Mapping palliative care systems in long term care facilities in Europe

PACE Work Package 1 and EAPC Taskforce Report

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EXECUTIVE SUMMARY

Background

Changes in population demography across Europe are leading to an increased proportion of older people needing to access appropriate care and support services. For some older people, living with multiple complex health conditions, a decision will be made to move into a long-term care facility (LTCF), as they are no longer able to live in their own homes. Residents in LTCFs will require palliative and end of life care within these facilities. This can be provided by health and social care staff working within, and external to, the organisation. The provision and development of palliative care in LTCFs has received increased attention. An EAPC Taskforce: *Palliative Care in Long-Term Care Settings for Older People,* reporting between 2010 to 2013, examined how palliative care was being developed in LTCFs in 13 European countries. This identified a range of different initiatives and interventions being developed and implemented across the 13 countries. The PACE (*Comparing the effectiveness of palliative care for older people in long term care facilities in Europe*) research programme funded to run from 2014-2019, includes a Work Package that develops the work of the Taskforce by establishing a second taskforce: *Mapping palliative care systems in long term care facilities in Europe* which considers palliative care provision in LTCFS across 29 European countries affiliated to the EAPC.

Note: in the context of this study and Taskforce, 'long-term care facilities' refers to a collective institutional setting where care is provided to older people onsite 24 hours a day, 7 days a week. The acronym 'LTCF' is used in the report.

Aim and Objectives

The aim of the study is to map and classify different structures, organizational models, and policies related to palliative care provision in long term care facilities in Europe.

The study has the following objectives:

1. To map the numbers, nature and types of European LTCFs
2. To identify the proportion of deaths in European LTCFs
3. To describe the funding and regulatory context for European LTCFs
4. To describe existing formal palliative care structures or services, organizations and policies at local, regional, national or international level and their development in European LTCFs
5. To collate examples of current palliative care practices and innovative approaches and their evidence base.

Methods

Data was collected 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 UK.

Two methods of data collection were undertaken: i) country mapping survey and ii) documentary review.

i) country mapping survey

The country mapping survey sought to describe the broader context for palliative care in LTCFs in each country, alongside examples of initiatives being undertaken to develop palliative care in LTCFs. Country informants were identified for 24 countries. Country informants received a survey

questionnaire. Data on the country context was collected about the following domains in each country: organisation of care; place of death; types of LTCFs and terminology; resident populations in LTCFs; status of LTC provision; funding of LTCF provision; regulation of LTCFs; and key drivers for change in LTCFs at national and regional levels.

Initiatives that promoted the provision of palliative care in LTCFs were identified that provided exemplars of good practice, rather than a comprehensive survey of all activity within each country.

ii) documentary review

Data on the LTCF context and palliative care provision in this setting were also sought from policy documents, research studies and reports to supplement the mapping surveys and provide data on the countries for which surveys were not be received.

The data collected from the mapping survey and documentary review was collated by country and domain. The data was compared across countries by the domains of interest. The typlogy of organisational change developed in the first Taskforce, and based on work by Ferlie and Shortell (2001) was used as an analytical framework to describe the drivers for change and initiatives that are being undertaken to develop palliative care in LTCFs.

Findings

The findings are presented in three parts. Part 1 presents an account of key features of included countries with regard to demography, LTCF characteristics and death and dying in this setting. Part 2 addresses the development of palliative care in LTCFs considering the wider policy context for such developments. In Part 3 data on exemplar initiatives are considered.

Country Context

Country demographics

These countries represented a range in terms of population size and proportion of older people. The countries ranged in population size from 323,000 (Iceland) to over 80 million (Germany). The proportion of the population that is 65 years and older varied between 7.6% in Turkey to just over 20% in Italy and Germany

LTCF characteristics

The data available about long-term care facilities concerned the proportion of beds in LTCFs for older people, the proportion for older people who reside in such facilities, the types of LTCFs, organizational status of LTCFS in terms of their location in the public, private or not-for-profit sectors and how care is funded for older people living in such facilities. The average number of long term care beds per 1000 inhabitants across the 20 countries providing data was 51.8 (Range 17.5 beds in Poland, to 79.5 beds in Luxembourg).

Three types of LTCF provision can be identified across Europe, classified according to how medical and nursing care services are provided. Type 1 facilities provide on-site medical and nursing care; Type 2 facilities provide on-site nursing care, but rely on external primary care medical support. Type 3 LTCFs rely on external primary care services for both medical and nursing care. The majority of countries provide two of these types of facilities and also differentiate between care for people with lower and higher levels of dependency.

Different patterns of organisational provision are present across Europe in terms of the organisational funding structures, with varying reliance on the public, not-for-profit and private sectors to deliver care in LTCFs. The proportion of the different providers appears to reflect the wider models of health funding. Where the social model of care is strong, the public sector is an important provider of LTCF care. Not-for-profit organisations are present in all countries to some extent.

Funding for care also reflects the wider health economy of each country, but mixed sources of funding exist in most countries. Funding is derived from public provision through health and social care funding, or personal funds held by individuals. Individuals may pay through private insurance, or their own capital and or income. In some countries, family members may be required to pay.

All countries have regulatory processes that shape how care is provided in LTCFs. Regulation is manifest in three ways:

1. Registration and certification (accreditation) of LTCFs
2. Requirements regarding standards of care, which may be enforcable or only recommendations
3. Quality monitoring systems and bodies.

These may be set and/or administered at a national and/or regional level.

LTCF population characteristics

The LTCF population characteristics were considered by the proportion of older people residing in LTCFs, the gender balance within facilities, and the presence of dementia in the LTCF population. Further information about length of stay, dependency levels and identified palliative care needs has also been collated (Table 5).

The proportion of older people living in LTCFs ranges from 0.3% (Cyprus) to just under 8% (Belgium) on data from 22 countries. Except in Turkey, the proportion of women exceeds men in LTCFS. The proportion of men aged 65+ living in LTCFs ranges from 23.6% in the Netherlands to 59% in Turkey. Limited data from 13 countries indicated that the proportion of people with dementia living in LTCFs varied from 13.4% (Hungary) to 70-80% (Sweden). There was less information on resident dependency levels, so comparisons were not possible.

Data was identified for 14 countries on length of stay. The average length of stay in LTCFs ranges from 63 days (Israel) to over 2000 days (60 months) in Luxembourg, with stays of over 1000 days (30 months) in the Netherlands and Ireland.

Death and Dying

Data on place of death were identified from 16 countries. The proportion of deaths amongst older people in LTCFs varied from no deaths in Albania to 61.1% of deaths in Finland, with the highest proportion of deaths in the countries with Type 3 LTCFs (e.g. health centre wards in Finland). Data on death rates and the proportion of residents receiving palliative care in LTCFs is too limited to draw clear conclusions.

Development of Palliative Care in LTCFs

Initiatives to develop palliative care in LTCFs were considered at a number of different levels: international, national, regional/networks and organisational including groups/teams and individual staff.

International collaboration: The current PACE project is the only example of international European collaboration focused on palliative care in LTCFs, although collaborations focused on palliative care and dementia are being undertaken.

National and Regional: An overview of the national and regional strategies that exist in each country has been collated. This shows there is wide variation in the development of palliative care and LTCF care and shows how palliative care in LTCFs is generally not well supported at a national or regional level by enforcable mechanisms. National directives and guidelines on palliative care provision in general are often operationalised and implemented at a more local level leading to further variance within countries. Examples of palliative care service delivery initiatives in LTCFs can be identified in many countries, and these have been compared to the general assessment of palliative care development in each country. This shows that there is no clear association between the level of palliative care development in a country and the extent to which palliative care provision is being developed in LTCFs.

Organisational including team and individual initiatives: A number of initiatives have been identified across the countries that are implemented at an organisational level engaging with staff in groups or individually. These include designated palliative care units/beds, person focused care interventions, care planning interventions, organisational policy development, organisational multi-dimensional interventions and education and training initiatives. What stands out here from the comparison between countries?

Discussion

A number of similarities and differences are identified across different European countries between the countries that participated in the mapping survey concerning the increased interest in this field, the differentiated service provision, issues of quality management and the extent to which strategic policy initiatives exist. The variation in palliative care development in LTCFs reflects the origins of palliative care and the extent to which it is still often primarily cancer-focused palliative care in some countries.

Examples of current palliative care practices and innovative approaches to the development of palliative care in LTCFs have been identified, but their evidence base is limited in many instances. Much work reported here has developed in practice, without rigorous evaluation in many instances. The WHO Public Health Strategy for Palliative Care 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 is also the case for palliative care in LTCFs.

It has been previously identified that education and training are required to support the development of palliative care in LTCFs, but are not sufficient in themselves; so an appropriate

policy framework specific to these settings is also needed. However, even with existing policy in place, this will not necessarily ensure the implementation of palliative care practices within organisations unless the policy is supported by effective implementation processes that include education, but also addresses how change can be facilitated in the organisation.

Conclusions

This mapping of palliative care provision in LTCFs has shown both the diversity of the LTCF sector in Europe, with examples of innovative interventions, and practices at national, regional and organisational levels. At a time of great demographic change and increased financial pressures, LTCFs 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. Many challenges lie in ensuring the delivery of palliative care in LTCFs in a consistent and high quality way. These challenges lie in ensuring that national policies, funding, regulatory and quality assurance frameworks specifically address palliative care for older people in LTCFs. This then needs to be supported by appropriate implementation approaches at more local and organisational levels to ensure staff are equipped to deliver palliative care with appropriate resources and support from within, and externally, to LTCFs.

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1. Background

There is growing evidence across Europe and other developed countries that the changing demography is leading to an older population (Albers *et al..* 2015). On average across OECD countries, the proportion of the population aged over 65 years has increased from less than 9% in 1960 to 15% in 2010 and is expected to nearly double in the next four decades to reach 27% in 2050 (OECD/European Commission 2013). To support an increased number of older people (65 years+) needing care in the coming years, there is a need to address the changing care demands and planning for new models of service provision that will be required. Across Europe and at a national level, particular consideration is being given to the place of long-term care for older people, with respect to models of service delivery and funding (OECD 2011; Riedel and Kraus 2011, Ökem 2015). Attention is often paid to ensuring that care delivery is of a high standard, as there are concerns about consistent quality provision across the sector (Nies *et al..* 2010) and about how the rights of older people in need of care are fulfilled (AGE Platform Europe, 2010). Long-term care may be provided in either people's own homes, the homes of family members or in institutional settings.

A move to a long-term care facility reflects an individual's needs for a higher level of care than can be provided in their domestic setting, even with family and statutory service support, where available (Ökem 2015). Older people living in such settings often have complex trajectories of dying: many people live with non-cancer co-morbidities, and there is a high prevalence of dementia in this population (Hall *et al.* 2011, Kojer and Schmidl 2011). It is recognised that many older people die in long-term care facilities (Hall *et al.* 2011). This raises challenges for medical, nursing and other practitioners in terms of dealing with physical and psychological symptoms, spiritual and social needs, financial problems, and other aspects of palliative and end of life care.
Dignified support towards the end of life in long-term care facilities needs a relational, appreciative (Pleschberger 2007) and a person-centred approach (Luherne 2012). This should ideally involve becoming informed about the past and current situation of the older person (socially and medically), and adapting to the person's wishes and expectations as much as possible. Long-term care facilities draw on a range of medical and, nursing and allied health specialists to meet the care needs of residents, including geriatrics, gerontology, primary care and palliative care.
Given recent developments in the residential long-term care sector from traditional institutions to more flexible residential care units and changes in funding for care, care management practices, and research, there is a need to maximize resources and expertise. The sector is known to have challenges with staffing in terms of recruitment, retention and ongoing training (Froggatt *et al.* 2009). Therefore, a sharing of good practice between countries and also between different disciplines, for example, geriatric and gerontological specialists, palliative care specialists, the hospice sector, long-term care practitioners, older people's organisations and informal carers' organisations, could be beneficial.

Within palliative care, the mapping of palliative care provision is well established in Europe (Centeno *et al.* 2007, 2013). However, the focus is upon the provision of specialist palliative care in a range of settings, with no mention of LTCFS in 2007 and some mention in the 2013 edition.

Systematic mapping of the LTCF sector with respect to palliative care provision and its development is required.

Between 2010 and 2013, an EAPC Taskforce *Palliative Care in Long-Term Care Settings for Older People* examined how palliative care was being developed in long-term care settings in 13 European countries (Froggatt and Reitinger 2013). The findings of the mapping exercise identified that across the countries surveyed, long-term care settings are generally categorised into two types. This reflected a division into care provision for people with low and high needs. In some countries a third level of care existed, allied to acute hospital settings. In most countries the funding status of providers of institutional long-term care was mixed with providers drawn from the private sector, public sector and voluntary, charitable or not-for-profit sector. The only exceptions were The Netherlands and Norway which at that time only worked with public sector providers. Funding for individuals residing in these facilities is drawn from a mixture of sources - state funding, health and social insurance, personal and/or family monies. In all countries regulation exists to ensure the quality of care provided in the setting – this is either overseen nationally or at a provincial level. The development of palliative care provision within long-term care settings is of increasing importance in all countries. Key drivers for this work exist at international, national, regional and local levels within the palliative care and long-term care context. For example, the recent World Health Assembly (2014) resolution '*Strengthening of palliative care as a component of integrated treatment within the continuum of care'* supports change in national health systems (World Health Assembly 2014).

Initiatives to support the development of palliative care provision in long-term care settings were identified from 12 countries: Austria, Belgium, France, Germany, Ireland, Italy, The Netherlands, Norway, Spain, Sweden, Switzerland and UK. Over 60 initiatives were identified and a number of common examples were identified. This was not intended to be a comprehensive inventory of all initiatives but rather give insights into different types of examples. The initiatives were categorised using a modified typology of change implementation developed by Ferlie and Shortell (2001). In the modified typology, initiatives were considered in terms of the focus of change and where the benefits of the change would be seen. This was considered at five levels: individual (resident, family, staff), team/group, organization, regional/network and national. It was noted that many initiatives for which information was provided worked across more than one level indicating the need to consider wider contextual matters in development of this work given its complexity and the inter relationships between the different levels identified.

One limitation identified with this work was the limited number of countries that were mapped in the survey. Some important geographic regions of Europe were not represented in the mapping survey and the development of palliative care systems in all countries was not systematically mapped and classified. This led to a need to extend the mapping to other areas of Europe.

A second EAPC Taskforce was convened in 2014, as part of the research being undertaken by the EUFP7 study: "*Comparing the effectiveness of palliative care for older people in long term care facilities in Europe*" (PACE). This research aims to extend the mapping survey to a wider number of European countries reflecting a more diverse range of countries, and pays greater attention to models of palliative care provision.

1.1 Definitions

The definitions concerning palliative care and long-term care facilities were drawn from the previous Taskforce (See Froggatt and Reitinger 2013).

The following definition of long-term care facility for older people (65+) was used:

- A collective institutional setting where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time;
- The care provided includes on site provision of personal assistance with activities of daily living;
- Nursing and medical care may be provided on-site or by nursing and medical professionals working from an organisation external to the setting. (Froggatt and Reitinger 2013: 14).

The research was not concerned with housing with care initiatives (such as assisted housing, sheltered housing). In housing with care contexts older people are tenants of their residence, and have either bought or rent their "living space". This is not the case in long-term care facilities.

2. Aims and objectives

Aim:

To map and classify different structures, organizational models, and policies related to palliative care provision in long term care facilities (LTCFs) in Europe.

Objectives:

1. To map the numbers, nature and types of European LTCFs
2. To identify the proportion of deaths in European LTCFs
3. To describe the funding and regulatory context for European LTCFs
4. To describe existing formal palliative care structures or services, organizations and policies at local, regional, national or international level and their development in European LTCFs
5. To collate examples of current palliative care practices and innovative approaches and their evidence base.

3. Methods

Two methods of data collection were undertaken: i) country mapping survey and ii) documentary review.

3.1 Country Mapping Survey

Country Recruitment and Participation

Data was sought from twenty nine countries in the mapping survey: 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 UK. By including these countries representation from Central and Eastern Europe was sought to broaden the mapping activity,

beyond the work of the first Taskforce, to reflect the different levels of resource, and differing patterns of state and family involvement in care provision (Kraus *et al.* 2010) across Europe.

Country informants

In order to facilitate the mapping exercise a network of country informants was identified in 24 of the countries (Appendix 1). Individuals agreed to be the point of contact for correspondence with regards to the collection of information about each country. Country Informants were identified as experts in the field of palliative care in long-term care facilities for older people, with relevant practice, research and/or education experience in this topic, and had links to other experts and specialist contacts within their respective countries. These individuals were identified through the partner organisations (for example, the EAPC, AGE Platform Europe, Alzheimer Europe and the European Forum for Primary Care).

Survey Tool

A 13 page document survey was designed, adapting sections used for the first EAPC Taskforce. Steering group feedback was received up to version 5 of the survey. The final, working version contained: Instructions and Definitions and three further sections: country informant information; country context data; and examples of existing interventions, initiatives and innovative practices (Appendix 2).

The country context data was collected about the following domains of LTCFs and palliative care in each country: organisation of care; place of death data; types of LTCFs and terminology; resident populations in LTCFs; status of LTC provision; funding of LTCF provision; regulation of LTCFs; and key drivers for change in LTCFs at national and regional levels (Table 1).

Care needs to be taken with international comparisons (Loucka *et al.* 2014). Whilst the same template was used to collect country data, each country informant used different sources to answer the questions (publications, political information, and other experts in the field) and some data is not directly comparable.

Data on the **initiatives** that promoted the provision of palliative care in LTCFs was sought that provided exemplars of good practice, rather than a comprehensive survey of all activity within each country. The following sources of data were utilised by the country informants:

- Published policy documents, statistics, reports and research;
- Personal expertise gathered through engagement in the field;
- Involvement of other national experts from professional network or specialist palliative care networks.

It should be noted, that although data was obtained from 29 participating countries, the data sets are not always complete so the findings vary in their comprehensiveness.

Table 1: Country Context Data Collection Domains

Domain	Explanation
Country	How care is organised in the country, by state, region or province.
Place of death	Proportion/s of deaths of older people in LTCFs.
Types of LTCFs and Terminology to describe these	▪ Names and titles used to describe LTCFs in country. ▪ Include different types of facilities with respect to how medical and nursing care are provided. ▪ Status of staff: employed by the LTCFs or employed by external organisations and visit the LTCFs to provide care. ▪ Training level and qualifications of care staff employed by the LTCFs.
Resident populations in LTCFs	Total national figures: ▪ of older people living in LTCFs, with gender figures if available. ▪ of older people receiving palliative care in LTCFs ▪ of older people with a dementia diagnosis in in LTCFs ▪ of mean length of stay of older people in LTCFs. ▪ resident dependency levels in LTCFs (Include national guidelines and tools used for measuring dependency levels).
Status of LTC provision	Funding status of providers of LTC for older people in the country e.g. private (for-profit), public (not-for-profit), voluntary or charitable (not-for-profit) sectors (includes the relative proportions of LTCFs (both numbers and %) in each category cited).
Funding of LTCF provision	Sources of funding for care in LTCFs for older people, with respect to: public funding, insurance, older person / resident and / or family monies.
Regulation of LTCFs	▪ How LTCFs are regulated ▪ National/state/regional regulatory bodies ▪ Standards or guidelines used ▪ How quality of care is controlled/measured in LTCFs. Any national standards and certification measure that apply ▪ Guidelines on minimum levels of staff: resident ratios, if exist
National and Regional Key Drivers for Change in LTCFs	Policy and practice drivers (from the palliative care long term care sector, geriatric medicine, or other sectors) for the development of palliative care for older people in LTCFs.

