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# PALLIATIVE CARE DEVELOPMENT IN THE MEDLANG PARTNER COUNTRIES

## Summative Report

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### 1. Introduction

The aim of this report is to present the situation of palliative care in the four European countries involved in the project. A template was developed by Transilvania University based on the European Association for Palliative Care (EAPC) – Palliative Care Atlas with questions exploring organizational, policy and educational aspects in the partner countries and also best practices. [2]

### 2. Report objectives

- To collect information on specific

sectorial impact, country differences, cultural specific aspects, etc.

- To identify innovative solutions that have been implemented & found to be effective to meet the needs of those who use/will use procedures on palliative medicine and develop palliative care.

### 3. Results

#### 3.1. Demographical Data and Provision of Palliative Care Services in the Partner Countries

The following tables highlight the variation of staffing ration in medical field

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and in palliative care among the four level, on the aspects revealed in Table 1: partner countries:

Provision of statistical data, at national

*Provision of statistical data, at national level\**

Table 1

Country	Population [millions]	Surface [km <sup>2</sup> ]	Density [inhabitants/km <sup>2</sup> ]	Gross Domestic Product	No. of doctors / 1000 inhabitants	No. of nurses / 1000 inhabitants
Romania	19,96	238,391	84.4	669.5 billion RON	2.5	5.8
Spain	46,81	505,990	92	\$ 1.407 trillion	4.6	5.2
Italy	60,78	301,338	201.7	\$ 2.066 trillion	4.2	7.7
Belgium	11,32	30,528	369.7	\$ 481.5 billion	4.9	16.8

Country	No. of patients in palliative care services	No. of doctors in palliative care services	No. of nurses in palliative care services
Romania [1]	no summative statistics	396†	6,500†
Spain	215,388	567	1,016
Italy	no summative statistics		
Belgium		1/200,000 inhabitants	3-4/200,000 inhabitants

*\*in different settings (hospitalized, institutionalized, assisted at home, etc.)*

*† trained personnel (not working effectively in a palliative care service)*

### 3.2. Is the Palliative Medicine/Care supported by Legislation?

All the project partner countries have some legal frameworks for the palliative care services to be developed within; the

data included in the table have to be regarded with cautions, as different partners have a broader or more specialized expertise concerning what is going on at national / strategical level (Table 2).

Table 2

*Legal frameworks for palliative care in project partner countries*

Country	Romania	Spain	Italy	Belgium
Legislation	O.M. nr. 916 / 23.12.1999, OM nr. 480 / 2005 OMECT nr. 2713 / 29.11.2007 Law nr. 339 / 2005 HG nr. 1915 / 2006 OUG nr. 115 / 2004 HG 76 / 2008	The legal foundation of information, informed consent, advanced directives and confidentiality are established at national level in the law 41 / 2027 Each Autonomous	Regional Law no. 30-866 del 25.10.2010 "Regional network for palliative and Centers" Regional Law	Law about rights of the patient Law about the palliative patient Law about euthanasia

	Law nr. 95 / 2006 Legislation for funding mechanisms for home based palliative care and palliative care inpatient units [6]	Region has defined the conditions related to the informed consent and advanced directives	no. 31-1482 del 11.02.2011	
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#### 4. Identification of National Strategies in Palliative Care

Palliative Care in Romania has started as a grassroot movement with *Hospice Casa Sperantei*, a Non-Governmental Organization (NGO) leading the development of services [5] and since 2010 developed a strategy based on levels of complexity of needs and territorial distribution of services as explained further. [6]

According to complexity of needs these structures will be developed according to include different levels of competencies, as follows:

1. **Level 1:** Support for self-care: offered to patients and their families by community medical assistance team with basic palliative care education, but also by specialized palliative care teams. This level assures that the patient and his family gain knowledge, abilities and self-confidence for self-care and for proper care in between medical staff interventions:
  - a. Non-pharmacological methods for control different symptom
  - b. Communication
  - c. Food and feeding
  - d. Bodily care
  - e. Mobilization techniques
  - f. Negotiation goals of care with professionals etc.
2. **Level 2:** Palliative approach represents direct care offered to patients and their families/carers by clinical staff with basic instruction in palliative care, having a certificate that confirms participation to different programs

accredited by competent institutions.

