



Promoting palliative care in the community: producing a toolkit to improve and develop primary palliative care in different countries internationally

*Full Report of the European Association of Palliative Care
(EAPC) Taskforce in Primary Palliative Care*



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Abstract

Background: A multi-disciplinary EAPC Taskforce was established in January 2012 to scope the extent of and learn what facilitates and hinders the development of palliative care in the community across Europe.

Aim: To document the barriers and facilitators for palliative care in the community; and to produce a resource toolkit that enthusiasts could use to facilitate the development of palliative care in different countries throughout Europe and possibly worldwide.

Design: Step 1) A survey instrument was sent to general practitioners with knowledge of palliative care services in the community in a purposefully diverse sample of European countries in 2012. Barriers and facilitating factors relating to providing community palliative care were identified and analysed. Step 2) A draft toolkit was then constructed suggesting how individual countries might best address these issues and an online survey was then set up for general practitioners and specialists to comment on and develop the toolkit. Iterations of the toolkit were then presented at international palliative care and primary care conferences.

An international systematic review of tools used to identify people for palliative care in the community was also conducted.

Results: A toolkit has been produced and refined, together with associated guidance, to help primary care and specialist palliative care leaders throughout Europe advocate for and develop palliative care in the community, "primary palliative care".

Conclusions: The four domains of the WHO Public Health Strategy provided a robust framework to collate the resources and structure the toolkit. The taskforce toolkit usefully supplements previous work to help community based palliative care services to be established to ensure adequate population coverage.

Keywords: Palliative care, primary palliative care, primary care, community palliative care

What is already known

- Most patients die before accessing either specialist or generalist palliative care
- For palliative care to be accessible to all in need it must be available in the community

What this paper adds

- Palliative care in the community is under-developed in many European countries
- A toolkit is now available to facilitate the development of palliative care in the community in different countries throughout Europe and the world

Implications for practice theory or policy

- National strategies should be drawn up to develop policies, education, implementation strategies, and drug availability in the community
- The toolkit outlines the steps that can be taken depending on the current stage of development in each country or region



Introduction

Throughout Europe in the last 50 years, palliative care has been developing both as a specialty and also by generalist doctors and nurses in different ways and to different extents. Most Europeans, unless they have cancer, still fail to access generalist or specialist palliative care. For palliative care to be accessible to all in need it must be available in the community. As well as dealing with clinically complex patients, specialist palliative care has a role to support and train generalists and to help develop palliative care in the community. Thus, in 2012 the EAPC formed a taskforce to take this strategic work forward, recognising that public health and primary care approaches should be embraced to promote universal coverage.

The taskforce webpage www.eapcnet.eu/Themes/Organisation/Primarycare.aspx drew attention to this activity and the initial work undertaken. It highlighted that primary care has a great potential to access and deliver effective palliative care to patients as it can:

- Reach patients with all life-threatening illnesses[1]
- Start at diagnosis of life threatening illness[2]
- Meet all dimensions of need: physical, social, psychological and spiritual[3]
- Provide care in clinics, care homes and at home, and prevent unnecessary hospital admissions[4]
- Support family caregivers and provide bereavement care[5]

We thus aimed to:

- Scope the current status of palliative care in the community in a representative sample of countries in Europe
- Document the barriers and facilitators for palliative care in the community
- Produce a resource toolkit that enthusiasts from primary care or specialist palliative care could use to help them facilitate the development of palliative care in different countries throughout Europe and the world

Methods (See figure 1: flow diagram of methods)

Step 1: Identifying barriers to and opportunities for palliative care in the community. The authors SAM and EvanR recruited a taskforce of experts drawing on established contacts with primary care colleagues from within the EAPC, the International Primary Palliative Care Network and via the Primary Palliative Care Research Group at the University of Edinburgh[6, 7]. A survey instrument was produced and piloted following discussions of the taskforce team. The survey instrument sought to profile each country with respect to the development of palliative care in the community. We also sought outline data about the development of primary care and specialist palliative care services to contextualise palliative care developments in the community. We also documented relevant developments in health policy related to this area, the vocabulary used, the perceived barriers and opportunities in each country to developing palliative care in the community, and the actual practice of identifying patients in the community



for palliative care. The survey was sent to a purposive sample of key informants with knowledge of palliative care services in a culturally diverse sample of European countries in 2012. The informants were invited via email contact from a list produced by taskforce members.

