agency has reserved some type of funding in the annual national health budget for palliative care provision. Palliative care activities are understood as those actions taken to improve palliative care provision.

QUESTIONS TO EXPLORE

- 1 Have funds from the national health budget been allocated for palliative care by the Ministry of Health or equivalent government agency? Options: Yes, No, I do not know.

ADDITIONAL INFORMATION

■ Wording for this indicator was derived from the WHO: “Is there funding for the following NCD and risk factor activities/functions (palliative care)?” WHO. Palliative Care for Non-Communicable Diseases a Global Snapshot from 2015 link: http://apps.who.int/iris/bitstream/10665/206513/1/WHO_NMH_NVI_16.4_eng.pdf) Also consulted was WHO. Assessing National Capacity for the Prevention and Control of Non-Communicable Diseases, Global Survey, 2015. Link: <http://apps.who.int/iris/bitstream/10665/246223/1/9789241565363-eng.pdf?ua=1>

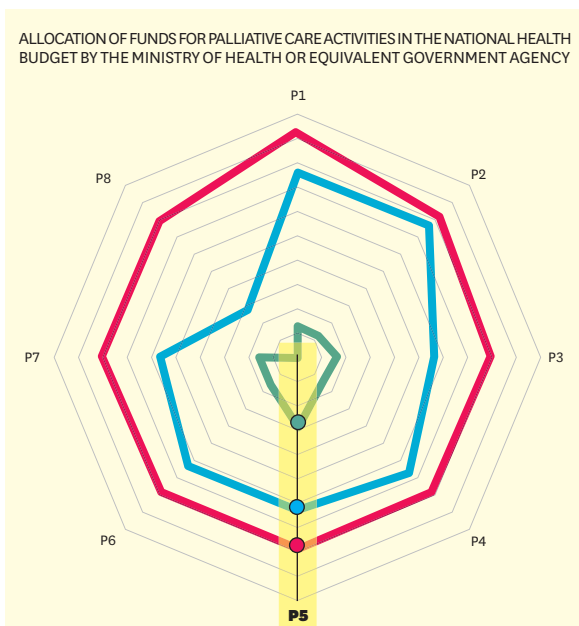
■ Wording has been adjusted to include components that were considered important from the APCA Atlas of Palliative Care in Africa, 2017.



Global Score (median/max, CI 95%) **8/9 (7-9)**

Content Validity Index (agreement on relevance) **0.62**

Disagreement Index **0.29**



P6

Inclusion of palliative care services in the basic package of health services

DEFINITION

National health systems design, approve and implement a basic package of basic healthcare services for Universal Health Coverage. This package is intended to meet the SDG 3.8 goal, through which all persons should be able to have access to quality essential health services without facing financial hardship. For the purpose of this study, inclusion of palliative care services in the basic package for universal health coverage is understood as explicit mention on the UHC basic package to palliative care service provision at the primary health care level.

ADDITIONAL INFORMATION

Information on the WHO- Universal Health Coverage webpage http://www.who.int/universal_health_coverage/en/ and on the Lancet Commission Report on Palliative Care were used for the wording and definition of this indicator [https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(17\)32513-8.pdf](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)32513-8.pdf)

According to the WHO, Palliative Care is defined as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (<http://www.who.int/cancer/palliative/definition/en/>).

QUESTIONS TO EXPLORE

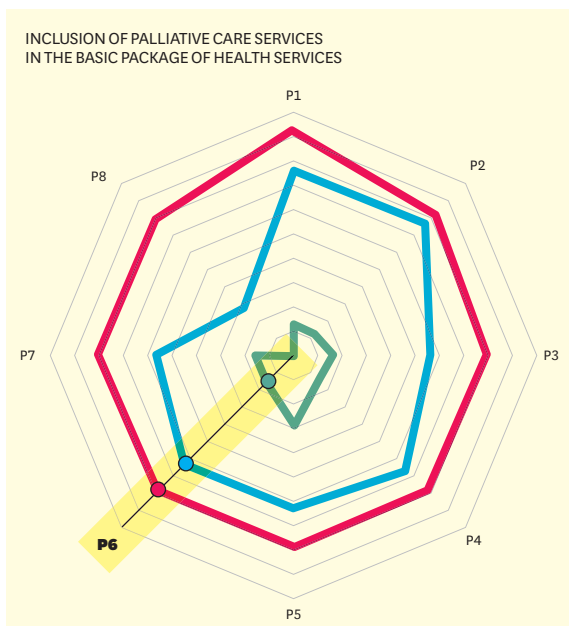
- Have palliative care services been included in the basic package of health services?
Options: Yes, No, I do not know.



Global Score (median/max, CI 95%) **8/9 (7-8)**

Content Validity Index (agreement on relevance) **0.62**

Disagreement Index **0.16**



P7 Inclusion of Palliative Care in the list of health services provided at primary care level in the national health system

DEFINITION

Usually and regulated through national health laws, countries establish a catalogue of services that stipulates those that should be available and provided at the primary care level in the country. One of those services included in the list should be palliative care. This indicator aims at assessing only the inclusion of palliative care in the list of services provided at primary care level but not its implementation. The inclusion of the specific palliative care term in the list is compulsory in order to answer “yes” to this indicator.

ADDITIONAL INFORMATION

■ Wording for this indicator has been adapted from the ALCP Palliative care indicators, 2013.

QUESTIONS TO EXPLORE

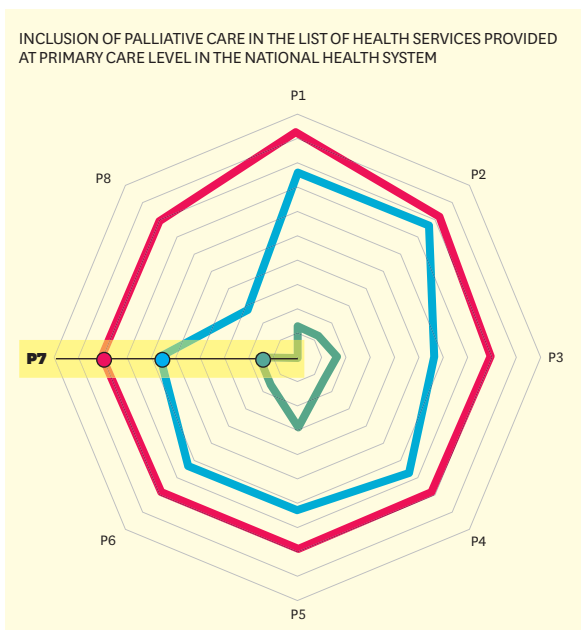
- 1 Is palliative care included in the list of health services provided at the primary care level in the national health system?
Options: Yes, No, I do not know.



Global Score (median/max, CI 95%) **8/9 (7-8)**

Content Validity Index (agreement on relevance) **0.57**

Disagreement Index **0.16**



P8

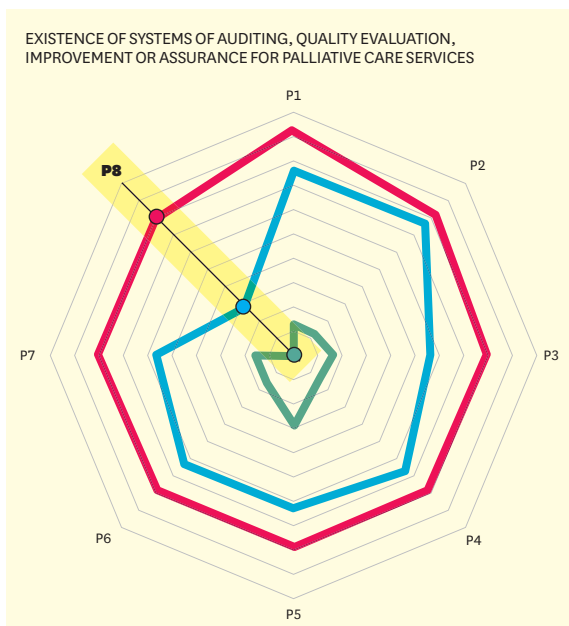
Existence of systems for auditing, quality evaluation, improvement or assurance for palliative care services



Global Score (median/max, CI 95%) **7/9 (7-7.6)**

Content Validity Index (agreement on relevance) **0.3**

Disagreement Index **0**



DEFINITION

Quality assurance in health care is ensuring the best quality in health care provision to patients, by engaging with appropriately trained professionals and the use of other resources. Auditing is one of the main approaches to manage quality assurance in health care provision. Systems of auditing are systems in place that seek to monitor and evaluate the quality of the palliative care services that are being provided in your country. Quality auditing may be implemented in different categories, for example in structures, processes and outcomes. They can be, but are not limited to, formularies, protocols, standards and/or guidelines among others set to assess palliative care services' quality (ie. Patients' satisfaction surveys).

ADDITIONAL INFORMATION

■ This definition has been elaborated using: Cooper et al. Implementing audit in palliative care: an action research approach. 2002. Journal of Advanced Nursing, 39(4), 360-369.