3.2 Documentary Review

The mapping survey was supplemented by data drawn from other reports and information from a policy and research perspective eg European Atlas of Palliative Care, EAPC Taskforce on Primary Care, the EUSTaCEA project (supported by the European Commission's DG JUST Daphne III Programme) and its follow-up project WeDO on the Wellbeing and Dignity of Older People (supported by the European Commission's pilot projects funding from DG EMPL). This provided data on all 29 countries included in the survey.

3.3 Data Analysis

The data collected from the mapping survey and documentary review was collated by country and domain. The data was compared across countries by the domains of interest. The typology of organisational change developed in the first Taskforce, and based on work by Ferlie and Shortell

(2001) was used as an analytical framework to describe the drivers for change and initiatives that are being undertaken to develop palliative care in LTCFs. A descriptive account of the key issues is presented here. Further sense checking was undertaken through a review of the findings by members of the Steering Group and PACE Dissemination partners.

Ethics Approval

Ethical approval was not sought as the data used in this mapping exercise was information already available in the public domain and in published literature.

4. Findings

The findings are presented in two parts (Sections 4 and 5). In Section 4, the country context information describes the findings regarding the demographic structure of the country (4.1), the organizational characteristics of LTCFs across Europe (4.2), the population residing in LTCFs (4.3) and the features of death and dying in LTCFs (4.4). In Section 5, an account of the ways in which palliative care is being developed within LTCFs is presented, considering the key drivers for change that would impact upon the development of palliative care within LTCFs are also identified.

4.1 Overview of country demographics

The countries involved in this mapping exercise represented a range in terms of population size and proportion of older people. The population size varied from 323,000 (Iceland) to over 80 million (Germany). As a proportion of the population, the proportion of the population that is 65 years and older varied between 7.6% in Turkey to just over 20% in Italy and Germany (Figure 1; Table 2).

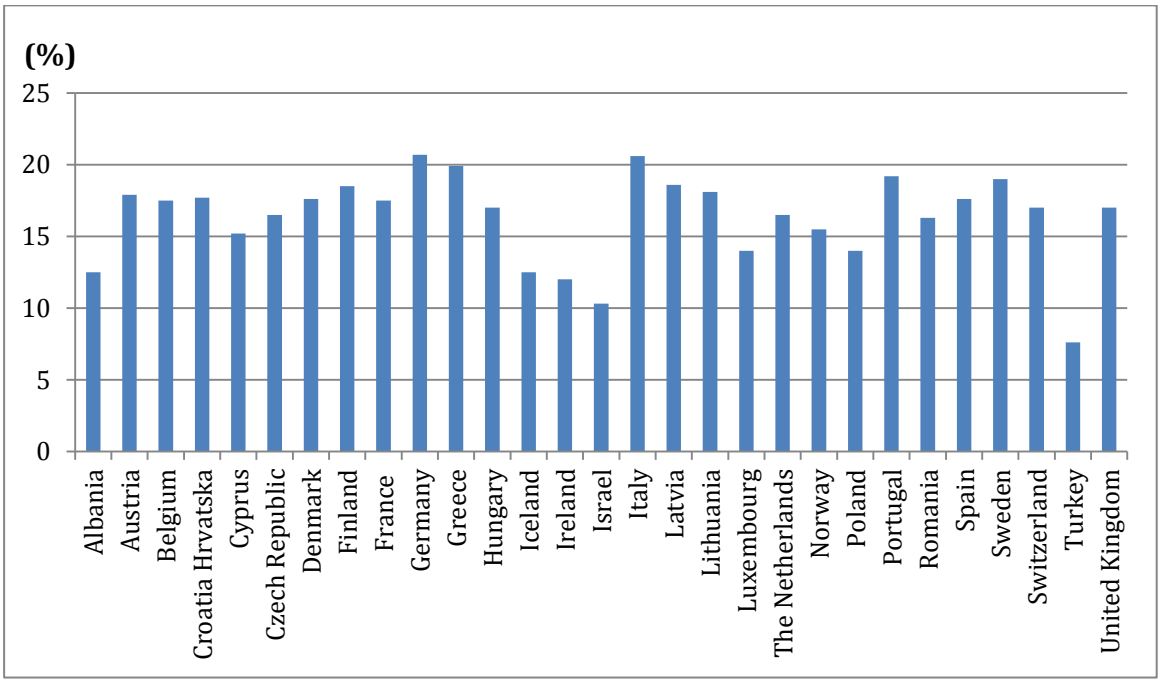

Figure 1: Proportion of population, aged 65+ (OECD 2012)

Table 2: Population, citizens 65+ and proportion of population 65+

Country	Population (Thousands)	No. of Citizens 65+ (Thousands)	Proportion of population, 65+ (%)
Albania[1]	289,3000	360,220	12.5
Austria[2]	8,426,311	1,512,261	17.9
Belgium[2]	11,128,250	1,942,293	17.5
Croatia Hrvatska[3]	4,285,000	758,633	17.7
Cyprus[4]	840,000	NK	15.2
Czech Republic[2]	10,509,290	1,734,367	16.5
Denmark[2]	5,591,572	983,941	17.6
Finland[2]	5,413,000	999,000	18.5
France [2,]	63,519,080	11,136,189	17.5
Germany[2]	81,932,160	16,941,731	20.7
Greece[2]	11,090,000	2,208,000	19.9
Hungary[2]	9,920,361	1,688,793	17.0
Iceland[2]	319,013	3,9736	12.5
Ireland[2]	4,585,400	549,300	12.0
Israel[3]	7,910,500	814,200	10.3
Italy[2]	6,091,6200	12,554,363	20.6
Latvia[5]	2,001,468	NK	18.6
Lithuania[5]	2,943,311	NK	18.1
Luxembourg[2]	530,946	74,158	14.0
The Netherlands[2]	16,754,960	277,0355	16.5
Norway[2]	5,019,000	780,000	15.5
Poland[2]	38,533,790	5,403,640	14.0
Portugal[2]	10,514,840	2,020,125	19.2
Romania[5]	19,947,311	NK	16.3
Spain[2]	46,146,580	8,099,824	17.6
Sweden[2]	9,519,374	1,806,474	19.0
Switzerland[2]	7,912,398	1,347,422	17.0
Turkey[2]	75,175,820	5,676,863	7.6
United Kingdom[2]	63,705,000	10,840,900	17.0

1. http://www.instat.gov.al/en/themes/population.aspx
2. OECD 2012 (http://stats.oecd.org/)
3. Croatia http://www.dzs.hr/default_e.htm
4. Cyprus http://www.cystat.gov.cy/mof/cystat/statistics.nsf/populationcondition_22main_en/populationcondition_22main_en?OpenForm&sub=2&sel=2
5. http://ec.europa.eu/eurostat/

NK: Not Known

4.2 Long Term Care Facility characteristics

The data available about long-term care facilities concerned the proportion of beds in LTCFs for older people, the proportion for older people who reside in such facilities, the types of LTCFs, organizational status of LTCFS in terms of their location in the private (for-profit), public (not-for-profit), or private (not-for-profit) sectors and how care is funded for older people living in such facilities.

LTCF bed availability

Data from the OECD (OECD 2012) (Figure 2) provides an indication of the proportion of long-term care beds available for older people. Where country data was not provided by the OECD, data from the Ancien project (Riedel and Kraus 2011) was used.

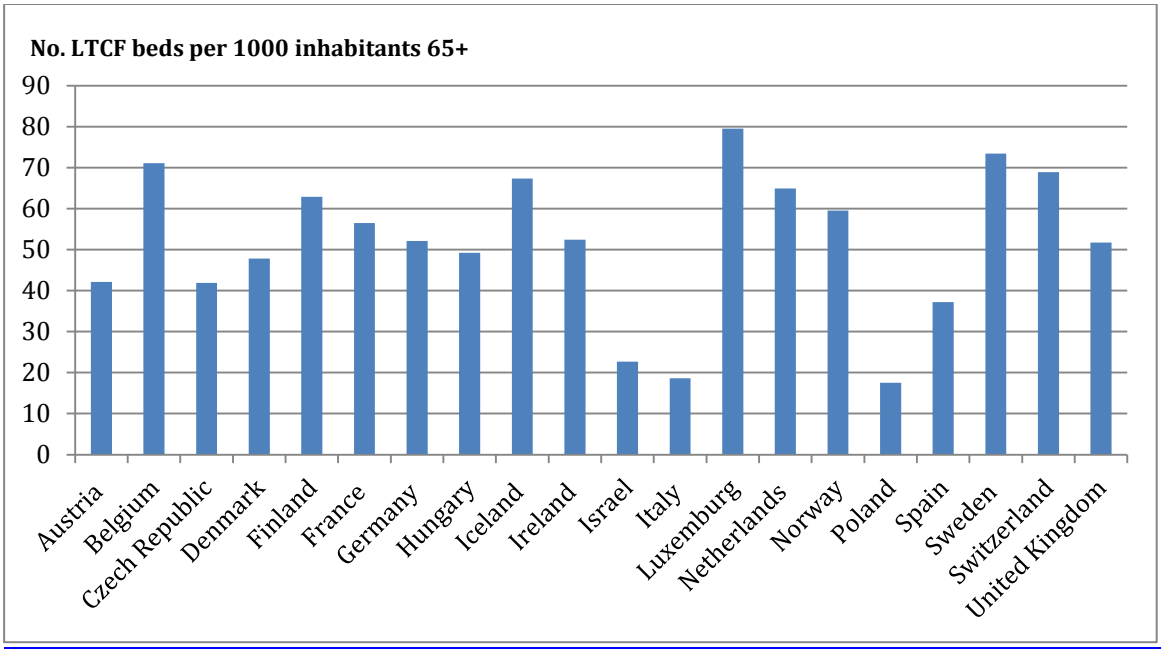

Figure 2: Long-term care beds in institutions for population 65+, (2011/closest year) (OECD 2013b)

Data was available for 20 countries. No data was available for: Albania, Croatia- Hrvatsk, Cyprus, Greece, Latvia, Lithuania, Portugal, Romania and Turkey. The numbers of long term beds vary greatly from only 17.5 beds per 1000 inhabitants 65+ in Poland, to 79.5 beds per 1000 inhabitants 65+ in Luxembourg. The average number of long term care beds per 1000 inhabitants across the 20 countries was 51.8. The average for the three Central and Eastern European countries (the Czech Republic, Hungary and Poland) was lower at 36.2 beds per 1000.

Types of Long-Term Care facilities

Three types of LTCF provision can be identified across Europe, on the basis of how medical and nursing services are provided, reflecting the underlying dependency of the residents (Table 3; Appendix 3). Facilities supporting the most dependent older people (Type 1) provide on-site physicians, nurses and care assistants (e.g. Netherlands, Italy, Norway). In some countries this provision is located in hospital like institutions and used for some types of support, often over a shorter time period (e.g. Austria, Finland, France, Germany). Type 2 facilities employ nurses and care assistants on-site, providing 24 hour a day/seven days a week nursing care and rely on

Table 3: Typology of LTCFS by Country

Country	No. of LTCFs	TYPE 1: **On-site:** physicians, nurses, care assistants	TYPE 2: **On-site:** nurses, care assistants **Off-site**: physicians	TYPE 3: **On-site**: care assistants, **Off site**: physicians, nurses	Typology not known
Austria (Riedel and Kraus 2011)	773	Geriatric centres (*Geriatriezentrum*)	Nursing homes (*Pflegeheim*)	Retirement homes (*Altenwohnheim, Seniorenresidenz*)	
Belgium	NK		Nursing Homes (*WoonZorgCentra*) with RVT *(Rust en Verzorgingstehuis)* and ROB *(Rustoord voor Bejaarden)* beds	(Homes for Older People (ROB)) Only a few of these facilities remain open.	
Cyprus	NK				• State Nursing homes • Private care homes • Local Community care homes
Czech Republic	NK				• Residential care • Rehabilitation and nursing • Pensioner homes • Residential homes for older people
Denmark	NK		Nursing homes (*plejehjem*)	Care homes (*plejeboliger*)	
Finland	160	Long-term care facilities	Long-term care facilities		
France		Hospital long term units (USLD)	Nursing homes: (EHPAD)	Retirement Homes (*maison de retraite, foyers lodgement*s)	
Germany (Schulz 2010)	11,029		Nursing home (*Pflegeheim*)	Old People's Home (*Altenheim/Altenwohnheim)* Home for Senior Citizens (*Seniorenheim*) with Nursing unit or Care ward (*Pflegestation)*	
Greece	NK				Residential Care Homes Nursing Care facilities
Hungary	NK	Nursing Homes		Residential Care Homes	
Iceland	NK		Nursing homes	Residential homes	
Ireland	589		Nursing homes	Residential care	

Israel	NK	Nursing homes	Nursing homes		
Italy	8,154	Nursing homes (RSA)	Homes for older people		
Latvia (Sosars 2010 cited in Centeno 2013)	18				Long-term social care (*Ilgstošassociālāsaprūpes*) Social rehabilitation facility (*sociālāsrehabilitācijasinstitūcija*)
Lithuania	NK		Nursing services (health care sector)	Social care institutions	
Luxembourg	NK		Nursing Home	Residential Care Home	
Netherlands	2000	Nursing homes (*Verpleeghuizen*)	Residential homes (V*erzorgingshuizen*);		
Norway	900 (Type 2)		Nursing Homes	Municipality homes	
Poland	NK	Care and treatment centres (ZOL-Zakład Opiekuńczo-Leczniczy) Care and nursing centres (ZPO- Zakład Pielegnacyjno-Opiekuńczy)	Residential homes (DPS-Dom Pomocy Społecznej)	Residential homes (DPS -Dom Pomocy Społecznej)	
Portugal	NK	Continuing Care Unit or convalescent units	Care homes/Residential Structure for Older People (*ERPI- Estrutura Residencial para Pessoas Idosas*) or "Lar"	Rest home or Assisted Residences (*Residências Assistidas*)	
Romania	122				Nursing home Residential care home
Spain	NK		Nursing homes *(Centros residenciales para personas mayores en situación de dependencia, Residencias assistidas)*	Residential homes *(Residencias para personas mayores, also Residencias de válidos)*	
Sweden	NK		Nursing homes (*Sjukhem*)	Group homes (*Gruppbiende for personer med demens*) Residential care facilities (*Ălder-domshem*)	
Switzerland (Gobet *et al.* 2009)	1,567	Nursing care homes (*Pflegeheim; Etablissement Médico-social (EMS); Casa di Cura Medicalizzata*)	Nursing care homes (*Pflegeheim; Etablissement Médico-social (EMS); Casa di Cura Medicalizzata*)	Older people's homes (*Altersheim; Maisons pour personnes agés; Casa di cura non medicalizzata*)	
Turkey	404		Nursing homes	Rest Homes	
UK (England)	17, 808		Care homes (nursing)	Care homes (residential care)	

medical provision from external providers (e.g. Ireland, UK). Residents with the lower levels of dependency are cared for in LTCFs where the only on-site care is provided by care assistants (Type 3). Nursing and medical provision is provided by local primary care services (e.g. Denmark, Hungary, Luxembourg). In the majority of countries, two types of provision exist. Three types of LTCFs can be found in Austria, Cyprus, Czech Republic, France, Poland, Portugal and Switzerland. The situation is continuing to change in terms of the long-term care sector and the funding and organisational models are evolving, with changes of provision and structure happening more recently in the Netherlands and Poland.

There are also new developments occurring with respect to care for older people with lower levels of need for health and social care, with an increasing rise in the use of supported housing to replace former low care residential facilities (e.g. Germany, Norway, Denmark, Israel, Portugal and Turkey) and the development of home care and networks of personal household and domestic services. These settings have not been addressed in the work of the Taskforce, but would warrant further investigation

LTCF Organisational status

Different patterns of organisational provision are present across Europe in terms of the organisational funding structures (Figure 3), with different reliance on public, not-for-profit and private sectors. The public sector funding of providers of long-term care dominates in countries with a strong social model; Riedel and Kraus (2011) describe a cluster that is "characterized by profound organizational depth and high levels of financial generosity" p. 15), e.g. Norway, Sweden, Denmark and Iceland. Not-for-profit providers are present in most countries but are significant providers in Luxembourg, Germany, Italy, Austria and France; these providers are often affiliated to faith based religious groups (predominantly Christian). Private providers are dominant in Ireland, Spain and the United Kingdom, but are also present in other countries. In Poland, NGOs are involved with provision.

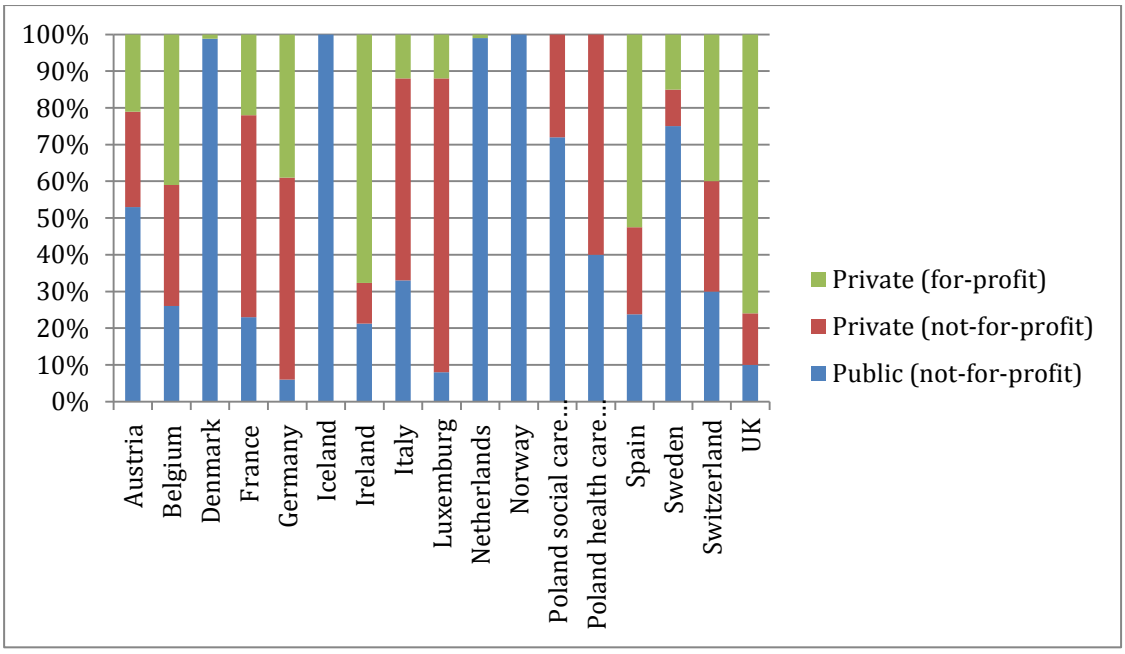

Figure 3: LTCF Providers by Organisational Status

These current patterns of organisational provision are changing, as new laws are implemented. For example in the Netherlands new reforms are opening up the 'market' further to for-profit (private) providers.

