

Policy Department  
Economic and Scientific Policy

# PALLIATIVE CARE IN THE EUROPEAN UNION

This study was requested by the European Parliament's Committee on the Environment, Public Health and Food Safety. (Ref.. to IP/A/ENVI/IC/2007-123)

Only published in English.

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Manuscript completed in May 2008.

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## Executive summary

The need for and the justice of a dignified, painless, and peaceful death is a vital conclusion to the course of a person's life and care. Differing from other fields of medicine, where the aim is to cure or rehabilitate the patient, palliative care seeks to promote the quality of life and the reduction of suffering throughout the course of illness; the preparation for and management of life closure, the dying process, and death; and for the family, care into bereavement. The advantages of such care are obvious: death is a natural event, and the medical profession, which is virtually always present in these circumstances, must understand how to deal with it in a natural and competent way. The challenges, too, are evident. Palliative care is a multi-faceted field which should manage pain relief, symptom control, caregiver well-being, existential and emotional issues and grief counselling. Facing these needs in a coordinated, sensitive way requires a multi-disciplinary team for each patient, personally implicated in promoting quality of life and human dignity.

With the well-known demographic changes which are taking place in the EU, palliative care will be of increased importance in providing care for the ageing population. Raised to the policy level, this translates to a need to efficiently use resources (both human and financial) to guarantee the best possible quality of care. Professionals must be trained, care must be accessible, and patients must be consulted and respected. In order to achieve these goals in Europe, different aspects of the field must be studied, both at a national and international level.

This report evaluates palliative care development in the 27 Member States, particularly in recent years, analysing persistent challenges, highlighting national practices which might serve as a model for other European countries, and identifying channels for further advancement.

**Study objectives:** In October of 2007, a closed invitation to tender was issued by the European Parliament Committee on Environment, Public Health and Food Safety for an external study on palliative care in Europe to be managed by the Economic and Scientific Policy Department (IP/A/ENVI/IC/2007-082). The objective of the requested report was "to establish a clear diagnosis on where the European Union as a whole, and every member state in particular, stand in respect to the proper definition, organisation, offering, and financing of palliative care; analyse some selected examples of best practices, discussing applicability in other places; and finally, present policy options that both the EU and the Member States could consider to improve the present situation." These conclusions were to be presented in a draft report upon four months of signing the contract, and one month later, in a final report consisting of no more than fifty pages.

**Methodology:** In December 2008, Prof. Jose Martin-Moreno, a medical doctor and public health specialist from the University of Valencia, Spain, was commissioned to lead the investigation. He then invited Dr. Carlos Centeno and Prof. David Clark, two internationally recognised palliative care experts, to join the study. He also invited Prof. Charles Normand, for his expertise in health system economics as well as Dr. Lydia Gorgojo, Dr. Jose-Joaquin Aznar and Ms. Meggan Harris, to initially complete the Valencia-based team. Following some early communications within the team (including teleconferences, e-mails, and meetings), consensus was reached on an index for the study and the potential authors of each section. The research team, with the additional help of Dr. Lukas Radbruch (president of the EAPC), invited other prominent researchers to take part in the study, focusing on their area of expertise. A literature review was carried out to identify the most important studies in the field of palliative care, and articles were uploaded onto a closed intranet in order to share them with the international investigators. From Valencia, Dr. Martin-Moreno and his team proceeded to contact Ministries of Health and other health authorities as well as national and regional palliative care associations in order to gather primary information on palliative care service provision in the Member States (see annex for full responses received).

The primary and secondary sources recovered were then used to compose a preliminary draft of the areas of assessment and on the country reports. This draft report was then sent to the European Parliament for an initial review while undergoing further review by the research team.

The present document is a reflection of this process; while the time available to carry out the study was relatively short, the valuable studies already existing on palliative care in Europe greatly facilitated the investigation.

The first key area of analysis was the **availability of healthcare services**. The report defines the different modalities of care offered throughout the EU, including in-patient care (in hospice and hospitals), out-patient care, day-care centres, and home care, as well as the specificity of paediatric services. There is considerable variety in the type of care offered in different countries/regions, although home care is generally recognised as the best option when medical and personal circumstances permit it. In this section, too, **opioid availability** is described, along with the main obstacles blocking its ideal use. These obstacles include legislative barriers, inadequate professional training and patient and doctor fears and prejudice.

The next section briefly covers **integrated healthcare networks**, a term which refers to the coherent organisation of primary care services, social support services, clinic, and hospital organisations. Good macro-management is necessary to ensure that care is determined by patient needs rather than the care facility, and here, we highlight the issues relevant in the context of palliative care. These include flexibility, good communication among healthcare service providers, clear roles within the care team and innovative techniques such as telemedicine which can help improve equity and quality of coverage.

**Human resources** are also an important area to describe when speaking about any healthcare field. Here, we describe the traditional members of a palliative care team: Specialists, GPs, nurses, psychologists, social workers, religious and spiritual support workers, paediatricians and volunteers. These carry out a variety of tasks and require specific training to fulfil their duties, training which is not always well-defined in current medical programmes and professional curricula. In this section, we describe the training that exists and offer some ideas on how it could be improved.

It is precisely the improvement of services that is the topic in the next section, on **quality assurance**. This is especially challenging in the field of palliative care, given that both the goal (quality of life, not cure) and the approach (“body and mind” rather than purely clinical) are different from traditional medical fields. However, universally recognised quality indicators do not exist that can effectively analyse the efficacy of the palliative care approach. A few quality control systems that do exist are briefly described, such as the Edmonton Symptom Assessment Score, the German Hospice and Palliative Care Evaluation, the Schedule for the Evaluation of the Individual Quality of Life, and the Liverpool Care Pathway for the Dying. These can sometimes be problematic, as the subjectivity of symptoms (such as pain and distress as well as the frailty of patients) make evidence-based analysis difficult. However, **palliative care research** is ultimately the best way to improve care. Compared to other fields of medicine, clinical investigation in this field is scarce and faces significant operational challenges. Both the mission (formulating effective assessment tools to measure quality of life) and the means (human and financial) present difficulties which need to be addressed.

One example of how palliative care is different from other medical fields is the emphasis on **emotional support**, which is described in detail in section 2.5. This part identifies the needs of the patient, his/her family, the staff and a few special considerations for terminally ill paediatric patients and their families. We find that terminally ill patients are especially vulnerable to psychological disorders, existential problems, depression, and suicidal wishes.

Their families, too, need support to deal with loss and grief. Often this key role is carried out by a variety of team members which can include psychologists, social workers and faith leaders. These professionals not only have the responsibility of caring for the patients' and their families' well-being, but also the well-being of the care team, which face problems such as burn-out.

The section on **legal and policy provisions** highlights a few trends in national legislation and national policy regarding palliative care. These include the first legislative mechanisms used to introduce palliative care into the national healthcare system (recognition as a medical discipline and inclusion in national cancer control plans), some national policy tactics used to manage care, and targeted legislation dealing with specific issues, including euthanasia, social provisions for patients and their caretakers, professional training, and allocations for research. The implications for the palliative care field as part of a future public health strategy for Europe are also briefly mentioned, with considerations for cross-border health issues and patient mobility.

The last area of assessment is the section on **financial mechanisms**. There are several main systems of providing palliative care to European citizens, which are all described here. These include tax finance, publicly-mandated finance, charitable and non-governmental organisations, user fees, and mixed financing approaches, which combine some of these systems.

Finally, we analyse the **Member States** based on the above criteria, briefly describing the general status of palliative care development and detailing how these services are offered to citizens at the national level. There are no countries which offer no services; all of them have some degree of development which deserves to be studied in a more extensive way than the snapshot which is offered here. There is also a rating system, developed specifically for the purposes of this study, included in this report, which provides some (although not perfect) orientation on development relative to other Member States. While advancement in this field is certainly related to economic development, we find that it is not the only factor. There are considerable disparities between and within countries which relate to both quality and access to care. Divisions can be perceived along different lines: wealthy/developing, rural/urban, east/west, decentralised/centralised management, and specialist/generalist care. Addressing these inequities at a European level is imperative in order to ensure quality end of life care to all European citizens.

Following the country reports, we briefly identify a few **best practices** which may serve as models for care at a country level or in the EU, and then we move to the **conclusions and policy options**.

Among our conclusions are problems which need to be addressed regarding equitable service coverage, quality of care, and how national legislation can work as a tool to promote the palliative care field.

The **policy options** section describes three alternative approaches:

First, a passive approach which trusts that public health tools already in place (such as a patients' bill of rights or minimum waiting-time standards) are enough to foment the advancement of this field.

Second, a more active approach would be to lay out a set of recommendations to the Member States in order to improve palliative care. There are numerous options which include setting standards for training, relaxing strict opioid legislation, encouraging volunteer programmes, and formulating national palliative care plans.

Finally, a more prescriptive approach towards Member States would be to pass directives or other legislation which specifically deal with palliative care. This would certainly be useful in countries that have no plan in place; however, as previously stated, most countries do have some legislation dealing with the field, which could create problems in harmonising different monitoring mechanisms and other European-wide standards.



# **1. Introduction and history of palliative care in Europe and the world**

## **1.1 Origins of modern palliative care in Europe**

Palliative care in the context of advanced disease and end-of-life care in the final months and weeks of life represent the last phase of health and social care for citizens before their death. These are matters of huge importance which create enormous challenges for health professionals, patients, families, and policy-makers. The acceptance of death as an unavoidable outcome and the inclusion of it in a care system whose pre-eminent goals are cure and rehabilitation is a complex matter. When death is seen as a medical failure rather than a natural inevitability, then supporting end-of-life patients and their loved ones with their physical and mental needs becomes problematic. For most of the 20<sup>th</sup> century, this situation was the reality throughout the world. However, in the late 1960s this began to change. In 1967 Cicely Saunders founded St Christopher's Hospice in South London, the first modern hospice in England, combining clinical care, psychological support, education and research. This full "body and mind" approach was singular in its recognition of real patient needs, and provided a platform for innovative practice and service delivery that is now developing in many different forms around the world.

This new field of palliative care helped define, from a clinical point of view, the needs and problems of the terminally ill patient. Following the diagnosis of an advanced, degenerative, and irreversible disease and the prognosis of a limited life expectancy, both the patient and the medical team must recognise the futility of further curative treatments. However, physicians and caretakers have the duty not to abandon their patients, and patients have the right to expect appropriate care in their last days. Although most palliative care in Europe is provided to cancer patients, this is but one of many advanced pathologies that cause suffering and pain—dementia, degenerative neurological diseases, chronic cardio-respiratory disease, liver cirrhosis, AIDS, and chronic renal insufficiency vary in symptoms, prevalence, and complexity, but their sufferers share the need for quality of life, pain relief, professional support and kindness to themselves and to their loved ones. The aims of palliative care and the elements to be addressed are broadly agreed by experts in the field: 1) attending to physical, psychological, social, spiritual and practical expectations and needs; 2) providing support to the family through loss, grief and bereavement; and 3) preparation for, and management of, the dying process and death. This is most effectively delivered by an interdisciplinary team which may complement and enhance disease-modifying therapy, or alternatively become the total focus of care.

These principles have struck a chord in other healthcare settings and countries worldwide, and beginning in the 1970's, first services began to appear elsewhere in Western Europe: in Norway (1976) Sweden (1977), Italy (1980), Germany (1983), Spain (1984), Belgium (1985) and the Netherlands (1991). In Eastern Europe and Central Asia, there were few palliative care developments in the years of Soviet domination, with notable exceptions such as a volunteer hospice service in Krakow, Poland as early as 1976. The fall of the Soviet Union was followed by palliative care developments in Hungary (1991); Bulgaria, Romania, the Czech Republic and Slovenia (1992); Lithuania (1993); Estonia and Latvia (1997); and Slovakia (1999).

These developments were guided and supported first by national activists in grassroots movements. Within the larger context of a more united Europe, however, many professionals began to seek cohesion with their European neighbours, leading to the 1988 formation of the first European advocacy group, the European Association for Palliative Care (EAPC), which came into being in Milan with 42 founding members, and which by 2005 represented the interests of 50,000 health care workers and volunteers across 40 countries [1].

In 1999 the Eastern and Central European Palliative Task Force (ECEPT) followed this lead [2]. Other key organisations within the worldwide and European hospice movement include the International Observatory on End of Life Care, Help the Hospices, The International Association for Hospice and Palliative Care, and of course the World Health Organisation (WHO). Together, these organisations have been dedicated advocates of palliative care, acting as a focus for scientific, clinical and social interest in the field. Activities include gathering regional data on hospice and palliative care, sharing experiences of achievements and obstacles, influencing health authorities and government institutions, setting standards to meet provision needs, and raising public awareness. The valuable work carried out by these groups (especially articles, books, and other data), and particularly from the EAPC Task Force on the Development of Palliative Care in Europe, has been an instrumental resource in the formulation of this report.

## **1.2 Policy recognition at the European level**

European policy-makers, too, have been able to recognise the importance of this burgeoning medical field. In 1989 and 1992 the European Parliament adopted resolutions on counselling and care of the terminally ill. The 1985 *Europe against Cancer* programme also referred to palliative care, though this was never fully exploited. The Council of Europe's interest in palliative care development began with its 1980 Report of the European Health Committee on "Problems related to death: care for the dying" and continued with the Parliamentary Assembly Recommendation 1418 (1999) on "The protection of the human rights and dignity of the terminally-ill and the dying."

In 2001, the European Health Committee, in its most ambitious action regarding palliative care yet, decided to address the issue by setting up a committee of experts which, over a two-year period, prepared a set of European guidelines for the field. Its report - *Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care* was adopted on 12 November 2003 at the 860th meeting of the Ministers' Deputies. The report sees palliative care as an essential service for the whole population and acknowledges that in many countries the major part of health care budgets is spent on people in the last years of life, though it is by no means the case that they receive the care that is most appropriate to their needs. It notes the great differences in the availability and quality of palliative care throughout Europe and argues that these need to be addressed through increased cooperation between countries. Drawing attention to the need to support families and other informal caregivers, it sees home as often the best place for palliative care, but not always and not for everybody. It also encourages all countries to devise national plans for palliative care in close collaboration with professionals and representatives of patients and families and to establish at least one national centre of excellence in the field. These national plans share the need to be based on appropriate needs assessments. Good quality palliative care, like other health services, should seek equitable access and continuous quality improvement underpinned by appropriate research evidence, both in policy and practice. The report also highlights other elements which are more singular to this discipline, such as problems in opioid availability and insufficient attention in the medical and nursing curriculum.

These recommendations appear to have been used quite actively in some countries with less-developed palliative care systems, particularly in Eastern Europe, where they have served as a tool for advocacy and lobbying. Their wider impact on national policy making and service development is more difficult to measure, but there is no doubt that since their publication, there have been some significant advances in the field. Today there are no Member States without palliative care services, though admittedly some have only a handful of initiatives to serve large populations.

It is clear nonetheless that development in many places remains patchy, uncoordinated and poorly integrated with wider systems of health and social care delivery.

This reality was recently addressed during the European Conference on Cancer, organised by the Slovenian Presidency on 7–8 February 2008. The importance of developing EU standards and norms for inpatient palliative care units, hospital palliative care support teams, home care teams; taking up the multidisciplinary model developed in palliative care; and inviting member states to adopt the EAPC ‘Budapest Commitments’ were explicitly stated in the conclusions of the conference.

This report seeks to evaluate palliative care development in the 27 Member States, particularly in the last five years, analysing persistent challenges, highlighting national practices which might serve as a model for other European countries, and identifying channels for further advancement. Indeed, numerous public health programmes offer opportunities for the funding of projects on palliative care, care of older persons, exchanging best practices, training for health care professionals and networking of organisations.

## 2. Areas of assessment

### 2.1. Availability of health care and related services

The wide variety of palliative care resources is reflected in a burgeoning scientific literature as well as in many forms of service delivery whose structures have been created or adapted according to the characteristics of the national health system and the political, economic and social situation. In Europe, palliative care services offer inpatient care (in hospice, in free standing units of various kinds and in hospital), home care, day care, and outpatient care; these usually operate in close partnership with mainstream services. Hospices often house a full range of services and professionals for both paediatric and adult patients, and hospital-based palliative care services are ideally linked with the specialty services dealing with the specific problems of patients at the end of their lives. In general terms, however, care is usually divided into two groups: inpatient and home-based care. Given that some palliative care teams provide both hospital and home care, the boundaries between these modalities are fluid and sometimes unclear.

The definitions associated with these different palliative care units, likewise, can be oblique. Acute hospital beds reserved for palliative care, specialised palliative care units, hospices, nursing homes, and long-term residences are often described with different labels in different settings. Other singular forms of care have been developed in Europe which are also not easily categorised. In Holland, for example, Almost-at-Home houses fall between hospice care and home care, providing attention to patients in an atmosphere that imitates a home and is usually run by volunteers [3], and in some countries, such as the Czech Republic, there are “respite services,” which provide temporary in-patient care for paediatric patients as well as lodging for their parents [4]. Distinctive care models are found in each country according to local preferences and contingencies. The following section itemises the main modalities of care offered to European patients.

#### 2.1.1. In-patient (hospice and hospital) care

The **hospice** is a specific care centre for terminally ill patients, where the patients receive treatment (known as palliative care) to help relieve pain and other symptoms causing discomfort. They will also receive a great deal of tenderness, care and skilled attention from trained medical, nursing and support staff, as well as from volunteers. This institution is the most emblematic model of a specialised palliative care centre in many northern European countries, epitomised by the oft-cited St. Christopher’s Hospice in London. Scientific literature repeatedly describes the unique philosophy of hospice care as a place which cultivates harmony and peace and transcends the title of “healthcare resource” to act as an active element in patient care. “Hospice,” for many, has come to be synonymous with palliative care itself and is included in palliative care association names as well as descriptions of home care services. Although these centres are common in many European countries, in others they do not exist at all—some authors cite the negative connotation that the word “hospice” holds in Mediterranean cultures, one explanation of why this type of care is scarce in Southern Europe. In other countries, such as Germany, hospices exist but are not as specialised as hospital units. In general “hospice” captures an approach which seeks to add to the provision of the healthcare system by incorporating a wider view of patients and families and which forges a close link with the skills resources and social capital of local communities.

Despite the fact that most people prefer to die at home, up to two-thirds of the population (often suffering from cancer) spend their last days in in-patient units within **hospitals** that are poorly equipped to deal with terminally ill patients. For this reason the delivery of palliative care in hospital settings is an important priority for development. The hallmarks of palliative care — communication and coordination, combined with excellent medical care — ensure that hospital patients with access to palliative care teams have smooth transitions between the hospital and appropriate services, such as home care, nursing homes, or hospice.

The majority of in-patient palliative care in hospitals is delivered by specialist teams (with and without beds), located in oncology institutions or general hospitals. Some of these are centres of excellence which stand out for their integrated care approach and serve as a model for their region or country. Among these is the palliative care service at the National Cancer Institute of Milan (Italy). After progressive advancement, today it is a cancer centre with deep pools of resources, offering integrated care at all levels of disease development. In addition, it is the site of the EAPC headquarters [5].

Another common way to provide palliative care in hospitals is through **palliative care support, or consultant teams**. These are usually comprised by qualified physicians and nurses who counsel other specialists (such as oncologists or GPs), assisting them in patient care without a rigid structure or specialised unit. Flexibility and adaptability to different settings make this type of palliative care team the most efficient way to care for terminally ill patients, at least in acute care centres.

### **2.1.2. Day-care**

These centres are specific to patients in need of some palliative care support during the day. Such facilities are usually open between 3-5 days a week (patients generally go once or twice a week) and provide social and psychological support as well as nursing treatments, baths, dental hygiene and complementary therapies. The degree of care provided often depends on the individual centre; some are volunteer-based and others have a diversified staff with all types of healthcare professionals. This type of centre is relatively rare outside the UK.

### **2.1.3. Out-patient care**

Ambulatory services are an important aspect of the continuum of palliative care. These may be stand-alone services or can be incorporated into another clinic such as oncology or infectious disease. An outpatient palliative care practice can offer a range of services, from ongoing symptom management to liaison with specialists and other services, telephone help lines and follow-up for patients discharged from inpatient services. The varied needs of patients and families can be addressed through a multi-level practice. Almost by definition, patients in such clinics are seen earlier in the course of their illness and may be receiving both palliative and curative/restorative therapy, including chemotherapy or radiotherapy.

### **2.1.4. Home care**

These services address the reality that most citizens prefer to die at home; recognition of this fact has led to the constant improvement in quality of this type of care in Europe, resulting in more qualified and more experienced staff to provide care in patients' homes. Like other forms of care, this modality is characterised by a variety of denominations and services offered, from 24-hour nurse care to mobile teams that regularly visit patient residences. Currently, in countries with more complete palliative care provision, the tendency is towards achieving a fuller geographic and population coverage. Ireland is a good example of this trend; there, all counties have palliative care home teams that operate in their territory. In the UK, too, most regions are covered by acute-support home teams.

Other countries have not yet been able to achieve equitable home care coverage, especially in rural areas, although there are successful programmes, such as in Extremadura, Spain and West Cumbria, UK which have been able to address the challenges implied by rural home care.

### **2.1.5 Paediatric palliative care**

Providing effective solutions to the palliative care needs of children is not an easy task. Throughout, and even after, the course of the illness this requires the involvement of a multidisciplinary team of carers from across a variety services and institutions which together provide a single reference point.

Family-based home-care is what most families want and should be the model for all paediatric palliative care service providers. It gives the child the opportunity to participate in family activities, greatly diminishes distress, offers important opportunities for communication and allows the responsibilities of care to be shared among extended family members. International research demonstrates how home-care service networks, together with temporary residential (hospice) alternatives, supported by specialised teams, offer the most effective, efficient and viable palliative care solutions for children. When, for any reason, these options are not possible, the specialised paediatric hospice offers a solution; it is a vital link in the network, offering multifaceted care and a continual connection to home care services. To address the unique problems in paediatric palliative care service provision, the organisation of specific networks where expert paediatric interdisciplinary teams work in close collaboration with other local, primary-care networks and hospitals is ideal.

### **2.1.6. Availability of medical, palliative drugs (including opioids)**

Studies around the world have consistently shown that all types of pain (acute, cancer, and chronic non-cancer) are routinely under-treated. There are many reasons for this, including lack of knowledge about how to treat pain on the part of healthcare practitioners, patient and professional fears and misunderstandings of the medications that are used to treat moderate to severe pain (opioid analgesics), as well as national regulatory barriers that restrict the availability of opioid analgesics. These factors lead to a pronounced inconsistency in the degree to which pain management and palliative care are developed and to inequality between and even within countries in access to pain medication and treatment. There may be great differences in what is available between urban and rural settings, hospital and at-home settings, and in the quantity of drugs prescribed. In general, opioid consumption data shows that opioid use and availability in Europe is higher than in most other countries throughout the world (although there is room for improvement), but these data also show significant variations *between* European countries (see Table 1 on opioid availability).

Although the recent introduction of fentanyl, oxycodone and hydromorphone, along with other transdermic and oral formulations, has greatly increased the range of products in Europe for opioid medication (traditionally morphine, codeine, tramadol, and methadone), certain drugs and/or formulations are not found everywhere. In France, for example, where palliative care is identified as a “right,” methadone was not available until 1995 [6], and in many countries, neither oxycodone nor oral methadone are among the available opioids (see Table 1).

Availability and use do not necessarily go hand in hand and research in this field shows that despite a wide variety of cheap and available opioids, consumption levels are sometimes variable even between neighbouring countries. This has been found to be the case in Belgium [7] and in Finland [8]. In Holland and Sweden, where drugs are freely available and prescription policies are liberal, consumption is also lower than the regional average.

One evidence-based explanation is that despite clear recommendations from the WHO regarding opioid prescription to treat pain for cancer or other advanced pathologies, reticence among physicians to prescribe strong opioids impedes proper pain management.

Another pending challenge in this area comes from bureaucratic limitations to opioid use—measures which include requiring forms to be filled out in triplicate, charging physicians for special prescription forms, limiting the quantity of drugs that can be prescribed at once, sending patients to other offices or institutions, or setting quick expiry dates for the prescriptions (see Table 2 on bureaucratic restrictions). In this respect, the most positive references have been found in Germany, Denmark, and the Netherlands, where there are few restrictions which differ from other medications.

Despite the many signs of discontent regarding opioid legislation in Europe, some researchers are generally satisfied with the situation in their countries. These include Germany [9], Bulgaria [10], Slovakia (where administration is free and use is rapidly increasing) [11], Spain [12], Hungary (although morphine and oxycodone are not free like the rest of the opioids) [13], Italy [14], Latvia [15], Lithuania [16], Poland (where they are free to cancer patients) [17], and Sweden [18].

## **2.2 Integrated Healthcare Networks**

While there is abundant literature on making healthcare programs integrated, interdisciplinary and managed in order to reduce fragmentation and improve continuity and coordination of care, only some part of this relates to palliative care issues.

Integrated Healthcare Networks (IHN) can be defined as primary care services, social support services, clinic and hospital organizations that have integrated in a coherent way into one system. Health systems that are successfully integrated and well managed see efficiencies in operations, cost-control opportunities and an increased ability to reach a larger population with their services as a result of integration.

In rural areas or where resources are scarce, the development of operational forms of interaction could be particularly relevant - such as interdisciplinary and team-based work with flexibility of roles and responsibilities, delegation of tasks and cultural adjustments [19].

In addition, programs such as integrated and managed care pathways, outreach programmes, shared care and telemedicine are relevant initiatives. These may be associated with greater equity in access to care, and more coherent services with greater continuity, but they are not necessarily linked to reduced costs; they may, in some cases, entail additional expenses. Such endeavours are, to a large degree, dependent on a well-functioning primary and secondary healthcare system as a base.

Greater flexibility in traditional professional roles and responsibilities, such as nurse practitioners or community pharmacists managing common conditions, is sometimes a temporary solution in order to alleviate a scarcity of personnel and resources [20]. Empowering primary-care practitioners by training and education combined with support and supervision, or generalist providers, particularly community and home-care nurses, have been in some cases successful in the delivery of primary palliative care [21-22].

The community hospital varies as to what services are provided, but usually has a core of GP inpatient beds, while some have consultant long-stay beds, primary care nurse beds or delivery beds run by midwives. Community hospitals may also play a role in palliative care, outpatient functions including day case surgery, specialist clinics and in telemedicine including teleradiology. It is also reported that telemedicine may contribute to acceptable services in palliative care and cancer treatment programs in remote and rural areas [23].

To summarise the need of proper integration, and as we previously mentioned, hospital-based palliative care services should closely work with the specialty services dealing with the specific problems of the patients at the end of their lives. This could also be interrelated to hospices and primary care services. In a nutshell, the idea is to ensure a proper transition to meet patient needs, using the whole range of possibilities, primary and inpatient care (hospice and hospital) as well as outpatient care, day care or home care, while taking into account the best possible options for each patient and in each context or circumstance.

## **2.3 Human Resources**

### **2.3.1 Specialist training for palliative care**

Palliative medicine is the medical discipline within the larger interdisciplinary field of palliative care. The rationale for the development of this new physician subspecialty is no different than for the development of other subspecialties—to make new knowledge practically available to patients, families, and their doctors, to guarantee its quality when treating patients, and to establish the minimum competences to be achieved by the doctor who is developing his or her skills in that field. The working field of palliative medicine is the patient with advanced disease and a limited prognosis, and where the focus is on the relief of suffering and the promotion of well-being as well as quality of life for the patient, family and loved ones. The body of knowledge, more complete now than ever before [24], relates to the control of pain and other symptoms; the holistic approach to social, emotional and spiritual needs; family care, including in bereavement; and, finally, interdisciplinary and team working issues. Indeed, doctors in this field must work closely with other professionals, most often in a supporting or consulting role, adopting a multidisciplinary approach that is ethically and professionally competent and which makes use of the necessary skills to evaluate and assist in complex situations of advanced and terminal illnesses.

There are different ways of certifying medical professionals; depending on the quantity of training, physicians might earn a specialist or sub-specialist certification. In Europe, full specialty status exists only in Great Britain and Ireland, while Poland, Romania, Slovakia, Germany, and France currently offer a subspecialty [25]. Furthermore, in 10 additional countries there are discussions and actions in progress relating to certification in palliative medicine; these developments are most advanced in the Czech Republic, Norway and Sweden. The certification process has also started in Finland, Iceland and Spain, and in Latvia, palliative medicine is certified as a specific area and work is being carried out to achieve sub-specialty certification. In Spain and France, the relevant qualification is referred to as a ‘specific area of competency’. Elsewhere the evidence is less clear, but there is information to show that there are at least postgraduate courses or university diplomas in Italy, Lithuania and Portugal. In Belgium, Hungary and Luxembourg, there are courses offered by different organizations.

