



European Association for Palliative Care Onlus (EAPC)

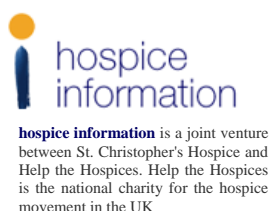
*The EAPC Task Force on the
Development of Palliative Care in Europe*

Palliative Care Facts in Europe for 2004

Current issues in the development of hospice and palliative care in Europe: the vision of “key collaborators” in each European country.

This Taskforce was established by the EAPC in 2004 with the following objectives:

1. To provide reliable information on the delivery of hospice and palliative care in Europe in a manner relevant to the EAPC; to intergovernmental organisations and to national and regional governments
2. To explore the current organisation of hospice and palliative care in Europe considering political and social issues; healthcare policies and the availability of palliative care resources countrywide
3. To facilitate access to information and communication between hospice and palliative care associations, societies and services that operate across Europe
4. To aid the identification of key persons who have studied the development of hospice and palliative care in their own setting and who may provide country specific data to assist policy makers, planners and professional associations



The International Observatory on End of Life Care (IOELC)

The Observatory is established in partnerships with organisations and individuals committed to the global development of palliative care.

Thank you very much for agreeing to take part in this study.

We are seeking information from health practitioners involved in the provision of palliative care across the whole of Europe including a total of 52 countries:

Albania	Czech Republic	Israel	Poland	Sweden
Andorra	Denmark	Italy	Portugal	Switzerland
Armenia	Estonia	Kazakhstan	Republic of Moldova	Tajikistan
Austria	Finland	Kyrgyzstan	Republic of Macedonia	Turkey
Azerbaijan	France	Latvia	Romania	Turkmenistan
Belarus	Georgia	Lithuania	Russian Federation	Ukraine
Belgium	Germany	Luxembourg	San Marino	United Kingdom
Bosnia and Herzegovina	Greece	Malta	Serbia and Montenegro	Uzbekistan
Bulgaria	Hungary	Monaco	Slovakia	
Croatia	Iceland	Netherlands	Slovenia	
Cyprus	Ireland	Norway	Spain	

The following questionnaire aims at exploring the current state of developments in palliative care in each European country.

The questionnaire mainly refers to some specific data on the availability of resources and to the epidemiology of palliative care. Before answering the questionnaire, you may wish to look at the SERIES OF DEFINITIONS given in Annexe A at the end of this document.

Please, answer *all* the questions as accurately as possible and refer to authors, full references and sources of information whenever possible. Make use of the space for COMMENTS to clarify your information and to describe distinct characteristics of services/health organizations in your country whenever you consider it appropriate.

After completing the questionnaire, please return it by email to

Dr. Amelia Giordano (amelia.giordano@istitutotumori.mi.it)

If there is any query, please do not hesitate to contact her, by e-mail: amelia.giordano@istitutotumori.mi.it, telephone (+39 02 23903390), fax (+39 02 23903393) or by post to the following mail address:

EAPC head office
INT, via Venezian 1
20133 Milano, Italy

QUESTIONNAIRE*

1. BACKGROUND QUESTIONS

1.1 What is your complete name?

1.2 What is the name of the palliative care institution you are based at?

1.3 What is your position in the palliative care institution you are based at?

1.4 What are your contact details?

Address:

Telephone/fax:

Email:

* **NB:** For the purpose of this study, this EAPC Task Force requires you to refer to **NATIONAL FIGURES** (and no to regional or local data) when answering the questionnaire. If national figures are not available, please state it in the 'comments' section, provide us with your estimates, if possible, and describe briefly the characteristics of the information you will provide and your sources.

2.- QUESTIONS ON PALLIATIVE CARE SERVICES

Please answer *all* questions considering the definitions given in Annexe A.

If reliable or official data is available, please fill in the “Exact number” box as accurately as you can. Please, provide full details of sources of information, if possible

If no reliable data is available, please fill in the “Estimate” box. Please, indicate the nature of the source on which your estimates are based. For instance, provide the title, year, authors and event of a presentation/publication; of conference proceedings, talks, pamphlets, publication in local/internal journals. If your estimates are based on your personal expertise, please describe briefly.