Funding for Long-Term Care

The funding for an individual's care and residency in long-term care facilities across Europe comes from a number of sources, and there is a variation in the proportion of funding from different sources across Europe (Appendix 4). The established structures for health and social care provision in each country determine funding in the LTCF sector. The sources of funding can be public provision through health and social care funding, or personal funds from individuals, obtained either through private insurance, or an individual's own capital/income. In some countries, in some situations, family members may be required to pay. Where medical care is provided through private medical insurance, this continues when an individual moves into a long-term care facility (e.g. Austria). Means testing of funding also occurs in a number of countries (Poland, Switzerland, United Kingdom – although what is assessed varies between the different countries in the UK). There is often a differentiation between funding for health care and funding for social care e.g. support for living costs. Health care can be funded by the public budgets, with a differentiation between medical and nursing care (e.g. UK). There are also instances where medical care is free to residents, but LTCF organisations pay GPs a retainer for extra services such as regular visits to the care home.

Elements of care such as personal care may be charged for (France, United Kingdom). In some countries it is the case that if an individual's capital or income falls below a certain level, there is state funding for care (e.g. Belgium, Germany, Italy, United Kingdom). Different approaches are used to ensure funding is available in the system to maintain the sector, e.g. in Norway all residents are required to pay 70% of their pension. Different funding mechanisms can apply in different provider types, e.g. payment is covered in a public LTCF, but not in a privately run facility (Cyprus).

Regulatory Processes and LTCFs

The long-term care sector is regulated in all countries (Table 4). This either occurs at a national or regional level depending upon the broader allocation of responsibility for health and social care provision in each country. Regulatory processes are manifest in three ways:

1. Through the registration and certification (accreditation) of LTCFs, either administered nationally or regionally;
2. Through requirements regarding standards of care
3. Through quality monitoring systems and bodies.

Some of these processes are enshrined in national laws, but not always. So, for example, national laws may exist which are implemented at a local/regional level (e.g. Austria, Belgium). The availability of standards or guidelines for care exist in nine countries (France, Greece, Iceland, Ireland, Israel, Poland, Portugal, Romania, UK). Regulation through inspection and accreditation may again occur nationally (e.g. England in the UK, Ireland) or regionally (Belgium, Germany, Italy).

Table 4: Regulatory processes relevant to LTCFs

	Registration and certification	**Standards of care**	**Quality monitoring processes**
Austria	Laws on: Nursing home residency (*Heimaufenthaltsgesetz*) Nursing home contract (*Heimvertragsgesetz*)		Provincial processes
Belgium	Regional certification of facilities, integration and co-ordination of services.	Regional oversight of standards of care about staffing levels, and policies about issues including: palliative care, use and storage of drugs, wound care and use of physical restraints.	Regional development of quality monitoring systems for nursing homes and homes for older people
France	National Agency for the assessment and the quality of social and health care services (Agence Nationale de l' Evaluation et de la Qualite des Etablissements Medico Sociaux, ANESM)	Recommendations of good practices in nursing homes.	Internal and external compulsory review for national certification
Germany	National level: *Pflegeversicherungsgesetz* SGB XI § 71et.al. The main law concerning nursing care insurance; regulates the content, range and quality of care. Federal state level: *Heimgesetze* - nursing home statutes; regulate the quality of LTCFs.	Charter of Rights of People in Need of Long-Term Care and Assistance (2005) (non-binding)	*Medizinischer Dienst der Krankenkassen MDK* (Medical service of the health insurance) observes the quality of care by impending unannounced inspections on the facilities *Heimaufsicht* (facility supervision) observes the quality of institutions by impending unannounced inspections on the facilities. *Heimverzeichnis*: trained volunteers monitor quality of life in residential care homes. Results are published online
Greece	National Action Plan **promotes quality assurance** as one of its aims. Local governments provide licenses to providers	Local government sets minimum standards.	A continuous system of quality care and rehabilitation to be provided throughout the health care system including LTCFs. Services regulated by the Ministry of Health and Social Solidarity. Reports not publically available.
Hungary	Social Act regulates care for older people.		
Iceland (Hjaltadóttir, *et al.* 2012)	LTCFs in Iceland are regulated at the governmental level by the Welfare Ministry and the Surgeon General.	Minimum standards for nursing homes.	

Ireland	National Level: The Health Act, 2007, Linked to the act are a number of regulations: 1. The National Quality Standards for Residential Care Settings for Older People (2009), overseen by HIQA. **2.** Registration of Designated Centres Regulations (2009) requires designated centres for older people to register with the Chief Inspector. Sets out fees structure.	National Quality Standards for Residential Care Settings for Older People in Ireland. 32 standards under 7 groupings - Rights, Protection, Health and Social Needs, Quality of Life, Staffing, the Care Environment, and Governance and Management.	Registration and inspection of all nursing homes by the Chief Inspector of Social Services. Results are made publically available.
Israel	LTCFs are regulated by the geriatric division in the Ministry of Health.	Guidelines for the establishment of a LTCF which includes physical conditions as well as staff: resident ratios and aspects of training levels. Guidelines are in place for complex nursing care, nursing care and psychological care	Each LTCF is audited and certification to operate provided for 3 months, 6 months, 1 year or 2 years. Extension of permits requires adhering to the standards of quality control supervision. **Quality control**s are performed in all geriatric LTCFs. Evaluation is undertaken by interdisciplinary teams.
Italy	National laws set general minimum requirements for institutional care. Regional laws set specific standards for accreditation.		
Latvia	Law on Social Services and Social Assistance (came into force on 1 January, 2003).		
Lithuania	Ministry of Health Care order Nr. V-14 2007 01 11, Ministry of Health Care order 2012-05-04 įsakymas Nr. V-393 *Source: http://www.sam.lt/* All types of regulatory body exist: country/state/region.		
Luxembourg	Regulation overseen by Ministry of Families		
Netherlands	Quality of care is regulated by law. Health Care Inspectorate (IGZ) supervises. Two laws directly concern the quality of care: 1) Law on quality of care (*Kwaliteitswet Zorginstellingen*; KWZ) 2) Law on professions in personal healthcare (*Wet op de Beroepen in de Individuele Gezondheidszorg*; Wet BIG). (Schols *et al.* 2014)		

Norway	Overseen at a national level by the Norwegian directorate of health and social affairs (*Pasientrettighetslov* 2000.12.01 nr 1208).		
Poland	Nationally, Ministry of Health and Ministry of Labour and Social Policy oversee LTCFs	Guidelines exist for minimum levels of staff resources and qualifications, resident ratios, infrastructure in ZOP/ZLO and staffing in DBS.	National Health Fund (NFZ)
Portugal	National legislation and implementation of regulatory quality measures (ISO 9001:2008) Social Security standards established for all LTCFs	Quality manuals (guidelines) outline minimum standards for implementation, development, services and technical skills of all providers.	Periodic inspections to the institutions that seek to ensure the quality of services and the ensuring of the beneficiaries rights.
Romania	Decree (Ordin) 246/2006 states the minimum specific quality standards for residential centres for older people in terms of organisation, administration, human resources, access to services, service provision.	Generic minimum specific quality standards for residential centres	
Spain	The act: *Ley de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia* (LAPAD), issued in 2006. Established for the first time specific rights of dependent people and their caregivers and recognises a 'right to long-term care'.		The Territorial Council on Dependency is expected to agree on quality criteria for the centres and services and quality indicators for the assessment, improvement and comparative analysis of the centres and services in the System.
Sweden	National Board of Health and Welfare is overseeing authority		
Switzerland	A national law sets out minimum standards in LTCFs.	Cantons set minimum standards of care, but not enforceable.	Cantons required to implement the law, but extent to which this happens varies.
Turkey	Regulations exist for National and Private Nursing Care Services and Centres		
United Kingdom	National oversight of LTCF regulation and registration by Department of Health or equivalent devolved government department in Scotland and Northern Ireland	National Minimum Standards exist in each nation in which Death and Dying are specifically mentioned.	Care homes are inspected by Care Quality Commission in England and Wales and Care Inspectorate in Scotland. Inspection reports available to the public.

4.3 LTCF population characteristics

The LTCF population characteristics were considered by the proportion of older people residing in LTCFs, the gender balance within facilities, and the presence of dementia in the LTCF population (Table 4). Further information about length of stay, dependency levels and identified palliative care needs has also been collated (Table 5).

Proportion of general population of older people (over 65 years)residing in LTCFs

When considering the proportion of older people (65 years +) living in LTCFs, (Figure 4), data was available for 22 countries. The percentage ranges from 0.3% (Cyprus) to just under 8% (Belgium). Three other countries have less than 1% of their population (65+) residing in LTCFS: the Netherlands, Poland and Turkey. Countries where greater than 5% of older people live in LTCFS are: Belgium (7.98), Luxembourg (7.9), Iceland (6.77), Switzerland (6.6) and Spain (5.4).

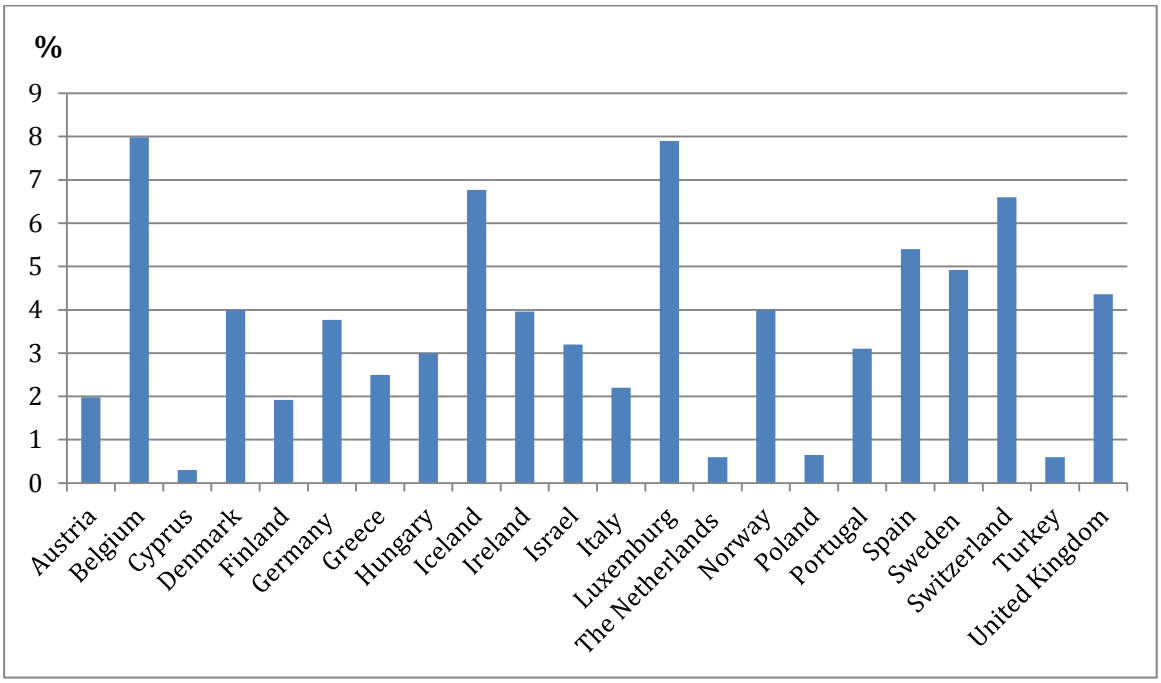

Figure 4: Proportion of older people (65 years +) living in LTCFs

Gender characteristics

Data was available for 15 countries. In most countries the population living in LTCFs is predominantly female. The proportion of men aged 65+ living in LTCFs ranges from 23.6% in the Netherlands to 59% in Turkey. The proportion of women ranges from 41% in Turkey to 76.3% in the Netherlands. Turkey is the anomaly in comparison with the rest of the data set as they are the only country where male residence in LTCFs exceeds female residence.

LTCFs and residents with dementia

Data was available from 13 countries and was not comparable, as the stage or definition of dementia or cognitive impairment was not always specified. From the data available (Table 5), the proportion of residents in LTCFs who live with dementia ranges from 13.4% recorded in Hungary to 70-80% recorded in Sweden. In addition some countries recorded variations in levels of cognitive

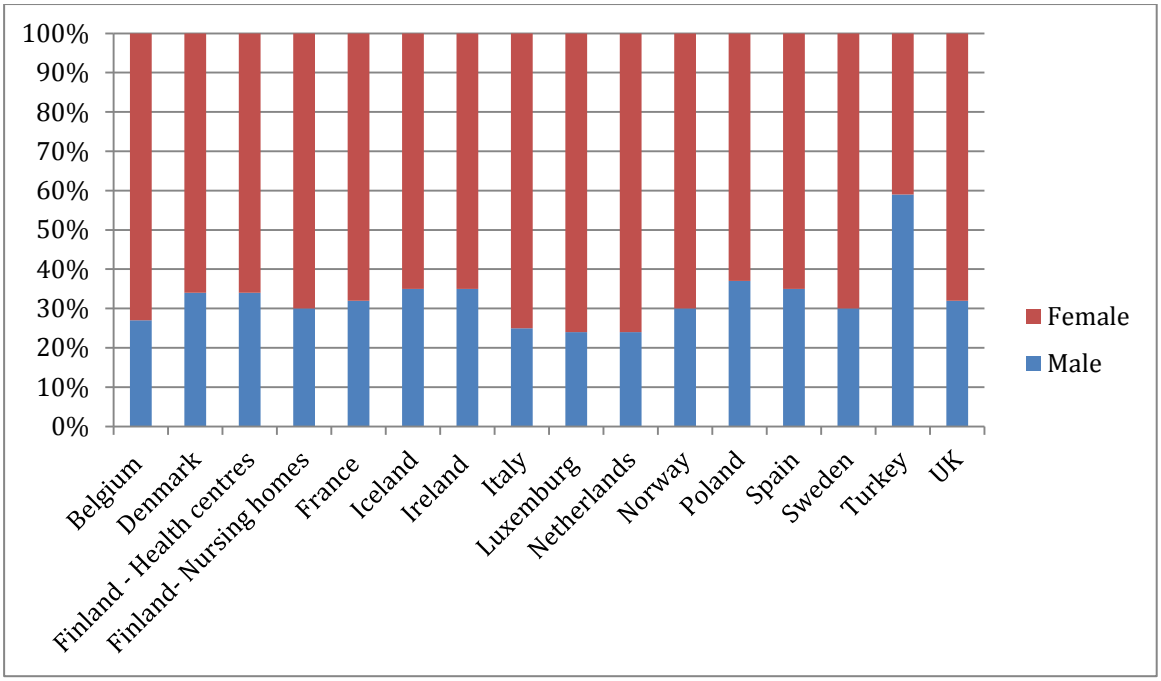

Figure 5: Population in LTCFs, by gender

Table 5: Proportion of residents living in LTCFs with dementia

Country (data of data)	**Proportion of residents living in LTCFs with dementia (%)**
Austria (2007)	52.5%
Denmark (2013)	66.6%
Finland (2012)	56% (health centres) 68% (nursing homes)
Germany (2007)	61% (60-74 years) 71% (75-84 years) 69% (85+ years)
Hungary (2008)	13.4%
Iceland (2014) (Eiríksdóttir, 2014)	63.2%
Ireland (2012) (Cahill , O'Shea, Pierce, 2012)	64.2%
Italy (2012)	<22% (severe dementia in nursing homes) 70% (significant cognitive impairment)
Netherlands (2012) (Boorsma *et al.* 2012)	57% nursing homes, 35.6% residential homes
Norway (2007) (Selbæk *et al.* 2007)	81 %
Sweden	70-80%
Switzerland (2014)	60 %
UK (2011/2013)	47.5% (dementia) 80% (significant memory impairment) (Alzheimer's Society 2013) 31% (cognitive impairment) (Kinley *et al.* 2013)

impairment (the UK and Italy). This highlights that over 75% of residents were experiencing some cognitive impairment but may not have received a dementia diagnosis.

Dependency levels

Information on dependency levels of older people living in LTCFS was limited across Europe. A number of countries listed the assessment tools and processes used (eg Ireland, Romania). Other countries provided information about the levels of need assessed which varied from four (eg Germany, Israel) to 10 levels (eg. Netherlands). Some countries described the different dimensions of assessment that were used eg Finland considers four domains: physical, psychiatric, cognitive and social (Noro and Alastalo 2014). The figures of need provided indicated high levels of dependency in LTCFS, e.g. Belgium described residents with low (28%) and high (72%) levels of dependency. In Poland, figures were provided that differentiated the types of LTCFs with higher dependency levels (31.1% of residents identified described as being bedridden) in ZOL/ZPO settings as compared to 12.8% of residents being bedridden in DPS settings (GUS, 2013).

Length of Stay

Data was identified for 14 countries (Table 6). The average length of stay in LTCFs ranges from 63 days (Israel) to over 2000 days (60 months) in Luxembourg, with stays of over 1000 days (30 months) in the Netherlands and Ireland. Some data showed that length of stay was greater in low dependency settings eg residential units in the Netherlands and residential care homes in the UK. Some information only provided proportions of residents and an overview of their stay, for example in Norway, 34,013 (77.5%) patients had a long term stay and 9,898 (22.5%) of patients had a short term stay.

4.4 Death and Dying in LTCFs

Data about the proportion of older adults who died in LTCFs was sought (Figure 6), with data identified from 16 countries. The data sources varied and the data may not be comparable. Three countries also provided data about death rates in LTCFs (Table 7) although this was not specifically requested. The proportion of deaths amongst older people in LTCFs varied from no deaths in Albania to 61.1% of deaths in Finland, with the highest proportion of deaths in the higher dependency settings (eg health centre wards in Finland).

Table 6: Average length of stay in LTCFs

Country	Length of stay (days)	Length of stay (months)
Denmark (Source: survey)	900 days	30 months
France (Wheel, 2014)	900 days	30 months (50% less than 13 months)
Germany (Schulz 2010)	M: 1350days F: 780 days	45 months 26 months
Iceland (Hjaltadóttir *et al.* 2011).	930 days	31 months
Ireland (Source: survey)	1080 days	36 months
Israel (2011) (http://mashav.jdc.org.il/?CategoryID=233&ArticleID=162 [Hebrew] (T 4.33, p 325))	63 days	2 months
Lithuania (http://www.sam.lt/)	Up to 120 days.	4 months
Luxembourg (Source: survey)	550 - 2005 days	18 - 63 months
Netherlands (Source: Vumc Interrai database LTCF 2008-2013)	Nursing homes 796 days (sd 1792) Residential units 1,168 days (sd 1957)	26 months 39 months
Poland (2012) (GUS 2013)	ZOL: 152 days ZPO: 139 days DPS: 260 days	5 months 4.6 months. 8.6 months
Sweden (2013) www.palliativ.se http://palliativ.se/wpcontent/uploads/2014/03/SvenskaPalliatvregistret2014.pdf	713 days	23 months
Switzerland	946 days	31.5 months
UK Fernandez & Forder 2011	Nursing home: 350 days Residential care home: 805 days	11.9 months 26.8 months

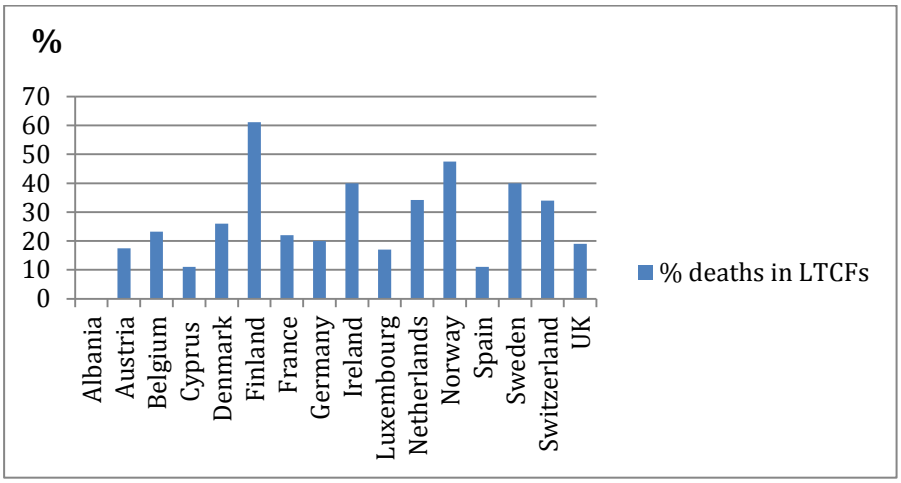

Figure 6: LTCFs as Place of Death

Table 7: Death Rate, the % of the population within LTCFs who die either in a particular year or within one year of admission

Country	Death Rate
Israel (2011)	2011: Overall death rate of **patients in LTCFs** was 15%, with a variance of 3-30% between the different LTCFs http://www.health.gov.il/UnitsOffice/HR/ITandINFO/info/Pages/Inpatient_Institutions.aspx
Italy (2009)	The annual death rate in NHs is 17% (of the total resident population). 25% die within a year of admission. (Network Non Autosufficienza, L'assistenza agli anziani non autosufficienti, Pesaresi F and Brizioli E, Report 2009).
UK (2013)	56% die within a year of admission to LTCF with nursing (Kinley *et al.* 2013).