This great disparity in the certification criteria for palliative medicine throughout Europe may need to be addressed in order to achieve the goal of fuller integration of palliative care within health systems. There is clearly a need for more informed debate about what level of certification is most appropriate for palliative medicine, including discussion of how a medical specialty or sub-specialty stimulates the overall development of the field. Formal recognition of the subspecialty of palliative medicine would set standards on which other specialists could rely to improve care for all patients and would also foment more development in the field by acting as an incentive to professional growth.



### **2.3.2 Basis training for General Practitioners (GPs)**

While advanced specialist training is clearly important, more basic and intermediate training for general practitioners and other specialists must not be neglected. Palliative care concerns the whole population and begins long before the terminal phase, when highly specialised care becomes more important. Indeed, only a low percentage of patients require specialised treatment at a given time, and many are accompanied by their family doctor from diagnosis until death. In order to provide palliative assistance early on in the illness and avoid complications and prejudices (opiophobia, death denial, difficult communication with the patients), all physicians need to understand the basic principles of this field. Furthermore, these competencies (acute and chronic pain management, announcing bad news, communication skills with patients and relatives) are not limited to palliative care, but enrich patient care in all settings. Progressive development of basic training for GPs would have a significant effect on overall patient care in all countries, and especially where a palliative care specialty does not exist. Ultimately, it would also act as a springboard for future development of the field.

Despite recommendations from the EAPC on teaching/training which have existed since 1992 (current guidelines can be accessed through the EAPC website [26]), a high degree of heterogeneity in graduate and post-graduate medical curricula is evident throughout Europe. The EAPC defines three levels of training for physicians: basic (for GPs), intermediate (for relevant specialists such as oncologists or neurologists, and specialised (described in the previous section). Only in France is there a national policy mandating a palliative care seminar to those seeking a medical degree, but even there, the number of course hours and the knowledge of the instructor varies greatly. In other countries, universities have the responsibility of organising care, and in many places (especially in Eastern Europe), palliative care is not featured in the medical curriculum at all. Given the different levels of palliative care development in the Member States, these disparities are logical, but in the context of a united Europe (where physicians can work abroad), some standard guidelines are appropriate.

Experts recommend an interactive approach based on group case studies, role playing, and mentorship. Multi-disciplinary knowledge of instructors and clinical experience for students is ideal. Courses should also include home care training—development of this modality has been shown to reduce costs for health systems as well as fulfilling patient wishes to die at home. Forty hours has been established as a desirable length for a basic course on palliative care in the last years of medical school, but some subjects, such as communication or bereavement support, could also be introduced in the pre-clinical years [26, 27].

Palliative care specialisation (or at least extensive clinical experience) for professors is ideal to ensure quality palliative care education even at the basic level—academic chairs are one key in overseeing general education and stimulating research and development in the field. Many countries do not have academic chairs in palliative care, and there is no clear trend that chairs are emerging in general [28]. Mandatory undergraduate education in palliative care, as part of a harmonised public health approach for Europe, would be one of the most effective measures to improve end of life patient care. While some countries do not have the human resources to implement these plans immediately, a realistic timetable for doing so, coupled with international cooperation, would be an excellent step forward.

### 2.3.3 Nurse training

While the evolution of general nurse training in Western Europe has led to a more academic focus (from a skills-based approach), training in Eastern Europe continues to be sporadic, haphazard, and inconsistent; the same is true of palliative care nurse training. Although the importance of nursing on the historical development of the palliative care movement is unquestionable [29], there have been few attempts to specify competencies and define the necessary training for this discipline. The concept of Palliative Care Clinical Nurse Specialist or Advanced Nurse Practitioner, which has demonstrable outcomes in terms of benefits to patients and services [30], is not well developed outside the UK and Ireland. Other problems, such as personnel mobility, access to learning materials and literature (most often available only in English), and limited career paths also limit development [31].

This said, there have been a number of developments in palliative nursing education at the European level in line with the goals of the W.H.O (2002) “approach”-based definition [32], including EAPC guidelines for palliative nursing education [33]. These offer suggestions as to content, knowledge and skills required to achieve a certain level of practice and have served as a basis for both undergraduate and postgraduate nurse education in 11 EU countries including the Netherlands, Belgium, Italy, France and Luxembourg. Of the three levels defined in the EAPC guidelines (basic undergraduate and postgraduate, advanced postgraduate, and specialist), usually only the first is easily available to nursing students. In addition, the fundamental position of palliative care in the curriculum is widely variable in terms of number of hours, content, and the expertise of the teacher. Clearly, evaluation of palliative care education remains weak, and a rigorous research agenda to address this is warranted.

According to EAPC guidelines, palliative care nurses should be able to demonstrate competency across five domains of nursing practice; the patient, the family, teamworking, societal aspects of care and the interface with the local health system. Advanced training should simultaneously bring about a deepening of exposure to the theoretical and clinical elements of the discipline, taking into account the need for self-awareness as a practitioner facing the deaths of others and its impact, the need for clearly channelled communication and the ethical dimension which underpins best palliative care practice. In demonstrating their competence, the palliative care nurse must be able to demonstrate the ability to observe, assess, instigate a response to patient need and evaluate its success or otherwise in every case and at every level according to experience and training.

The development of skills should focus (at the basic level) on the comfort measures that can be undertaken to alleviate and soothe, rather than necessarily treat, for example, the attention to mouth care, positioning, pressure area care and fluid balance. It is particularly important to develop training at this level in a more cohesive way. The advent of the internet and on-line learning has been shown to be a useful tool—at least one U.K. nurse educator has developed a successful on-line programme for nurses working in developing countries. At the advanced level<sup>1</sup>, there should be a stronger grounding in the wider clinical aspects of pain and symptom assessment and treatment, as well as skills to address the complexities of family care. For specialist nurses, those skills should be practiced in dedicated palliative care units where the shift may be based on degrees of autonomy and the ability to make clinical decisions independent of other practitioners.

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<sup>1</sup> It should be noted that the level B guidelines were developed with the needs of a nurse who may act as a local reference person (for example, in a nursing home), as well as someone working in a non-specialist clinical area.

At a European level, engagement with nurse educators around the development of curricula which responds to the professional needs of nurses and the care needs of patients and service users is the next step to an integrated palliative nursing education programme for Europe.

#### **2.3.4 Special training for paediatric palliative care**

Only a carefully and adequately prepared care team can provide the professional solutions to the needs of families of children with terminal illness without diminished professionalism and suffering 'burnout'. All the care team members must receive, in addition to specific technical preparation, formal training in communication techniques, in particular how to break bad news to families and negotiate care objectives and care programs. Team building skills; knowledge of the different stages of cognitive and physical development in children and the different approaches thereby necessary; understanding of the clinical, psychological and relational problems that chronic illness and death determine in the child and the relative solutions for treatment, and how to identify and manage physiological and pathological symptoms of bereavement are also key areas.

It is important that the care team includes as part of their care program the review and discussion of cases of deceased children under the guidance of professionally trained counsellors who can help the care team to cope with emotive and decisional issues resulting from bereavement. It is also important that expert support is provided for those dealing for the first time with terminally ill children.

#### **2.3.5 Social workers**

Social workers' role in palliative care focuses on evaluating and managing the needs of the family: their capacity to deal with illness, caretaking, financial difficulties, organisational issues, disputes about treatment, family crises, grief and loss. In order to help families confront these difficult issues, a social worker needs to be knowledgeable in family mediation, crisis intervention and the stages of grief, as well as social support networks and basic methods of social research. Social workers also have a key role in organising and coordinating volunteer work in palliative care services.

The foundation for these skills is laid early. While there is not usually any specific palliative care training at an undergraduate level, general preparation in crisis management and individual/ community problem solving in the face of loss (economic or human) is a good basis for social work in palliative care and has traditionally been complemented by multidisciplinary palliative care courses. Indeed, university degrees in social work (present in most European countries) have favoured the overall improvement of social services throughout the continent, progress which has continued to develop with the appearance of a more specialised Masters in Social Work. Post-graduate education in palliative care is normally taught in the course of Clinical Social Work, although the development of a palliative care Masters in Social Work is also underway in some countries. These courses should expand on the content mentioned above as well as provide extra training in teamwork, management of social programmes, research and application of research findings, and knowledge of the basic symptoms of advanced and terminal illness. Especially encouraging in this aspect is the work being carried out by an accreditation agency created by several European social work associations, the "European Network for Quality Assurance in Social Professions" (ENQASP), which is working to standardise curricula and quality at a European level.

#### **2.3.6 Training for psychologists**

The specific role of psychologists in palliative care is covered in detail in section 2.5 of this report. Here we will provide a general outline of the training needed to perform these functions.

In Europe, palliative care psychology is not a well-defined field. In some universities, it is included as a subject in broader programmes such as health psychology, chronic illness psychology, or gerontology [34, 35]. Most attempts at a standardised curriculum for palliative care psychologists (initiated in large part by the EAPC and other palliative care associations [36, 37] have adopted criteria on competencies, skills, and content from similar fields, such as psycho-oncology [38-41] or medicine [42]. These are in line with European directives, which have established two levels of training complexity for psychosocial work, basic and advanced [36]; these should be ideally complemented by continuing education to ensure that professionals keep up with the field and consistently provide innovative techniques to patients.

**Basic training** would require a minimum of about 40 undergraduate hours to teach the key concepts of palliative care for psychologists who are not specifically dedicated to the field. Biomedical and psychological aspects of advanced illness and symptom control would be included in the curriculum along with communication skills, emotional needs assessment, and bereavement support.

These competencies would be further developed in **post-graduate education** for those working full-time in palliative care. An advanced course (about 2 years or 600 hours, including advanced apprenticeship) would have to encompass, in addition, detailed courses on oncology and other terminal pathologies, including symptom management, as well as psychopharmacology, psychotherapy, bioethics and counselling. The palliative care psychologist has a central role within the multi-disciplinary team—not only does he or she have to comprehend the physical needs and manage the psychological health of the patient, but also of the family, caretakers, and palliative care staff, who, without proper training and support, can suffer from burnout and emotional distress.

### **2.3.7 The role of volunteers**

Volunteering in palliative care is a measure of a community's support for people at the end of life and also the subject of considerable government interest as attempts are made to rekindle engagement and trust in civil society and to achieve social integration in multi-ethnic, multi-cultural, multi-faith contexts. As well as enhancing service provision, volunteers can help to mobilise local support, be involved in income generation and cost savings, ensure a variety of community representation and normalise death, dying and bereavement. When they return to the communities in which they live, they can influence public attitudes and the skills they acquire and contribute to general community well-being and cohesion. Individual volunteers also gain confidence and skills and reap the benefits of social citizenship. In short, volunteers in palliative care should be seen as a key element of social capital. This capital is not always adequately exploited, even in countries where there are many volunteers; often there is not sufficient consensus on what their role should be, leading to some degree of confusion within the multi-disciplinary team.

Volunteers can undertake diverse roles and tasks in palliative care services, either related to clinical care (personal care, offering practical support to patients at home, bereavement support) or non-clinical areas (education, administrative support, fund-raising). In order to fully integrate the work of the volunteer with the multi-professional team, careful selection, induction, training, supervision and support is needed.

The future development of palliative care volunteers in Europe needs to embrace the challenge of creating equal access to volunteering opportunities. In the UK, for example, 37% of refugees and asylum seekers use this route to take their first steps to integrate into society, but volunteer service is less common in Southern and Eastern Europe. Accredited and externally recognised training is important both to ensure quality and to recognise volunteer contributions.

## 2.4 Quality assurance

With a more rapid increase in development and implementation of palliative care in Europe in recent years, new players have got involved in its provision. For patients and their families it will be paramount to ensure that quality is maintained and improved whilst coverage increases. The WHO definition of palliative care requires early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual [43] problems, clearly aiming for the highest quality.

However, the WHO definition has been criticised precisely in this regard. The request for perfect work may need to be put in the realistic context of daily routine. A differentiated approach to quality in palliative care is required. Following Donabedian [44], quality should be related to structural attributes as well as to processes and outcomes of care.

Palliative care has been described as “intensive comfort care,” or a “high person, low technology” approach. The staff to patient ratio in most palliative care services then must be higher than in other kinds of services. Multiprofessional team work is mandatory for specialised palliative care, with at least physicians and nurses, and preferably other professions such as psychologists, social workers, physiotherapists and chaplain included.

Structural quality can be described with the ratio of nurses and physicians per bed, the number of professions in the team and the percentage of team members with palliative care qualifications. For a public health approach, criteria for structural quality would be the population served, the area of coverage and the availability of 24-hour on-call service. However, better structural quality does not necessarily produce a better outcome, as engagement and enthusiasm or volunteer work can contribute significantly to the outcome of resource poor teams. In a nationwide survey in palliative care units in Germany, more staff was not correlated with better outcomes (Fig. 1) [45].

Procedural quality in palliative care is difficult to assess because there are no diagnostic or therapeutic procedures that are unique to palliative care. Some treatments that are deemed typical of palliative care services such as the use of very specific drugs are required only in a small percentage of patients. The holistic and empathic approach so central to palliative care is difficult to assess. Possible options for the assessment of procedural quality are the use of standardized documentation systems, regular multi-professional case conferences, as well as multi-professional visits or ward rounds. As the availability and use of opioids for pain management in palliative care is still a major obstacle in many European countries, the percentage of patients with severe pain but who are not receiving opioids (according to the so-called ‘Pain Management Index’) has been used as a conservative marker of inadequate cancer pain management [46]. For a public health approach, the amount of opioids used in a country has been recommended as a marker of procedural quality.

Economic calculations for palliative home care have argued that cost increases for home care teams will be balanced by fewer costs for inpatient treatment, as inpatient treatment often is triggered by insecurity and anxiety of patients, families and non-specialised physicians. Palliative home care should enable patients to stay home if they so wish and avoid inpatient admission. In consequence less inpatient treatment days in the final year of life has been discussed as an indicator of procedural quality in palliative care. However, this line of argument does have an inherent danger, as patients may be denied inpatient treatment in a palliative care unit even if it is indicated, when staff do not want to endanger the predefined goals.

Outcome can be assessed with checklists for physical symptoms and psychosocial and spiritual problems. The Rotterdam checklist questionnaire or the Edmonton Symptom Assessment Score (ESAS) [47] have been used in large surveys. Considering the subjective nature of most symptoms and problems, self-assessment from the patients would be preferable. However, many patients with advanced disease are frail; without appropriate support they may find it difficult to answer questionnaires and checklists. For these reasons, documentation systems in palliative care often rely on assessment by staff, which shows adequate though not perfect correlation with patients' self-assessment.

More comprehensive than symptom checklists, quality of life assessment has also been used for palliative care. Health-related as well as disease-specific questionnaires have been recommended. The European Organisation for Research and Treatment of Cancer (EORTC) has recently released a quality-of-life questionnaire for cancer patients receiving palliative care with 15 questions (EORTC-15-PAL) [48], although this kind of research is still in its beginnings. A more individual approach is offered by the Schedule for the Evaluation of the Individual Quality of Life (SEIQoL) [49].

More complex evaluation systems have been offered with the German Hospice and Palliative Care Evaluation (HOPE), the Palliative Outcome Score (POS) and the Liverpool Care Pathway for the Dying (LCP) [50-52]. These systems try to integrate assessment and documentation with quality assurance and audit measures.

HOPE offers a benchmarking to participants of the yearly 3-month survey [50]. Figure 2 shows the percentage of patients discharged at the end of inpatient treatment, with lower percentages signifying more patients dying in the unit. The percentage of discharges is higher in oncology units compared to palliative care units, with hospices treating most patients until death.

POS and its predecessor Support Team Assessment Schedule (STAS) include a patient and a staff version of a concise questionnaire, covering pain and symptom control as well as other dimensions such as the time spent waiting for treatment and general well-being [51].

The LCP was developed to extend the hospice experience into non-specialised service settings and hospitals in particular [52]. Patients should be registered into the LCP when life expectancy is estimated at 48 to 72 hours. The care pathway includes checklists on reduction of burdening therapies, communication and information with carers as well as checklists and algorithms for symptom control. The LCP is provided in an audit procedure, with needs assessment and training in the beginning and re-evaluation by external auditors after a predefined period of time.

However, only a few randomised controlled trials have evaluated the efficacy of palliative care compared to non-specialised care. These studies have found few differences in pain or symptom control or in quality of life between the groups [53-55]. This highlights the difficulties in assessing quality in palliative care and contradicts widespread clinical experience that attests to the benefits of palliative care orientation. The discussion on optimal outcome indicators is still open, with several research units and collaborative groups currently investigating this field. Because both the end-point (palliation and not cure) and the approach (global care rather than concrete procedures) are different than in other medical fields, new quality indicators have to be identified. For example, family satisfaction one month after the death of the patients was significantly higher when patients had received palliative care compared to the control group [56].

For a public health approach, the percentage of patients dying at home has been suggested as the optimal quality indicator, as most patients want to stay at home until death. However, as with inpatient admissions, this may reduce inpatient treatment (even in palliative care units) that would benefit the patient. A large US survey found that whether or not people die in hospital is powerfully influenced by characteristics of the local health system but not by patient preferences or other patient characteristics [57]. Hence, the use of death at home as a quality indicator is dependent on the availability of a complete and integrated palliative care network.

In conclusion, quality assurance in palliative care is necessary, but the discussion on the optimal quality assessment and monitoring is still open. Systems with benchmarking or audit cycles offer a chance for ongoing development and critical appraisal of strengths and weaknesses of the service. We should aim to better characterise quality as the result of healthcare policies, of doing the appropriate things in the appropriate way, of the image of the organisation as perceived by the users (patients and relatives) and providers, and of the definition of the service by ensuring the existence of standards of quality care that are continually updated [58].

#### **2.4.1 Palliative care research**

Despite the natural acceptance of research as an integral element of all fields of medicine and health care, the place for research in palliative care has been a cause of considerable debate. The objections stem from the fragility of the patients, the complex pattern of symptoms (distress and suffering), the ethical dilemma proceeding from clinical trials on dying patients, and the lack of valid and reliable outcome measures. Furthermore, it has been argued that dying should not be integrated into a research agenda. These concerns have contributed to a pronounced scarcity in quality research which today most clinicians lament; the majority of publications on palliative care research have been of descriptive/observational nature, and few randomized controlled studies have been published [59]. Currently, palliative care experts advocate more research, arguing that the fragility of patients and the complexity of cases should encourage rather than discourage further investigation. While there are obviously ethical issues which must be addressed, eluding them by not trying to improve end-of-life care is not a solution. At the same time there is rich potential for studies which do not require direct patient involvement, but which focus on the audit and evaluation of care, as well as research on service configurations, costs and models of delivery. Despite the problems, there is a growing constituency of researchers working in palliative care in Europe and this has been much strengthened by collaborations between clinicians, social scientists and health services researchers, as well as basic scientists. Palliative care has done a great deal to foster inter-disciplinary approaches to research problems using a mix of qualitative and quantitative methods and acknowledging that the complex interventions that make up palliative care require sophisticated and sensitive research designs.

The WHO Regional Office for Europe recently published *Solid Facts: Palliative Care*, describing several gaps in research on effective palliative care [60]. Research on the aetiology and treatment of non-cancer pain and symptoms, barriers to accessing care, and the care of patients with diseases other than cancer is urgently needed. Other areas needing more in-depth study include the care of older people and those from different cultural groups, the social, psychological and spiritual aspects of palliative care, and the development of assessment tools. A continuing challenge for researchers is how to study and determine needs in a sensitive way and how to synthesise patients' and relatives' views with other evidence to find effective solutions. Better use of existing data on palliative care and the development of mechanisms to routinely monitor emerging needs and quality of care are also necessary.

Useful areas for international comparison include variation in models, costs of care, and spending on palliative care services. An important question is how indicators could be meaningfully used to compare care. These might include morphine use, the proportion of non-cancer patients cared for, the proportion of patients who die in pain, and palliative support for patients in nursing homes [60].

A recent review on research in Europe reports the small number and precariousness of research groups [59]. Data in scientific literature on research centres in European countries are very limited and usually refer to well established institutions that have managed to develop their own programs, such as groups in Aachen, Belgium, Barcelona, Budapest, Milan, Lancaster, London, Palermo, and Trondheim. At a European level, particular attention has to be paid to the activities of the European Association for Palliative Care Research Network (EAPC RN) [61], which has taken a leading role in fomenting palliative care research collaboration within Europe. This group has developed and published guidelines and position papers of experts in scientific journals and has collaborated in establishing palliative care-oriented scientific journals, moves which have significantly contributed to the increase of best practices in the field [62, 63]. The EAPC RN also hosts a well-attended semi-annual conference on research in palliative care, with the participation of researchers from around the world.

Funding is another unresolved matter for palliative care research in Europe. In the United Kingdom, where palliative care development has reached the highest level in Europe (including the existence of large research centres), only 0.18% of the oncology research budget is invested in palliative care, as opposed to 0.9% for the United States [64]. Few Member States provide sustained funding for palliative care research, and outside the UK there are few academic chairs in palliative medicine, palliative care nursing and other related academic areas. Other challenges include the need for an international research agenda and international collaboration, continuous funding, training clinicians in palliative care research, and offering them positions which combine clinical commitments with research [65].

The attention to palliative care research from national or European institutions and organisations is quite recent. It is striking that scientific literature includes no references to official support before 2005. New initiatives are emerging, however; for example, with support from a consortium of contributors led by the National Cancer Research Institute, the UK has established two innovative research collaboratives in supportive and palliative care: the Cancer Experiences Collaborative (CeCo) [66, 67] and Collaborative Complex Assessment, Trials and implementation of Services (COMPASS) [68]. Plans are also underway to create an all-Ireland Institute for Hospice and Palliative Care that will seek to promote research across the two jurisdictions of the Republic of Ireland and Northern Ireland [69]. In 2006, during the sixth framework the European Palliative Care Research Collaborative (EPCRC), several Specific Targeted Research Grants were founded under the heading of Cancer [61]. A year later, the European Commission's executive agency for the Public Health Programme (PHEA) funded the EUPHEA in order to identify the best practices in palliative care in Europe. Recently (in 2008) two grants have been funded within a specific call of the 7th Framework on end of life care: Reflecting the Positive Diversity of European Priorities for Research and Measurements in End of Life Care (PRISMA); and Optimizing Cancer Patient Care Through the Advancement of Research and Education (OPCARE).



These efforts reflect the growing acceptance and support of research in the palliative care context and prompt the question of what future support is necessary. In summary, several areas could be recommended for policy-makers and research funders: a) development of national strategies for palliative care research and expansion of investment in this area across all diseases; b) investment in developing national data sets for palliative care; c) monitoring of research funds to ensure proportional funding for palliative care; and d) encouragement of innovative research (ideas that are most likely to make a difference in practice) to help people with serious chronic illnesses to live and die well [60].

## **2.5 Emotional and spiritual support**

Optimal palliative care includes not only the use of proper medical and therapeutic interventions but also psychological interventions. As part of the palliative care team, the psychologist, social worker, faith leader or counsellor plays a critical role that extends beyond the management of the psychological symptoms and syndromes of patients into areas that include existential issues, family and caregiver support, bereavement, doctor-patient communication, education and training [70, 71].

### **2.5.1 Patient needs**

Diagnosis and treatment of advanced diseases such as cancer provoke a series of dramatic changes (physical, psychological, spiritual and interpersonal) that affect the patient and his or her family as well as their loved ones [72]. The majority of studies show alarming prevalence rates of up to 85% of psychopathological disorders, namely depression, anxiety and cognitive disorders in terminally ill patients [73]. Functional changes and the emergence of physical symptoms, then, coexist with a lot of emotional, social and spiritual effects on the individual, including the impact of loss and the challenge of facing impending death [74]. Hopelessness, loss of meaning and existential distress, disability, bodily disfigurement, fear of loss of dignity, social isolation, feelings of greater dependency on others or the perception of being a burden are also common in terminally ill patients and characterize a state of demoralization [75]. Patients with terminal illnesses, such as advanced cancer, are particularly vulnerable to psychiatric disorders and complications [70, 76-79] as well as suicidal wishes, often expressing the desire for a hastened death or assisted suicide (see Tables 3 and 4) [80-93].

A range of psychotherapeutic interventions [84-98] has been demonstrated as quite effective and useful for patients struggling with advanced life threatening illness [99]. Their primary aims are to reduce psychological symptoms and improve quality of life and wellbeing through: a) establishing a bond that decreases the sense of isolation experienced with terminal illness; b) helping the patient face death with a sense of self worth; c) correcting misconceptions about the past and present; d) integrating the present illness into a continuum of life experiences; e) exploring issues of separation, loss and the unknown that lies ahead; f) helping the patient mobilise inner resources by emphasizing past strengths and supporting previously successful ways of coping; and g) helping the patient to modify plans for the future, and perhaps even to accept the inevitability of death. [99]. These interventions should be directed towards both patient and family [100], including spiritual counselling and clinical procedures.

Spiritual care for the dying patient is, like other elements of palliative care, best provided through a multidisciplinary team, which may also include a chaplain [101]. One southern European study highlights the protective role that spirituality/faith plays among most cancer patients (80%) towards psychological morbidity as well as how they deal with illness [102]. The great interest in spirituality, faith, and religious beliefs and their role in palliative care point to the need for the development of interventions [103-109] that address emotional distress and “spiritual suffering” [99].

Strengthening relationships with loved ones, relieving burden, and achieving a sense of spiritual peace have been identified by patients with advanced cancer as among the most important facets of end of life care [110].

In addition to counselling and psychotherapeutic interventions, a psychiatric intervention may be required to deal with neuropsychiatric symptoms and syndromes such as mood disorders (depression), cognitive impairment disorders (delirium), anxiety, insomnia, and suicidal ideation. Two main clinical strategies are used: the first is a symptom management approach, including use of psychotropic agents to treat symptoms rather than specific syndromes (e.g., neuropathic pain, insomnia, appetite, nausea, anxiety); the second is a syndrome-based approach, including use of psychotropic agents to treat a specific identifiable syndrome (e.g. major depression or anxiety disorders). Depending on the specific clinical presentation both approaches can be used [99].

### **2.5.2 Family-oriented support**

Psychological symptoms and psychiatric disorders must be understood in the context of the patient and family as the unit of concern [111], and the impact of the patient's disease on the family merits special attention, particularly in palliative care [112]. Family caregivers struggle with their own losses and changing roles while dealing with their concerns about their care giving abilities [113]. A literature review [114] identified 11 separate issues of concern for family members: emotional strain, physical demands, uncertainty, fear of the patient dying, altered roles and lifestyles, finances, ways to comfort the patient, perceived inadequacies of services, existential concerns, sexuality and non-convergent needs among household members. Family members are often referred to as "second order patients" [112, 115] but they are also "second-order therapists" in that they provide the majority of care to their relative [112]. Therefore, caregivers may experience severe mood disruption, such as depression, anxiety and fatigue [116].

To alleviate stress, overall burden and associated depression, the most important element that interdisciplinary palliative care can provide is good **communication** [117]. In an end of life study across three European countries, severe communication problems were found among up to 40% of cases [111]. Three main areas are particularly important: a) empathetic information giving from professionals to patients; including the essential disclosure of diagnosis as a critical communication issue (highly influenced by cultural factors) [118]; b) communication between the patient and their family regarding end-of-life issues and; c) communication between the different professionals involved in care, such as between doctors and nurses and between community and inpatient settings, to avoid contradictory or redundant information and ambiguity [111]. Evidence suggests that good communication skills are of critical relevance in palliative and cancer care and specific training programs for oncology health professionals have been developed and recommended to be part of their routine education [119].

Supporting the family during the process of **bereavement** is also a central issue. Although grief is a normal reaction to a loss of a loved one, support during this process should not be neglected [112] as a way to prevent pathological process. Thus bereavement care is considered an important part of palliative care [99]. Actively listening to the person, allowing expression of the feelings that family members can or want to express, reassuring them about the normality of these reactions, offering support and maintaining follow-up are important for the bereaved family [112].

