Palliative Care in Long-Term Care Settings for Older People

EAPC Taskforce 2010-2012

R E P O R T

January 2013

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European Association for Palliative Care
EAPC Onlus: Non profit-making Association
Non Governmental Organisation (NGO) recognised by the Council of Europe

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1. Executive Summary

1.1 Background

With an ageing population across Europe, older people's needs for care and support are increasing in amount and complexity. Increasing numbers of older people are living with dementia. For some older people changes in physical, psychological and/or social circumstances will require a move into a long-term care facility as they can no longer be supported to live in their own homes. These older people will go on to require palliative and end of life care within these facilities, supported by staff working within, and external to, the organisation. The development of palliative care within the setting has received increased attention and many initiatives and interventions are being developed and implemented to promote high quality palliative care provision by staff working in the settings, and joint working with external staff, volunteers and relatives. There is much to learn by identifying and sharing examples of such initiatives across different countries.

A European Association of Palliative Care Taskforce on Palliative Care in Long-Term Care Settings for Older People was established in 2010, to undertake the first European wide review of these issues. For the purposes of this Taskforce long-term care settings for older people were defined as collective institutional settings where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time. This excluded housing settings with care provision, as the individuals are tenants in their own right. An inclusive definition of palliative care was utilised, based upon the WHO definition (Sepulveda et al 2002) and acknowledging understandings from geriatric medicine and gerontology.

1.2 Aim and Objectives

Aim: To identify and map the different ways of developing palliative care in long-term care settings across Europe.

Objectives:

1. To define long-term care settings for older people and the nature of palliative care in these settings;
2. To identify practice development initiatives being undertaken to develop the provision of palliative care in long-term care settings for older people;
3. To map palliative care initiatives across different European countries ;
4. To create a compendium of good practice interventions.

Methods

A two phase mapping exercise was conducted, working with identified country informants from each partner country. Phase 1 entailed the collection of contextual information about palliative care and long-term care provision for older people in each country. The information obtained concerned: the older population, the nature and types of long-term care settings, the wider funding and regulatory context and other key drivers for change that would impact upon the development of palliative care within the setting. In Phase 2, country informants were asked to identify practice

development, educational and research initiatives that had sought to develop palliative care practice within the long-term care setting. Data about each initiative, its focus and impact was requested. These examples were summarised and collated to be posted on a website as a resource (www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc/).

1.3 Findings

- Country context

Data was provided from 13 countries across Europe: Austria, Belgium, France, Germany, Ireland, Italy, The Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and UK about long-term care settings for older people.

Across Europe long-term care settings are generally categorised into two types, reflecting a division into low and high needs for older people residing in them. In some countries a third type exists, allied to acute hospital settings. The funding status of providers of institutional long-term care in most countries was mixed status 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 only use public sector providers. Long-term care is funded for individuals residing in these facilities by, again 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 – whether this is overseen nationally or at a provincial level does vary. 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 national, regional and local levels within the palliative care and long-term care context.

- Initiatives

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 have been 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. They 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, organisation, 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.

1.4 Discussion

Across Europe a number of common themes can be identified that shape the development of palliative care in long-term care settings. These concern the increasing emphasis upon supporting older people to remain in their own homes and the recognition that long-term care facilities are home for the older people who live there, the differentiated provision available to meet different

levels of need, and the importance of quality management and assurance processes to support developments in care.

There are also differences across Europe relating to the different levels of responsibility for care development within palliative care and long-term care, the role of different types of provider and the place of family and volunteers as carers.

The modified typology used to classify the initiatives presented here has been useful. It has allowed the following issues to be considered with respect to the development of palliative care in long-term care facilities. It is important to acknowledge the complexity of such initiatives, and the different levels of change that are or potentially can be affected. The sustainability of initiatives can be questioned when their origins lie in short term project work. The place of the organisation as being key to sustainable change is identified and is the place where change across the different levels can be mediated.

1.5 Conclusions

This Taskforce sought to identify and map the different ways of developing palliative care in long-term care settings across Europe. The objectives outlined at the start of the Taskforce have been met and also provided detailed country context information in order to understand better some of the common challenges and issues faced across Europe in terms of care provision for older people requiring long-term institutional care. This has direct relevance to the practice development work described here, as it provides the context for such initiatives and their potential for sustainability and lasting change. The findings and issues described here are also relevant to other settings where older people reside, such as supported housing, although there may be differences that require identifying.

The work of the Taskforce on Palliative Care in Long-term Care settings for Older People can be summarised as a developing network, where expertise and experience from a range of European countries is being exchanged and collated in different forms. This Taskforce report provides a useful baseline for future work within the clinical practice and research domains.

1.6 Recommendations

The Taskforce addressed different perspectives and were of relevance to three groups of people and organisations working in the field of palliative care in long-term care organisations: practitioners, researchers and members of the European Association of Palliative Care (EAPC). The following recommendations can be made on the basis of the findings of our work:

Practice organisations within long-term care and palliative care

Much information collated here has been generated from practice organisations within the long-term care and palliative care fields. It is important that the findings of the Taskforce are made available to these agencies. The examples presented are not exhaustive and further helpful initiatives will exist that are not presented here. Therefore, further work is required to:

- consider how to share findings with practice organisations and settings within each partner country and across borders;
- ensure the ongoing collation of examples and resources and find out how the hospice movement, volunteers and civil society can be involved in this work;

- acknowledge the high proportion of people with dementia living in long-term care settings and integrate knowledge and expertise from dementia care with palliative and hospice care.

Research

Funded research has been an important source of information for the initiatives collated by the Taskforce. A wide range of methodologies have been used within such research. There is a need to:

- identify the challenges of doing research with the older people population living in this setting;
- integrate the perspectives of the people concerned: residents, patients, people with dementia, relatives, informal care persons;
- appreciate the palliative care work that already is delivered by staff and informal care;
- deepen the insights that organisations play in the delivery of multi-level change processes;
- promote the rigorous evaluation of initiatives seeking to promote the provision of palliative care in long-term care settings;
- identify what evidence is required to support the implementation of findings arising from research;
- agree appropriate outcome measures to evaluate changes in the quality of palliative care provision;
- establish European research collaborations to support further developments in this area building upon the Taskforce work;
- ensure participatory dialogue is present with residents, relatives, all citizens and political groups, where appropriate to the study focus and design.

EAPC

The role of the EAPC in supporting the development of palliative care in long-term care settings for older people continues to be important. The EAPC already recognises the importance of this work through its support of the Taskforce, and the presence of workshops, oral and poster presentations in its Congresses. Further consideration of separate streams of work specifically about long-term care settings would further raise the profile of this area of important palliative care provision:

- establish higher profile within conferences, through pre-conference workshops;
- streams of papers under this topic (separate older people from paediatrics);
- identify ways to coordinate work in this area across different organisations;
- address the delivery of high quality research that supports the provision of palliative care in long-term care settings.

2. Acknowledgements

We would like to thank following people for their support of the work of this Taskforce – their ideas, examples and enthusiasm for the work have been valuable:

- Country informants: Georg Bollig, Manuel Luís Vila Capelas, Clodagh Cooley, Marie-France Couilliot, Vito Curiale, Luc Deliens, Claudia Gamondi, Marjolein Gysels, Geralyn Hynes, Lennarth Johansson, Frank Kittelberger, Roland Kunz, Julie Ling, Mary McCarron, Mirella Minkman, Massimo Monti, Maria Nabal, Jane Österlind, Roeline Pasman, Bettina Sandgate-Husebø, Tinne Smets, Marian Villez.
- Advisory Group: Sigrid Beyer, Vito Curiale, Luc Deliens, Sue Hall, Hubert Jocham, Mary-Lou Kelley, Frank Kittelberger, Sophie Pautex, Jenny van der Steen, Marie-Claire Vannes.
- Wider network of informants and supporters.
- Hazel Morbey for her valuable work in collating much of this information during 2011.
- Participants at the ESF Exploratory Workshop on New Housing Models for People with Dementia towards the End-of-Life held in Vienna in December 2011.
- The EAPC Board for supporting the establishment and ongoing work of the Taskforce.

Collaborations during the Taskforce group

The work of this Taskforce built on recent work undertaken by the EAPC Taskforce Palliative Care for Older People: Better Practice which identified within its remit initiatives specifically in the long-term care sector. Close links were also established with the EU funded PRISMA project and the EUGMS Geriatric Palliative Care Interest Group in order to share expertise across these different initiatives.

3. Background

There is growing recognition across Europe and other developed countries of the changing demography of nations that is leading to an older population. Consequently, there is much work being undertaken to address the changing care demands and planning of new models of service provision that will be required to support an increased number of older people in the coming years. 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). 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, Leichsenring et al 2010).

A significant proportion of older people die in long-term care settings (approximately 20% in the UK (Office for National Statistics 2004). 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). This raises challenges for medical, nursing and other practitioners in terms of dealing with physical and psychological symptoms, spiritual and social needs and other aspects of palliative care. Working with long-term care settings also requires palliative care specialists to consider issues of organisational change as new initiatives are developed between different disciplines e.g. psychosocial support or physiotherapy. Volunteers who are the majority of those involved in hospice care also need to learn from elderly care, dementia care and geriatrics to be empowered to visit residents of long-term care settings and support their families. Dignified support towards the end of life in long-term care settings needs a relational and appreciative approach (Pleschberger 2007).

Long-term-care settings for older people in many European countries can be described as “female life worlds“(Reitinger, Heimerl, Pleschberger 2005). Residents, professionals, relatives, informal care givers and volunteers are often women. Therefore, gender aspects have to be considered in palliative care in these institutions and in the care provision for older people. On an individual level, for example, it is important to consider the biographical aspects of men and women and their specific gender-roles. Gender-specific symptom-development and expression e.g. of pain should be considered. On an interactional level especially body-care-work needs gender-sensitive handling. At a structural level questions of gender-justice concerning care-work-load and remuneration, gender-specific division of labour and hierarchical representation of male and female workforce have to be discussed critically (Reitinger and Lehner 2009, Reitinger and Beyer 2010). Other aspects of diversity which could warrant similar attention include ethnicity and sexuality

Given the marginalization of these institutions for older people within mainstream society with respect to funding for care, and research, there is a need to maximize resources and expertise. It is recognised that a sharing of good practice between countries and also between palliative care specialists, the hospice movement and long-term care practitioners would be beneficial. It is acknowledged that this Taskforce focuses on a specific setting where older people live and does not address all models of housing for older people.

Since 2007, an ongoing strand of work has been developed across Europe, under the auspices of the European Association of Palliative Care (EAPC). Informal meetings were held about palliative care in long-term care settings attracting between 15 and 30 participants from twelve countries at

conferences in 2007, (Budapest), 2008 (Trondheim) and 2009 (Vienna). Two invited symposia on long-term care and palliative care were on the conference programme in 2007 and 2009. A website was established that sought to promote this work: Palliative Care *and Long-term Care Settings for Older People: Worldwide* Resources (Froggatt and Heimerl 2008). In 2010 an EAPC Taskforce was formally recognised (Froggatt and Reitinger 2011) to undertake a focused piece of work in this area. This work will be first synthesis of data across Europe in this area.

3.1. Aims and objectives

Aim

To identify and map the different ways of developing palliative care in long-term care settings across Europe.

Objectives:

1. To define long-term care settings for older people and the nature of palliative care in these settings
2. To identify practice development initiatives being undertaken to develop the provision of palliative care in long-term care settings for older people
3. To map palliative care initiatives across different countries
4. To create a compendium of good practice interventions.

3.2. Definitions

In order to undertake the work of the Taskforce, definitions concerning palliative care and long-term care settings were clarified in order to ensure consistency and comparability for the work across Europe.

3.2.1. Palliative Care

Different definitions for palliative care exist and there is no agreed definition for palliative care in long-term care settings. A number of broader definitions were considered by the Taskforce, reflecting the heterogeneity of terms used across Europe and worldwide (Radbruch et al, 2009, 2010). These included general definitions provided by the World Health Organisation (Sepulveda et al 2002), those focused on older people (Ross et al 2000) and more specific ones developed within the field of geriatric palliative medicine (Pautex et al 2010)(Table 1).

Table 1: Definitions of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: • provides relief from pain and other distressing symptoms; • affirms life and regards dying as a normal process; • intends neither to hasten or postpone death;

- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(Sepulveda et al 2002)

End-of-life Care for Seniors

A broader definition that encompasses more than the terminal care phase. This term originates from North America and has been used particularly in the context of the care of older people.

> End-of-life care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement (Ross et al 2000: 9).