Limited data was available on the death rate in LTCFs and no data available in relation to the percentage of all people with dementia who die in a LTCF or the percentage of people in a LTCF with dementia who die per year or within one year. The data available on those receiving palliative care in LTCFs was also limited and variable in its form (Table 8). France records that 74% of residents sign an agreement with a palliative care team. In Switzerland 50% of residents receive palliative care and in Luxembourg 136 people received it in 2012.

Table 8: Palliative care residents in LTCFs

Country	Palliative Care Status
France (Source: survey)	48% residents have their end of life managed by family carers; 74% sign a convention with a palliative care team (or hospital or community team); 62.5% ask for help in the last year.
Iceland (1996-2006) (Source: survey)	12.3% of nursing home residents were receiving palliative care
Luxembourg (Source: survey)	2012: 136 people receiving palliative care
Netherlands (Source: survey)	A 'generalist' care approach with GPs, providing palliative care. Can consult specialists in palliative care in difficult cases.
Poland (Source: survey)	DPS: Palliative care is provided in the same way as for other community dwelling citizens. ZOL/ZPO: professional staff trained to provide basic palliative care and patients can be seen by palliative care specialists in outpatient clinics.
Spain (Source: survey)	Advanced dementia and palliative care in non-cancer patients + oncologic patients: 15-20%. Centres with specific palliative care criteria: 25-30%.
Sweden (Source: survey)	70 % of all deaths in LTCF are registered in the Swedish Register of Palliative Care (SRPC)
Switzerland (Source: survey)	About 50% of residents receive palliative care.
UK (Kinley *et al.* 2013)	20% residents seen by specialist palliative care nurse

These national averages do not necessarily represent equitable access to palliative care within countries, as there is evidence that regional differences exist within countries e.g. in Italy (Beccaro *et al.* 2007) and the UK (Dixon *et al*. 2015).

5. Palliative Care Developments

In order to describe the ways in which palliative care is being developed in LTCFs across Europe, the Ferlie and Shortell's modified typology of change (Froggatt and Reitinger 2013) (Table 9) was used to classify and present the findings. Initially, international colllaborations are described. At a strategic level, the wider national and regional approaches that support these developments are then considered. Operational initiatives are then presented that occur for, and within, organisations with teams and individuals.

Table 9: Enhanced Typology of Change

Enhanced Typology of change
International: collaboration between different countries
National
Regional / Networks
Organisation Group / Team Individual (staff, family, resident)

5.1 International Collaborations

The few examples of international collaboration provided in the survey were all indirectly related to the development of palliative care provision in LTCFs and had a more general focus upon wider care provision for older people. Examples include: the WE-DO project promoting the wellbeing and dignity of older people which has developed a quality framework for long-term care services (www.wedo-partnership.eu). Implementation of the INTER-RAI tool for long-term care has occurred in a number of countries: Belgium, England, Finland, France, Germany, Iceland, Italy, Netherlands, Norway, Spain, Sweden, Switzerland. The tool aims to improve the quality of life of older people through use of comprehensive assessment system.The uptake within each country is variable and not universal (www.interrai.org/long-term-care-facilities.html).

The only example of a European wide collaboration focused specifically upon palliative care in LTCFs is the PACE research programme which is the driver for this Taskforce/WorkPackage. Other examples of international collaboration include another EU funded study: IMPACT, looking at the optimal organisation of services for palliative care and dementia care (www.impactpalliativecare.eu). There are also EAPC Taskforces, which have relevance, for example the EAPC White Paper on dementia and palliative care: (www.eapcnet.eu/Themes/Clinicalcare/EAPCWhitepaperondementia.aspx).

5.2 National and Regional level

At a national and regional level the strategic policy context for the development of palliative care, is described for these countries, drawing on previous work including the EAPC Atlas which categorised countries according to six groups (Table 10). Specific legislation, strategies and

standards that focus specifically on palliative care development in LTCFs are also identified (Table 11) need to be considered alongside the regulatory and quality assurance context for each country (Table 4). National activity is often also delivered at a regional level, where dependent upon the administrative political structures, regions (e.g. States, provinces, Cantons) may hold legislative powers to determine care provision.

Table 10: Levels of Palliative Care Development (Lynch at al 2013)

Group 1	No Known Hospice-Palliative Activity	
Group 2	Capacity Building Activity	No services established; evidence of initiatives to create the capacity for development of hospice-palliative care services.
Group 3a	Isolated Palliative Care Provision.	Small number of hospice-palliative care services; high reliance on donor funding; variable, not well-supported palliative care activism
Group 3b	Generalised Palliative Care Provision	Several hospice-palliative care services; multiple sources of funding; development of palliative care activism in several locations; some training and education by hospice organizations
Group 4a	Preliminary Integration into Mainstream Service Provision	Variety of palliative care providers and types of services; critical mass of palliative care activism in a number of locations; limited impact of palliative care on policy; large numbers of training and education initiatives
Group 4b	Advanced Integration into Mainstream Service Provision	Multiple service providers provide all types of palliative care in all settings; critical mass of palliative care activism across the country; great impact on palliative care policy; development of recognized education centres; academic links with universities; existence of a national palliative care association.

Table 11 presents data on the context for palliative care development in LTCFs, outlining 1) the level of palliative care development of the country, 2) the current policy context and 3) the palliative care service provision models being used and how palliative care is being provided in LTCFs. To classify the level of palliative care development of a country, we used the current classification identified by Lynch *et al.* (2013) (Table 10) in the Global Atlas on Palliative Care which describes the level of palliative care development with respect to number and types of palliative care services, funding, education, medication patterns and policy markers.

Some countries that are classified as having a good integration of palliative care (Level 4a and 4b) may have good examples of service initiatives in LTCF, but no policy integration (Belgium, Finland, Ireland). Other countries with a high level of integration have neither policy nor service developments (Poland). Where palliative care provision is in early stages of development (Level 3a: isolated provision and 3b: generalised palliative care provision) there is generally no engagement with LTCFs (for example, Albania, Turkey). However, some countries at earlier stages of development are actively engaging to develop palliative care in LTCFs e.g. Croatia, the Czech Republic. There is limited activity in countries in Central and Eastern Europe, reflecting isolation in work being undertaken, so it is not known beyond its immediate locality.

National policies that specifically addressed palliative care provision in LTCFs were only present in a few countries (Austria, Belgium, France, Ireland, Norway, Spain, Switzerland, UK), and then usually within/as part of broader palliative care strategies or guidelines (e.g. England in the End of Life Care Strategy or Greece in the National Public Health Plan).

The countries that had the most advanced approach to the development of palliative care in LTCFs with respect to national policies and initiatives around palliative care provisions in LTCFs were Austria, Belgium, Ireland, Switzerland and the UK. Here there are examples of national palliative care strategies with explicit mention of palliative care provision in LTCFs as providers of palliative care, supported by programmes of support and initiatives to develop the practice (Table 11). This is led by national and or state government (UK, Switzerland) and or non-governmental umbrella organisations (Austria). Other active countries have integrated palliative care provision supported through funding systems (Belgium, Ireland).

Regional demonstration projects (e.g. Austria), the development of networks (eg Netherlands – ACTIZ, PALLIACTIEF, AGORA) and umbrella bodies to bring interested parties together also support the development of palliative care in LTCFs, (e.g.in the UK the National Council for Palliative Care; Scottish Partnership for Palliative Care) and act as drivers for change. The only clearly regional initiative identified was in Belgium where "*Guidelines for the implementation of palliative care in long term care facilities for older people"* (Leidraad voor implementatie van palliatieve zorg in woonzorgcentra) were developed by the Federation Palliative Care Flanders for the Flanders region. Other examples of regional initiatives provided by participants were generally organisational initiatives undertaken within specific geographic regions, and are described later.

Table 11: Country Palliative Care and LTCF policy and service contexts
(Data sources: country informants' survey responses and EAPC Global Atlas (Centeno *et al.* 2013, Lynch *et al.* 2013))

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Albania	Group 3b Generalised palliative care provision	• 2010 Standards for Palliative Care by the Ministry of Health • 2011 National Strategic Plan for Palliative Care • 2014 Palliative Care law passed	• Limited palliative care service provision – mainly home care based.
		• No policies identified relating palliative care to LTCFs	• No evidence of engagement with LTCFs
Austria	Group 4b Advanced integration	• National Health Care Plan of Austria addresses hospice and palliative care • 2004 National Plan of Palliative Care (Abgestufte Hospiz und Palliativversorgung (2004) (Graded hospice and palliative care plan). Written. Supported by all federal states with own hospice and palliative care plans. • Legislation relates to 'living wills' and family carer leave • Number of standards and guidelines issued by Austrian Federal Health Institute (2012), Hospice Austria (since 2000) and Austrian Ministry of Health (2012)	• Palliative care service provision of all types (in-patient hospice, home care, hospital, day care)
		• Active engagement in LTCFs since 2005 • 2008 Standards for hospice and palliative care in nursing homes available • 2009 Austrian advisory board for Hospice and Palliative Care in Nursing Homes established • Criteria for Palliative Care integrated in the "*National Certificate of Quality* " (NQZ) for nursing homes	• 20% of LTCFS active in palliative care provision • National project 'Hospice and Palliative Care in Nursing Homes' (led by Hospice Austria) initiated • Since 2004 regional projects integrating Hospice and Palliative Care into LTCFs undertaken

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Belgium	Group 4b Advanced integration	• Legal provision for palliative care since 2002, supported by later laws and royal decrees • No national palliative care strategy exists • Biannual Commissions to review palliative care provision held	• Palliative care service provision of all types (in-patient hospice, home care, hospital, day care)
		• Provision of palliative care in all care settings including LTCFs present in all standards and guidelines	• Funding mechanism to support GP and palliative care support in LTCFs • Networks Palliative Care support implementation of palliative care in LTCFs. • Palliative support teams, teams of palliative care experts in LTCFs who support other caregivers, patients and their relatives in matters concerning palliative care
Croatia Hrvatska	Group 3b Generalised palliative care provision	• 2003 legislation permits development of palliative care services • Ministry of Health adopted a strategic plan for the development of palliative care, 2014-2016. The goal of the strategic plan is that palliative care is available 24/7 and becomes equally available in all parts of the country	• Limited services exits in form of mobile palliative care team and home care support.
		• No legal framework for standards in palliative care • No policies identified relating palliative care to LTCFs	• The Croatian Association of Hospice Friends visit nursing homes twice per week.

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Cyprus	Group 3b Generalised palliative care provision	• Palliative care being addressed in National Cancer Control Strategy (under development)	• Palliative care services in In-patient hospice and day care
		• No policies identified relating palliative care to LTCFs	• No formal developments in LTCFs • NGOs from cancer organisations offer palliative care in LTCFs if they are referred and are cancer patients. • Occasionally and informally LTCFs will contact palliative care consultants /nurses for informal support
Czech Republic	Group 3b Generalised palliative care provision	• 2011 Health Care Services Act for health care provision passed that recognised and defined different forms of palliative care provision (inpatient, outpatient and homecare services) as specific forms of health care. • National Palliative Care Strategy developed but not adopted by the government (as of 2013)	• Palliative care service provision of all types (in-patient hospice, home care, hospital, day care
		• No policies identified relating palliative care to LTCFs	• 2010 onwards: Formal training of nurses in palliative care , supported by regional authorities • Some hospice homecare services offered by residential homes.

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Denmark	Group 4a Preliminary integration	• A range of legislation exists relevant to palliative care provision focused on medicines, primary care, accreditation standards • 2010 Cancer Plan (3rd edition) emphasises palliative care • 2012 National Board of Health published Recommendations for Palliative Care (*Anbefalinger for den palliative indsats*)	• Palliative care service provision of all types (in-patient hospice/palliative care units, home care, hospital, day care)

		• "*Quality of Life and Self-determination in Nursing Homes*". Report from Commission of the Elderly. Ministry of Children, Gender Equality, Integration and Social Affairs. (http://sm.dk/publikationer/livskvalitet-og-selvbestemmelse-pa-plejehjem)
		• No policies identified relating palliative care to LTCFs
			• National initiative: Strengthening the quality of palliative care in nursing homes
			  • Describe best practices
			  • Develop an educational programme for staff in LTCFs
			http://socialstyrelsen.dk/aeldre/livskvalitet-og-selvbestemmelse/program-livskvalitet-og-selvbestemmelse

Finland	Group 4a Preliminary integration	• 2003 Ministry of health guidelines for palliative care • 2010-2020 cancer program emphasises palliative care • 2012 Position paper on human dignity, hospice care and euthanasia by the National Advisory Board on Social Welfare and Health Care Ethics.	• Palliative care service provision of all types (in-patient hospice/palliative care units, home care, hospital, day care)
		• No policies identified relating palliative care to LTCFs	• Initiatives to provide education for LTCF staff about palliative care and dementia

Country	Level of Palliative Care Development	• Current Policy Context for Palliative Care and LTCFs	• Service provision palliative care and palliative care in LTCFs
France	Group 4b Advanced integration	• Legal provision: 1999: "Equal access to palliative care" Act:; 2005 "Patients' rights and the end of life" Act • 2008: Department of Health's official instructions on the organisation of palliative care • 2008 -2012 National Strategy for Palliative Care supported by development of palliative care standards	• Palliative care service provision of all types (in-patient palliative care units, home care, hospital, day care)
		• Development of PC in nursing homes is an explicit objective in the 2005 law. • Governmental Alzheimer program 2008-2012 highlights the need for palliative care in LTCFs • Legislation supports provision of palliative care in LTCFs, e.g. Home hospitalisation" ("HAD") can provide palliative care in nursing homes (decree 2007)	• Hospital and home palliative care support teams visit LTCFs
Germany	Group 4b Advanced integration	• Since 1996 Regulations concerning the funding of hospice work in hospices and in home care settings exist (§ 39a SGB V) • 2007 legislation providing for right to access to specialised palliative care whenever needed, at any time and in all situations enacted • No national palliative care strategy	• Palliative care service provision of all types (in-patient palliative care units/hospices, home care, hospital, day care)
		• Regulations may apply to LTCFs • 2006 onwards guidelines for the implementation and development of hospice and palliative care in LTCFs developed by hospice and palliative care organisations • No policies identified relating palliative care to LTCFs	• Model projects of palliative care development in LTCFs exist • Deutsche Palliative Stiftung (German Palliative Care Foundation) developed training manuals for LTCF staff

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Greece	Group 3a Isolated provision	• 2007 Ministerial Decree re hospice building and organisation • No Palliative Care Strategy or Guidelines • Palliative Care mentioned in National Plan for Public Health (2008 -2012)	• Limited palliative care provision (in-patient hospice, home care, day care)
		• No policies identified relating palliative care to LTCFs	• One example of a palliative care education project in LTCFs
Hungary	Group 4a Preliminary integration	• National Palliative Care Standards (Professional Guidelines of Palliative Care of Terminally Ill Cancer Patients), supported by other legislation about palliative care • National Cancer Control Programme addresses palliative care	• Palliative care provision country-wide (in-patient hospice, hospital, home care, day care)
		• National Strategy concerning Senior Citizens available • In development: National Strategy concerning older people with dementia • No policies identified relating palliative care to LTCFs	• No formal palliative care development in LTCFs • Some hospice home care services or mobile teams support terminally ill patients in nursing homes.
Iceland	Group 4b Advanced integration	• No specific legislation about palliative care, but addressed in Patients' Rights Act No 74/1997 which includes laws regarding a patient's right to refuse treatment and right to die with dignity. • 2009 Clinical Guidelines on Palliative Care published • National Cancer Plan addresses palliative care.	• Palliative care provision in-patient units, hospitals, home care, day care)
		• No policies identified relating palliative care to LTCFs	• Since 2012, based in the Reykjavik metropolitan area, formal development work in nursing homes undertaken through identification of palliative care beds, education and use of the Liverpool Care Pathway.