### **2.5.3 Support for terminal paediatric patients and families**

The child's psychological (support, acceptance, trust, self-esteem, safety, belonging), communication (understanding, discussion, sharing), social (education, play, interaction with groups and friends) and spiritual needs are very often not addressed. They are usually delegated to the family and only rarely form part of a comprehensive care scheme. These individual needs are constantly evolving, both in intensity and prevalence, conditioned by the child's physical, psychological and emotional development, by the phase of the disease and its effect on cognitive and physical development. Whatever the child's life expectancy and however compromised or complex the child's future development may be, these essential aspects condition all forms of intervention, from the more traditional medical treatments (pharmacological treatments, supplementation or replacement of vital functions or organs) to those involving or affecting other sectors of society, such as the child's personal growth, education, culture, creativity, spirituality and role in the community.

For parents of terminally ill paediatric patients, support from qualified staff is equally important. The death of a child of any age is a deeply distressing experience, difficult to accept and to overcome. Grief is often accompanied by other painful emotions: feelings of guilt, frustration, anger, denial and fear of the future. Bereavement management is then a fundamental part of the work of the palliative care team. The most important aspects are an honest, supportive and constant dialogue (from diagnosis until death) with the family regarding the child's illness and prognosis; the family's participation in health care planning and decision making; accessible resources and tools to help family members deal with psychological issues and bereavement, both before and after the child's death; and a suitable setting reserved for the child and family.

### **2.5.4 Staff issues**

Many studies have documented the high risk of **burnout** and/or clinically significant anxiety or depression in oncology and palliative care staff. Burnout symptoms (i.e. emotional exhaustion, depersonalization and poor personal accomplishment at work) have been associated with lower confidence in communication skills and higher expectations of negative outcome following physician-patient communication [119-120]. As this psychosocial stress has been better understood, a broad-based group of interventions has been developed, including cognitive measures to improve competence and communication skills [121-129] and emotional ones in the form of group-based experiences geared to improve self-awareness and cohesiveness [115].

## **2.6 Legal and policy provisions**

Reflecting both the heterogeneity of European health systems in general as well as the unequal development of the palliative care in individual countries and regions, legislation regarding this field can take many forms. Measures depend on how many resources are available for health care and how these are managed as well as the origin of palliative care development—whether this emerges in grassroots movements and popular support through civil society or in a more structured, top-down approach from the government.

### **2.6.1 National policy-making**

Most often, the first legislation related to end of life care takes one of two forms: a) formally recognising palliative care as a medical discipline; or b) integrating palliative care provisions into a national cancer plan. The former approach has the advantage of providing a legal grounding for patients to demand appropriate care as well as of empowering government to set up programmes and subsidise previously existing private initiatives.

The latter's strength resides in stipulating specific publicly funded coverage for the population which most often requires palliative care. These two measures alone are not enough to guarantee palliative services to all citizens who need them, but they do open the door for future advancement.

Future development can then take several paths. The degree to which public healthcare is decentralised is important; further measures can be largely dependent on regional resources and political will. Regional governments can develop palliative care independently of their neighbours, with significant variations in quality and access. On the one hand, this can lead to creative and successful pilot programmes, such as we see in Catalonia (Spain), Northrhine-Westfalia (Germany), and the north of Italy. On the other hand, this model also makes countries vulnerable to problems of inequitable service coverage. In an effort to correct these drawbacks, some countries have developed national plans or minimum service provision requirements and standards while preserving local management competencies, as is the case in Spain, and particularly in Belgium. This approach has been quite successful in this country due to the detailed guidelines and legislation which stipulate what services are necessary in each local network. Other countries with centralised health systems, such as France, the Netherlands and Poland have passed palliative care legislation at a macro level, with country-wide standards and national accreditation for centres, courses, and associations.

Another tactic, which builds on the foundation of integrating palliative care into national cancer plans, extends different health plans to include palliative care. Estonia is in the process of integrating palliative care into HIV treatment plans, while Sweden extends services in all relevant branches of healthcare (cancer, stroke, elderly care, etc.). In this case, palliative services are not separate nor symbiotic from the general health system, but rather an integral element of general healthcare services. The UK seems to be a hybrid of all these tendencies, reflecting the sometimes nebulous nature of these definitions.

### **2.6.2 Targeted legislation, including the ethical dilemma of euthanasia**

Specific, issue-related legislation can be passed independently or in conjunction with national policy plans. These measures aim to address precise questions, such as opioid availability, social support for relatives, professional training, and euthanasia.

The most controversial topic, of course, is euthanasia, although this term is often incorrectly used as a catch-all for several distinct processes related to a patient's right to choose how and when to die. These terms are defined in detail in a position paper published by the EAPC in 2003, "Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force" [130]. Advance directives, especially those known as living wills or Do Not Resuscitate Orders, deal with a patient's right to refuse futile treatments, such as tube feeding, or extraordinary life-saving measures in a health crisis. Terminal sedation is a term applied to the use of sedatives to relieve pain in the last few days of life. These measures should not be confused with euthanasia. Although assisted suicide is closely connected with euthanasia, there is an important distinction between them: who is responsible for taking the final action. If a doctor provides a patient with drugs for self-administration with the purpose of helping him/her commit suicide, this is referred to as assisted suicide. On the other hand, if the doctor personally performs a patient's request to inject the drugs, this is considered euthanasia.

Only two countries in the EU (the Netherlands and Belgium) currently allow euthanasia by law, although the Luxembourgese Parliament is discussing the issue as well. Laws regulating this practice are very strict and require that the patient has full access to palliative care, including psychological support. This responds to the argument traditionally sustained by palliative care experts that patients who are able to maintain an acceptable quality of life are less likely to want to commit suicide.

Scientific research and experience supports this claim; palliative care physicians note that requests for euthanasia are reduced to anecdotal episodes once adequate palliative care is provided [131]. This is the official stance of the EAPC, which seeks to clearly separate euthanasia from palliative care, while at the same time establishing the necessity to develop quality palliative care before euthanasia is considered in legislation [130]. “Dying with dignity,” usually a euphemism for euthanasia, would then be a more complex process, including a) knowing, if desired, the truth about one’s diagnosis, prognosis, and possible treatments; b) receiving, if desired, curative or palliative treatments which could be beneficial to health or quality of life; c) refusing, if desired, any treatment; d) receiving, if desired, physical, spiritual, or psychological treatment; e) living the process of illness and dying with the support of family and community and receiving the proper psychosocial support to do so; and f) choosing, if desired, how and when death will occur. According to this theory, the lack of any of these elements constitutes the violation of the right to die with dignity; the first five elements are taken for granted throughout the palliative care field while the last is expressly omitted by some authors and vigorously defended by others [131]. Views which have emerged in the defence of euthanasia claim its gradual integration with end of life care, although these views are usually not supported within the palliative care field, because it is commonly felt that euthanasia and palliative care are not easily reconcilable approaches to deal with end of life issues.

Another issue which seems to be controversial for some general practitioners, patients, and policy-makers, but is not controversial at all for palliative care experts, is legislation limiting opioid use. The overwhelming majority of palliative care experts advocate opioid legislation in line with WHO recommendations [132], which guarantee access to medication for those who are suffering from pain. Many countries, however, have laws in place which strictly limit who can receive and dispense opioids. Some bureaucratic barriers include limitations on how many days’ worth of medicine can be prescribed at a time, limiting where drugs can be dispensed, requiring a special license for physicians or patients, or requiring duplicate or triplicate prescription forms (see Table 2 for country-specific legislation). Facilitating the process for opioid prescriptions is one relatively simple and cost effective way to quickly improve quality of life for many patients; a collaborative project between the EAPC, WHO and the International Observatory on End of Life Care (to be funded by the EC under FP7) will address these issues in 12 European countries – Access to Opioid Medications in Europe [133].

Another cost-effective measure which some countries have adopted to help relatives to look after dying patients at home is the stipulation of a 3-6 month leave (paid or unpaid) for workers. Some of these measures are not aimed specifically at palliative care—for example, the law might be targeted towards dependent relatives in general or the care of the elderly. However, laws which aim to provide social support for families with a terminally ill member can be a very effective way to care for citizens according to their wishes while achieving an optimal use of resources. Other specific legislation targets the fomentation of research, official accreditation of professionals (covered in detail in section 2.3 on Human Resources), and minimum standards for quality and service provision. For the latter, proper needs assessment tools are essential.

### **2.6.3 Palliative care in the context of a health services strategy for Europe**

The Treaty of Lisbon amending the Treaty on European Union and the Treaty establishing the European community was adopted by the Intergovernmental Conference and signed in Lisbon on 13 December 2007 by the representatives of the 27 Member States. But they will only be effective (by the beginning of 2009) if they are ratified by the 27 Member States in accordance with their respective constitutional requirements. It will enter into force on 1 January 2009, provided that all instruments of ratification have been deposited, or, failing that, on the first day of the month following the deposit of the last instrument of ratification.

The potential ratification of this Treaty plus the conclusions of the so-called "high level reflection on patient mobility and healthcare developments in the European Union," as well as other recent actions considering new perspectives and needs from patients, health services and Health Systems throughout the different Member States, may provide a solid ground to new opportunities and areas of cooperation related to palliative care services within the EU.

## **2.7 . Financial planning models**

The patterns of financing of palliative care in European countries reflect the relatively recent recognition of the importance of these services, and the different stage of development. To an extent there is diversity within countries as well as between countries as the development of services has run ahead of national or state policies. In some cases the patterns of financing reflect the important role played by voluntary and charitable organisations in putting in place palliative services, and their continuing role in developing policy and practice.

The extent to which palliative services draw on the same mechanisms as other health and social care varies, and at present there is a larger role for private and voluntary sources of funds than for the health sector as a whole. The United Kingdom, Romania and Germany are particular examples of this; whereas in Spain, France and Sweden, for example, there is much more emphasis on funding from mainstream sources. In some countries there is a shift towards fuller integration of palliative care, and a shift towards the use of the 'normal' sources of funds, but as the experience has been mixed, and in some cases, such as Lithuania these funds have been seen as inadequate. Given the uneven pace of development of palliative care it is likely that some differences will remain for the foreseeable future. The next section outlines some features of the different sources of finance and the ways in which they have been used.

### **2.7.1 Public and publicly mandated finance**

*Tax finance:* Public funding of health and social care in Europe is a mixture of funds from central taxation, tax at the state or regional level and local taxes. This picture is further complicated by the tendency for more local levels of government to be funded by combinations of local and national tax resources. Although it is typical for local government to finance and provide services within national policy frameworks, more local systems of finance can allow diversity in spending on and provision of services. In other ways there are few important difference resulting from the level of government at which responsibility for financing lies.

There are very different tiers of government in the different EU countries, and no simple system of classification fully captures this diversity. While constitutionally there are important implications of federal and unitary states, in this instance the main question is whether the public finance is at the level of the national government or at a lower level. For the purposes of this report public finance will be classified as national (or federal) level or at the level of sub-national jurisdictions such as the Lander in Germany and the constituent nations of the UK, provinces in Spain and counties in Sweden.

The evidence suggests that countries with more devolved responsibility for funding services show significant diversity between different jurisdictions – for example in Italy the funding reflects the local variation in availability of resources.

*Publicly mandated finance:* Some countries in the European Union have systems of publicly mandated health care finance, organised through social health insurance organisations or sickness funds. In most countries such funds provide cover to the whole population, although in some cases there are small groups that are not included. The key features of this funding are compulsion (i.e. membership is obligatory) and solidarity (i.e. access to care depends on clinical need and contributions are income related). While there are important differences between tax and other publicly mandated funding, in each case the goal is to remove financial barriers to access.

### **2.7.2 Voluntary and charitable finance, and non-governmental organisations**

Voluntary and charitable organisations have played a key role in many countries in the development of and support for palliative care. In some cases the main contribution has been to capital costs, with local fundraising to build and equip facilities to provide palliative care. In others the funding also provides for some or all of the running costs. Government finance is sometimes channelled through such organisations, further complicating the picture. Voluntary organisations have, in some cases, a religious affiliation, and funding is usually a mixture of support from foundations, wealthy individuals, sponsorship by commercial organisations, local fundraising and legacies.

### **2.7.3 User fees and charges**

Some palliative care providers (although very few) levy user fees or charges on recipients. These charges may cover all or part of the cost, and may be means tested. User fees are usually used in combination with other sources of funding, and at least some people are normally exempted from all or part of the fees. De facto user fees have emerged in some cases where other sources of funds are inadequate to provide the full range of services.

### **2.7.4 Complex and multiple sources of finance**

In practice the financing of palliative services often uses combinations of the different sources described above. To the extent to which the data allow, the description of financing in individual countries and the patterns of financing across Europe aims to show the balance of use of funding from different sources. The aim will also be to show how this balance is changing over time.

## **2.8 Ranking and rating system of palliative care in the EU**

The comparative study of palliative care systems in Europe is a relatively new research domain, and therefore, available data are still preliminary [134]. Wright and colleagues have recently carried out a study on the levels of development of palliative care worldwide [135]. The authors classify all countries into four groups: 1. No known hospice-palliative care activity; 2 Capacity building activity. 3 Localized hospice-palliative care provision. 4 Countries where hospice-palliative care services are reaching a measure of integration with mainstream service providers. According to these criteria, all EU countries are placed in the top two groups of development (Fig. 3). Among the countries with the least advanced palliative care fields are several from Eastern Europe, Portugal, Malta, and Luxembourg.

A further form of comparative analysis in the field is being carried out by the EAPC Task Force on the Development of Palliative Care in Europe, which has developed a classification to compare national situations based on both precise figures of resource allocation and on broader conditions that favour future advancements.

This classification is based on previously published information; however, this ranking system has been specially formulated for the purposes of this report. It should be noted that the primary data collected during this investigation is not included, and the situations in some countries may have changed to varying degrees. Despite its limitations, this classification represents the most complete ranking system available for Europe today, although it is fully expected by this study's researchers that, with time, it will improve to reflect a more accurate image of national development.

The quantitative data on **palliative care resources** was taken primarily from the 2005 EAPC study [136], validated by national scientific associations and published in the *EAPC Atlas of Palliative Care* in 2007 [137]. It includes: in-patient PC units, hospital support teams, home care teams, palliative care beds, and palliative care physicians (Table 5). Using these criteria, the first tier of countries is ranked, in order of palliative care resource allocation, as follows: the UK, Sweden, Ireland, the Netherlands, Poland, Luxembourg, Austria, Spain, France, Belgium, and Italy. A second tier of Member States is formed by Germany, Latvia, Finland, Denmark, Lithuania, Hungary, Bulgaria, Cyprus, Slovenia, and the Czech Republic. The least developed European countries are Greece, Malta, Romania, Portugal, Slovakia, and Estonia.

The second set of criteria for evaluation is **vitality** and refers to the existence of a critical mass of activists and professionals who increase the likelihood of short- and middle-term service development. The estimates of this data have been kindly provided by members of the EAPC Task Force (mostly from the Central Office), and include: presence of a national association, existence of a palliative care service directory, number of attendees at EAPC conferences, specialty accreditation for physicians, national publications on palliative care development, and paediatric service provision (Table 6). It is interesting to note that certain countries with relatively few services, such as Romania, do boast a healthy vitality index. Countries with both few resources and little palliative care vitality include Slovenia, Latvia, Portugal, Slovakia, Bulgaria, Cyprus, Lithuania, and Estonia.

The global index of European palliative care development, then, is a synthesis of these two elements, **available resources** and **vitality** of the field. The first is given a weight of 75% of total development, while the latter counts for 25%. (Table 7 and Fig. 4). Based on these figures, and awarding 100% of the possible score to Great Britain, the highest ranked State, the index is as follows: the countries with a ranking of between 50-85% of the UK's development are, in order of development, Ireland, Sweden, Netherlands, Poland, France, Spain, Germany, Belgium, Luxembourg, Austria, Italy, Denmark, Finland, and Latvia. Those between 25-50% are Lithuania, Hungary, Bulgaria, the Czech Republic, Slovenia, Cyprus, Romania, Malta, Greece, Portugal, and Slovakia. Estonia, at 8%, is the least developed Member State in terms of palliative care development.



### 3. Country Reports

*Notes on country reports:* Data from the country reports has been compiled by using both primary and secondary information. Previously published material includes country reports from the *EAPC Atlas of Palliative Care in Europe*, online reports from the International Observatory on End of Life Care, *Transitions in End of Life Care, Helping people at the end of their lives*, and a doctoral thesis by Javier Rocafort. Unless otherwise noted, all quantitative information, including the approximate number of palliative care services, beds, workforce, etc. are taken from the *EAPC Atlas*. In addition, all population figures are 2008 estimates taken from the Slovenian Presidency's website on Member States [138]. Primary information includes letters, e-mails, and other correspondence gathered throughout the course of this study from European ministries of health, national health authorities and national palliative care associations. Please see the annex included in this report for the full responses.

#### 3.1 Austria

rank (as of 2006):	11 (67/100) <sup>2</sup>	Palliative care (PC) beds (approx.):	209
population:	8.2 million	PC services:	55

**General status:** Palliative care in Austria has the short- to medium-term potential to be very commendable, but at present its programmes stop just short of high achievement. Pending the implementation of national palliative care plan (originally planned to begin in 2006), it not yet fully integrated into the national health system. This plan is optimistically scheduled to be complete in 2012; however, no agreement has been reached regarding the financing mechanisms, so some prolongation can be expected. There is also a process underway to formulate procedural standards for hospice and in-patient care, which will complement current regulations on structural quality of centres [139]. At present, it is generally available to adult citizens (though not to children) in a variety of forms, including hospice care, in-patient care and support in hospitals, and home care. Hospital services are funded by the national healthcare system while hospice and home care teams are subsidised by the government to varying degrees. Training and professional education is present but is not comprehensive, and public and governmental attitudes towards palliative care are positive but not entirely knowledgeable [137].

Note: Updated information on palliative care service provision is collected annually by Dachverband Hospiz Österreich (Hospice Austria). The report for 2007 will be finished in May 2008.

#### Availability:

In-patient units:	18	Hospital Support teams:	10
Hospices:	7	Home care teams:	17
Day centres:	2	Paediatric services:	none

Opioids: Provision limited by bureaucratic obstacles for pharmacies and patients as well as personal prejudices of physicians

Note: There is also a large number (116) of hospice teams, made up of trained volunteers [139].

**Human resources, training, and research:** There are approximately 700 professionals and nearly 2000 volunteers who work in the field of palliative care. Nurses are given 60 hours of training in their undergraduate studies and can opt for 160 hours of advanced training, while physicians and other professionals are trained in optional certification courses.

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<sup>2</sup> Please see section 2.8 for more information on the rating system.

One important characteristic of palliative care staff is the wide base of well-trained volunteers, who receive up to 70 hours of training. For physicians, there is no palliative care specialty, one probable explanation for the dearth of independent research in this country [137, 140].

**Emotional support:** There are no official bereavement teams in Austria; however, 25 psychologists and 30 faith leaders work in the palliative care field to take care of patients’ and loved ones’ emotional needs [137].

**Legal provisions:** Palliative care is not fully integrated into the national healthcare system yet, although there are structural standards for centres and there is a working group which is devising a national palliative care plan. The Ministry of Health has repeatedly acted on the behalf of the palliative care field, including it in national documents relating to funding and resource allocation, discussing the Council of Europe report (2003) with palliative care associations and experts, recognising it as a human right, and supporting steps to ensure the availability of care to all citizens. Another important measure has been to approve a 6 month leave (9 months if the patient is a child) for workers taking care of sick or dying relative. Euthanasia is not legal in Austria, nor are there significant initiatives to promote this agenda; however, living wills (Do Not Resuscitate Orders) have been legal since 2006 [137, 139].

**Financial models:** The national healthcare system funds hospital stays in their entirety with fixed stipends given to centres; this amount is gradually reduced after 21 days until reaching 50% of the original quantity—this is meant to give hospitals an incentive to stabilise patients and encourage them to spend time at home, where hopefully they will be attended by a home care team [141]. National healthcare also subsidises hospices, home care teams, and day centres. Negotiations among Austrian policy-makers are underway to incorporate these other modalities into the national system, but no conclusions have been reached [139]. The term “hospice and palliative care” is present in government documents relating to the financing of the healthcare system. [137]

**3.2 Belgium**

rank (2006):	9 (69/100)	Palliative care beds (approx.)[142]:	375
population:	10.5 mil.	PC services:	182

**General status:** Some indicators of the vitality and strength of the young but burgeoning palliative care field in Belgium are the three regional federations of palliative care (one each for Flanders, Brussels, and Wallony) [142], the comprehensive integration within the national health system [137] and the general awareness of both the population and the health authorities on the subject. Belgium is divided into 28 well-organized “palliative networks,” which liaise with GPs to provide palliative care to patients upon request. National legislation states that palliative care is a right, and all patients in the country should have access to it. The most significant gap in an otherwise model system is the lack of standardised training for palliative care physicians and GPs, including the omission of pain management courses in general medical curricula [143].

Please note that most of the information in this country report dates back to 2005; however, a national updated report is expected to be published in spring 2008 by the Federal Evaluation Commission for Palliative Care.

**Availability:**

In-patient units:	29*	Hospital Support teams [142]:	118
Hospices:	0	Home care teams [142]:	28
Day centres:	5*	Paediatric services:	2 home care teams*

Despite the availability of palliative medicine, opioid use is low in comparison with other western nations, indicating that much pain goes untreated [143].

Note: Although hospices are not customary in Belgium, every nursing home has a certain number of beds allocated to palliative care and is associated with its regional network [142].

\* data available for Flanders only

**Human resources, training, and research:** There are approximately 900 full- or part-time physicians, more than 3,000 nurses, 1,000 volunteers, and 300 other workers in the palliative care field [137]. It should be noted that most physician care is provided by GPs; there is no medical specialty nor is palliative care included in the medical curriculum. On the other hand, there is a specialty for nurses [143]. A 1997 Royal Decree stipulates that palliative care professionals as well as volunteers should be specially trained for their duties, which has stimulated heterogeneous courses throughout the country, including in residences for the elderly and in nursing homes. There are also several on-going research programmes [143, 144].

**Emotional support:** This aspect of care is generally recognised as an integral element to palliative services. More than 200 psychologists and faith leaders work in palliative care in Belgium, including a specialist on bereavement support for every palliative care unit or team [137]. In addition, emotional support training is included in a 100-hr. course for palliative care team leaders [143].

**Legal provisions:** Belgium is one of the few European countries with a comprehensive palliative care plan, which stipulates that the 28 “palliative networks” (covering between 300,000 and 1,000,000 inhabitants each) should provide professional care for any patient that requests it [137, 142]. Provisions are made for informative campaigns, training (including some for volunteers), availability of care, compensation for workers looking after a dying relative, palliative care within hospitals and nursing homes, professional support, and palliative care association accreditation [137]. However, health authorities failed to insist on specialist accreditation for physicians and pain management courses for GPs [143]. Euthanasia is legal under strict conditions, including full access to palliative care services [137].

**Financial models:** Palliative Care in Belgium is almost exclusively funded by the government, with only 2 non-government services [137]. TOPAZ day centres are lauded for their cost-effectiveness and constitute a new model for care [143].

**3.3 Bulgaria**

rank (2006):	18 (44/100)	Palliative care beds (approx.):	No data
population:	7.8 million	PC services (approx.):	42

**General status:** The palliative care movement in Bulgaria is in its infancy, with only a few pockets of activists mostly based within the NGO-supported hospices and the oncology departments in hospitals. There appears to be some rivalry between the two, which could be counter-productive to patient care. There are numerous other issues to be examined in this field in Bulgaria. The most commonly cited priorities by Bulgarian palliative care professionals and activists are a) funding for experienced and competent NGOs; b) fomenting and strengthening national and international palliative care networks; c) developing palliative care legislation and integrating it with the national health system; d) raising public awareness; and e) supporting palliative care workers, who face demotivation and burnout [145]. Although there are many dedicated professionals to this growing field in Bulgaria, the programmes often face financial difficulties, bureaucratic entanglements, and professional misconceptions.

**Availability:**

In-patient units:	0	Hospital Support teams:	0
Hospices:	16	Home care teams:	25
Day centres:	0	Paediatric services:	1

Opioids: Bureaucratic obstacles make opioid provision problematic. There is a 7-day limit on prescription validity, and only 15 days' worth of doses can be prescribed at a time [146].

**Human resources, training, and research:** There are approximately 40 non-certified physicians, 130 nurses, 25 psychologists and psychiatrists, and about 100 volunteers who work in this field [146]. Institutional palliative care training is limited to one masters course in the Medical College of Vratsa and a few palliative care courses offered to nurses [137], although in 2004-05 a nursing course took place in Plovdiv (later suspended due to lack of funding) [146]. Some NGOs, such as the Palliative Care Fund, also offer courses for palliative care workers. There is no data on Bulgarian research in this field.

**Emotional support:** This is provided by psychiatrists and psychologists in some hospitals, but there are no official bereavement or psychological support teams [137]. One manifestation of the lack of emotional support offered to patients and their families came from a respondent to a 2002 EAPC survey, who complained, "The concept of palliative care is just medication, and too medically oriented . . .we should have a public health approach." [146].

**Legal provisions:** Neither palliative care nor euthanasia are present in Bulgarian legislation to any degree.

**Financial models:** Due to the shortage of public funds, all palliative care is currently funded privately or by NGOs [146].

**3.4 Cyprus**

rank (2006):	21 (41/100)	Palliative care beds (approx.):	18
population:	776,000	PC services:	15

**General status:** There is little public support and no official policy for palliative care programmes, only a few support teams in oncological units of hospitals. Care is mostly provided by NGOs and is home-based. The one hospice aims to limit stays to 14 days in order to ensure a rotating availability and encourage patients to spend time at home. Professionals in the field usually study abroad, resulting in well-trained personnel in a country where no palliative care specialty is currently offered. Positive progress is being made in terms of population awareness and interdisciplinary cooperation, aided by seminars and lectures hosted by two active national associations as well as contacts within the national healthcare system [146]. Responding to a questionnaire sent out during the present study, one palliative care activist from the Cyprus Anti-Cancer Society (CACs) listed availability of care and standardised guidelines as priorities for improved care in Cyprus [147].

**Availability [146]:**

In-patient units:	0	Hospital Support teams:	3
Hospices:	1	Home care teams:	6
Day centres:	5	Paediatric services:	0

Opioids: These are available, without too many bureaucratic barriers. However, they are not always used correctly.

**Human resources, training, and research:** There are approximately 4 doctors, 50 nurses, about 30 other workers, and some 100 volunteers on the island [146]. The only training available in Cyprus is conducted by the Cyprus Association of Cancer Patients and Friends (PASYKAF) in the form of seminars and courses [143].

**Emotional support:** Both CACS and PASYKAF offer psychological support in their services as well as aromatherapy, music and art therapies, and reflexology. [146]

**Legal provisions:** Neither palliative care nor euthanasia is mentioned in any national legislation [137].

**Financial models:** The state-run healthcare programme is based in hospitals; there are no other types of health centres or any other primary care structure [143]. Hence, two of the three hospital support teams are funded publicly, but the rest of the available palliative care services are funded by NGOs.

**3.5 Czech Republic**

rank (2006):	19 (44/100)	Palliative care beds (approx.):	310
population:	10.3 million	PC services:	16

**General status:** Despite a few very noteworthy services, the state of palliative care in the Czech Republic is generally inadequate. Physicians and palliative care professionals feel insufficiently trained for their jobs, and coordination within the state healthcare system is poor—patients are often moved several times in the last few weeks of their lives. Specialised hospice care is only available to 1% of terminal patients, and patients often suffer from inadequately controlled pain. However, things are slowly changing—the public is more and more aware of the needs of the dying, and international cooperation—one priority for Czech activists—is improving [140]. National associations and private NGOs are dedicated advocates to this growing field, helping to fill the gap left by government passiveness. A new post-graduate specialty in palliative medicine as well as various investigations published in the country are other promising signs, and while currently palliative care seems to be low on the agenda of the Health Ministry (which is currently undergoing a radical transformation), the field is slowly advancing. [137, 148]

**Availability [148]:**

In-patient units:	0	Hospital Support teams:	1
Hospices:	12	Home care teams:	4
Day centres:	0	Paediatric services:	1 day centre 1 respite centre

**Opioids:** Not all GPs are licensed to prescribe morphine, which, like all strong opioids in the Czech Republic, requires a special prescription. This can limit the provision of medicine [145].

**Human resources, training, and research:** There are approximately 40 physicians, who work mostly part-time, about 120 nurses and 200 or so volunteers working in palliative care, although the role of the latter is not well integrated into the general healthcare team [137, 140]. Since 2005, doctors who wish to complete a specialty course in palliative medicine may do so in a one-year post-graduate course. Palliative care is also featured in pre- and post-graduate courses in medical and nursing school. One textbook on palliative care guidelines has also been published, *Palliative Medicine*, by Prof. Jiri Vorlicek [137]. In addition, articles on palliative medicine regularly appear in scientific journals [145].

