



# Palliative care integration indicators: an European regional analysis

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## ABSTRACT

**Objective** To estimate the capacity of European countries to integrate palliative care (PC) into their health systems through PC service provision for patients of all ages, with different care needs and diseases, in various settings and by a range of providers.

**Methods** Secondary analysis of survey data from 51 countries with 22 indicators explored the integration of available PC resources for children, for patients of all ages, at the primary care level, for oncology and cardiac patients, and in long-term care facilities. We also measured volunteer participation. Results were quantified, converted into weighted subscores by area and combined into a single 'Integration Capacity Score (ICS)' for each country.

**Results** Thirty-eight countries reported 543 specialised paediatric PC services. One-third of all surveyed countries reported 20% or more of patients with PC needs at the primary care level. Twenty-four countries have a total of 155 designated centres that integrate oncology and PC. Eight countries were pioneering cardiology services that integrate PC. Eight reported a volunteer workforce of over 1000 and 12 had policies regulating PC provision and interventions in long-term care facilities. Across all indicators, 39 countries (76%) score from low to very low integration capacity, 8 (16%) score at an intermediate level, and 4 (8%; the Netherlands, UK, Germany and Switzerland) report a high-level integration of PC into their health systems.

**Conclusion** Variable progress according to these indicators shows that most European countries are still in the process of integrating PC into their health systems.

## INTRODUCTION

The burden of non-communicable diseases (NCDs) is increasing throughout Europe. By 2030, cardiovascular disease, Alzheimer's and other dementias will be the leading causes of death, followed

## Key messages

### What was already known?

- Palliative care is an essential component of universal health coverage; it relieves serious health-related suffering, improving quality of life and patient satisfaction.

### What are the new findings?

- Experts in different settings developed indicators that allowed measurement of levels of palliative care integration in Europe.
- The Integration Capacity Score is the first step towards quantifying palliative care integration across a health system.

### What is their significance?

- Integration analysis provides decision-makers with a tool for national health system planning.
- It indicates the extent to which palliative care is being integrated into paediatric care, primary care, oncology and cardiology in long-term care facilities, as well as the extent of volunteer participation in palliative care integration.

by oncological diseases.<sup>1</sup> Children aged 0–14 years represent 5.8% of decedents, doubling the current need for both adult and paediatric palliative care (PC).<sup>2</sup> PC service delivery for all age groups with PC needs could mitigate the projected health system overload from NCDs.<sup>3</sup>

To date, comparative national evaluations of PC delivery have focused on specific resources: policies, funding, specialised education, access to PC medications and specialised PC services.<sup>4–8</sup> Experts now recognise the need to integrate PC into health and social care systems, in addition to providing specialised provision, to ensure effective service provision for all populations with PC needs across the continuum of care.<sup>9 10</sup>

The WHO European Region countries are integrating PC in a variety of ways. Some focus on continuity of care across all levels and settings,<sup>11</sup> while others make PC available in the community.<sup>12</sup> Some systems integrate PC into the continuum of cancer care,<sup>13</sup> while others provide PC interventions in long-term care (LTC) facilities<sup>14</sup>; some provide paediatric PC<sup>15</sup> and some are broadening the PC workforce.<sup>16</sup> Others understand PC integration as specialised provision, evaluating it in terms of progress in the delivery of specialised services, access to medicines, education and policy.<sup>17 18</sup> No studies to date have combined these perspectives to describe and compare countries' overall capacities to provide integrated PC at the health system level.

Acknowledging the varied approaches, PC integration can be understood as a country's capacity to prevent and relieve serious health-related suffering through PC provision for adults and children, at different care levels (specialised and primary), for such diverse diseases as cancer, organ failure, frailty and dementia, in diverse care settings, including the community, and by other providers than health professionals, such as volunteers.<sup>4 19 20</sup>

The 2019 Atlas of Palliative Care in Europe<sup>21</sup> collected indicators measuring specialised services and identified and gathered more general indicators of PC

integration that have been published elsewhere.<sup>11</sup> This study aims to examine PC integration capacity across WHO region countries using those indicators (table 1).