QUESTIONS TO EXPLORE

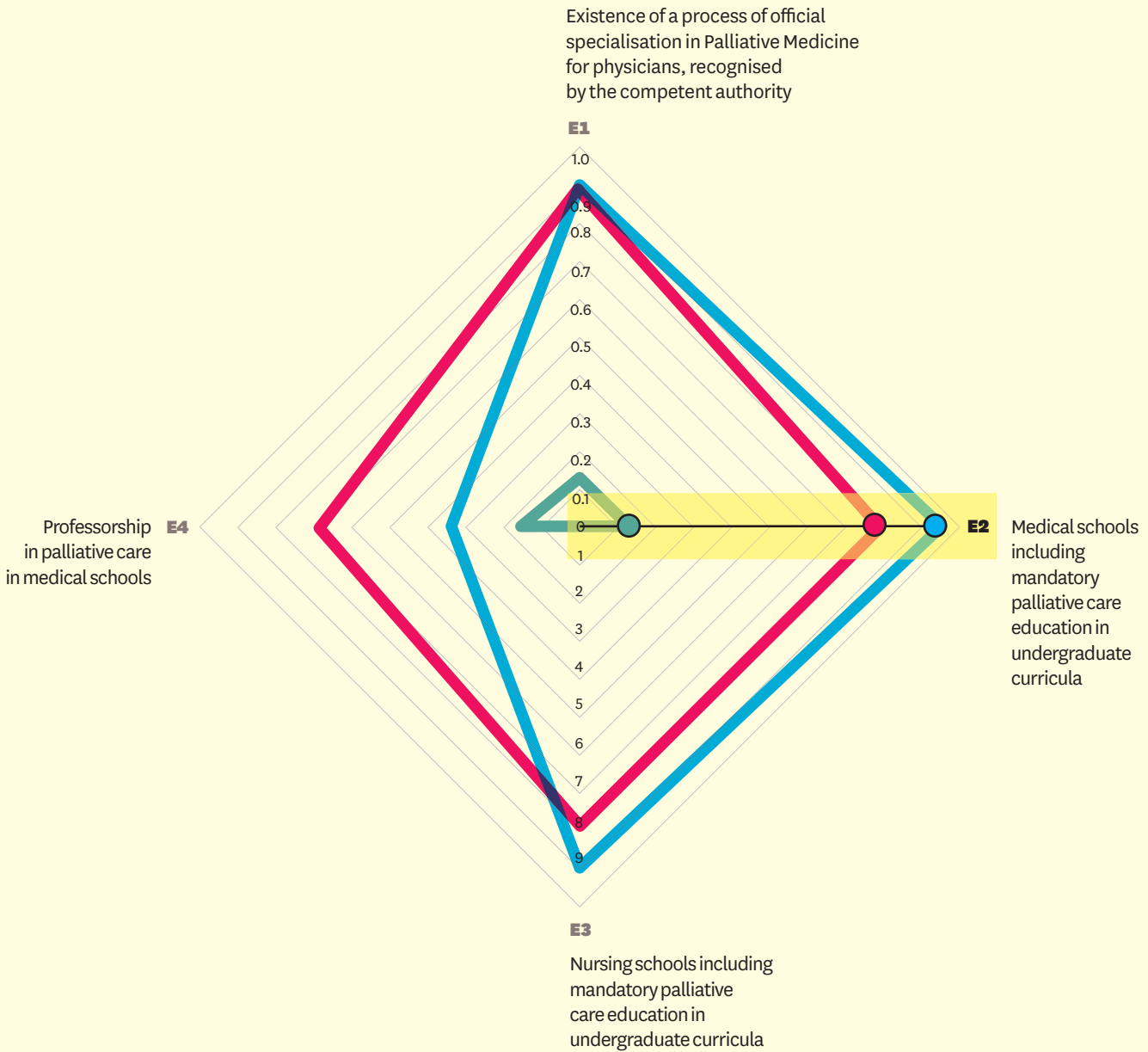
- 1 Existence of systems of auditing, quality evaluation, improvement, or assurance for palliative care.
Options: Yes, No, I do not know.
- 2 If Yes, please indicate the level at which auditing is being performed.
Options: National, Regional, Local.



Education Indicators



At a glance



METRICS

Global Score: Degree to which one indicator reflects palliative care development at the national-level.

Range: 1 to 9.

Content Validity Index (I-CVI): Level of agreement of the top relevance per indicator. The I-CVI reflects coherence among experts rating the indicator. An I-CVI of 1 indicates 100% unanimity among experts, rating that indicator at the highest score. An I-CVI of 0.3 means at least one-third of the experts rated that indicator at the highest score.

Range: 0 to 1.

Disagreement Index (DI): Level of disagreement on a rated item based on inter-percentile ranges. It is a commonly used statistical measure to assess the dispersion of a distribution. A DI ≥ 1 means high-agreement among experts' ratings, while DI ≤ 1 shows low-agreement among experts.

Range: 0 to 1.

E1

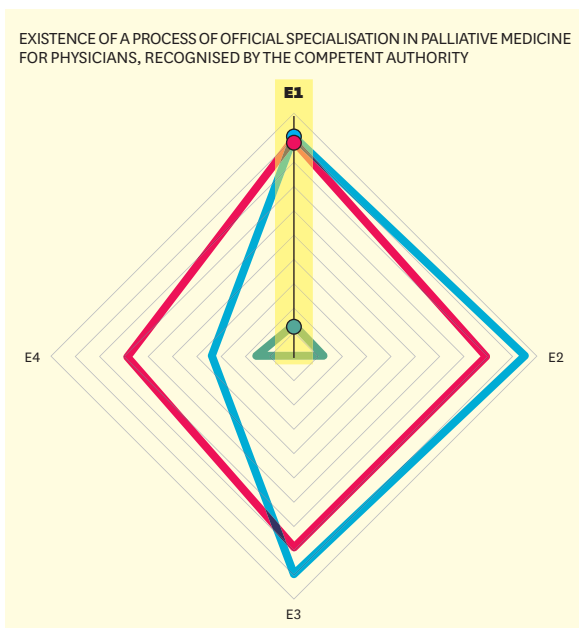
Existence of a process of official specialisation in Palliative Medicine for physicians, recognised by the competent authority



Global Score (median/max, CI 95%) **9/9 (8-9)**

Content Validity Index (agreement on relevance) **0.9**

Disagreement Index **0.13**



DEFINITION

Official specialisation in palliative medicine refers to any formal process (or schedule of training/education) that provides official certification and accredits a higher level of competence to the physician working in the area of palliative medicine.

QUESTIONS TO EXPLORE

- 1 Existence of an official process for the specialization in palliative medicine for physicians, accredited by the national responsible authority (as specialty, sub-specialty, special area of competence or other advanced accreditation diploma). Options: Yes; No, but a process of specialisation is in progress; No, but a specialisation done abroad is officially recognized in the country; No, but we have a certification of competence with a diploma (not granted by the national competent authority); No, there is no established, in progress, or, recognised specialisation process or diplomas to certify competency; and I do not know.
- 2 Which of the following specialised palliative care educational processes for physicians are available in your country? (You may select more than one answer). Options: Specialty, Sub-specialty, Process of Sub-specialisation but with different denomination as for example Special Area of Competence or Special Field of Competence and I do not know).
- 3 What is the title for the process of official specialisation in Palliative Medicine in your country? Please provide its name in your native language?
- 4 Please provide the name of it in English.
- 5 Please estimate the number of palliative care physicians (currently working in your country) officially certified through a process of specialisation recognised by your country's competent authority?

ADDITIONAL INFORMATION

- Specialty process refers to higher education for physicians which leads to an official accreditation as a specialist in palliative care after the completion of the program. A pre-requisite for specialization is a medical degree from an accredited medical school.
- A sub-specialty usually requires the obtention of a previous specialty too.
- Other titles as Special Area of Competence or Special Field of Competence usually require the obtention of a previous specialty.
- Diploma, such as an Advanced Accreditation Diploma, refers to training levels that are not the highest attainable qualification level available in the country. It can usually be accessed without the requirement of a previous specialty and in some cases without a formal process of training. Clinical experience or other specific requirements are deemed as a prerequisite to access this process.
- Master's degrees from Universities are excluded from this classification of official processes of specialisation in palliative medicine, unless they officially certified the clinical competence.
- In some countries official specialisation process in Palliative Medicine is not available. However, the national authorities have enabled legal frameworks that allow the recognition of specialisation processes undergone abroad.
- Wording for this indicator has been adapted from the book: "Specialization in Palliative Medicine for Physician in Europe 2014, A supplement of the EAPC Atlas of Palliative Care in Europe", and from: Centeno et. al "Comparative analysis of specialization in palliative medicine processes within the World Health Organisation European region", 2015, Journal of Pain and Symptom Management.

E2

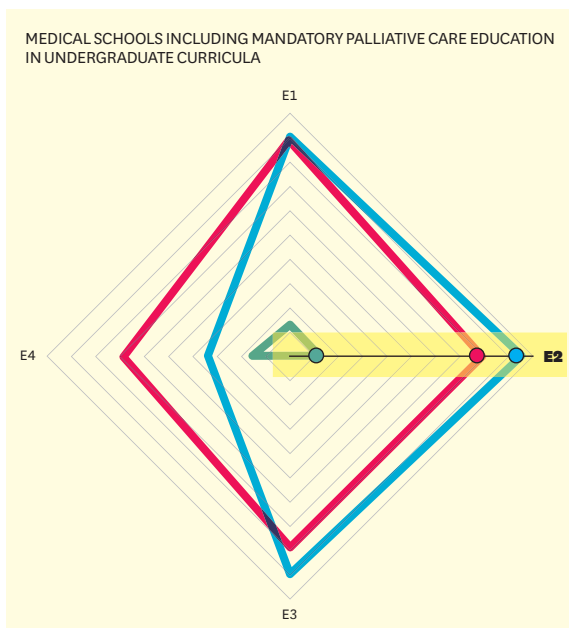
Medical schools with mandatory palliative care education in undergraduate curricula



Global Score (median/max, CI 95%) **8/9 (8-9)**

Content Validity Index (agreement on relevance) **0.95**

Disagreement Index **0.13**



DEFINITION

A mandatory component means that palliative medicine is included as compulsory teaching for all medical students in order to graduate .

QUESTIONS TO EXPLORE

- 1 Total number of medical schools in the country.
- 2 Number of medical schools that offer an mandatory course or subject specifically dedicated to palliative care as part of their curricula.
- 3 Number of medical schools that offer mandatory palliative care education in combination with other related disciplines (e.g. a mandatory course of Oncology and palliative care).
- 4 Estimate of medical schools offering mandatory clinical clerkship/ placement in palliative care to its students (%) (estimate).

ADDITIONAL INFORMATION

- An independent subject or course with the name “palliative” included in the title.
- In combination with other disciplines, means that palliative care is taught in combination with related disciplines such as Oncology, Primary Care, Geriatrics, among others. When this is the case, usually palliative care appears in the title of the course or subject (Oncology and Palliative Care), included in the denomination of the course.
- A mandatory component means that palliative medicine is included as compulsory teaching for all medical students in order to graduate.
- An optional component means that palliative medicine is included as elective or optional teaching but is not required for all medical students to graduate.
- For the purpose of this project, undergraduate education is defined as course or specific module with-

in a course, which includes the basic aspects of palliative care. Basic aspects of palliative care include as stated by the EAPC Recommendations for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools: —The identification, evaluation and treatment of the most frequent symptoms and its management —The physical, psychological, social and spirituals aspects of care —End-of-life ethical and legal issues —Communication issues with the patient, relatives and caregivers as well as teamwork and self-reflection.

■ Clinical clerkship should be offered at a specific palliative care service and not in other services like Oncology or Internal Medicine.

■ The wording of this indicator has been adapted from the WHO: Proportion of medical schools which include palliative care education in undergraduate curricula (i.e. ratio of medical schools with palliative care at undergraduate level to total medical schools) (WHO Planning and Implementing Palliative Care Services, 2016; <http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf?ua=1>). Further adaptation on the wording and its definition has been performed based on the EAPC Atlas of Palliative Care in Europe (2013), APCA Atlas of Palliative Care in Africa (2017) and the EAPC Recommendations for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools.

