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Original Study

Palliative Care Development in European Care Homes and Nursing Homes: Application of a Typology of Implementation

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A B S T R A C T

Background: The provision of institutional long-term care for older people varies across Europe reflecting different models of health care delivery. Care for dying residents requires integration of palliative care into current care work, but little is known internationally of the different ways in which palliative care is being implemented in the care home setting.
Objectives: To identify and classify, using a new typology, the variety of different strategic, operational, and organizational activities related to palliative care implementation in care homes across Europe.
Design and methods: We undertook a mapping exercise in 29 European countries, using 2 methods of data collection: (1) a survey of country informants, and (2) a review of data from publically available secondary data sources and published research. Through a descriptive and thematic analysis of the survey data, we identified factors that contribute to the development and implementation of palliative care into care homes at different structural levels. From these data, a typology of palliative care implementation for the care home sector was developed and applied to the countries surveyed.
Results: We identified 3 levels of palliative care implementation in care homes: macro (national/regional policy, legislation, financial and regulatory drivers), meso (implementation activities, such as education, tools/frameworks, service models, and research), and micro (palliative care service delivery). This typology was applied to data collected from 29 European countries and demonstrates the diversity of palliative care implementation activity across Europe with respect to the scope, type of development, and means of provision. We found that macro and meso factors at 2 levels shape palliative care implementation and provision in care homes at the micro organizational level.
Conclusions: Implementation at the meso and micro levels is supported by macro-level engagement, but can happen with limited macro strategic drivers. Ensuring the delivery of consistent and high-quality palliative care in care homes is supported by implementation activity at these 3 levels. Understanding where each country is in terms of activity at these 3 levels (macro, meso, and micro) will allow strategic focus on future implementation work in each country.

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Changes in population demography across Europe are leading to an increased proportion of older people needing to access higher levels of care and support services.[1] For some older people living with multiple complex health conditions, a decision will be made to move into a care home when they are no longer able to live independently in their own homes. Across Europe there is diversity in the national policy, funding, and regulatory structures within which care homes operate.[2] As residents in care homes become more frail, they may require palliative and end-of-life care within these facilities. Health and social care staff working within, and external to, the organization can provide this care.

The implementation of palliative care in care homes has received increased international attention over the past 10 years. In 2013, A European Association of Palliative Care (EAPC) Taskforce: Palliative Care in Long-Term Care Settings for Older People, reported on how palliative care was being developed in care homes in 13 European countries. This Taskforce identified that different initiatives and interventions were being developed and implemented.[3,4] The PACE (Comparing the effectiveness of PAlliative CarE for older people in long-term care facilities in Europe) research program[5] extends this work in a second EAPC Taskforce: Mapping Palliative Care Systems in Long-Term Care Facilities in Europe. This considers the development of palliative care provision in care homes across a larger number of European countries affiliated to the EAPC.

In the context of this study, the term "care home" is used to refer to a collective institutional setting in which care is provided to older people on-site 24 hours a day, 7 days a week, including facilities with on-site and off-site nurses and medical staff.[3] This term includes a range of facility types offering different levels of social and health care.[5] The term care home is concerned with long-term care facilities based in the community, and does not include rehabilitation or subacute facilities, as included in a recent nursing home definition.[6]

Within palliative care, the mapping of palliative care provision is well established in Europe.[7–9] The focus of such work is on the provision of specialist palliative care in a range of settings, but limited attention has been paid to specialist and generalist palliative care provision in care home environments.[7–9] The mapping work to date has been cross-sectional, and the underlying methodology and reliability of data sources used questioned.[10] This static approach, also, does not capture implementation activity that would promote the ongoing development of palliative care into care home practice. Although implementation strategies across palliative care more widely have been identified, using education process mapping, feedback, multidisciplinary meetings, and multifaceted approaches,[11] they lack a clear underlying rationale. There is therefore a need to underpin the current interest in palliative care provision in care homes with an empirically derived typology for implementation that can be used internationally, nationally, and organizationally to monitor and compare future activity by service providers, regulators, and policy makers.