## METHODS

### Study design

We conducted a secondary analysis of the 2019 European Atlas<sup>21</sup> with regard to the integration of PC in the WHO European Region (n=54 countries). Data on 22 PC indicators were used as markers of integration in six areas: paediatrics, primary care, cardiology, oncology, LTC facilities and volunteering (three to five indicators per area; table 1).<sup>22</sup> As already reported,<sup>11</sup> the selection of areas and indicators reflected existing official European Association for Palliative Care Task Forces in 2018 and some relevant literature.<sup>10 12 13 23–25</sup>

### Sources of information

An ad hoc network of incountry experts<sup>11</sup> gathered the markers (see full list for paediatrics on p56, LTC on p76, volunteers on p80, primary care on p84 and cardiology on p88 of the 2019 Atlas of Palliative Care in Europe<sup>21</sup>). Experts were selected based on the following criteria: (1) members of the EAPC Task Forces; (2) authors of technical and scientific documents related to the area (searched through PubMed and Google Scholar using the following keywords:

**Table 1** Identified indicators for assessment of PC integration into the health system\*

Areas	Experts consulted	Indicators
Paediatric	Professor Julia Downing, Ms Joan Martson, Ms Lizzie Chambers	Number of paediatric PC services for children in hospitals. Number of paediatric PC services for children in home care. Number of paediatric PC services for children in hospices.
Cardiology	Dr Pablo Díez Villanueva, Dr Manuel Martínez Sellés	Existence of pioneering cardiology services providing PC. Inclusion of PC topics in cardiology congresses and vice versa. Existence of periodical meetings between the national PC and cardiology association. Number of publications regarding PC provision in cardiology services.
Oncology	Online database search: ESMO, ClinicalTrials.gov and Scopus	Existence of certified centres for the integration of oncology and PC. Clinical trials on early integration of PC in oncological treatments. Number of publications on the integration of PC and oncology.
Primary care level	Professor Dr Scott Murray, Dr Sebastien Moine	Percentage of PC patients identified at the primary care level. Existence of incentives to promote early identification of PC patients at the primary care level. Existence of official policy documents regulating primary PC (laws or strategies/plans/policies) and primary PC education.
Long-term care facilities	Professor Katherine Froggatt, Dr Lieve van den Block	Existence of official documents regulating PC provision at LTCFs. Existence of PC training programmes for staff working at LTCFs. Existence of publications regarding the provision of PC at LTCFs. Collaboration frequency between PC teams and LTCFs (estimate). Fund allocation for the provision of PC at LTCFs.
Volunteers in hospice and PC	Ms Leena Peltari, Ms Ros Scott	Number of volunteer hospices. Number of PC volunteers. Existence of data collection systems to track PC volunteering activities. Existence of training programmes for PC volunteers.

\*Source: Arias-Casais *et al.*<sup>22</sup>

LTCFs, long-term care facilities; PC, palliative care.

“Area” AND Palliative Care AND “Country”); and (3) nominations from the leaders of the EAPC Task Forces. Experts completed an online survey with the indicators per area of expertise. The exception was oncology, where PC integration was measured using an online search in public databases: European Society for Medical Oncology (ESMO),<sup>26</sup> ClinicalTrials.gov<sup>27</sup> and Scopus.<sup>28</sup>

#### Rating system: the Integration Capacity Score

The Integration Capacity Score (ICS) was designed to estimate the capacity of countries to integrate PC into health systems. A three-tier scoring system was developed for the dichotomic indicators (yes/no): 0 points for non-responsive indicators due to lack of an identified informant; 1 point when the results were unreported or negative; and 2 points for nominally positive results. Results were standardised per 100 000 inhabitants and the median was calculated for the ordinal indicators. Scores of 0 and 1 were assigned in dichotomic indicators, but 2 points were given if the results were below the median and 3 points if above the median (only applied for paediatric PC services, certified centres for the integration of oncology and PC, and number of hospice volunteers). As this is an ordinal data classification, we decided to assign a value of 0 if there were no informants. As per the diversity of sources used to identify informants, informant absence was interpreted as a null degree of PC activity at a particular area.<sup>29–31</sup> The country integration score (ICS) was obtained through the sum of the subscores of indicators in each area (table 2).