Geriatric Palliative Medicine is the medical care and management of older patients with health-related problems and progressive, advanced disease for which the prognosis is limited and the focus of care is quality of life. Therefore GPM:

- combines the principles and practice of geriatric medicine and palliative care;
- focuses on comprehensive geriatric assessment; relief from pain and other symptoms; and management of physical and psychological problems; integrating social, spiritual, and environmental aspects;
- recognizes the unique features of symptom and disease presentation, the interaction between diseases, the need for safe drug prescribing, and the importance of a tailored multidisciplinary approach for older patients receiving palliative care and their family;
- emphasizes the importance of autonomy, the involvement in decision-making, the existence of ethical dilemmas;
- calls for good communication skills when discussing and giving information to older patients and their families;
- addresses the needs of older patients and their families across all settings (home, long-term care, hospices and hospital);
- pays special attention to transitions within and between settings of care; and
- offers a support system to help families cope during the patient's terminal phase of care.

(Pautex et al 2010: 790)

The Taskforce was concerned with how staff and carers, working in long-term care (LTC) organisations provide palliative care for older people and their engagement with specialist palliative care services. It was recognised that palliative care is provided by two distinct categories of health and social care professionals:

- The care staff providing the day-to-day care to patients and carers in their homes, in hospitals and in long-term care settings for older people. They usually provide a palliative care approach. The term general palliative care may also be used to describe non-specialist palliative care clinicians, who frequently treat people with life-limiting conditions. (Radbruch et al 2009);

- The staff who specialise in palliative care (for example, medical consultants, clinical nurse specialists and other members of specialist multidisciplinary palliative care teams). Specialist palliative care may be provided in specialist palliative care settings such as hospices, but also in hospitals, people's own homes and long-term care settings for older people.

Engagement with the development of palliative care provision in long-term care settings therefore needs to be inclusive of these different types of staff and their role in supporting palliative care for older people living and dying in long-term care settings. Specific recognition of the importance of the place of residence as shaping how, and what, palliative care is provided, is not always acknowledged. Definitions that explicitly mention this, such as that provided by Pautex et al (2010) are helpful in this respect.

The Taskforce endeavoured to be inclusive in terms of a definition of palliative care, as in the examples presented here and recognises the different understandings of palliative care held by a range of professional perspectives. It also acknowledges that developments in other areas such as care for people with advanced dementia are highly relevant to the older people living in long-term care settings.

3.2.2. Definition of Long-Term Care Settings

For the purposes of the work of this Taskforce the following definition of long-term care setting for older people was agreed:

- 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.

A distinction was made between housing with care initiatives (such as assisted housing, sheltered housing) and long-term care settings. 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

settings. This Taskforce does not specifically address palliative care in housing with care settings, but recognises that similar issues in this setting have been identified (Sloane et al 2003, Easterbrook and Vallelly 2008). The findings of this Taskforce may well be relevant for housing with care settings.

4. Methods

4.1. Ethics

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

4.2. Country Participation

Thirteen countries were involved in the work of the Taskforce: Austria, Belgium, France, Germany, Ireland, Italy, The Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and UK. In involving these countries we sought to represent the breadth of Europe from the North to the South, alongside identifying willing informants from the relevant countries. Although we made some efforts it was not possible to include representatives from Eastern Europe. We are aware that our results, therefore, are not representative for this region; since the situation of older people and their care provision differs significantly from the situation in Western Europe, with respect to resources and state and family involvement in care provision (WHO 2011, p 15).

4.3. Country informants

In order to facilitate the mapping exercise a network of country informants was identified (Appendix 1). They had agreed to be the point of contact for correspondence with regards to the collection of information about each country. They were identified as experts in the field of palliative care in long-term care settings for older people, with relevant practice, research and/or education experience in this topic, and had links to experts and specialist contacts within their respective countries.

4.4. Phase 1: Country contexts

Country informants were invited to collate the information about their country under a number of headings (Table 2). These provided information about the population, nature and types of LTC settings, the wider funding and regulatory context and other key drivers for change that would impact upon the development of palliative care within the setting. This information would enable the later information about the initiatives described in each country to be contextualised.

Care needs to be taken with international comparisons. Whilst a similar template was used to collect data from each country, each country informant used different sources to answer the questions (publications, political information, other experts in the field). Additionally, the data presented here are also drawn from existing data sources to complement the data provide by the country informants. Therefore, the conclusions drawn can only be indicative.

Table 2: Country Context Information

	Explanation
Country	State the name of the country here: *In some countries care may be organised by state or province. Please indicate if this is the case and whether the information provided refers to country level or state level information.*
Terminology and types	The names and titles used to describe long-term care settings in the country; the different types of setting with respect to the provision of medical and nursing care.
Status of LTC providers	The funding status of providers of long-term care in the country - private sector, public sector, voluntary, charitable or not-for profit sector. Relative proportions in the country.
Funding for Long-term Care	How is long-term care funded, with respect to state funding, insurance, person and or family monies?
Regulation	How is the long-term care regulated? Do regulatory bodies exist? Are there any standards or guidelines issued by them?
Key Drivers for Change	What are the drivers for the development of palliative care in long-term care? These may come from the palliative care world, the long-term care sector, or elsewhere.

4.5. Phase 2: Initiatives

A similar process was undertaken for the collection of data about initiatives that existed to promote the development of palliative care in LTC settings. The country informant was asked to identify and collate examples of such initiatives using agreed templates (Appendices 2 & 3). Country informants used the following methods to collate the data about the initiatives:

- National resources, statistics, reports and research that has been published;
- Expertise that country informants themselves had gathered through their engagement in the field;
- Involving other national experts of their professional network or specialized palliative care networks.

We were not seeking a complete list of all initiatives from each country, rather exemplars of good practice that would be helpful for practitioners and researchers from other countries to know about. Information about the initiatives presented here is in English, but links to further information about the initiatives may be to the language of the country of origin.

Initial analysis was undertaken by members of the core group and then presented to a workshop at the EAPC conference in Lisbon in 2011, for discussion and agreement.

5. Findings

The findings are presented in two parts. The country context information considers the data obtained about the population, nature and types of LTC settings, the wider funding and the regulatory context. The findings about the different types of initiatives also incorporates the country context information about the key drivers for change that would impact upon the development of palliative care within the setting.

5.1. Phase 1: Country context

The countries involved in this mapping exercise ranged in population size from 4.5 to over 80 million. As a proportion of the population the percentage of 65+ individuals varied between 11.4 and 21% (Table 3).

Table 3: Population and Proportion of 65+ Inhabitants

Country	Population (million)	No. Citizens 65+	Proportion of population (%)
Austria[1]	8.4	1.5	17.3
Belgium	10.8	NK	17.0
France	65.0 (including overseas population)	10.9	16.9
Germany	81.8	16.9	20.6
Ireland[2]	4.5	0.53	11.4
Italy	60.3	12.2	20.4
The Netherlands	16.6	2.5	15.2
Norway	4.9	0.74	14.8
Portugal	10.6	1.8	17.7
Spain	47.0	7.9	17.2
Sweden	9.4	1.7	18.0
Switzerland	7.8	1.3	17.3
United Kingdom	61.0	9.8	15.8

Source: OECD (2011)(unless stated otherwise)

[1] Statistics Austria 2012

[2] Central Statistics Office Ireland (2011)

Data from the OECD (2011) (Table 4) 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.

The numbers vary greatly from only 16 beds per 1000 inhabitants 65+ in Italy to over 84 beds per 1000 inhabitants 65+ in Sweden. This data is supported by findings from the Ancien (Assessing needs of Care in European Nations) project (Riedel and Kraus 2011).

Table 4: Long-term care beds per 1000 inhabitants 65+

Country	Long-term-care beds per 1000 inhabitants 65+ (data year)
Austria	70 (2008)[1]
Belgium	71.1 (2010)[2]
France	52 (2010)[2]
Germany	48 (2010)[2]
Ireland	47 (2010)[2]
Italy	16 (2010)[2]
The Netherlands	69.5 (2010)[2]
Norway	NK
Portugal	NK
Spain	21.3 (2010)[2]
Sweden	84.4 (2010)[2]
Switzerland	72 (2010)[2]; 68.3 (2010)[3]
United Kingdom	56 (2010)[2]

1. Riedel and Kraus (2011**)**
2. OECD (2011)
3. OFS (2012)

5.1.1. Types of Long-Term Care facilities

Table 5 presents a summary of the types of long-term care facilities present in each of the countries. Across these 13 countries there appears to be a common pattern of provision with a dominant two types of provision existing across Europe related to the dependency of the residents. Each country provides care for older people with high dependency and needs, as well as people who are less dependent.

High dependency is met either in what are generically called nursing homes, where nursing care is provided/available 24 hours a day, seven days a week, and there is access to medical care, either on-site (e.g. Netherlands, Italy, Norway) or from the local primary care services (e.g. Austria, France, Germany, Ireland, UK). In some countries there is a third type of provision for people with higher levels of need for support where hospital like institutions are still used for some types of support, often over a shorter time period (e.g. France, Germany).

Older people with lower needs and dependency receive care in institutions where social and personal care is provided 24 hours a day, seven days a week. Health care is provided by nurses, doctors and other health care professionals who work for external organisations and have to visit the long-term care settings.

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 of the use of supported housing to replace former residential low care facilities (e.g. Germany, Norway). This setting has not been addressed in the work of the Taskforce.

Table 5: Terminology and Types of LTC Settings

Country	**Terminology and types**
Austria	1. **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. 2. **Retirement homes** (*Altenwohnheim, Seniorenresidenz*): provide a place of residence and personal care if necessary. Focus on social activities and social care. 3. **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.
Belgium	1. **Nursing homes**: (*Rust-en Verzorgingstehuizen/Maisons de repos et de soins*) nursing care and living facilities for older people with moderate to severe limitations; 2. **Residential care**: (*Maison de repos pour personnes agees/Rustoorden voor Bejaarden*) homes for older people with low to moderate limitations.
France	1. **Hospital long-term units** (*Unité de soins de longue durée, USLD*) : provide nursing and medical care and more or less social activities As of December 2007: 10, 300 long-term homes for older people (127 rooms per 1000 persons >75 y old), 675000 residents, (25% in USLD, 75% in EHPAD (see below). 2. **Nursing homes**: (*Etablissement d'Hébergement pour personnes agées dépendantes, EHPAD*) provide personal and nursing care, 24 hours a day, 7 days a week. Medical care (medical treatment) is provided by GPs 3. **Retirement Homes** (M*aison de retraite, Foyers logements*) place of residence, services, and social activities. Personal help, nursing and medical care by community care , nurses and GPs.
Germany	1. **Nursing homes** (*Pflegeheime*): provide personal and nursing care (domestic

	help and basic care), 24 hours a day, 7 days a week. Medical care and treatment is provided by attending physicians. Approx. 10.000 Long-term facilities Short term nursing homes (including day care/night care) approx. 1.100 Approx 675.000 people receive care in long-term facilities, (32% of all people receiving nursing care). 2. **Geriatric centres/Geronto-psychiatric facilities**: same as nursing homes; but some with their own medical staff. 3. **Retirement homes** (*Altenh(wohn)heime*): provide a place of residence (including domestic help) and personal care if necessary. Focus on social activities and social care. Approx. 300 (but numbers declining). 4. Rising number of **supported housing arrangements** (*Betreutes Wohnen*)**,** where people buy or rent an apartment in a housing complex with care services available on demand.
Ireland	1. **Private and voluntary nursing homes** include for profit and 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. A small number of nursing homes employ other medical practitioners on their staff such as psychologists and psychiatrists for their dementia or behaviour units whilst others have a full time medical officer onsite paid by the nursing home. 2. **State run residential care** provides personal and 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.
Italy	1. **Nursing homes** (*Residenze sanitarie assistenziali*): for totally dependent older people with health-care related needs, provide personal and nursing care, 24 hours a day, 7 days a week. Medical care is usually provided by specialised nursing home medical staff. 2. **Nursing homes for partially dependent older people** (*Residenze protette*): provide a place of residence, personal care 24 hours a day, 7 days a week, and nursing care if necessary (some hours per day). Medical care: General Practitioner and Specialist consultations. Focus on social activities and social care. 3. **Care homes for older people mildly dependent** (*Residenze/Comunità per anziani*): provide personal care and help, nursing and medical care provided by primary care services.
The Netherlands	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.