Aims and Objectives

The aim of the study was to map and classify different structures, organizational models, and policies related to palliative care provision in care homes in Europe. We report in this article on the following specific objectives:

1. To describe existing formal palliative care structures or services, organizations, and policies at local, regional, and national levels that support the development and provision of palliative care in care homes.
2. To develop a typology for palliative care implementation in care homes.

Methods

We collected data from 29 European countries: Albania, Austria, Belgium, Croatia Hrvatska, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Latvia, Lithuania, Luxembourg, The Netherlands, Norway, Poland, Portugal, Romania, Spain, Sweden, Switzerland, Turkey, and the United Kingdom. We used 2 methods of data collection: (1) country mapping survey and (2) documentary review.

Country Mapping Survey

In the country mapping survey, we sought to describe the broader context for palliative care in care homes in each country, alongside the identification of examples of initiatives undertaken to develop palliative care in care homes. We aimed to identify country informants in as many European countries as possible. These were individuals with expertise

Table 1
Definition and Scoring of 3 Levels of Implementation Activity

Level	Definition	Domains of Activity	Scoring
Macro	National or regional drivers that support palliative care provision in care homes	• Policy directives/documents/strategies/guidelines • Legislation • Financial provision and mechanisms • Regulatory processes and quality assurance processes	1 point awarded for activity identified in any 1 of these 4 domains Range: 0–4
Meso	Implementation activities to support the development of palliative care in care homes	• Education programs • Tools/frameworks • Services supporting long-term care facilities • Service development projects/research into palliative care practice	1 point awarded for activity identified in any 1 of these 4 domains Range: 0–4
Micro	Extent of organizational provision of palliative care in care homes	• No evidence of palliative care activity in any care homes in country • Minimal activity: isolated examples of palliative care provision in care homes • Some activity: examples of palliative care provision identified in some regions/providers • Widespread activity: palliative care provided in some care homes across different regions/providers • Full activity palliative care provided in all care homes in country	Country scored on extent of palliative care provision in care home organizations • No activity: 0 • Minimal activity: 1 • Some activity: 2 • Widespread activity: 3 • Full activity: 4

Table 2
Examples of Domains of Macro-Level Activity

Domain	Example
Policy directives/ documents/strategies/ guidelines	UK (England): National End-of-Life Care strategy published in 2008 specifically focuses on care homes as a place where people die and require palliative care provision
Legislation	France: "Patients' Rights and the End-of-Life" Act (2005): explicit objective regarding palliative care in care homes
Financial provision and mechanisms	Poland: Palliative care can be funded through care budgets in care homes depending on type of facility
Regulatory processes and quality assurance processes	Austria: Criteria for Palliative Care integrated in the "National Certificate of Quality" for nursing homes

in palliative care in care homes with relevant practice, research, and/or education experience, and links to other experts and specialist contacts within their respective countries. We identified the informants through their involvement in a previous study[2] and partner organizations (the EAPC, AGE Platform Europe, Alzheimer Europe, and the European Forum for Primary Care). Informants were identified for 25 countries; no contacts were found for 4 countries (Albania, Croatia Hrvatska, Latvia, Romania). Country informants received a survey questionnaire, developed by the research team, based on previous work.[2] Data on the country context were collected between 2014 and 2015 about the following domains in each country: organization of care in care homes, care homes as a place of death, types of care homes and terminology, resident populations in care homes, funding status of care home providers (public, not-for-profit, private), funding of resident care, regulation of care homes, and key drivers for change in care homes at national and regional levels. Initiatives that promoted the provision of palliative care in care homes were identified as exemplars of good practice, alongside any perceived barriers to change.