The results of this survey were analysed by SAM, LS and AF using a framework identified from the WHO Public Health Strategy for Palliative Care[8]. Barriers and facilitating factors relating to the provision of palliative care in primary care settings were mapped using the four framework categories of policy, implementation, education and availability of medicines, and an analytical framework. We thus identified and grouped various resources which would be of value to those seeking to further develop palliative care in community settings.

Step 2: Developing and refining the toolkit. A draft toolkit was then constructed, summarising the current barriers and opportunities, and then suggesting various innovations and approaches, again using the WHO framework as a useful public health way to overview such innovations. The toolkit was distributed electronically with an online questionnaire through the International Primary Palliative Care Network and also posted and publicised on the EAPC website with an online questionnaire. This resulted in 33 responses to the online survey exploring the applicability of the toolkit resource across countries[9]. Using an iterative approach, summary findings of the online survey about the utility of the toolkit and the draft toolkit itself were then presented to 60 delegates at a workshop at the 13th World Congress of the EAPC in May 2013 and also to 12 delegates at a Primary Care (WONCA) World Conference in June 2013. The draft toolkit was then further refined to contain the most useful and relevant links to resource material that would make it work as a practical document internationally.

Realising the fundamental importance of and challenges in identifying people with palliative care needs so they can access palliative care services, we also conducted an international systematic review of tools used to identify people for palliative care in the community. Ethics permission was granted by the University of Edinburgh.

Results

Step 1: Country profiles were received and collated for 20 European countries (see figure 2). The collated data from these individual country reports is presented in Appendix 1 with summary detail provided below.



Figure 2: Country Profiles completed

Overview of Specialist Palliative Care: There was a great diversity in the extent and type of specialist palliative care provided in European countries, with three categories evident: those that have extensive, moderate or limited specialist palliative care provision (see section 1 of appendix 1).

Palliative Care Teaching: Undergraduate teaching takes place in 50% of countries and some postgraduate teaching in all. There is a wide range of clinical and research courses from in-service training to diplomas and masters or PhD level.

Primary Care Services: GPs work together ranging from individually to large groups. In 50% of countries community nurses work with GPs, which facilitates multi-disciplinary palliative care. Various systems exist for acute and repeat house-calls (see appendix 1).

Place of death: In most countries respondents considered that most people died in hospital with Albania, Armenia, Switzerland and Sweden as exceptions. Generally very few people died in hospices and in Switzerland and Sweden 50% die in care homes. Most people prefer to die at home if they (and their family) can be adequately supported there.

Development of Primary Palliative Care: In two of the twenty countries surveyed GPs kept lists of patients with palliative care needs (Spain and UK): generally no systematic way of identifying patients was used. In eight out of 20 countries some frameworks of end-of-life care are advocated e.g. Gold Standards Framework in UK. Despite the availability of simple and helpful tools, GPs still identified too few people for palliative care before they die. Identifying and recording patients on a palliative care register did not necessarily lead to “end-of-life” conversations. Advance care planning was rare even in patients with cancer. Specialist



advice was available in nearly all countries by telephone, out-patient referral and some at the patients home or day centre. Countries tended to fall into three groups: limited, moderate or extensive generalist palliative care provision. During the iterative feedback process it was revealed that specialists and general practitioners in Italy had done considerable work in palliative care in the community but this was hidden from international literature as the training manuals and procedures were published in Italian.

Terms Used: The terms “hospice” or “palliative care” were not widely used although where they were a stigma was reported. Terms such as “supportive care” or “care of the critically ill” or simply “care” emerged as useful phrases.

Research in Primary Palliative Care: A number of papers relating to palliative care in the community are listed at the end of appendix 1, which show encouraging recent activity in several countries.

The systematic literature review revealed only four tools used in primary care to identify patients nearing the end of life [10-14]. However, three other tools were identified, through contact with authors and experts in the field, as also having been developed to aid identification of this cohort [15-17].

Step 2 Developments of a Toolkit for the advocacy and development of primary palliative care (See Toolkit document)

A toolkit to signpost interested parties to documents and examples of practice and to give practical guidance was drafted and refined through the process above where 105 individuals had input in refining the draft toolkit. After an initial statement about the potential of palliative care in the community, and a summary of typical barriers and themes in each country (see Table 1), this 4 page hyperlinked document utilises the 4 domains of the WHO public health strategy for palliative care to highlight examples of innovations and best practice in various European countries [8].