Norway	**1. Nursing homes** (*Syke hjem*) provide personal and nursing care (domestic help and basic care), 24 hours a day, 7 days a week. About 900 NHs with 40 000 beds. These institutions take care for about 60 000 patients every year. Additionally Nursing homes provide medical care. 2. **Retirement homes** (A*ldershjem*) were reduced in the last years with a move to supported living at home. (**Geriatric centres** also exist. They do not provide long-term care, but only offer short term admissions with the aim of diagnosing dementia).
Portugal	1. **Nursing homes** (*Lares):* accommodation (place of residence), domestic help and basic care (personal care and hygiene), 24 hours, 7 days a week, nursing and medical support (treatment), social and psychological support. It may have occupational therapy and physiotherapy. Linked to the Ministry of Social Welfare (social protection and welfare). 2. **Residences for elderly people** (*Residências assistidas):* accommodation (place of residence), domestic support, 24 hours, 7 days a week. Personal basic care (hygiene) can be provided if necessary, alongside medical support and nursing, social and psychological care. Occupational therapy and physiotherapy and other services like hair dresser, can also be available. Accommodation is hotel-like. 3. **Continuing care units** *(Unidades de cuidados continuados):* temporary housing, personal basic care (hygiene) provided 24 hours, 7 days a week. Nursing and medical support (treatment) provided 24 hours a day. Social and psychological support, occupational therapy and physiotherapy provided in an interdisciplinary action. Linked to the Ministry of Health.
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. 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).
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.
United Kingdom	1. **Care homes (nursing)**: (formerly called nursing homes) provide personal and nursing care 24 hours a day, 7 days a week. Medical care provided by primary care services. 2. **Care homes (personal care)** (formerly called residential care homes) provide only personal care. Nursing and medical care provided by primary care services.

5.1.2. Status of Long-Term Care providers

In all the countries presented here, the status of long-term care providers is drawn from a range of economies: public sector, not-for-profit and private sector (Table 6).

Table 6: Status of Long-Term Care Providers

Country	
Austria	Mixed status of providers **Public provision:** especially community supply (53 %); **Not-for-profit Organisations**: many of them established by faith based providers (26%); **Private providers:** (21%) (Badelt and Österle 2001). Responsibility for an appropriate provision of social services lies within the provinces. An alternative categorisation differs between four providers: provinces, municipalities, social organisations (*Sozialhilfeverbände*) and social services (Federal Ministry of Social Security, Generations and Consumer Protection 2005).
Belgium	Mixed status of providers Residential care services provided by: Local **Public Centres for Social Welfare** (OCMW/CPAS) (25%) **Not-for-profit organisations** (30%) **For-profit private organisations** (45%) Federale Overheidsdienst Economie (2009) Statbel http://statbel.fgov.be/nl/binaries/studie_rusthuissector_tcm325-96287.pdf
France	Mixed status of providers **Public providers** (58%) **Not-for-profit organizations** (religious groups, corporate organisations)(26%) **Private providers** (16%) See: www.drees.sante.gouv.fr/IMG/pdf/seriestat142-2.pdf
Germany	Mixed status of providers **Public providers** (mainly communities) (6 % of all long-term facilities supply 7% of all beds) **Non Profit Organisations**, many of them established by religious groups) (55 % of all long-term facilities supply 59% of all beds) **Private-for-profit providers**: (39 % long-term facilities supply 34% of all beds) Statistisches Bundesamt (2008)
Ireland	Mixed status of providers 574 nursing homes: **Public sector**: 21% (n=123) **Voluntary sector**: 11% (n=64) **Private sector**: 67% (n=387) (HIQA, 2012) In 2012, 28305 beds available. **Private and voluntary beds**: 76% (n=21426) **Public beds**: 24%(n=6879). (Unpublished report, Nursing Homes Ireland)

Italy	Mixed status of providers (265,326 beds for institutional care in Italy): **Public provision** (30%-37%) **Not-for-profit** (50%) **and private for-profit** (20%) combined (50%-57%); **Mixed provision – 6%** (ISTAT 2008, Allen et al 2011)
The Netherlands	**Public Provision** (0%) **Not-for-profit provision** (80%) **Private for profit provision (**20%) (Allen et al 2011, Riedel and Kraus 2011 p. 16)
Norway	Sole provider – **public provision**.
Portugal	Mixed status provider **Public institutions** – decreasing in number **Not-for-profit organisations** (*Misericórdias* - Private Institutions of Social Solidarity) - institutions (associations, foundations, parishes centres or other religious organisations) that make agreements with the state. **Private institutions** - managed by private (private individual or groups) for profit. (OECD 2011) No figures available
Spain	Mixed provider status **Public Sector** (24%) **Private sector** (76% owned) (24% not-for-profit, 53% private for profit) (OECD 2011, Allen et al 2011) This changed between 2002-2008: **public + private places created**, also private management with public financing increased. Other data suggests: 5,499 care homes: **Public sector** (26.5%) **Private sector** (71.6% in the private sector (profit and not-for-profit organisations) No data (1.9%) 344,048 beds in long-term care settings, **Public homes** (26.6%) **Private homes** (71.9%) No data 1.5% (Equipo Portal Mayores, 2011)
Sweden	Mixed provider status **Municipality public provision** (75%) **Private not-for-profit** (10%) **Private for profit run provision** (15%) The municipality provision might decrease in a near future, due to ongoing changes in the system. (Allen et al 2011)

Switzerland	Mixed provider status **Public sector** (30%) **Private sector** (70%) private not-for profit 30%, private for-profit 40% (OFS 2012, Allen et al 2011)
United Kingdom	Mixed provider status **Public sector provision** (10%) in some localities only; **Not-for-profit organisations** (14%) large chains to small groups; **Private provision** (76%) Corporate organisations; small business chains; owner managed enterprises. (OFT 2005).

Different patterns of provision emerge as summarised in Table 7 with data from Table 6. The public sector funding of providers of long-term care dominates in countries with a strong social model (Riedel and Kraus 2010 talk about a cluster that is "characterized by profound organizational depth and high levels of financial generosity" p. 15), e.g. Norway and Sweden. Not-for-profit providers are present in most countries but are significant providers in 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. (Care needs to be taken with this data as the data is either about beds or provider organisations).

Table 7: Percentage of Providers by Status (See Table 5 for data sources)

(Note that where data on providers was not available, data on beds was used.

Country	Public	Not-for-profit	Private
Austria (providers) (Badelt and Österle 2001)	53	26	21
Belgium (providers)	25	30	45
France (providers) (Allen et al 2011)	23	55	22
Germany (providers) (Statistisches Bundesamt 2008)	6	55	39
Ireland (providers) (HIQA 2012)	21	11	67
Italy (providers) (Allen et al 2011)	30	50	20
Norway (providers)	100	0	0
The Netherlands (providers) (Allen et al 2011)	0	80	20

Portugal	NK	NK	NK
Spain (OECD 2011)	24	24	53
Sweden (providers) (Allen et al 2011)	75	10	15
Switzerland (beds) (OFS 2012)	30	30	40
United Kingdom (beds) (OFT 2005)	10	14	76

5.1.3. 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 (Table 8). The established structures for health and social care provision in each country determine funding in this 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 instances, 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 (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 but other 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 still funding for care (e.g. 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.

Table 8: Funding for Care in Long-Term Care Settings

Country	Funding Sources
Austria	Three main sectors of 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). For all: medical treatment covered by statutory health insurance. Private contributions towards care comes from personal state pensions, private care insurance, personal assets.

Belgium	Residential and home nursing care services are covered by the universal health insurance system (Federal Compulsory health Insurance law of 14 July 1994), which is financed with social security contributions paid by workers, employers, and retirees, and by general taxes. 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).
France	The cost is calculated according to : - accommodation (set price) - daily living assistance (according to the needs assessment for the Activities of Daily Living - ADL) - 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 non 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	The main sectors of German Care 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 between the contribution provided by the insurance and the real costs. This gap can vary between 10 and 40 % (up to several hundred € per month). - Social welfare assistance (*Sozialhilfe*) is provided to cover long-term care costs for people in financial need.
Ireland	Mixed. Individuals 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 - based on gross earnings, 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.
Italy	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.
The Netherlands	In publically run facilities costs are covered by: 1. Public long-term care insurance (AWBZ) exceptional Medical Expense Act; assessment is needed by an independent organization - CIZ 2. Income dependent cost-sharing for residents of nursing homes and care homes. The AWBZ is funded by social security premiums, taxes and co-payments. For private organisations people can use personal budgets (PGB's; assessment is needed by an independent organization CIZ) for the care needed. Apart from that people pay all costs for living in a private institution.
Norway	Long-term care patients have to use 70% of their pensions to fund their care; The rest is financed by the social system from the municipalities, which receive funding support from the government. All Norwegian inhabitants pay the same public insurance. More recently private insurance can be purchased, but this is not usual practice. Older people are not required to sell their house or use family money.
Portugal	Mixed funding available. 1) Private contributions (pensions, personal assets, private care insurance) and public resources that result from the agreements between the state and the private institutions. 2) Private contributions (pensions, personal assets, private care insurance). 3) Public funding.

Spain	Mixed funding (same in all Autonomous Communities, but different percentages depending on the Regional or Local Government) 1. Public 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. Beneficiaries must contribute financially to the funding of services by means of a co-payment, depending on their degree of dependency and their personal financial situation. Care homes: up to 90% of income depending on acquisitive level. Medical care free to all, although care homes may have their own GPs.
Sweden	Mixed funding. More than 75% of the older people's care system is financed by state taxes. Personal contributions are means tested.
Switzerland	Mixed funding used. Contributions come from: - the older person or their family (means are tested) - health insurance for nursing and medical care; - local authority funding
United Kingdom	Individual receiving care undergoes means testing. Needs assessed for nursing care provision in nursing homes, but nursing care provided free to residents in care homes (personal care) by primary care nurses Medical care free to all, although some care homes may pay GPs a retainer for extra services such as regular visits to the care home. Varies between the UK nations e.g. Scotland provides free personal care, whereas in England this funding source is means tested.

The type of provider can also determine what care is funded in an institution in some countries. For example care provided in publically run facilities in The Netherlands and Italy is funded, in part by public monies, but also through a contribution from the older person (or family) themselves, subject to means testing.

5.1.4. Regulatory Processes

The long-term care sector is regulated in all countries (Table 9). 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. So, for example, national laws may exist which are implemented at a principality/regional level (e.g. Austria, Belgium). Regulation through inspection and accreditation may again occur nationally (e.g. England in the UK, Ireland) or regionally (Germany, Italy). In Germany and France there are specific regulations for palliative care in nursing homes.

Table 9: Regulatory Structures

Austria	National level: Nursing home residency statutes (*Heimaufenthaltsgesetz*) Nursing home contract statutes (*Heimvertragsgesetz*). Provinces are responsible for adequate professional quality assurance and control of social services. (Required minimum standards for institutional care are agreed upon in the Article 15a B-VG agreement 1993) Provincial legislation regulates care standards and structural frames, considerable differences between the 9 provinces. No legal regulations concerning Palliative Care. Guidelines for the implementation and development of Hospice and Palliative Care in nursing homes.
Belgium	Federal level: Law on Palliative Care (26/10/2002) Regional level: certification of facilities, integration and co-ordination of services, development of quality monitoring systems for nursing homes, day care centres and homes for the elderly. Flemish Decree on Residential and Home Care (*Woonzorgdecreet*, 13 March 2009), which stimulates the coordination and cooperation between residential and home care services. 'Maximum Bill' (*Maximumfactuur*) introduced in 2001 to alleviate the financial burden of the chronically ill.
France	Most of the nursing homes (EHPAD) are linked by a tripartite agreement between the nursing home, the National Health Care services and local authorities: they get governmental and local funding but have to provide an amount of services to the residents and develop a quality improvement policy. Recommendations of good practices in nursing homes, internal and external compulsory review - National Certification (Agence Nationale de l' Evaluation et de la Qualite des Etablissements Medico sociaux, ANESM) - Palliative care (PC) has to be implemented in nursing homes (law on "droits du patient et de la fin de vie" 2005) - but no data available on palliative care activity in nursing homes - Some palliative care units and palliative care teams in geriatric hospitals.
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 the LTF. Few differences between the 16 states. National and state level exist regulations for the inspection of quality: - *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 Since 2007 legal regulations (SGB V § 37b) concerning *Specialized Palliative*

	Care exist and apply also for long-term facilities.
Ireland	National Level: The Health Act, 2007, provides for the establishment of the Health Information and Quality Authority (HIQA) and for the registration and inspection of all nursing homes by the Chief Inspector of Social Services. 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. There are 32 standards under 7 groupings - Rights, Protection, Health and Social Needs, Quality of Life, Staffing, the Care Environment, and Governance and Management. 2. Registration of Designated Centres Regulations (2009) requires designated centres for older people to register with the Chief Inspector and sets out the relevant fees to be paid. 3. Care and Welfare of Residents in Designated Centres for Older People Regulations (2009) (as amended) underpin the National Quality Standards for Residential Care Settings for Older People in Ireland. An amendment in 2012 removed the requirement in some nursing homes for a nurse to be on duty at all times and for the nurse in charge of such facilities to have experience in gerontology.
Italy	National laws set general minimum requirements for institutional care. Regional laws set specific standards for accreditation.
The Netherlands	The quality of care is regulated by law. The Health Care Inspectorate (IGZ) has a role as supervisor. 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).
Norway	On a national level by the Norwegian directorate of health and social affairs (*Pasientrettighetslov* 2000.12.01 nr 1208).
Portugal	A set of Social Security standards is established for all types even with different requirements for each one - periodic inspections to the institutions that seek to ensure the quality of services and the ensuring of the beneficiaries right's - national legislation and quality manuals (guidelines) that establish minimum standards for implementation, development, services and technical skills of all providers.
Spain	*Ley de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia* (LAPAD), the act, issued in 2006, established for the first time specific rights of dependent people and their caregivers. 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	The National Board of Health and Welfare is the Swedish national expert and

	supervisory authority for elder care.
Switzerland	There is a national law that sets out minimum standards. Cantons are required to implement the law, but the extent to which this happens and how varies upon cantonal laws.
United Kingdom	National Minimum Standards exist against which care homes are inspected by an inspectorate now located in a health care body in England and Wales (Care Quality Commission). In Scotland care homes are regulated by the Care Inspectorate. The Care Inspectorate use an audit tool derived from two documents (Scottish Partnership for Palliative Care and the Scottish Executive 2006).