E3

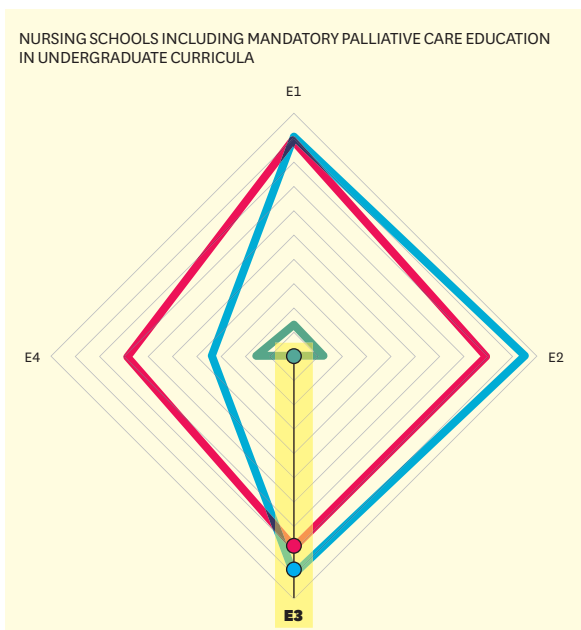
Nursing schools with mandatory palliative care education in undergraduate curricula



Global Score (median/max, CI 95%) **8/9 (8-8)**

Content Validity Index (agreement on relevance) **0.9**

Disagreement Index **0**



DEFINITION

A mandatory component means that palliative medicine is included as compulsory teaching for all medical students in order to graduate.

QUESTIONS TO EXPLORE

- 1 Total number of Nursing schools in the country.
- 2 Number of nursing schools which offer an mandatory course or subject specifically dedicated to palliative care as part of their curricula.
- 3 Number of nursing schools which offer palliative care education in combination with other related disciplines (i.e. a mandatory course of Oncology and palliative care).

ADDITIONAL INFORMATION

■ An independent subject or course with the name “palliative” included in the title.

■ In combination with other disciplines, palliative care is taught in combination with related disciplines such as oncology, primary care, geriatrics, among others. When this is the case, palliative care appears in the title of the course or subject (Oncology and Palliative Care), included in the denomination of the course.

■ A mandatory component means that palliative medicine is included as compulsory teaching for all nursing students in order to graduate.

■ An optional component means that palliative medicine is included as elective or optional teaching but is not required for all nursing students to graduate.

■ For the purpose of this project, undergraduate education is defined as course or specific module within a course, which includes the basic aspects of palliative care. Basic aspects of palliative care include as stated by the EAPC Recommendations for the Development of Under-

graduate Curricula in Palliative Medicine at European Medical Schools:

—The identification, evaluation, and treatment of the most frequent symptoms and its management.

—The physical, psychological, social and spiritual aspects of care.

—End-of-life ethical and legal issues.

—Communication issues with the patient, relatives and caregivers as well as teamwork and self-reflection.

■ The wording of this indicator has been adapted from the WHO: Proportion of medical schools which include palliative care education in undergraduate curricula (i.e. ratio of medical schools with palliative care at undergraduate level to total medical schools) (WHO Planning and Implementing Palliative Care Services, 2016; <http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf?ua=1>). Further adaptation on the wording and its definition has been performed based on the EAPC Atlas of Palliative Care in Europe (2013), APCA Atlas of Palliative Care in Africa (2017) and the EAPC Recommendations for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools.

E4 Professorship in palliative care in medical schools

DEFINITION

Professorship refers to the number of accredited professors specific to palliative care in the top three levels of the official academic ladder.

QUESTIONS TO EXPLORE

- 1 Number of Full Professors in palliative care at medical schools in your country (1st level).
- 2 Number of Associate Professors in palliative care at medical schools in your country (2nd level).
- 3 Number of Assistant Professors in palliative care at medical schools in your country (3rd level).

ADDITIONAL INFORMATION

■ Full Professor: an individual who has attained the highest level of official accreditation as a teacher, granted by an academic institution and recognized by the Ministry of Education or equivalent authority. Depending on the country, different denominations are available for example Professor, Associate Professor, etc. In some countries within the highest level of teaching accreditation categories might exist, grading Full Professors based on academic and professional achievement or performance.

■ Associate Professor: a mid-level professor with an official accreditation, usually in track to the highest level (Full professor). The Ministry of Education or an equivalent responsible authority must grant the accreditation. This refers to the step before being a full professor, which means achieving the highest level of official accreditation.

■ Assistant Professor: an entry-level professor with an official accreditation, usually in track to the mid-level (Associate professor).

■ None of these categories include any other sort of academic positions, which can teach at Universities without official teaching accreditation.

■ Wording and questions for this indicator are derived from: Noguera et al. How experienced professors teach Palliative Medicine in European Universities? A cross-case analysis of eight undergraduate educational programs, 2018, Journal of Palliative Medicine (accepted for publication).

■ In the case where a professor teaches in several centres, please detail to which centre is the Professor associated.

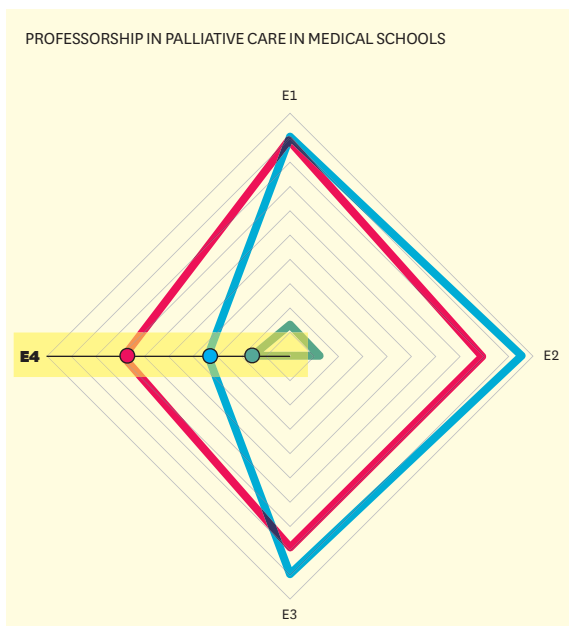
■ When asked about type of professors, as in different countries can have different names, in brackets is suggested a level between 1st and 2nd or 3rd meaning that we are pointing the top category of professor or others categories that follow the top one.



Global Score (median/max, CI 95%) **7/9 (7-8)**

Content Validity Index (agreement on relevance) **0.33**

Disagreement Index **0.16**

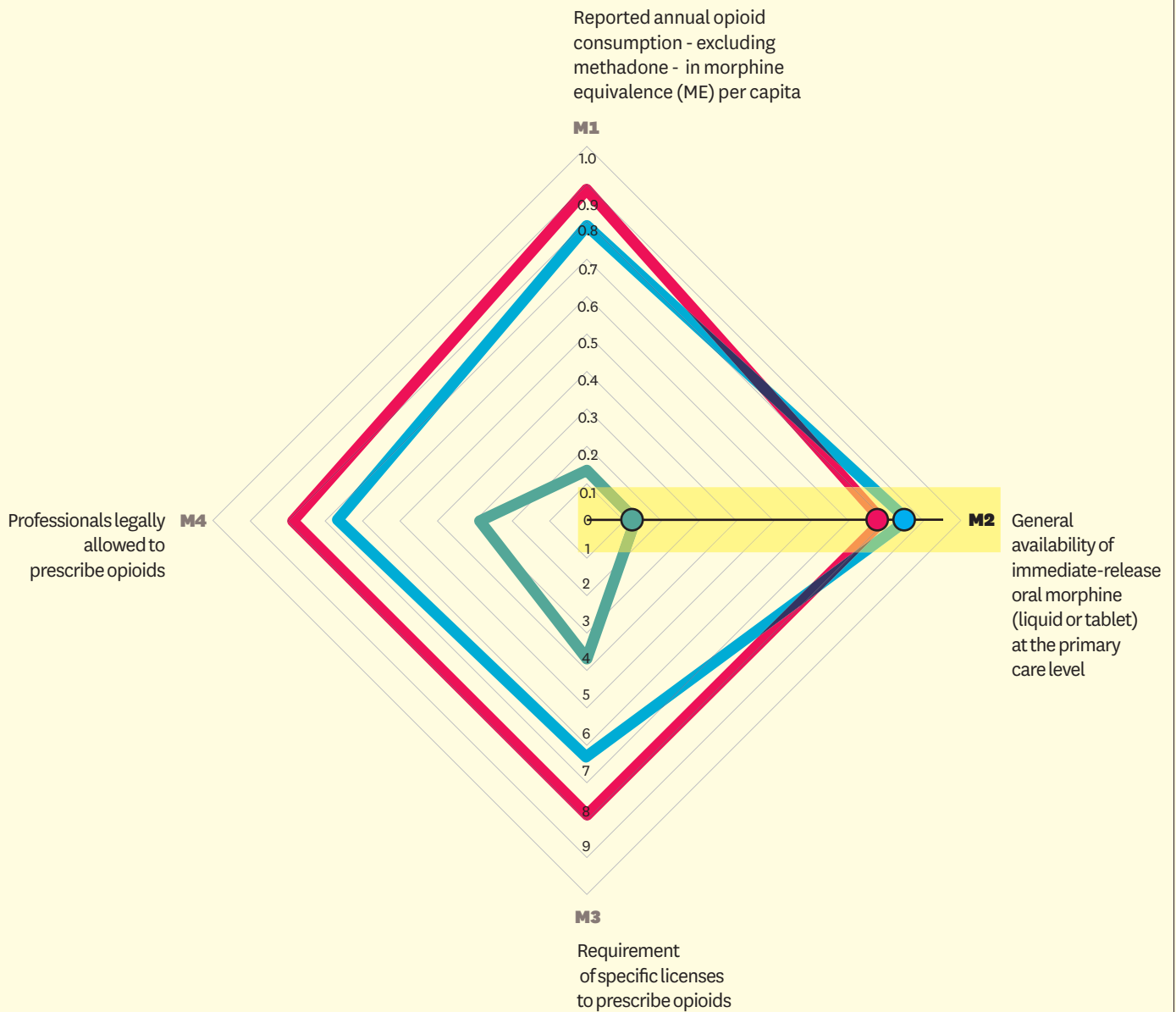




Use of Medicines Indicators



At a glance



METRICS

Global Score: Degree to which one indicator reflects palliative care development at the national-level.

Range: 1 to 9.

Content Validity Index (I-CVI): Level of agreement of the top relevance per indicator. The I-CVI reflects coherence among experts rating the indicator. An I-CVI of 1 indicates 100% unanimity among experts, rating that indicator at the highest score. An I-CVI of 0.3 means at least one-third of the experts rated that indicator at the highest score.

Range: 0 to 1.

Disagreement Index (DI): Level of disagreement on a rated item based on inter-percentile ranges. It is a commonly used statistical measure to assess the dispersion of a distribution. A DI ≥ 1 means high-agreement among experts' ratings, while DI ≤ 1 shows low-agreement among experts.

Range: 0 to 1.