Table 1 - Barriers and Opportunities for Primary Palliative Care:

Barriers	Opportunities in some countries
Lack of knowledge and skills within primary care	Training opportunities available in some countries
Financial systems not permitting reimbursements for palliative care	Examples of established primary care infrastructure and financial incentives
Policy and practical problems with opiate prescribing	National strategies supporting palliative care
Lack of professional or specialist support	Developing clinical networks
Poor identification of patients requiring palliative care	GP accessibility to all patients
Limited public understanding of palliative care	Increasing political support and public advocacy campaigns



The resources were grouped and incorporated on the basis of their potential use in the diverse countries in which it is hoped this toolkit will be used, and limited to restrict the toolkit to a manageable 4 pages. Please see toolkit document for details.

The final section of the toolkit suggests initial steps that might be taken depending on the stage of development of the country of interest:

1. Identify key individuals or organisations interested e.g. GP, pharmacy and community nurse organisations, palliative care specialists.
2. Convene a local or national meeting or working group to discuss specific challenges and solutions.
3. Collate data supporting the need for and potential outcomes of palliative care in the community.
4. Seek to establish improvements in each of the four domains of the public health model. Review the resources and documents linked within this toolkit to scope potential approaches which may be of benefit.

Discussion

Principal findings: We first profiled the provision of and barriers and opportunities for palliative care in the community in 20 European countries. Based on this information we developed a resource toolkit and gained feedback on it from many individuals and at two international meetings. The 4 domains of the WHO Public Health Strategy provided a robust framework to use to collate the resources and to structure the toolkit. The toolkit usefully supplements previous work describing core competences in palliative care for members of the specialist palliative care teams and can be used to respond to the call to develop more palliative care in the community by generalists [18].

Strengths and weaknesses of the study: The variety of methods employed allowed us to capture information from different sources and settings. The EAPC Atlas for Palliative Care in Europe 2013 offers much greater detail on specialist services[19]. The two workshops held at the EAPC Congress and WONCA Conference to refine the toolkit were well attended with the latter attracting delegates from South America, New Zealand and Africa as well as Europe: therefore the toolkit has global relevance and input from primary care as well as specialist palliative care.

What is already known and what this review adds: The recent publication of the EAPC Atlas of Palliative Care highlights the lack of formal data available on primary palliative care services across member nations, and this study provides both information and suggested actions[19]. Toolkits of this type have been produced elsewhere with excellent examples coming from the African Palliative Care Association (APCA) who also have produced a variety of resources that different African countries can access to promote policy developments and services[20]. Such tools have helped advocacy work in Uganda to overcome barriers to opiate prescribing. The APCA toolkit and also recent work from the Latin American Palliative Care Association also have a wide focus incorporating both primary and secondary services in their guidance[21].



Implications for clinical practice and research: We have produced a toolkit highlighting some excellent innovative work that has been undertaken throughout Europe. The country profiles and content of the EAPC Atlas also highlights the considerable work that is still to be done. All 4 domains of the WHO Public Health Strategy for Palliative Care must be developed simultaneously and there is clear need for work to define the core competencies and service configurations required for the delivery of primary palliative care. Increased recognition of the need for community based palliative care services to be established alongside specialist provision in order to ensure adequate population coverage is vital if the vision set out in the Prague Charter is to be realised [22]. Access to essential medications remains a challenge and must be tackled through national advocacy, education and support. A number of countries are already starting to use the toolkit, which has already been translated into French.