5.1.5 Key Drivers for Change

The development of palliative care provision within long-term care facilities is being supported by a number of drivers for change that are present at different levels within the health and social care system: nationally, regionally and locally (Table 10). At a national level, legislation has been enacted as described above that aims to improve the quality of care provided in these settings. The presence of setting specific regulations and standards that may have specific reference to palliative care (e.g. England, Scotland) seek to drive what care is provided. National programmes of development whether focused on palliative care (e.g. England in the UK, Ireland, Spain, Sweden), or more broadly on aged care and/or dementia care (for example, France, Norway, Sweden, the UK) also provide an impetus for change.

Table 10: Key Drivers for Change

Austria	Federal and National concepts that include Palliative Care for nursing homes. Regional projects integrating Hospice and Palliative Care into long-term care settings. Integrating criteria for Palliative Care within the "*National Certificate of Quality* " (NQZ) for nursing homes.
Belgium	Initiatives of the Networks Palliative Care to implement palliative care in long-term care settings. Initiatives to improve the coordination between various aspects of home care, eg the *Cooperation Initiatives in Home Care* in Flanders and 'Coordination Centres for Home care Services' in Wallonia. Palliative support teams, teams of palliative care experts in long-term care facilities who support other caregivers, patients and their relatives in matters concerning palliative care.
France	Development of PC in nursing homes is an explicit objective in the 2005 law. Governmental Alzheimer program 2008-2012 highlights the needs of PC in care homes Palliative care teams tend to provide PC in care homes. "Home hospitalisation" ("HAD") can provide palliative care in nursing

	homes (decree 2007). Barriers : "no specific funding and shortage of staff (psychologists, night nurses)" (R Aubry) Key drivers: "agreements with palliative care networks and hospital palliative care teams and development of caregivers training" (R Aubry, Report of the National Committee on Palliative Care development, 2008).
Germany	Guidelines for the implementation and development of hospice and palliative care in nursing homes are mainly initiated by the hospice and palliative care organisations since 2006. Only recently providers began to initiate those projects in their own. However, regulations concerning the funding of hospice work in hospices and in home care settings exist since 1996 (§ 39a SGB V) and applied to hospice services in long-term facilities to some extent.
Ireland	National policy on palliative care for all in place since 2001; The 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; Recent implementation of National Quality Standards for Residential Care Settings for Older People in Ireland which includes a standard for end of life care; HSE and IHF authored report on palliative care for all; High profile campaign led by the Irish Hospice Foundation in collaboration with the HSE- Hospice Friendly Hospitals Programme including (1) a national audit of end of life care in acute hospital and HSE continuing care settings; (2) National Quality Standards for End of Life Care (3) a National Practice Development Programme focused on developing person-centred workplace cultures, (4) a National Final Journeys communication programme. Irish Hospice Foundation Hospice at Home programme; and Places to Flourish toolkit.
Italy	1. In Italian Law (38/2010) and the Decree of application is explicitly stated that the treatment of pain and palliative care should be extended to all care settings, including nursing homes and long-term institutions. This recent law has the potential to drive change for this population in this setting. 2. The Italian Society for Palliative Care (SICP) representing doctors, nurses, psychologists and other professionals has a specific interest in the extension of palliative care aimed at the older population. 3. Italian Geriatrics Society (SIGG) is engaged in initiatives aimed at improving palliative care access for older people in any setting of care including the nursing home. 4. Further work is required by SIGG and SICP to develop joint programs and projects in this area.

	5. The presence of hospices located within Nursing Homes can influence palliative care provision within the wider nursing home through the transfer of knolwedge and practices. There are 24 (14.6%)of hospcies located in nursing homes in Italy.
The Netherlands	Ministry of Health, Health Care Inspectorate, national umbrella organisations (for instance ACTIZ, PALLIACTIEF, AGORA), professional organisations for nursing home physician and nurses, nursing home staff.
Norway	The Government's aim is for more people to die in nursing homes. This is part of a wider development regarding palliative care provision in all care settings. A number of policy strategy documents (cancer plan, care of seriously ill and dying, treatment and care for the incurably ill and the dying) have supported this since 1984. More recently: Norwegian Standard for Palliative Care (2004) http://www.palliativmed.org/asset/32504/1/32504_1.pdf). ISBN 82-8070-028-5. National Cancer Strategy 2006-2009. The Dementia Plan (Norwegian ministry of health and care services, 2007).
Portugal	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*)
Spain	- National Plan on Palliative Care *'Plan Nacional de Cuidados Paliativos'* (Ministerio de Sanidad y Consumo 2001) covers all patients from the public health network on a free basis. Care homes are considered in the plan along with primary care and hospitals. Some improvement measures for care homes are defined. The possibility of palliative care units in care homes is considered. Conceptually well developed, but not fully deployed. - National Cancer Strategy (2006): there is a focus on Palliative Care applied in all care levels. - National Palliative Care Strategy *(Estrategia Nacional de Cuidados Paliativos*, Spanish Ministry of Health 2007): with the objective of establishing appropriate, achievable and measurable commitments by the Autonomous Communities to contribute to the homogeneity and improvement of palliative care in the National Health System. No explicit mention of care homes, although there is acknowledgement that coordination among care levels is needed. - National Palliative Care Strategy. 2010-2014 Update *(Estrategia Nacional de Cuidados Paliativos. Actualización 2010-2014*, Spanish Ministry of Health 2011): There is an objective within strategic line 2 on Organisation and Coordination that *special homes* must have the same coverage as the general population. It is acknowledged that training for

	professionals in these settings is needed. Almost all Regional Governments have developed their own Palliative Care Plans. 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).
Sweden	The work with national guidelines for Palliative care (led by The National Board of Health and Welfare) . National guidelines for Dementia care (The National Board of Health and Welfare). Establishment of Svenska palliativregistret (SPR) – this records information about all deaths in Sweden (voluntarily recorded at the present). Provides useful information about deaths in all settings, with the potential to be used as an audit tool. (See www.palliativ.se/mainfrm.aspx (in Swedish)).
Switzerland	National strategy for palliative care published in 2009, with an emphasis on the care for older people wherever they live, including long-term care settings. Cantonal awareness varies with respect to the implementation of this strategy.
United Kingdom	England: End of Life Care Strategy (DH 2008) - Strong emphasis upon improvement of care in care homes. Dementia Strategy (DH 2009) identifies needs of people with dementia towards the end of life needing to be met, many of whom are living in care homes. The Social Care Institute for Excellence provides education and training resources and help for staff working in care homes about all care issues including palliative care. See www.scie.org.uk

Regionally, regulation can continue to be a driver. Regional demonstration projects (e.g. Austria), the development of networks to bring interested parties together, national umbrella organisations also promote this work eg The Netherlands – ACTIZ, PALLIACTIEF, AGORA, UK – National Council for Palliative Care; Scottish Partnership for Palliative Care)

Locally, there are more specific initiatives between single long-term care facilities or a group of providers to engage with specialist palliative care services. Much of this impetus for change has been driven by the hospice and palliative care sector. Challenges exist in terms of addressing wider cultural perspectives, sometimes linked to specific clinical disciplines eg in Italy.

5.2 Phase 2: Initiatives to support the development of palliative care in long-term care settings

Over 60 initiatives were identified throughout the second phase of the survey. Initiatives were identified in the following countries: Austria, Belgium, France, Germany, Ireland, Italy, The Netherlands, Norway, Spain, Sweden, Switzerland and the UK. The initiatives have been classified using a typology for change framework. Previous efforts have been undertaken to develop a typology of implementation of palliative care in nursing homes (e.g. Heller et al 2007, Froggatt et al

2011). The framework used here was developed by Ferlie and Shortell (2001) and was adapted in light of the expertise in organisational change processes and the typologies developed for "palliative care in nursing homes" (Heller et al 2007, Heimerl 2008) for use by the Taskforce to ensure that a multi level approach to the existence of initiatives was represented in the findings (Table 11). As can be seen the typology of the Taskforce differentiates between initiatives that focus on "individual", "group/team", "organization", "regional/networks" or "national" interventions. The specification "regional/networks" and "national" is based on the insight that, especially in the work of palliative and hospice care in long-term care settings, collaboration across organisational boundaries supports integration of expertise and the development of a palliative care culture.

Table 11: Typology of Initiatives

Ferlie & Shortell (2001)	**EAPC Taskforce typology**
Individual	Individual (staff, family, resident)
Group / team	Group / Team
Organisation	Organisation
Larger System / Environment	Regional / Networks
	National

The initiatives have been classified according to their type, by the level of intervention and also by the focus of the initiative: staff, residents and/or family. Appendix 4 lists a summary of all the submitted initiatives and indicates their classification by type and focus. Contact details for each initiative are also given. Further information about the initiatives will be provided on the website (www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc/).

Many of the initiatives identified address more than one of the levels of the typology (individual, team, organisation, network and national level). The following account presents examples of initiatives. The examples illustrate the typology and show good practice in the field of palliative care in long-term care settings. The abbreviations in brackets indicate how the example is listed in the table that can be found in Appendix 4 (e.g. "Nor3", "Ger1").

5.2.1 Individual – resident focused

In some initiatives there is a clear focus on the needs of the older person resident in a long-term care setting, leading to the development of guidelines for decision making (Fra1) or protocols to assist in the delivery of care. The SAVERA Scale for example that is used in Belgium (Belg4) is an evaluation instrument to find out when a resident or patient enters the terminal phase and terminal care needs to be started. The internationally disseminated Liverpool Care Pathway is implemented in different long-term care settings in some of the countries involved, e.g. Italy, Sweden, Netherlands (Box 1) and Norway.

Box 1: Implementation of the Dutch version of the Liverpool Care Pathway (LCP) (Neth3)

The initiative was originally started by a partnership between Liverpool, Erasmus MC Rotterdam and the Comprehensive Cancer Centre Rotterdam (Integral Kankercentrum Rotterdam). After research and implementation in the southwest region of the Netherlands, the national interest has increased tremendously. More and more individual professionals, health care organizations, politicians and health insurance companies are interested.

5.2.2 Individual – family focused

Some initiatives, as illustrated here from the Netherlands (Box 2), address the specific needs of family members of people with dementia living in long-term care settings.

Box 2: Palliative care for older people with dementia – a guide for caregivers (Neth5)

Originally, the booklet was developed by researchers and clinicians in French-speaking Canada, based on qualitative research with families of people with dementia in long-term care settings. Subsequently, the booklet was translated in Dutch, Japanese, and Italian, and adapted to the local (national) situation where needed. In each of the countries, as well as in English and French speaking Canada, families and staff (nurse, and physicians) have evaluated the booklet. So far, this has already resulted in further adaptations made to the Dutch and Japanese versions. In the Netherlands, representatives from the Alzheimer society, nurses and physicians were involved in further revisions.