Documentary Review

Data on the care home context and palliative care provision in this setting were also sought from publically available international statistics from the Organisation for Economic Co-operation and Development, research studies focused on mapping long-term care[12] and palliative care,[8] and national reports and country-level statistics. This provided contextual data to supplement the data provided by country informants and some data for the 4 countries for which surveys were not received.

The data collected from the mapping survey and documentary review were collated by country and domain, and then compared across countries by the domains of interest. We used an adapted typology of organizational change[3] based on work by Ferlie and Shortell[13] to classify the drivers for change and initiatives being undertaken to develop palliative care in care homes. We focus here on 3 levels of implementation activity that support the development of palliative care in care homes in a country: macro-, meso-, and micro-level activity (Table 1). We scored each country for each of the 3 levels based on evidence identified from the survey and secondary data sources.

Findings

The long-term care context in each country and the specific examples on international, national, and organizational initiatives are described elsewhere.[14] Here we consider the development and implementation of palliative care provision and related activities in care homes across countries.

Macro: National and Regional Levels

The macro-level drivers for the implementation of palliative care in care homes at a national and regional level (eg, province, state, canton) reflect the different ways in which health and social care legislation and policies are enacted in individual countries. We classified the drivers into 4 main types: policy, legislation, financial, and regulatory (Table 2). Through this classification it is possible to see the extent to which there is specific attention paid to palliative care provision in care homes at a national/regional level (Figure 1; Supplementary Data 1).

Only 7% (n = 2) of countries addressed palliative care provision in care homes at a national or regional level either in 4 (Belgium) or 3 (United Kingdom) domains (Figure 1). More than half of the countries surveyed (55%; n = 16) (Albania, Croatia Hrvatska, Cyprus, Czech Republic,

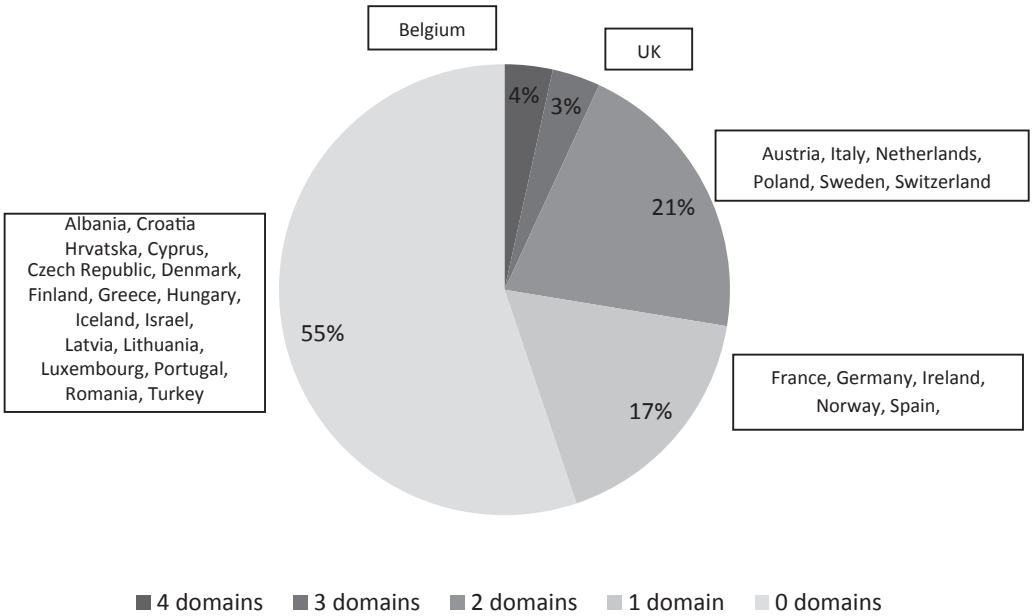

Fig. 1. Number of macro domains engaged with across 20 European countries.