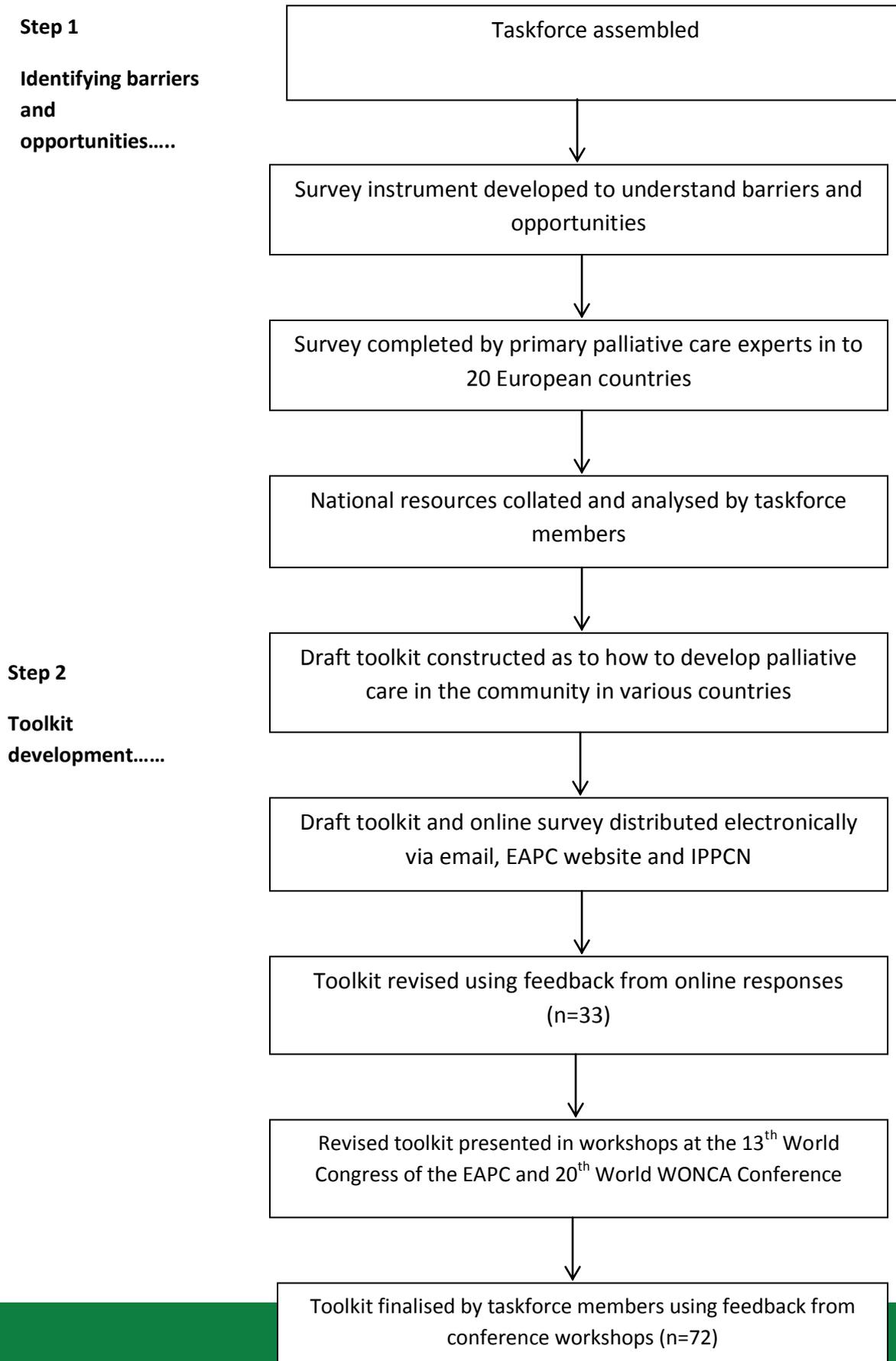
Dissemination: The work of the taskforce has and will be highlighted through palliative care and primary care organisations including but not limited to the European Association of Palliative Care, the IAHP, eHospice, national organisations, primary care organisations, such as WONCA, regional and national organisations, and various websites.

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Declaration of interest: The authors are all advocates for palliative care in the community.

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Figure 1 – Process of identifying barriers and opportunities for palliative care in the community and then developing the toolkit





TOOLKIT FOR THE DEVELOPMENT OF PALLIATIVE CARE IN THE COMMUNITY

PURPOSE OF THIS DOCUMENT

This resource is being developed by the EAPC in liaison with WONCA to help support and guide individuals and organisations in Europe and possibly worldwide seeking to further develop palliative care services in primary care settings. The principles outlined in the EAPC Prague Charter and particularly that access to palliative care as a human right underpins this work. In 2014 the WHO has recommended that palliative care should be integrated in primary care services, and this toolkit gives practical guidance on the steps required.

WHY IS DEVELOPING PALLIATIVE CARE IN THE COMMUNITY IMPORTANT?