M1

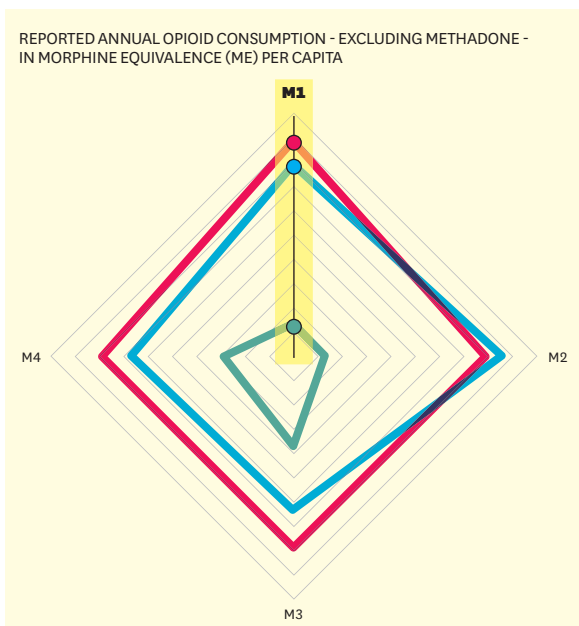
Reported annual opioid consumption - excluding methadone - in morphine equivalence (ME) per capita



Global Score (median/max, CI 95%) **9/9 (8-9)**

Content Validity Index (agreement on relevance) **0.81**

Disagreement Index **0.13**



DEFINITION

These data represent the amounts of opioids distributed legally in a country for medical and scientific purposes to those healthcare institutions and programs that are licensed to dispense to patients, such as hospitals, nursing homes, pharmacies, hospices and palliative care programs.

QUESTIONS TO EXPLORE

- 1 Source of information: data on opioid consumption is obtained from the latest available reported consumption to the International Narcotics Control Board (INCB) based on data provided by the Pain and Policy Studies Group (PPSG), University of Wisconsin. <http://www.painpolicy.wisc.edu/opioid-consumption-data>

ADDITIONAL INFORMATION

■ Opioids included: Morphine, Fentanyl, Hydromorphone, Oxycodone and Pethidine (not methadone).

■ Unit of Measure: Milligrams per capita per year, expressed in morphine equivalence.

■ These data represent the amounts of opioids distributed legally in a country for medical and scientific purposes to those healthcare institutions and programs that are licensed to dispense to patients, such as hospitals, nursing homes, pharmacies, hospices, and palliative care programs.

■ Consumption does not refer to the amounts dispensed to, or used by, patients, but rather to amounts distributed to the retail level. The opioid consumption data are displayed in milligrams per capita (or per person), which is calculated by first converting the raw consumption data we receive from INCB from kilograms to milligrams and then dividing by the population of the country for a particular year. United Nations population data is used. This provides a population-based statistic that allows for comparisons between countries.

■ Wording for this indicator has been adapted from Pain and Policy Studies Group (PPSG), University of Wisconsin and used in the APCA Atlas of Palliative Care in Africa, 2017.

M2

General availability of immediate-release oral morphine (liquid or tablet) at the primary care level

DEFINITION

Indicates whether or not the country has immediate-release oral morphine (liquid or tablet) generally available in primary health care facilities in the public health sector. (Global Health Observatory indicator views, WHO, 2016; <http://apps.who.int/gho/data/node.imr>). This information will be retrieved from WHO Country Capacity Survey Database 2015 and 2017

QUESTIONS TO EXPLORE

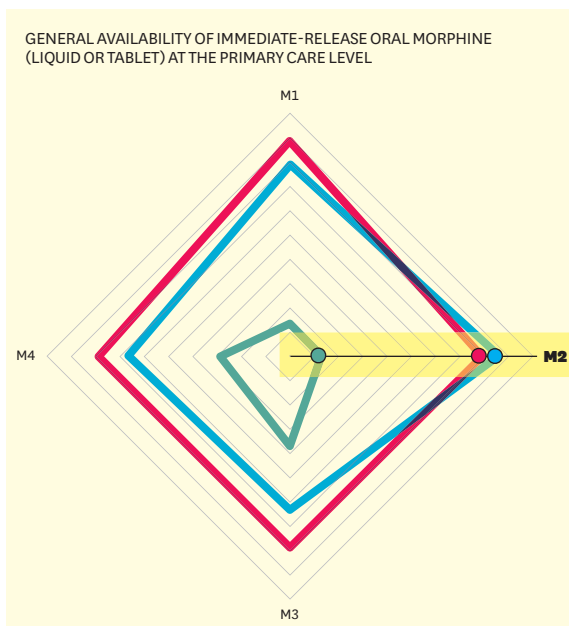
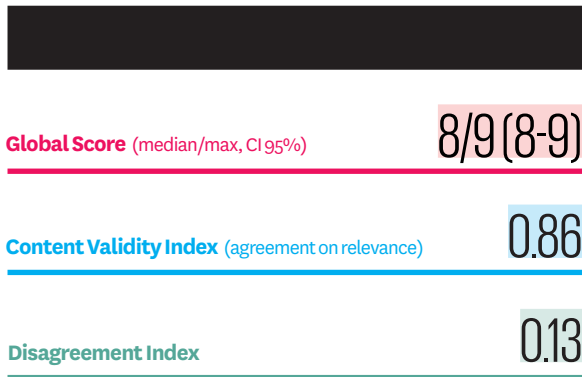
- 1 General availability of immediate-release oral morphine (liquid or tablet) at the primary care level. Categories: yes, no, I don't know.

ADDITIONAL INFORMATION

■ Some facilities may use immediate-release oral morphine for surgical use and not specifically for palliative care pain management. However, it is still interesting whether immediate-release oral morphine (liquid or tablet) is generally available in primary health care facilities in the public health sector.

■ General availability - according to Sharkey et al. article - refers to immediate-release oral morphine available in over 50% of pharmacies (<http://journals.sagepub.com/doi/pdf/10.1177/0269216317716060>)

■ Wording for this indicator has been adapted from APCA Atlas of Palliative Care in Africa, 2017. Include are also components that we felt were important from the APCA Atlas of Palliative Care in Africa, 2017.



M3

Requirement of specific licenses to prescribe opioids

DEFINITION

This indicator explores the existence of opioids prescriptions in each country and some of its constraints like time limitations and patient registration.

QUESTIONS TO EXPLORE

- 1 Prescription of opioids requires a special prescription form?
Options: Yes, No, I do not know.
- 2 Prescriptions are limited to:
Options: Few days, Few weeks (less than a month), Few months (more than one month), No limit, I do not know.
- 3 Do regulations require a patient to register as an opioid user in order to receive a prescription for an opioid analgesic?
Options: Yes, No, I do not know.

ADDITIONAL INFORMATION

■ Patient registration is a process that patients, particularly outpatients, follow to be registered to be eligible to receive opioid prescriptions for the management of cancer pain (N.I Cherny et al. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative (2010). Annals of Oncology).

■ This indicator has been explored by N.I Cherny et al, and by the ATOME Project (Acces to Pain Medications in Europe). In some cases patients are required to register and are evaluated by an external commission to be eligible for receiving opioids.

■ The list of medicines presented in this indicator has been adapted from World Health Organisation's Essential Medicines in Palliative Care (2013), the Lancet Commission Report on Palliative Care (2017).

■ Wording of this indicator has been retrieved from: N.I Cherny et al. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative (2010). Annals of Oncology.



Global Score (median/max, CI 95%)

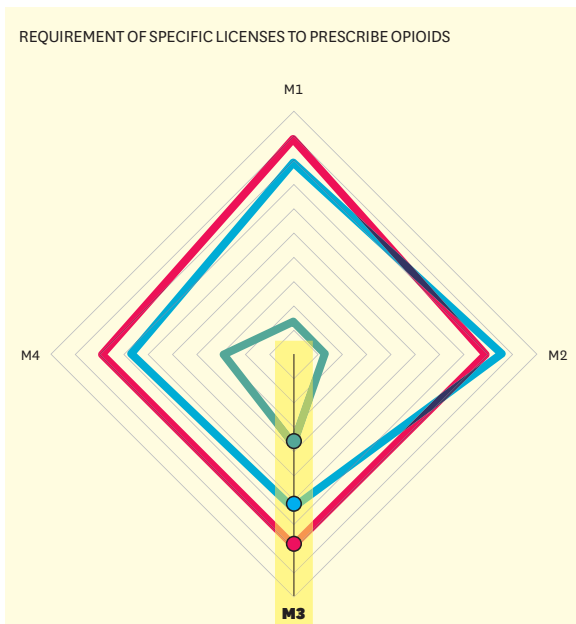
8/9 (6-8)

Content Validity Index (agreement on relevance)

0.52

Disagreement Index

0.37



M4

Professionals legally allowed to prescribe opioids

DEFINITION

This indicator explores who can prescribe opioids.

QUESTIONS TO EXPLORE

- 1 Which of the following professionals are allowed to prescribe opioids in your country? (You may select more than one answer)

Options: All General Practitioners and Family Doctors, All Specialist physicians, Some specialist physicians (i.e. Oncologists, Internists, Surgeons), Physicians trained in Palliative Medicine, Nurses trained in palliative care, All Nurses, I do not know, Other (please specify).

ADDITIONAL INFORMATION

■ Special authority/license may include prescriptions limited to certain medical specialties or sub-specialties (i.e. Oncologist) or specific opioid-prescribing licenses that allow opioids to be prescribed only with special permits or authorization or only in emergency situations. If no such restrictions exist, then a primary care provider, such as a family doctor, can always prescribe opioids without any of the restrictions above. (Cleary et al, 2013).

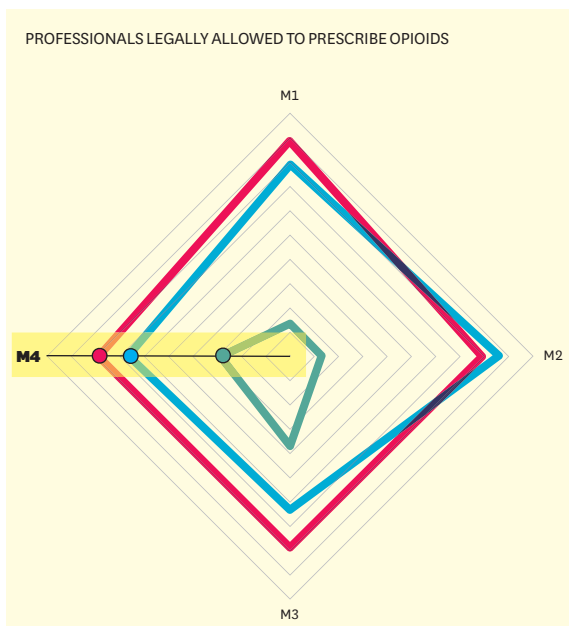
■ Wording for this indicator has been adapted from the APCA Atlas of Palliative Care in Africa, 2017.



