

EAPC Task Force on the Development of Palliative Care in Europe

Carlos Centeno describes the work of the EAPC Task Force on the Development of Palliative Care in Europe and its current status

In April 2002, and following a proposal from those responsible for the Spanish Directory on Palliative Care, the board of directors of the EAPC started considering the possibility of devoting special attention to a project on the development of palliative care in Europe. In June 2003, after examining different possible approaches, Carlos Centeno, a member of the board of directors, was assigned the role of setting up the team.

From the beginning, the EAPC deemed it necessary to make it a collaborative effort that would bring together experience from other groups and institutions already working to promote palliative care in their own countries. The result was the creation of a task force team that includes: the International Observatory on End of Life Care (IOELC), Hospice Information (itself a partnership between Help the Hospices and St Christopher's Hospice, UK) and the International Association for Hospice and Palliative Care. Since then, the work team has met seven times and has added more members and changed others (see [Table 1](#)). A preliminary report on the work of this team was published in 2004.¹

Collaborators in Europe

At one of the first meetings of the task force, it was decided to include within its remit all of the countries that make up the World Health Organization (WHO) European Region – a total of 52 countries.

From the beginning, it was considered necessary to count on the co-operation of a key person in each country – someone with extensive knowledge of the reality of palliative care in their location. National palliative care associations were also asked to take part through their chairperson or secretary. The task of identifying and contacting all the collaborators

Table 1. Members of the EAPC Task Force on the Development of Palliative Care in Europe (February 2006)

Name	City (Country)	Position in the Task Force
David Clark	Lancaster (UK)	IOELC, EAPC Board
Luis Alberto Flores	Valladolid (Spain)	EAPC Member
Javier Rocafort	Badajoz (Spain)	EAPC Member
Anthony Greenwood	Lancaster (UK)	IOELC, Information Officer
David Prail	London (UK)	Help the Hospices
Liliana de Lima	Houston (USA)	IAHPC
Amelia Giordano	Milan (Italy)	EAPC Head Office
Tom Lynch	Lancaster (UK)	Research Assistant
Simon Branch	London (UK)	Help the Hospices, Information Officer
Carlos Centeno	Pamplona (Spain)	EAPC Board, Chair

was assigned to a research assistant in co-operation with Amelia Giordano from the EAPC Head Office, and Liliana de Lima from the IAHPC. By March 2006, 43 key persons and 42 representatives of national associations from 44 different countries had been contacted and agreed to participate.

Work methods

Keeping in mind the general goal of evaluating the degree of development of palliative care in

Key points

- In April 2002, the board of directors of the EAPC started considering the possibility of devoting special attention to a project on the development of palliative care in Europe.
- The information and analysis being assembled by the Task Force on the Development of Palliative Care in Europe will provide a unique overview of palliative care provision, achievements and challenges at the pan-European level.

Europe, four work methods were outlined: a literature review, a review of all the existing directories of palliative care, as well as two different international studies: one qualitative and the other quantitative, to be carried out through specific surveys.

The literature review

The first study consists of a systematic review of articles published in the ten-year period up to 2005 on the development of palliative care in each of the 52 countries included in the study. The research was carried out mainly through two of the main databases: PubMed and CINHALL. Studies in English, French and Spanish were examined and information extracted on six main topics: the provision of palliative care through specific services; health policy; funding; training on palliative care at different levels; scientific associations; and research programmes. For each country, a summary of the information broken down into these categories was placed on a template, including its corresponding bibliographic references.

The person in charge of the literature review is Dr Javier Rocafor, from the Programa Regional de Cuidados Paliativos de Extremadura. The review includes more than 300 articles, out of which nearly 100 are about palliative care in the United Kingdom. These are being analysed separately. To date, about 65% of the remaining 200 articles have been reviewed and data has been extracted. The work method as well as the main bibliometrics [please clarify?] will be presented in the next EAPC congress.

The literature review makes it possible to witness the progress and changes in palliative care in each country over the last ten years. It also provides a detailed summary of the references, and permits identification of key people who have studied and reported information on the development of palliative care in each country.