**Emotional support:** There are about 20 faith leaders and 15 psychologists and social workers working in the field. However, both the public and professional populations view emotional suffering as the most poorly addressed issue for the dying [137]. Gronemeyer and colleagues touch on one possible factor for this deficiency (at least regarding religious support), suggesting that many Czechs are reluctant to accept spiritual guidance; older generations who came of age in a time of political oppression may feel mistrust towards “dogmatic views of the world” and are afraid that spiritual care coming from faith leaders could result in forced Christian indoctrination on their deathbed [140].

**Legal provisions:** Euthanasia is not legal, and the last law specifically dealing with palliative care dates back to 1965 [137]. However, the need to develop palliative care is briefly mentioned in the 2006 National Oncology programme, consisting of one paragraph [148].

**Financial models:** Public Health Insurance (PHI) funds cover about half of palliative care costs. The Ministry of Health subsidises another 20-40%, local authorities contribute with an additional 5-10%, and the rest is covered by private donations. One major breakthrough occurred in 2006, when regulations for home-care costs were published by government authorities. Terms of compensation for this type of care are still under discussion. [148]

**3.6 Denmark**

rank (2006):	13 (56/100)	Palliative care beds (approx.):	90
population:	5.4 million	PC services:	34

**General status:** The Danish palliative care field is characterised by a degree of inconsistency. Five regions (prior to 2007, 14 counties) manage resources for hospital and secondary healthcare autonomously, while the local municipalities are responsible for primary care [137, 149, 150]. This has led to a variety of financing models and priorities which often differ from guidelines set out at a national level; yet generally speaking, the resources devoted to palliative care in Denmark seem to be inferior to those in other Western European countries [137, 140, 149]. New legislation has specifically addressed palliative care service provision, though. In 2004 a “Hospice Law” was passed, introducing a requirement to build one hospice for each of the 14 counties; since then, the number of hospices in Denmark, as well as the number of specialised home care teams, has more than doubled [137, 149]. Patients suffering from pain here also have good access to opioids. On the other hand, there is a serious need for implemented standards regarding education (see below) and management (each hospice is run not by professionals, but rather a board of volunteers). The two major issues, then, that should ideally be tackled are standardised guidelines for care (including training and quality control), and a larger proportion of resources dedicated to this area [137].

**Availability:**

In-patient units:	1	Hospital Support teams:	6
Hospices[149]:	14	Home care teams [149]:	13
Day centres:	0	Paediatric services:	0

**Opioids:** Opioids are widely available, and their *per capita* use in Denmark is the highest legal use in the world [143].

**Human resources, training, and research:** There are about 30 physicians, 220 nurses, approximately 30 other professionals, and roughly 100 volunteers working in palliative care [137]. Volunteers are often viewed with scepticism and reserve by professionals, who do not know what role they should play in patient care [140]. Professional access to training is not uniform; palliative care is not a specialty in Danish universities. The only specialty education is incorporated within the field of oncology during a 3-day course. [143].

There is a “Nordic diploma course” as well, offered to doctors and nurses working in palliative care, but it does not have official accreditation from the government. A national association, the Danish Society of Palliative Medicine (DSPaM) was founded in 2001 and is devoted to promoting the education and training of palliative care professionals [137]. One significant shortcoming in these heterogeneous courses, however, is the lack of training offered to GPs, who maintain the leading role in the care of their patients even after a terminal diagnosis. Many GPs wish for more training—the only organised effort to provide it is a booklet on palliative medicine published in 2004 by the Danish College of General Practitioners [143, 150].

**Emotional support:** Throughout the country, there are 6 faith leaders and 5 psychologists who work in palliative care, and no bereavement support teams [137]. Some hospices also have other professionals, such as music therapists, who contribute to emotional support [140].

**Legal provisions:** National legislation from 2004 led to the government-funded construction of one hospice per county, to be managed by each semi-autonomous region. In addition, the National Cancer Plans of 2004 and 2005 recommend allocating more resources for palliative care to cover the needs of all patients with incurable, progressive diseases, although the regions have no obligation to follow these guidelines [140, 150]. Euthanasia is not legal in Denmark, although there is a small organisation that supports this legislation [137].

**Financial models:** Each hospice and other palliative care service has full statutory funding from the central government, and the five regions in Denmark are responsible for allocating funds to different healthcare needs. Lobbying from volunteer organisations has also spurred more interest in palliative care from the central government, which has initiated a “hospice foundation” to fund these institutions [137].

**3.7 Estonia**

Rank (2006):	27 (8/100)	Palliative care beds (approx.):	0
population:	1.3 million	PC services:	9

**General status:** Palliative Care remains rather undeveloped in Estonia, due to several causes. First, and as seen in other Eastern European countries, lack of funds tends to translate into a more pronounced focus on curative medicine—patients who only need symptom control are not admitted into hospitals. Secondly, care of terminally ill patients seems to be of little interest to most doctors, who have not been trained to deal with pain nor psychologically prepared to deal with death. Hence, apart from patients treated within the context of cancer societies and more recently HIV organisations, which do have a reasonably good care network, terminally ill patients cannot generally find a doctor who will treat them. The 9 home care teams which have served seven counties since 1997, then, are a major step forward in a country where the dying often go unattended by professional care. Palliative care activists in Estonia have called for international support in the following areas: a) advocacy at the government level, b) incorporating palliative care training into the medical curricula, c) raising public awareness, and d) promoting 2-3 publicly funded regional palliative care units or hospices [145]. Recent initiatives from the government have begun to address these issues, although it is too soon to know if they will be successful [151].

**Availability [145]:**

In-patient units:	0	Hospital Support teams:	0
Hospices:	0	Home care teams:	9*
Day centres:	0	Paediatric services:	0

Opioids: Strong opioids, including morphine, are available in the Estonian Cancer Centre in Tallinn. A special prescription is required.

\*note: The average time of patient care is six weeks, a time period dependent not on patient needs nor medical advice, but availability of funds.

**Human resources, training, and research:** There is no quantitative information available on the palliative care workforce in Estonia. The only regular training in palliative medicine at the moment is carried out by one person, Kaiu Suija, in the form of lectures through the Estonian Cancer Society. Short courses (ranging from 2 days to 4 weeks) have also been provided by the Finnish Cancer Society and the University of Tampere (Finland) [145]. In the near future, however, this may change significantly. Within the three national plans (see Legal Provisions, below), increased training as well as public awareness campaigns are listed as priorities [151].

**Emotional support:** This aspect of care is highly neglected; treatment is centered on medication and physical symptoms [145].

**Legal provisions:** There is no national palliative care strategy in Estonia, although in the past three years it has been featured in at least three official documents relating to healthcare, including a long-term care network development plan 2004-2015, the National Cancer Strategy 2007-2015 and Estonian National HIV and AIDS Strategy 2006-2015 [151]. Euthanasia is not legal, nor are there any initiatives to seek legalisation [137].

**Financial models:** The Estonian healthcare system, overseen by the Ministry for Social Affairs, is funded by social health insurance. The governing bodies of these funds are the Central Sickness Fund and seventeen regional sickness funds, which reimburse a portion of the costs for each home visit [145]. Although the national health system suffers from a shortage of funding and personnel, health authorities see increasing financial coverage for those who need palliative care as an important near-term challenge [151].

**3.8 Finland**

rank (2006):	14 (54/100)	Palliative care beds (approx.):	75
population:	5.3 million	PC services:	30

**General status:** While Finland has clear challenges ahead in some aspects of palliative care, several indicators suggest that access to palliative care is generally available and steadily improving in quality. These indicators include the existence of a national association, significant advances in training and education of physicians (including GPs) and nurses, and a modest body of research based in the country. However, it cannot be said that palliative care is an advanced field in Finland; indeed, the field does lack several key elements. Organisation is not ideal, training in home care for GPs has yet to become the norm, and there is a real need for patient-focused care, qualitative research, and attention to non-cancer patients. There is a lack of specific legislation in palliative care, though this may be misleading; the general approach to healthcare in Finland is horizontal in order to ensure a minimum of bureaucracy and maximum resource efficiency [152].

**Availability [137]:**

In-patient units:	2	Hospital Support teams:	10
Hospices:	4	Home care teams:	10
Day centres:	4	Paediatric services:	0

Opioids: Prescription to outpatients requires a special form, and opioid consumption remains relatively low [143].



**Human resources, training, and research:** There are about 60 physicians and 450 nurses working mostly part-time, as well as about 250 volunteers. Several educational developments have taken place recently in Finland, including the institution of professorships, an increase of palliative medicine units and pain units in university hospitals, and the development of a two-year specialist course in palliative medicine as well as participation in the “Nordic diploma courses.” [137, 152] Only one college of nursing offers a specialist course in palliative care [152]. Research is also growing as the palliative care culture at universities develops. In addition, in February of 2008, detailed national guidelines on “The Care of Dying Patients” were published online at [www.kaypahoito.fi](http://www.kaypahoito.fi). These “are being implemented in the field, but so far voluntarily” [152].

**Emotional support:** There is very little published information on psychological support offered to Finnish patients, only one mention that it is offered to patients in Pirkanmaa Hospice, the first in the country [143].

**Legal provisions:** The Finnish Ministry of Health affirms that general health policy dealing with patient rights, access to healthcare, and minimum waiting times are sufficient to guarantee access to palliative care. The focus of future initiatives will aim to provide continuing education to palliative care professionals and to ensure a “total-care” approach that addresses all patient needs, not just physical ones [152]. Euthanasia is not legal; however, scientific literature seems to indicate that this practice takes place, however discreetly [153].

**Financial models:** Hospital care is funded by local government. Hospices are funded by NGOs or by personal adverse event insurance [137, 152].

**3.9 France**

rank (2006):	6 (74/100)	Palliative care beds (approx.):	1615
population:	63.4 million	PC services:	471

**General status:** Despite a few imperfections in French palliative care services, such as professional prejudices against prescribing opioids, the French system is noteworthy for the wide availability and variety of free palliative care services, the research structure which is solidifying thanks to the support of the Ministry of Health, and the continued backing by the parliament. Care is usually based from the hospital, with a majority of palliative care teams dedicated to working in this setting, although recently home care has also seen rapid development [140]. In the last ten years, the vitality of this field has grown enormously, evidenced by the quantity of palliative care associations which have sprung up (110 organisations under the umbrella of the *Société Française d’Accompagnement et des Soins Palliatifs* (SFAP), representing 15,000 members) and consistent legislation (renewed approximately every three years) which defends palliative care as a right for all citizens. [137,143] The formulation and implementation of a national plan on palliative care has also been named as one of the three health priorities of the President of the Republic [154].

Note: Most information provided in this report is from 2005-06; however, there is an exhaustive report, published by the Ministry of Health in January of 2008 and available in French, which contains up-to-date information on all aspects of care [154].

**Availability:**

In-patient units:	78	Hospital Support teams:	309
Hospices:	0	Home care teams:	84
Day centres:	0	Paediatric services*:	unknown

Prescription of pain medicine still requires a special form. There is strong resistance to these drugs from both GPs and many palliative care physicians [143].

\*note: Paediatricians in France do not generally support palliative care facilities only for children.

**Human resources, training, and research:** There are nearly 400 physicians and almost 2,000 nurses working in palliative care in France [137]. The number of other professionals and volunteers is unknown, although one sample hospital support team in Paris consisted of two doctors, five nurses, a psychologist and a secretary [143]. While there is an optional post-graduate course in palliative care (required for those working in the field [140]) and teaching hospitals incorporate palliative care education into their courses as well as carrying out research, many French doctors have lamented that their pain management training is insufficient [143]. These concerns have been addressed by public policy to some degree; in July of 2006, the *Direction Générale de la Santé* (General Board of Health) published a document intending to introduce key concepts of palliative care to GPs, including home care, pain management, and family support [155].

**Emotional support:** There is very little information available on this aspect of care in France; however, the data that does exist suggests that hospital support teams are consulted for psychological support (either for the patient or the caregiver) in approximately one third of their interventions [143].

**Legal provisions:** Palliative care legislation in France dates back to 1986, with regular revisions and updates. It recognises the right to palliative care for any patient that requires it. The law also makes provisions for education and training as well as compensation for family members who take a 3-month leave from work to care for a dying relative [143]. Euthanasia and assisted suicide are not legal, despite a burgeoning pro-euthanasia movement [137]. However, advance directives (Do Not Resuscitate Orders) are legal under French law, a provision which was included in the 2005 law on patients’ rights and end-of-life care [156].

**Financial models:** Financially speaking, palliative care is fully integrated into the national health system, which is free to all residents. Palliative care provisions include specific mechanisms for home-care funding [143].

**3.10 Germany**

rank (2006):	8 (70/100)	Palliative care beds (approx.):	2034
population:	82.5 million	PC services:	331

**General status:** Due perhaps to the political separation of Germany prior to 1989, palliative care development in this country continues to be uneven, although it is growing steadily and spreading to most areas. The region of Nordrhein-Westfalen is clearly the most developed, sponsoring research projects and pilot programmes to test different care models, while other regions have little or no care available. Population awareness is also less than ideal, although efforts made by organisations such as the German Association for Palliative Medicine have been taking steps to address this for the past several years. Political will is positive, as manifested in a 2005 treaty between the CDU, SPD, and FDP to show support for the comfort and care of the dying; however, the government has, up to now, only incompletely included palliative care within the university structure and the financial infrastructure of the national healthcare system [137].

### Availability:

In-patient units:	116	Hospital Support teams:	56
Hospices:	129	Home care teams:	30
Day centres:	11	Paediatric services:	1 in-patient unit 8 paed. hospices 7 hospital support teams

Opioids: Weak opioids are available freely as a normal prescription, but strong opioids are underprescribed and still require a triplicate application form, although this process is improving continuously through renewed legislative mechanisms [143].

Note: Only hospital teams, hospices and home teams in which specialisation was ensured were counted; there are approximately 1,000 volunteer based home teams, a reflection of the emphasis which is made on treating patients in their homes [137, 140]. There are also about 65 day centre services based from hospices and hospitals [137]. Other sources report up to 216 hospices, although, again, specialised training of staff is often absent [143].

**Human resources, training, and research:** There is no data that breaks down the palliative workforce in Germany, but it is estimated that there are approximately 80,000 staff (including a majority of volunteers) who work in the field [137, 140]. While education and training options are improving (including, since 2003, a new sub-specialty in palliative medicine), basic lectures in palliative medicine should be increased, and pain management courses are either non-existent or inadequate in most medical and nursing schools [143]. The research infrastructure also needs more public support to develop [137].

**Emotional support:** There are around 430 bereavement support teams in hospices and hospice services and another 50 that operate in hospitals [137]. Scientific literature also indicates that psychologists, social workers and clergy constitute an integral part of the in-patient palliative care units in hospitals, caring for patient needs [143].

**Legal provisions:** In the past five years, numerous new legislation and administrative measures have supported the promotion of quality and availability of palliative care throughout Germany, including a study commissioned by the Bundestag to make recommendations on the improvement of care for the terminally ill [137]. The most significant legislation that has followed has been the inclusion and financing of home care in the national health infrastructure; this guideline (identified as: § 37b SGB V) only came into effect in March 2008 [157].

**Financial models:** The financing mechanisms for palliative care in Germany are complicated and depend on the type of care. Hospital care is either subsidised or included in the state healthcare system (if the unit is on the official hospital budget). A 1997 law stipulates that hospices receive a daily subsidy for their patients as well, although generally hospice care is paid for with a mixture of insurance, donations, and private payments [143]. The funding of home care has just been included within the NHS through sickness funds [157].

### 3.11 Greece

rank (2006):	24 (37/100)	Palliative care beds (approx.):	no data*
population:	10.5 million	PC services:	29

\*Although no exact figures are available, there are probably 2-3 palliative care beds in some Oncology departments and Anaesthesia departments.

**General status:** Palliative care is undeveloped in Greece compared to much of the EU, although there is a growing will to advance this field, as evidenced by the presence of two national associations which carry out work in training, advocacy, and promotion of care.

There are a few home care teams and many volunteer support teams in hospitals [137], and the number of “pain-relief” units has increased dramatically since an organisational framework was established in February of 2008 [158]. The high number of volunteers suggests that there is fertile ground for future improvement, although at present there is insufficient government support. In addition, public awareness is low (though positive [143]), there is no professional accreditation, and there are great difficulties in obtaining opioids due to bureaucratic obstacles.

**Availability:**

In-patient units:	1	Hospital Support teams:	20
Hospices:	0	Home care teams:	9
Day centres:	3	Paediatric services:	0

Opioids: Bureaucratic processes impede the effective prescription of opioids, especially for non-cancer patients.

Note: While there is only one complete palliative care unit, there are “chronic pain-relief units” in 41 public hospitals, which are attended by qualified staff and treat in-patients and out-patients for pain [159].

**Human resources, training, and research:** There are only about 100 professionals dedicated exclusively to palliative care, but there are other physicians and specialists, such as oncologists and anaesthesiologists, who work in palliative care part-time. The majority of the workforce, though, are volunteers, numbering approximately 50,000. Several heterogeneous options for professional training exist, although no specialty or sub-specialty in palliative care is currently offered [137]. The University of Athens offers elective courses of less than eight hours for medical students; the number of students choosing to take this course is increasing [160]. The principles of palliative medicine are also taught to nurses, although no practical experience is imparted. Oncologists are trained at a graduate or post-graduate level in pain management. The Hellenic Association for Pain Control and Palliative Care (HAPCPC) also offers a four-month course which includes the topics of pain management, psychological support and communication, quality of life, ethical issues, and bereavement [143].

**Emotional support:** There are approximately 40 psychologists working mostly part-time in the palliative care field who help patients face their terminal illness. Bereavement teams (3 for adults and 2 for children) are usually organised by volunteers, although Greek ceremonies, and specifically commemoration masses held after a death, are a timeless and vital custom which have helped people deal with their grief since ancient times [137].

**Legal provisions:** In 2005, a measure was passed by the Greek government affirming that doctors must relieve pain and promote quality of life through palliative care [137]. Palliative care has also been included in the Greek Cancer Control Plan, and health authorities have been in contact with palliative care experts in order to plan further development in the field [161]. In August of 2007, some guidelines for hospices were set by the government, and a regulatory framework has been formulated for home care and palliative services in cooperation with the Hellenic Society for Palliative and Symptomatic Care for Cancer and non Cancer Patients (HSPSCCC) [160]. The most recent legislation regarding palliative care was the establishment of a framework stipulating the presence of “chronic pain-relief” units in all hospitals [158].

**Financial models:** There is little to no support from the government; of the 29 services available in the country, only six have public support [137]. Most palliative care services are based on volunteer work [137], although there are important contributors, such as the Jenny Karezi Foundation, which provides financial support to the Areteion University Hospital in Athens [161].

### 3.12 Hungary

rank (2006): 17 (44/100) Palliative care beds (approx.) [129]: 189  
population: 10.1 million PC services: 57

**General status:** Significant advances have been made in this field in Hungary since the fall of the Soviet Union, especially in Budapest, although there are many rural pockets where services are not available at all [146, 162]. The achievements are strongly rooted in education, which the Hungarian Hospice Palliative Association (HHPA) has always advocated and promoted. Public awareness has also been raised by successful celebrity campaigns which have garnered national attention and financial support. However, currently, only about half of those in need of palliative care receive it [146]. Activists cite the need for more involvement of practicing physicians in order to more fully develop the field [163], whereas the Ministry of Health alludes to the need for more information for patients and a more stable financing structure [162].

#### **Availability** [129-30]:

In-patient units:	17	Hospital Support teams:	4
Hospices:	1	Home care teams:	34
Day centres:	2	Paediatric services:	0

Opioids: Widely available, though a double prescription is required.

**Human resources, training, and research:** There are approximately 1100 palliative care workers in Hungary, including about 100 physicians and over 500 nurses, but few volunteers. Much of their education is organised by the HHPA, including two nationally-accredited courses (basic and advanced) for physicians. In addition, there is a one-year post graduate course for nurses. Access to these courses has grown substantially since the 2006 National Cancer Programme was published, which included elements of palliative care. Palliative care workers also have access to a number of textbooks, WHO standards, and Council of Europe recommendations published in Hungarian. However, it is not fully integrated into the general medical curricula, and there is no specialist accreditation for palliative care [146].

**Emotional support:** Although there are only two official bereavement support teams and psychologists only account for 4% of the homecare workforce, many psychologists and nurses have carried out 120 hr. courses on bereavement support [146, 162].

**Legal provisions:** Since 1997, Hungary has passed several important measures on palliative care, including the Health Care Act of 1997, minimum standards for hospices (2004), and the National Cancer Control Programme (2006). These establish palliative care as a human right, provide guidelines for services, and incorporate palliative care into national cancer services [146,163]. Neither euthanasia nor assisted suicide figure in national legislation [137].

**Financial models:** Monies received from the National Health Insurance Fund cover 42 out of 57 hospice services [130]. These are supplemented by other sources, including foundations, grants, private donations, and a 1% tax which can be awarded to the organisation that the taxpayer chooses [146].

### 3.13 Ireland

rank (2006):	2 (85/100)	Palliative care beds (approx.):	147
population:	4.2 million	PC services:	44

**General status:** Palliative care in Ireland has a long history, which has led to a well-rooted recognition of its importance to the community as well as a complex and well-developed organisation within the country. Historically, it has sprung from religious origins, and currently it is mostly provided by specialist nurses supported by palliative care physicians, with an extensive network of home-care teams who care for both adults and children (most children die at home with access to palliative home-care services) [164]. Although some unevenness still persists, the government and the Ministry for Health and Children have acted aggressively in the past few years to tackle inequitable service provision and to meet ambitious benchmarking goals [165].

#### Availability:

In-patient units/hospices:	8	Hospital Support teams:	22
Home care teams [164]:	28	Day centres:	5
Paediatric services:	1 hospital support team		

Opioids: Availability is good, although there are a few bureaucratic barriers which limit use.

**Human resources, training, and research:** There are between 20-40 full-time physicians working in palliative care, but most care is given by the 350 nurses who work throughout the country. There are about 50 other palliative care professionals as well [137]. Since 1995, palliative medicine has been a recognised specialty in Irish medical schools, and aspects of it are imparted in undergraduate medical courses through 2-5 one-hour lectures by specialists as well as some teaching in a hospice setting [143]. The research environment is also quite healthy in Ireland, due in part to its long history of palliative care; Our Lady's Hospice in Dublin and Marymount Hospice in Cork date back to the late nineteenth century, preceding the modern hospice movement by nearly 100 years [166].

**Emotional support:** Patients and their families are supported by their doctors and psychologists on staff; in addition, there are numerous support organisations for terminal patients and their loved ones throughout the country [137].

**Legal provisions:** The recent re-modelling of the national healthcare structure has coincided with several important developments in palliative care in Ireland [165]. Building on and improving previous legislation (on quality, national standards, specialist status for physicians and nurses, and ambitious provision quotas), at least four key policy documents have included provisions for palliative care [137, 143, 165]. These aim to address problems highlighted in *A baseline study on the provision of hospice/specialist palliative care services in Ireland*, which was carried out by the Irish Hospice Foundation in 2006. That same year, palliative care was included for the first time in the framework social partnership agreement and in Ireland's cancer control strategy. The 2007-2013 National Development Plan also contained specific commitments to improve palliative care service provision, and the 2007 Programme for government promised to tackle regional inequity [165].

**Financial models:** Healthcare in Ireland is mainly funded from general taxation, and most services are delivered or funded through the Health Services Executive (HSE). The HSE recently replaced a decentralised system of Health Boards that managed services funded by the Government. Funding of palliative care varied substantially under the Health Boards, with per capita spending varying from zero to €12, with three of the Boards spending nothing on palliative care.

The differences partly reflect attempts to focus public resources in areas of very low provision. Private and voluntary spending is also unevenly distributed, but is generally higher in the areas with low levels of public spending. More than half of the public spending is on inpatient services, and more than a third of the cost of home nursing is funded by voluntary contributions.

### 3.14 Italy

rank (2006):	12 (67/100)	Palliative care beds (approx.):	1095
population:	58.5 million	PC services:	258

**General status:** Because Italy has Europe’s oldest population, palliative care is becoming increasingly important [140]. Like other countries with highly decentralized governments, Italy’s provision of palliative care services to its citizens is characterised by inconsistency. In this country, the inequality of access seems to be roughly proportional to each region’s socioeconomic reality: northern Italians statistically have a much higher probability of being attended (at home or in hospitals and hospices) by physicians at the end of their lives than their southern counterparts [167]. Palliative care training is plagued by the same problem, with most of the courses taking place in the North. Palliative care is not a recognised specialty, though, and most care (which is generally home-based) is currently coordinated through oncologists, anaesthesiologists, and general practitioners, who are not always adequately trained in pain management and emotional support [137]. These shortcomings, however, are currently being addressed at a national level. In 2006, the *Progetto Bambino* (Children’s Project) was launched by the Ministry of Health and the Maruzza Foundation to establish networks of paediatric home care (one has been completed and three more are planned) [168]. There is also a Ministry of Health commission featuring prominent palliative care experts which is formulating a national plan on palliative care [169].

Note: During the formulation of this report, the two national associations, Società Italiana di Cure Palliative (SICP) and Federazione Cure Palliative (FCP), provided a number of key documents in Italian related to legislation and palliative care development since 2006. These documents, while alluded to in parts of this country report, were unable to be examined in depth. However, they are available in the annex which accompanies this report.

#### Availability:

In-patient units:	5	Hospital Support teams:	NK
Hospices:	90	Home care teams:	153
Day centres:	10	Paediatric services[168]:	7 home/hospital services

Opioids:	Widely available, but often misused or underused	1 hospice 1 regional home care network (Veneto, 5.7 mil. inhabitants)
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**Human resources, training, and research:** There are over 2000 doctors and nurses working in palliative care; however, there is little official training [137]. Volunteers play an important role as well, although in the South, many families prefer to take charge of their relatives’ care themselves [140]. Most palliative care education depends on private institutions—there are a few post-graduate courses and other training courses for doctors and nurses, though the formation varies widely according to the region and institution. Palliative care workers do not enjoy recognition as such, and pain management is not adequately taught at an undergraduate level [143].

**Emotional support:** About 140 psychologists provide support and bereavement support to patients and their families, although this staff only participates in about 40% of the palliative care services offered [137].

**Legal provisions:** Healthcare is largely managed regionally in Italy, a policy which has produced a wide variety of care models and reimbursement systems throughout the country. These are somewhat structured by a series of laws passed in 1999-2000 which provide for regional hospice networks and minimum organisational guidelines. As of 2005, there were also government initiatives to institute a post-graduate specialty course and to legalise advance directives, but no information is available on how these measures evolved [137]. In 2006, a home-caring network was also established in the country (specific documents relating to this can be found in the annex) [169].

**Financial models:** Just as the healthcare system varies across regions, so do the funding models. It is estimated that 250 services are funded by the government, while 137 depend on NGO's and private donations. A further 155 receive finances from both the public and private sector [137]. The criteria for this cost breakdown is not consistent, although it can be said that most home-care teams are not publicly funded.

**3.15 Latvia**

rank (2006): 15 (52/100) Palliative care beds (approx.) [134]: 113  
 population: 2.3 million PC services [134]: 8

**General status:** Palliative care in Latvia is a young field (officially initiated only in 2004) and faces challenges in funding and public awareness [170]. Associations and activists lament that there is little public money devoted to these services and little awareness among the population. Professionals face poor training, difficult working conditions and low salaries, while patients face difficulties in receiving adequate services through the national health system [137]. Government sources have expressed their commitment to improving access to services and have recently taken some steps to improve the situation by including palliative care in The National Cancer Control Programme [170]. However, international cooperation would accelerate the further development of this new field in Latvia—advocacy at the European level could be key.

**Availability:**

In-patient units [134]:	7	Hospital Support teams:	0
Hospices:	0	Home care teams:	0
Day centres:	2	Paediatric services:	1 out-patient unit

Opioids: Legally available, but insufficient funding limits real access

**Human resources, training, and research:** There are approximately 60 palliative care workers, including about 14 physicians and 40 nurses [137]. Like other Baltic and Eastern European countries, volunteer staff is virtually non-existent [140]. Professionals can opt for a palliative care area of expertise and/or take part in annual course offered to physicians and nurses [137, 146]. In an IOELC survey, training was the number one issue that palliative care activists wanted to see resolved, even above increased funding [146].