Global Score (median/max, CI 95%) **8/9 (7-9)**

Content Validity Index (agreement on relevance) **0.67**

Disagreement Index **0.29**



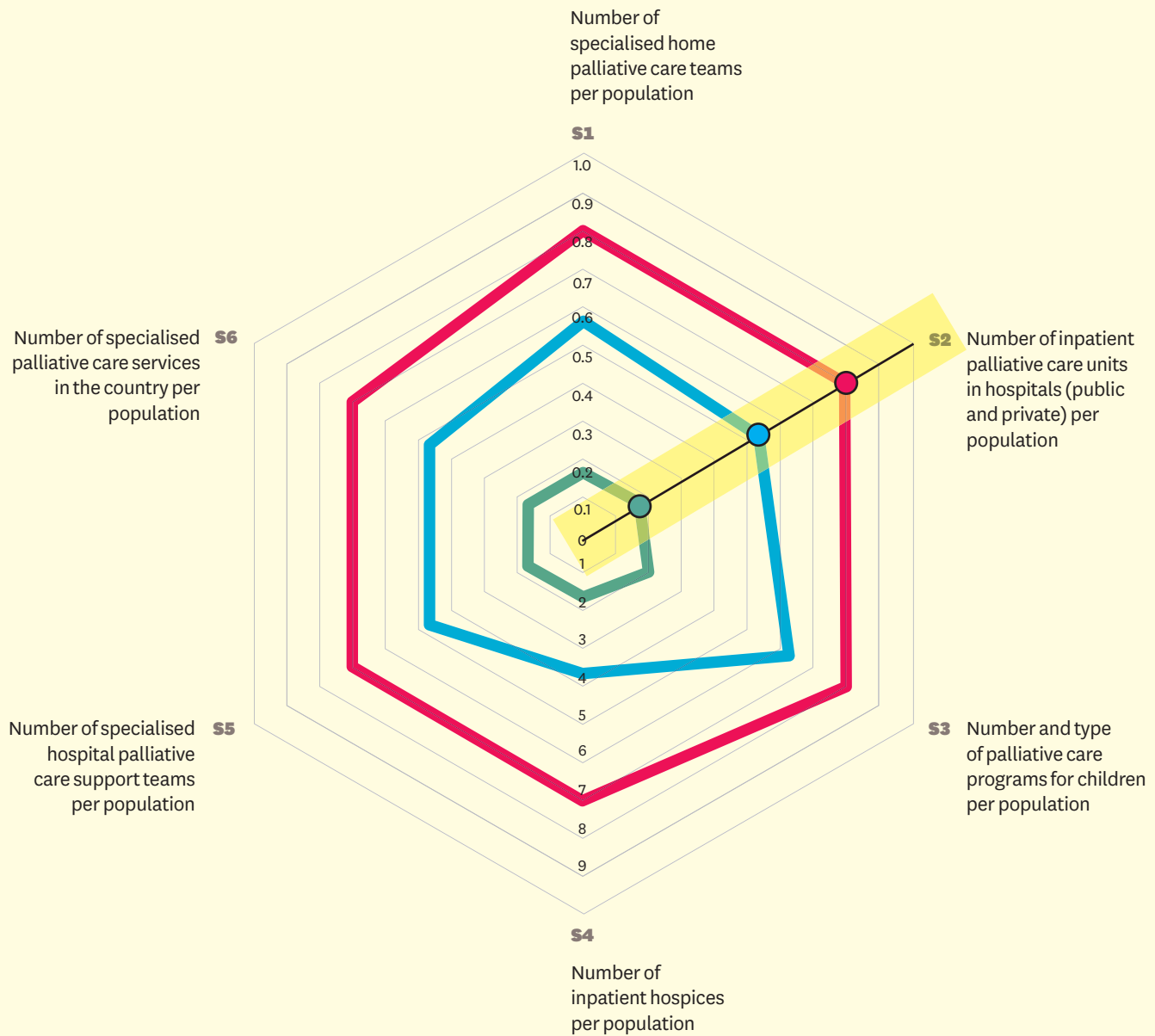


S

Service Provision Indicators



At a glance



METRICS

Global Score: Degree to which one indicator reflects palliative care development at the national-level.

Range: 1 to 9.

Content Validity Index (I-CVI): Level of agreement of the top relevance per indicator. The I-CVI reflects coherence among experts rating the indicator. An I-CVI of 1 indicates 100% unanimity among experts, rating that indicator at the highest score. An I-CVI of 0.3 means at least one-third of the experts rated that indicator at the highest score.

Range: 0 to 1.

Disagreement Index (DI): Level of disagreement on a rated item based on inter-percentile ranges. It is a commonly used statistical measure to assess the dispersion of a distribution. A DI ≥ 1 means high-agreement among experts' ratings, while DI ≤ 1 shows low-agreement among experts.

Range: 0 to 1.

S1

Number of specialised home palliative care teams per population

DEFINITION

Home palliative care teams provide specialised palliative care services to patient staying at home, their families and carers. Patients at home usually suffer from chronic, life-limiting health problems such as cancer, advanced cardiac, renal and respiratory diseases, HIV/AIDS and chronic neurological disorders among others. In addition to visiting patients at their homes, these teams also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home.

QUESTIONS TO EXPLORE

- 1 Number of specialised home palliative care teams (estimate).

ADDITIONAL INFORMATION

■ These teams are composed by two to five professionals who are usually a doctor and a nurse with palliative care training, plus a social worker, administrative staff and others. In some contexts community health workers and volunteers may also be part of the team.

■ For the purpose of this study we have excluded palliative care mixed teams from the count of this indicator. palliative care mixed teams are those that usually take care of patients in two settings: at home and at palliative care services in hospitals.

■ If an organisation or a palliative care unit or service counts with different home palliative care teams, please count each one individually. For example, if a palliative care unit at a hospital counts with three home palliative care teams that provide care, these are considered as three different branches and would be thus counted separately.

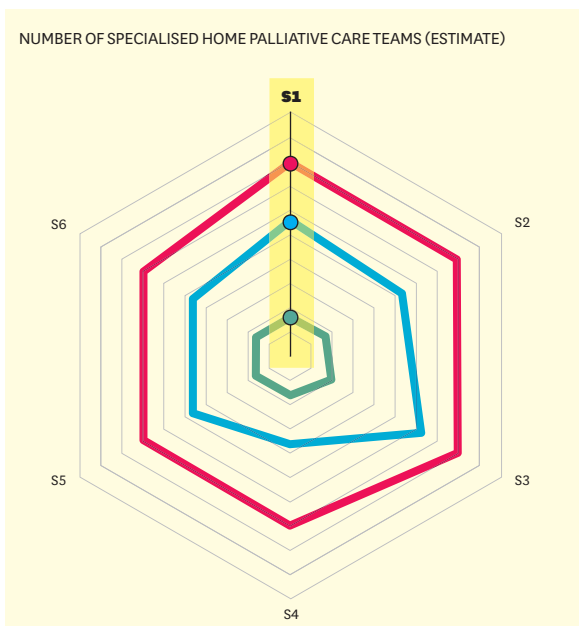
■ Wording and definition of this indicator has been adapted from the APCA Atlas of Palliative Care in Africa, 2017 and the EAPC Atlas of Palliative Care in Europe, 2013. For its definition (World Health Organisation, Planning and Implementing Palliative Care Services, 2016) was also consulted.



Global Score (median/max, CI 95%) **8/9 (7-8)**

Content Validity Index (agreement on relevance) **0.57**

Disagreement Index **0.16**



S2

Number of inpatient palliative care units in hospitals (public and private) per population

DEFINITION

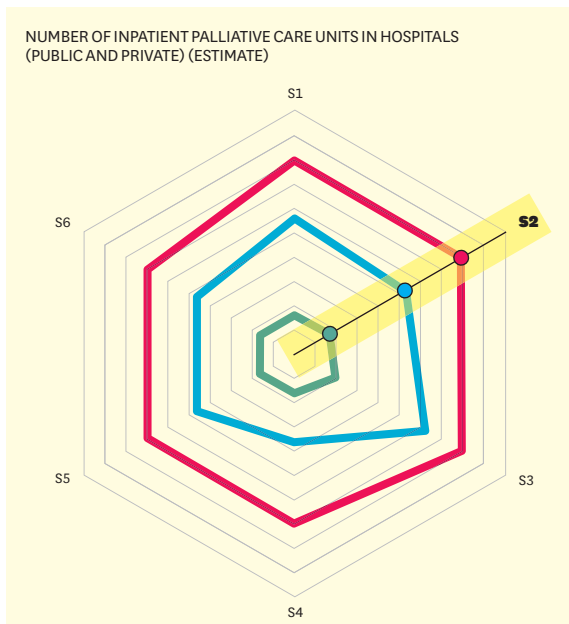
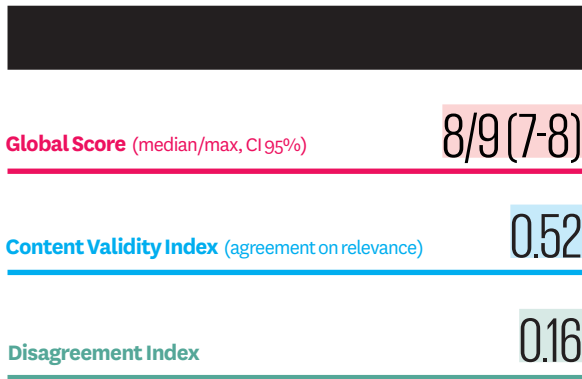
These units provide specialist inpatient care; they require highly qualified and multidisciplinary palliative care trained teams, with at least one doctor and one nurse as a core.

QUESTIONS TO EXPLORE

- 1 Number of inpatient palliative care units in hospitals (public and private) (estimate).

ADDITIONAL INFORMATION

- This indicator will be presented on the total number of hospitals of the country. The total number of hospitals will be searched by the very research team in official European Registries. For Europe, a distinction between private and public hospitals, and between tertiary and non-tertiary would be ideal, but has not been asked as for feasibility issues given the sources of information.
- This indicator does not explore the size of the unit or number of beds available because it is not feasible to obtain by national-level experts.
- Wording and definition of this indicator has been adapted from the one used in the APCA Atlas of Palliative Care in Africa, 2017 and in the EAPC Atlas of Palliative Care in Europe, 2013.



S3

Number and type of palliative care programs for children per population

DEFINITION

Palliative care services with programs specific to pediatrics includes: free standing hospices and hospices for children that are a part of public or NGO hospitals, any kind of other hospices or home care teams, support teams in hospitals, palliative care units, inpatient units in hospices specific for children, etc.

ADDITIONAL INFORMATION

■ They do not refer to services admitting both adults and children, but specifically trained services for palliative care paediatric provision.

■ In this indicator, one organisation may have more than one local branch that offer programmes specific to paediatrics; we consider each branch as a separate service when the community of the local branch has local ownership, local proactivity, and local focal point of the service.

■ This indicator wording has been adapted from the APCA African Atlas of Palliative Care, 2017.