#### Levels of PC integration

The maximum ICS was 53 across all areas. Countries were grouped into four levels according to their score: countries were designated as having high integration capacity when the ICS was  $\geq 75\%$  of the attainable points, intermediate level when between 50% and 75%, low level when between 25% and 50%, and very low when  $\leq 25\%$  (table 2).

## RESULTS

A total of 160 experts participated in the survey, with no information reported in 8 countries (Azerbaijan, Bosnia and Herzegovina, Liechtenstein, Iceland, North Macedonia, Monaco, Montenegro and Uzbekistan). Country information varied by domain: 38 countries reported on paediatrics, 34 on primary care, 19 on LTC, 15 on volunteering and 12 on cardiology. Twenty-seven countries reported some PC integration into oncology.

#### Paediatric PC

Thirty-eight European countries identified a total of 543 paediatric PC services, the majority of which (54%) provided home care, followed by hospices (24%) and by hospitals (22%). Eleven countries

reported three types of services, nine declared hospitals and home care, five home care and hospices, and one hospital services and hospices.<sup>32</sup> Some 62% of the available services are concentrated in five countries: UK (n=98), Poland (n=74), Germany (n=53), France (n=44) and the Netherlands (n=42). The UK reported the greatest number of PC services providing paediatric PC (especially in hospice settings), while France reported the highest number of hospital programmes and Poland the most home care services (online supplemental appendix 1).

#### PC integration at the primary care level

One-third of all countries reported identifying 20% or more of patients with PC needs at the primary care level, whereas four countries estimated identifying between 60% and 100% of all patients at the primary care level. Spain and Kazakhstan reported the highest number of patients in primary care. Eight countries use different incentives to encourage identification of PC patients: Spain and Luxembourg offer economic incentives; Germany, the Netherlands, UK and Armenia offer economic incentives plus academic or curricular recognition (eg, overtime payments, teaching or ongoing education); and Kyrgyz Republic and Serbia offer academic recognition plus incentives in the form of days off, shorter hours and bonus pay. Furthermore, experts from 31 countries identified PC policies in primary healthcare, 13 had both specific laws and a strategic plan, 9 had specific legislation, and 9 had strategic plans for patient care at primary level care (online supplemental appendix 1).

#### PC integration for oncology patients

Designated centres for integrated oncology and PC certified by the European Society for Medical Oncology were identified in 24 countries. Of a total of 155 services, 60% are located in five countries: Italy (n=39), Germany (n=24), Spain (n=15), the Netherlands (n=14) and Belgium (n=9). Up to 19 clinical trials on early integration of PC in oncological treatment were identified in 10 countries; France, Italy and Switzerland account for 60% of the studies. Research shows 168 articles on PC integration into oncology originating in 20 countries, of which over half were produced in Germany, Israel, Italy, Switzerland and the UK (online supplemental appendix 1).

#### PC integration into Long-term Care Facilities [LTF]

Policies regulating PC provision into LTC services were reported in 24% of the countries, with 17 countries noting collaboration between LTC professionals and PC teams as the mechanism of integration. Kyrgyz Republic, Belgium, Austria and Lithuania reported a high level of collaborations. Experts reported various types of PC training in LTC facilities in 31% of the countries: one offers formal training to 90% of professionals in residences, four to 60%–90%, three to