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Ireland	Group 4b Advanced integration	• 2001 National policy on palliative care for all in place • 2007-2013 Government's National Development Plan 2007-2013 includes a commitment to provision of support for the development of specialist palliative care and inpatient units, palliative care community support beds, day services and ancillary supports; • 2008 Palliative Care for All report (HSE and IHF) • HSE- Hospice Friendly Hospitals • Irish Hospice Foundation Hospice at Home programmes; and Places to Flourish toolkit.	• Palliative care services in-patient units, hospitals, home care, day care
		• 2008 National Quality Standards for Residential Care Settings for Older People in Ireland includes a standard for end of life care; • No policies identified relating palliative care to LTCFs	• Specialist palliative care team support for LTCFs • Limited formal initiatives for palliative care development
Israel	Group 4a Preliminary integration	• 2005 'Dying Patient Act'- Palliative Care defined as a right of every Israeli citizen. • 2009 Director General of the Ministry of Health set a goal to make Palliative Care services in the community and hospitals available for all by 2013	• Palliative care services in-patient units, hospitals, home care, day care
		• 2010 Director General of the Ministry of Health set standards for the management of units of complex nursing care including a requirement that health care professionals will be trained in palliative care (http://www.health.gov.il/hozer/mr04_2010.pdf). • No policies identified relating palliative care to LTCFs	• Initiatives to provide palliative care in LTCFs starting

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Italy	Group 4b Advanced integration	• Palliative Care Legislation n. 38, 15/3/2010 (*Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore*) • Palliative Care standards published 2007, 2010, 2012.	• Palliative care services in home care and hospices
		• Palliative Care Legislation n. 38, 15/3/2010 stated that treatment of pain and palliative care to be extended to all care settings, including LTCFs • No policies identified relating palliative care to LTCFs	• 24 (14.6%) of hospices located within Nursing Homes. • No other formal initiatives to develop palliative care in LTCFs
Latvia	Group 3a Isolated provision	• State Oncology Programme (2009-2015) includes palliative care (Hall *et al.* 2011)	• Limited palliative care services in hospitals
		• No policies identified relating palliative care to LTCFs	• No information on palliative care provision in LTCFs
Lithuania	Group 3b Generalised palliative care provision	• 2007-2008 Health Care Ministry order – palliative care legally recognised • National Plan of Palliative Care in progress	• Limited palliative care services in hospitals, day care, home care
		• No policies identified relating palliative care to LTCFs	• No palliative care provision in LTCFs (provided in nursing hospitals)
Luxembourg	Group 4a Preliminary integration	• Laws on palliative care *(Loi relative aux soins palliatifs, a la directive anticipée et a l'accompagnement en fin de vie*) and euthanasia (*Loi sur l'Euthanasie et l'Assistance au Suicide*) enacted • No palliative care strategy • Standards and guidelines relating to long-term care services defined by quality commission in 2007 (Koster & Ribeiro 2010)	• Palliative care services in-patient units, hospitals, home care
		• No policies identified relating palliative care to LTCFs	• Since 2009 a «reglement grand-ducal», requires that 40% of LTCF employees attend a 40 hours palliative care course (run by Ministry of Family) • Examples of mobile teams supporting LTCF staff

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Netherlands	Group 4a Preliminary integration	• Ministry of Health action plan for palliative care written: Installation Platform Palliative Care (2006-2011)	• Palliative care services in-patient units, hospitals, home care, day care • Establishment of Palliative Care Networks organisations across country with consultation units/services
		• No policies identified relating palliative care to LTCFs	• Establishment of palliative care units in 20% nursing home LTCFs. • Engagement between LTCFs (residential homes for elderly) and Palliative Care networks happening • Funding for Best Practice projects in palliative care in LTCFs available to palliative care networks
Norway	Group 4b Advanced integration	• No specific legislation about palliative care provision • National Plan/Strategy of Palliative Care (*Nasjonalt handlingsprogrammed retningslinjer for palliasjon i kreftomsorgen)* incorporates: • National Palliative Care Standards	• Palliative care services in-patient units, hospitals, home care, day care
		• LTCFs mentioned in national guidance on palliation in cancer care • Government aims to support people to die in nursing homes. Supported by Palliative Care Strategy, National Cancer Strategy (2006-2009), and Dementia Plan (2007)	• Some formal initiatives regarding palliative care provision in LTCFs

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Poland	Group 4b Advanced integration	• 2009 Ministry of Health Act guarantees services in palliative and hospice care. • 2011 National Palliative Medicine Council established to develop norms and guidance for implementation of Act • Standards of palliative care listed in Ministry of Health Act • Funding available for palliative care or long term care	• Palliative care services in-patient units, hospitals, home care, day care
		• No policies identified relating palliative care to LTCFs	• No information on formal palliative initiatives with LTCFs • Funding models allow for palliative care provision
Portugal	Group 3b Generalised palliative care provision	• 2006 Law enacting National Network for Continuing Care (recognizing the right to palliative care) • 2012 Law on Palliative Care establishing the National Network for Palliative Care • 2012 National Palliative Care Program established	• Palliative care services in hospitals, home care and day care
		• No policies identified relating palliative care to LTCFs • Implementation of regulatory quality measures (ISO 9001:2008) - Creation of Quality Manuals for social providers • Long-term Care National Network (*Rede Nacional de Cuidados Continuados*) established	• No information on palliative care provision in LTCFs
Romania	Group 4b Advanced integration	• No specific palliative care legislation • 2012 a National Strategy for Palliative Care written • National Program for Palliative Care developed but awaiting government approval and funding	• Limited hospice, hospital and day care services
		• No policies identified relating palliative care to LTCFs	• No information on palliative care provision in LTCFs

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Spain	Group 4a Preliminary integration	• 2006 National Cancer Strategy has a focus on Palliative Care applied in all care levels. • 2007 National Palliative Care Strategy *(Estrategia Nacional de Cuidados Paliativos*, Ministry of Health) • 2010-2014 National Palliative Care Strategy Update *(Estrategia Nacional de Cuidados Paliativos. Actualización 2010-2014*, Ministry of Health 2011): • A draft bill has been recently passed by the Spanish Government to specifically regulate end-of-life care (*Anteproyecto de Ley de Cuidados Paliativos y Muerte Digna*, May 2011).	• Palliative care services in-patient units, hospitals, home care, day care
		• National Palliative Care Strategy 2007 has no explicit mention of LTCFs. It is acknowledgement that coordination among care levels is needed. • National Palliative Care Strategy Update 2011 has objective about LTCFs and ensuring the same provision of care for residents as the general population. Acknowledged that training for professionals in these settings is needed.	• Little evidence of formal palliative care interventions in LTCFs
Sweden	Group 4b Advanced integration	• No palliative care strategy • 2011 National guidelines for Dementia care (National Board of Health and Welfare) • 2012 -2014 national palliative care programme • 2013 National guidelines for Palliative care (led by the National Board of Health and Welfare)	• Palliative care services in-patient units, hospitals, home care, day care
		• No policies identified relating palliative care to LTCFs	• No information on formal initiatives with LTCFs. • Use of palliative care quality registry.

Country	Level of Palliative Care Development	Current Policy Context for Palliative Care and LTCFs	Service provision palliative care and palliative care in LTCFs
Switzerland	Group 4b Advanced integration	• 2011, fifteen cantons included provision of palliative care in health legislation • 2010 – 2012, 2013 -2015 National Strategy for Palliative Care • 2010 Palliative Care Guidelines issued	• Palliative care services in-patient units, hospitals, home care, day care
		• National Strategy for Palliative Care has emphasis on care for older people wherever they live, including LTCFs. • Quality criteria for palliative care in LTCFs exist	• Specialist palliative care offered in a few LTCFs • Association of Residential Homes (Curaviva) provide in-house palliative care training for LTCF staff
Turkey	Group 3b Generalised palliative care provision	• Palliative Care considered in National Cancer Control Program • Palliative Care National Strategy planned	• Palliative care service provision in in-patient hospices and hospitals
		• No policies identified relating palliative care to LTCFs	• No formal initiatives with LTCFs
United Kingdom	Group 4b Advanced integration	• No specific palliative care legislation • Palliative Care strategies published in England (2008) , Scotland (2008), Wales (2008) and Northern Ireland (2010) • Palliative care standards available in England, Scotland, Wales and Northern Ireland	• Palliative care services in-patient units, hospitals, home care, day care
		• English End of Life Care Strategy includes specific area focused on improvement of palliative care in care homes. • English Dementia Strategy (DH 2009) identifies needs of people with dementia towards the end of life, many of whom are living in LTCFs • English National Minimum Standards for Care Homes address death and dying in a specific standard.	• Formal initiatives to develop palliative care in LTCFs through the End of Life Care programme in all four nations. Includes the use of Gold Standards Framework for Care Homes, Six Steps to Success, Route to Success tools. • Social Care Institute for Excellence provides education and training resources and help for staff working in LTCFs about care issues including palliative care. (www.scie.org.uk)

5.3 Organisational Initiatives with Teams and Individuals

Organisational initiatives to develop the provision of palliative care in LTCFs were identified from the mapping survey. These initiatives addressed different ways to ensure palliative care was provided for residents in LTCFs, through designated units, care interventions, care planning interventions, organisational policy development, organisational multi-dimensional interventions and education and training (Appendix 5 and 6).

Designated palliative care units were identified in four countries (Denmark, Iceland, Netherlands, Norway) (Box 1); the location of hospices and specialist palliative care units in LTCFs is seen as a way to diffuse knowledge to LTCF staff within the setting. Other service models rely on external teams to support staff in LTCFs (for example Hungary, Iceland, Luxembourg).

Box 1: Designated palliative care beds in LTCFs (Iceland)

Two nursing homes designated two palliative care beds each especially for newly admitted nursing home residents with estimated less than 6 months to live.
The initiative was supported by:

- *one day educational program based on the End of Life Nursing Care Consortium (ELNEC-Ger) and was developed for the nursing home staff;*
- *two clinical nurse specialists in palliative care from the local hospital*

The introduction of care interventions, focused on the specific needs of residents, were identified. These included Life Circles for people with dementia (Belgium), Namaste Care (UK), VELA - eValuation of Efficacy of Lenitherapy in Alzheimer disease and dementia (Italy), the Liverpool Care Pathways for the last days of life (Iceland), Support Clowns for people with dementia (France).
A number of care planning interventions are being introduced across Europe either focused on advanced care planning for individuals (Belgium) (Box 2), Ireland (Let Me Decide), or addressing the wider coordination of care (UK (Coordinate My Care)). Projects to institute end of life care policies in LTCFs (Belgium) were also being undertaken. Mention was made of initiatives to improve symptom management through the projects identified above.

Box 2: Bruges Advanced Care Planning Model in LTCFs (Belgium)

A model for implementation of ACP in LTCFs was developed by a multidisciplinary group from Bruges in Flanders, Belgium. Based on existing literature and experiences in Flanders, the group developed a step by step plan for implementation of ACP. Initiation of ACP discussions can be flexible, but should take place within three months after admission to the facility, and preferably as soon as possible after admission. The resident needs to be seen in his or her context; the patient and the relatives together discuss the care. The ACP discussion should not be limited to a list of medical treatment possibilities in specific situations, but should rather focus on care needs, formulated as general care goals focused on: maximal comfort, maintenance of functions, and life prolonging. The care goals can be translated in a care plan and will thus help tailor care to the patient's needs. The general practitioner should be involved in conducting these discussions.
The ACP process comprises five steps:
Step 1: introduces the subject,

Step 2: evaluate expectations about the future,
Step 3: identify the goals for the last phase of life,
Step 4: document the directives,
Step 5: re-evaluation and updating of specific care options.

Documents have been developed to record these discussions

The Bruges model for ACP was tested with residents of a LTCF. No problems were found in conducting the discussions with the residents and family members and they experienced these discussions as very positive. However, in depth quantitative or qualitative research of this initiative is lacking.

For further information see Raes *et al.* (2010)

Organisational interventions were also identified, incorporating some of the different elements described above, to create a multi-dimensional intervention that address the different components of high quality palliative care and its provision. Originating in the UK, a number of initiatives have been identified: Gold Standards Framework for Care Homes (Box 3), Routes to Success, Six Steps to Success (Box 4), PACE Steps to Success (Box 5).

Box 3: Gold Standards Framework for Care Homes (UK)

The Gold Standards Framework aims to promote high quality of care through organisational and practice change for residents in the last year of life. The programme centres on 7Cs: improved communication, coordination, continuity, control of symptoms, care of the dying, carer support, and continued education.

In the UK, since 2004, over 2,500 care homes have undertaken the two-year programme. The programme involves a formal accreditation process after completing the programme and then re-accreditation every 3 years .

There is evidence of the positive impact of the GSF programme in care homes on resident outcomes (both direct and staff reported) ie communication, continuity of care of the dying, reduced resident deaths in hospital, and a reduction in crisis admissions to hospital or crisis events (Kinley et al. 2013).

Further information: www.goldstandardsframework.org.uk

Box 4: Six Steps to Success/ The Route to Success Programme for Care Homes (UK)

The Six Steps to Success programme was a regionally developed initiative (in NW England), later adopted by the English End of Life Care programme as the Route to Success initiative. It provides a framework for care homes to provide end of life care. It addresses the six steps in the nationally identified pathway to quality end of life care. A facilitator provides 7 workshops and training for staff around a number of areas: communication, advance care planning, identification of people with palliative care needs, assessment, care planning, and review, coordination of care, delivering high quality care, care in the last days of life and Liverpool Care Pathway, care after death and overall evaluation.

Box 5: PACE Steps to Success (European initiative led by Belgium)

PACE is a European funded project (FP7, 2014-2019) comparing the effectiveness of palliative care for older people in long term care facilities in Europe and aims to advise policy-makers on optimal palliative care practices. PACE compares the effectiveness of health care systems with and without formal palliative care structures in long term care facilities in 6 EU countries (Belgium, the Netherland, Italy, Finland, Poland, United Kingdom), and investigates the impact of a health service intervention ‚PACE Steps to Success' aimed at integrating palliative care in LTCFS' structures, on patient, family and staff outcomes and on cost-effectiveness in a cluster controlled trial.

Based on the UK initiatives (GSF for Care Homes and Routes to Success) the PACE Steps to Success programme has been developed to be used across Europe. The programme aims to enhance palliative care through facilitating organisational change and supporting staff to develop their roles around palliative care, aiming to ensure all residents receive high-quality palliative care through the introduction of six steps:

i. *Discussion as the end of life approaches*
ii. *Assessment, care planning and review*
iii. *Co-ordination of care*
iv. *Delivery of high quality care in LTCFs*
v. *Care in the last days of life*
vi. *Care after death*

An external facilitator supports PACE Coordinators identified from within each LTCF. There are 3 stages of the programme: Preparation, Implementation of the 6 steps and Consolidation.

Based on the results of the trial, PACE will develop tools to assist practitioners and policy and decision-makers to make evidence-based decisions regarding optimal palliative care practices in long term care facilities.
For further information: www.eupace.eu

Interventions focused on teams working in LTCFs, and individual staff are integrated within the organisational interventions identified above, and primarily delivered through the provision of education and training. Education initiatives were identified in many countries (examples provided from Austria, Denmark, Germany, Hungary, Poland, UK) (Box 6) and also for staff groups external to LTCFs (Poland) in order to support the staff further. One initiative developed by a hospice used an education passport (UK) to facilitate learning across LTCFs, recognising the movement of staff between facilities.

Box 6: Educational Competency in palliative care for LTCF staff (Denmark)

As part of a larger programme of work to develop educational training and competencies for staff in 6 LTCFs, one element focuses upon palliative care. The aim is to develop multidisciplinary courses on palliative care for staff in nursing homes. The courses are undertaken by care workers, nurses and physiotherapists and occupational therapists.
Evaluation is undertaken using the ASCOT-measure (Adult Social Care Outcomes Toolkit).
Further information: http://socialstyrelsen.dk/aeldre/livskvalitet-og-selvbestemmelse/program-livskvalitet-og-selvbestemmelse (in Danish)

Another team focused intervention identified is the use of reflective debriefing groups (UK) (Box 7) which have both an educative and supportive function (Hockley 2014).

Box 7: Reflective Debriefing Groups (UK)

Reflective debrieifing groups are run for staff working in LTCFs, following the death of a resident. Using a structured process the following aspects of the death of a resident are discussed:

- *The person/event.*
- *What happened leading up to the death/event*
- *How staff feel things went*
- *What could have been done differently*
- *What do we need to change as a result of this reflection*

The groups have been shown to facilitate learning at three levels: being taught, developing understanding and critical thinking, alongside providing support for staff (Hockley 2014).

6. Discussion

This Taskforce has mapped and classified different structures, organizational models, and policies related to palliative care provision in long term care facilities (LTCFs) in Europe. This discussion considers the issues that have arisen from this process of mapping and classifying the provision of palliative care in LTCFS across Europe, identifying common issues and differences across Europe, relating these to the wider international context. The findings about the LTCF context, the population living and dying there and the ways in which palliative care in LTCFs is occurring or being developed are considered. Examples of current palliative care practices and innovative approaches to the development of palliative care in LTCFs have been identified, but their evidence base is limited in many instances. Much work reported here and in the previous Taskforce (Froggatt and Reitinger, 2013) has developed from practice, without rigorous evaluation in many instances.

A number of themes and issues are raised from the work regarding the country contexts and the nature of the initiatives.

6.1 Country context

A number of similarities and differences are identified across Europe between the countries that participated in the Taskforce concerning the increased interest in this field, the differentiated service provision, issues of quality management and the extent to which strategic policy initiatives exist.

There is an increasing recognition of the changing demand for care with an increasingly older population across Europe. How that is being addressed in specific countries varies, especially with respect to palliative care, and the extent to which this approach to care is being integrated into broader ageing, and public health and other related strategies.

There is evidence in all countries surveyed of a care system that has differentiated provision to meet specific clinical needs, with different staffing levels and types to reflect the level of medical and nursing need required to be met. Three types of provision can be identified with different locations of physicians and nurses determining the type utilized. The different models of medical care (either on-site or off-site) impacts upon how palliative care can be provided and accessibility to drugs, as required.

All countries have systems and processes in place to ensure the quality of care provided for older people in LTCFs. The systems used to ensure this happens vary from the use of legal frameworks, registration and certification, and standards of care. However, the presence of these frameworks, and their implementation is not consistent in reflecting the extent to which they are enforced. Specific policy initiatives that supported the provision of palliative care in LTCFs was even less visible in many countries.

Funding for palliative care in LTCFs is an interesting issue, as in order to ensure this happens requires working across two sectors: the LTCF funding system and the health/palliative care models. As has been described funding for care in LTCFs is from diverse sources and varies cross Europe reflecting the broader health and social economy in each country.

6.2 Palliative Care Initiatives

The way in which palliative care is developed in LTCFs in each country will partly reflect the way in which palliative care has been developed more generally. In considering palliative care structures across these countries, there appears to not always be a clear relationship between stage of palliative care development in general (ie the extent to which palliative care is integrated into mainstream service provision) and the extent to which palliative care is being developed/delivered in LTCFs.

In some instances the lack of palliative care provision in LTCFs reflects the presence of a different model of institutional care for older people, e.g. in Lithuania, palliative care is provided in nursing hospitals for this population, rather than LTCFs. The limited engagement in some countries may also reflect the origins and ongoing emphasis of palliative care on cancer, and a lack of attention the needs of people with non-cancer conditions (Pereira *et al.* 2015).

A recent review of improvement strategies in palliative care (van Riet Paap *et al.* 2015) described several different ways in which the organisation of palliative care was being improved: educational, process mapping, feedback, multi-disciplinary meetings, and multi-faceted implementation strategies. Only 14 out of 68 studies reviewed were concerned with the improvement of palliative care provision in in LTCFs. The most effective intervention were identified as being focused on the delivery of education to physicians. These improvement strategies mirror those identified in this mapping survey, although given the differing roles of physicians in LTCFs, it may be that education for other care professions will be more important in the LTCF setting.

In terms of specific LTCF initiatives, Froggatt *et al*. (2006) identified that three areas of development to support palliative care in LTCFs were reported: service delivery models, 'interventions' that facilitate care for individuals, and tool development. In terms of service

delivery these could be categorised as: provision of hospice services, establishment of specialist palliative care units, consultation services and education initiatives (Ersek and Wilson 2003). The activities identified in this survey agree with these earlier categorisations with examples of service delivery models, interventions for the care of individuals and education being described. Countries at earlier stages of general development of palliative care in LTCFs as identified in the Global Atlas on Palliative Care describe two types of activity: consultations from specialist palliative care teams (e.g. France), or provision of education for LTCF staff (e.g. Finland, Luxembourg).

Many of the initiatives identified can be classified as focusing upon change at more than one of the levels of development as advocated by Ferlie and Shortell (2001). This is particularly exemplified in the multi-component interventions described earlier such as the GSF for Care Homes intervention or PACE Steps to Success, which considers both the development of teams and staff, but also aspects of organisational readiness. In order to effectively develop and provide palliative care in LTCFs, it needs to be considered as a complex intervention.

The main focus of most of these interventions is upon staff development as the means to improve care. It has been shown that education is necessary, but not sufficient (Froggatt 2001, Nolan *et al.* 2008) in order to ensure change. An understanding of organisational change and the precursors necessary for effective change is required for any new initiatives to be effectively implemented (Heimerl 2008). The need for effective implementation strategies for the use of best evidence is increasingly recognised.