Resources:
English and French (Canada) www.expertise-sante.com/guide_arcand_caron
Italian www.alzheimer-aima.it/libri.htm
Dutch www.vumc.nl/afdelingen/Centrum-Ouderenonderzoek/Producten-Activiteiten/afgeronde-producten-activiteiten/Zorg-rond-het-levenseinde/

5.2.3 Individual - staff

Many initiatives concentrated on developments that addressed change at an individual level particularly for care staff. The focus on knowledge and competencies in palliative care developments assumes that a focus on individual learning and improvement for staff will have an impact on the quality of care provided to older people in long-term care settings. The following initiatives are described: education, leadership development, and clinical assessment tool development.

- *Education*

Training for care professionals working in long-term care settings has a high profile. Initiatives can be found in nearly all the countries who contributed to the survey. Examples from Sweden (Box 3), Norway (Box 4), Ireland (Box 5) illustrate important aspects of education delivery.

Box 3: Palliative Care in Special Housing (nursing homes, care homes or group home) in Sweden (Swe1)

The intervention involved about 3600 Staff i.e. Registered Nurses (RN), Assistant nurses (AN) and Care assistants (CA), mainly ANs and CAs. Physicians have to a lesser extent taken part in the intervention. In autumn 2007, the National board of Health and Welfare approved an application from the Health and Medical Services Administration (HSN-f) in Stockholm County Council, so incentive funds could be given to municipalities in the county for action in health care for the elderly. The overall aim of the intervention was to increase staff skills in palliative care through education and consultation efforts and thereby increase the quality of care at the end of life for older people living in Special Housing. A basic assumption in the project is that education in palliative care and the opportunity for consultancy support from Specialised palliative home care team should result in improved quality of care in care homes, which can lead to fewer transfers to the elderly and terminally ill people from the home of health and social care accommodation to the emergency care. Different models of education have been tested and evaluated. Eight municipalities and four different local areas in one big municipality have been involved in the intervention.
Further information: www.pvis.se *(in Swedish).*

Box 4: Teach the teachers – Education program in long-term care, Bergen, Norway (Nor3a, 3b)

In 2007 the "Dignity Center – Care for the frail old" started a comprehensive, national wide teaching program: "Teach the teachers". The target group of this program is the care staff in long-term-care, in home care and in nursing homes: nurses, assistant nurses, physicians, etc. The concept encompasses 4 seminars three days each throughout a year. All participants receive the complete teaching material and presentations. They learn to teach others in their organisation. All participants are committed to establish a teaching program locally at their home site, in their nursing home or municipality, as a follow up. More than 200 people have participated. Local teaching programs are established from these participants in 40 municipalities (which is 10 % of Norwegian municipalities – the goal is 100%).

Box 5: End of Life Care Link Nurse Initiative for Residential Care Settings for Older People in Ireland (Ire1)
An education programme for end of life care link and associate nurses from residential care settings was devised and delivered by five hospice education centres. 41 residential care settings participated sendng 107 Registered Nurses acting as either Link or Associate Nurses to attend a 5 day education programme. These nurses were then asked to deliver a 7 month blended learning education programme to staff in their own facility. An evaluation was undertaken.

- *Leadership development*

Another focus on individual development can be seen in learning processes of leadership that is very important to change a long-term care setting. Management influences the kind and degree of palliative care that can grow within an organization personal and professional growth of leading persons can improve palliative and end-of-life care for older dependent people. A well-known

method that enables decision making also in palliative care can be seen in “data feedback” where certain inputs, processes, structures or outcomes are observed within e.g. a palliative care team and then reported to management.

- *Clinical assessment tool development*

Some initiatives reported within the survey show research activities that improve e.g. pain assessment for people with dementia, methodological insights into certain instruments or nutrition guidelines (eg France Box 6). These focus mainly on the needs and wishes of the older dependent person as individual with his or her living situation. This clinical assessment supports the development of palliative care in long-term care settings with basic knowledge and specialized results that help being aware of those who are at the center of all care activities.

Box 6: Nutrition management of older people in palliative care situations in France (Fra 4)
Implementation of an online guide to help care practitioners to decision making regarding nutrition and hydration of old residents in palliative care or at terminal stage.
The guide is based on case studies that illustrate guidelines to align care with national standards.
Further information: www.sfap.org

5.2.4 Group and Team

The provision of palliative care requires staff to address the challenges of interdisciplinary work and ensuring good communication within, and between, teams. Understanding each other, talking with each other and being aware that this is by no means always easy - especially in critical situations such as ethical decision making or end-of-life care – therefore seems to be a basic competence for teams engaged in palliative care. Some of the initiatives reported in the survey focused on inter-disciplinary and multi-professional education and team work.

- *Inter-professional education*

Besides educational efforts undertaken in specialised palliative care for the different disciplines that are involved, there are initiatives focused on inter disciplinary and inter professional education. One of the examples presented here is an important tool for the development of palliative care in long-term care settings in France (Box 7), the other one is a collaboration project in Sweden (Box 8).

Box 7: MOBIQUAL initiative in France (Fra1)

A nationally developed initiative to implement a training tool to improve the quality of care in long-term care facilities for old people and more specifically in nursing homes. It is aimed at training caregivers coming from different disciplines around a number of areas: pain, palliative care, depression and should be embedded in a continuous process to improve quality of care. The purpose is to enhance the knowledge, skills and practices of the caregivers. It is based on guidelines, assessment tools, procedures, (video) case studies to discuss in multi professional teams.

Further information: http//:www.Mobiqual.org

Box 8: A dignified death palliative care in nursing home in Sweden (Swe4)

This intervention is designed as a collaborative project between the county council and the municipality and involves education of staff from both organisations. All professionals, nurses, physicians, associate nurses and care assistants have undertaken the same courses. The intervention includes separate lectures, an IT-based educational program together with reflection about real situations. As a result of the intervention a palliative care team has established. This team holds continuous follow ups and educates other professionals.

- *Inter-professional rounds*

Inter-professional work can be supported both through educational initiatives, but also through reflective rounds in interdisciplinary contexts. Some of the initiatives tell about these kind of "inter-professional rounds" where situations from every day work can be talked about, different perspectives can be formulated and in some projects joint ethical decision making can be supported. The example here comes from France (Box 9).

Box 9: Implementing a Guide for decision making to withdraw or withhold treatments in geriatric situations relative to the Leonetti law in France (Fra1)

This initiative works collaboratively between multidisciplinary health professional working in different settings. The initiative is led by a Geriatric Taskforce of the SFAP (Societe Française d'Accompagement et de Soins Palliatifs) which is implementing palliative care in long-term care settings. It is based on the futility care concept and addressed to old residents with long terminal illnesses and dying patients. It focuses on skills and preparation to improve patient care through a guide to decision making. This is process-based approach to support decisions. It includes several steps aimed at deliberation and resolution including all the professionals (decision tree). The guide presents six clinical situations that have to be analysed by a multi professional team. In accordance with the "Leonetti law" the authors insist on the necessity to respect the wishes (anticipated or not) of the resident therefore to assess the capability to express his or her will even if the person is mentally impaired.

5.2.5 Organisations

The organisational context for change is important in long-term care settings, as it is within the organisational culture that individuals and teams work and operate. These organisations are the living environment for the older people, at the same time the working place for the professionals and as social systems they take over certain "functions" within society. Therefore, it is not surprising that some of the initiatives in the countries involved focus on this organisational aspect when palliative care is supposed to be integrated into long-term care settings.

- Knowledge management / transfer

Specialist palliative care teams can support long-term care organisations and teams working in such settings with knowledge management and the development of competencies. At the same time reflection and connection between existing attitudes, knowledge and experience concerning

palliative care and end of life care within the organisation can enhance the potential for changes to be undertaken.

Quality improvement initiatives play an important role as management and management systems gain importance in health care and social care organisations. One of the best documented examples comes from Spain (Box 10) , the other from the Netherlands (Box 11) where practical tools for integrative palliative care are described.

Box 10: SARquavitae project: Networks of care in Spain (Sp5)

The main objectives are the improvement of palliative care in all SARquavitae long-term care settings for older people and the development of service proposals and palliative care programs that make of SARquavitae a referent in the provision of quality palliative care at our centres and services.

The SARquavitae network of care aims to provide palliative care to patients with advanced diseases and their families at care homes also offerin social and health services at home and a call centre if needed.

Features of the care model

1. *Personalised care management and integral care provided to chronic patients through networking and technological platforms.*
2. *Case management with multidisciplinary assessment, therapeutic planning and advanced care planning.*
3. *Coordination with the palliative care services in the territory.*
4. *Evaluation of health and social outcomes: impact and effectiveness of care, services satisfaction.*
5. *Dissemination of good practices.*

Key features of the project

- *Integral, integrated and personalised care, focused on quality of life according to personal values and preferences.*
- *Care services to all patients (cancer, other chronic diseases, geriatric) coming from public and private sectors.*
- *Advanced identification of chronic patients with palliative care needs with the validated instrument NECPAL.*
- *Network of care with different services (call centre and home care 24x7, different technical devices, accessibility, etc.)*
- *Competent and committed leadership.*
- *Technological development: On-line health record (GCR®), social and health data shared with different care levels; advanced call-centre and other devices.*

Implementation

- *The Implementation plan includes the structural adaption of the units in the care homes where it will be implemented (in 7 Spanish cities), specialised training of professionals, technical equipment of the units and working together with other care resources.*

Professionals go through a six-month palliative training that includes theoretical contents, practical case management and the development of specific protocols to be implemented in the different SARquavitae units.

Box 11: "This is how we do it": practical tools for embedding integrative palliative care within an organisation for nursing homes and residential homes in the Netherlands (Neth2)

A Care Programme for the Implementation and Quality Control for Palliative Care has been designed. The programme aims at improved palliative care for all patients in the catchment area of the participating health care institutions with life threatening diseases (psychogeriatric diseases, oncology and organ failure), who benefit from palliative care from the time of their initial diagnosis, during their illness trajectory and in the terminal phase.

Strategies:

- *Implementation of national guidelines on palliative care*
- *Emphasizing the role of the Education Centre for Expertise in Palliative Care accessible (since 2004) for professionals in all facilities and in the home care.*
- *Implementation of the Dutch version of the Care Pathway for the Dying in different parts of the organisation. In 2012 it is aimed to build a digital version of the care pathway in the existing digital Electronic Patients Dossier.*
- *More close cooperation with the specialised palliative home care and the general hospital.*
- *Research to be continued building on experience since several years*

Organisational Steps:

- *Installation of a Steering Group chaired by the Board of the organisation including representatives of the organisation and of the regional network.*
- *Closer cooperation between the palliative care units to be able to support other facilities with less experience in palliative care. The consultation team is already working in the home care situations and in a general hospital for improvement of the quality of palliative care.*
- *A structural audit to be part of the program. Several palliative units have already a quality of care award*

- Specialist Palliative Care Units in Long-Term Care Settings

A structural change to integrate palliative care into nursing homes is the establishment of specialized palliative care units or dedicated beds within long-term care settings. This approach is based on the assumption that it can be decided between those residents or patients who are in need of palliative care and those who are not. In some situations this might be quite clear while in others there also could raise difficult questions about accessibility and eligibility. On the other hand specialized palliative care units within a long-term care setting can have effects as a competence centre and therefore support the whole organization in the care for people in need of palliative care. Countries where these units exist include Italy and Norway. In Norway this strategy is important within the National Palliative Care Program (Box 12).

Box 12: Establishment of palliative care units and dedicated beds in nursing homes in Norway (Nor 6)

During the last 10-15 years palliative care units have been established in nursing homes across Norway. A unit is defined as having four or more beds. Some nursing homes in small communities have "ear-marked" one or two beds for palliative care and equipped the facilities for friends and family. The Norwegian National Palliative Care Program (2007, revised 2010) holds recommendations for tasks, clinical services, organisation, personnel, facilities and equipment for palliative care units in nursing homes and for nursing homes without a designated palliative care unit. The government has provided grants for staff training (courses, post graduate education) that many communities have applied for. At present there are palliative care units in 33 Norwegian nursing homes.

- Organisational development

Organisational development has been identified as an important way to develop a palliative care culture on long-term care settings. Organisational change entails both top down support for bottom up processes involving residents, families and staff. Starting with the identification of current good practice through self reflection the next steps to provide better palliative care are identified. Organisational development initiatives have been reported mainly by England, Germany, the Netherlands and Austria. Specific examples from Germany (Box 13), Austria (Box 14) and the UK (Box 15) are presented here:

Box 13: Living until the end – Palliative care in long-term care settings of the „Inner Mission Munich" in Germany (*Leben bis zuletzt – Palliativbetreuung in Alten-und Pflegeheimen der Inneren Mission Műnchen*) (Ger2)

The initiative implements the idea of hospice and palliative care into 7 long-term care settings of the provider and started in 2001 with a top-down decision - using a bottom up approach. Staff, residents,patients and families have been involved from the very beginning of the organisational change process.. The cooperation between the long-term care settings, the local hospice movements and specialized palliative care e.g. palliative care units is tight. Close networks with similar projects (Düsseldorf, Bremen, Berlin, Leverkusen, Hamburg, Hannover) and international partners (e.g. IFF Vienna) are important drivers for the palliative care culture changes.