**Emotional support:** Each palliative care unit includes bereavement support, although there is only information on one psychologist and three social workers dedicated to palliative care [137]. Legislation from 2006, however, legally stipulates that terminal children and their families should have access to psychological support [170].



**Legal provisions:** In 2004, palliative care was first recognised as a system, and, working closely with the Palliative Care Association of Latvia (PCAL) and with WHO documents, new legislation has been passed since then to foment development. This includes funding for a home visit, hospital services, monthly payments to outpatient centres, and psychological support for terminally ill children. A new National Cancer Control Programme is currently being developed as well, although the results have not been published yet [170]. Although euthanasia and assisted suicide are not legal, there is one organisation, the Alpha & Omega Society, which advocates legalisation [137].

**Financial models:** All services are funded by the government, but often these funds fall short, obligating patients to buy their opioids after the first dose, for example, or contributing to a high turnover of professionals due to low salaries [137, 146].

#### 4.16 Lithuania

rank (2006):	16 (46/100)	Palliative care beds (approx.):	52
population:	3.4 million	PC services:	10

**General status:** The recent incorporation of palliative care training into the curriculum of Kaunas Medical University, new legislation dealing with palliative care, and working groups held between the Ministry of Health and the Lithuania Palliative Medicine Association (LPMA) in the past few years are all positive indications of the progress which this field is making in Lithuania [137, 171]. General economic development resulting from the incorporation of Lithuania in the EU has also already had a favourable effect on palliative care provision—legislation from 2008 has increased the health budget and set middle-term aims to provide at least 180 palliative care beds to citizens [172]. Although there is little public awareness of what palliative care is, and the training of newer professionals in the past couple of years has not had a great effect on older physicians working in the field, palliative care’s place within the general health system has grown and consolidated considerably in the last five years [137, 172].

#### Availability:

In-patient units:	6	Hospital Support teams:	1
Hospices:	0	Home care teams:	3
Day centres:	0	Paediatric services:	0

Opioids: Availability is adequate, and some bureaucratic obstacles to prescription have recently been relaxed.

**Human resources, training, and research:** There are about 40 professional palliative care workers, including approximately 9 doctors and 20 nurses, as well as about 35 volunteers. Since 2005, palliative care training has been available at one of the two main medical learning centres, Kaunas Medical University [137]. Palliative care physicians, nurses, social workers and GPs have access to both undergraduate and post-graduate courses, although these new educational opportunities have not yet been able to meet demands for trained professionals in the field [137, 171]. There is little palliative care research here.

**Emotional support:** Each hospital inpatient unit has a priest working with patients [171], and support from a psychologist can be requested by patients (most multi-disciplinary palliative care teams have a social worker, but not always a psychologist) [172].

**Legal provisions:** Apart from legislation concerning opioid prescriptions, no official measures had taken effect regarding palliative care prior to 2007. However, in 2007 palliative care was formally approved and defined as a discipline by the government, a move which has opened the door for more official support and set specific standards on professional care teams, training for physicians and service provision [171, 172]. Neither euthanasia nor assisted suicide are legal here [137].

**Financial models:** There is a system of reimbursement for palliative care (147 Lt (€43,2)/day/patient), but this stipend does not cover all necessary expenses [171]. An additional 10,000,000 Lt (approximately €2.9 million) have been budgeted for future development (primarily in beds and technological resources) [172].

### 3.17 Luxembourg<sup>3</sup>

rank (2006):	10 (68/100)	Palliative care beds (approx.):	39
population:	< 500,000	PC services:	4

**General status:** The strengths of Luxembourg’s palliative care programme include an ideal availability of opioids, a relatively high ratio of services to population, and a variety of initiatives to support this sector. On the other hand, these initiatives are not coordinated at a national level, there is no medical research university, and pain management training needs to be improved among GP’s. As noted in the section on legal provisions, though, the government has recently taken new steps to upgrade its provision of palliative care. At the moment, it is too soon to predict what effects this new legislation will have, but it is clear that palliative care in Luxembourg is a dynamic field which will experience significant changes in the next few years.

#### Availability:

In-patient units:	1	Hospital Support teams:	1
Hospices:	0	Home care teams:	2
Day centres:	0	Paediatric services:	0

Opioids: Freely available, but there is a lack of education among doctors and nurses.

**Human resources, training, and research:** There are approximately 100 palliative care professionals in Luxembourg, including 13 part-time doctors and 80 nurses, as well as about 110 volunteers. Although currently there is no specialist accreditation, there are numerous training courses for nurses, physicians, and volunteers. The research network, though, needs to be strengthened, as the only source of secondary information on Luxembourg comes from the EAPC’s *Atlas of Palliative Care in Europe*.

**Emotional support:** There is a psychologist on staff for each palliative care team who is available to support patients and their families.

**Legal provisions:** Prior to 2008 palliative care had only been mentioned in two general healthcare bills [137]. However, in February 2008, both a government-sponsored bill on palliative care and a parliamentary initiative on the legalisation of euthanasia and assisted suicide were passed. Both bills are currently undergoing review to “harmonise” them; the final, modified text will be presented for approval in mid-May 2008 [173].

**Financial models:** The national palliative care association, Omega 90, is partially funded by the Ministry of Family and Social Integration. Hospital palliative care services are covered under the national health plan, and home care services are subsidised by it.

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<sup>3</sup> With the exception of the section of legal provisions, all information on Luxembourg has been taken from [137].

### 3.18 Malta

rank (2006):	23 (38/100)	Palliative care beds (approx.):	>8
population:	400,000	PC services:	2

**General status:** Specialised palliative care services are mostly provided by two specialist teams at the Malta Hospice Movement (MHM) (twinned with the Hayward House Macmillan Palliative Care Unit in England) and the Oncology Department at Sir Paul Boffa Hospital; these work together with patients to coordinate home care, day care, and in-patient care [137, 174, 175]. Provision of hospital in-patient beds does not currently meet demand (there are often waiting lists in the hospital for the 8 in-patient beds); however, plans to upgrade the hospital include a new palliative care ward. Overall strengths of palliative care services in Malta include a positive multidisciplinary team-working environment, highly accessible care during normal hospital hours, and good basic training for undergraduate medical students and GPs. On the other hand, specialist training is often lacking, care outside of normal working hours is inadequate, and non-cancer patients have more difficulties in accessing quality palliative care [175].

#### Availability [174, 175]:

In-patient PC units:	0*	Hospital Support teams:	1
Hospices:	1	Home care teams:	1
Day centres:	1	Paediatric services:	0

Opioids: Available only in state hospitals; no data found on prescription habits

\*Although there is no specialised palliative care unit at the moment, there are 8 beds dedicated to palliative care within the Oncology Unit of the state hospital (which also offers one pain clinic and an out-patient unit). All non-hospital services listed in this section are provided by one multi-disciplinary team through the MHM.

**Human resources, training, and research:** There are two main multidisciplinary teams, including doctors, nurses, psychologists, therapists, social workers, occupational therapists, chaplains, and physiotherapists [175, 176]. Basic palliative care education is included in the undergraduate medical curriculum as well as the vocational training for GPs, and the subject is also featured in the Masters of Family Medicine [175]. However, formal specialist training is not offered.

**Emotional support:** There are a few chaplains and one psychologist working in the field to aid patients and their families in their distress, and organised bereavement support is provided by key workers and trained staff of the MHM [137, 176].

**Legal provisions:** Although the MHM has been involved in talks with the Department of Health to promote palliative care, currently there is no national plan in this respect [137, 176]. A National Cancer Plan has been drawn up, in which palliative care is included, but it is still awaiting political approval [176]. There are also a few legal provisions to provide financial aid to caretakers who look after their sick relatives, although these measures are aimed at taking care of the elderly (patients must be over 60) rather than for terminally ill patients [175]. Neither euthanasia nor assisted suicide are legal here [137].

**Financial models:** Hospital services are completely covered by the social security system, and the MHM receives one-third of its resources from the government—the rest is privately funded by the NGO's resources [137].

### 3.19 Netherlands

rank (2006):	4 (81/100)	Palliative care beds (approx.):	755
population:	16.3 million	PC services:	148

**General status:** Palliative care is well-developed and structurally complex in Holland, though with an emphasis on general (rather than specialised) care, and leadership coming from the public administration rather than a grassroots movement [140]. Indeed, there is an established government commitment to this field, which covers some, but not all, medical costs and also foments training and research; nevertheless, palliative medicine is not a recognised specialty—most care is provided by GPs, who are not always adequately trained [137]. Another pending need is public awareness campaigns to eliminate fears of addiction to pain medication [137]. In general, though, the conviction that quality palliative care services are necessary if euthanasia and assisted suicide are to be legal (which they are) has been instilled in Dutch policy-makers, contributing to a well-developed legal base for these services and strong public support (in 2007, for the first time, palliative care was mentioned as an agenda topic when the latest government was elected) [143, 177].

#### Availability\*:

In-patient units:	4	Hospital Support teams:	50
Hospices:	84	Home care teams:	NK
Day centres:	NK	Paediatric services:	4 hospices
Opioids:	Available, but often underprescribed or misused.	2 home care teams	4 hospital support teams

\*Note: The figures on service provision do not cover all the palliative care available *per se*; there are other institutions which are not defined as “palliative” but which provide these services, such as approximately 35 day-care centres for cancer patients and many nursing homes.

**Human resources, training, and research:** There are approximately 800 professionals working mostly part-time in palliative care, including about 200 doctors and 400 nurses, as well as roughly 6000 volunteers [137]. While there is currently no specialisation in palliative medicine, there are numerous training courses for professionals in the field [137]. Special attention should be paid to education in Holland, as euthanasia is sometimes seen to be the only option for patients suffering intense pain. The research environment here is quite healthy, with numerous ongoing investigations [143].

**Emotional support:** Most palliative care services include an element of professional or volunteer psychological support, although the quality of this service is much higher if offered by professionals [137].

**Legal provisions:** A national palliative care network was established in 1995, and since then, this has been updated and improved by several policies [143]. Six “academic clusters” have the support of the government for research, and moves have been made by health authorities to fully integrate hospices and palliative care into the national health care system [137, 143], including setting quality assurance mechanisms for institutional certification [177]. Euthanasia and assisted suicide are legal in Holland [143].

**Financial models:** Although the government has invested large sums of money to the support of research, training, hospitals, and quality management, many palliative care services (and especially home care) still rely on a combination of other sources for funds, including private donations and insurance, NGO’s, and grants [137].

### 3.20 Poland

rank (2006):	5 (77/100)	Palliative care beds (approx.):	1667
population:	38.7 million	PC services:	362

**General status:** Poland is unique in Eastern Europe with regard to palliative care; it began in the 1970's, still under Soviet rule, and was closely tied to the Catholic Church, *Solidarity* (a union which supplemented national health care provision), and displaced intellectuals [145]. These circumstances resulted in a well-rooted movement that stands out in Eastern Europe as a model of care; in the late 1980's and early 1990's, the field began to be integrated in the public system [140]. Paediatric services in Poland are especially developed in comparison both to its neighbours and to the rest of the EU. That said, of course further development would be ideal, specifically in terms of funding, equity of provision (there are still large holes in coverage in many rural areas), standardised organisational structures, quality assurance (often non-governmental institutions provide better care than public ones) and continued research-network development [137, 140, 145]. Polish health authorities cite further aims to improve quality control (i.e. accreditation of centres, Health Technology Assessments, monitoring objective and subjective quality indicators) and to develop a more integrated healthcare network which provides palliative care throughout the course of the illness, not only when this has been declared terminal [178].

#### **Availability** [137, 178]:

In-patient units:	69	Hospital Support teams:	2
Hospices:	59	Home care teams:	232
Day centres:	12	Paediatric services:	7 hospices
Opioids:	Freely available for all cancer patients [143]		30 home care teams

**Human resources, training, and research:** There are nearly 2000 professionals working in the palliative care field, including over 500 physicians and more than 1000 nurses; on the other hand, there is no record of volunteer work. There is also specialist accreditation here for both nurses and physicians, although so far there have not been enough graduates to cover the need [137]. In addition, there are numerous other training courses both for adult and paediatric palliative medicine at undergraduate, post-graduate, and certificate levels. The research network in Poland is relatively developed, though, especially paediatric research [143].

**Emotional support:** Most multi-disciplinary teams include a psychologist, chaplain and social worker, indicating that emotional and bereavement support are well attended. The historic roots of palliative care in Poland, stemming in large part from the Church, suggest that spiritual counsel is a central aspect of care [178].

**Legal provisions:** "Dying peacefully with dignity" has been recognised as a right in Polish law since 1991, preceding most of Western Europe in this aspect [143]. It is formally and fully included in the national health system, which has historically supported the field in health policy and training initiatives [137]. The last of these has been the inclusion of palliative care in the National Programme of Neoplasm Control, which aims to ensure availability of palliative care at every stage of cancer [178].

**Financial models:** In the past, government support enabled much of the development in palliative care in this country, but in 2002, official funds dedicated to palliative care were significantly reduced. Currently, only about 40% of costs are covered by the government in the form of reimbursements from the Polish Health Sickness Fund [137, 145].

### 3.21 Portugal

rank (2006):	25 (30/100)	Palliative care beds (approx.):	53
population:	10.5 million	PC services [179, 180]:	13-22

**General status:** Palliative care development in Portugal began much later than its neighbours; the first palliative care unit (within the Portuguese Institute of Oncology) opened only in 1996 [143]. Since then, and despite activism led by the *Associação Portuguesa de Cuidados Paliativos* (APCP), these services have grown very slowly, with only incomplete implementation of government programmes. However, in the past two years, development has accelerated: when the last exhaustive study on palliative care in Europe took place in 2005-06, only 7 palliative care teams existed. Now, the APCP website lists thirteen accredited services and the Ministry of Health lists twenty-two (Ministry figures from December of 2007 are more in line with the APCP website, which could account for the discrepancy). In addition, there is a National Plan on Palliative Care, which is meant to conclude in 2016—in the short term, it aims to double services offered in 2008 [180]. The Ministry of Health aspires to meet WHO standard levels of care (a close and very successful precedent has been achieved in Catalonia, Spain). European support of these ambitious goals could both reinforce health authorities' conviction of the necessity to provide quality palliative care to its citizens as well as provide assistance to Portuguese professionals seeking to expand a very new field.

#### Availability [179, 180]:

In-patient PC units:	9	Hospital Support teams:	9
Hospices:	0	Home care teams:	3
Day centres:	1	Paediatric services:	1 home care team
Opioids:	Freely available in hospitals		1 hospital support team

**Human resources, training, and research:** There are approximately 100 professionals dedicated to palliative care in Portugal, including 20 mostly part-time physicians and about 60 nurses [114]. There are a few training courses in Lisbon and Oporto—a Master's course in the Lisbon Faculty of Medicine and basic and continuing education courses in the Portuguese Institute of Oncology in Oporto [137, 143, 181]. No specialty is offered, but mentoring programmes led by some of the more active professionals have been planned.

**Emotional support:** Within most palliative care units, there is a psychologist on staff, although there are no specific bereavement teams or special support activities on record [137].

**Legal provisions:** There are some official documents related to pain management and palliative care networks, including a National Plan on Palliative Care and a circular calling for 25 in-patient units by 2010, but these have not always been implemented on the ground [137, 179]. Euthanasia and assisted suicide are not legal here.

**Financial models:** Most services are funded by the government, but at least 3 are financed by a combination of public and private funds [137].

### 3.22 Romania

rank (2006):	22	Palliative care beds (approx.) [182]:	150
population:	21.6 million	PC services [146, 183]:	36

**General status:** Following the overthrow of the Ceaucescu regime, Romanian palliative care developed in large part due to international initiatives which provided funding and guidance to national movements. One result of this collaboration is Casa Sperantei ("House of Hope"), a partnership organisation between Romanian and British palliative care activists which was modelled on St. Christopher's Hospice in England.

Following some important political upheaval in the country in the 1990's and supported by the EU (with grants for training and development), the government and health authorities finally seem to be taking an interest in a movement which has mostly developed parallel to its institutions. There is a significant lack of finances, however, not only for palliative care, but for healthcare in general, and this is probably the most challenging problem to be tackled at the moment [146].

**Availability** [146,183]:

In-patient units:	2	Hospital Support teams:	2
Hospices:	7-9*	Home care teams:	10-17*
Day centres:	1	Paediatric services:	5 hospices
Opioids:	Since 2005 opioid laws have improved greatly, and now are freely available		2 hospital support teams 6 home care teams 1 day centre

\*Collected data is inconsistent on this point. However, a minimum data set on specific resources dedicated to these services is being formulated through the Ministry of Health, including types of care available and human resources. It is scheduled to conclude by the end of 2008.

**Human resources, training, and research:** In 2005, there were an estimated 66 full-time palliative care workers, including 17 physicians and 38 nurses [146]. Doctors can opt for a specialty course of 12 weeks; since 2000, when the courses began, about 150 have completed it and 78 are scheduled to do so in 2008 [183]. There is no nursing specialty, but training is available in several official and hospice-sponsored centres throughout the country—in total, nearly 10,000 workers have completed palliative care training [146, 183].

**Emotional support:** Most spiritual support is provided by priests on staff at public hospitals and volunteer priests at private or non-governmental institutions, although there are a few psychologists in some centres, notably Casa Sperantei, that also provide this support [146, 183].

**Legal provisions:** Since 2002, several important measures have been passed regarding palliative care, including published standards for services (2002), a law on patients' rights (2003), a 2005 law relaxing strict bureaucratic processes for opioid prescription, and other laws stipulating the provision of palliative care in non-governmental health services and increases in salaries for workers [146, 183]. Currently, there is no national plan for palliative care in effect, however, there is a strong lobby for this and in fact one is being formulated through the Ministry of Public Health under the auspices of a National Plan for Cancer Control [182-183].

**Financial models:** The government funds entirely or in part the in-patient units through the national insurance funds; however, home care is not included, and many hospice organisations depend on international support, private donations, and other sources of income to meet costs [146,183].

**3.23 Slovakia**

rank (2006):	26 (27/100)	Palliative care beds (approx.):	>27
population:	5.4 million	PC services:	14

**General status:** Although there are associations which act as advocates for palliative medicine and care, this discipline is poorly developed in Slovakia [146]. Unfortunately, at the present time, the obstacles seem to outweigh the positive actions.

Palliative medicine is seen as a threat by GPs and other specialists, curbing the potential for an integrated medical approach [146]; additionally, healthcare is often described as paternalistic—doctors often hide the diagnosis from the patients in an effort to “protect” them [140]. This will presumably change as the effects of a new medical specialty in palliative medicine are felt. There is a shortage of funds for health care, and both education and service provision are inadequate [146]. Obstacles to obtaining strong opioids also limit effective pain management, although it should be noted that there are 34 out-patient pain clinics which help alleviate the lack of organised palliative services [143,146].

**Availability [184]:**

In-patient units:	5	Hospital Support teams:	0
Hospices:	7	Home care teams:	1
Day centres:	0	Paediatric services:	1

Opioids: Strict bureaucratic barriers on prescription and co-payment required for most pain medication.

**Human resources, training, and research:** No information was found on the workforce capacity of palliative care in Slovakia; however, the Minister of Health, in contact with this research team, has alluded to financial problems, both for the national health system and for patients, to access a multi-disciplinary team which includes social workers or psychologists. There are few volunteers and a shortage of teaching staff to cover needs for the new specialty in palliative medicine (offered since 2007). There are at least two teaching hospitals and one University Chair of palliative medicine, though, which are positive signs that future development will have a foundation in medical education. In addition to regular congresses on palliative medicine and pain management, there is also a new journal on palliative medicine and pain management (product of collaboration with Czech specialists) which will begin circulation in 2008 [184].

**Emotional support:** Emotional support for patients and their families is the competency of faith leaders in Slovakia [146, 184]. This is due to two main reasons: first, the solid link between hospice care and religion [146], and secondly, the difficulty patients have in accessing affordable care from psychologists—health insurance does not cover non-medical specialties [184]. Volunteers also provide some emotional support [140].

**Legal provisions:** Palliative care was listed as a priority by the government in 2000, but since then has faced financial difficulties in implementing its goals (in 2002, there were 23 hospice projects planned, of which only ten have been carried out) [146, 184]. The official recognition of palliative medicine as a medical specialty in 2006, as well as the initiation of specialty training programmes in 2007 have been other significant advances in this young field.

**Financial models:** In 2002, it was accorded that palliative care services would be jointly funded by the Public Health Insurance and Public Social Insurance funds, a recognition of palliative care’s health and social dimensions [146]. However, at the current time, many patients must still contribute to their own care with co-payments in medication, hospital visits and hospice care. From a legal perspective, the recognition of palliative care as a specialty in 2006 allowed licensing of hospice activities, which cleared the way for grants and donations, but these do not always cover costs [184].

**3.24 Slovenia**

rank (2006):	20 (43/100)	Palliative care beds (approx.):	34
population:	2 million	PC services:	8



**General status:** Despite an active and dedicated national association (Hospic), and a Palliative Care Development Institute, progress in this field is slow in Slovenia. Poor organisation, inadequate education and unclear standards for this discipline are all exacerbated by a general lack of medical staff in the country and a lack of public financing [137]. Education and home care still need more development, as well, as most care is hospital-based [137]. A strong impetus is necessary and imminent, however: a national plan on palliative care is ready, illustrating the government's willingness to face the challenges this field presents [185]. Once this document is published and sufficient time has passed for the effects to be apparent, the situation will have to be re-evaluated.

**Availability:**

In-patient units*:	1	Hospital Support teams:	2
Hospices:	3	Home care teams [185]:	1 (covering 7 regions)
Day centres:	0	Paediatric services:	0

Opioids: Fully available, but poorly used.

Note: Paediatric patients are usually cared for in the ICU of the University Clinical Centre or in the paediatric clinic's oncology department.

\*The national association, Hospic, has indicated that this number has increased significantly in the past year; however, no quantitative data is available.

**Human resources, training, and research:** There are at least 25 professional palliative care workers (with no doctors) and over 130 volunteers working in home care [185]; no data is available on the rest of the workforce in Slovenia. According to Hospic, these workers collaborate with GPs and oncologists to handle pain management, as there is no specialty in palliative care. Physicians often study abroad, although now palliative medicine has made it into the curriculum for those studying family medicine, public health, and oncology. There are also traditional courses and seminars organised for palliative care workers, and printed guidelines on pain management have been distributed by the Chamber of Family Medicine [137].

**Emotional support:** The president of Hospic, Tatjana Zargi, emphasises in a letter to our research team that spiritual support (which is not necessarily religious) and counselling is a central aspect of the care they offer. At least four psychologists and one family support coordinator are on staff throughout the country.

**Legal provisions:** No record of legislation specifically dealing with palliative care prior to 2004 was found during this study. However, that year a pilot study on the implementation of palliative services was begun, and the results and recommendations are now ready [137, 185]. Euthanasia and assisted suicide are not legal.

**Financial models:** Medical services, including home nursing services, are funded by the government's obligatory health insurance system and social security system [145]. Other end-of-life services provided by hospice organisations are free to the patient and their family and funded by donations, grants, and other sources of revenue [185].

**3.25 Spain**

rank (2006):	7 (74/100)	Palliative care beds (approx.):	1098
population:	44.4 million	PC services [186]:	350

**General status:** Palliative care coverage is uneven in Spain, with some highly developed regions, such as Catalonia and Extremadura, other medium-developed regions, like the Basque Country or Cantabria, and a few regions with relatively little development, such as Galicia [137].

Curiously, this seems to have less to do with the economic power of the province than with the will of the regional governments, as Extremadura and Catalonia represent opposite ends of the socio-economic spectrum. Another general trend in Spain is the important role of family (especially women) in looking after dependent relatives, and in this area, recent laws (see below) have begun to address these realities. The central government has also vigorously pursued the increase of palliative care service provision [187]. Indeed, in the next 2-3 years, it is set to nearly double, reaching 700 services compared to the approximately 350 offered now [186].

**Availability:**

In-patient units:	95	Hospital Support teams:	27
Hospices:	0	Home care teams:	139
Day centres:	28	Paediatric services:	2 in-patient units
Opioids:	Available, but often underused		

**Human resources, training, and research:** Roughly 1600 professionals work in the field, including nearly 500 physicians and about 800 nurses. Nine universities offer undergraduate medical courses in this subject, and about half of the nursing schools offer courses (mostly elective) at an undergraduate level. There is no doctorate course offered at this time, but there are six Masters throughout the country, and palliative care elements are included in the curricula of various other specialties, such as oncology. The research environment is also relatively healthy, with more government grants planned to stimulate further investigation [187].

**Emotional support:** Over a hundred psychologists and about 40 religious leaders work in the field to care for patients’ and their families’ emotional needs, although officially there are only 2 bereavement support teams [137]. This element of care is well represented in the Ministry of Health’s 2007 report on a Strategy for Palliative Care.

**Legal provisions:** Palliative care is recognised as a basic right under Spanish law and described as a high priority to this research team by health authorities [187, 188]. Recently, several important legislative measures have been passed to promote its development, including a 2006 law to financially assist relatives and caretakers of dependent persons as well as an exhaustive 2007 report analysing the current situation and outlining a national strategy on palliative care [187, 189]. The execution of these recommendations is taking place with the oversight of an evaluating committee which modifies planning according to new evidence [188, 190]. Seven new regional plans are also in place [186]. Euthanasia and assisted suicide are not legal.

**Financial models:** Healthcare in Spain is covered by the social security system, which includes palliative care. However, only about 60-65% of palliative care costs are covered by the government. The rest are covered by private entities with a variety of funding sources [143].

**3.26 Sweden**

rank (2006):	3 (84/100)	Palliative care beds (approx.):	650
population:	9 million	PC services:	105

**General status:** Palliative care is generally very well developed in Sweden. General healthcare is supported and managed autonomously by the 60 county councils and overseen by the Board of Health and Welfare [137, 191]. This organism is currently formulating guidelines and quality indicators on care for those with chronic diseases (from prevention to palliative care) with the aim of increasing the efficiency, quality, and equity in the health system [191].

The Swedish National Registry of Palliative Care and the Swedish Council for Palliative Care are two non-governmental organisations which also monitor quality and support development of the field [191]. The pending challenges here include more precise standards for end-of-life care in nursing homes, more training for medical personnel at universities, and more paediatric palliative care [137, 143]. Another issue which has recently drawn attention, as in many European countries, is the future funding capacity of the government for healthcare, which faces a rapidly ageing population and rising medical costs [143].

**Availability:**

In-patient units:	40	Hospital Support teams:	10
Hospices:	5	Home care teams:	50
Day centres:	8	Paediatric services:	2
Opioids:	Easily available [143]		

**Human resources, training, and research:** Approximately 300 physicians and 1500 nurses work in palliative care as well as a large number of physiotherapists and social workers. Professionals and volunteers have access to a variety of palliative care training courses held by hospices and universities, including a Diploma of Palliative Medicine offered to physicians [137, 143]. There are also a number of ongoing research projects taking place in the country [143].

**Emotional support:** There is no data on the number of psychologists and faith leaders working in palliative care, nor any specialised training they may receive. The *EAPC Atlas* does cite bereavement services which are provided by palliative care team staff.

**Legal provisions:** The first national standards on palliative care were published in 1979, an indicator of the importance this field has had historically. It is fully integrated within the national health system, with additional laws which cover an 8-week leave of absence to look after a dying relative [143]. A national report on palliative care was also recently published by the National Board of Health and Welfare, which will be considered by health authorities for future development [192]; an investigation to formulate a National Cancer Strategy, including palliative care, is also underway [191].

**Financial models:** Virtually all palliative services are covered by the government, with the exception of day centres, which are not always publicly-funded [137].

**3.27 United Kingdom**

rank (2006):	1 (100/100)	Palliative care beds (approx.):	3180
population:	59.8 million	PC services:	882

**General status:** The UK was the cradle of the modern hospice movement, and its pioneer, Dame Cicely Saunders, defined the full ‘total care’ approach that is still embraced by professionals all over the world today. This country continues to be the leader in palliative care development in Europe in the quantity of services offered, the high standards expected, and in the research environment. The UK is currently developing a full End of Life Care Strategy for England – the first of its kind in the world. It is also the first country to announce a national strategy for paediatric palliative care (in February 2008) [193]. However, palliative care activists are not satisfied with the care offered—it is perhaps a testament to the high development of palliative care in the United Kingdom that they are so well-informed of the flaws of the system and so specific on further reforms that need to be carried out. Britain suffers a shortage of medical personnel in palliative care where many vacant posts are unfilled due to insufficient qualified applicants. Training is also an issue as well as drug availability outside of normal working hours [137].