Table 3
Examples of Meso-Level Implementation Activities

Implementation Activity	Example
Education/training	Denmark: Education project in 6 facilities in which palliative care competencies for staff addressed through multidisciplinary education as part of wider staff competency development in the care homes setting. Germany: Deutsche Palliative Stiftung (German Palliative Care Foundation) developed training manuals for care home staff.
Tools/frameworks (eg, care pathways, checklists, quality assurance processes, organizational change programs)	Iceland: The Liverpool Care pathway for the last days of life was introduced into facilities in the metropolitan rea of Reykjavík. Sweden: Use of the Palliative Care registry ensures regular review of care and quality assurance processes in place. United Kingdom: Gold Standards Framework for Care Homes: A program of organizational change that provides a structured process of change to improve palliative care provision in care homes.
Service models (services supporting care homes to deliver palliative care)	Croatia Hrvatska: Croatian Association of Hospice Friends visits nursing homes regularly. Luxembourg: Hospice at home teams support residents in care homes.
Service development/research (projects or research into palliative care practice in care homes)	Belgium: Introduction of the guideline for implementation of palliative care in care homes was led by the Federation Palliative Care Flanders. Ireland: Undertaken a "Let Me Decide" project to introduce a care planning intervention into care homes supported by the Irish Hospice Foundation.

Denmark, Finland, Greece, Hungary, Iceland, Israel, Latvia, Lithuania, Luxembourg, Portugal, Romania, Turkey) had no evidence of any activity in any national/regional domain. Eight countries addressed palliative care provision in care homes in policy documents (Austria, Belgium, Italy, Netherlands, Spain, Sweden, Switzerland, United Kingdom) and 7 countries had addressed this through regulatory processes (Austria, Belgium, Germany, Ireland, Poland, Switzerland, United Kingdom).

Meso-Level Implementation Activities

At a meso level, implementation of palliative care was promoted by development activities that were provided by a range of bodies (nongovernmental organizations, palliative care providers, care home providers) and were delivered across more than 1 facility. Four types of implementation activity were identified, building on the work of van Riet Paap et al.[11] We classified meso-level activities as follows: education and training, use of tools/frameworks, service models supporting care homes, and service development projects or research into palliative care practice (Table 3). These activities could be undertaken nationally or regionally or even within organizations. Based on the data provided, we rated each country, according to the evidence available, for the presence of each type of implementation activity (Figure 2; Supplementary Data 2).

In 28% (n = 8) countries (Austria, Belgium, Denmark, Germany, Ireland, Netherlands, Switzerland, United Kingdom) there was evidence of all 4 types of implementation activities. In just under half of the countries there was no evidence of any activity type (Albania, Cyprus, Latvia, Lithuania, Portugal, Romania, Spain, Turkey) (28%; n = 8) or only 1 type of activity (Croatia Hrvatska, Finland, Greece, Hungary, Israel, Italy) (21%; n = 6). The most frequent activities present were the use of service provision models (62%; n = 18) and education activity (59%; n = 17). However, there are no consistent data on the educational programs in terms of their length or the level of curriculum. Within countries, activity also could vary by facility type. For example, in Poland, staff education is a requirement for staff working in nursing homes, but service provision through hospice at home services can be delivered only in social care facilities.

Micro Level of Engagement

The micro level refers to the proportion of care homes in each country that are directly engaged in providing palliative care for their residents. There are no central registries of care home engagement in palliative care provision, so the assessments are necessarily crude (Figure 3; Supplemental Data 3). There is currently no evidence of palliative care provision in care homes in 17% (n = 5) of countries (Albania, Latvia, Lithuania, Romania, Turkey), minimal activity in 42% (n = 12) of countries (Croatia Hrvatska, Cyprus, Czech Republic, Finland, Greece, Hungary, Iceland, Israel, Italy, Poland, Portugal, Spain), some activity in 17% (n = 5) of countries (Denmark, France,