More patients will benefit from palliative and end-of-life care if it is delivered in the community by Primary Healthcare Teams. For this to happen GPs and nurses working together in the community will require training and support by specialist palliative care teams. They will also need adequate time, financial and practical resources, and the ability to prescribe morphine when appropriate.

Primary Care has a unique position and potential to deliver effective palliative care to patients. It can:

- Reach patients with all life-threatening illnesses
- Start early in the course of life-threatening disease.
- Meet all dimensions of need: physical, social, psychological and spiritual
- Provide care in clinics, care homes and at home thus preventing unnecessary hospital admissions
- Support family carers and provide bereavement care

A SNAPSHOT OF CURRENT ISSUES

Country profiles have been collated for 20 European nations and we have identified barriers and opportunities for the development of primary palliative care. These reports, alongside data from specialist palliative care provision, demonstrate that although there are examples of excellence which can be celebrated, there are numerous challenges which need to be overcome. (See Appendix 1)

Barriers	Opportunities
Lack of knowledge and skills among GPs and nurses	Training opportunities available in some countries
Financial systems not permitting reimbursements for palliative care	Examples of established primary care infrastructure
Issues hindering opiate prescribing	New national strategies supporting palliative care
Lack of professional or specialist support	Developing clinical networks in many countries
Poor identification of patients requiring palliative care	All patients have access to primary care
Limited public understanding and stigmatisation of and palliative care	Increasing political support



INNOVATIONS AND BEST PRACTICE APPROACHES

The WHO Public Health Strategy for Palliative Care, shown in the figure below, highlights the need for developments in the following 4 domains as a framework for improving palliative care services¹:

- 1) Appropriate policies
- 2) Availability of Education and training
- 3) Availability of medicines
- 4) Implementation across all levels of society



POLICY INITIATIVES IN EUROPE

A supportive national policy is an overarching requirement to facilitate the development of palliative care provision in the community. Several countries have succeeded in developing national end of life care strategies which incorporate a primary care focus. Consider the relevance of the following to your country:

- [Legal right to palliative care in statute and 'Charter for the critically ill and the dying' in 2010 \(Germany\)](#)
- [National steering committee in Primary Palliative Care \(Ireland\)](#)
- [National Plan for Palliative Care in 2010 \(Portugal\)](#)
- [Strategy for palliative care development adopted in 2009 \(Serbia\)](#)
- [National strategy for palliative care with increasing focus on community care \(Switzerland\)](#)
- [National End of Life Care Program 2008 \(England\)](#)
- [Living and Dying Well 2008 \(Scotland\)](#)
- [Action plan by Ministry of Health \(Albania\)](#)

These national strategies can provide an effective foundation for comprehensive palliative care provision covering all sectors of the health and social care systems.

FOR CONSIDERATION: Is there currently a national strategy for palliative care in your country? Does the provision of services in the community feature strongly in the strategy? If no strategy currently exists consider how the examples above could inform local policy.

¹ Stjernsward J, Foley KM, Ferris FD. The Public Health Strategy for Palliative Care. J Pain Symptom Manage 2007;33:486-493



EDUCATIONAL INITIATIVES IN EUROPE

The WHO strategy for palliative care also recommends educational Initiatives aimed at both the public and healthcare professionals. Examples, such as the [Dying Matters Coalition](#) in England and [Good life, Good death, Good grief](#) in Scotland, have been established with the aim of engaging society in becoming more open about death, dying and bereavement.

GP training curricula have also been developed in several countries such as Italy and Spain, and opportunities exist for GPs to gain postgraduate certificates and diplomas in palliative care by distance learning.

[RCGP Curriculum Statement on End of Life Care](#)

[Cardiff University Palliative Care Education](#)

FOR CONSIDERATION: Are efforts underway to reduce barriers to discussing death, dying and bereavement? What palliative care training do GPs and community health teams currently receive in your country?

IMPLEMENTATION FRAMEWORKS IN THE COMMUNITY IN EUROPE

A good example of how a palliative care approach can be integrated in the community is the [Gold Standards Framework](#). It is a systematic evidence based approach to optimising the care for patients in the last months of life being delivered by GPs. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any illness in the community.

The [NECPAL CCOM-ICO program](#) in Spain provides a further example of a successful implementation program incorporating training, strategic plans and guidelines for practice.