Further information: www.hospizprojekt.de

Box 14: Hospice and Meäutik in Caritas Socialis, Austria (Aut 6)

The organisational change project in collaboration between a provider organisation and an academic research partner focused on the development of a values based culture concerning living with death and dying (2004-2006). Combining top-down and bottom up processes 6 project groups around different themes were established: "ethics and communication", "total pain" "mäeutic relationships","integration of palliative medicine", "palliative care in a day care centre" and "ethics and legal issues". Each of those groups that represented one institution within the provider organisation elaborated practical tools to improve their daily routines. Social exchange within and between organisations were organised. Two major changes that were establisehd and integrated into the institution were ethical rounds and the post of a doctor of specialist palliative medicine. The core issue of interdisciplinary ethical awareness highlights the importance of a new understanding of ethics within long-term care settings. Care ethics (Tronto 1994) and organisational ethics (Krobath and Heller 2010; Bartosch et al. 2005) help to integrate different professional ethical perspectives. Communicative cultures can develop new perspectives in palliative care for, and with, residents.

Box 15: Gold Standards Framework for Care Homes (UK 4)

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, Over 2,000 care homes have undertaken the two-year programme.The programme involves a formal accreditation process after completing the programme and then every 3 years for re-accreditation.

Further informatiopn: wwwgoldstandardsframeworkorg.uk

5.2.6 Regional Cooperation and Networks

Initiatives may also focus upon regional cooperation, within a region, or as networks, addressing actions at an inter-organisational level. This perspective helps to recognise the importance of regional contextual factors e.g. rurality or religious backgrounds in certain areas. As in organisations these initiatives can be implemented top down or grow as"grass roots" networks. Examples of each approach are provided from Norway (Box 16), Germany (Box 17), Austria (Box 18). Other initiatives at this level also have been reported from the Netherlands, and Belgium.

Box 16: Intercommunity project: cooperaton in palliative care in Norway (Nor1)

This is a co-operative project between the city of Stavanger and eight nearby municipalities/ communities, Stavanger University Hospital, and the Development Centre for Nursing Home Care and Home Care in the county of Rogaland, South-Western Norway. The project has received government funding to improve intercommunity cooperation in palliative care.

Project aim: To ensure all communities in the area are able to provide quality palliative care.

Key Tasks:

1. Identify patients in need of palliative care by introducing criteria from the Gold Standards Framework (GSF, UK)

2. Register palliative care patients in nursing homes and home care

3. Offer an individual care plan to palliative care patients that have three or more different care

providers
4. Increase knowledge and skills in palliative care, underlining the Interdisciplinary approach.
5. Educate staff in palliative care tools and pathways (ESAS, LCP, "safety box", individual care plan)
6. Do a survey of palliative care expertise and availability in all nine municipalities
7. Establish guidelines/recommendations for intercommunity use of palliative care beds and units in nursing homes.
The project started in 2010 and is ongoing.

Box 17: Network palliative care in nursing homes (*Netzwerk Palliativbetreuung im Pflegeheim,* NPP), Germany (Ger10)

The initiative started within the Diakonie in Bavaria as response to a growing number of projects of implementation and integration of hospice care and palliative care in long-term care settings in Germany. It started in 2003. It mainly serves as a virtual network, based in a platform of e-mail circulation of regular information letters during the year. Every other year participants meet for a conference.

Box 18: Hospice and Palliative Care plan in Tyrol, Austria (Aut 5)
In the Austrian province Tyrol a three year multi-level organisational action research project was undertaken with the following objectives:

- *To develop a regional specific concept for integrated palliative care;*
- *To generate knowledge and foster communication among local actors and stakeholders;*
- *To integrate palliative care into the regional health-care systems;*
- *To supervise the integration-processes and consult local health care policy.*

The networking process included nursing homes as well as other important regional actors and providers in palliative care.

5.2.7 National

Initiatives on national level, that include nationwide changes in the political environment as well as legal regulations, health and social care strategies and quality standards for palliative care in long-term care settings are important system factors influencing the palliative care culture. The following aspects show the widespread activities in the countries involved. Table 12 provides an overview the key initiatives at this level.

Table 12: National Initiatives

Country	Environment / System
Austria	• Guidelines for implementation and development of hospice and palliative care in nursing homes. • National certificate of quality (NQZ) for nursing homes includes palliative care.
Belgium	• Networks palliative care initiatives. • Law on Palliative Care (2002).
France	• Palliative care in nursing homes law (2005). • Government Alzheimer's Program (2008 – 2012). • Home hospitalisation (HAD) – can provide palliative care in nursing homes (decree 2007).
Germany	• Legal regulations from 2007 for long-term care facilities • Regulations of hospice work in long-term care facilities (1996). • Joint recommendations for palliative care in nursing homes by the hospice association and the association of palliative medicine (2012)
Ireland	• Standard 16 for care at the end of life as part of their National Quality Standards for Residential Care Settings for Older People.
Italy	• National law ensures access to palliative care and pain therapy in all care settings, including Nursing Homes.
Netherlands	• Government objective for more people to remain at home or in the nursing home.
Spain	• National Palliative Care Plans and Strategies (2001, 2007, 2010-14). • Draft legislation recently passed by the Spanish Government to specifically regulate end-of-life care (*Anteproyecto de Ley de Cuidados Paliativos y Muerte Digna,* May 2011).
Sweden	• National guidelines for palliative care currently being developed. • National guidelines for dementia care.
Switzerland	• Swiss Academy of Medical Sciences Medical-Ethical guidelines: " Treatment and Care of elderly people who are in need of care" (2004) • National Strategy for Palliative Care. National Ministry of Health . 2009-2012. • *Qualité Palliative:* Society for quality in palliative care has

	established criteria for long-term care settings regarding palliative care provision (2011).
United Kingdom (England)	• National minimum standards for care provision in long-term care settings • End of Life Care Strategy (DH 2008). • End of Life Care Programme. • Dementia Strategy (DH 2009). • Quality Markers.

- Legal system

All European countries who participated in the survey have a legal framework for regulation concerning long-term care settings (Table 8). How palliative care is integrated into these regulations varies across the countries. Specialized regulations concerning palliative care exist in many countries, but most of them are not directed specifically towards older people or long-term care settings. In Italy, for example, there exists a national law for pain assessment that only applies to medical facilities and has no specific impact on long-term care settings. In France, palliative care has to be implemented in nursing homes by law (*droits du patient et de la fin de vie,* 2005), in Belgium a law on palliative care was implemented in 2002. In Germany, regulations concerning long-term care facilities and hospice work in long-term care facilities exist since 1996. In England, there are national minimum standards regulating palliative care in long-term care facilities.

- National strategies

National strategies that include objectives and aims concerning palliative care in long-term care settings for older people do exist in different ways in these countries. In England, a combination of the End of Life Care strategy with a strong emphasis upon improvement of care in care homes, the End of Life Care programme and the dementia strategy all address different aspects important for those living and dying in nursing homes and similar institutions. The national End of Life Care programme has a specific strand of work concerned with care homes (Box 19).

Box 19: National End of Life Care programme, England (UK3)

Case studies, publications and resources, drawing upon practical examples of initiatives that have worked to support the development of palliative care in care homes.

Three specific inititaives are being promoted in 2012:

- ***The route to success in end of life care – achieving quality in care homes***
  Addresses the six steps identifed in the End of Life Care Strategy that need to be addressed in order to deliver high quality end of life care in care homes.
- ***Quality of end of life care in care homes assessment tool***
  A tool developed to ascertain information about the quality of end of life care and a means to analyse this.
- ***Six Steps to Success Training Programme for Care Homes***
  A regionally developed initiative (developed in NW England) to implement 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. Utilises a facilitator to provide 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 LCP, care after death and overall evaluation.

In the Netherlands, as another example, the objective of the government is that more older dependent people can stay at home or remain in nursing homes, which can be seen as part of a broader palliative care strategy.

- Quality development, standards and guidelines for palliative care in long-term care

Quality management and quality assurance are increasingly important processes in long-term care settings (See Table 11 for further examples of such approaches). In Austria (Box 20), England and Ireland there are specific palliative care standards that are integrated in the National Quality Certificates. In Sweden, National Guidelines for Dementia already exist and National Guidelines for Palliative Care are currently being developed. It is important to be aware of the interconnections that bring together issues of care for older people in long-term care settings, dementia care and palliative care.

Box 20: Hospice and Palliative Care in nursing homes in Austria (Aut1)
The project on hospice and palliative care in nursing homes is initiated by Hospice Austria in collaboration with Funds "Healthy Austria" (Fonds Gesundes Österreich) and regional provider organisations within different provinces of Austria. Integration of Palliative Care and Hospice is undertaken in training courses with the "Curriculum Palliative Praxis Geriatrie" as well as in organisational change processes. Managment and interdisciplinary teams are involved and quality standards concerning Hospice and Palliative Care are incorporated in the National Quality Certificate (NQZ) on National level.
Further information: www.hospiz.at/

- Funding policies

The issue of funding policies addresses issues of numbers and funding for specialist care personnel engaged in long-term care settings and the integration of medical treatments with gerontological/geriatric care. A tension and gap can be stated between the increasing demands and needs for palliative care in long-term care settings that is accepted widely (as identified through research, and also politically supported) and the financial resources that are available within public budgets. Due to the current economic situation, cutbacks in funding especially in health and social affairs can be observed throughout Europe. These funding constraints will also impact upon long-term care for older people.

In Belgium (Box 21) a national scheme provides a way to support the extra costs associated with the provision of palliative care in long-term care settings.

Box 21: Funding of Palliative Care in long-term care facilities in Belgium (Bel1)

This national initiative (top down), started in 1997 and supports the care of terminally ill patients in long-term care facilities for the elderly. To promote palliative care in long-term care facilities each nursing home and home for the elderly should have a "palliative function". This means that each facility must join a palliative network and make a practical agreement with a facility that has 'SP-beds' (beds for palliative care). To support the care of terminally ill patients in long-term care facilities for the elderly, each facility has a Palliative Support Team. This team consists among others of the coordinating and advising physician and the head nurse of the facility. Since 2001, the nursing homes and homes for the elderly can invoke an allowance for support of, increased awareness by, and training of, staff in palliative care. The financial support of the palliative care function is by means of a flat allowance per day stay in a facility. The initiative includes support for highly dependent and terminally ill patients.

6. Discussion Conclusions and Recommendations

This Taskforce reports here two elements of work concerning the development of the provision of palliative care in long-term care settings: country contexts and initiative information. In order to understand how palliative care provision is being supported in long-term care settings, knowledge about the sector as a whole is required, and its variation cross Europe. Hence, the presentation of information about the country, the types of long-term care settings, the status of long-term care providers, how this care is funded, regulated and the key drivers for change. Whilst there are many similarities with respect to this context there are also differences that need to be taken into account when looking to transfer initiatives from one country to another. A number of themes and issues are raised from the work regarding the country contexts and the information about the initiatives.

6.1 Country context

A number of *similarities are identified across Europe* between the countries that participated in the Taskforce concerning the increased interest in this field, the differentiated service provision and issues of quality.

- Increasing interest and an emphasis upon support at home

Increasing need and interest in the provision of care for dependent older people can be observed. There is a common emphasis upon supporting older people to remain in their own homes towards, and at, the end of life. This also applies to long-term care settings, which are regarded as the person's home. The change in client structure demands higher support and nursing as well as death and dying being important phases of living in long-term care settings. The growing number of people with dementia living in long-term care settings has also been recognized as needing special attention.

- Differentiated provision by need

Whilst the needs for care and support experienced by individual older people living in long-term care facilities, may be common across countries, the settings where they live and die, do vary. Provision of long-term care settings is based on different kinds of facilities. Often there are institutions that combine living arrangements for the dependent older person with nursing (traditional nursing

homes). There are also models that have their focus on housing with care being organised additionally. These organisational structures shape how hospice and palliative care can be provided. It is important to be aware of these distinctions, and not assume the sector is homogenous in its management of health and social care needs.

- Quality management and assurance

In all of the countries involved a common focus in long-term care settings concerns the quality of care provided (referred to variously as quality management, control or assurance). The presence of processes to manage quality care provision is important, and can be used positively to support new developments. However, it can also be viewed critically in the light of an additional work load required to complete documentation and audits without extra resources. It has also been critically questioned by some whether it is possible to standardize the hospice philosophy in this way (Clark 2004, Gronemeyer and Heller 2007).

