

EAPC task force on the development of palliative care in Europe: autumn 2004

Information relating to the development and provision of palliative care across Europe remains difficult to obtain and is often of variable quality. In many countries, palliative care is an unknown discipline, or is still at an early stage of its evolution compared with those countries that initially founded the hospice and palliative movement. Europe is fast becoming a community of economic co-operation, policy harmonisation and cultural exchange. The EAPC is also growing each year, representing more and more national and regional associations, with an increasing number of members.

Governments and healthcare providers are interested in the organisation of healthcare systems across the continents. Many of those working in palliative care are eager to find new ideas and stimulus through an understanding of how programmes work abroad and through learning from the experiences of colleagues, relating to issues such as the care of the elderly, pain management and end-of-life care.

The EAPC has a responsibility to co-ordinate the collection and dissemination of information about the provision of palliative care in Europe. To focus particularly on these issues, it intends to carry out the first comprehensive overview of the palliative care provision throughout Europe. This work will allow us to assess palliative care development across many countries.

In June 2003, the EAPC Board agreed to the creation of a task force. The work of the task force is of great importance, affecting activities at policy level. This systematic study will reflect important collaboration with other national and professional institutions and associations. As a starting point, we will look at the World Health Organization European region comprising 52 countries. Countries will be included if one of the following criteria is met:

- Those with a national association of palliative care (whether they belong to the EAPC or not)
- Those countries that are members of the European Union (Box 1, overleaf).

Members of the task force

The members of the task force are:

- Carlos Centeno, Spain, Chair
- David Clark, UK, Chair of the International Observatory on End of Life Care (IOELC)
- Javier Rocafort, Spain, Spanish Association of Palliative Care (SECPAL) webmaster
- Luis Alberto Flores Pérez, Spain, in charge of the SECPAL directory
- Liliana de Lima, USA, Executive Secretary of the International Association of Hospice and Palliative Care (IAHPC)
- David Prail, UK, Chief Executive of Help the Hospices (HH)
- Anthony Greenwood, UK, Information Officer from the IOELC
- Amelia Giordano, Italy, EAPC Head Office.

A contact for each participating country is also now being designated (Box 2, overleaf).

Participating institutions

This task force is a collaboration between: EAPC Onlus; the International Observatory on End of Life Care; Help the Hospices; and the International Association of Hospice and Palliative Care.

Goals of the task force

Our main objective is to assess the degree to which palliative care is developing in Europe. The secondary goals are:

- To explain the current organisation of hospice and palliative care, taking into account political, social and healthcare policy, and related factors

Key points

- Information relating to the development and provision of palliative care across Europe remains difficult to obtain and is often of variable quality.
- The EAPC has a responsibility to co-ordinate the collection and dissemination of information about the provision of palliative care in Europe.

Box 1. Countries of Europe (WHO European region) with inclusion criteria for the survey on the development of palliative care

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

Box 2. 'Correspondent' members of the task force already contacted

Austria	Franz Zdrahal	Lithuania	Arvydas Seskevicius
Belgium	Tina De Vlieger	Luxembourg	Marie-France Liefgen
Bulgaria	Dimitar Dimitrov	Malta	Antoinette Shah
Croatia	Anica Music	Moldova	Valeriu Sava
Czech Republic	Zdenek Bystricky	Netherlands	André Rhebergen
Denmark	Marianne Klee	Norway	Marit Jordhøy
Finland	Kaija Holli	Portugal	Isabel Galrica Neto
France	Marilène Filbet	Romania	Daniela Mosoiu
Georgia	Rema Gvaminchava	Russian Federation	Olga Usenko
Germany	Friedemann Nauck	Slovakia	Kristina Krizanová
Greece	Kyriaki Mystakidou	Spain	Luis Alberto Flores Pérez
Hungary	Katalin Hegedeus	Sweden	Carl Johan Fürst
Iceland	Velgerdur Sigurdartottir	Switzerland	Florian Strasser
Ireland	Tony O'Brien	Turkey	Seref Kömürcü
Israel	Nathan Cherny	Ukraine	Vladislav Mykhalsky
Kazakhstan	Valeriy Smola		

- To facilitate access and communication between relevant hospice and palliative care associations and societies that operate in Europe
- To identify key people who have studied the process of hospice and palliative care development in their own setting and who may provide country-specific data to assist policy makers, planners and professional associations.

Work method

There are four lines of work:

1. A literature review and summary of any published work on the development of palliative care in each country. This job will be carried out by Javier Rocafort with the help of Anthony Greenwood
2. An international survey of the boards of the national associations of palliative care, seeking opinions about the general situation,

strengths and opportunities for palliative care in each country

3. An international survey of experts within each country, to gather concrete data about the state of palliative care service delivery and organisation within that country
4. Research on the national directories of services, whether published, printed or online.

Funding for the task force

Funding has been secured for the first two years, with support from Mundipharma Europe, Help the Hospices and the EAPC itself. In the future, further financial help will be sought.

Present situation

- The task force has been formed and collaborative agreements reached with other organisations.
- A collaborative agreement has been reached with each participating institution.

- Meetings in London (UK) and Salamanca (Spain) have taken place, with the majority of work being carried out by email.
- A document detailing the goals and precise work method of the task force has been completed.
- Funding has been secured.
- Contact with the boards of the associations is being established.
- Contact with individual experts from each country is being established.
- Work on the survey drafts is progressing.
- Roughly half of the literature review has been carried out.

Upcoming plans

The two surveys will be carried out between November 2004 and January 2005 and the literature review will be finished by December 2004. We aim to present the preliminary results at the next EAPC Congress in Aachen. In addition, a review of the analysis of the Directories of Services of European countries will be published in the first half of 2005.

Final results

The final results of the task force will appear in the form of a monograph, which will include:

- A report detailing the current state of palliative care in each of the 52 participating countries. The report will consist of a summary of all the existing literature for each country, a reference list, comments from the Board of the National Associations and the data collected by the correspondent designated for each country
- A comprehensive, comparative analysis carried out by the members of the task force. This will be presented as an Atlas of Palliative Care in Europe.

Carlos Centeno, Area de Medicina Paliativa, Clínica Universitaria, Universidad de Navarra, Pamplona, Spain; David Clark, Institute for Health Research, Lancaster University, UK; Javier Rocafort, Programa de Cuidados Paliativos Servicio Extremeño de Salud, Mérida, Spain; Luis Alberto Flores Pérez, Centro de Salud Medina del Campo, Valladolid, Spain