QUESTIONS TO EXPLORE

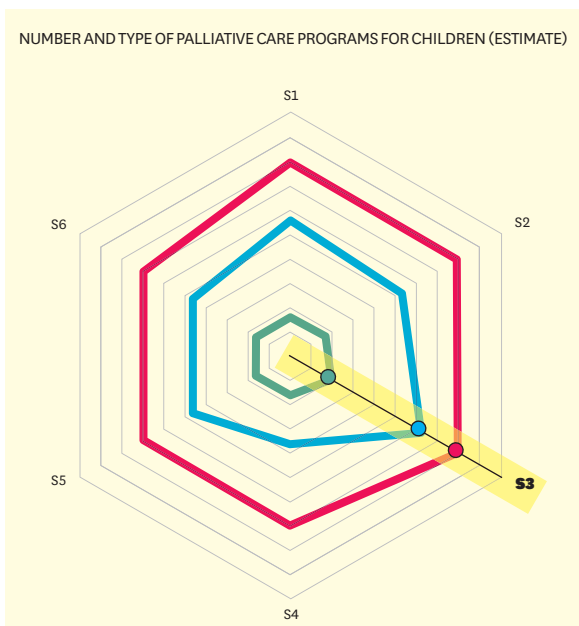
1. Number of adult palliative care services that care for children with palliative care needs.
2. Number of palliative care services with palliative care programmes specific for children.
 - a. In inpatient Hospices (lower-case).
 - b. In hospitals provided by palliative care Support (consultation) team.
 - c. In hospitals provided by palliative care units teams.
 - d. In home palliative care programmes.
 - e. In day Care (lower-case) programmes.
 - f. In other services or programmes (please indicate).



Global Score (median/max, CI 95%) 8/9 (7-8)

Content Validity Index (agreement on relevance) 0.62

Disagreement Index 0.21



S4

Number of inpatient hospices per population

DEFINITION

An inpatient hospice is a facility admitting patients in their last phase of life, when treatment in a hospital is not necessary and care at home or at a nursing home is not possible. They are usually free-standing facilities and they require multi-professional teams. Ideally, there should be, at least, one nurse per bed and a physician trained in Palliative Medicine available 24 hours a week. Other components of the team can be dedicated psychosocial and spiritual workers and volunteers.

ADDITIONAL INFORMATION

■ Wording and definition of this indicator has been adapted from the EAPC Atlas of Palliative Care in Europe, 2013 and the EAPC White Paper on standards and norms for hospice and palliative care in Europe, 2009.

QUESTIONS TO EXPLORE

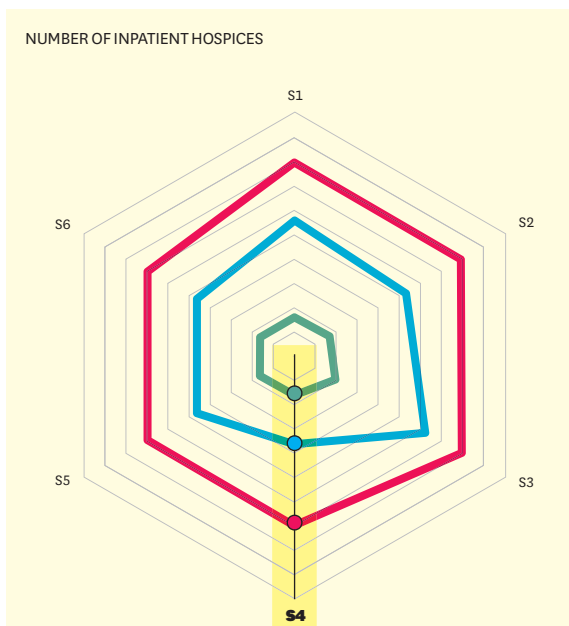
- 1 Number of inpatient hospices .
- 2 Total number of beds available in all inpatient hospices.



Global Score (median/max, CI 95%) **7/9 (7-8)**

Content Validity Index (agreement on relevance) **0.38**

Disagreement Index **0.16**



S5

Number of specialised hospital palliative care support teams per population

DEFINITION

These teams work providing specialist palliative care advice and support to other clinical staff, patients and their families in the hospital setting. They liaise with other services in and out of the hospital to offer support to other healthcare professionals working in hospital units and polyclinics, who are not specialised in palliative care and offer formal and informal education within the hospital setting. These are multi-professional teams with at least one doctor and one nurse with specialised palliative care training and other professionals like psychologists and social workers. These teams may be also known as consultation services or teams. They are different from palliative care Units teams.

ADDITIONAL INFORMATION

- This concept may be applied to residential homes and the hospital-based home care support team.
- For the purpose of this study we have excluded palliative care mixed teams from the count of this indicator. palliative care mixed teams are those that usually take care of patients in two settings: at home and at palliative care services in hospitals.
- Although the size of these teams is relevant, asking national level experts to provide this information is not feasible. Therefore, this information is not asked.
- Wording and definition of this indicator has been adapted from the EAPC Atlas of Palliative Care in Europe, 2013.

QUESTIONS TO EXPLORE

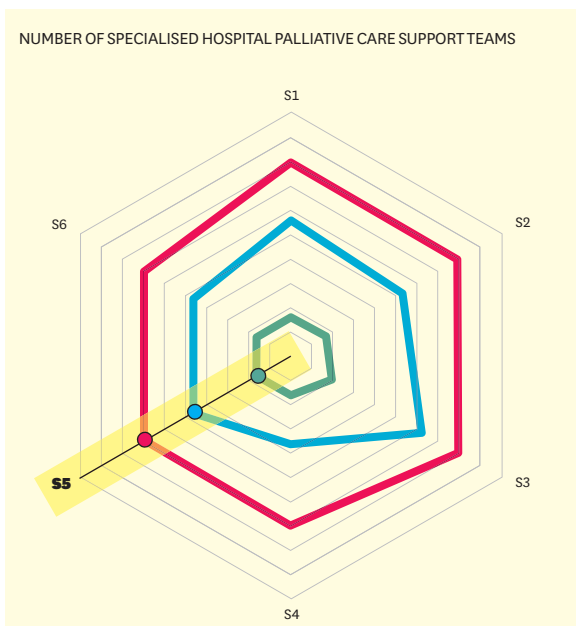
- 1 Number of hospital palliative care support teams.



Global Score (median/max, CI 95%) **7/9 (7-8)**

Content Validity Index (agreement on relevance) **0.48**

Disagreement Index **0.16**



S6

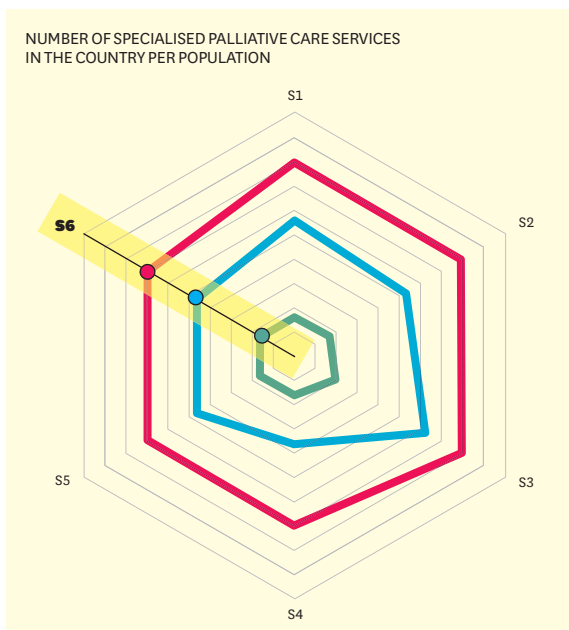
Number of specialised palliative care services in the country per population



Global Score (median/max, CI 95%) **7/9 (7-8)**

Content Validity Index (agreement on relevance) **0.48**

Disagreement Index **0.16**



DEFINITION

Palliative care services refers to the total number of services in the country, including, but not limited to, free standing hospices, hospices that are a part of public or NGO hospitals, any kind of other hospices or home care teams, support teams in hospitals, palliative care units, inpatient units in hospices, paediatric palliative care hospices and services, etc.

QUESTIONS TO EXPLORE

- 1 Number of specialised palliative care services in the country (estimate).

ADDITIONAL INFORMATION

■ In this indicator, one organisation may have more than one local branch; we consider each branch as a separate service when the community of the local branch has local ownership, local proactivity, and local focal point of the service. For example, if one Hospice located in a given city provides palliative care services to three other towns or cities, it is understood that this hospice has three different branches within a larger organisation. We would consider these to be three different services, which are sometimes referred to as “satellites” of the “primary” or mother organisation (Clark et al., 2007).

■ This indicator does not explore the provision of palliative care at the generalised level (ie. primary care). Importantly, generalised palliative care provision will be explored in another part of the study.

■ For the purposes of this study, specialised palliative care services is understood as services whose main activity is the provision of palliative care. These services generally care for patients with complex and difficult needs and therefore require a higher level of education, staff and other resources. Specialist palliative care services require a team approach, combining a multi-professional team with an interdisciplinary mode

of work. Team members must be highly qualified and should have their main focus of work in palliative care (White paper on standards and norms for hospice and palliative care in Europe: Part 1: Available from: https://www.researchgate.net/publication/279547069_White_paper_on_standards_and_norms_for_hospice_and_palliative_care_in_Europe_Part_1 [accessed Oct 08 2018].)

■ The population was calculated as per 100,000 people, as used in official publications by the WHO and in global studies on palliative care development (The WHPCA Global Atlas of palliative care, the EAPC White Paper on palliative care Norms and Standards).