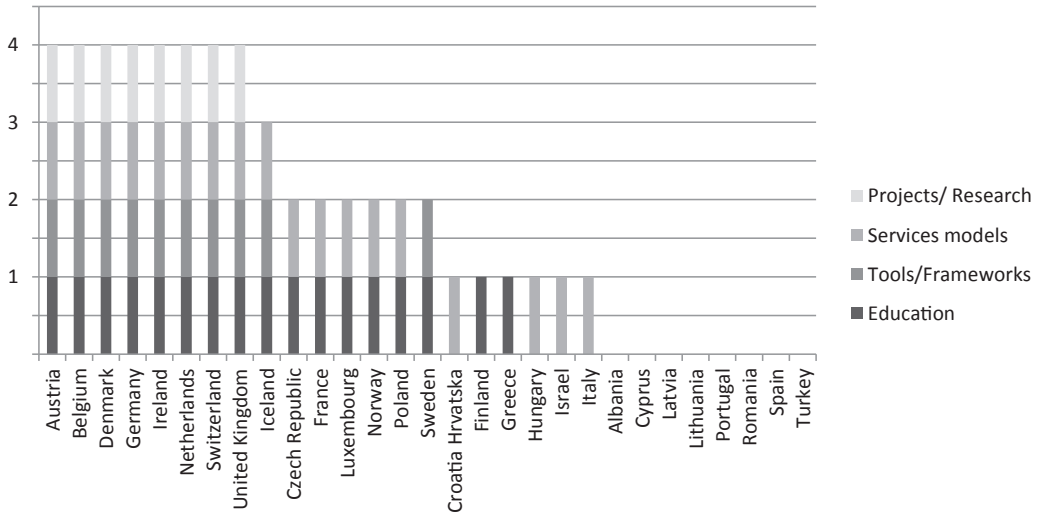

Fig. 2. Extent of meso-level activity by country.

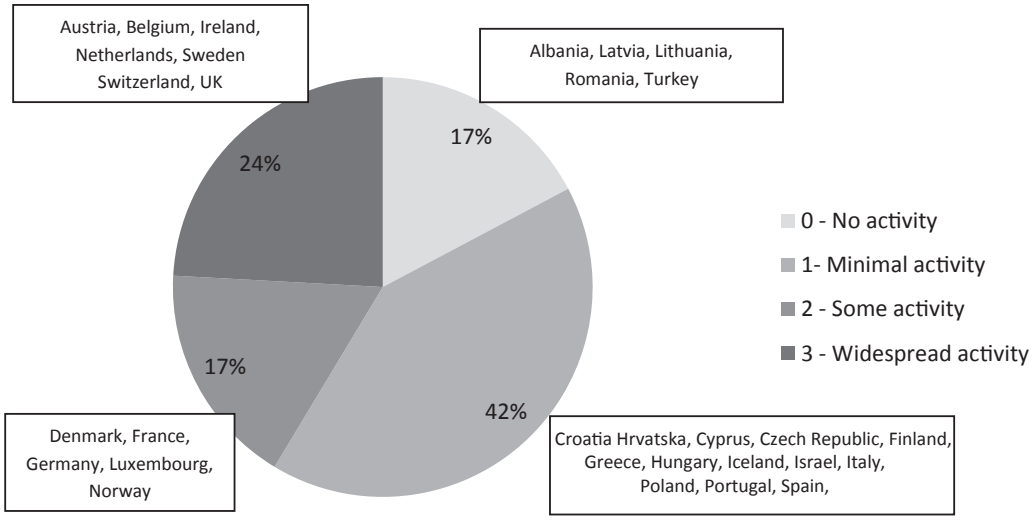

Fig. 3. Extent of micro-level palliative care development activity.

Germany, Luxembourg, Norway), and extensive activity in 24% (n = 7) of countries (Austria, Belgium, Ireland, Netherlands, Sweden, Switzerland, United Kingdom). In no country is there evidence of palliative care provision in all care home facilities.