3. **Level 3:** Specialized palliative care assures direct care offered to patients and their families/carers, but also includes consultancy for level 1 and 2 of competence. It is provided by professional interdisciplinary teams with specialized studies in palliative care field: doctors with palliative care competence, nurses, social workers, psychologists, therapists, clerics and other staff with palliative care competence, according to national standards of palliative care.

#### TERRITORIAL

**Local:** as much as possible the care should be offered to patients in the places where they live through:

- Primary care services but with some training in palliative (palliative care approach)
- Specialized palliative care services:
  - Home care, day centers
  - After hours call service for patients

**Regional** there will be developed specialized palliative care services:

- Inpatient units
- Coordination of services
  - Palliative care networks
- Consultancy for level 1 and 2 (call centers for professionals, education centers for patients and families with hotline)

At **National level** some activities will be planned jointly by palliative care providers like:

- Producing and dissemination of

- standards and clinical protocols
- Professional review of quality of care
  - Advocacy, education, research
  - National awareness campaigns

#### 4.1. National Strategy about Palliative Care in Spain

Spanish Society for Palliative Care (SECPAL) was created in 1992. It is the body that brings together more than 1800 professionals working in the field. Since 1994, SECPAL publishes the "Palliative Medicine" magazine (*Medicina Paliativă*), scored with 0.162 in Journal Citation Reports-2013. Indexed journal in: Science Citation Index, Scopus, ScienceDirect) which is the only Spanish publication specialized in hospice-palliative care, so that shows the work carried out in Spain and Latin America. This multidisciplinary journal aims to share knowledge and experiences in order to respond to the multidimensional patient care and his/her immediate environment. Training programmes, congresses and meetings organized by this body have increasingly greater impact on Spanish society. In 2001 Núñez Olarte published an article about the key ethical issues in clinical practice in palliative and end-of-life care in Spain and how these issues are influenced by Spanish culture. Although there is a general consensus that a new philosophy of care is needed, the interpretation and application of this general philosophy are different in diverse sociocultural contexts. The Spanish palliative care movement has shifted its focus from starting new programs to consolidating and expanding the training of the professionals already working in the existing programs. Still, as said above, half of the terminally ill does not receive the required assistance. Universities have not incorporated palliative medicine at the undergraduate levels and the current lack of specialists in this field is still not alleviated.

Despite that mass media coverage has greatly increased in the last years (see below), Spain needs a law to ensure a dignified death for all patients. The current law requires that doctors offer palliative care but the formulation of this obligation is extremely ambiguous. Andalusia is the first region that regulated dignified death with the approval of the Bill of Rights and Guarantees of the Dignity of Persons in the Process of Death. This law prohibits aggressive therapy and allows patients to refuse treatment that artificially prolong their life permitting palliative sedation to alleviate the suffering of the sick. Navarra and Aragon in 2011 passed similar laws. The foremost national newspapers and public access information sources have extensively faced the topic in the last five years. Accordingly, in the library of the best-selling newspaper in Spain (*El País*), for the period 2010-2015 there are more than 800 news and opinion articles related to palliative care and end-of-life issues.

Since January 2015, the Spanish public television has addressed the issue of palliative care with two documentaries, an interview with a specialist and a movie. All were broadcasted around February 4, World Cancer Day.

**In Italy** the continuing development of palliative care must be accompanied by an extraordinary attention on some strategic points, to make them available to all patients who need them, and to ensure that they best express the level of social and health care evolution, so that they are developing not only in number, but in quality too. The first aspect is the appropriateness of care: to get better systems to recognize the need of care, the timing of care, and to develop quality assessment and performance improvement. The second aspect is the attention to human factor, (someone called the Palliative Care the Science of Compassion

- The National Institute of Nursing Research Summit, USA, 2011): to bring to patient's home technology but also good skills in helping relationship, and this means to improve strategies and programs to provide health professionals with specific personal training and team training, education and support. The third aspect is the attention to multidisciplinary approach in palliative care: through cooperation among physicians, nurses, psychologists and other health professionals, and no less important are social workers, chaplains and every other allied people who can contribute to diminish patient's suffering. This means promoting and implementing a specific and firm network which needs maintenance and updating to be appropriate to the needs of the patient and of the care team.

Finally, the fourth aspect is the indispensability of involving all the patient's family in the process of care; through a family centered approach that embraces all the family members (and the family is defined by the patient), during the patient's illness and after his death, in the bereavement process.