## Original research

**Table 2** Integration Capacity Score (ICS)\*†

Integration capacity level (n of countries)	Country	Types of OECD\$ healthcare systems‡	Paediatrics (max 9)	Cardiology (max 8)	Oncology (max 7)	Primary care (max 7)	Long-term care (max 12)	Volunteering (max 10)	ICS (max 53)
High (n=4)	The Netherlands	Etatist SHI	9	7	6	7	12	10	51
	UK	NHS	8	8	6	6	12	7	47
	Germany	SHI	7	5	6	6	11	8	43
	Switzerland	SHI	5	5	7	5	9	9	40
Intermediate (n=8)	Belgium	Etatist SHI	6	0	7	4	12	9	38
	Czech Republic	Etatist SHI	6	7	4	4	7	8	36
	Denmark	NHS	9	7	6	5	9	0	36
	Italy	NHI	4	5	7	4	10	6	36
	Poland	Etatist SHI	7	0	5	5	10	8	35
	Spain	NHS	5	8	6	7	9	0	35
	Austria	SHI	7	0	6	0	11	10	34
	France	Etatist SHI	6	0	6	2	12	7	33
Low (n=18)	Kyrgyz Republic	—	4	0	3	7	12	0	26
	Hungary	Etatist SHI	7	0	5	5	0	8	25
	Ireland	NHI	9	6	5	5	0	0	25
	Portugal	NHS	6	7	5	4	0	3	25
	Serbia	—	4	0	3	7	0	9	23
	Albania	—	7	4	3	5	0	2	21
	Romania	—	6	0	6	2	0	7	21
	Israel	Etatist SHI	7	0	6	0	7	0	20
	Lithuania	—	4	0	3	0	12	0	19
	Sweden	NHS	3	6	5	5	0	0	19
	Armenia	—	3	0	3	4	4	3	17
	Greece	—	4	0	4	2	7	0	17
	Luxembourg	SHI	7	0	3	7	0	0	17
	Norway	NHS	3	0	7	5	0	0	15
	Slovenia	SBMT	4	0	6	5	0	0	15
	Moldova	—	8	0	3	3	0	0	14
	Russian Federation	—	4	0	4	0	6	0	14
	Turkey	—	5	0	5	4	0	0	14
Very low (n=21)	Finland	NHS	4	0	4	5	0	0	13
	Tajikistan	—	4	0	3	5	1	0	13
	Ukraine	—	6	0	3	4	0	0	13
	Kazakhstan	—	4	0	3	5	0	0	12
	Malta	—	3	0	3	5	0	0	11
	Belarus	—	7	0	3	0	0	0	10
	Cyprus	—	3	0	4	3	0	0	10
	Latvia	—	7	0	3	0	0	0	10
	Slovak Republic	Etatist SHI	7	0	3	0	0	0	10
	Georgia	—	6	0	3	0	0	0	9
	Bulgaria	—	1	0	4	3	0	0	8
	Croatia	—	0	0	3	5	0	0	8
	Estonia	Etatist SHI	3	0	5	0	0	0	8
	Azerbaijan	—	3	0	3	0	0	0	6
	Bosnia and Herzegovina	—	3	0	3	0	0	0	6
	Iceland	NHS	3	0	3	0	0	0	6
	Liechtenstein	—	3	0	3	0	0	0	6
	North Macedonia	—	3	0	3	0	0	0	6
	Monaco	—	3	0	3	0	0	0	6
	Montenegro	—	0	0	3	0	0	0	3
	Uzbekistan	—	0	0	3	0	0	0	3

\*Available data from palliative care activity in six areas of the health system were rated to create an integration subscore by area explored: 0 point: no experts identified; 1 point: at least one expert was identified, but no reported activity data; 2 points: available activity data (if ordinal values are below the median); 3 points: ordinal activity data above the median. The country integration score (ICS) is obtained with the sum of the subscores of integrations in each area of the health system explored.