It is also possible to represent visually the level of meso- and micro-level activity in each country (Figure 4).

Figure 4 shows that countries in which we identified greater evidence of meso-level activities also showed greater micro-level engagement in palliative care delivery in care home organizations. In some countries, there are a full range of implementation initiatives, and a large proportion of facilities are providing palliative care (Austria, Belgium, Denmark, Switzerland, Ireland, Netherlands, United Kingdom). Some countries are engaging with these issues but not yet to the higher levels of activity (Germany, France, Luxembourg, Norway). There are many countries with no, or minimal meso and micro activity, around a palliative care provision in care homes (Croatia Hrvatska, Cyprus, Finland, Greece, Hungary, Israel, Italy, Latvia, Lithuania, Portugal, Romania, Spain, Turkey).

Discussion

This study has provided the first international overview of a palliative care provision and development in care home settings. It proposes a new typology to categorize palliative care implementation in care homes on three levels.

The implementation of palliative care into care homes depends on many factors. Palliative care in this setting is generally not well supported at national or regional levels by enforceable mechanisms, such as legislation or regulation. Legislation influences issues such as staffing levels, staff qualifications, and any obligation for palliative care training and facility accreditation/licensing. Nonenforcable national policy directives and guidelines on palliative care provision are often written for application in any care setting and do not necessarily pay specific attention to the context of care in care homes. Funding policy, can facilitate or hinder the implementation of palliative services in care homes. Funding models for care can create opportunities for new care models, such as palliative care, through funding for specialist types of

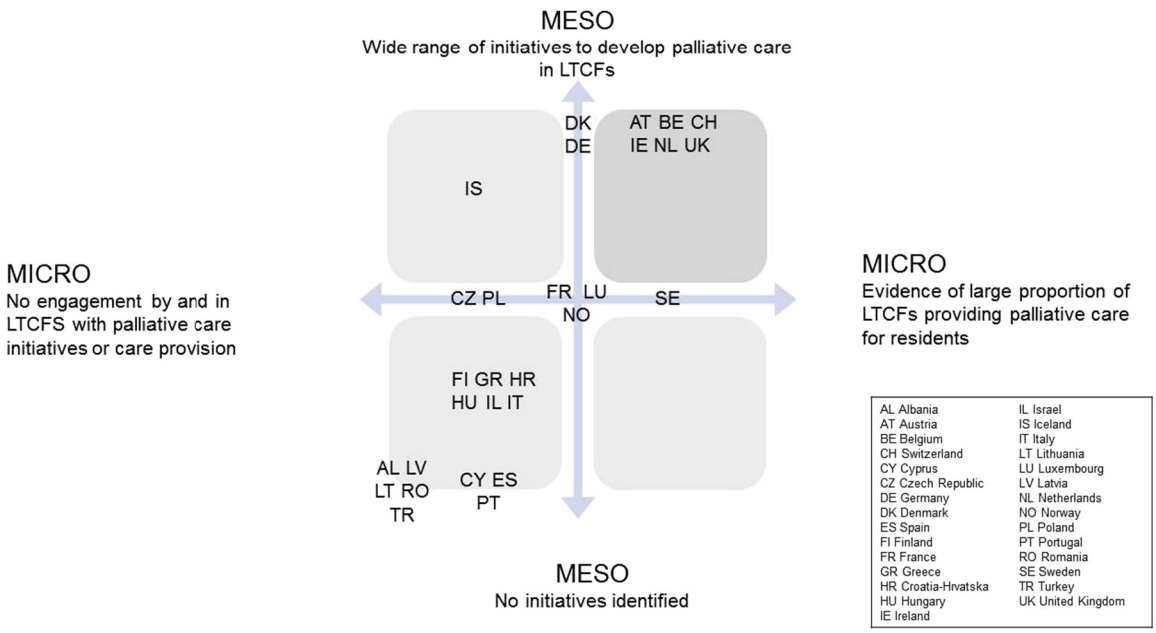

Fig. 4. Comparing meso- and micro-level activity across 29 European countries.

care. These national/regional implementation drivers are then operationalized and implemented at an organizational (micro) level, leading to further variance within countries.