The World Health Organization definition of Palliative Care and the Guidelines published all over the world stress this aspect, that becomes particularly necessary and complex when the dying patient is a mother or a father of young children, or when the patient is a child. Specific, affordable and flexible guidelines of care are needed. [3, 4]

#### **4.2. Guidelines for Palliative Care in Primary Care Settings and Specialty Level Palliative Care need to be better Identified**

Moreover, a palliative care organization must be able to look beyond the formal systems of care, and have to research in the

community other resources, such as self-help or mutual aid, or other non-formal systems of care, whose extraordinary effectiveness was observed in many fields, like addiction, disability, and so on. Of strategic importance appear to be a multicultural approach in Palliative Care, and not only to a multi-professional care strategy. Palliative care is the result of the work of many different professionals, but also of many different components of society.

**In Belgium**, the palliative care offer is equitably distributed in the different regions of the country, regardless of the care location of the patient (home, hospital, specialised retirement home, etc.). A coherent plan equipped with a comprehensive legislative framework was developed in 1997, thanks to the consultation and combined efforts of the experts in palliative care united in federations, and the Authorities.

The first palliative care service and palliative home care team were created more than 25 years ago (first initiative dates 1985). From 1991 onwards the Ministry of Social Affairs financed experiments for palliative care at home, in hospitals and in nursing homes. Palliative networks were created in 1997 (Royal Decree of June 19, 1997) (KB 1997a). Today there are 25 networks (1 network/300.000 inhabitants). These networks cover the entire Belgian territory (15 networks in Flanders, 1 bilingual network in Brussels, 8 networks in Wallonia and 1 network in the German-speaking community). The networks develop the following activities (Fig. 1):

- to heighten public awareness;
- to organize palliative care trainings for health caregivers and for volunteer persons;
- to coordinate different local actions like defining cooperation protocols to

guarantee an optimal complementarity between organisations and services;

- to give advice and logistic support in order to enhance the efficiency of the

actions and the support to patients;

- to evaluate the palliative services and to estimate the gap between needs and services.

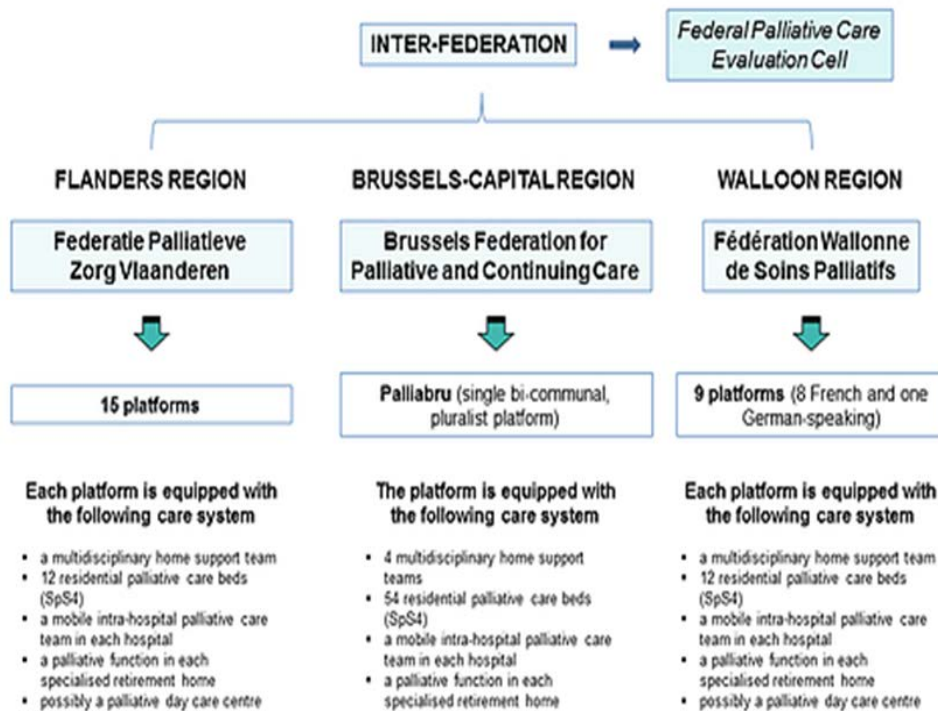


Fig. 1. *Distribution of palliative care offer in Belgium*

## 5. Identification of Specialized Services in Palliative Care (Table 3)

Table 3

*Specialized services in palliative care in countries involved in MedLang project*