**Availability:**

In-patient units:	63	Hospital Support teams:	305
Hospices:	158	Home care teams:	356
Day centres:	257	Paediatric services:	34 hospices
Opioids:	Good availability during standard working hours, but some reluctance to prescribe morphine from GPs	112 hospital support teams 112 home care teams	

**Human resources, training, and research:** There are between 6000-7000 professionals in the field, including nearly 5000 nurses and about 750 physicians; they are further supported by a vast network of some 70,000 volunteers [137]. The UK was the first country in the world to recognise palliative medicine as a specialty, and, indeed, still stands out as one of the optimal study centres for the field, both in medicine and nursing [143]. Palliative care advocates now cite a need for a broader palliative care curriculum at lower levels, in undergraduate courses and in general medical school, in order to prepare GPs to deal with patient pain in acute settings [137]. Medical research in the UK, including palliative medicine, is well established in a number of academic research centres.

**Emotional support:** The number of psychologists working in palliative care is unknown; however, since the time of Dame Cicely Saunders, emotional support has been a pillar of British palliative care. Unfortunately, there is a lack of quantitative data to accurately describe the current situation. However, we do know of several bereavement services offered throughout the country, including a Bereavement Network in Northern Ireland launched in 2006 [194].

**Legal provisions:** After years of palliative care development on the margin of the NHS, this discipline has now gained considerable ground in national health strategy, being incorporated in broader plans addressing disease control and management. Since 2000, several important national and regional initiatives have been launched to promote access to end-of-life care and improve the quality of care provided. These include generous investments from the NHS, action plans on including palliative care in the 34 national cancer networks, technological resource allocations in Northern Ireland, and numerous published guidelines on different aspects of care [137, 194]. An end-of-life initiative for England was launched in 2003 and in summer of 2008 the Department of Health will publish a full End of Life Care Strategy for England [193]. In 2008 a national strategy on children's palliative care was also launched, providing clear guidelines to local commissioners, health providers, and regulators on goals and policy strategy for paediatric palliative care services [193]. Euthanasia and assisted suicide are not legal.

**Financial models:** The approximate breakdown of services funded by the government are as follows: 30% of inpatient care, 59% of home care, 23% of day care, and 83% of hospital support; the rest are financed by a combination of public and private funds [137]. There is some variation between the four component countries, since funding of health and social care is devolved.

## 4. Best practices

With the wide range of different models of palliative care delivery in the European countries and the differences in concepts and terminology evident from comparative research, the call for common standards has been raised. Considering the scope of palliative care, beacon models may be used as best practice examples in different settings.

Best practices examples are defined by two qualities: they are well defined or at least well described and their efficacy is proven by research evidence or expert experience – with evidence too of wider impact on policy and practice, nationally and sometimes internationally. However, research evidence on ‘best practice’ is still missing for many settings, and consequently the selection of examples may seem patchy or arbitrary. Although there are commendable examples of palliative care projects throughout the world, including Africa, Asia, and the Americas, we have chosen to focus on European examples, with the hope that the dissemination of this report will lead to future collaboration between Member States. We understand that geographical and cultural proximity are key to these partnerships.

### 4.1 Availability of health care and related services

The first modern hospice was **St. Christopher’s Hospice**, founded in 1967 by Dr Cicely Saunders. Since then the service has developed continuously, and now includes an inpatient unit with 4 wards, a creative living (day care) centre serving a large number of patients continuously, home care teams with high coverage of the neighbouring areas, psychological and bereavement support, as well as information, education and research facilities ([www.stchristophers.org.uk](http://www.stchristophers.org.uk)). St. Christopher’s Hospice has been a beacon model of a comprehensive palliative care centre since its opening, constantly introducing new options such as taking the creative living activities from the day care centre to the patient’s home [195].

The model has been exported to a number of settings, including poorer countries such as Romania, where **Casa Sperantai** was opened in 1992 with the help of the UK-based **Ellenor Foundation**. It now boasts an inpatient hospice unit, day care centres, outpatient clinics, home care teams both for children and adults, and a training centre with the capacity to care for up to 500 patients at a time [196]. It still largely depends on international support to meet operational costs, but the relationship between British and Romanian activists in this and other institutions in Romania is a model of how international mentorships can stimulate national development. Romania has acknowledged palliative care as a medical subspecialty and has overcome the regulatory barriers to the prescription of opioids in a legislation drafted by a commission of pain and palliative care specialists in 2005.

Elsewhere in Eastern Europe, Clark and Wright identify other ‘beacons’ of good practice which have sprung from local efforts and which are financed primarily by national funds. **Poznan, Poland** is probably the most outstanding centre of palliative care in this respect. Three main hospices, St Jan Kanty Hospice, the Hospice at the University of Medical Sciences, and Hospice Pallium, lead the notable developments taking place in this small city, which has also held the headquarters of the Eastern and Central Europe Palliative Care Task Force (ECEPT) since the 1998 Poznan Declaration. The availability of services in this city is astounding—in 1998, nearly 85% of terminally ill cancer patients received attention from home care teams. Poznan is also a centre for training, research, and policy-making; professionals and palliative care activists from there have had an enormous influence on national policy and regional development.

In **Trondheim, Norway** an excellent example of a tertiary referral centre for palliative care can be found based within an oncology hospital. The service includes a 12-bed acute palliative care unit, an outpatient unit, a hospital-based consultation service and a home care team, which consists of doctors, nurses, social workers, physical therapists, dieticians, and chaplains. The mean length of stay at the inpatient unit is ten days, exactly the same as for the department of oncology. Twenty five percent of patients are discharged home, 20 percent go to a nursing home and approximately 55 percent die on the unit.. The palliative medicine unit has also established an agreement to collaborate with the city of Trondheim in the care of patients at two nursing homes [197].

#### **4.2 Integrated health care networks**

Spain boasts two prime examples of how network development programmes can be implemented in both urban and rural settings. In **Catalonia**, after 15 years of planning and investment, the regional government has been able to achieve coverage of 95% of the area, with comprehensive palliative care networks in 14 districts [198]. Specialist home care teams, hospital inpatient units, outpatient clinics, support teams in acute and chronic care hospitals, and long-term care centres are coordinated to provide care to all patients, including children and geriatric patients. An early key to this development was the use of hospital support teams, which proved a cost-effective way to provide palliative support to a large number of patients while raising awareness of palliative care in other specialties [199]. The project, inspired by WHO recommendations, has shown surprising cost efficiency, with more money saved from reduced acute and emergency hospital beds, and higher satisfaction of patients and family than with conventional care.

Another Spanish region, **Extremadura**, has also had a great deal of success in providing palliative care coverage to its population, which is scattered throughout a large geographical area. Characterised by a high number of mobile palliative care teams, this model is capable of providing care in a cost efficient way to a rural population. Serving patients with all types of diseases in the community and in acute hospitals, it is fully integrated in the regional health network. Qualitative and quantitative control mechanisms are also in place to maintain basic standards of care [199].

#### **4.3 Human resources**

Clearly, one pillar of any kind of medical care provided is appropriate staff training and qualifications. In the case of palliative care, professional training is highly heterogeneous throughout the Member States, despite guidelines formulated by the EAPC in an effort to lay the foundation for a shared educational approach in the Europe. Few countries offer specialties in palliative care for doctors and nurses, and only in Ireland and the UK is full specialty status awarded. In **Britain**, this specialty is also coupled with a contractual commitment from GPs to provide palliative care [140]. Gronemeyer and colleagues observed that this compact has contributed towards better collaboration and communication between general practitioners and specialists as well as a more positive attitude towards palliative care specialists in general. In **Ireland**, the cornerstone of palliative care provision are the specialist nurses. There are currently 24 consultants in palliative medicine in Ireland (a number greater than the number of oncologists) and approximately 350 nurses providing mostly home care.

Other countries and institutions with less resources also stand out for their commitment to professional training. The **Hungarian Hospice Foundation**, founded in 1991 at St Margit's Hospital, Budapest, initially focused on public awareness and education—only after two years did it establish a multi-disciplinary care team for patients. However, the numerous courses motivated and trained other professionals, who began small hospice organisations throughout the country.

The early idea in Hungary that education and training are the backbone of palliative care is still strong today—Budapest is a key centre for palliative care research in Eastern Europe, and numerous textbooks and scientific literature are available in Hungarian to medical students, physicians, nurses and other professionals.

Gronemeyer and colleagues also describe one country—**Germany**—which has been able to tap into an enormously valuable human resource: volunteers. Approximately 80,000 volunteers provide nearly 95% of palliative care in this country. The volunteer population is made up of mostly retirement-aged women, and their duties are largely dependent on personal skills or prior work experience. Belying the general misconception that younger volunteers are somehow more communicative or supportive, these volunteers have an important role in psychosocial support. They can also work in the general administration of care, including secretarial work. Preliminary as well as continuing educational training courses are required and are seen as a fundamental element to prepare volunteers for their essential role.

There are a range of Certificate, Diploma and Masters offerings across universities, palliative care services and different countries, often with little collaboration or comparative ‘currency’ between them. The International Observatory on End of Life Care at Lancaster University, UK is currently working on plans for a European Doctoral Programme in Palliative Care, with international partners.

#### **4.4 Quality assurance**

Two basic necessities to ensure quality palliative care are research and the effective implementation of research findings. To these should be added appropriate mechanisms for audit as well as clinical and organisational governance. While palliative care research in general is undeveloped compared to other medical disciplines, there are numerous examples of praiseworthy programmes which investigate clinical and psychosocial aspects as well as national service provision. International and European initiatives also play a central role in improving end of life care for citizens.

Regarding individual research centres, the Department of Cancer Research and Molecular Medicine of the **Norwegian University of Science and Technology** has reached beacon status for translational research into symptom control, cross-linking palliative care research with other research areas such as genetics. As treatment of physical symptoms is only one of the cornerstones of palliative care, qualitative research into psychological and social sciences is highly relevant for the development of palliative care. The Department of Palliative Care, Policy and Rehabilitation of the **King’s College in London** is renowned for leadership in many projects and collaborations.

National health authorities and palliative care associations from several European nations have also commissioned exhaustive qualitative and quantitative studies at a national level in order to evaluate progress and identify best practices as well as areas needing improvement. This type of study is an invaluable tool for policy-makers, as it provides an analysis of palliative care programmes in a national context. Some of the countries which we know have or are currently conducting these studies include **Austria, Belgium, France, Italy, Spain, Ireland, Germany, Sweden, the Netherlands, Poland, Romania** and **the UK**.

At a European and international level, various initiatives are underway to formulate standards and compare national development. The **EAPC Research Network** has published numerous expert and consensus papers ([www.eapcnet.org](http://www.eapcnet.org)). It has also recently remitted a white paper on norms and standards for palliative care in Europe that is currently being prepared for publication. The **European Palliative Care Research Collaborative** is presenting the first results of its work ([www.epcrc.org](http://www.epcrc.org)), and **PRISMA** and **OPCARE** have started to work recently.

The **European Commission's Executive Agency for the Public Health Programme (PHEA)** has recently funded a new project on best practices in palliative care. These collaborations reach critical mass and will lead to a steep increase in the quality and amount of palliative care research in Europe.

The **International Observatory on End of Life Care** at Lancaster University has described and compared palliative care development in over 60 different countries and areas in Europe and beyond, using a social science perspective. It also comprises a large multi-disciplinary team including chairs in Hospice Studies and in Palliative Medicine.

#### **4.5 Paediatric palliative care**

Most countries do not provide any specialised paediatric palliative care; however, there are important initiatives being carried out which suggest that this aspect of palliative care is gaining more recognition. The **UK** has just launched a National Strategy on Children's Palliative Care, which provides detailed guidelines to local governments and service providers. The **Progetto Bambino**, sponsored by the Maruzza Foundation and the Italian Ministry of Health, aims to provide home care to children by way of regional networks. One of these, in Veneto, is in operation now, and three more are being planned. The region of **Northrhine-Westfalia** has also recently started a model project on paediatric palliative care, supporting two competence centres to implement local and regional networks ([http://www.mags.nrw.de/06\\_Service/001\\_Presse/001\\_Pressemitteilungen/pm2007/070403/index.html](http://www.mags.nrw.de/06_Service/001_Presse/001_Pressemitteilungen/pm2007/070403/index.html)). In addition, a standard for paediatric palliative care has been published recently by the EAPC task force on palliative care in children and adolescents [200].

#### **4.6 Financial planning models**

Although in most European countries hospital care is free and other services are subsidised to some degree, there are very few countries that cover 100% of costs (hospice, home care, medication, etc.) within the national health system. Of these, **France** and **Belgium** stand out for the universal access and high levels of service provision present. However, in many countries palliative care services are provided free of charge to some people, based on some form of means testing or entitlement, and in many others access is subsidised.

The lack of free and universal access based on need reflects in part the stage of development of palliative and end of life care services. An interesting example is **Slovakia**, where the statutory health insurance system funds some services (that are provided free of charge to users) and other services are provided at little or no charge by a range of organisations, and these are funded by a mixture of grants, donations and other voluntary sources of funds. In some respects the hospice movement in the UK has used this approach, with government mandated funds playing only a partial role.

#### **4.7 Legal and policy provisions**

Cancer control initiatives containing provisions for palliative care have traditionally been the entry point for legislation in this field, although these have the inherent drawback of limiting care provisions to cancer patients. National palliative care plans are generally recognised as a better tool to ensure service provision to end of life patients, and **Belgium** is one of the recognised leaders in this respect. In the 1990's, a series of laws laid the foundation for an organised palliative care system, including a) palliative care leave for relatives/caretakers; b) the integration of palliative care in nursing homes; c) public awareness campaigns; d) quantitative and qualitative standards for services and associations; e) training and continuing education for staff; f) logistical collaboration between service providers; g) development of day centres; and h) legalised euthanasia under very strict conditions.



The Belgian system is organised in local palliative care networks which are regulated by the central government, and while planners stopped just short of an ideal system (failing to institute a physician specialty), the palliative care networks are able to provide care for almost anyone who desires it.

Other, more targeted legislation is also noteworthy. Apart from Belgium, several countries have legal provisions which allow leave for workers looking after dying or dependent relatives, such as **France**, **Austria**, and, to a lesser extent, **Malta** (legislation is aimed at care of the elderly, not terminally ill patients). Opioid legislation and use is also important; in this respect, **Denmark** and the **Netherlands** have some of the most liberal legislation in Europe (see Table 2 for specific provisions). **Romania** has also made important advances in opioid legislation in the past few years and is a model in Eastern Europe of how political will and commitment can be an instrument for replacing antiquated laws which prevent patients from access to pain relief.

In **the UK** a government sponsored initiative led to the implementation of an End of Life Care Initiative in 2004. This consisted of the ‘roll out’ to mainstream services – and particularly those caring for patients with non-cancer advanced disease – of three key instruments: the Gold Standards Framework; the Liverpool Care Pathway for the dying patient; and the Preferred Place of Care tool. The initiative seeks to improve quality of care at the end of life for all patients, regardless of their diagnosis, enabling more patients to live and die in the place of their choice. This limited initiative is to be followed by a full End of Life Care Strategy for England, to be published in summer 2008.

## 5. General conclusions and policy options

### 5.1. The relevance of the underlying challenge and the goals of the report

With the well-known demographic changes which are taking place in the EU, palliative care will be of increased importance in providing care for the ageing population. Raised to the policy level, this translates to a need for efficient use of resources (both human and financial) to guarantee the best possible quality of care. Professionals must be trained, care must be accessible, and patients must be consulted and respected. In order to achieve these goals in Europe, different aspects of the field must be studied, both at a national and international level. This report seeks to evaluate palliative care development in the 27 Member States, particularly in recent years, analysing persistent challenges, highlighting national practices which might serve as a model for other European countries and identifying channels for further advancement.

### 5.2. The overall diagnosis

The palliative care field has advanced considerably in the last 5-10 years throughout Europe, and there are numerous national initiatives underway to further improve quality and equitable service coverage in the Member States. These measures attest to the dynamism of the palliative care field, but they also increase the complexity of comparative analysis. The ranking system used in this report (see section 2.8 for a detailed explanation) was specially formulated using data from a 2006 international study, and many of these most recent developments are not reflected (although they are described in the individual country reports). Two sets of criteria were used to calculate palliative care development: *palliative care resources*, which are weighted at 75% of the total index; and the perceived *vitality* of the field (critical mass of activists and professionals who increase the likelihood of short- and middle-term resource development), which are weighted at 25%. The global index, then, is a synthesis of these two elements.

It should be reiterated that this system does not take into account the latest developments, nor is it possible to include all relevant factors in all countries. Also, it is a relative rather than an *absolute* ranking of development. Therefore it should only be used to provide an **orientation** of a country's status, and in no case should be considered definitive. Based on these figures, and awarding 100% of possible score to Great Britain, the highest ranked State, the index is as follows: The countries which can claim between 50-85% of the UK's development are, in order of development, Ireland, Sweden, Netherlands, Poland, France, Spain, Germany, Belgium, Luxembourg, Austria, Italy, Denmark, Finland, and Latvia. Between 25-50% of the UK's development are Lithuania, Hungary, Bulgaria, the Czech Republic, Slovenia, Cyprus, Romania, Malta, Greece, Portugal, and Slovakia. Estonia, at 8%, is the least developed Member State in terms of palliative care development. The rank of each country is also listed at the beginning of the country reports; alternatively, please see Table 7 and Figure 4 to compare results of the global index.

It is interesting to note that although palliative care is usually more advanced in wealthier countries or regions, this is by no means the only factor in development. Finland's stage of palliative care development, for example, is comparable to Latvia, while Poland is ranked higher than France, Belgium, and Germany. Great differences in service provision exist within countries as well. Sometimes, these differences have to do with socio-economic status (such as in Italy), and other times the lines are drawn between rural and urban areas (such as in Hungary). Regional political will seems to be among the most important influences in Spain, and the presence of autonomous organisational structures is the key impediment to equitable service coverage in Denmark.

However, in each of these countries, and indeed throughout the Member States, it is clear that differences in availability and quality in palliative care persist and need urgent attention.

This can be accomplished by increased cooperation between countries and with the continued guidance of European health authorities. The report arising in 2001 from the European Health Committee and leading to the *Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care* was an example of how European leadership can stimulate national advancement in palliative care; policy-making is an excellent tool to foment the development of this essential field.

In our analysis of key areas of the palliative care field, we have also reached the following conclusions:

- Availability of services: each country has different formulae to provide care to their citizens, although generally home care is preferred. However, we understand that the EU should not be too specific in resource allocation recommendations. On the other hand, European leadership would be useful in other areas: adult cancer patients constitute the overwhelming majority of patients with access to palliative care in all countries; services should be extended as much as possible to children and citizens with other diseases. In addition, national legislation often impedes adequate opioid availability, this needs to be tackled with commitment and resolve. Opioid use is not ideal either; however this is more related to training and awareness than national legislation.
- Integrated health networks should be better articulated in order to ensure the best use of resources, following a multidisciplinary approach.
- Human resources: Most terminally ill patients remain under the care of their primary healthcare team and not under specialised care. Including palliative care in the undergraduate curricula of all nurses and physicians could quickly improve end of life care for many European citizens. Accredited specialisation would be an ideal complement to basic courses; when this is not feasible due to human or financial resource shortages, international cooperation (scholarships, mentorship of centres) could be an alternative path to short-term development. The role of volunteers should not be dismissed either, as they represent an invaluable human resource.
- Quality assurance: we have found that there are neither universally accepted standards for palliative care provision nor for professional accreditation; more research is needed to formulate quality indicators and to define the preparation needed in this field. This is an area which needs further development.
- Emotional and spiritual support should be consistently considered, including the perspectives related to patient needs, family-oriented support and staff burnout. Support for terminally ill paediatric patients and families may need particular attention.
- Research: a lot of pending questions need to be appropriately tackled through research. This would be the only way to identify evidence-based solutions in different settings. European support in this area could be an excellent path towards achieving a unified research platform. Because the field is relatively young, there is an opportunity to build this infrastructure from the bottom up and to learn from experiences in other fields such as cancer.
- Finance: Given the increasing understanding that palliative care services provide high priority needs it would be desirable if access were available on the same terms as for other health and social care, and that funding should ensure that this can be achieved. While such integration would in general be desirable, the history of innovation and development from voluntary and charitable organisations might mean that the funding and management of palliative services would remain more diverse than for acute hospital services.

As a whole, the EU has the tools and the expertise necessary to face these challenges. There are numerous centres of excellence throughout Europe that are actively tackling these issues; these centres (described in detail in section 4) can act as models or mentors for other organisations. Indeed, correctly managed international cooperation and networking maximise results and strengthen both the field and the wider society.

### 5.3. Some policy options

In light of this complex reality, and a range of potential operational policy options could be considered:

**Option 1:** status quo: Trust that palliative care will develop by encouraging the use of general public health tools already in place in most countries, such as the Patients' Bill of Rights or regulations limiting the waiting time in healthcare centres. If palliative care were officially included in healthcare services offered by the national health service, no new laws would be necessary.

**Pros:** This horizontal approach respects national competencies and eliminates the need to create complicated monitoring systems and tools to ensure that the rules are complied with. Usually the only possible tool is the threat of financial penalties. New legislation is also perceived to increase bureaucracy and inflexibility, and recommendations and guidelines are not sufficiently practical.

**Cons:** Great differences in the availability and quality of palliative care throughout Europe suggest that this approach may be ineffective. It is clear that development in many places remains patchy, uncoordinated and poorly integrated with wider systems of health and social care delivery. A "push" from the EU could stimulate national development; indeed, the *Recommendation Rec (2003) 24* has been followed by numerous national initiatives. Furthermore, failing to pass EU measures could be discouraging to patient groups and national palliative care associations who actively seek more public support.

**Option 2:** General recommendations (but not new legislation) promoted by the European Parliament:

**Pros:** any practical developments need to be based on appropriate needs assessments. This has proven to be very useful in some countries with less-developed palliative care systems, particularly in Eastern Europe, where recommendations can be used as a tool for advocacy and lobbying. This would still respect the idea expressed by some Member States' ministries which do not see the need for any new EU legislation, although they would accept certain guidelines in the palliative care field.

**Cons:** this would perhaps be perceived as a too modest contribution in a field where basic equity and proper European harmonisation needs to be ensured.

Potential recommendations which could be considered :

- Encourage all countries to devise national plans for palliative care and end of life care in close collaboration with professionals and representatives of patients and families and to establish at least one national centre of excellence in the field.
- Promote availability and proper use of opioids when needed (through guidelines)
- Promote integrated healthcare networks which include proper attention to palliative care
- Improve information and knowledge systems, including support for research and evaluation in the areas highlighted above, as part of the next EU Framework Programme.

- Promote plans for palliative care training at both basic and advanced levels of health staff education (particularly in medicine and nursing). Building capacity: skills, knowledge, confidence, networks.
- Encourage countries to facilitate specialist certification / accreditation of physicians and other professionals who work in the palliative care field. This could be accomplished through the establishment of academic chairs in countries with strong general palliative care infrastructures or perhaps scholarships and international partnerships for countries with less development.
- Promote trained volunteering programmes, which are both cost-efficient for the health system and personally rewarding for the volunteer.
- Promote specific programmes and measures to provide emotional, social, and financial support to families /relatives of patients at the end of their lives.
- Promote national palliative care research as well as a European palliative care research agenda, ensuring specific budget for the field.
- Identify and promulgate best practices in palliative care.
- Forge partnerships and collaboration. Commission periodic, detailed studies, in order to update the situation and to carry out self-assessment and benchmarking within and between Member States. This might be done with the help of credible and experienced organisations or with the formation of a parliamentary committee such as “MEP’s for Palliative Care,” which might be similar to the committee “MEP’s Against Cancer.”

Please also refer to our previous diagnosis related to conclusions within the key areas of the palliative care field.

**Option 3:** New legislation (directives) and proactively led actions promoted by the European Parliament, ensuring patient rights and access to proper palliative care:

Pros: this would be the bravest option and would certainly be useful in countries with the necessity to develop palliative care systems. This could be complemented with all or some of the previously systematised recommendations

Cons: complexity of the legislative generation at the European level; harmonisation between countries (many of whom have palliative care plans in place) would be problematic.

Potential legislation and proactively led actions promoted by the European Parliament which could be considered :

- Act or Directive on the Status and Rights of Patients, guaranteeing equal rights of patients, and the European regulation on access to health care and minimum waiting times—these already guarantee and cover the main topics of the palliative care field.
- Ensure availability of opioids when needed (through proper legislation)
- Development of an EU strategy, action plan and monitoring system.
- Creation of a dialogue with Member States to identify priorities and an action plan and consider the need for Council Recommendations, as above
- Launching of an EU Platform for palliative care to promote cross-sectoral cooperation (health, education, social services...) in line with the objectives of the proposed strategy
- Establishment of an interface between policy and research to promote the development of indicators, certification for professionals and monitoring systems and to propose priorities for palliative care

- Development of resources, materials, tools and services
- Public policies that enable palliative care to be mainstreamed
- Declaration of palliative care as a basic human right
- Creation of a European reference centre or European Institute of Palliative Care to monitor and guide research, track service development and promote evidence based policy, education and practice
- Develop a “road map” for cross-border cooperation between Member States and/or specifically support rights of patient mobility between countries

The research team which has carried out this report would like to acknowledge their respect and esteem for the competencies of the European Parliament and its members, who are ultimately responsible for deciding which is the correct path for guiding future European development in this field. We are aware of the extraordinary dynamism of the field and the context. The potential ratification of the Treaty of Lisbon plus the conclusions of the so-called "high level reflection on patient mobility and healthcare developments in the European Union," as well as other recent actions considering new perspectives and needs from patients, health services and Health Systems throughout the different Member States, may provide a solid ground to new opportunities and areas of cooperation related to palliative care services within the EU.

It has been our intention throughout the investigation to describe the main elements and challenges facing palliative care in Europe, provide concise, accurate information regarding the status of the Member States (giving the opportunity to relevant stakeholders to share their perspectives), and highlight a few of the many outstanding examples of best practices in this field. We hope that in doing so, we have been able to empower European Parliament Members to make an informed decision regarding future measures on palliative care initiated by this organism. A few possible measures have been briefly listed in this section; these should by no means be interpreted as the only options which could improve palliative care, but rather a compendium of ideas which are open to debate and refinement.

## Cited bibliography /references

- [1] About the EAPC. European Association of Palliative Care) [Online]. Available from: URL: <http://www.eapcnet.org/about/about.html> [14.2.2006]
- [2] Luczak J, Kluziak M. 'The formation of ECEPT (Eastern and Central Europe Palliative Task Force): a Polish initiative.' *Palliat Med* 2001; 15:259-60.
- [3] Francke AL, Kerkstra A. 'Palliative care services in the Netherlands: a descriptive study.' *Issues Law Med* 2002; 18:111-26.
- [4] Children's Hospice. Kliczek Foundation) [Online]. Available from: URL: <http://www.kliczek.org/> [14.4.2008]
- [5] De Conno F et al. 'Palliative Care in a National Cancer Center: Results in 1987 vs. 1993 vs. 2000.' *J Pain Symptom Manage* 2003; 25:499-511.
- [6] Larue F et al. 'Oncologists and primary care physicians' attitudes toward pain control and morphine prescribing in France.' *Cancer* 1995; 76:2375-82.
- [7] Bauwens S et al. 'Attitudes and knowledge about cancer pain in Flanders. The educational effect of workshops regarding pain and symptom control.' *Palliat Med* 2001;15:181-9.
- [8] Hinkka H et al. 'Assessment of pain control in cancer patients during the last week of life: comparison of health centre wards and a hospice.' *Support Care Cancer* 2001; 9:428-34.
- [9] Radbruch L et al. 'What is palliative care in Germany? Results from a representative survey.' *J Pain Symptom Manage* 2002; 23:471-83.
- [10] Gancheva A, Kirkova J. Palliative care in Bulgaria. 'Presentation for the palliative medicine advanced course.' *Puszczykowo* (Poland), May 24th-29th, 1998.
- [11] Sadovska O. 'Department of palliative care in Bratislava and the development of the palliative care movement in Slovakia.' *Support Care Cancer* 1997; 5:430-4.
- [12] Gomez-Batiste X, Porta J, Tuca A. 'Palliative care at the Institut Català d'Oncologia, Barcelona.' *Eur J Palliat Care* 2003; 10:205-8.
- [13] Muszbek K, Toldy-Schedel E. 'Hungary: palliative care--a new challenge.' *J Pain Symptom Manage* 2002; 24:188-90.
- [14] Blengini C, Ventafridda V. 'Use and cost of opioids in Italy.' *J Pain Symptom Manage* 2000; 20:397-8.
- [15] Hare A, Gorchakova A. 'The growth of palliative care for children in Latvia.' *Eur J Palliat Care* 2004; 11:116-8.
- [16] Kujawska-Tenner J, Luczak J. 'First Lithuanian-Polish Symposium on Palliative Care.' *Prog Palliat Care* 1996; 4:131.
- [17] Luczak J, et al. 'Poland: cancer pain and palliative care.' *J Pain Symptom Manage* 2002; 24:215-21.
- [18] Furst CJ. 'Perspectives on palliative care: Sweden.' *Support Care Cancer*. 2000; 8:441-3.
- [19] Rygh EM, Hjortdahl P. 'Continuous and integrated health care services in rural areas. A literature study.' *Rural Remote Health* 2007; 7:766.