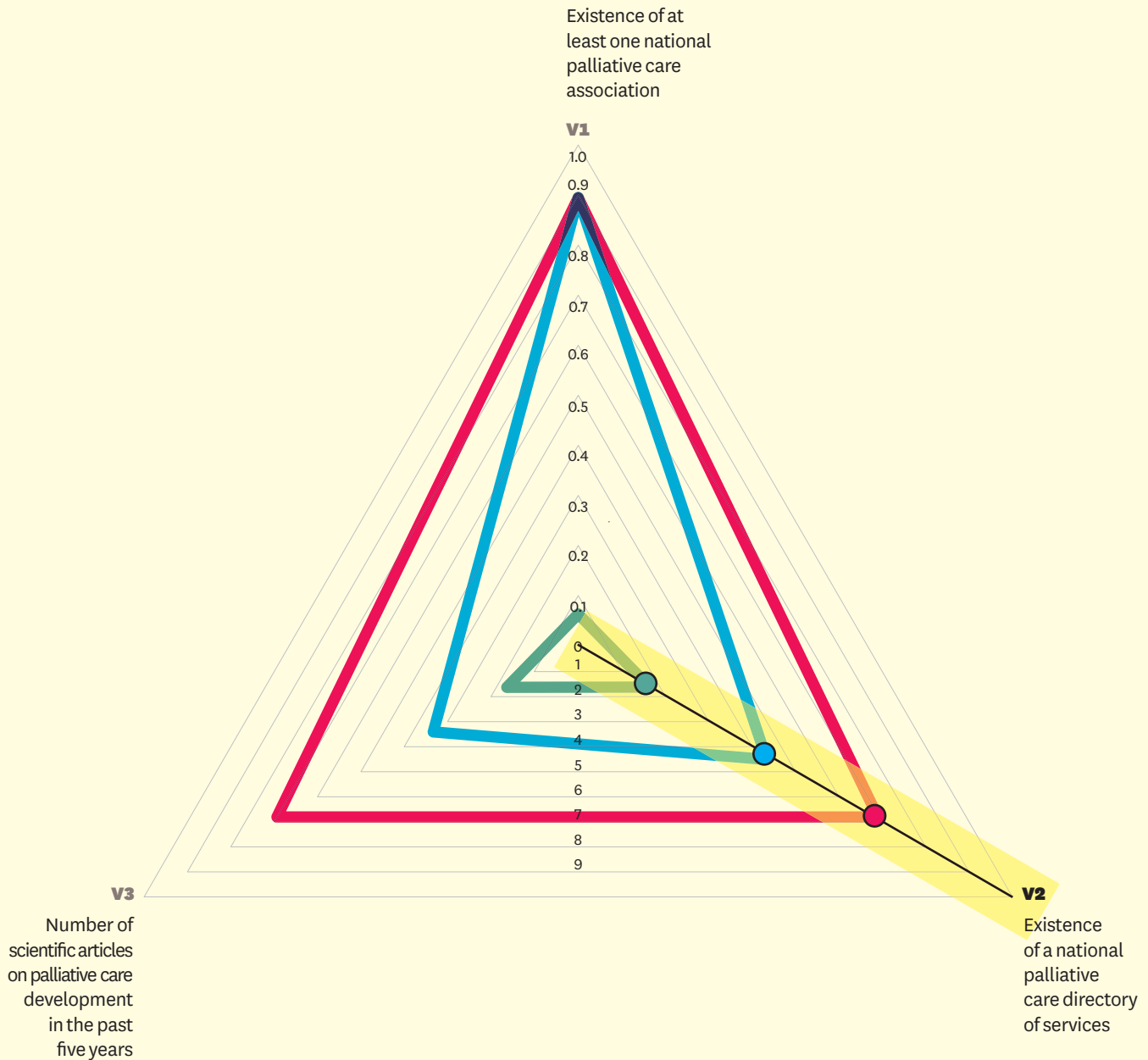
■ Wording and definition of this indicator has been adapted from the one used in the APCA Atlas of Palliative Care in Africa, 2017 and in the EAPC Atlas of Palliative Care in Europe, 2013.



**Professional
Activity Indicators**



At a glance



METRICS

Global Score: Degree to which one indicator reflects palliative care development at the national-level.

Range: 1 to 9.

Content Validity Index (I-CVI): Level of agreement of the top relevance per indicator. The I-CVI reflects coherence among experts rating the indicator. An I-CVI of 1 indicates 100% unanimity among experts, rating that indicator at the highest score. An I-CVI of 0.3 means at least one-third of the experts rated that indicator at the highest score.

Range: 0 to 1.

Disagreement Index (DI): Level of disagreement on a rated item based on inter-percentile ranges. It is a commonly used statistical measure to assess the dispersion of a distribution. A DI \geq 1 means high-agreement among experts' ratings, while DI \leq 1 shows low-agreement among experts.

Range: 0 to 1.

V1

Existence of at least national palliative care association

DEFINITION

In this question, we gathered data on professional organisations focusing specifically on palliative care. We are excluding those associations that promote palliative care or that have interest in palliative care but are not composed by palliative care professionals (i.e. National cancer association).

ADDITIONAL INFORMATION

- A palliative care association should:
 - Have a national scope.
 - Be interdisciplinary: gathers and admits all professionals with palliative care interest and/or training.
 - Be dedicated to palliative care, which should be reflected on the foundation objectives of the association.

QUESTIONS TO EXPLORE

- 1 Existence of a national palliative care association.
Categories: Yes, no, I don't know.
- 2 When was it created?
- 3 Please provide the name of your national association in your native language.
- 4 Please provide the name of your national association in English.
- 5 Existence of any other palliative care national association .

Categories: Yes, no, I don't know.

- 6 Please provide the name of other national palliative care association(s) in your native language.
- 7 Please provide the name of those national palliative care association(s) in English.

- Existence of a national association for palliative care or a national association equivalent for palliative care. An equivalent can be a national coordinating group that has not the status of association but that gathers professionals with interest in palliative care issues.

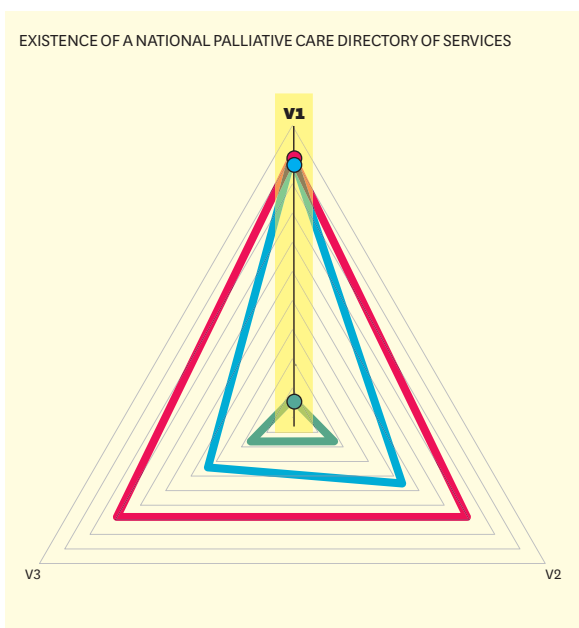
- Wording for this indicator has been adapted from the APCA Atlas of Palliative Care in Africa, 2017; and the EAPC Atlas of Palliative Care in Europe, 2013.



Global Score (median/max, CI 95%) **9/9 (8.2-9)**

Content Validity Index (agreement on relevance) **0.9**

Disagreement Index **0.06**



V2

Existence of a national palliative care directory of services

DEFINITION

A national palliative care directory of services compiles information on specialist palliative care service providers, national, regional or local palliative care organisations and community support agencies. This information is usually presented in lists with details such as the name of the service, address, postal code and health professionals composition..

ADDITIONAL INFORMATION

■ A palliative care provider is understood as a medical, nursing or allied health professional who provides primary care with a palliative approach to patients with a life-limiting illness. A specialist palliative care provider is any of the above, recognised as a specialist by a national authority body, who provides primary or consultative care to these patients at medical facilities.

■ Wording and additional information for this indicator has been gathered from the EAPC Atlas of Palliative Care in Europe, 2013.

QUESTIONS TO EXPLORE

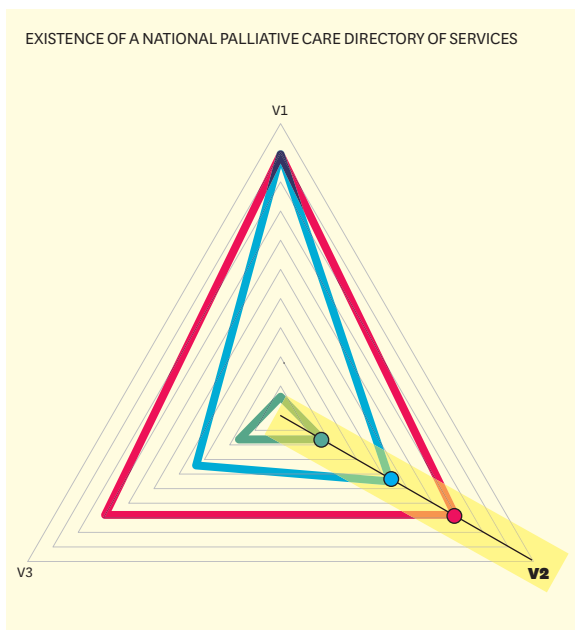
- 1 Existence of a directory of services in your country.
Options: Yes, No, I do not know.
- 2 When was it created?
- 3 If yes:
Options: It is printed, It is online // If online, please provide a link to it:



Global Score (median/max, CI 95%) 7/9 (7-8)

Content Validity Index (agreement on relevance) 0.43

Disagreement Index 0.16



V3

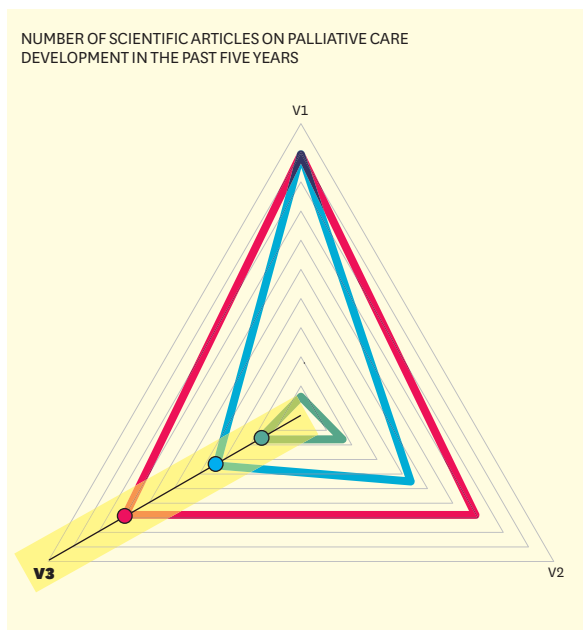
Number of scientific articles on palliative care development in the past five years



Global Score (median/max, CI 95%) **7/9 (7-8)**

Content Validity Index (agreement on relevance) **0.33**

Disagreement Index **0.16**



DEFINITION

Development in this context refers to processes, structures, policies and resources that support the delivery of palliative care. An independent search on PubMed, CINAHL and Embase should be launched to identify the number of articles on development per country.

■ In PubMed, papers published from 2008–18: (“Palliative care”[MeSH] OR “palliative medicine”[MeSH] OR “hospice and palliative care nursing”[MeSH] OR “hospices”[MeSH] OR “hospice care”[MeSH] OR hospice*) AND (“Country”[MeSH]).

■ In CINAHL: (MH “Country”) AND (MH “Hospices”) OR (MH “Hospice Care”) OR (MH “Palliative Care”) OR (MH “Hospice and Palliative Nursing”) OR (MH “Hospice Patients”).

■ In Embase: (palliative therapy) OR (palliative nursing) OR (cancer palliative therapy) OR (hospice care) OR (hospice) OR (hospice patient) OR (hospice nursing) AND (Country.mp)

QUESTIONS TO EXPLORE

- 1 An independent search on PubMed, CINAHL and Embase should be launched to identify the number of articles on development per country.

ADDITIONAL INFORMATION

■ Inclusion criteria: Mention at least one dimension of the WHO palliative care public health strategy (education, policy, implementation of palliative care services, or medicine availability) plus vitality; and provide country-level data.