Country	Specialized services in palliative care
<b>Romania</b>	Types of patients cared for: children with life limiting diseases, adults mainly with cancer, but also with non-cancer diseases like dementia and different organ failure Mechanisms of funding for the services in different settings: state (governmental) funds, private funds, donations, campaigns Number/Types of services: in 2013: inpatient units: 38; homecare: 19; day centres: 4; outpatient: 5
<b>Spain</b>	Standard resources related to palliative care: a) a support team available for each kind of area of palliative care, i.e. primary medicine, specialized or tertiary; b) a home care service team available per 100-150,000 inhabitants, c) hospital service and day hospital or ambulatory service in the hospital
<b>Italy</b>	Hospital services Outpatient services Pediatric services – see table

<b>Belgium</b>	<p>The palliative home care teams are the extra-mural component of the Belgian PC system. They were created to support caregivers in the first line of care. The Royal Decree of Oct 13, 1998 (KB 1998) defined minimal criteria for the agreements between these teams and the 'Comité van de Verzekering voor Geneeskundige Verzorging' of the National Institute for Health and Disability Insurance (INAMI-RIZIV). Today, 28 teams signed such an agreement (at least 1 per regional network),</p> <p>1 per 200,000 inhabitants. Typical constitution of a palliative home care team is 2.6 fte per team; for 100 patients per year, as follows: 1 physician (part-time); 1 coordinator; 3-4 nurses, 1 psychologist, 1 administrative co-worker</p> <p>The missions of palliative home care team were defined in the conventions with INAMI-RIZIV</p>
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## 6. Identification of Support

Country	Specialized literature or organizations
<b>Romania</b>	<p><a href="https://eapcnet.wordpress.com/2015/05/13/new-beginnings-all-change-at-the-eapc/Hospice%20Casa%20Sperantei">https://eapcnet.wordpress.com/2015/05/13/new-beginnings-all-change-at-the-eapc/Hospice%20Casa%20Sperantei</a>. One of the 7 models for developing palliative care presented in World Wide Palliative Care Atlas [6]</p> <p>Asociația Națională de Îngrijiri Paliative (ANIP) – National Palliative care Society</p> <p>Palliative Care Commission in the Ministry of Health</p>
<b>Spain</b>	<p>National Program about Palliative Care (Plan Nacional de Cuidados paliativos) and National Strategy about Palliative Care (Plan Nacional de Cuidados Paliativos) promoted by the National Health System</p>
<b>Italy</b>	<p><a href="http://www.fremedicaljournals.com/">http://www.fremedicaljournals.com/</a></p> <p><a href="http://www.academicjournals.org/">http://www.academicjournals.org/</a></p> <p><a href="http://www.biomedcentral.com">www.biomedcentral.com</a></p> <p><a href="http://www.bmj.com.bvs.cilea.it">www.bmj.com.bvs.cilea.it</a></p> <p><a href="http://www.ncbi.nlm.nih.gov">www.ncbi.nlm.nih.gov</a></p> <p><a href="http://www.sciencedirect.com">www.sciencedirect.com</a></p> <p>ACCD Sito dell'Associazione cremonese per la cura del dolore</p> <p>ACP - Bergamo Sito Associazione Cure Palliative Bergamo</p> <p>ANLAIDS Associazione nazionale per la lotta all'AIDS</p> <p>Associazione Antea Sito di Antea</p> <p>Associazione Volontari Presenza Amica Collegamento al Sito dell'Associazione</p> <p>Federazione Cure Palliative (FCP) Onlus Federazione che riunisce oltre 70 organizzazione No Profit Italiane</p> <p>Fondazione Floriani Sito della Fondazione</p> <p>Fondazione italiana di leniterapia Collegamento al sito ufficiale della Fondazione Italiana di Leniterapia</p> <p>Fondazione Maruzza Lefebvre D'Ovidio Onlus Sito Fondazione Maruzza Lefebvre D'Ovidio Onlus</p> <p>Fondazione Lu.V.I. Sito della Fondazione</p> <p>Fondazione Maria Teresa Chiantore Seràgnoli Sito della fondazione</p> <p>Lega italiana per la lotta contro i tumori Collegamento al sito della Lega Tumori</p> <p>S.A.M.O.T. Onlus Sito Società per l'Assistenza al Malato Oncologico Terminale</p>
<b>Belgium</b>	<p>Money for training via part C of the health insurance allowance (MB 2001; 2003).</p> <p>From the first of July 2008, an additional budget is available for a part-time palliative reference person</p>