- [20] Chapman JL et al. 'Systematic review of recent innovations in service provision to improve access to primary care.' *Br J Gen Pract* 2004; 54: 374-81.
- [21] Phillips JL et al. 'Enhancing palliative care delivery in a regional community in Australia' *Aust Health Rev* 2006; 30:370-9.
- [22] Kelley ML, Habjan S, Aegard J. 'Building capacity to provide palliative care in rural and remote communities: Does education make a difference?' *J Palliat Care* 2004; 20:308-15.
- [23] Campbell NC et al. 'Systematic review of cancer treatment programs in remote and rural areas' *Br J Cancer* 1999; 80:1275-80.
- [24] Von Gunten CF, Lupu D. 'Recognizing Palliative Medicine as a Subspecialty: What Does It Mean for Oncology?' *J Support Oncol* 2004; 2:166-74.
- [25] Centeno C et al. 'Official Certification Of Doctors Working In Palliative Medicine In Europe: Data From An EAPC Study In 52 European Countries.' *Palliat Med* 2007; 21:683-7.
- [26] Filbet M et al. '*Curriculum In Palliative Care For Undergraduate Medical Education, Recommendations of The Eapc*'. Milan, EAPC; 2007. Available from: URL: <http://www.eapcnet.org/download/fortaskforces/physicianstf/pc-curr-undergraduatemededu.pdf> [04.04.2008]
- [27] *National Cancer Control Programmes Policies and managerial guidelines*. 2nd edition. WHO (2002) p 84 Lloyd-Williams M, Macleod RD, 'A systematic review of teaching and learning in palliative care within the medical undergraduate curriculum.' *Med Teach* 2004; 26:683-690.
- [28] Kaasa S, Hjermstad MJ, Loge JH. 'Methodological and structural challenges in palliative care research: how have we fared in the last decades?' *Palliat Med* 2006; 20:727-34.
- [29] Clark D editor. '*Cicely Saunders Founder of the Hospice Movement Selected Letters 1959-1999*' Oxford: Oxford University Press, 2002.
- [30] Larkin P. 'Nurses and Nurse Practitioners'. In: Walsh D et al (eds.) *Palliative Medicine*. Philadelphia: Elsevier, 2007.
- [31] Filbet, M, Larkin, P. 'Palliative Education in Europe' In: Wee B and Hughes N (eds.) *Education in Palliative Care: Building a Culture of Learning*. London: Clarendon Press, 2007.
- [32] World Health Organization. 'Definition of palliative care 2002' Available from: URL: <http://www.who.int/cancer/palliative/definition/en/print.html> [25.10.2005].
- [33] Larkin P. 'Developing a nurse education network across Europe'. *Int J Palliat Nurs* 2005; 11:420-2.
- [34] Lunt I. 'A common framework for the training of psychologists in Europe'. *European Psychologist* 2002; 7:180-91.
- [35] Lunt I et al. *EuroPsyT- a framework for education and training for psychologists in Europe*. Brussels: EFPPA, 2001.
- [36] EAPC. 'Recommendations for Palliative Care Education in Europe'. Steering Committee Education of the European Association for Palliative Care. Lyon, 24-26 November 2000.
- [37] Fernández Fernández ME et al. 'Estándares de formación psicológica en Cuidados Paliativos.' *Med Pal* 2004; 11:174-9.



- [38] Die-Trill M, Holland J. 'A model curriculum for training in psycho-oncology.' *Psycho-Oncology* 1995; 4:169-82.
- [39] Dolbeault S, Szporn A, Holland J. 'Psycho-Oncology: where have we been? Where are we going?.' *Eur J Cancer* 1999; 35:1554-8.
- [40] ASPBOA. *Standards of Care for the management of distress in patients with Cancer*, 1999.
- [41] Baider L, Wellisch DK. *Psycho-Oncology. Training program Curriculum-IPOS OR ASPBOA 1998-2001*.
- [42] EAPC. Report and recommendations of a workshop on palliative medicine education and training doctors in Europe. Brussels, March 20th-21st, 1993.
- [43] Sepulveda C et al. 'Palliative Care: the World Health Organization's global perspective.' *J Pain Symptom Manage* 2002; 24:91-6.
- [44] Donabedian A. 'The quality of care. How can it be assessed?' *JAMA* 1988; 260:1743-8.
- [45] Nauck F et al. 'Kerndokumentation für Palliativstationen - Strukturqualität und Ergebnisqualität.' *Z Palliativmed* 2002; 3:41-9.
- [46] Larue F et al. 'Multicentre study of cancer pain and its treatment in France.' *Br Med J* 1995; 310:1034-7.
- [47] Bruera E et al. 'The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients.' *J Palliat Care* 1991; 7:6-9.
- [48] Groenvold M et al. 'The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care.' *Eur J Cancer* 2006; 42:55-64.
- [49] Waldron D et al. 'Quality-of-life measurement in advanced cancer: assessing the individual.' *J Clin Oncol* 1999; 17: 3603-11.
- [50] Lindena G et al. *Qualitätssicherung in der Palliativmedizin - Ergebnisse der Kerndokumentation 1999-2002. Z Arztl Fortbild Qual Gesundheitswes* 2005; 99:555-65
- [51] Hearn J, Higginson IJ. 'Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group.' *Qual Health Care* 1999; 8:219-27.
- [52] Ellershaw JE, Murphy D. 'The Liverpool Care Pathway (LCP) influencing the UK national agenda on care of the dying.' *Int J Palliat Nurs* 2005; 11:132-4.
- [53] Hanks GW et al. 'The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team.' *Br J Cancer* 2002; 87:733-9.
- [54] Jordhoy MS et al. 'A palliative-care intervention and death at home: a cluster randomised trial.' *Lancet* 2000; 356:888-93.
- [55] Jordhoy MS et al. 'Quality of life in palliative cancer care: results from a cluster randomized trial.' *J Clin Oncol* 2001; 19:3884-94.
- [56] Ringdal GI, Jordhoy MS, Kaasa S. 'Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial.' *J Pain Symptom Manage* 2002; 24:53-63.
- [57] Pritchard RS et al. 'Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment.' *J Am Geriatr Soc* 1998; 46:1320-1.

- [58] Martin-Moreno JM. 'The Importance of Being Quality.' *Qual Health Care* 2007; 1: 9-11.
- [59] Kaasa S, Hjermstad MJ, Loge JH. 'Methodological and structural challenges in palliative care research: how have we fared in the last decades?' *Palliative Medicine* 2006; 20:727-34.
- [60] Davies E, Higginson IJ (eds.). *Palliative care: the solid facts*. Copenhagen: WHO Regional Office for Europe, Copenhagen, 2004. Available from: URL: <http://www.euro.who.int/document/E82931.pdf>
- [61] The Association for Palliative Care Research Network (EAPC RN) [Online]. Available from: URL:<http://www.eprc.org>
- [62] Hanks GW et al. 'Morphine and alternative opioids in cancer pain: the EAPC recommendations.' *Br J Cancer* 2001; 84:587-93.
- [63] Kaasa S, Radbruch L. 'Palliative care research - priorities and the way forward.' *Eur J Cancer* 2008 Mar 26 [Epub ahead of print].
- [64] Higginson IJ. 'End-of-life care: lessons from other nations.' *J Palliat Med* 2005; 8:S161-S73.
- [65] Fainsinger RL. 'Global Warning in the Palliative Care Research Environment – Adapting to Change (invited lecture).' *EAPC Research Forum, May 2008*.
- [66] National Cancer Research Institute. *Supportive and palliative care research in the UK: Report of the NCRI strategic planning group on support & palliative care*. London: National Cancer Research Institute, 2004
- [67] Cancer Experiences Collaborative. [Online]. Available from: URL: <http://www.ceco.org.uk/>. [13.05.2008]
- [68] Compass Collaborative. [Online]. Available from: URL:<http://www.compasscollaborative.com/index.htm>. [13.05.2008]
- [69] All-Ireland Institute for Hospice & Palliative Care. [Online]. Available from: URL:<http://www.allirelandnci.org/pdf/communique4.pdf>. [13.05.2008]
- [70] Breitbart W, Marotta RF, Call P. 'AIDS and neuroleptic malignant syndrome.' *Lancet* 1988; 2:1488-9.
- [71] Breitbart W, Chochinov HM (eds.). *Handbook of Psychiatry in Palliative Medicine*. New York: Oxford University Press, 2000.
- [72] Grassi L, Travado L. 'The role of psychosocial oncology in cancer care.' In: Coleman MP et al (eds.). *Responding to the challenge of cancer in Europe*. Ljubljana: Institute of Public Health of the Republic of Slovenia, 2008, pp. 209-31.
- [73] Koch U, Mehnert A. *Psychosocial Assessment in Cancer Patients. Multilingual Core Curriculum in Psycho-Oncology*. International Psycho-oncology Society. Available from: URL: <http://www.ipos-society.org>
- [74] Noorani NH, Montagnini M. Recognizing depression in palliative care patients. *J Palliat Med* 2007; 10:458-64.
- [75] Kissane D, Clarke DM, Street AF. 'Demoralization syndrome- a relevant psychiatric diagnosis for palliative care.' *J Palliat Care* 2001; 17:12-21.
- [76] Breitbart W, Holland JC (eds). *Psychiatric Aspects of Symptom Management in Cancer Patients*. Washington, DC: American Psychiatric Press, 1993.

- [77] Breitbart W et al. 'Neuropsychiatric syndromes and psychological symptoms in patients with advanced cancer. *J Pain Symptom Manage* 1995; 10:131-41.
- [78] Breitbart W, Sparrow B. 'Management of delirium in the terminally ill.' *Progress in Palliat Care* 1998; 6:107-13.
- [79] Breitbart W, Chochinov H, Passik S. 'Psychiatric symptoms in palliative medicine.' In: Doyle D et al (eds.). *Oxford Textbook of Palliative Medicine*, (3rd ed.) New York: Oxford University Press, 2004, pp. 746-71.
- [80] Bolund C. Suicide and cancer: II. Medical and care factors in suicide by cancer patients in Sweden. 1973-1976. *J Psychosoc Onc* 1985; 3:17-30.
- [81] Farberow NL, Schneidman ES, Leonard CV. 'Suicide among general medical and surgical hospital patients with malignant neoplasms.' *Medical Bulletin* 9, Washington, DC, U.S. Veterans Administration, 1963.
- [82] Fox BH et al. 'Suicide rates among cancer patients in Connecticut.' *J Chronic Dis* 1982; 35:85-100.
- [83] Louhivuori KA, Hakama J. 'Risk of suicide among cancer patients.' *Am J Epidemiol* 1979; 109:59-65.
- [84] Ayd F. 'Amoxapine: a new tricyclic antidepressant.' *Int Drug Ther Newsl* 1979; 14:33-40.
- [85] Lloyd AH. 'Practical consideration in the use of maprotiline (ludiomil) in general practice.' *J Int Med Res* 1977; 5:122-5.
- [86] Farberow NL, Ganzler S, Cuter F, Reynolds D. 'An eight year survey of hospital suicides.' *Suicide Life Threat Behav* 1971; 1:184-201.
- [87] Rosenfeld B, Krivo S, Breitbart W, et al. 'Suicide, assisted suicide, and euthanasia in the terminally ill.' In: Chochinov HM, Breitbart W (eds.). *Handbook of Psychiatry in Palliative Medicine*. New York: Oxford University Press, 2000, pp 51-62.
- [88] Breitbart W. 'Suicide in cancer patients.' *Oncology* 1987; 1:49-55.
- [89] Chochinov HMC et al. 'Desire for death in the terminally ill.' *Am J Psychiatry* 1995; 152:1185-91.
- [90] Breitbart W, Rosenfeld BD, Passik SD. 'Interest in physician-assisted suicide among ambulatory HIV infected patients.' *Am J Psychiatry* 1996, 153:238-42.
- [91] Emmanuel EJ et al. 'Euthanasia and physician-assisted suicide: Attitudes and experiences of oncology patients, oncologists and the public.' *Lancet* 1996; 347:1805-10.
- [92] Holland JC. 'Principles of psychooncology.' In: Holland JC and Frei E (eds.). *Cancer Medicine* (3rd Ed.) Philadelphia, PA: Lea & Febiger, 1993, pp 1017-33.
- [93] Breitbart W. 'Cancer pain and suicide.' In: Foley K et al (eds.). *Advances in Pain Research and Therapy*. (Vol. 16). New York: Raven Press, 1990, pp. 399-412.
- [94] Spiegel D, Spira J. *Supportive- Expressive Group Therapy: A treatment Manual of Psychosocial Intervention for Women with Recurrent Breast Cancer*. Stanford, CA: Stanford University School of Medicine Department of Psychiatry, 1991.
- [95] Rodin G, Gillies LA. 'Individual psychotherapy for the patient with advanced disease.' In: Chochinov HM and Breitbart W (Eds), *Handbook of Psychiatry in Palliative Medicine* New York: Oxford University Press, 2000, pp. 189-96.

- [96] Markowitz JC et al. 'Treatment of depressive symptoms in human immunodeficiency virus-positive patients.' *Arch Gen Psychiatry* 1998; 55:452-7.
- [97] Lewis MI, Butler R. 'Life review therapy: Putting memories to work in individual and group psychotherapy.' *Geriatrics* 1974; 29:165-69.
- [98] Pickrel J. 'Tell me your story: Using life review in counseling the terminally ill.' *Death studies* 1989; 13:127-35.
- [99] Breitbart et al. *The IPOS "Pocket" Handbook of Palliative Care for the Psycho-oncologist*. IPOS Press, 2008 (in press).
- [100] Chochinov HM, Holland JC. 'Bereavement: a special issue in oncology.' In: Holland JC and Rowland JH (eds.). *Handbook of Psycho-oncology: Psychological Care of the Patient With Cancer*. New York: Oxford University Press, 1989, pp.612-31.
- [101] Meador K. 'Spiritual Care at the End of Life: What Is It and Who Does It?' *NC Med* 2004; 65:226-8.
- [102] Travado et al. *Does spirituality make a difference?* Report from the Southern European Psycho-Oncology Study (SEPOS) 2008 (under submitted).
- [103] Breitbart W. Spirituality and meaning in supportive care: spirituality-and meaning centered group psychotherapy interventions in advanced cancer. *Support Care Cancer* 2002; 10:272- 80.
- [104] Kissane D et al. 'Cognitive existential group therapy for patients with primary breast cancer-techniques and themes.' *Psycho-oncology* 1997; 6:25-33.
- [105] Frankl VF. *The doctor and the soul*. New York: Random House, 1955/1986.
- [106] Chochinov HM. 'Dignity-conserving care-A new model for palliative care: helping the patient feel valued.' *JAMA* 2002; 287:2253-60.
- [107] Chochinov HM et al. 'Dignity in the terminally ill: a cross-sectional, cohort study.' *Lancet* 2002; 360:2026-30.
- [108] Greenstein M, Breitbart W. 'Cancer and the experience of meaning: A group psychotherapy program for people with cancer.' *Am J Psychother* 2000; 54:486-500.
- [109] Breitbart W, Heller KS. 'Reframing hope: Meaning-centered care for patients near the end of life.' *J Palliat Med* 2003; 6:979-88.
- [110] Field MJ, Cassel CK. *Approaching Death: Improving Care at the End of Life*. Washington: National Academy Press, 1997.
- [111] Higginson IG, Costantini M. 'Dying with cancer, living well with advanced cancer.' In: Coleman MP et al (eds.). *Responding to the challenge of cancer in Europe*. Ljubljana: Institute of Public Health of the Republic of Slovenia, 2008, pp 231-53.
- [112] Caraceni A, Grassi L. *Delirium-acute. confusional states in palliative medicine*. New York: Oxford University Press, 2003.
- [113] Goetschius SK. 'Caring for families: the other patient.' In: Matzo ML and Sherman DW (eds.). *Palliative Care Nursing: Quality Care to the End of Life*. New York: Springer, 2001, pp. 245-74.
- [114] Lewis FM. 'The impact of cancer on the family: a critical analysis of the research literature.' *Patient Educ Couns* 1986; 8:269-89.
- [115] Lederberg M, Massie MJ 'Staff support and training in Psycho-oncology.' In: Holland J (ed.). *Psycho-Oncology*. New York: Oxford University Press, 1998, pp. 1035-69.

- [116] Wellish D. 'Family and Palliative Care' In: Chochinov HM and Breitbart W (eds.). *Handbook of psychiatry in palliative medicine*. New York: Oxford University Press, 2000, pp. 275-336.
- [117] Given BA, Given CW, Kozachiv S. 'Family support in advanced cancer.' *CA Cancer J Clin* 2001; 51:213-31.
- [118] Centeno C, Núñez Olarte JM. 'Questioning diagnosis disclosure in terminal cancer patients: a prospective study evaluating patients' responses.' *Palliat Med* 1994; 8:39-44.
- [119] Travado L et al. 'Physician-patient communication among Southern European cancer physicians: The influence of psychosocial orientation and burnout.' *Psycho-Oncology* 2005; 14:661-70.
- [120] Ramirez AJ et al. 'Mental Health of hospital consultants: the effects of stress and satisfaction at work.' *Lancet* 1996; 347:724-8.
- [121] Grassi L et al. 'A communication intervention for training Southern European oncologists to recognize psychosocial morbidity in cancer patients. I-Development of the model and preliminary results on physicians' satisfaction.' *J Cancer Edu* 2008 (in press)
- [122] Back AL et al. 'Teaching communication skills to medical oncology fellows.' *J Clin Oncol* 2003; 21:2433-6.
- [123] Baile WF et al. 'Improving physician-patient communication in cancer care: outcome of a workshop for oncologists.' *J Cancer Educ* 1997; 12:166-73.
- [124] Fallowfield L, Lipkin M, Hall A. 'Teaching senior oncologists communication skills: results from phase I of a comprehensive longitudinal program in the United Kingdom.' *J Clin Oncology* 1998; 16:1961-8.
- [125] Fallowfield L et al. 'Enduring impact of communication skills training: results of a 12-month follow-up.' *Br J Cancer* 2003; 89:1445-9.
- [126] Maguire P. *Assessing patients with cancer. The content, skill and process of assessment*. Manchester: Psychological Medicine Group, Cancer Research Campaign, 1996.
- [127] Parle M, Maguire P, Heaven C. 'The development of a training model to improve health professionals skills, self-efficacy and outcome expectancies when communicating with cancer patients.' *Soc Sci Med* 1997; 44:231-40.
- [128] Razavi D et al. 'Testing health care professionals' communication skills: the usefulness of highly emotional standardized role-playing sessions with simulators.' *Psychooncology* 2000; 9:293-302.
- [129] Razavi D et al. 'How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of post training consolidation workshops.' *J Clin Oncol* 2003; 21:3141-9.
- [130] Materstvedt LJ et al. 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force.' *Palliat Med* 2003; 17:97-101.
- [131] Gómez Sancho M, Ojeda Martín M. 'Medicina paliativa y eutanasia.' In: Gómez Tomillo et al (eds.). *Aspectos médicos y jurídicos del dolor, la enfermedad terminal y la eutanasia*. Madrid: Fundación Lilly, 2008, pp. 519-72.
- [132] World Health Organization. *Achieving balance in national opioids control policy: guidelines for assessment*. Geneva: World Health Organization, 2002.

- [133] World Health Organization. *Access to Controlled Medications Programme. Biennial Report 2006-2007*. Geneva: World Health Organization, 2008 (doc WHO/PSM/QSM/2008). Available from:  
URL:[http://www.who.int/medicines/areas/quality\\_safety/ACMP\\_Biennial\\_Report\\_2006-07\\_EN.pdf](http://www.who.int/medicines/areas/quality_safety/ACMP_Biennial_Report_2006-07_EN.pdf)
- [134] Clark D, Centeno C. 'Palliative Care in Europe: An Emerging Approach To Comparative Analysis.' *Clin Med*. 2006; 6:197-201.
- [135] Wright M et al. 'Mapping levels of palliative care development: a global view.' *J Pain Symptom Manage* 2008; 35:469-85.
- [136] Centeno C et al (EAPC Task Force.) 'Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC Task Force.' *Palliat Med* 2007; 21:463-71.
- [137] Centeno C et al. *EAPC Atlas of Palliative Care in Europe*. Milan: IAHP Press, 2007.
- [138] Slovenian Presidency of the EU 2008. Member State Information. [Online]. Available from: [URL:http://www.eu2008.si/en/About the EU/Member States/index.html](http://www.eu2008.si/en/About_the_EU/Member_States/index.html) [2.04.2008].
- [139] Schermann-Richter U (Federal Ministry of Health). 'Palliative Care in Austria.' E-mail dated 28.04.2008.
- [140] Gronemeyer R et al. *Helping people at the end of their lives: hospice and palliative care in Europe*. Berlin: Lit Verlag, 2005.
- [141] Baumgartner, J (Hospice Austria, Austrian Palliative Care Association). 'Study on PalCare in EU (with attachment).' E-mail dated 09.05.2008.
- [142] Federale Evaluatiecommissie Palliatieve Zorg. *Evaluatierapport Palliatieve Zorg*. Brussels: Federale Overheidsdienst Volksgezondheid, 2005.
- [143] Rocafort, J. *Estudio del desarrollo y consolidación de los cuidados paliativos en Europa a través de la literatura científica* [doctoral thesis]. Pamplona: University of Navarra, 2007.
- [144] *Monitoring End of Life Care*. Available from: URL:<http://www.endoflifecare.be>. [10.04.2008].
- [145] Clark D, Wright M. *Transitions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia*. Great Britain: Open University Press, 2003.
- [146] *International End-of-Life Care Observatory*. Country Reports. Available from: URL:<http://www.eolc-observatory.net> [3.03.2008].
- [147] Pantehki, S (Cyprus Anti-Cancer Society). 'Questionnaire pc associations.' E-mail dated 27.2.2008.
- [148] Cerná E (Association of Hospice Palliative Care Providers). 'Re: Palliative Care Questionnaire.' E-mail dated 10.04.2008.
- [149] Jespersen, B A (Danish Society of Palliative Medicine). 'Re: Danish Society of Palliative Medicine.' E-mail dated 13.03.2008.
- [150] Aasøe, M (National Board of Health). Letter dated 30.04.2008.
- [151] Normet I (Deputy Secretary General for Health Policy). 'Palliative Care in Estonia.' E-mail dated 14.03.2008.

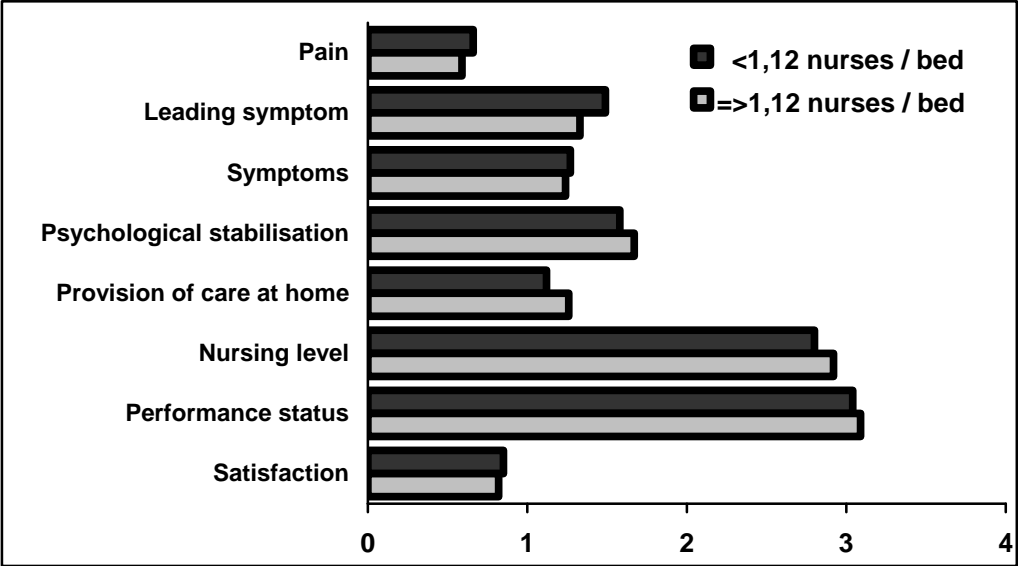
- [152] Risikko P (Minister of Health and Social Services, Finland). Letter dated 11.03.2008.
- [153] Hildén HM, Louhiala P, Palo J. 'End of life decisions: attitudes of Finnish physicians.' *J Med Ethics* 2004; 30:362-5.
- [154] Comité national de suivi du développement des soins palliatifs et de l'accompagnement. *Rapport de fin d'exercice*. Paris: Ministère de la Santé, de la Jeunesse et des Sports, 2008.
- [155] Institut National de Prévention et d'Education pour la Santé. 'Les patients en fin de vie: Soins palliatifs et accompagnement.' Available from: URL:<http://www.inpes.sante.fr/> [25.04.2008]
- [156] Act 2005-370 of 22 April, on Patients' Rights. (JORF number 95, 23.04.2005).
- [157] Obert HW (German Ministry of Health). 'Palliative Care.' E-mail dated 01.04.2008.
- [158] Ministerial Decision No Y4a/162012, regarding chronic pain units. (Official Journal of the Government No 150 B 1/02/2008).
- [159] Raidou, F (Head of the Directorate of International Relations, Ministry of Health and Social Solidarity). Letter dated 12.05.2008.
- [160] Vadalouca, A (Hellenic Society for Palliative and Symptomatic Care for Cancer and non Cancer Patients). 'Study on palliative care in the EU.' E-mail dated 25.03.2008.
- [161] Mistakidou, K (Hellenic Association for Pain Control and Palliative Care). 'Study on palliative care.' E-mail dated 13.03.2008.
- [162] Talas K and Toth I (Minister of Health, Hungary). 'Re: Palliative Care in Hungary.' E-mail dated 8.04.2008.
- [163] Hegedus, Katalin (President of the Hungarian Hospice Palliative Association). 'Re: Study on Palliative Care in the European Union.' E-mail dated 26.03.2008.
- [164] Murphy M, Quinlan P. 'Managing Palliative Care Services in the Irish Republic.' In: Ling J and O'Siorín L (eds.). *Facing Death: Palliative Care in Ireland*. Maidenhead: Open University Press, 2005, pp.33-42.
- [165] Murray, Eugene. 'Has Ireland's national policy benefited palliative care?' *EurJ Pall Care* 2008; 15:2
- [166] Ling J, O'Siorain L. 'Introduction.' In: Ling J and O'Siorín L (Eds). *Facing Death: Palliative Care in Ireland*. Maidenhead: Open University Press, 2005, pp. xxi-xxiii.
- [167] Beccaro, M, Costatini M, Franco Merlo DF: ISDOC Study Group. 'Inequity in the provision of and access to palliative care for cancer patients. Results from the Italian survey of the dying of cancer (ISDOC).' *BMC Public Health* 2007; 7:66.
- [168] Benini F (Department of Paediatrics, Univerisity of Padua). 'Re: Eur Parliament Palliative Care project - Sharing draft report and asking for feedback.' E-mail dated 24.04.2008.
- [169] Floriani F, Zaninetta, G (President Federazione Cure Palliative, President Società Italiana di Cure Palliative). 'Re: Palliative Care in Italy- SICP - FCP.' E-mail dated 29.03.2008.
- [170] Ploriņš A (State Secretary of Latvia). 'Re: Referring to your letter of 18 February 2008.' E-mail dated 13.03.2008.
- [171] Šeškevičius A (Lithuania Palliative Medicine Association). 'Re: Study on Palliative Care in the European Union.' E-mail dated 18.03.2008.