In spite of important policy developments which have been identified, and are required to create the right preconditions for the implementation of palliative care, this does not automatically mean that in individual organisations, in staff care practices, palliative care will be provided consistently and with high quality for older people.

The WHO Public Health Strategy for Palliative Care (Stjernsward *et al.* 2007) suggests development in four domains to improve palliative care services: Appropriate policies, availability of education and training, availability of medicine and implementation cross all levels of society. In considering this strategy for LTCFs the same four domains need to be addressed (Table 12) These domains offer a way to frame future developments that will reflect wider palliative care development initiatives, for example in primary are.

6.3 Limitations of this study

This study is limited by the quality of data obtained from the participating countries and documentary sources. A lack of data about initiatives could reflect either that there is no activity in the country or that it has not been collected. Some documentary sources eg the EAPC Atlas (Centeno *et al*. 2013) do not explicate the detail of the LTCF sector across Europe and its different structures, so the data provided about palliative care provision in these settings as supplied by this source may be limited. Data about drug availability in LTCFs was not sought, although wider country data is available through the EAPC Atlas (Centeno *et al*. 2013).

Family and the role of residents has been conspicuous by its absence in this mapping exercise, reflecting to an extent the focus of the survey, but also different approaches to the role of family

and residents in care provision, especially when frail and often with cognitive impairments. Similarly the role of volunteers has not been identified in any of the initiatives presented. There is the potential to draw on the expertise on the hospice sector and their use of volunteers.

Table 12: Best Practice Approaches for Palliative Care in LTCFs.

Strategy Domain	National	Organisational
Policy	• Palliative care for older people in LTCFs mentioned in relevant health plans/ strategies eg older people palliative care, dementia plans • Funding models support palliative care delivery in LTCFs	• Clear structures and processes to support the delivery of palliative care in the organisation
Education	• Agreed curriculum and competencies for palliative care in LTCFs	• Regular, ongoing palliative care education for all LTCF staff and external staff supporting them (eg GPs, palliative care specialists)
Drug Availability	• Broader policies re drug availability present (opioids and other drugs)	• Local systems to ensure appropriate drug availability
Implementation	• National taskforce to ensure strategic policies in place with respect to strategies, funding and quality assurance mechanisms	• Engage with structured intervention packages to ensure a systematic approach to palliative care development

7. Conclusions

This mapping of palliative care provision in LTCFs has shown both the diversity of the LTCF sector in Europe, with examples of innovative interventions and practices at national, regional and organisational levels. LTCFs are an important component of the health and social care economy especially for a proportion of frail older people. They are also the place where these people will experience their dying and deaths. Many challenges lie in ensuring the delivery of palliative care in LTCFs in a consistent and high quality way. These challenges lie in ensuring national policies, funding, regulatory and quality assurance frameworks address palliative care for older people in LTCFs. This then needs to be supported by appropriate implementation approaches at more local and organisational levels to ensure staff is equipped to deliver palliative care with appropriate resources and support from within and externally to the LTCFs.

This is a time of change in Europe, with rapid demographic changes that are occurring, beyond those described with respect to ageing. Current population movement across and within Europe is, and will continue to change the demand for health and social care and also the workforce profile. The current international financial context and the implementation of austerity measures in many European countries again has an impact upon care provision for older people in LTCFs,

through changes in funding systems of care. The longer term impact of these broader changes is not yet known.

7.1 Recommendations

These recommendations have been derived from consultation with stakeholder groups (Age Platform, Alzheimer Europe, European Association for Palliative Care and the European Forum for Primary Care).

POLICY MAKERS (National/Regional):

- Review legal frameworks for palliative care provision (including access to opioid medication) in LTCFs to ensure LTCFs can deliver palliative care
- Address national health and social care strategies and wider policy strategies around dementia and age-friendly environments to support delivery of high quality palliative care at the end of life including in LTCFs
- Ensure that registration, certification and accreditation bodies of LTCFs include quality PC delivery as part of their evaluation/assessment criteria
- Develop quality standards and guidelines for palliative care in LTCFs (in partnership with relevant professional associations)

HEALTH AND SOCIAL CARE BODIES:

- Work towards integration of services across health and social are, including LTCFs, to support continuity of care provision for older people with palliative care needs in LTCFs.

LTCFs:

- Establish partnerships between LTCFs and specialist palliative care providers
- Support implementation of palliative care in LTCFs through use of structured palliative care multi-faceted interventions that address: care planning, multidisciplinary working, symptom management, family and staff support, care in the last days of life, integration,
- Support staff training in palliative care in an ongoing way
- Implement indicators for quality of palliative care monitoring

RESEARCHERS:

- Develop a typology of activity (policy and clinically based) to describe levels of palliative care development in LTCFs;
- There is a need to identify comparable data sets across and beyond Europe around palliative care and LTCFs and better understand what are the preconditions for optimal palliative care in LTCFs;
- Further studies regarding the implementation of palliative care into LTCFs are required to develop an evidence base about the best ways to undertake implementation of palliative care in this setting;
- Further studies about the impact of education and training upon the development of palliative care in long-term care facilities.

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APPENDIX 1: Country Informants

COUNTRY	COUNTRY INFORMANT(S)
Austria	Dr Elisabeth Reitinger: Alpen-Adria Universitat
Belgium	Dr Tinne Smets: Universiteit Brussel
Cyprus	Barbara Pitsillides: The Cyprus Association of Cancer patients and friends Andreas Papageorgiou: The Cyprus Association of Cancer patients and friends
Denmark	Mette Raunkiaer: Danish knowledge centre for palliative care Katherine H. Schwartz-Nielsen
Finland	Prof. Harriet Finne-Soveri: National Institute of Health and Welfare, Helsinki
France	Dr Marie-France Couilliot: Universite Paris
Germany	Dr Ingrid Eyers: British Society of Gerontology Thomas Sitte (Section 3)
Greece	Dr Evrydiki Petta: Palliative Care Unit (P.C.U.) "GALILEE" of the Holy Metropolis of Mesogaia and Lavreotiki, Spata Attikis.
Hungary	Agnes Zana: Semmelweis University
Iceland	Asss. Prof. Ingibjörg Hjaltadóttir
Ireland	Dr Catherine Sweeney: University College Cork
Israel	Dr Tikva Meron: The University of Nottingham
Italy	Dr Massimo Monti
Lithuania	Arvydas Seskevisus: Lithuanian Society of Palliative Medicine Aurelija Blazeviciene: Lithuanian University of Health Sciences
Luxembourg	Lydie Diederich: Assication Luxemburg Alzheimer Michèle Halsdorf: Assication Luxemburg Alzheimer Jang Hamen: University of Luxembourg Marcelle Diederich: Nadine Schartz:
Norway	Reidun Karin Sandvik: Universitetet i Bergen
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The Netherlands	Dr Roeline Pasman: VU University Medical Centre Amsterdam
Turkey	Bilge Kalanlar: Hacettepe Universitesi
United Kingdom	Dr Julie Kinley: St Christopher's Hospice Dr Jo Hockley: formerly St Christopher's Hospice

APPENDIX 2: Survey template

MAPPING PALLIATIVE CARE SYSTEMS IN LONG TERM CARE FACILITIES FOR OLDER PEOPLE IN EUROPE

INSTRUCTIONS FOR COMPLETION OF THIS SURVEY

- Please complete the following survey Tables in as much detail as possible:
  - **Tables 1 & 2**: Country summary and context information.
  - **Tables 3 - 6**: Specific details of examples of interventions & initiatives.

- If some questions are not relevant to your examples of interventions/initiatives, or you cannot obtain the information, please collaborate with a colleague who may assist with the information, or if appropriate, leave the question blank.

- The aim of the survey is to obtain the MOST IMPORTANT EXAMPLES in your country. It is NOT asking you to describe ALL relevant developments here.

- **Please see** next page for definitions and terms used in this survey.

Terms and definitions used in this survey:

- **WHO *definition of Palliative care*:**
  A multidisciplinary approach that improves the quality of life of patients and their families facing 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/existential*.

- **A *long-term care facility* for older people is:**
  - A ***collective institutional facility*** where care is provided for older people who live there, ***24 hours a day, seven days a week***, for an ***undefined period*** of time;

  - The care provided includes:
    - ***On site provision* of *personal assistance*** with activities of daily living;
    - ***Nursing and medical care*** may be provided ***on-site*** or by nursing and medical *professionals* working from an organisation ***external*** to the setting.

- **Facilities may be *private, voluntary or publically funded.***

- ***Terms for long term care facilities* vary across Europe and may include:**

  Continuing care units ***Geriatric centres***

  Group homes **Geronto-psychiatric facilities**

  Hospital long-term units ***Nursing homes***

  Residential care **Older people's homes**

  Residences for elderly people **Retirement/resting homes**

  Supported housing arrangements

- **LTCFs *= long term care facilities***
  LTC *= long term care*

* http://www.who.int/cancer/palliative/definition/en/ **accessed 26.03.14**

- **<u>SECTION ONE</u>: *SUMMARY INFORMATION***

<u>Please complete ALL sections</u>

COUNTRY:	
COUNTRY CODE:	*PLEASE leave blank for administration*

<u>Table 1 Country contact information</u>:

Name of person completing survey:	Title: First name: Last name:
Position:	**Phone number: (**with international dialling code**)**
Organisation: Name: Location:	**Email address:**

SECTION TWO: ORGANISATION OF PALLIATIVE CARE [PC] IN LONG TERM CARE FACILITIES [LTCFs]

Table 2 Country context information - please complete as fully as possible

Section	Request Information
Country	• In some countries care may be organised by state, region or province. How is care organised in your country? • Please indicate which is the case and if the information provided in this table refers to country, state, region or province level.
Place of death	• Provide proportion/s of deaths of older people in LTCFs. PLEASE PROVIDE REFERENCES FOR SOURCES USED
Types of LTCFs and Terminology to describe these	• Give names and titles used to describe LTCFs in your country. • Include different types of facilities with respect to how medical and nursing care is provided. • Are staff employed by the LTCFs or employed by external organisations and visit the LTCFs to provide care? • Describe the training level and qualifications of care staff employed by the LTCFs.
Resident populations in LTCFs	• Provide total national figures: ▪ of older people living in LTCFs, with gender figures if available. ▪ of older people receiving palliative care in LTCFs. ▪ of older people with a dementia diagnosis in in LTCFs. ▪ of mean length of stay of older people in LTCFs. • Do national guidelines exist for measuring resident dependency levels in LTCFs? If available, please provide the tools used in your country and national figures. PLEASE PROVIDE REFERENCES FOR SOURCES USED
Status of LTCF provision	• Provide the funding status of providers of LTC for older people in your country e.g. private (for-profit), public, voluntary, charitable or not-for-profit sectors. • Include the relative proportions of LTCFs (both numbers and %) in each category sited.

Funding of LTCF provision	• How are LTCFs for older people funded, with respect to: public funding, insurance, older person / resident and / or family monies?
Regulation of LTCFs	• How are LTCFs regulated? • Identify regulatory bodies that exist in your country/state/region etc? • What standards or guidelines are issued by them? • How is quality controlled/measured in LTCFs? If any, what national standards and certification measure apply? • Do guidelines exist for minimum levels of staff: resident ratios? • Provide website links if available.
Key Drivers for Change in LTCFs at national/regional levels	• What are the policy and practice drivers for the development of Palliative Care for older people in LTCFs? • Note those that come from the palliative care world, the long term care sector, geriatric medicine, or other influences.

SECTION THREE: PALLIATIVE CARE INTIATIVES

'Initiatives' refers to any specific specialist or general palliative care developments, practices and innovative approaches at different organisational levels in Tables 3-6. These levels are:

INTERNATIONAL, NATIONAL, REGIONAL/NETWORK, ORGANISATIONAL.

Table 3: Country initiatives (*International level*) - please complete all sections where possible

For guidance, an example of a UK completed table can be found in the Appendix attached with this survey

1) Are there any INTERNATIONAL LEVEL developments concerning the development of palliative care in long term care facilities for older people being undertaken in your country (e.g. international networks, cooperation with international associations)?

Yes ☐ No ☐

If yes, please **LIST** below up to **5 initiatives** and provide **details of ONE initiative** that has impact/outcome evidence:

1. *provide name, location, contact email, website if available.*
2.
3.
4.
5.

DETAILS OF ONE INITIATIVE:

Initiative Title:

Contact Details for Initiative:

Name:

Organisation:

Email:

Telephone:

How is the initiative undertaken? Please describe details of the structure and organisation of the intervention, including:

- How was change undertaken – top down (e.g. government organisational directive), bottom up (e.g. long term care setting initiated), or collaboratively?
- Was a new structure introduced e.g. to improve accessibility, affordability or availability of palliative care in LTCFs?
- Which staff professionals were involved? Which other organisations/stakeholders were involved?
- Which patient groups did it involve? (diagnosis, gender, age, other specific characteristics)
- How were older people involved in the palliative care development?
- How was change assessed and measured?
- Are future developments from this work planned?

What are the outcomes of this initiative? (Please tick all that apply)

- Improvement in quality of life for older people in need of care (including assessment of quality of life) ☐
- Better support & involvement of, informal carers, family and friends ☐
- Greater levels of staff knowledge and skill about palliative care ☐
- Better staff assessment and/or management of symptoms ☐
- Greater support for professional carers ☐

- Introduction of a care pathway ☐
- Advanced care planning ☐
- Introduction of a new service or development (please provide name) ☐
- Other (please specify) ☐

Please give further information about this intervention that describes processes and outcomes. Please attach any reports or publications that are available.
Any other relevant information:

Table 4: Country initiatives (*National level*) - please complete all sections where possible

2) Are there any NATIONAL LEVEL developments concerning the development of palliative care in long term care facilities for older people being undertaken in your country (e.g. national law, policy, strategies, professional guidelines, funding)?

Yes ☐ No ☐

If yes, please **LIST** up to **5 initiatives** and provide **details of ONE initiative** that has impact/outcome evidence:

1. *provide name, location, contact email, website if available.*
2.
3.
4.
5.

DETAILS OF ONE INITIATIVE:

Initiative Title:
Contact Details for Initiative:
Name:
Organisation:
Email:
Telephone:

How is the initiative undertaken? Please describe details of the structure and organisation of the intervention, including:

- How was change undertaken – top down (e.g. government organisational directive), bottom up (e.g. long term care setting initiated), or collaboratively?
- Was a new structure introduced e.g. to improve accessibility, affordability or availability of palliative care in LTCFs?
- Which staff professionals were involved? Which other organisations/stakeholders were involved?
- Which patient groups did it involve? (diagnosis, gender, age, other specific characteristics)
- How were older people involved in the palliative care development?
- How was change assessed and measured?
- Are future developments from this work planned?

What are the outcomes of this initiative? (Please tick all that apply)

- Improvement in quality of life for older people in need of care (including assessment of quality of life) ☐

- Better support & involvement of, informal carers, family and friends ☐
- Greater levels of staff knowledge and skill about palliative care ☐
- Better staff assessment and/or management of symptoms ☐
- Greater support for professional carers ☐
- Introduction of a care pathway ☐
- Advanced care planning ☐
- Introduction of a new service or development (please provide name) ☐
- Other (please specify) ☐

Please give further information about this intervention that describes <u>processes</u> and <u>outcomes</u>. Please <u>attach</u> any reports or publications that are available.

Any other relevant information:

Table 5: Country initiatives (*Regional/Network* level) - please complete all sections where possible

3) Are there any REGIONAL/ NETWORK projects addressing the development of palliative care in long term care facilities for older people being undertaken in your country (e.g. policies, development of guidelines)?

Yes ☐ No ☐

If yes, please **LIST** up to **5 initiatives** and provide **details of ONE initiative** that has impact/outcome evidence:

1. *provide name, location, contact email, website if available.*
2.
3.
4.
5.

DETAILS OF ONE INITIATIVE:

Initiative Title:

Contact Details for Initiative:

Name:

Organisation:

Email:

Telephone:

How is the initiative undertaken? Please describe details of the structure and organisation of the intervention, including:

- How was change undertaken – top down (e.g. government organisational directive), bottom up (e.g. long term care setting initiated), or collaboratively?
- Was a new structure introduced e.g. to improve accessibility, affordability or availability of palliative care in LTCFs?
- Which staff professionals were involved? Which other organisations/stakeholders were involved?
- Which patient groups did it involve? (diagnosis, gender, age, other specific characteristics)
- How were older people involved in the palliative care development?
- How was change assessed and measured?
- Are future developments from this work planned?

What are the outcomes of this initiative? (Please tick all that apply)

- Improvement in quality of life for older people in need of care (including assessment of quality of life) ☐
- Better support & involvement of, informal carers, family and friends ☐
- Greater levels of staff knowledge and skill about palliative care ☐
- Better staff assessment and/or management of symptoms ☐
- Greater support for professional carers ☐
- Introduction of a care pathway ☐
- Advanced care planning ☐
- Introduction of a new service or development (please provide name) ☐
- Other (please specify) ☐

Please give further information about this intervention that describes <u>processes</u> and <u>outcomes</u>. Please <u>attach</u> any reports or publications that are available.

Any other relevant information:

<u>Table 6:</u> <u>Country initiatives (*Organisational level*) - please complete all sections where possible</u>

4) Are there any <u>ORGANISATIONAL LEVEL</u> projects addressing the development of palliative care in long term care facilities for older people being undertaken in your country (e.g. development of policies, documentation, standards, staff education in a LTCF or a group of LTCFs)?

Yes ☐ No ☐

If yes, please **LIST** up to **5 initiatives** and provide **details of ONE initiative** that has impact/outcome evidence:

1. *provide name, location, contact email, website if available.*
2.
3.
4.
5.

DETAILS OF <u>ONE</u> INITIATIVE:

Initiative Title:

Contact Details for Initiative:

Name:

Organisation:

Email:

Telephone:

How is the initiative undertaken? Please describe details of the structure and organisation of the intervention, including:

- How was change undertaken – top down (e.g. government organisational directive), bottom up (e.g. long term care setting initiated), or collaboratively?
- Was a new structure introduced e.g. to improve accessibility, affordability or availability of palliative care in LTCFs?
- Which staff professionals were involved? Which other organisations/stakeholders were involved?
- Which patient groups did it involve? (diagnosis, gender, age, other specific characteristics)
- How were older people involved in the palliative care development?
- How was change assessed and measured?
- Are future developments from this work planned?

What are the outcomes of this initiative? (Please tick all that apply)

- Improvement in quality of life for older people in need of care (including assessment of quality of life) ☐

- Better support & involvement of, informal carers, family and friends ☐
- Greater levels of staff knowledge and skill about palliative care ☐
- Better staff assessment and/or management of symptoms ☐
- Greater support for professional carers ☐
- Introduction of a care pathway ☐
- Advanced care planning ☐
- Introduction of a new service or development (please provide name) ☐
- Other (please specify) ☐

Please give further information about this intervention that describes <u>processes</u> and <u>outcomes</u>. Please <u>attach</u> any reports or publications that are available.