		Exact number	Estimate	Sources of information
2.1	Total number of Palliative Care Services for adults			
	(a) Number of Palliative Care Units			
	(b) Number of Hospices			
	(c) Number of Hospital Palliative Care Teams (or hospital supportive care teams or mobile palliative care teams)			
	(d) Number of Home Palliative Care Teams			
Comments				

2.- QUESTIONS ON PALLIATIVE CARE SERVICES (continue...)

		Exact number	Estimate	Sources of information
2.2	Total number of Day Care Centres for adults			
Comments				

		Exact number	Estimate	Sources of information
2.3	Number of beds allocated to adult palliative care inpatients (including palliative care units', hospices, hospitals' and nursing homes' beds)			
	(a) in palliative care units			
	(b) in hospices			
	(c) in acute hospitals			
	(d) in hospitals for chronically ill patients			
	(e) in nursing homes			
Comments				

2.- QUESTIONS ON PALLIATIVE CARE SERVICES (continue...)

2.4	Please, describe briefly the current state of developments of palliative care for children in your country at the present time			
2.5	If possible, please state the following:			
		Exact number	Estimate	Sources of information
	Total number of Palliative Care Services for CHILDREN			
	(a) Number of Paediatric Palliative Care Units			
	(b) Number of Paediatric Hospices			
	(c) Number of Paediatric Hospital Palliative Care Teams (or hospital supportive care teams or mobile palliative care teams)			
	(d) Number of Paediatric Home Palliative Care Teams			
Comments				

2. - QUESTIONS ON PALLIATIVE CARE SERVICES (continue...)

2.6	Please, describe briefly how bereavement support is provided in your country at the present time			
2.7	If possible, please state the following:			
		Exact number	Estimate	Sources of information
	Total number of Bereavement Support Teams			
	(a) Number of bereavement support teams for adults			
	(b) Number of bereavement support teams for children			
Comments				

2. - QUESTIONS ON PALLIATIVE CARE SERVICES (continue...)

2.8	The development and the availability of palliative care services tend to differ significantly between rural and urban areas in several countries[†]. Please, describe the current state of developments of palliative care in RURAL areas in your country at the present time

[†] **NB:** please refer to Annexe A for a definition of rural and urban areas.

3. - QUESTIONS ON PALLIATIVE CARE WORKFORCE CAPACITY

Please answer *all* questions considering the definitions given in Annexe A.

If reliable or official data is available, please fill in the “Exact number” box as accurately as you can. Please, provide full details of sources of information, if possible

If no reliable data is available, please fill in the “Estimate” box. Please, indicate the nature of the source on which your estimates are based. For instance, provide the title, year, authors and event of a presentation/publication, of conference proceedings, talks, pamphlets, publication in local/internal journals. If your estimates are based on your personal expertise, please describe briefly.

		Exact number	Estimate	Sources of information
3.1	Number of palliative care physicians [‡]			
	(a) working full time in palliative care			
	(c) working part time in palliative care			
Comments				

[‡] **NB:** please answer questions 3.1 and 3.2 bearing in mind definitions given in Annexe A (page 20 of this document).

3. - QUESTIONS ON PALLIATIVE CARE WORKFORCE CAPACITY (continue...)

		Exact number	Estimate	Sources of information
3.2	Number of palliative care nurses			
	(a) working full time in palliative care			
	(c) working part time in palliative care			
Comments				

3. - QUESTIONS ON PALLIATIVE CARE WORKFORCE CAPACITY (continue...)

		Exact number	Estimate	Sources of information
3.3	Number of social workers			
3.4	Number of psychologists			
3.5	Number of physio-therapists			
3.6	Number of occupational therapists			
3.7	Number of volunteers			
3.8	Number of chaplains (or other spiritual/faith leaders)			
Comments				

4. - QUESTIONS ON THE PALLIATIVE CARE POPULATION

Please answer *all* questions considering the definitions given in Annexe A.

If reliable or official data is available, please fill in the “Exact number” box as accurately as you can. Please, provide full details of sources of information, if possible

If no reliable data is available, please fill in the “Estimate” box. Please, indicate the nature of the source on which your estimates are based. For instance, provide the title, year, authors and event of a presentation/publication, of conference proceedings, talks, pamphlets, publication in local/internal journals. If your estimates are based on your personal expertise, please describe briefly.

		Exact number	Estimate	Sources of information
4.1	Percentage of cancer patients cared for by a palliative care specialist service in your country			
Comments				
		Exact number	Estimate	Sources of information
4.2	Percentage of HIV/AIDS patients cared for by a palliative care specialist service in your country			
Comments				

4. - QUESTIONS ON THE PALLIATIVE CARE POPULATION (continue...)