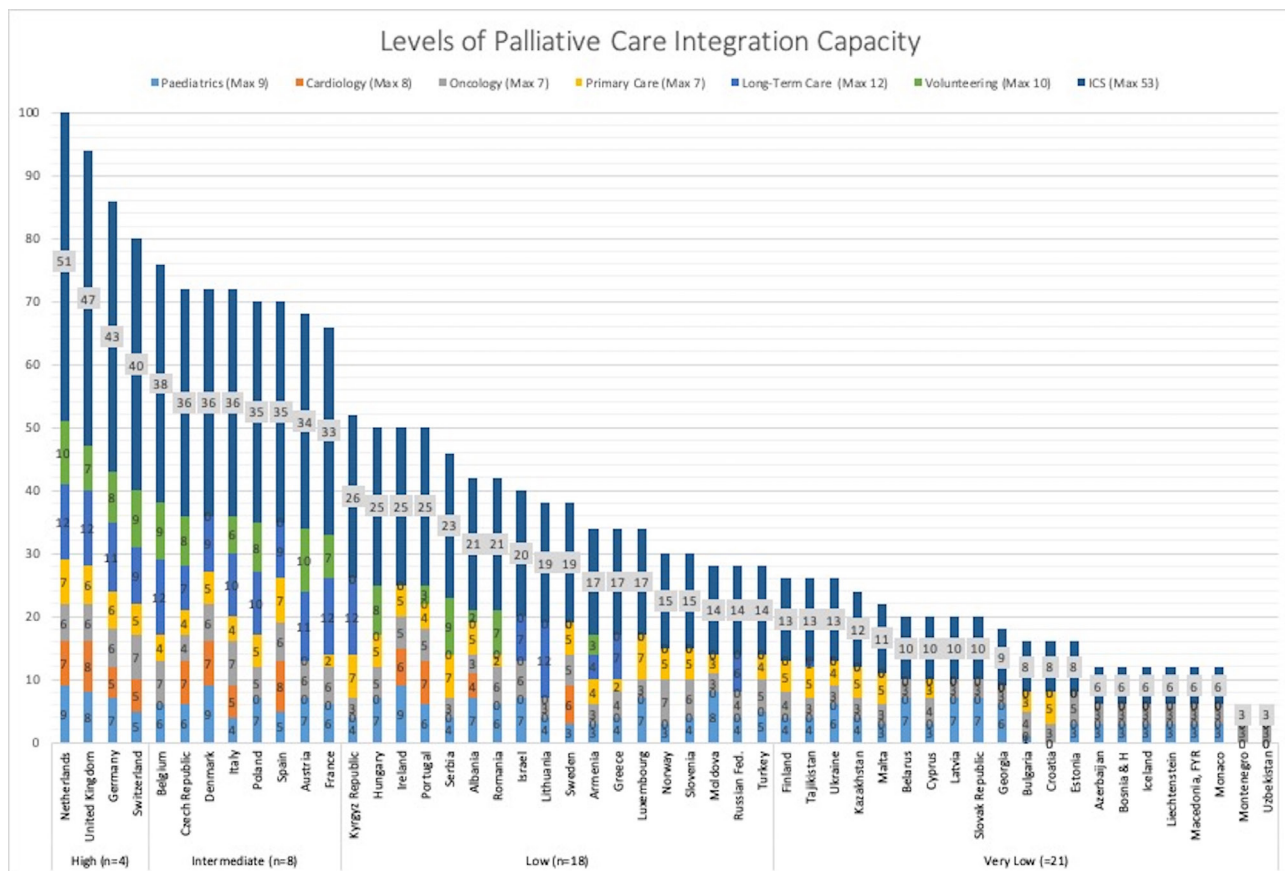
†Activity data of each health system area explored, as obtained in the European Association for Palliative Care Atlas survey, are available in online supplemental appendix 1.

‡Source: Böhm *et al*.<sup>42</sup>

\$OECD: The Organisation for Economic Co-operation and Development.

NHI, National Health Insurance; NHS, National Health Service; SBMT, social-based mixed type; SHI, social health insurance.