Any other relevant information:

THANK YOU FOR COMPLETING THIS MAPPING SURVEY

Appendix 3: Table 3: Organisational Structure of LTCFs by Country

Austria	**Health care system:** 1. **Geriatric centres** (*Geriatriezentrum*): provide personal, nursing and medical care 24 hours a day, 7 day a week. Focus is on medical and inter-disciplinary health care. **Social care system:** 2. **Nursing homes** (*Pflegeheim*): provide personal and nursing care (domestic help and basic care), 24 hours a day, 7 days a week. Medical care (medical treatment) is provided by primary care service providers. 3. **Retirement homes** (*Altenwohnheim, Seniorenresidenz*): provide a place of residence and personal care if necessary. Focus on social activities and social care.
Belgium	1. **Nursing Homes (WZC):** Nursing care and living facilities for elderly persons with moderate to severe limitations. Nursing and medical care provided onsite. Includes both RZT and ROB beds. 2. **Homes for the Elderly (ROB):** Nursing care and living facilities for elderly persons with low to moderate limitations. Nursing and medical care provided offsite. Small number of these facilities. Omzendbrief WVG/KWAL/07/1 van 21 februari 2007 betreffende de vervanging van de omzendbrief van 2 juli 2004 houdende de kwalificatievereisten van de verzorgende personeelsleden in de rusthuizen
Cyprus	**Homes for the elderly.** 1. **Nursing state care homes:** The government run facilities offer more geriatric nursing facilities for more acute and chronic conditions. 2. **Private care homes**: Private institutions are not as well equipped for acute medical care and take on chronic care only. 3. **Local Community care homes** also exist. From Cyprus report (Loizou 2010)
Czech Republic	LTC provision (and funding) is institutional care, which is partly provided within: 1. **Residential care:** The health care system concentrates on the LTC services for the disabled 2. **Rehabilitation and nursing:** Long-term sick provided with aftercare in hospital departments and LTC homes (LDN) under the supervision of the Ministry of Health (MoH). 3. **Pensioner homes:** Social services system. This concentrates on services provided to dependent and vulnerable people, among whom are also the elderly. Supervised by the Ministry of Labour and Social Affairs (MoLSA) **Residential homes for the elderly:** Some residential homes now offer hospice home care services
Denmark	1. **Nursing homes** (plejehjem): Conventional Nursing homes, with services and living occurring mostly in the same area. 2. **Care homes** (plejeboliger): Care homes are assisted living homes with permanent staff and a separate service area.

Finland	Health centre long-term wards and nursing-homes together are called institutional care, in Finland. **Health centres** 1. Health centres traditionally provide acute care for acutely ill (often aged) persons. In addition some of these centres also have long-term facilities for those who are very ill and cannot return back home. Chronic care in the health centre wards (=LTCFs) is currently being downsized by order of the parliament (29th Nov 2013). 2. Performs under the health act; delivers medical care **Nursing homes** Performs under the social act; delivers personal (and in small extent medical) care
France	Three types of facility 1. **Hospital long term units** (USLD): provide nursing and medical care and more or less social activities (=1.1% of all LTCFs). 2. **Nursing homes:** (EHPAD = "accommodation facilities for the dependent elderly") (=82% of all LTCFs) provide personal assistance and nursing care, 24 hours a day, 7 days a week. Medical care by external GPs but there is, on site, a medical manager (half time or less). 3. **Retirement Homes**: "maison de retraite", 1.3 % of all LTCFs and "foyers logements", 15% of all LTCFs. Place of residence, social activities. External personal assistance.
Germany	LTCFs are often part of a 'Seniorenzentrum' with a range of services including day centres (Tagespflege), home care services (Haeusliche Pflege) and sheltered accommodation (Betreutes Wohnen). 1. **Nursing/ care home (*Pflegeheim*):** A Pflegeheim provides health and social care 24/7. The move into the Nursing Home tends to take place once someone qualifies for Care level 1 of the LTC funding categories. Medical care by external GP's. 2. **'Nursing unit' or 'Care ward' (*Pflegestation*):** A unit within an Altenheim/Altenwohnheim (Old People's Home) or 'Seniorenheim' (Home for Senior Citizens) will all be staffed according to the residents formally accessed level of dependency. 3. **High end services:** Seniorenresidenz the name indicates a facility for the top end of the market, where potential future residents are screened for their ability to pay for 'high end' services which can also include nursing care in specialized units.
Greece	1. **Nursing care:** Residential private or limited public including Church and NGO. Classed as social care facilities, but have an obligatory ratio of nurses, as well as cooperating with relevant medical specialists, physiotherapists, occupational therapists and other health care personnel. Cannot accept people with complicated care needs (including cancer) who are cared for in hospitals. (Mastroyiannakis & Kagialaris 2010)
Hungary	**1. Nursing Homes** (care homes with nursing) provide personal and nursing care

	24 hours a day, 7 days a week. Medical care provided by primary care services, employed internal to the facility. 2. **Residential Care Homes** (care homes without nursing) provide only personal care. Nursing and medical care provided by primary care services, employed internal to the facility.
Iceland	1. **Nursing homes** or nursing wards in geriatric institutions intended for elderly individuals who are too ill to reside in Residential Homes. These provide nursing, medical services and rehabilitation facilities. Special facilities available for elderly individuals showing symptoms of dementia. The services shall be based on individual assessments of the health and social needs of the elderly person. Short-term stays available. 2. **Residential homes** (Homes for the elderly, communal residences and apartments) designed for the needs of the elderly who are unable to maintain a home in spite of home care services. 24 hour surveillance, a security system in each apartment and a choice of varied services, such as catering, laundry, cleaning and social and recreational activities. Facilities available for nursing, medical aid and rehabilitation. Services based on individual assessments of the needs of the person and shall be geared to assistance to self-help. All staff is internal, however residents might seek special medical care externally paid by the nursing home. http://eng.velferdarraduneyti.is/media/acrobat-enskar_sidur/Act-on-the-Affairs-of-the-Elderly-No-125-1999-with-subsequent-amendmends.pdf
Ireland	1. **Nursing homes** (Private) include private (for- profit) and private (not-for-profit) agencies. They provide personal care and nursing care 24 hours a day and 7 days a week. Medical care is provided by general practitioners. 2. **Residential care** (State run) provide personal and full nursing care 24 hours a day, 7 days a week. In addition under Section 38 of Health act, voluntary hospitals provide long term care on behalf of the state.
Israel	**Dependent elderly:** **Nursing homes**. 24/7 nursing care, and often medical care as well. Care is divided into: **Nursing care** – There is permanent and severe physical disability (mobility, activity of daily living [ADL]). Licenced and supervised by the Ministry of Health; **Mentally-frail care** – There is mobility but a permanent and considerable cognitive disability, with a need for help with ADL and 24/7 personal safeguard. Licensed and supervised by the Ministry of Health; **Complex nursing care** – There is severe functional and medical complexity such as: pressure sores, respiratory problems, intravenous treatment, terminal illness). Managed by the HCOs; **Frail care** – There is mild to moderate decline in ADL and a need for partial help. They are usually cared for in Parents-Homes, managed by the Ministry of Welfare and Social Services. Most staff employed by the LTCF, including nurses, physicians, and consultant physicians. HCOs provide medicines and pay for acute hospitalisations. In complex nursing care the medical team is part of the LTCF. Some professions such as laboratory

	and imaging professional may be external to the LTCF. http://www.health.gov.il/English/Topics/SeniorHealth/Hospitalization/Pages/HospitalizedElderlyInInstitutions.asp
Italy	1. **Nursing Homes:** (Residenze Sanitarie Assistenziali): for wholly dependent older people with health-care related needs, provide personal and nursing care, 24/ 7. Medical care is usually provided by specialised Nursing Home medical staff. 2. **LTC facilities for partially dependent older people**: (Residenze Assistenziali): provide a place of residence, personal care 24/7, and nursing care if necessary (some hours per day). Medical care: General Pratictioner and Specialist consultations. Focus on social activities and social care. Source: AUSER, Indagine sulle RSA in Italia, 2012 (www1.auser.it).
Latvia	Long-term social care 'Ilgstošassociālāsaprūpes' Social rehabilitation institution 'sociālāsrehabilitācijasinstitūcija
Lithuania	From Ancien Report: 1. **Nursing services (health care sector):** Facilities for long-term medical treatment with nursing services are available for patients with chronic diseases or disabilities. The patient can be treated in the long-term care institution (called 'supportive treatment hospitals') if suffers from a disease included in list of medical indications approved by the Ministry of Health. 2. **Social care institutions**: LTC is provided for those who are totally dependent and who need the permanent care of professionally trained caregivers. Social care institutions are available in all the main regions of the country under the supervision of local governments. The minimum duration of stay is one month. From Survey: Šv. Klaros supportive and nursing hospital (Utena) – state level. (St. Clare's Hospice in Utena, Lithuania.)
Luxemburg	1. **General Nursing Home** (Specialised LTCF) 2. **Residential Home** (Mixed LTCF)
Netherlands	LTC facilities providing help for somatic ill patients, in need of nursing home care, psychiatric/geriatric wards, palliative care and special care wards for dementia care, and rehabilitation. 1. **Nursing homes:** provide nursing and medical care 24/7. Medical care provided by special trained 'elderly care physicians' (nursing home physician). 2. **Retirement homes:** provide nursing care 24/7. Medical care provided by General Practitioner. Some private initiatives occur (mainly small scale, for instance for patients with dementia).
Norway	1. **Nursing homes** (*Verpleeghuizen*): provide nursing and medical care 24 hours a day, 7 days a week. Medical care provided by specially trained nursing home physicians. 2. **Residential homes** (V*erzorgingshuizen*); provide nursing care/assistance 24 hours a day, 7 days a week. Medical care provided by a General Practitioner. Some residential homes provide a psychogeriatric unit for dementia within their facility so increasing the level of care they offer.
Poland	Residential or nursing homes (not only older people). LTC provided within the framework of:

	1. **Health care system - LTC institutions**: **Nursing and care services:** **Care and treatment (ZOL):** Doctors are employed full time. Doctor on duty 24/7; plus nurses, physiotherapists, caregivers and other professionals. **Care and Nursing**: **(ZPO)** Zakład Pielęgnacyjno-Opiekuńczy. Doctor available on call; plus nurses, physiotherapists, caregivers and other professionals. 2. **The LTC institutions social care system (funded by state budget based on State Social Aid) are:** **3. Care homes with nursing:** DPS - Dom Pomocy Społecznej: Protection as well as supportive and educational services. Provides personal (by care assistants) and/or nursing (by nurses) care 24/7; rehabilitation (physiotherapy, occupational therapy) and psychotherapy in site. Dietician service. Care by social worker employed on site. The residents of DPS may be permanent.
Portugal	**1. Continuing Care Unit or convalescent units**: temporary housing, personal basic care (hygiene), 24 hours, 7 days a week. Nursing and medical support (treatment) 24 hours, social and psychological support, occupational therapy and physiotherapy in an interdisciplinary action - Link to the Ministry of Health. **2. Care homes or Residential Structure for Older People (ERPI- Estrutura Residencial para Pessoas Idosas):** accommodation (place of residence), domestic help and basic care (personal care and hygiene), 24/7, nursing and medical support (treatment), social and psychological support. It may have occupational therapy and physiotherapy - Link to the Ministry of Social Welfare (social protection and welfare). **3. Rest home or Assisted Residences (Residências Assistidas):** accommodation (place of residence), domestic support 24/7. It may have personal basic care (hygiene) if necessary, medical support and nursing, social and psychological. It may have occupational therapy and physiotherapy and other services like hair dresser, for example - features hotel accommodation.
Romania	1. **Nursing home care** (old-age home) – temporary or permanent services. 2. **Residential care**: Institutional care in day care centres, clubs for the elderly, temporary care homes, assisted living arrangements, social apartments and accommodation, as well as other similar settings (Law 17/2000). Romania has a major shortage of institutionalised services. Home care is the most commonly used care option for dependent older people. There is a greater shortage in the rural areas, where most activities are performed by NGOs and public services of home care are scarce. Source: Ancien Report, 2010.
Spain	**1. Nursing homes** *(Centros residenciales para personas mayores en situación de dependencia, also Residencias asistidas):* provide personal, nursing and medical care 24 hours a day, 7 days a week. Social support and leisure activities, physiotherapy, occupational therapy and psychological care. **2. Residential homes** *(Residencias para personas mayores, also Residencias de válidos):* provide personal care 24 hours a day, 7 days a week, social support and leisure activities. It may offer physiotherapy, occupational therapy and psychological care, depending on the Autonomous Community. Residential

	apartment services and foster care services for older people (Pisos tutelados) Supported housing arrangements services related to domestic needs and personal care carried out by accredited entities or companies. This includes telecare services (fulfilling emergency and preventive function) Usually defined as *care homes,* since the passing of the ACT 39/2006, of 14th December, on the Promotion of Personal Autonomy and Care for Dependent Persons (known as Dependency Law). 3. **Social Services centres**: external care provided by Primary Health Care GP and a nurse. In general all LTCs depend on Regional Ministries of Social Affairs or on Regional Health Ministries. **Private LTCs:** • High standing • Small LTCs. Medical and nursing care is provided for the Health Centre reference to them for geographic location.
Sweden	1. **Nursing homes** (*Sjukhem*) 2. **Group homes** (*Gruppbiende for personer med demens*) 3. **Residential care facilities** (*Ălder-domshem*) All provide personal and nursing care 24 hours a day, 7 days a week. Medical Care (by physicians) is provided by the county council.
Switzerland	1. **Nursing care homes** (*Pflegeheim; Etablissement Médico-social (EMS); Casa di Cura Medicalizzata*). For patients in need of daily nursing care not available at home. Medical care provided by nursing home physicians or general practitioners (family doctors). 2. **Older people's homes** (*Altersheim; Maisons pour personnes agés; Casa di cura non medicalizzata*). For older people requiring less nursing care but needing assistance with personal care; medical care provided by family doctors.
Turkey	1. **Nursing homes or long-term care facilities for elderly people.** For older people at and over the age of 55 who suffer from social and/or economic deprivation and need special care 2. **Private Rest Homes and Care in Rehabilitation Centres:** For older people at and over the age of 55 who suffer from social and/or economic deprivation and need the care services of an organization 3. **Rest Homes**: provide services to people, over 60 years old, who do not have any chronic illnesses but are in need of special care. 4. **Nursing and Rehabilitation Centres for Elderly Persons:** provide services to people, over 60 years old, who do not have any chronic illnesses but are in need of rehabilitation and special care. (http://www.coe.int/t/dghl/standardsetting/hrpolicy/other_committees/cddh-age/Good_Practices/TURKEY.pdf)
UK	1. **Care Homes (nursing):** provide personal and nursing care with nurse(s) on duty 24/7. Medical care provided by primary care services (external to care home); however, an increasing number paying a retainer to GP practice to secure a specified service. 2. **Care Homes (personal care**): provide only personal care. Nursing and medical care provided by primary care services (external to care home).

Appendix 4: Funding for Care in Long-Term Care Facilities

Country	Funding Sources
Austria	Mixed funding 1) Public sector via social Three main sectors of the social welfare system: - Social insurance - Social protection - Social assistance Federal Long-Term Care Allowance Act: Federal funding for long-term care (received by person in need, care levels from 1 to 7), Provincial funding for long-term care (received by person in need). 2) Health Insurance (statutory) covers medical treatment. **In general**, the individual is responsible for financing his/her stay in a residential or nursing home from personal income/assets, which typically consist of a retirement pension plus a care allowance for LTC. If the care recipient's income and assets do not cover the fees, the respective provider of **social assistance** covers the difference.
Belgium	Mixed funding through insurance 1) Health insurance covers residential and home nursing care services (Federal Compulsory Health Insurance law of 14 July 1994). Universal health insurance is financed with social security contributions paid by workers, employers, and retirees, and by general taxes. 2) Cash benefits for long-term care recipients for non-medical expenses: Allowance for Assistance to Elderly Persons (federal level) and monthly allowance (for patients who score highly on an assessment of activities of daily living scale) paid by Flemish long-term care insurance (regional level).
Cyprus	Mixed funding If in a public LTCF, the government covers the costs. If in a private (not-for-profit; charitable) LTCF, the government assistance is means tested and client pays in their pension. The different between the pension and fee will be topped up by the government.
Denmark	The residents are required to contribute financially on a monthly basis by paying rent, but nursing care and medical care is free of charge.
Finland	Mixed funding by organizational type **Health centres:** • Some municipalities purchase services from other municipalities. Long-term care starts when funding status changes from acute to long-term, 3 months after admission, unless on medical grounds it can be determined a recovery is not possible. • In institutional LTC's the resident pays a maximum of 85% of his/her net income to cover the costs. Municipalities cover any remaining part of the cost. Care includes accommodation, food, clothes, health care. **Nursing homes:**

	• Long-term care starts when the person enters a nursing home. • The resident pays maximum 85% of his/her net income to cover the costs. Municipalities cover any remaining costs. Care includes accommodation, food, clothes, health care.
France	The cost is calculated according to : - accommodation (set price) - daily living assistance (according to the needs assessment for the Activities of Daily Living) - nursing care (set price) - Accommodation fees paid by the resident, welfare funding can be provided by the local authorities (departmental council welfare) (in public or not-for-profit homes) - ADL assistance fees paid by resident; financial help can be provided by the local authorities (according to the level of impairment and to the resident's income) - Nursing care fees and chronic therapeutics: free for the resident (funding from the National Health Care organisation) - Medical care provided by GPs, cost recovered by the National Health Care insurance and private insurance (although for some diseases the medical care is almost totally free for the patient).
Germany	Mixed funding - Obligatory individual care insurance (*Pflegeversicherung*) plus mandatory individual health insurance (*Krankenversicherun*g) pays part of the costs in long-term care facilities - Private contributions towards care: pensions, private care insurance, personal assets and family money (eg. children), to cover the gap (10 and 40 %) between the contribution provided by the insurance and the real costs. - Social welfare assistance (*Sozialhilfe*) is provided to cover long-term care costs for people in financial need.
Hungary	Mixed funding by care provision **Health care:** full coverage is ensured. Public services are primarily financed by the National Health Insurance Fund, and from contributions and tax-based revenues. Drugs and medical aids are accessible typically with a co-payment. Facilities providing chronic care usually require a flat rate contribution from the patients. **Social care:** funded by a combination of central/local government and out-of-pocket contributions. User charges for institutional care can be fully paid by the user or a third party, if the total fee cannot be paid in full. The charge amounts to a maximum of 80% of an individual's monthly income or 60% for provisional residential care. User charges for social care vary between local authorities. In 2008, local government contributions represented 46% of all public LTC expenditure. *(OECD, 2011).*