- [172] Vaitkiene, R (Secretary of the Ministry of Health). Letter dated 09.04.2008.
- [173] Mousty R (First Government Advisor, Ministry of Health of Luxembourg). Letter dated 5.03.2008.
- [174] Shah A (The Malta Hospice Movement). 'Re: Study on Palliative Care in the European Union.' E-mail dated 19.02.2008.
- [175] Dalmas, M (Director Health Policy Development and EU Affairs). 'Re: Study of Palliative Care.' E-mail dated 20.04.08.
- [176] Shah A (The Malta Hospice Movement). 'Re: Questionnaire.' E-mail dated 26.03.2008.
- [177] Gootjes J (Netherlands Palliative Care Network). 'Information the Netherlands.' E-mail dated 1.04.2008.
- [178] Ministry of Health. 'Information on the organisation of palliative and hospice care in Poland.' Warsaw: Ministry of Health, 2008.
- [179] Equipas Cuidados Paliativos. Associacao Portuguesa de Cuidados Paliativos. Available from: URL:<http://www.apcp.com.pt/index.php?n=equipas-c.-paliativos&cod=90&subCat=90> [28.03.2008]
- [180] Parra da Silva, F (Cabinet Chief of the Ministry of Health). Letter dated 28.03.08
- [181] Ferraz Goncalves JA. 'A Portuguese palliative care unit.' *Support Care Cancer* 2001; 9:4-7.
- [182] Bogdan C (The Romanian Society of Palliatology & Thanatology). 'RE: From SRPT Romania.' E-mail dated 12.03.2008.
- [183] Vladu C (General Directorate for Policies, Strategies, and Quality Management in Health (Romania)). 'RE: Palliative care in Romania.' E-mail dated 14.03.2008.
- [184] Valentovic, I (Minister of Health of Slovakia). Letter dated 20.03.2008.
- [185] Zargi T (Slovenian Hospice Association). Letter dated 12.03.2008.
- [186] Gómez Batiste X (Sociedad Española de Cuidados Paliativos). 'Informe solicitado por el Parlamento Europeo relativo a Cuidados Paliativos en los países de la UE.' E-mail dated 25.03.2008.
- [187] Ministerio de Sanidad y Consumo. *Estrategia nacional de cuidados paliativos*. Madrid: Ministerio de Sanidad y Consumo, 2007.
- [188] Infante Campos A (General Director of the Quality Agency for the NHS). 'RE: Datos para Informe solicitado por el Parlamento Europeo relativo a Cuidados Paliativos en los países de la UE.' E-mail dated 24.03.2008.
- [189] Act 39/2006 of the 14 of December, on the Promotion of Personal Autonomy and Care for Dependent Persons. BOE number 299 [15.12.2006].
- [190] Infante Campos A. (General Director of the Quality Agency for the NHS). 'RV: Martin Moreno- Cuidados Palitivos.' E-mail dated 2.04.2008.
- [191] Weilandt L (Health Care and Medical Services Department of the National Board of Health and Welfare). 'Palliative Care Sweden.' E-mail dated 7.04.2008.
- [192] Leion S (Ministry of Health and Social Affairs, Sweden). 'Information on Palliative Care, S2008/1759/Sr.' E-Mail dated 10.03.2008.
- [193] Szyjanowicz, A (Customer Service Centre, Department of Health, UK). Letter dated 15.03.2008.

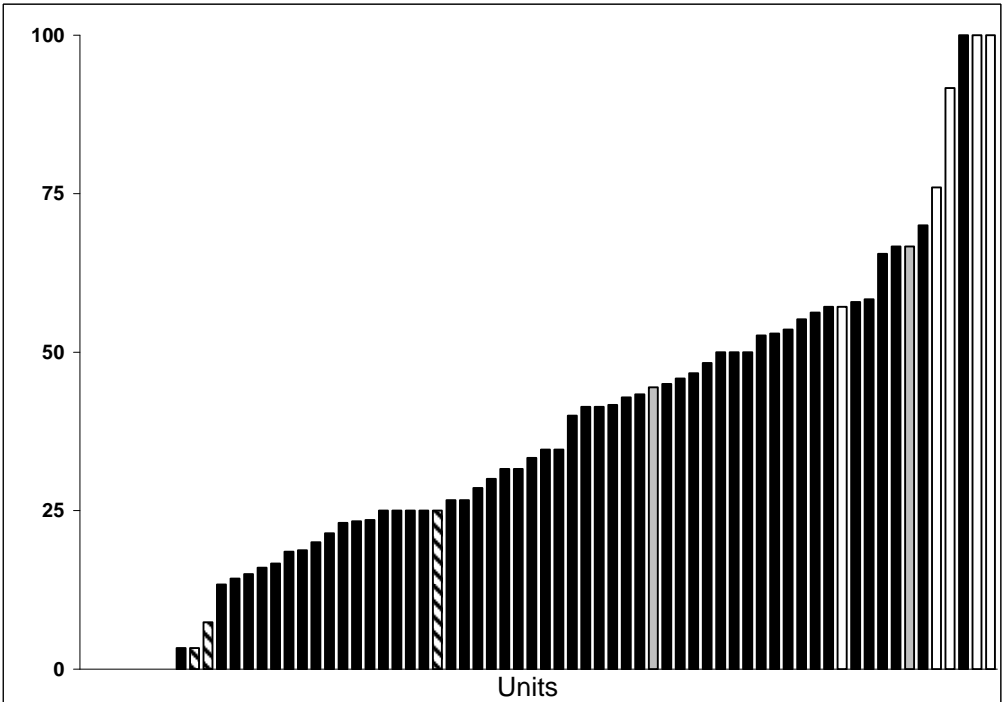


- [194] MacDonnell S (Chair of the NICaN Supportive and Palliative Care Network). 'Re: Comprehensive Study on Palliative Care in the European Union.' E-mail dated 22.03.2008.
- [195] Monroe B et al. 'St Christopher's and the future.' *Omega* 2007; 56;63-75.
- [196] Mosoiu D et al. Reform of drug control policy for palliative care in Romania. *Lancet* 2006; 367:2110-7.
- [197] Jordhøy MS et al. 'A palliative-care intervention and death at home: a cluster randomised trial.' *Lancet* 2000; 356:888-93.
- [198] Gómez-Batiste X, Paz S. 'Public palliative care: review of key developments and implementation issues.' *Current Opinion in Supportive and Palliative Care* 2007; 1:213-7.
- [199] Gómez-Batiste X et al. 'Catalonia WHO palliative care demonstration project at 15 Years (2005).' *J Pain Symptom Manage* 2007; 33:584-90.
- [200] EAPC Task Force on Palliative Care for Children and Adolescents. 'IMPACT: standards for pediatric palliative care in Europe'. *Eur J Pall Care* 2007; 14:2-7.

**Figure 1.** Intensity in different dimension of palliative care at the end of treatment in 44 palliative care units with 1087 patients, comparing units with lower and with higher ratio of nurses per bed. The median ration was 1.12 (from the evaluation of the Hospice and Palliative Care Evaluation HOPE in 2000, modified from [38]).



**Figure 2.** Benchmarking showing the percentage of patients discharged home at the end of inpatient treatment in 69 units with 1546 patients. Arrows indicate units with 0% of patients discharged (HOPE 2002, modified from [41]).



**Figure 3. Levels of palliative care development in the European Union on a global scale**

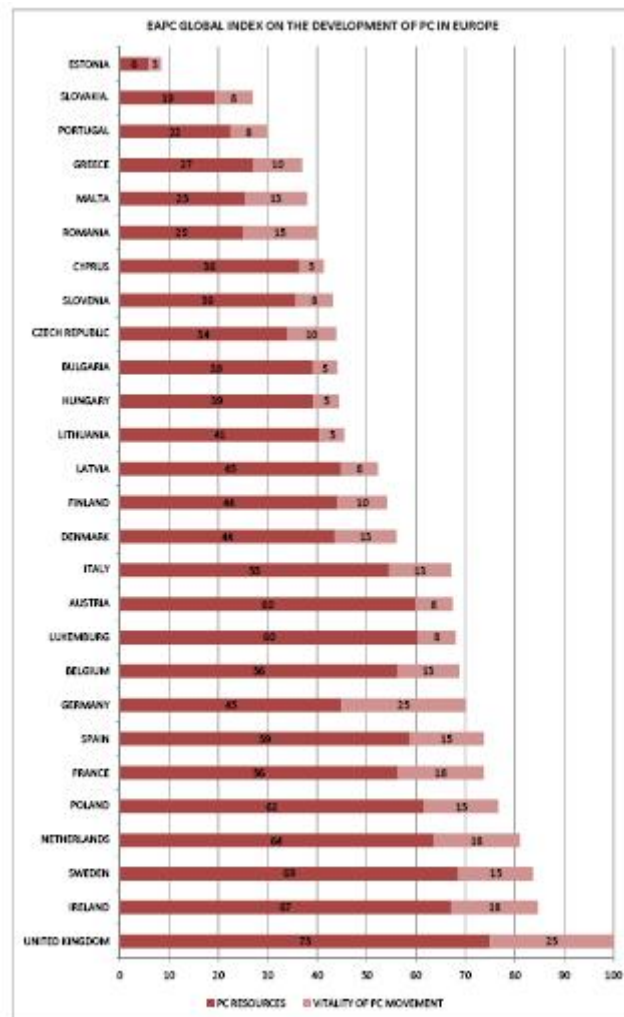
<b>4. Approaching integration</b>	<b>3. Localized provision</b>	<b>2. Capacity building</b>	<b>1. No known activity</b>
<p>Countries where hospice-palliative care services are reaching a measure of integration with mainstream service providers. These countries are characterized by a critical mass of activists; multiple providers and service types; an awareness of palliative care on the part of health professionals and local communities; the availability of strong, pain-relieving drugs; an impact of palliative care upon policy; the development of recognized education centers; academic links forged with universities; and the existence of a national association</p>	<p>This group of countries is characterized by the development of a critical mass of activists in one or more locations; the growth of local support; the sourcing of funding; the availability of morphine; the establishment of one or more hospice-palliative care services; and the provision of training by the hospice organization</p>	<p>Here, there is evidence of wide-ranging initiatives designed to create the organizational, workforce, and policy capacity for hospice-palliative care services to develop. Activities include: attendance at, or organization of, key conferences; personnel undertaking external training in palliative care; lobbying of policy-makers and health ministries; and an incipient service development, usually building on existing home care programs.</p>	<p>Although we have been unable to identify any palliative care activity in this group of countries, we acknowledge there may be instances where, despite our best efforts, current work has been unrecognized.</p>

Austria	Bulgaria	None identified	None identified
Belgium	Cyprus		
Denmark	Czech Republic		
Finland	Estonia		
France	Greece		
Germany	Latvia		
Hungary	Lithuania		
Ireland	Luxembourg		
Italy	Malta		
Netherlands	Portugal		
Poland	Slovakia		
Romania			
Slovenia			
Spain			
Sweden			
United Kingdom			

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Source: Wright M, Wood J, Lynch T, Clark D. 'Mapping levels of palliative care development: a global view.' *J Pain Symptom Manage* 2008 (forthcoming).

**Figure 4. EAPC Global Index on the Development of PC in Europe**



**Table 1. Principal opioids available in the EU 27**

Countries	Opioid Availability						
	Codeine	Morphine	Transdermal Fentanyl	Oxycodone	Oral Methadone	Oral Transmucosal fentanyl	Hydromorphone
Austria	Available	Available	Available	Unavailable	Available	Available	No data
Belgium	Available	Available	Available	Unavailable	Available	Available	Available in some forms
Bulgaria	Available	Available with maximum dose limits	Available	Available in some forms	Available	Available	Available in some forms
Cyprus	Available	Available	Available	Unavailable	Unavailable	Available	Available in some forms
Czech Republic	Available	Available	Available	Available	Available	Available	No data
Denmark	Available	Available	Available	Available in some forms	Available	Unavailable	Available in some forms
Estonia	Available	Available	Available	Available in some forms	Available	Available	Available in some forms
Finland	Available	Available	Available	Available	Available	Available	Available in some forms
France	Available	Available	Available	Available	Available	Available	Available in some forms
Germany	Available	Available	Available	Available with maximum dose limits	Available	Available in some forms	Available in some forms
Greece	Available	Available	Available	Available	Available	Available	No data
Hungary	Available	Available	Available	Unavailable	Unavailable	Available	Available in some forms
Ireland	Available	Available	Available	Available	Available	Available	No data
Italy	Unavailable	Available with maximum dose limits	Available	Available with maximum dose limits	Available	Available	Available in some forms
Latvia	Available	Available in some forms	Available	Available	Available	Unavailable	Available in some forms
Lithuania	Available	Available	Available	Available	Available	Available	No data
Luxembourg	Available	Available	Available	Available	Available	Available	Available in some forms
Malta	Available	Available	Available	Available	Available	Available	No data
Netherlands	Available	Available	Available	Available	Available	Unavailable	Available in some forms
Poland	Available	Available	Available	Unavailable	Available	Available	Available in some forms
Portugal	Available	Available	Available	Available	Unavailable	Available	Available in some forms
Romania	Available	Available with maximum dose limits	Available	Available in some forms	Available	Unavailable	Available in some forms
Slovakia	Available	Available	Available	Available in some forms	Unavailable	Available	Available in some forms
Slovenia	Available	Available	Available	Available	Available	Available	No data
Spain	Available	Available	Available	Available	Available	Available	Unavailable
Sweden	Available	Available	Available	Available	Available	Available	No data
UK	Available	Available	Available	Available	Available	Available	Available in some forms

Source: Cherny N. 'Preliminary report from the ESMO survey of opioid availability in Europe '. E-mail dated 16.4.08.

**Table 2. Legal restrictions on opioid use in Europe**

Countries	Legal limitations in opioid prescription						
	Prescription limited to <28 days	Special license for patients required	Special license for physicians required	Duplicate or triplicate prescription forms required	Limitations on where opioids can be dispensed	Telephone orders by a physician to a pharmacist not permitted	Physician-directed pharmacist corrections not permitted
Austria							
Belgium							
Bulgaria							
Cyprus							
Czech Republic							
Denmark							
Estonia							
Finland							
France							
Germany							
Greece							
Hungary							
Ireland							
Italy							
Latvia							
Lithuania							
Luxembourg							
Malta							
Netherlands							
Poland							
Portugal							
Romania							
Slovakia							
Slovenia							
Spain							
Sweden							
UK							

Bureaucratic barriers exist  
 No legal barriers

Source: Cherny N. ‘Preliminary report from the ESMO survey of opioid availability in Europe’. E-mail dated 16.4.08.

**Table 3. Factors Associated with Increased Risk of Suicide in Patients with Advanced Disease**

- 
1. Pain or other physical suffering
  2. Advanced illness with a poor prognosis
  3. Depression or feelings of hopelessness
  4. Disinhibition due to delirium
  5. Loss of control\* and feelings of helplessness
  6. Physical impairment
  7. Pre-existing psychopathology
  8. Substance/alcohol abuse
  9. Family history of suicide
  10. Emotional or physical fatigue and exhaustion
  11. Lack of social support or social isolation.
- 

\* “Loss of control” refers to both the helplessness induced by physical symptoms or deficits, as well as the inability to control one’s environment

Source: Breitbart W (Ed). *The IPOS “Pocket” Handbook of Palliative Care for the Psycho-oncologist*. IPOS Press, 2008 ( in press). Reproduced with permission.

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**Table 4. Important Social Factors in the Desire for Hastened Death among the Terminally Ill**

- 
1. Social support
  2. Spiritual well being
  3. Quality of life
  4. Perception of oneself as a burden to others
- 

Source: Breitbart W (Ed). *The IPOS “Pocket” Handbook of Palliative Care for the Psycho-oncologist*. IPOS Press, 2008 ( in press). Reproduced with permission.



**Table 5. Indicators and Ranking of National Palliative Care Developments in EU**

Country (2)	Units: Hospice and PC		hosp support		Home Care		Beds/100.000		points B	PC physicians	points P	TOTAL POINTS	RANKING
	Units	points U	teams	points HST	Teams	points HC	inh.						
UNITED KINGDOM	3,7	25	5,1	24	5,9	26	5,3	25	0,7	24	124	1	
SWEDEN	5,0	26	1,1	16	5,5	25	-	23	-	23	114	2	
IRELAND	2,0	15	5,5	26	3,5	23	3,7	22	1,0	25	111	3	
NETHERLANDS	5,4	27	3,1	23	-	21	4,4	24	0,1	10	105	4	
POLAND	3,4	24	0,1	7	6,1	27	4,4	23	0,4	21	102	5	
LUXEMBURG	2,2	20	2,2	21	4,4	24	6,6	27	0,0	8	100	6	
AUSTRIA	3,1	23	1,2	18	2,1	17	2,6	19	0,4	22	99	7	
SPAIN	2,2	19	0,6	13	3,2	21	2,5	18	1,1	26	97	8	
FRANCE	1,3	11	5,1	25	1,4	14	2,7	20	0,6	23	93	9	
BELGIUM	2,8	21	7,4	27	1,4	15	2,1	16	0,1	14	93	10	
ITALY	1,6	13	-	17	2,4	19	1,9	14	1,7	27	90	11	
GERMANY	2,8	22	0,7	14	0,4	7	2,5	17	-	14	74	12	
LATVIA	2,2	18	0,0	6	0,0	4	5,4	26	0,3	20	74	13	
FINLAND	1,1	10	1,9	20	1,9	16	1,4	11	0,2	16	73	14	
DENMARK	1,3	12	1,1	17	0,9	12	1,7	13	0,2	18	72	15	
LITHUANIA	1,7	14	0,3	11	0,9	11	1,5	12	0,3	19	67	16	
HUNGARY	1,1	8	0,4	12	2,8	20	1,4	10	0,1	15	65	17	
BULGARIA	2,1	17	0,0	5	3,3	22	0,0	7	-	14	65	18	
CYPRUS	1,1	7	0,0	3	2,1	18	1,9	15	0,2	17	60	19	
SLOVENIA	2,0	16	1,0	15	1,0	13	0,2	8	0,0	7	59	20	
CZECH REPUBLIC	1,0	6	0,1	10	0,4	8	2,7	21	0,1	11	56	21	
GREECE	0,0	2	1,8	19	0,8	10	0,0	5	-	9	45	22	
MALTA	0,0	3	2,6	22	0,0	5	0,0	6	0,0	6	42	23	
ROMANIA	0,4	5	0,1	8	0,5	9	-	6	0,1	13	41	24	
PORTUGAL	0,4	4	0,1	9	0,3	6	0,5	9	0,1	9	37	25	
SLOVAKIA	1,1	9	0,0	4	0,0	3	0,0	4	0,1	12	32	26	
ESTONIA	0,0	1	0,0	2	0,0	2	0,0	3	-	2	10	27	

INDICATORS: indicators on services (units, support hospital team or home care) are in number of services per million of inhabitants; indicators for pc beds and pc physicians are in number per 100.000 inhabitants

POINTS: we give points for each indicator: 27 points for the country with the highest ratio of a indicator and we give 1 point for the lowest one. The Ratio of the 27 EU Countries is calculated as follow: we assume equal weight for each indicators. The total is the sum of all points and rate the 27 countries over 135 points. Where a

SOURCES: All the indicators are built with data from the FACT Questionary: a 2005 survey of the European Association of Palliative Care in Europe, EAPC, based in the best available data or the best possible estimation done by an expert in each country, with peer review from the National Palliative Care Association.

**Table 6. Vitality of Palliative Care Movement in each EU Country**

Country	Physician Certification (1)	Existence of a National Association (2)	Audience to PC Congress (2)	Directory of services published (2)	Valid information in the scientific literature (1)	paediatric pc units (4)	total vitality	ranking
UNITED KINGDOM	2	1	1	1	2	3	10	1
GERMANY	2	1	1	1	2	3	10	2
IRELAND	2	1	2	1	1	0	7	3
FRANCE	2	1	1	1	2	0	7	4
POLAND	2	1	0	0	1	2	6	5
NETHERLANDS	0	1	2	0	2	2	7	6
ROMANIA	2	1	0	0	1	2	6	7
SWEDEN	1	1	2	0	2	0	6	8
SPAIN	1	1	1	1	2	0	6	9
BELGIUM	0	1	2	0	2	0	5	10
FINLAND	1	1	1	0	1	0	4	11
ITALY	0	1	1	1	2	0	5	12
DENMARK	1	1	2	0	1	0	5	13
MALTA	1	1	2	0	1	0	5	14
CZECH REPUBLIC	1	1	0	0	1	1	4	15
GREECE	0	1	1	0	1	1	4	16
LUXEMBURG	0	1	2	0	0	0	3	17
AUSTRIA	0	1	1	1	0	0	3	18
SLOVENIA	0	1	1	0	1	0	3	19
LATVIA	1	1	0	0	1	0	3	20
PORTUGAL	0	1	1	0	1	0	3	21
SLOVAKIA	2	0	0	0	1	0	3	22
BULGARIA	0	1	0	0	1	0	2	23
HUNGARY	0	1	0	0	1	0	2	24
CYPRUS	0	0	1	0	1	0	2	25
LITHUANIA	0	1	0	0	1	0	2	26
ESTONIA	0	0	0	0	1	0	1	27

(1) Physician certification: 0: no information on any kind of accreditation or project of accreditation; 1: information obtained on accreditation as specialty or subspecialty in project; 2: PC is already recognized as specialty or subspecialty (data from Centeno, 2007)

(2) Data from EAPC Head Office providing by Annella Giordano, 1st semester 2006.

(3) Criteria of the bibliographic review: medicine and dental databases; 1990-2005; in english; Terms: "Palliative Care" or "hospice care" & "name of each country"; reading title filter and reading abstract filter. Valid information in the literature: 0: not enough information; 1: enough information about this country in less than 10 articles; 2: more than 10 articles (Data from Socofon, 2007)

(4) Paediatric PC resources: 0: different levels of development; 1: some specific resources without PC Units or Hospitals; 2: specific resources for inpatients and outpatients; 3: a significant number of all kind of resources (more than a few for that population). Estimation from data of EAPC Atlas of PC, 2007

**Table 7. Resources and Vitality Index a Proposal for an EAPC**

COUNTRY	RESOURCES INDEX	Resources in relation with UK	VITALITY INDEX	Vitality in relation with UK	EAPC INDEX (75% resources + 25% vitality)
	total points (max 135)	max 75%	total points (max 10)	max 25%	
UNITED KINGDOM	124	75	10	25	100
IRELAND	111	67	7	18	85
SWEDEN	114	69	6	15	84
NETHERLANDS	105	64	7	18	81
POLAND	102	62	6	15	77
FRANCE	93	56	7	18	74
SPAIN	97	59	6	15	74
GERMANY	74	45	10	25	70
BELGIUM	93	56	5	13	69
LUXEMBURG	100	60	3	8	68
AUSTRIA	99	60	3	8	67
ITALY	90	55	5	13	67
DENMARK	72	44	5	13	56
FINLAND	73	44	4	10	54
LATVIA	74	45	3	8	52
LITHUANIA	67	41	2	5	46
HUNGARY	65	39	2	5	44
BULGARIA	65	39	2	5	44
CZECH REPUBLIC	56	34	4	10	44
SLOVENIA	59	36	3	8	43
CYPRUS	60	36	2	5	41
ROMANIA	41	25	6	15	40
MALTA	42	25	5	13	38
GREECE	45	27	4	10	37
PORTUGAL	37	22	3	8	30
SLOVAKIA	32	19	3	8	27
ESTONIA	10	6	1	3	8

RESOURCES INDEX: is an index resulted of a comparison of the development of specific PC resources for adults between the 27 EU countries: we consider indicators of resources (visits, support hospital/teams, home care, beds, pc physician) per population and we point 27 to the highest indicator and 1 to the lowest one. There are 5 indicators the maximum will be 135 points. That index indicates the development already achieved in PC in a nation.

VITALITY INDEX: is an index resulted of the comparison of the level of vitality of the PC Movement in each country as follow we mean "vitality" as it reflected in the sum of the pertinence of 5 indicators previously defined: existence of a directory of services, existence of a national society, existence of certification for PC physician, articles published, attended to PC Congress (see Table Vitality); the maximum level of vitality considered was 30. For the EAPC ratio vitality is 25% of the total. That index would indicate the possibility of develop PC in the next future.

EAPC INDEX: we have defined an EAPC INDEX as an index of the total palliative care development: the development that is already achieved plus the possibility of develop PC in the next future. We have assumed 75% for resources that already exist and 25% for the vitality of PC.

**This report is dedicated to the memory of Jose-Joaquin Aznar, a dear friend, colleague, and original team member of ours as well as a loving husband and father to his family. He passed away during the period of this research investigation due to an unexpected hemorrhagic stroke at the age of 44. Jose-Joaquin generously shared his enthusiasm and positive attitude with us at the inception of the project. Although he could not contribute as originally planned due to his sudden death, he has been and will always be a source of inspiration to all of our team. We hope that this report serves as a humble and heartfelt homage to his memory.**

## Acknowledgements

We would like to express gratitude to the *European Parliament* for giving us this opportunity and to the *Ministries and Competent Authorities of the European Union countries* for allowing us to share the latest country-specific information.

This study would not have been possible without the collaboration, advice, and resources provided to us by an extraordinary number of dedicated professionals. The first of these that we would like to thank is Prof. Lukas Radbruch, president of the European Association for Palliative Care, who was enormously helpful from start to finish, providing us with expert contacts and sound knowledge of the field. Likewise, we would like to express our appreciation to the entire EAPC for the body of quantitative and qualitative research and valuable information that was available to us during our investigation and for their generous cooperation in facilitating it to us, and particularly to the EAPC Taskforce on the Development of Palliative Care in Europe for sharing its resources so generously and collegially. We also want to express our sincere thanks to Antonio Fernández, who greatly assisted us in building a closed website which our team used to share articles and information of interest during this investigation.

We would also like to express our gratitude to the international researchers who collaborated in our study, providing their expert opinions on the complexities of their specialties: Stein Kaasa (research), Franca Benini (paediatrics), David Oliviere (volunteers), Phil Larkin (nursing), Luzia Travado (psychosocial support), Nathan Cherny (opioid availability), Inmaculada Martín Sierra (social workers), Marilène Filbert (GP training), Marina Martínez (psychologist training), Javier Rocafort, for his global knowledge of European palliative care, and once again, Lukas Radbruch (best practices and quality control).

Finally, our humble thanks to the Ministries, national associations, and professionals across Europe who answered our queries on palliative care in their country with detailed and thought-provoking responses which reflect a collective effort worthy of the highest praise and appreciation. Representing their ministries of health and other health authorities across the continent, we would like to thank Marie Aasøe (Denmark), Ivi Normet (Estonia), Paula Risikko (Finland), Hans-Walter Obert (Germany), Ms F. Raidou (Greece), Mary Harney (Ireland), Krisztina Talas and Ibolya Toth (Hungary), Armands Ploriņš (Latvia), Rima Vaitkiene (Lithuania), Raymond Mousty (Luxembourg), Miriam Dalmás (Malta), Margret Hink (the Netherlands), Ana Jorge and Filomena Parra da Silva (Portugal), Cristina Vladu (Romania), Ivan Valentovic (Slovakia), Andreja Peternelj (Slovenia), Lena Weilandt (Sweden), Alberto Infante (Spain), and Alex Szyjanowicz (the United Kingdom). From national palliative care associations, we want to thank Johann Baumgartner (Hospice Austria, Austrian Palliative Care Association), Arsene Mullie and Anne-Marie De Lust (FCPF in Belgium), Sophia Pantehki (CACS in Cyprus), Eva Cerná (AHPCP in the Czech Republic), Bodil Abild Jespersen (DSPaM in Denmark), Godefroy Hirsch (SFAP in France), Kyriaki Mystakidou (HAPCPC in Greece), Athina Vadalouca (HSPSCCNCP in Greece), Katalin Hegedus (HHA in Hungary), Ruth Phillips (IAPC in Ireland), Lorna Nevin (NICN in Northern Ireland), Francesca Floriani and Giovanni Zaninetta (the FCP and SICP in Italy), Arvydas Seskevicius (LPMA in Lithuania), Antoinette Shah (Malta Hospice Movement), Jaap Gootjes (NPTN in the Netherlands), Constantin Bogdan (SRPT in Romania), Tatjana Zargi (Hospic in Slovenia), Xavier Gomez-Batiste (SECPAL in Spain), and Lucy Sutton (National Council for Palliative Care in the UK).

This is not an all-inclusive list, and we would like to thank all of those not mentioned here who have contributed to this study. All of these people have helped shed light on this important field and make this report what it is. It should be noted, however, that only the study team is responsible for any weaknesses, limitations or problems with this report.