Directories of services

Six printed palliative care directories and ten online versions have been identified from a total of ten European countries. For each of the directories, its structure and design were studied as well as the information that it provided on the teams that work in each country.

Luis Alberto Flores is in charge of the research on the directories. He is responsible for the Spanish Directory on Palliative Care. He was helped by Simon Brasch, from Help the



The task force aims to provide an overview of the palliative care situation across the whole of Europe

Hospices in London, UK and by Dr Álvaro Sanz, also from the Spanish Directory team. The analysis of the directories has been concluded and a comparative study will be sent to a peer-review journal shortly.

This study provides accurate information on the number of teams in some countries. The comparison of this information with the data obtained from the literature review and from the collaborators in those countries can be used as a means of quality control. The task force analysis of the directories will also allow us to design and publish a guide on advice on how to develop such national directories. Indeed, some members of our team have already provided assistance for new directories currently being developed in Sweden, Argentina and Portugal and we are ready to help other associations that may seek support of this kind.

Qualitative study: Eurobarometer 2005

A survey specifically designed for completion by the boards of national associations forms a third strand of the work of the task force. The qualitative survey seeks to elicit opinions relating to the current state of palliative care in each country and includes questions relating to opportunities, strengths and weaknesses as well as the viewpoint of the national associations on current and forthcoming challenges. Some specific questions relate to national health policies and the influence of the recent Recommendations on Palliative Care from the

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Council of Europe,² as well as issues relating to the availability of opioids in each country. The Eurobarometer, with its qualitative method, provides expert opinions and legitimate assessments of the state of palliative care in Europe. It also shows, from the perspective of the boards of national associations, the achievements and breakthroughs that have been made in each country. Knowing the milestones of certain countries in this way may indeed serve as an indication of what path to follow in neighbouring settings.

The person in charge of this piece of work is Professor David Clark, from Lancaster University, UK. By February 2006, 42 countries (81% of the total) had responded to the Eurobarometer survey. The data will be analysed thematically by geographical region and by the degree of development of palliative care. The global analysis will be sent to a suitable peer-reviewed journal.

Quantitative study: facts questionnaire

A second specific survey was designed in order to collect data and figures on palliative care service provision in each country. This is known as the palliative care 'Facts' questionnaire and it is addressed to a previously identified key person. It aims to gather data about the number and type of specific resources available; the number and type of professionals involved; the target population; the funding of services; and the accreditation of professionals.

The 'Facts' questionnaire provides data that allow for a preliminary comparison of different features of the development of palliative care. A graphic representation of the results will be shown in the form of maps of palliative care development in Europe. At the EAPC Congress on Research, in Venice, in May 2006, a first map of specific resources of palliative care in Europe was presented. Some of the data obtained through the 'Facts' questionnaire can be interpreted as a sign of the degree of progression of palliative care in each country. It follows that the future development of palliative care in a country could depend to a large extent on the position of the national palliative care movement. Combining current data obtained through the 'Facts' questionnaire with other data on the state of palliative care might enable the production of an overall ranking of palliative care development for each country.

The person in charge of this study is Professor Carlos Centeno from the University of Navarra.

Thirty-six countries (69% of the total studied) had answered by late February 2006.

Other outcomes

Combining and summarising all the information gathered from each country will lead to the production of a set of specific EAPC country reports. The information can be added to that generated by previous studies.³⁻⁶ We intend to disseminate these EAPC country reports as widely as possible. They will be available through the web pages of the EAPC as well as via links from the web pages of the other participating organisations within the task force.

In addition, it is planned to publish a monograph, provisionally entitled *A First Atlas of Palliative Care in Europe*. Such an atlas will contain geographic representations of the most important information collected, as well as each of the EAPC country reports.

In conclusion, the information and analysis being assembled by the Task Force on the Development of Palliative Care in Europe will provide a unique overview of palliative care provision, achievements and challenges at the pan-European level. The results of the work of the task force will be presented in a way that facilitates better understanding and comparison of the palliative care situation in each country as well as an analysis that draws attention to variations and similarities across a vast and diverse region of 52 countries.

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