		Exact number	Estimate	Sources of information
4.3	Percentage of patients with an incurable medical condition other than cancer or HIV/AIDS cared for by a palliative care specialist service in your country			
Comments				

4. - QUESTIONS ON THE PALLIATIVE CARE POPULATION (continue...)

		Exact number	Estimate		Sources of information
4.4	Number of PATIENTS [§] who die at home in your country		number		
			percentage		
4.5	Number of PATIENTS who die in general hospitals in your country		number		
			percentage		
4.6	Number of PATIENTS who die in nursing homes in your country		number		
			percentage		
4.7	Number of PATIENTS who die in other health care institutions in your country (different from hospitals and nursing homes)		number		
			percentage		
Comments					

[§] **NB:** it refers to the number of people within the general population who die at home, in hospitals, in nursing homes or in other health care institutions.

4. - QUESTIONS ON THE PALLIATIVE CARE POPULATION (continue...)

		Exact number	Estimate		Sources of information
4.8	Number of PALLIATIVE CARE PATIENTS** who die at home in your country		number		
			percentage		
4.9	Number of PALLIATIVE CARE PATIENTS who die in general hospitals in your country		number		
			percentage		
4.10	Number of PALLIATIVE CARE PATIENTS who die in nursing homes in your country		number		
			percentage		
4.11	Number of PALLIATIVE CARE PATIENTS who die in other health care institutions in your country (different from hospitals and nursing homes)		number		
			percentage		
Comments					

** **NB:** it refers specifically to the number of patients within palliative care who die at home, in hospitals, in nursing homes or in other health care institutions.

5. - QUESTIONS ON FUNDING

Please answer *all* questions considering the definitions given in Annexe A.

If reliable or official data is available, please fill in the “Exact number” box as accurately as you can. Please, provide full details of sources of information, if possible

If no reliable data is available, please fill in the “Estimate” box. Please, indicate the nature of the source on which your estimates are based. For instance, provide the title, year, authors and event of a presentation/publication, of conference proceedings, talks, pamphlets, publication in local/internal journals. If your estimates are based on your personal expertise, please describe briefly.

		Exact number	Estimate		Sources of information
5.1	Total number of palliative care services funded by the government		number		
			percentage		
Comments					
		Exact number	Estimate		Sources of information
5.2	Total number of palliative care services funded privately or by non-governmental organizations		number		
			percentage		
Comments					

5. - QUESTIONS ON FUNDING (continue...)

		Exact number	Estimate		Sources of information
5.3	Total number of palliative care services supported by a combination of private and public funds		number		
			percentage		
Comments					

6. - GENERAL QUESTIONS

Please, answer the following five general questions

6.1 - Is there specialist accreditation for palliative care professionals in your country at present time? Please describe briefly.

6.2 - Please list in order of importance the five most frequently used strong opioids, their route of administration and their estimated cost for one month treatment at the lowest dose in your country at present time.

Strong opioid	Route of administration	Estimated costs
(i)		
(ii)		
(iii)		
(iv)		
(v)		

6.3 - Please use the space below to comment on any other issues you may consider of relevance for the development of palliative care in your country.

Thank you very much indeed for your time and participation.

ANNEXE A

DEFINITIONS

Due to the great diversity that exists in the nature, availability and provision of palliative and hospice care amongst countries and countries' national health care systems in Europe, a series of terms has been defined as follows:

Supportive careⁱ

“ is care that helps the patient and their family to cope with cancer and treatment of it, from pre-diagnosis through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment”

Palliative care

The National Institute for Clinical Excellence (NICE)ⁱⁱ defines palliative care as:

‘...the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.’

Palliative care is based on a number of principles and it aims to:

- *provide relief from pain and other distressing symptoms*
- *integrate the psychological and spiritual aspects of patient care*
- *offer a support system to help patients to live as actively as possible until death*

- *to help the family to cope during the patient's illness and in their own bereavement*
- *be applied early in the course of illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy) and it should include investigations to better understand and manage distressing clinical complications.*

Specialist palliative care servicesⁱⁱⁱ are those services with palliative care as their core speciality. These services are needed by a significant minority of people whose deaths are anticipated, and may be provided:

- Directly through the specialist services
- Indirectly through advice to a patient's present professional advisers/carers

Specialist palliative care services include:

- **Inpatient palliative care units**

are usually within or attached to a hospital building and have beds exclusively allocated to palliative care. They provide multidisciplinary and specialized palliative care to incurable and terminally ill patients. They may offer formal education and training opportunities to health professionals and volunteers. Inpatient palliative care units are usually funded by national or regional trusts.