■ The wording of this indicator has been adapted from the APCA Atlas of Palliative Care in Africa, 2017; and the article: Rhee JY et al. Publications on Palliative Care Development Can Be Used as an Indicator of Palliative Care Development in Africa, 2017, Journal of Palliative Medicine

■ Disclaimer: The ideal indicator would be “Number of scientific articles dealing entirely or partially with palliative care development in the past five years, in local language and local journals, and in international peer reviewed journals (available in Pubmed)”. However, this task seems not feasible.



Further Information



Additional Indicators to assess palliative care development

In this section, other very frequently used indicators that were included in the consensus process are

presented. However, these indicators were not included in the process because they did not fulfill the

defined consensus criteria. Access to an online repository is possible by clicking [here](#).

DOMAIN	CODE	NAME
Medical schools including any kind of palliative care education in undergraduate curricula	7	Not fulfilling GS and I-CVI criteria
Years of experience offering palliative care education in undergraduate curricula in the country	6.3	Not fulfilling RMF criteria
Nursing schools including mandatory palliative care education in undergraduate curricula	7.7	Not fulfilling GS and I-CVI criteria
Nursing schools including any kind of palliative care education in undergraduate curricula	6.3	Not fulfilling RMF criteria
Years of experience offering palliative care education in undergraduate nursing curricula in the country	5.2	Not fulfilling RMF criteria
Professorship in palliative care in nursing schools	6.8	Not fulfilling GS and I-CVI criteria
Financial burden to patients accessing palliative care	6.8	Not fulfilling RMF criteria
Number of mixed palliative care support teams (estimate)	6.5	Not fulfilling RMF criteria
Number of day hospices or day care centers for palliative care	6.3	Not fulfilling RMF criteria
Number of programs or teams of volunteers dedicated to palliative care	5.5	Not fulfilling RMF criteria
Number of palliative care patients cared for by specialised palliative care teams (per year)	6.7	Not fulfilling GS and I-CVI criteria
Number of physicians working in palliative care per population (estimation)	6.5	Not fulfilling RMF criteria
Number of palliative care services in the country per population	7.2	Not fulfilling GS and I-CVI criteria
Oral morphine available in >50% of pharmacies	7.3	Not fulfilling GS and I-CVI criteria
Cost of opioid analgesics to the consumer	7.3	Not fulfilling GS and I-CVI criteria
Use of opioids in S-DDD (statistical defined daily dose) per million inhabitants per day	6.7	Not fulfilling GS and I-CVI criteria
Total morphine consumption (Kilograms)	6	Not fulfilling GS and I-CVI criteria
Number of participants in the national palliative care congresses or equivalent	7	Not fulfilling GS and I-CVI criteria
Number of participants from the country in the international palliative care congresses or equivalent	6.3	Not fulfilling RMF criteria
Existence of international support for training of palliative care providers	6.5	Not fulfilling GS and I-CVI criteria
Existence of international grants to fund palliative care development in general	6.3	Not fulfilling RMF criteria
Existence of international funding to support infrastructure development/improvement	5.7	Not fulfilling RMF criteria



Suggested literature on the field of Palliative Care development around the world

1. **ATOME:** Access to Opioid Medication in Europe. Final Report and Recommendations to the Ministries of Health, 2014.
2. **Beek KV, Woitha K, Ahmed N, et al.:** Comparison of legislation, regulations and national health strategies for palliative care in seven European countries (Results from the Europall Research Group): A descriptive study. *BMC Health Serv Res* 2013;13:275.
3. **Berterame S, Erthal J, Thomas J, et al.:** Use of and barriers to access to opioid analgesics: A worldwide, regional, and national study. *Lancet* 2016;387:1644–1656.
4. **Bingley A, Clark D:** A comparative review of palliative care development in six countries represented by the mid-dle east cancer consortium (MECC). *J Pain Symptom Manage* 2009;37:287–296.
5. **Carrasco JM, Lynch TJ, Garralda E, et al.:** Palliative Care Medical Education in European Universities: A Descriptive Study and Numerical Scoring System Proposal for Assessing Educational Development. *J Pain Symptom Manage* 2015;50:516–523.
6. **Caruso Brown AE, Howard SC, Baker JN, et al.:** Reported availability and gaps of pediatric palliative care in low- and middle-income countries: A systematic review of published data. *J Palliat Med* 2014;17:1369–1383.
7. **Centeno C, Bolognesi D, Biasco G:** Comparative analysis of specialization in palliative medicine processes within the World Health Organisation European region. *J Pain Symptom Manage* 2015;49:861–870.
8. **Centeno C, Garralda E, Carrasco JM, et al.:** The Palliative Care Challenge: Analysis of Barriers and Opportunities to Integrate Palliative Care in Europe in the View of National Associations. *J Palliat Med* 2017;20:1195–1204.
9. **Centeno C, Lynch T, Garralda E, et al.:** Coverage and development of specialist palliative care services across the World Health Organisation European Region (2005–2012): Results from a European Association for Palliative Care Task Force survey of 53 Countries. *Palliat Med* 2015;30:351–362.
10. **Centeno C, Pons JJ, Lynch T, Donea O, Rocafort J, Clark D.** EAPC Atlas of Palliative Care in Europe 2013. Milan: EAPC Press; 2013
11. **Chambaere K, Centeno C, Hernandez EA, et al:** Palliative care development in countries with a euthanasia law. Report for the Commission on Assisted Dying Briefing Papers. London, U.K.: Commission on Assisted Dying, 2011.
12. **Chan N, Chan N, Menon S, Goh CR:** Policies on palliative care for older people in Asia. In: Van den Block L, Albers G, Pereira SM, et al. (eds): *Palliative Care for Older People: A Public Health Perspective*. New York, Oxford University Press, 2015. Chapter 6, p. 60–69.
13. **Cherny NI, Baselga J, de Conno F, Radbruch L:** Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: A report from the ESMO/ EAPC opioid policy initiative. *Ann Oncol* 2010;21:615–626.
14. **Cherny NI, Cleary J, Scholten W, et al.:** The global opioid policy initiative (GOPI) project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: Introduction and methodology. *Ann Oncol* 2013;24(Suppl. 11):xi7–13.
15. **Clark J, Gardiner C, Barnes A:** International palliative care research in the context of global development: A systematic mapping review. *BMJ Support Palliat Care* 2016;8:7–18.
16. **Connor SR, Downing J, Marston J:** Estimating the global need for palliative care for children: A cross-sectional analysis. *J Pain Symptom Manage* 2017;53:171–177.
17. **De Lima L, Hidalgo L, Morante R, Parodi J:** Policies on palliative care for older people in Latin America and the Caribbean. In: Van den Block L, Albers G, Pereira SM, et al. (eds): *Palliative Care for Older People: A Public Health Perspective*. In: Van den Block L, Albers G, Pereira SM, et al. (eds): *Palliative Care for Older People: A Public Health Perspective*. New York, Oxford University Press, 2015. Chapter 10, p. 95–103.
18. **De Lima L, Pastrana T, Radbruch L, Wenk R:** Cross-sectional pilot study to monitor the availability, dispensed prices, and affordability of opioids around the globe. *J Pain Symptom Manage* 2014;48:649.e1–659.e1.
19. **De Lima L, Wenk R, Krakauer E, et al.:** Global framework for noncommunicable diseases: How can we monitor palliative care? *J Palliat Med* 2013;16:226–229.
20. **Delgado E, Barfield R, Baker J:** Availability of palliative care services for children with cancer in economically diverse regions of the world. *Eur J* 2010;46:2260–2266.
21. **Duthey B, Scholten W:** Adequacy of opioid analgesic consumption at country, global, and regional levels in 2010, its relationship with development level, and changes compared with 2006. *J Pain Symptom Manage* 2014;47:283–297.
22. **Etkind SN, Bone AE, Gomes B, et al.:** How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 2017;15:102.
23. **Fadhil I, Lyons G, Payne S:** Barriers to, and opportunities for, palliative care development in the Eastern Mediterranean Region. *Lancet Oncol* 2017;18:e176–e184.
24. **Fraser BA, Powell RA, Mwangi-Powell FN, et al.:** Palliative care development in Africa: Lessons from Uganda and Kenya. *J Glob Oncol* 2017;4:1–10.
25. **Froggatt K, Payne S, Morbey H, et al.:** Palliative Care Development in European Care Homes and Nursing Homes: Application of a typology of implementation. *J Am Med Dir Assoc* 2017;18:550.e7–550.e14.
26. **Froggatt KA, Reitingger E, Froggatt K, Brazil K, Heimerl K, Hockley J, Kunz R, Morbey H, Parker D, Husebø B.** Palliative Care in Long-term Care Settings



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ICS & ATLANTES

ABOUT ICS

The Institute for Culture and Society (ICS) was created to help fulfil one of the principal objectives of the University of Navarra; namely to further the study of Humanities and Social Sciences. Through international, academic debate, the ICS aspires to establish an authentic dialogue in search of scientific answers, practical ideas, innovative proposals and other relevant contributions to help resolve the principle challenges of today's society.

Within the ICS (and in collaboration with prestigious experts from countries throughout the world), research is promoted with the goal of developing projects of high scientific quality and social relevance in the following four areas: Poverty and Development; Family, Education and Society; Contemporary Art; Globalization, Human Rights and Interculturalism.

ABOUT ATLANTES

In 2012 the Institute for Culture and Society (ICS) embarked upon the ATLANTES Research Programme "Human dignity, advanced illness and palliative care". The work of the programme is interdisciplinary, international and with a strong focus on the contribution of the humanities and social sciences, and with the goal of improving scientific and public understanding of the work of palliative care.

The overall objective of this five-year programme is to promote in society a positive attitude toward the care of patients with advanced, irreversible illness, from a perspective based on the dignity of the person and the role of medicine itself. ATLANTES will adopt perspectives from history, psychology, sociology and anthropology to illuminate the understanding of palliative care. It will also encompass contributions from public health, geography, communication studies and education.

ATLANTES will promote reflection on fundamental aspects of palliative care as well as the implementation of strategies to promote palliative care at institutional, professional and societal levels. Among its sub-projects will be a study of the intangibles in the interaction between palliative care and the individual; the anthropological and spiritual foundation of palliative care; a ranking of the development (and associated Atlases) of palliative care in both Europe and Latin America; education in palliative medicine, a workshop on "The message of palliative care" and a Think Tank on ethics and advanced illness

ATLANTES will approach these issues in a manner consistent with the work of an academic institution: scientific investigation, professional training and dissemination of the knowledge acquired. This will be done in ways that are consistent with the institutional characteristics of the University of Navarra, and with a clear willingness to co-operate with other institutions that work for similar objectives, as well as those who may adopt differing perspectives.

More information: <http://www.unav.es/centro/cultura-y-sociedad/>





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