There are also *differences* across Europe relating to the different levels of responsibility for care development within palliative care and long-term care, the role of different types of provider, the integration of medical services and the place of family as carers:

- Responsibility for care

Responsibility for care varies between and within countries. Within country differences exist in many countries, where regions, provinces, nations all have different levels of responsibility for different aspects of care provision, funding development and regulation. Key areas of difference exist within countries, where strong regional government can be as influential as national government, so resulting in different approaches within a country, eg the UK, Switzerland, Germany, Austria. This adds to the challenges of understanding the setting in all its complexity.

- Different funding models

The different emphases placed upon the role of public, private and not-for-profit sector shapes the way in which care is funded and provided. Within some countries faith based not-for-profit organisations are particularly important providers of services.

- Integration of medical services

The integration of medical competence differs across models within countries and across countries and shapes how palliative care can be delivered in the setting. Traditional nursing home models rely on nursing care and collaborate with General Practitioners. Other institutions have medical doctors as employees and therefore medical competence is more present within the organization and in contact with residents.

- The role of family and relatives

The role of the family in care provision for older people varies across Europe (OECD 2011), which in turn shapes the extent to which long-term care settings are required for care provision, and the way in which care is provided within them, by whom. Gender-roles in caring work, by family and paid workers also vary.

- The role of volunteers and informal care

Although there has not been an explicit question concerning the relevance of volunteers in hospice and palliative care in long-term care settings in the data collection process, anecdotal evidence indicates that there different approaches exist across Europe to the role of volunteers and informal carers in this setting. Countries. Due to cultural values, attitudes and engagement as volunteers is quite common in some countries whilst in others it seems to be quite unusual. The history of hospice movement and palliative care plays a vital role for volunteering and infomal care for people at the end of their life. This warrants further study.

6.2 Palliative Care Initiatives

A number of observations can be made about the initiatives collated here regarding the complexity of initiatives undertaken to develop palliative care practice in long-term care settings; their sustainability; and the place of the organization in such developments

- Complexity of palliative care developments

The initiatives that were collated and presented in this report show a high level of complexity and an increasing number had multi-foci-approaches, with different ways to improve care for older people. Change processes at different levels were often designed within one palliative care initiative, e.g. a pain assessment initiative may entail collaboration between a nursing home and the local hospice organization to improve care for individual older people, alongside the formulation of national guidelines. National policy initiatives require implementation at regional, local, and organisational level if they are to have an impact upon care delivery.

The initiatives identified and described here can be described according to their focus of intervention and the level of change sought (eg individuals/teams/organisations), and the beneficiaries of the change (eg individuals such as care staff, and or family members, older people). So for example educational initiatives can be designed for care workers, interdisciplinary teams or for family members, with an outcome of better care for older people.

Some of the initiatives had a clinical focus seeking to address clinical issues around medical care. Other initiatives took a broader perspective looking at the wider cultural context for change within which care is provided.

- Issues of sustainability

Many of the initiatives described here had their origins as projects either within service development or research. Whilst this work has identified helpful and relevant initiatives, they were usually time limited , so raising questions about their longer teem sustainability. Sustainability occurs, where political will is translated into funding and other practical support for initiatives in palliative care in long-term care settings. Evaluation of the initiatives that are organised are still valuable as they can provide evidence about what is needed to develop a palliative care culture, but their long-term impact, is limited, unless further funding or ways to integrate new practices into current work can be identified.

- The place of the organisation

What has become clear in the work of this Taskforce is need to fully recognize the importance of the role of the organisation in this development work. This has been supported by the use of the

modified Ferlie and Shortell (2001) typology for change. Within the levels of typology, the initiatives undertaken at any level are mediated through the long-term care organisation. Therefore further work needs to be undertaken to identify ways to engage more effectively with organisations in a sustainable and collaborative way.

The modified framework for change has proved useful for this Taskforce and requires further development and consideration to see if it can be used within research, education and practice to support the development of palliative care in these settings. As the discussion of some of the initiatives show it seems to be fruitful to integrate an "international" level within the framework, because collaboration between countries already exists and needs recognition (Table 13).

Table 13: Enhanced Typology of Change

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

6.3 Conclusions and Recommendations

This Taskforce sought to identify and map the different ways of developing palliative care in long-term care settings across Europe. The objectives outlined at the start of the Taskforce have been met (Table 14). The Taskforce has also provided detailed country context information in order to understand better some of the common challenges and issues faced across Europe in terms of care provision for older people requiring long-term institutional care. This has direct relevance to the practice development work described here, as it provides the context for such initiatives and their potential for sustainability and lasting change. The findings and issues described here are also relevant to other settings where older people reside, such as supported housing, although there may be differences that require identifying.

The work of the Taskforce on Palliative Care in Long-term Care settings for Older People can be summarised as a developing network, where expertise and experience from a range of European countries is being exchanged and collated in different forms. This Taskforce report provides a useful baseline for future work within the clinical practice and research domains.

Table 14: Review of Objectives and Actions of the Taskforce

Objective	Actions
1. To define long-term care settings for older people and the nature of palliative care in these settings	A working definition of long-term care settings for older people was presented and provided focused parameters for the Taskforce. An inclusive definition of palliative care was used.
2. To identify practice development initiatives being undertaken to develop the provision of palliative care in long-term care settings for older people	Information on 62 initiatives from 12 European countries has been provided. A modified typology for change has been proposed that allows the complexity of such initiatives to be acknowledged and
3. To map palliative care initiatives across different countries	The initiatives identified have been presented by country, as well as their focus and benefits.
4. To create a compendium of good practice interventions.	A summary compendium is presented in Appendix 4 of this report, and is also available online: (www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc/).

The Taskforce addressed different perspectives and were of relevance to three groups of people and organisations working in the field of palliative care in long-term care organisations: practitioners, researchers and members of the European Association of Palliative Care (EAPC). The following recommendations can be made on the basis of the findings of our work:

Practice organisations within long-term care and palliative care

Much information collated here has been generated from practice organisations within the long-term care and palliative care fields. It is important that the findings of the Taskforce are made available to these agencies. The examples presented are not exhaustive and further helpful initiatives will exist that are not presented here. Therefore, further work is required to:

- consider how to share findings with practice organisations and settings within each partner country and across borders;
- ensure the ongoing collation of examples and resources and find out how the hospice movement, volunteers and civil society can be involved in this work;
- acknowledge the high proportion of people with dementia living in long-term care settings and integrate knowledge and expertise from dementia care with palliative and hospice care.

Research

Funded research has been an important source of information for the initiatives collated by the Taskforce. A wide range of methodologies have been used within such research. There is a need to:

- identify the challenges of doing research with the older people population living in this setting;
- integrate the perspectives of the people concerned: residents, patients, people with dementia, relatives, informal care persons and their diversity;
- appreciate the palliative care work that already is delivered by staff and informal care;

- deepen the insights that organisations play in the delivery of multi-level change processes;
- promote the rigorous evaluation of initiatives seeking to promote the provision of palliative care in long-term care settings;
- identify what evidence is required to support the implementation of findings arising from research;
- agree appropriate outcome measures to evaluate changes in the quality of palliative care provision;
- establish European research collaborations to support further developments in this area building upon the Taskforce work;
- ensure participatory dialogue is present with residents, relatives, all citizens and political groups, where appropriate to the study focus and design.

EAPC

The role of the EAPC in supporting the development of palliative care in long-term care settings for older people continues to be important. The EAPC already recognises the importance of this work through its support of the Taskforce, and the presence of workshops, oral and poster presentations in its Congresses. Further consideration of separate streams of work specifically about long-term care settings would further raise the profile of this area of important palliative care provision:

- establish higher profile within conferences, through pre-conference workshops;
- streams of papers under this topic (separate older people from paediatrics);
- identify ways to coordinate work in this area across different organisations;
- address the delivery of high quality research that supports the provision of palliative care in long-term care settings.

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8. Appendices

8.1 Appendix 1: Country informants

Country	Country informants
Austria	Sigrid Beyer, Katharina Heimerl, Elisabeth Reitinger
Belgium	Luc Deliens, Tinne Smets
France	Marie-France Couilliot, Marian Villez
Germany	Georg Bollig, Frank Kittelberger,
Ireland	Clodagh Cooley, Geralyn Hynes, Julie Ling, Mary McCarron
Italy	Vito Curiale, Massimo Monti
Netherlands	Mirella Minkman, Roeline Pasman,
Norway	Bettina Sandgathe-Husebø
Portugal	Manuel Luís Vila Capelas
Spain	Marjolein Gysels, Maria Nabal
Sweden	Lennarth Johansson, Jane Österlind,
Switzerland	Claudia Gamondi, Roland Kunz
UK	Katherine Froggatt, Jo Hockley

8.2 Appendix 2: Survey: Form 1 Overview

COUNTRY:	
Name of person completing survey: (title/forename/surname)	
Position:	**Phone number:**
Organisation:	**Email address:**

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

Yes No

If yes, please list below and complete the attached form for each International initiative

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

Yes No

If yes, please complete the attached form for each National International initiative

3) Are there any REGIONAL/ NETWORK projects addressing the development of palliative care in long-term care settings for older people

being undertaken in your country (e.g. development of guidelines, Palliative Care Culture development)?

Yes No

If yes, please complete the attached form for each Regional/Network initiative

4) Are there any ORGANISATIONAL LEVEL projects addressing the development of palliative care in long-term care settings for older people being undertaken in your country (e.g. development of policies, documentation, standards, staff education)?

Yes No

If yes, please complete the attached form for each Organisational level initiative.

5) Are there any interdisciplinary projects being undertaken with staff TEAMS and/or FAMILIES to develop palliative care in long-term settings for older people in your country (e.g. ethical rounds, family case conferences)?

Yes No

If yes, please complete the attached form for each interdisciplinary staff/family initiative.

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6) Are there any interventions undertaken to develop palliative care in long-term settings directed at INDIVIDUAL OLDER PEOPLE LEVEL in your country (e.g. pain and symptom management, social needs, spiritual care)?

Yes No If yes, please complete the attached form for each older person focused initiative
7) Are there any interventions undertaken to develop palliative care in long-term settings directed at FAMILY/FRIENDS in your country (e.g. family support and bereavement care)? Yes No If yes, please complete the attached form for each family focused initiative

8.3 Appendix 3: Form 2 Initiative Information

Country:
Initiative Title:
Contact Details for Initiative: Name: Organisation: Email: Telephone:
Type of Initiative: (Please tick all that apply) International National Regional/networks Organisational Interdisciplinary Individually Focused(Older person/Family)

Who is the initiative focused on? (Please tick all that apply)

Individuals (resident)

Individuals (family members)

Individuals (staff)

Families/Friends

Staff teams within long-term care organisations

Staff teams across organisations

How is the initiative undertaken? Please describe details of the structure and organisation of the intervention.

- How was change undertaken – top down (e.g. government organisational directive), bottom up (e.g. long-term care setting initiated), or collaboratively?
- Which staff professionals were involved?
- Which patient groups did it involve? (diagnosis, gender, age)

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

Improvement in quality of life for older people

Better support for 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 list any further information about this intervention e.g. reports or publications which describe the intervention and its outcomes.