### 7. Is the Palliative Care visible/debated at National Level?

Country	Visibility of palliative care at national level
Romania	<p><a href="https://eapcnet.wordpress.com/2015/05/13/new-beginnings-all-change-at-the-eapc/">https://eapcnet.wordpress.com/2015/05/13/new-beginnings-all-change-at-the-eapc/</a> National Conference of Palliative Care (1998 – 2016)</p> <p><a href="https://www.anip.ro/conferinta-nationala/editii-anterioare/">https://www.anip.ro/conferinta-nationala/editii-anterioare/</a> Governmental Commission for Palliative Care, National Palliative Care Association (NAPC), regularly meetings with NAPC members</p> <p>National Palliative Care journal: Paliatia.ro, <a href="http://www.paliatia.eu/new/">http://www.paliatia.eu/new/</a> Since May 2014 a palliative care column in the national medical magazine <i>Viața medicală</i> with a palliative care article published every second week</p> <p><a href="https://www.facebook.com/media/set/?set=a.635455646535881.1073741830.1982%2047400256710&amp;type=3">https://www.facebook.com/media/set/?set=a.635455646535881.1073741830.1982%2047400256710&amp;type=3</a></p>
Spain	<p>Cancer Pain Release, <a href="http://www.whocancerpain.wisc.edu/">http://www.whocancerpain.wisc.edu/</a> Hospice Information, <a href="http://www.hospiceinformation.info/">http://www.hospiceinformation.info/</a> IAHPC, <a href="https://hospicecare.com/home/">https://hospicecare.com/home/</a> World Hospice Palliative Care Online, <a href="mailto:avril@hospiceinformation.info">avril@hospiceinformation.info</a> Palliatif (en français), <a href="mailto:irzpalli@vtx.ch">irzpalli@vtx.ch</a> Medicina Paliativa, <a href="http://www.secpal.com/medicina_paliativa/index.php">http://www.secpal.com/medicina_paliativa/index.php</a></p>
Italy	<p>Many examples of National conferences/events on palliative care Many examples of Scientific journals on palliative care</p>
Belgium	<p>Specialized recent literature in palliative care: In Medline(PubMed) we could identify 78 publications on palliative care from Belgian authors published in the last 5 years</p> <p><a href="http://www.belgium.be/nl/gezondheid/gezondheidszorg/levenseinde/palliatieve_zorgen/">http://www.belgium.be/nl/gezondheid/gezondheidszorg/levenseinde/palliatieve_zorgen/</a> <a href="http://www.portal4care.be">www.portal4care.be</a></p> <p>Palliative care (Palliatieve zorg): <a href="http://www.palliatief.be">http://www.palliatief.be</a> Early planning of your care (vroegtijdige planning van je zorg): <a href="http://www.delaatstereis.be">www.delaatstereis.be</a></p> <p>Children and teenagers confronted with palliative care (kinderen en jongeren geconfronteerd met palliatieve zorg): <a href="http://www.palliatieve-zorg-en-kinderen.be">www.palliatieve-zorg-en-kinderen.be</a> Guidelines palliative care (richtlijnen palliatieve zorg): <a href="http://www.pallialine.be">www.pallialine.be</a> Brussels Federation of Palliative care (Fédération Bruxelloise de Soins Palliatifs et Continus): <a href="http://www.fbsp-bfpz.org/">www.fbsp-bfpz.org/</a> Palliative care in the Walloon Region (Fédération Wallonne des Soins Palliatifs): <a href="http://www.soinspalliatifs.be">www.soinspalliatifs.be</a></p> <p>Pluralistic association of palliative care in Brussels Capital Region (Pluralistische Vereniging voor Palliatieve Zorg van het Brussels Hoofdstedelijk Gewest): <a href="http://www.palliabru.be">www.palliabru.be</a></p> <p>Life information forum LEIF (Levenseinde Informatie Forum): <a href="http://www.leif.be">www.leif.be</a> Cancer center (Kankercentrum): <a href="http://www.e-cancer.be">www.e-cancer.be</a> Cancer Foundation (Stichting tegen Kanker): <a href="http://www.kanker.be">www.kanker.be</a> Flemish League against Cancer (Vlaamse Liga tegen Kanker): <a href="http://www.vlk.be">www.vlk.be</a></p>