The World Health Organization Public Health Strategy for Palliative Care[15] proposes that appropriate policies, availability of education and training, availability of medicine, and implementation across all levels of society are required to develop palliative care at a country level. This reflects wider knowledge about approaches to change within the health care system, requiring attention at all levels of the system.[13] This is also the case for palliative care in care homes. It has been previously identified that education and training are required to support the development of palliative care in care homes, but these are not sufficient in themselves,[16] so an appropriate policy framework specific to these settings is also needed. However, even with the existing policy in place, this will not necessarily ensure the implementation of palliative care practices within organizations unless the policy is supported by effective implementation processes that include education, and also address how change can be facilitated in the organization.

Overall, we identified low levels of palliative care development and delivery in care homes. The variation in palliative care development in care homes reflects the origins of palliative care and the extent to which it is still often primarily cancer-focused palliative care in some countries.[7,8] Interestingly, this low level of palliative care activity in care homes does not reflect prior findings on the global mapping of specialist palliative care development in countries commissioned by the Worldwide Palliative Care Alliance[17] (Supplementary Data 4). A number of countries that were previously classified as being at levels 4a and 4b, indicating "preliminary or advanced integration of palliative care into mainstream services" are clearly not currently integrated with the care home sector. For example, Finland, Hungary, Israel, Romania, and Spain, although indicating integration of specialist palliative care into services (usually hospitals or care in the community), have little evidence of a countrywide focus on palliative care provision in care homes at the macro, meso, or micro level.

We note that, between countries, there is a great diversity in the amount and quality of data available, reflecting the status of care home organization within and across countries; and the dynamic situation with respect to funding and ongoing organizational change within countries. The use of self-reported data from expert informants in countries has provided insight into activities in the different countries, but this does not provide a comprehensive overview of all activity in a country, as regional differences can distort patterns of service provision.

Conclusions

At a time of great demographic change and increased financial pressures, care homes are an important component of the health and social care economy, especially for a significant proportion of frail older people. They are also the place where these people will experience their dying and deaths. Macro and meso factors at two levels shape palliative care development and provision in care homes at the micro organizational level. Across Europe there is generally a limited strategic engagement through macro-level activity, such as specific legislation, policy guidelines, regulation, or funding mechanisms. Development at the meso and micro levels is supported by macro-level engagement, but also can happen with limited macro strategic drivers. This implementation typology offers a structure with which to review the extent of nationally led and locally supported palliative care activity and development in care homes, and through which to direct future activity.

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Appendix

Supplementary Data 1
Macro: National/Regional Activity

Country	Policies	Legislation	Regulation	Funding	Score
Albania	0	0	0	0	0
Austria	1	0	1	0	2
Belgium	1	1	1	1	4
Croatia Hrvatska	0	0	0	0	0
Cyprus	0	0	0	0	0
Czech Republic	0	0	0	0	0
Denmark	0	0	0	0	0
Finland	0	0	0	0	0
France	0	1	0	0	1
Germany	0	0	1	0	1
Greece	0	0	0	0	0
Hungary	0	0	0	0	0
Iceland	0	0	0	0	0
Ireland	0	0	1	0	1
Israel	0	0	0	0	0
Italy	0	1	0	1	2
Latvia	0	0	0	0	0
Lithuania	0	0	0	0	0
Luxembourg	0	0	0	0	0
Netherlands	1	0	0	1	2
Norway	1	0	0	0	1
Poland	0	0	1	1	2
Portugal	0	0	0	0	0
Romania	0	0	0	0	0
Spain	1	0	0	0	1
Sweden	1	0	0	1	2
Switzerland	1	0	1	0	2
Turkey	0	0	0	0	0
United Kingdom	1	0	1	1	3
Total	8	3	7	6	