**Figure 1** Levels of palliative care integration into the national health systems across Europe.

40%–60%, three to 20%–40%, and five to less than 20%. Twelve countries have publications researching PC at Long-term Care Facilities (LTF) and 12 report public funding for their work (online supplemental appendix 1).

#### PC provision by volunteers

Fifteen countries provided data on hospice and PC volunteers. Nearly all reported volunteer training systems. Of the countries, 16% estimated a volunteer workforce of over 1000 and 20% of hospices had volunteer teams. Germany had the highest number of teams (n=1316). Furthermore, some nine countries had databases for PC volunteers. Austria is an example of good practice with 184 volunteer hospice teams, over 1000 PC volunteers, PC volunteer tracking systems and specific PC volunteer training programmes (online supplemental appendix 1).

#### PC integration for cardiac patients

Cardiology services pioneering integration of PC were identified in eight countries. Eleven of those included PC topics at national cardiology congresses or vice versa and, in line with this, research supports this activity with several publications on PC provision in cardiology guidelines and services by French, Austrian, Greek, Spanish, Slovenian, Latvian, North Macedonian and Montenegro authors. Three countries held

regular meetings between experts from national cardiology associations and the respective PC national association (online supplemental appendix 1).

#### Estimated levels of PC integration across Europe

The Netherlands (51 of 53, 96%), UK (47 of 53, 89%), Germany (43 of 53, 81%) and Switzerland (40 of 53, 75%) had the highest ICS in the WHO European Region (see figure 1). These countries demonstrate capacity to integrate PC, with consistently high scores across all integration indicators except cardiology. Eight other countries had intermediate ICS, generally scoring well, but having low levels of volunteering and little integration into cardiology and primary care. Although almost a quarter (24%) of European countries had high or intermediate levels of integration, the majority (39 countries or 76%) had low or very low levels of PC integration (table 1).

Some countries with intermediate or low levels of integration score higher in particular areas. For instance, Denmark and Ireland report high levels of paediatric PC provision (subscore: 9 points); Spain, Luxembourg, Kyrgyz Republic and Serbia score highest for PC integration at the primary healthcare level (7 points); Italy, Belgium and Norway have clearly begun integrating PC into oncology (7 points); Kyrgyz Republic, Belgium, France and Lithuania have integrated PC into LTC settings (12 points); Austria

leads in volunteering for hospice and PC (10 points); and Spain is integrating PC into cardiology services (8 points) (table 2).

## DISCUSSION

There is limited availability of information regarding PC integration into identified domains of health systems and what there is varies greatly between countries. Although PC integration appears to be progressing in paediatric, primary and oncological care, progress is slower for cardiology, the volunteer sector and LTC settings. These results, obtained by exploring six different domains where EAPC expert groups were available, provide credible preliminary data to measure achievements in PC integration across the health systems of European countries. This research can be expanded to explore integration into other important health system priorities such as dementia, renal failure, advanced chronic obstructive pulmonary disease, psychiatry and social care.

Only 4 out of 51 European countries consistently indicated a high level of integration across specific populations (children), at the generalist level (primary care), for different diseases (cancer and heart failure), by different providers (volunteers) and in other care settings (LTC). Representing 7% of the countries studied, the overall results demonstrate that the majority of health systems are unprepared to manage population-level PC needs beyond selected specialised provision. Moreover, preparedness is uneven across subregions, with small residual samples of Central and Eastern European countries showing reasonable levels of PC integration (Czech Republic, Poland and Kyrgyz Republic). By contrast, countries located in the Western region, mostly high-income ones, had the highest average ICS (the Netherlands, UK, Germany and Switzerland).