Iceland	Mixed funding 1) State funding from the government covers most costs *2)* Older person pays a monthly fee that is based on pension income, decided by the Ministry of Welfare.
Ireland	Mixed funding sources. Older person receiving financial support for care undergo means testing, although individuals can choose to pay privately and not be means tested. The Nursing Home Support Scheme is universal but means tested and subject to their ability to pay, for people with higher levels of dependency, who require long-term nursing home care in approved public and private facilities. Services covered by the scheme are nursing and personal care; basic aids and appliances to assist an individual with activities of daily living, bed and board and laundry service. Medical care – is means tested. People aged 70 or over are entitled to free medical care. This constitutes between 95 and 98% of all people over 70 years. Those individuals who are less than 70 years and who are not entitled to free medical care (%) pay for the costs of GP and other specialist services but are eligible for support with medication costs through the Drugs Payment Schemes.
Israel	Mixed funding 1) State funding for government run LTCFs and financial support for individuals (10-20%) 2) Older person and family also contribute (Chernichovsky *et al*. 2010)
Italy	Mixed funding Two components of the total nursing home rate: - "health care rate" (for medical and nursing care, drugs and medical equipment); - "social rate" (for accommodation and other services). The type of facility lived in can determine what is paid for: - in fully private facilities the users can be asked to pay for all the expenditure. - in public/private facilities, recognised by the Regional Health System, the user is admitted after being assessed by a geriatrician working in the Regional Health System: "health care rate" is covered by Regional Health System, "social rate" is covered by the users. Municipalities pay the "social rate" for low-income people, after social assessment. Regional Health System pays the full nursing home rate in post-acute situations (30/60 days). The estimated contribution towards nursing home expenditure is: 44% Regional Health System; 47% the users, 9% the municipalities.
Netherlands	Mixed funding In publicly run facilities, costs are covered by: 1. State funding through public long-term care insurance (AWBZ) exceptional Medical Expense Act; assessment is needed by an independent organization - CIZ 2. the older person is means tested for cost-sharing for residents of nursing

	homes and care homes. For private organisations 1) some state funding via personal budgets (PGB's; assessment is needed by an independent organization CIZ) for the care needed. 2) Older person pays all costs for living in a private institution.
Norway	Mixed funding 1) state funding municipalities fund care; they receive funding support from the government. All Norwegian inhabitants pay the same public insurance; 2) the older person has to use 70% of their pensions to fund their care; 3) private insurance can be purchased, but this is not usual practice. Older people are not required to sell their house or use family money.
Poland	Mixed funding **Health care:** (contracted by NFZ-Narodowy Fundusz Zdrowia – National Health Fund based on Health Insurance Act). **Social care:** (funded by state budget based on State Social Aid). **ZOL/ZPO and DPS:** Individuals are required to contribute financially to the cost of accommodation up to 70% of their retirement pension (means tested). Any costs not covered by individuals are paid by **ZOL/ZPO** based on a contract with NFZ (National Health Fund). In **DPS** if the family can pay (according to specific threshold) it has to pay the rest of real cost of stay in **DPS**. This exceeds significantly the average retirement pension and average monthly salary in Poland. In **ZOL/ZPO** the cost of medical care including drugs and dressing materials are provided free of charge based on common health insurance. In **DPS** the nurses and care assistants provide nursing care free to residents in care homes. The same applies to other services (rehabilitation, social care, psychotherapy, dietician). Medical care (GP, specialist visits, emergency and hospital care, diagnostic and treatment procedures) provided free of charge based on common health insurance; drugs only partly refundable by NFZ.
Portugal	Mixed funding 1) state funding that result from the agreements between the state and the private institutions. 1) the older person or their family provide private contributions (pensions, personal assets, private care insurance) and public resources
Spain	Mixed funding (same in all Autonomous Communities, but different percentages depending on the Regional or Local Government) 1) state funding: through the Dependency Law financed by the Central and Regional Governments (taxes and contributions) and through Regional Social Services Laws. Services are of a priority nature, but when the competent Administration is unable to offer them (public or subsidised), the individual is entitled to receive financial benefits (to buy private services, for informal caregivers or to hire personal caregivers) 2) the older person or their family must contribute financially to the funding

	of services by means of a co-payment, depending on their degree of dependency and personal financial situation. 3) Medical care free to all, although care homes may have their own GPs.
Sweden	Mixed funding. 1) state funding - state taxes finance more than 75% of the older people's care system. 2) the older person or their family (means tested)
Switzerland	Mixed funding. 1) state funding via the local authority 2) the older person or their family (means tested) 3) health insurance for nursing and medical care
United Kingdom	Mixed funding. 1) State funding covers health care: nursing care provided free to residents in care homes (personal care) by primary care nurses. Medical care free to residents all, the older person or their family (means tested) 2) the older person or their family (means tested). Needs assessed for nursing care provision in nursing homes. Varies between the UK nations e.g. Scotland provides free personal care, whereas in England this funding is means tested.

Appendix 5: Organisational and team palliative care initiatives

COUNTRY	NATIONAL LEVEL	REGIONAL/NETWORK LEVEL	ORGANISATION LEVEL
Austria	1. Hospice and Palliative Care in Nursing Homes, Hospice Austria, Vienna 2. Standards of Quality for Hospice and Palliative Care in Austrian Nursing Homes, Hospice Austria	1. "For all those who are in need – Integrated palliative care – the Vorarlberger Model" 2. Hospice and Palliative Care in Tyrol, Austria: Development of General and Specialised Palliative Care in the Health Care	1. Hospiz und Mäeutik – Hospice and Maieutic, CS – Caritas Socialis, Vienna, christina.hallwirth-spoerk@cs.or.at, http://www.cs.or.at/deutsch/home.html 2. Curriculum Palliative Geriatrics, Hospice Austria, Marina
Belgium	1. Funding of the "palliative function" in nursing homes and homes for the elderly	1. Guidelines for implementation of palliative care in long term care facilities for the elderly from the Federation Palliative Care Flanders ('Leidraad voor implementatie van palliatieve zorg in woonzorgcentra') 2. Life circles tailored to persons with dementia in a LTCF ("leefcirkels op maat van personen met dementie in een woon- en zorgcentrum"). WZC De Wingerd, Leuven, with financial support of the King Boudouin Foundation (2009) location, contact email, website if available. 3. Invention study based on Patient Respecting Choices to be started in LTCFs in Flanders (RCT) 2015-2019 Contact: Prof. Dr. Lieve Van den Block (lvdblock@vub.ac.be), End-of-life Care Research Group, Vrije Universiteit Brussel & Ghent University, Belgium.	1. Development of a model for implementation of advance care planning in long term care facilities (Brugge) (details below) 2. Life circles tailored to persons with dementia in a LTCF ("leefcirkels op maat van personen met dementie in een woon- en zorgcentrum"). WZC De Wingerd, Leuven, with financial support of the King Boudouin Foundation (2009) 3. Invention study based on Patient Respecting Choices to be started in LTCFs in Flanders (RCT) 2015-2019 Contact: Prof. Dr. Lieve Van den Block (lvdblock@vub.ac.be), End-of-life Care Research Group, Vrije Universiteit Brussel & Ghent University, Belgium. 4. Implementation of advance care planning in older people with dementia (King Boudouin
Denmark	1. National recommandations for palliative care. Danish Health and Medicines Authority. Location: Axel Heides Gade, 2300 København S, DK; email: sst@sst.dk; website: http://sundhedsstyrelsen.dk/publ/Publ2011/SYB/Palliation/PalliativeIndsats_anbef.pdf 2. Municipal healthcare services – accreditation standards, 1st version 2011, The Danish Healthcare Quality Programme, DDKM, IKAS. Location: Olof Palmes Allé 13, 1. th. 8200 Aarhus N, DK; email: info@ikas.dk; website: http://www.ikas.dk/IKAS/English/Print-and-download.aspx 3. Palliative care in primary health care: Clinical guidelines. College of General Practitioners. Location: Øster Farimagsgade 5, Postboks 2099, DK; email: dsam@dsam.dk; website: http://www.e-pages.dk/dsam/172074491// 4. 43 anbefalinger på baggrund af Ældrekommisionens rapport "Livskvalitet og selvbestemmelse på plejehjem" [43 Recommendations based on a Report from Ældrekommisionen [Commission of the Elderly] "Quality of Life and Self-determination in Nursing Homes"]. The Ministry of Children, Gender Equality, Integration and Social Affairs. Location: Holmens Kanal 22, DK-1060 København K; email: sm@sm.dk; website: http://sm.dk/publikationer/livskvalitet-og-	1. "Project Palliative Care in the Nyborg Municipality". Location: Nyborg Kommune, Torvet 1, 5800 Nyborg; email: kommune@nyborg.dk, then@nyborg.dk 2. "Project Palliative Care in the Odsherred Municipality". The project was concerned with testing of a cooperation model between Lynghuset, general practice in Odsherred Municipality and Multidisciplinary Pain Centre/Palliative Clinic, Holbæk Hospital. The purpose of the project was to improve the municipal palliative effort to people, who are suffering from life-threatening diseases through development of interdisciplinary and cross-sectorial cooperation. Location: Odsherred Municipality, Nyvej 22, 4573 Højby; email: malgl@odsherred.dk, 3. "Project Palliative Care in the Gentofte Municipality". The project is concerned with competency development. Location: Gentofte Municipality, Bernstorffsvej 161, 2920 Gentofte; email: gentofte@gentofte.dk, Ingelise Bøggild Iensen, ibj@gentofte.dk; website: http://www.gentofte.dk/da/Borger/Sundhed/Til-de-praktiserende-l%C3%A6ger/Palliativ-indsats 4. "Life and death at nursing homes". The project was concerned with competency development by different methods. Location: Copenhagen Municipality; email: pavi@sdu.dk, Mette Raunkiær, Raunkiaer@sdu.dk Ref: Raunkiær, M., & Timm, H. (2010). Development of	1. "A Dignified Death". The project is described below. Location: Holmegårdsparken, Ordrupvej 32, 2920 Charlottenlund; email: info@holmegaardsparken.dk, Connie Engelund, ce@holmegaardsparken.dk 2. "The Dignified Death". The LTCF is working to improve the palliative care by focusing on the dignified death. Location: Fuglesangsgården, Trekanten 1, 8500 Grenaa; email: Helle Thomsen, ht@norddjurs.dk, Birgitte Bastiansen, birb@norddjurs.dk 3. Kildevæld Sogns Plejehjem. The LTCF is constantly improving the palliative care by competency development and new initiative. Location: Helsingborggade 16, 2100 København Ø; email: kildevaelsogn@suf.kk.dk, Margit Lundager, LB72@suf.kk.dk 4. Haandværkerforeningens Plejehjem. The LTCF was one of the first nursing homes in Denmark, which developed and opened as special department only for people with the need of palliative care. Location: Haandværkerhaven 29 a+b, 2400 København NV; email: Randi Krogdal Steen ZR4P@SUF.KK.DK; website: www.hvfkbh.dk/ejendomme/plejehjem/

COUNTRY	NATIONAL LEVEL	REGIONAL/NETWORK LEVEL	ORGANISATION LEVEL
Finland	1. The National Advisory Board on Social Welfare and Health Care Ethics ETENE is an organ hosted by the Ministry of Social Welfare and health. • The purpose of The National Advisory Board on Social Welfare and Health Care Ethics is to discuss general principles in ethical issues in the field of social welfare and health care and concerning the status of patients and clients as well as to publish recommendations on them. The Advisory Board submits initiatives, publishes statements and provides expert assistance, prompts public debate, and disseminates information on national and international ethical issues in the field of social welfare and health care. • 21st July 2012 Position: Human Dignity, Hospice Care and Euthanasia International observations indicate that a harmonious view on euthanasia has not been found. In the background are different views on what kind of measures can and should be part of providing good care and dying with dignity. ETENE's view is that the discussion on euthanasia should focus on whether euthanasia is an ethically sound solution for patients who are suffering unbearably, for whom adequate relief cannot be found by using present methods, and who wish to die. NOTE: LTC is not addressed separately, by ETENE 2. Consensus statement 3-5th February 2014 (in Hanasaari) of the issue "Death in old age" stated by Finnish Medical Society Duodecim and Academy of Finland http://www.duodecim.fi/web/kotisivut/koulutus/-/naytasivu/83042/144683		
France	1. Creation of the 3rd French National Observatory on End of life care "Observatoire National de la Fin de Vie, 35 rue du Plateau 75019 Paris Tél : +33 (0)1 53 72 33 28; contact@onfv.org; www.onfv.org has conducted various studies and surveys including "End of life in older people" and one "in EHPAD" (nursing homes) 2. Report "State of art of the palliative care in France," 2010 http://www.sante.gouv.fr/IMG/pdf/Rapport_Etat_des_lieux_du_developpement_des_soins_palliatifs_en_France_en_2010.pdf 3. MOBIQUAL: « Mobilisation to improve the Quality of Care for old people; mobiqual@sfgg.org; http://www.mobiqual.org/ training tool for care givers in nursing homes, MOBIQUAL initiative is one of the most interesting initiative, because it is a nationally diffused and widely used training tool. In fact it is a very well design tool, very practical. Its utilisation is growing up. Use and related practices are		the "support" Clown: Maintain or restore the relationship with residents with severe communication disorders (Alzheimers)

COUNTRY	NATIONAL LEVEL	REGIONAL/NETWORK LEVEL	ORGANISATION LEVEL
Germany	1. The Deutsche Palliative Stiftung' (German Palliative Care Foundation) has developed training manuals for care home staff that are being	1. In Northrhein Westphalia Dr. Veronika Schonhofer-Nellessen has developed and validated a training course Implementation of Palliative	1. The SeniorenZentrum Krefeld, situated in town in Northrhein Westphalia
Greece			1. Staff education and support in a nurse home in Spata Attikis, Greece Improvement of pain assessment and management for patients with cancer living in the Nurse House (N.H.) "Anastasis" of the Holy Metropolis of Mesogaia and Lavreotiki in Spata Attikis.
Iceland		1. Implementation of Liverpool Care Pathways in LTCF in Metropolitan area of Reykjavik2.	1. Designated palliative care beds in two determined nursing homes. Implementation and education concerning palliative care. Cooperation between Eir Nursing Home, Skogarbær Nursing Home and the National University Hospital, Landspitali.
Ireland	1. Let Me Decide 1. Centre for Gerontology and Rehabilitation, University College, Cork		
Italy		The project VELA (eValuation of Efficacy of Lenitherapy in Alzheimer disease and dementia)	
Norway		1. Valhalla omsorgssenter. Marvikveien 20, 4631 Kristiansand	
Spain			1. The Catholic Orders: Camilos brothers (Tres Cantos) and brothers of San Juan de Dios (San Jose Institute) and the Laguna Centre have places for the care of people in the end stages of their lives Quavitae Sarl (Arturo Soria) has implemented a number of places for PC in the Residential Center in
The Netherlands	1. Verbindingsproject palliatieve zorg en dementia; Else Stapersma, Vilans Utrecht, Vilans, Kenniscentrum langdurende zorg, Utrecht, E.Stapersma@vilans.nl; website: http://www.vilans.nl/ and *http://www.goedevoorbeeldenpalliatievezorg.nl/Vindplaats/Dementie-en-palliatieve-zorg* 2. STerven op Eigen Manier (Dying in your own way); Bert Buizert, Stichting STEM Gouda, bert.buizert@stichtingstem.info; website: *http://www.stichtingstem.info/* 3. LCP in NL: implementation of the Dutch version of the Liverpool Care Pathway (LPC); Anneke Dekkers a.dekkers@iknl.nl & Lia van Zuylen c.vanzuylen@erasmusmc.nl 4. Best practices in palliative care. "This is how we do it": practical tools for embedding integrative palliative care within an organization (foundation) for nursing homes and homes for the elderly; Frans Baar, Regional Palliative Care Centre Laurens Cadenza, Leerhuizen Palliatieve		

COUNTRY	NATIONAL LEVEL	REGIONAL/NETWORK LEVEL	ORGANISATION LEVEL
United Kingdom	1. Gold Standards Framework in Care Homes http://www.goldstandardsframework.org.uk/care-homes-training-programme	1. Developing end-of-life care in care homes using the GSFCH programme Jo Hockley & Julie Kinley, Care Home Project Team, St Christopher's Hospice, London SE26 6DZ. j.kinley@stchristophers.org.uk; *www.stchristophers.org.uk/care-homes* 2. Namaste Care. Min Stacpoole & Jo Hockley, St Christopher's Hospice, London SE26 6DZ. m.stacpoole@stchristophers.org.uk *www.stchristophers.org.uk/care-homes/research/namaste* 3. Developing quality end of life care in care homes using the Family Perception of Care Scale. Jean Levy & Fran Conway, Care Home Project Team, St Christopher's Hospice, London SE26 6DZ. *J.levy@stchristophers.org.uk* 4. Coordinate My Care – within care homes (nursing) across five clinical commissioning groups. Deborah Mellish & Dovile Milaseviciene, Care Home Project Team, St Christopher's Hospice, London SE26 6DZ. *D.milaseviciene@stchristophers.org.uk* 5. 5 steps to 5 success – developing quality end of life care in care homes	Many hospices run their own proejcts to support LTCFs, eg Prospect Hospice Education Passport www.prospect-hospice.net/GPs-and-Healthcare-Professionals/Care-home-professionals/Education-Passport

Appendix 6: Focus and Outcomes of Selected Initiatives

Country	Initiative	Outcome									Focus						
		Improvement in quality of life	Better support and involvement of carers, family and friends	Greater levels of staff knowledge and skill	Better staff assessment and/or management of symptoms	Greater support for professional carers	Introduction of a care pathway	Advanced care planning	New service or development	Other	Individual - resident	Individual - family	Individual- staff	Family/friends	Staff teams – long term care organisations	Staff teams – across organisations	Public perceptions and policy
Austria	Hospice and Palliative Care in Nursing Homes, Hospice Austria, Vienna		●	●	●	●				●			●		●		
Austria	Hospice and Palliative Care in Tyrol, Austria	●	●			●		●							●	●	
Belgium																	
Belgium	Guidelines for implementation of palliative care in long term care facilities for the elderly	●		●	●	●			●				●		●		
Denmark	Project Palliative Care in the Nyborg	●	●	●	●	●	●								●		
Germany	Implementation of Palliative Care in Nursing Homes for Older People	**No data**															
Iceland	Implementation of Liverpool Care Pathways in LTCFs	●	●	●	●	●	●	●	●						●	●	
Denmark	Strengthening of Palliative Care in Nursing Homes (LTCFs) in Denmark (Part of a larger program:	●		●	●	●		●							●		

	Quality of Life and Self-determination in Nursing Homes.)																
Germany	'Deutsche Palliative Stiftung' (German Palliative Care Foundation) training manuals for LTCF staff														•		
Hungary	Hospice-palliative care training (40 hours) for social carers, accredited by HHPA	•		•	•	•	•		•							•	
Iceland	Implementation of Liverpool Care Pathways in LTCF in Metropolitan area of Reykjavik	•	•	•	•	•	•	•	•						•	•	
Ireland	Let Me Decide	•	•	•	•	•		•	•						•		
The Netherlands	Palliative care and dementia	•	•	•	•	•		•							•	•	
Austria	Hospiz und Mäeutik – Hospice and Maieutic		•	•	•	•			•						•	•	
Belgium	Development of a model for implementation of advance care planning in long term care facilities		•			•		•	•		•						
Denmark	A dignified death (livsafslutning)	•	•	•	•	•	•	•	•	•			•		•		
France	The support clown	•	•	•	•	•	•			•	•						
Germany	Qualified nursing with PC qualification	**No data**													•		

Greece	Improvement of pain assessments/ management (cancer patients) - nurse home.	•			•	•								•			
Iceland	Designated palliative care beds in two determined nursing homes.	•	•	•	•	•	•	•	•		•		•				
Italy	The project VELA (eValuation of Efficacy of Lenitherapy in Alzheimer disease and dementia)	•		•	•								•		•	•	
Luxemburg	LTCF: 'Bäim Goldknapp' mobile service	•	•	•	•	•	•	•	•				•		•		
Norway	Lindrende enhet I Bamble kommune [Palliative Care Unit in Bamble]	•	•	•	•	•	•	•	•		•		•				
UK	Developing end-of-life care in care homes using the Gold Standards Framework in Care Homes programme.	•	•	•	•	•	•	•	•	•					•	•	•