Supplementary Data 2
Meso: Implementation Activities

Country	Education	Tools/ Frameworks	Service Models	Projects/ Research	Score
Albania	0	0	0	0	0
Austria	1	1	1	1	4
Belgium	1	1	1	1	4
Croatia Hrvatska	0	0	1	0	1
Cyprus	0	0	0	0	0
Czech Republic	1	0	1	0	2
Denmark	1	1	1	1	4
Finland	1	0	0	0	1
France	1	0	1	0	2
Germany	1	1	1	1	4
Greece	1	0	0	0	1
Hungary	0	0	1	0	1
Iceland	1	1	1	0	3
Ireland	1	1	1	1	4
Israel	0	0	1	0	1
Italy	0	0	1	0	1
Latvia	0	0	0	0	0
Lithuania	0	0	0	0	0
Luxembourg	1	0	1	0	2
Netherlands	1	1	1	1	4
Norway	1	0	1	0	2
Poland*	1	0	1	0	2
Portugal	0	0	0	0	0
Romania	0	0	0	0	0
Spain	0	0	0	0	0
Sweden	1	1	0	0	2
Switzerland	1	1	1	1	4
Turkey	0	0	0	0	0
United Kingdom	1	1	1	1	4

*In Polish Type 2 facilities (which have on-site nurses) only hospice at home services can visit to support residents. In Polish Type 1 facilities (which have on-site nurses and doctors) basic education in palliative care for all nursing staff is a requirement.

Supplementary Data 3
Micro: Palliative Care Service Provision in Care Homes

Country	Score
Albania	0
Austria	3
Belgium	3
Croatia Hrvatska	1
Cyprus	1
Czech Republic	1
Denmark	2
Finland	1
France	2
Germany	2
Greece	1
Hungary	1
Iceland	1
Ireland	3
Israel	1
Italy	1
Latvia	0
Lithuania	0
Luxembourg	2
Netherlands	3
Norway	2
Poland	1
Portugal	1
Romania	0
Spain	1
Sweden	3
Switzerland	3
Turkey	0
United Kingdom	3

Micro: Delivery of care: 0, No activity; 1, Minimal activity; 2, Some activity; 3, Widespread activity; 4, Full activity.

Supplementary Data 4
World Palliative Care Association Country Classification[17]

Country	Macro	Meso	Micro	Score	Classification
Belgium	4	4	3	11	4b
United Kingdom	3	4	3	10	4b
Austria	2	4	3	9	4b
Netherlands	2	4	3	9	4a
Ireland	1	4	3	8	4b
Germany	1	4	2	7	4b
Norway	1	4	2	7	4b
Switzerland	2	2	3	7	4b
Denmark	0	4	2	6	4a
France	1	2	2	5	4b
Poland	2	2	1	5	4b
Sweden	2	0	3	5	4b
Iceland	0	3	1	4	4b
Italy	2	1	1	4	4b
Luxembourg	0	2	2	4	4a
Czech Republic	0	2	1	3	3b
Portugal	0	2	1	3	3b
Croatia Hrvatska	0	1	1	2	3b
Finland	0	1	1	2	4a
Greece	0	1	1	2	3a
Hungary	0	1	1	2	4a
Israel	0	1	1	2	4a
Spain	1	0	1	2	4a
Cyprus	0	0	1	1	3b
Albania	0	0	0	0	3b
Latvia	0	0	0	0	3a
Lithuania	0	0	0	0	3b
Romania	0	0	0	0	4b
Turkey	0	0	0	0	3b

Key: 4b, advanced integration into mainstream service provision; 4a, preliminary integration into mainstream service provision; 3b, generalized palliative care provision; 3a, isolated palliative care provision.