These findings support previous publications reporting the absence of and uneven PC integration into the majority of health systems. Paediatric services for the estimated 170 000 children in Europe with PC needs are largely undeveloped. Specialised services are usually provided at hospitals and hospices, since PC may not be integrated with general paediatric practice.<sup>24 32</sup> As most European countries have yet to establish a mechanism to identify patients with PC needs at the primary care level, the percentage of PC patients in primary care is rising slowly. Murray *et al*<sup>12</sup> noted that, although general practitioners in two countries (Spain and UK) tracked patients with palliative needs, there was no systematic way to identify patients with PC needs. The EAPC primary care reference group produced a toolkit to support national leaders and clinicians to develop PC services in primary care.<sup>33</sup> It was updated in 2019 and is available free of charge with a video and has been translated into many languages to promote global integration of PC into primary care and develop outcome measures.

Regarding different disease groups, although there are some signs of integration for oncology patients through designated centres for integrated oncology and PC in a few Western European countries, PC is integrated into cardiology services in only eight countries, as reported earlier by the Heart Failure Atlas and the EAPC.<sup>34</sup> Eight countries engage the public by integrating volunteers into care, although most lack accurate registers, a finding that correlates with previous studies of volunteer services.<sup>25 35</sup> PC interventions in LTC facilities are generally unregulated and professional education in LTC facilities is lacking, leaving much room for improvement in this domain.<sup>36 37</sup>

This preliminary review of the PC integration capacity of countries in the European region cannot be compared with existing studies, which have explored PC integration at specific levels using different methodologies that vary according to researchers' interpretations of the concept of integration. For instance, some studies have approached integration from a more clinical perspective<sup>13 38 39</sup> or from a professional and organisational perspective of integration.<sup>4 40 41</sup> The present study analyses a variety of indicators of integration from a wide set of macro-level perspectives, raising the possibility that our findings can be compared with other research on integration at a national level to determine the relationship between specialised development and PC integration.<sup>18</sup> Another option would be to include a validated typology of health systems into the analysis<sup>42</sup> in order to determine whether certain types of health systems are more frequently associated with comprehensive integration of PC than others. Clark *et al*<sup>18</sup> describe integration as '(national) comprehensive provision of all types of PC by multiple service providers' and 'a broad awareness of PC on the part of health professionals, local communities, and society in general'. They report 19 European countries with an advanced level of integration, compared with our finding of 12 countries with intermediate and high levels of integration. Interestingly, they report that nearly all high-income countries have either advanced or preliminary level of integration. This suggests that either a high level of specialised PC provision predicts a high level of PC integration provision or vice versa. A recent study in Scotland shows lack of PC integration in an unscheduled and emergency care services, suggesting another potential area for study of integration.<sup>43</sup>

The design of the ICS aligns with the trend of constructing synthetic measurements to evaluate public health phenomena (allowing for useful estimates and predictions) and is an essential complementary tool for specialised assessments. A country evaluating both perspectives of PC provision will be able to identify its systematic gaps in effectively matching population needs. A comprehensive model of palliative care provision must combine specialized and general resources to reduce deficits and expand opportunities to offer

care to people with palliative needs at different levels of the health system.

To our knowledge, since this is the first pan-European study of indicators of PC integration across all patient groups and settings, it has some limitations. First, the nature of an expert analysis implies that the validity of the results strongly depends on the accuracy of the data, which are estimates (rarely the product of systematic registries). Second, by selecting new indicators and limiting areas of integration, we excluded some areas as explained above. Third, the lack of a single consensus definition of PC integration makes it a challenge to design a single monitoring framework.

Progress towards composite indicators represents an improvement in the estimation of overall PC service delivery. However, future research should not be limited to interpreting these indicators, but should use them to supplement measures of specialised PC provision and public awareness of PC. Accurate estimates of the actual PC coverage at the population level entail combining all three pillars. Similarly, future efforts should, ideally, include indicators of the integration of generalist PC into routine health and social care national data sets, such as the percentage of people identified with PC needs before their deaths.<sup>22</sup>

## CONCLUSION

Most European countries are in the early stages of integrating PC into their respective health systems. EAPC Task Forces are helping to coordinate and accelerate the integration agenda by convening champions across disciplines from all European countries and from some other regions to help all in need to benefit from integrating a PC approach into the continuum of clinical care.

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