- **Hospices**

usually operate outside the national health care system, and are mainly funded by non-governmental organizations, charitable foundations or particulars. They provide multidisciplinary and specialized palliative care to incurable, terminally ill and dying patients; respite care and day care. They may also offer formal or informal education and training opportunities to health professionals and volunteers.

- **Hospital Palliative Care Teams**

they provide specialist palliative care advice and support to other clinical staff, patients and their families/carers in the hospital environment; offer formal and informal education, and liaise with other services in and out of the hospital^{iv}. Other known hospital-based palliative care teams, such as

hospital supportive care teams and hospital mobile teams are also included in this definition for the purpose of this study.

- **Home palliative care teams**

they provide specialized palliative care to incurable, terminally ill and dying patients and support to their families/carers at the patients' home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home.

Professionals involved in providing palliative care fall into two distinct categories^v:

- those providing day-to-day care to patients and carers
- those who specialized in palliative care (e.g. palliative care consultants and specialist nurses in palliative care who devoted most of their professional time to palliative care); some of them may be accredited or not (this depends very much upon the availability of pathways for accreditation in palliative care in the country)

- **Day Care Centre**

refers to spaces in hospitals, hospices, palliative care units or in the community especially designated to promote pleasurable activities amongst palliative care patients. Patients usually spend a few hours or part of the day in the day care centre. In these centres, formal medical consultations do not usually take place, but patients may have some treatments done (such as a blood transfusion or a course of chemotherapy) while in the centre. Complementary therapies, such as massage, acupuncture, reflexology or others are frequently provided in the day care centre.

Number of palliative care physicians

refers to the total of physicians working in palliative care in the country at the present time. They might work in palliative care on a full time basis (including physicians who devote most of their professional time to palliative care) or on a part time basis.

Number of palliative care nurses

refers to the total of nurses working in palliative care in the country at the present time. They might work in palliative care on a full time basis (including nurses who devote most of their professional time to palliative care) or on a part time basis.

Number of palliative care or hospice beds

refers to the number of beds exclusively allocated to palliative care in either hospitals, other health care institutions, palliative care units or hospices. They are made available to palliative care patients with complex problems who would benefit from the continuous support of a multidisciplinary specialist palliative care team. It does not include hospitals' or other health care institutions' beds in general or specialized wards different from palliative care occasionally allocated to palliative care patients.

Funding for services

refers to the financial support available to palliative care services in your country. Financial aid may come from the government, private institutions, non-governmental organizations, charitable foundations and other sources.

Urban^{vi}

of pertaining to, or constituting a city or town. It usually refers to settlements with a population of 10,000 or more residents.

Rural^{vi}

of pertaining to the country or country life. It usually refers to settlements with a population of less than 10,000 residents.

References:

- ⁱ National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) (2002) *Definitions of Supportive and Palliative Care*. Briefing paper 11 London, National Council for Hospice and Specialist Palliative Care Services working definition cited in the National Institute for Clinical Excellence (NICE) (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. The Manual. London, National Institute for Clinical Excellence
- ⁱⁱ National Institute for Clinical Excellence (NICE) (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. The Manual. London, National Institute for Clinical Excellence available at <http://www.nice.org.uk/pdf/csgspmanual.pdf> visited on November 2004
- ⁱⁱⁱ National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) (1998) *Reaching out: Specialist Palliative Care for Adults with Non-malignant diseases*. Occasional paper 14 London, National Council for Hospice and Specialist Palliative Care Services
- ^{iv} National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) (1996) *Palliative Care in the Hospital Setting*. Occasional Paper 10. London, National Council for Hospice and Specialist Palliative Care Services
- ^v National Institute for Clinical Excellence (NICE) (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. The Manual. London, National Institute for Clinical Excellence available at <http://www.nice.org.uk/pdf/csgspmanual.pdf> visited on November 2004
- ^{vi} Interim report of the inter-departmental urban-rural definition group: Classification and delineation of settlements available at <http://www.consultationni.gov.uk/urbanreport.pdf> visited on January 2005