Any other information:

Thank You

8.4 Appendix 4: Country initiatives - Overview

CODE	COUNTRY	INITIATIVE TITLE	CONTACT	TYPE					FOCUS					
				Regional / networks	Organisational	Group / team	Individual - staff	Individual – other staff	Individuals – residents	Individuals – family	Individuals - staff	Family / Friends	Staff teams – long-term care orgs	Staff teams – across organisatio
Aut1	Austria	Hospice and Palliative Care in Nursing Homes (HPCPH Hospiz und Palliative Care im Pflegeheim)	Sigrid Beyer sigrid.beyer@hospiz.at	•	•		•		•	•	•		•	•
Aut2	Austria	International network across German speaking countries. „network palliative care in nursing homes" (NPP)	Klaus Wegleitner klaus.wegleitner@aau.at Andreas Heller andreas.heller@aau.at	•							•		•	•
Aut3	Austria	Curriculum Palliative Praxis Geriatrie	Marina Kojer, Martina Schmidl marina.kojer@me.com, martina.schmidl@wienkav.at			•	•				•		•	
Aut4	Austria	Evaluating sustainability in Palliative Care in Nursing homes: A Collaboration between Austria and Germany	Katharina Heimerl, Andreas Heller katharina.heimerl@aau.at, andreas.heller@aau.at	•	•	•	•	•					•	•
Aut5	Austria	Hospice and Palliative Care plan in Tyrol	Klaus Wegleitner klaus.wegleitner@aau.at	•	•	•							•	•
Aut6	Austria	Hospice and Meäutik in Caritas Socialis	Andreas Heller andreas.heller@aau.at		•	•	•	•	•	•		•	•	•
Aut7	Austria	Gender in a long-term care setting in Tirol	Elisabeth Reitinger elisabeth.reitinger@aau.at		•	•	•	•	•	•	•		•	

Aut8	Austria	Palliative Care in Geriatric Centre Liesing, Vienna	Katharina Heimerl Katharina.heimerl@aau.at													
Belg1	Belgium	Funding of the palliative function in nursing homes and homes for the elderly.	Paul Vanden Berghe paul.vanden.Berghe@palliatief.be	•	•		•			•		•		•		
Belg2	Belgium	Guideline 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')	Paul Vanden Berghe paul.vanden.Berghe@palliatief.be	•								•		•		
Belg3	Belgium	Monitoring of discomfort in elderly patients with dementia based on automatic image recognition.	Rudiger De Belie (Director of WZC De Wingerd, Leuven, Belgium)				•			•						
Belg4	Belgium	The Savera scale as indicator for the terminal phase	Paul Vanden Berghe paul.vanden.Berghe@palliatief.be				•			•						
Belg5	Belgium	Giving the end-of-life back to people. Advance care planning in Flanders	Paul Vanden Berghe paul.vanden.Berghe@palliatief.be	•	•					•	•	•				
Belg6	Belgium	Funding of the palliative function in nursing homes and homes for the elderly	Paul Vanden Berghe paul.vanden.Berghe@palliatief.be	•						•		•		•		
Fra1	France	Implementing a Guide for decision making to withdraw or withhold treatments in geriatric situations relative to the Leonetti law.	Dr Véronique MORIZE veronique.morize@ccl.aphp.fr	•			•							•	•	

Fra2	France	Pilot studies on Strategies using Alternative treatments for painful elderly in long-term care facilities.	Dr V Darees veronique.darees@jvr.aphp.fr				•			•		•			
Fra3	France	Palliative Care Networks practices in nursing homes.	Dr Nathalie Nisenbaum reseauarcenciel@wanadoo.fr	•										•	•
Fra4	France	Nutrition of the old person in palliative care situations.	Dr Abitbol gabriel.abitbol@brc.aphp.fr	•			•			•		•		•	•
Fra5	France	MOBIQUAL: = Mobilisation to improve the Quality of Care for old people	Sebastien Doutreligne mobiqual@sfgg.org	•	•	•	•					•		•	•
Ger1	Germany	End-of-Life-Care des Diakonischen Werks Bayern.	Frank Kittelberger fkittelberger@t-online.de		•	•				•	•	•		•	•
Ger2	Germany	Leben bis zuletzt – Palliativbetreuung in der Alten- und Pflegeheimen der Inneren Mission Műnchen	Frank Kittelberger fkittelberger@t-online.de	•	•	•				•	•	•		•	•
Ger3	Germany	Vernetzte Palliativbetreuung – Fortentwicklung der Organisationskultur des Sterbens in der Diakonie in Dűsseldorf	Dr. Nada Ralic nada.ralic@diakonie-duesseldorf.de		•	•				•	•	•	•	•	•
Ger4	Germany	Leben und Sterben – Lebensbegleitung ist Sterbebegleitung in der Caritas (CBT) Köln-Leverkusen	Franz-Josef Stoffer f.stoffer@cbt_gmbh.de		•	•				•	•	•	•	•	•
Ger5	Germany	Miteinander _ Fűreinander: Fűr ein liebevoll begleitetes Sterben in den Häusern der Bremer Heimstiftung	Petra Scholz petra.scholz@bremer_heimstiftung.de		•	•				•	•	•	•	•	•

Ger6	Germany	Projekte Palliative Praxis für ältere Menschen	Julia Hoeter julia.hoeter@bosch-stiftung.de		•			•						•	•
Ger7	Germany	Bavarian participation in the network "Vernetzungstreffen" of the Alpen-Countries Austria, Switzerland & Germany	Frank Kittelberger fkittelberger@t-online.de	•									•		•	•
Ger8	Germany	Joint venture between the Diakonie of Bavaria and Hungary	Frank Kittelberger fkittelberger@t-online.de	•						•	•	•	•	•	
Ger9	Germany	Diakonisches Werk der EKD Zentrum GRP, Arbeitsfeld hospiz und Palliative Care	hospiz@diakonie.de	•	•					•	•	•	•	•	•
Ger10	Germany	Netzwerk Palliativbetreuung im Pflegeheim (NPP) ('network palliative care in nursing homes')	Frank Kittelberger fkittelberger@t-online.de	•	•					•	•	•	•	•	•
Ger11	Germany	Palliative Geriatrie, Berlin	Dirk Müller dirk.mueller@unionhilfswerk.de	•	•	•	•					•	•		•
Ire1	Ireland	End of Life Care Link Nurse Initiative for Residential Care Settings for Older People	Kevin Connaire kconnaire@sfh.ie				•							•	•
Ire2	Ireland	Introductory End of Life Education Programme for Staff Working in Residential Care Settings for Older People	Orla Keegan orla.keegan@hospice-foundation.ie				•							•	
Ire3	Ireland	Irish Hospice Foundation: Hospice Friendly Hospitals Palliative care for all project	Hospice Friendly Hospitals: grace.osullivan@hospice-foundation.ie Palliative Care for All: marie.lynch@hospice-foundation.ie				•							•	

It1	Italy	VELA Project (Evaluation of Efficacy of Lenitherapy in Alzheimer desease) aims to transfer knowledge and palliative care practices into nursing homes.	Massimo Monti monti.massimo@tin.it		•	•	•					•		•	
Neth1	Netherlands	Implementation of a new function of 'consulting palliative care nurse' (verpleegkundig zorgconsulent palliatieve zorg) in long-term settings	R.J.A. Krol r.krol@iko.nl	•	•	•	•					•		•	
Neth2	Netherlands	Best practises 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 P. M. Baar f.baar@laurens.nl		•	•	•			•	•	specialised	•	•	•
Neth3	Netherlands	Implementation of the Dutch version of the Liverpool Care Pathway (LCP)	Anneke Dekkers dekkers@ikr.nl			•	•			•	•	•	•		
Neth4	Netherlands	Combi Care	Franca Horstink-Wortel F.Horstink@RIVAS.nl		•	•	•	•							
Neth5	Netherlands	Palliative care for older people with dementia – a guide for caregivers	Jenny v.d. Steen, Marcel Arcand j.vandersteen@vumc.nl Marcel.Arcand@USherbrooke.ca		•		•	•							
Neth6	Netherlands	Psychogeriatric palliative care unit, a special unit for people in the end of dementia or dementia and a terminal disease	R. Bosters, A.M.M.L.van der Heijden antoinette.vanderheijden@tantelouise-vivensis.nl												
Neth7	Netherlands	Memorial Box	Franca Horstink-Wortel F.Horstink@RIVAS.nl			•	•			•	•	•			

Nor1	Norway	Intercommunity project: cooperation in palliative care	Kristin Eikill kristin.eikill@stavanger.kommune.no	•												
Nor2	Norway	Assessment of Pain in Patients with Mental Impairment	Bettina S. Husebø bettina.husebo@isf.uib.no				•			•		•		•	•	
Nor3	Norway	Teach the teachers – Education program in LTC, Dignity Centre, Red Cross Nursing Home, Bergen, Norway	Stein Husebø sthusebo@c2i.net				•			•		•		•	•	
Nor4	Norway	Focus seminar for 5th year medical students in nursing home medicine and palliative care, and hospitation in nursing homes of the municipality of Bergen	Bettina S. Husebø bettina.husebo@isf.uib.no					•		•						
Nor5	Norway	Palliative care in the nursing home	Bettina S. Husebø bettina.husebo@isf.uib.no		•		•			•	•	•	•	•		
Nor6	Norway	Establishment of palliative care units and dedicated beds in nursing homes	Dagny Faksvåg Haugen dagny.haugen@helse-bergen.no	•	•					•	•	•	•	•	•	
Nor7	Norway	Implementing Liverpool Care Pathway for Care of the Dying in Norwegian nursing homes	Grethe Skorpen Iversen grethe.skorpen.iversen@haraldsplass.no			•	•			•	•	•	•	•	•	
Nor8	Norway	Safety box – medications for symptom relief to the dying	Sebastian von Hofacker sebasdtian.vonhofacker@haraldsplass.no			•	•			•		•		•	•	
Sp1	Spain	Plan on palliative care in long-term care settings in Cataluña and Madrid	Dr. Iciar Ancizu iancizu@sarquavitae.es	•	•									•	•	
Sp2	Spain	"Qualy" End-of-Life Observatory/WHO Collaborating Center for Palliative Care Programs, Catalan Institute of Oncology, Hospital Duràn-Reynals	Dr. Iciar Ancizu iancizu@sarquavitae.es	•	•									•	•	

Sp3	Spain	Qualy/SARquavitae project: improvement of palliative care in all SARquavitae long-term care settings for older people	Dr. Iciar Ancizu iancizu@sarquavitae.es		•	•				•	•	•			
Sp4	Spain	"Comprehensive Care for Patients with Advanced Illnesses and their Families" Program	Dr. Xavier Gómez-Batiste xgomez.whocc@iconcologia.net	•		•	•			•	•	•	•		
Sp5	Spain	NECPAL: Identification of patients with advanced disease and in advanced disease status (SEAT) with prognosis of limited life requiring palliative care	Dr. Iciar Ancizu iancizu@sarquavitae.es			•	•	•		•	•	•		•	
Swe1	Sweden	Palliative care in Special Housing (nursing homes / care homes or group homes)	Christina Riddebäck RN christina.riddeback@sll.se Jane Ősterlind, RN PhD jane.osterlind@esh.se	•			•					•			
Swe2	Sweden	Study Circle as a method for better palliative care in elder care	Maria Martini maria.martini@grkom.se				•					•		•	
Swe3	Sweden	Liverpool Care Pathway (LCP in Sweden)	Marie-Louise Ekeström, RN Mary-Jane Windus, RN Palliative Centrum Stockhomssjukhem	•		•	•			•	•	•		•	•
Swe4	Sweden	A dignified death- palliative care in nursing home.	Sonja Ljung, medical responsible nurse (MAS) sol@robertsfors.se	•		•	•					•		•	•
Swe5	Sweden	National guidelines for palliative care	Arvid Widenlou Nordmark, The National Board of Health and Welfare	•						•				•	
Swi1	Switzerland	Community development of palliative care in north east Switzerland	Steffen Eychmüller steffen.eychmueller@kssg.ch	•	•	•	•	•		•	•	•	•	•	•
Swi2	Switzerland	Implementation and Improvement of a Palliative Care Concept in a Medium sized Nursing Home	Anita Fischer anita.fischer@spital-limmattal.ch		•	•				•	•		•	•	

Swi3	Switzerland	Development and improvement of a general palliative care approach in the nursing home of Laupen (Bern)	Egloff Werner / Jenni Giovanna werner.egloff@bz-laupen.ch		•	•				•	•	•			
Swi4	Switzerland	A perfect End to a Life: Dignity at life's end	Schmid Christoph c.schmid@curaviva.ch Beat Vogel bvogel@caritas.ch	•	•	•								•	•
UK1	UK (England)	Croydon Care Homes Initiative.	Jacqueline Goodchild NHS Croydon	•	•	•	•			•		•		•	
UK2	UK (England)	Six Steps to Success.	NW End of Life Care programme for Care Homes www.endoflifecumbriaandlancashire.org.uk/six_steps.php	•	•	•	•			•	•	•		•	
UK3	UK (England)	National End of Life Care programme	www.endoflifecareforadults.nhs.uk/care-settings/carehomes information@eolc.nhs.uk	•	•	•	•	•		•	•	•		•	•
UK4	UK	Gold Standards Framework for Care Homes	www.goldstandardsframework.org.uk/GSFCareHomes		•	•	•			•		•		•	•
UK5	UK	Promoting end of life care in nursing homes using an integrated care pathway for the last days of life	Jo Hockley j.hockley@stchristophers.org.uk			•								•	
UK6	UK (Scotland)	Developing high quality end of life care in nursing homes: an action research study	Jo Hockley j.hockley@stchristophers.org.uk			•								•	
UK7	UK (Scotland)	The implementation of 2 end of life care tools in nursing care homes.	Jo Hockley j.hockley@stchristophers.org.uk	•	•							•		•	•