### 8. Provision of Examples of best Practices / Projects on Innovative Solutions that have been implemented and found to be effective to meet the Needs of those who Use / will use Medical Procedures

Country	Examples of best practices / projects
<b>Romania</b>	<p>IZERZO: “Integration of medical oncology and palliative care procedures in various institutional and economical settings: Development of tailored interventions based on patient needs and testing of its preliminary efficacy on patient reported outcomes, tumour control and costs” financed by Romanian-Swiss Research Programme – IZERZO 142226</p> <p>Swiss-Romanian Cooperation Programme: Overcoming disparities on access to quality basic palliative care in the community. Through the Romanian-Swiss partnership, the barriers encountered by cancer patients and their families in accessing palliative services at the community level were identified; The model of basic palliative care by family doctors was developed; The model was piloted in 4 counties; It has been promoted and advocacy activities have been performed for national implementation.</p> <p><a href="http://www.studiipaliative.ro/dezvoltare/ingrijire-paliativa-de-baza-prin-medicii-de-familie/proiect/">http://www.studiipaliative.ro/dezvoltare/ingrijire-paliativa-de-baza-prin-medicii-de-familie/proiect/</a></p>
<b>Spain</b>	<p>Universidad Autónoma de Madrid: máster en Cuidados Paliativos y Tratamiento de Soporte del Enfermo con Cáncer  <a href="http://www.uam.es/ss/Satellite/es/1242654675830/1242656616884/estudi%20opropio/estudioPropio/Master_en_Cuidados_Paliativos_y_Tratamiento_de_Sop%20orte_del_Enfermo_con_Cancer.htm">http://www.uam.es/ss/Satellite/es/1242654675830/1242656616884/estudi%20opropio/estudioPropio/Master_en_Cuidados_Paliativos_y_Tratamiento_de_Sop%20orte_del_Enfermo_con_Cancer.htm</a></p> <p>Universidad de Valladolid: máster en cuidados paliativos  <a href="https://www.enclaveformacion.com/master-paliativos/">https://www.enclaveformacion.com/master-paliativos/</a></p> <p>Universidad de La Rioja: máster universitario en cuidados paliativos pediátricos:  <a href="http://www.unir.net/salud/master-cuidados-paliativos-pediatricos/54920001406/">http://www.unir.net/salud/master-cuidados-paliativos-pediatricos/54920001406/</a></p> <p>Máster universitario en enfermería en cuidados paliativos (Univ. de Navarra):  <a href="http://www.universia.es/estudios/unav/unav-master-universitario-enfermeria-cuidados-paliativos/st/193269#">http://www.universia.es/estudios/unav/unav-master-universitario-enfermeria-cuidados-paliativos/st/193269#</a></p> <p>Enfermería en los Cuidados Paliativos. Hospitalización Domiciliaria (Escuela de Ciencias de la Salud. Centro adscrito a la UCM):  <a href="http://www.emagister.com/enfermeria-cuidados-paliativos-hospitalizacion-domiciliaria-cursos-2576225.htm">http://www.emagister.com/enfermeria-cuidados-paliativos-hospitalizacion-domiciliaria-cursos-2576225.htm</a></p>
<b>Italy</b>	<p><a href="http://www.cure-domiciliari.it/files/Testimonianza.pdf%20www.aniarti.it">http://www.cure-domiciliari.it/files/Testimonianza.pdf%20www.aniarti.it</a></p> <p>Osservatorio delle Buone Pratiche nelle Cure Palliative            Federazione Cure Palliative</p>
<b>Belgium</b>	<p>Starting with early identification of palliative care patients by general practitioners (GPs), the <b>Care Pathway for Primary Palliative Care</b> (CPPPC) is believed to help primary health care workers to deliver patient- and family-centered care in the last year of life. The care pathway has been pilot-tested, and will now be implemented in 5 Belgian regions: 2 Dutch-speaking regions, 2 French-speaking regions and the bilingual capital region of Brussels. The overall aim of the CPPPC is to provide better quality of primary palliative care, and in the end to reduce the hospital death rate (Leysen B, 2015).</p>

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