Both The GSF and NECPAL resources include guides to help clinicians identify patients who may benefit from a palliative care approach. Development of tools and resources to aid in the identification of patients with palliative care needs is currently an area of interest in several research institutes given that uncertainty as to who should be categorised as a palliative care patient remains a significant barrier to palliative care provision in primary care. Find out what is happening locally, and consider how these developments might be implemented. [A recent systematic review](#) has identified a handful of approaches that have been established to date:

- [GSF Prognostic Indicator Guidance](#)
- [Supportive and Palliative Care Indicators Tool \(SPICT\)](#)
- [Radboud Indicators for Palliative Care Need \(RADPAC\)](#)
- [The NECPAL Tool](#)
- [Quick Guide](#)
- [Rainone et al](#)

FOR CONSIDERATION: Are palliative care services delivered following a systematic and co-ordinated approach? How are patients in the community with supportive and palliative care needs currently identified?

DRUG AVAILABILITY: ACTION POINTS PROMOTING COMMUNITY PALLIATIVE CARE

A detailed review of opiate availability was conducted within the European Pain Policy Initiative, a joint program of work undertaken by the European Society for Medical Oncology (ESMO) and the European Association for Palliative Care (EAPC). The major recommendations include:



1. **Formulary restrictions:** The ESMO and EAPC endorse the standards of the WHO essential medicines list as a minimal standard for opioid formulary. This minimal formulary should include oral codeine, immediate release morphine, controlled release morphine tablets and injectable morphine. We concur with the more expansive formulary described by the IAHPIC as a preferred minimal standard but this may be aspirational at this time. We note that the advice the IAHPIC that governments should not approve controlled release morphine, fentanyl or oxycodone without first guaranteeing widely available immediate release oral morphine.
2. **Regulatory restrictions:** The ESMO and the EAPC echo the WHO and the INCB in calling for government examination of drug control policies and repeal of over vigilant or excessive restrictions that impede good clinical care of cancer pain. Examples of such restrictions include requirements for patients to have a special permit or restrictions on care settings where opioids can be prescribed, restrictions on prescribing privileges to limited physician specialties, arbitrary dose limits, excessive restrictions on the number of day's supply that can be prescribed.
3. **Emergency prescribing:** Regulatory provision should be made for emergency prescriptions of opioids for patients in severe pain who cannot obtain a physical prescription. The ESMO and the EAPC support the approach of the Drug Enforcement Administration of the United States which permits emergency prescription by telephone or facsimile to the pharmacist. The pharmacist must ensure the veracity and validity of the prescription before dispensing the controlled substance and the prescriptions must be transcribed to hard copy by the pharmacist and retained (Title 21, Code of Federal Regulations section 1306.21).
4. **Special prescription forms:** The requirement for special prescription forms is not considered an excessive burden *PER SE*. Forms must be readily available to prescribers and that the process of procuring them not be excessively burdensome so as to provide a disincentive to do so.
5. **Dispensing:** Pharmacists must have the authority to correct technical errors in consultation with the prescribing physician

<http://www.eapcnet.eu/Themes/Policy/OpioidaccessibilityEurope.aspx>

FOR CONSIDERATION: How do the prescribing arrangements and availability of opiate and other medications in your country compare to the ideals described above?

NEXT STEPS IN DEVELOPING COMMUNITY PALLIATIVE CARE IN YOUR NATION

The intention of this document and its revisions is to help support the development of primary care services in the community. The following are possible steps that can be taken depending on the current stage of development in each country or region:

1. Identify key individuals or organisations in your country interested in the development of palliative care in the community e.g. GP organisations, palliative care specialists.
2. Convene a meeting or working group to identify and discuss local challenges and solutions.
3. Use the EAPC taskforce in Palliative Care in the Community database to contact experts who may be able to provide some specific guidance on relevant issues.
4. Seek to establish improvements in each of the 4 domains of the public health model in order to create a balanced system of provision. Review the resources and documents linked within this toolkit to scope potential approaches which may be of benefit.
5. Collate data supporting the need for and potential outcomes of palliative care in the community.

EAPC PALLIATIVE CARE IN PRIMARY CARE TASKFORCE: COLLATED DATA FROM INDIVIDUAL COUNTRY REPORTS

The following data has been collated from country reports completed by individuals with an interest in and knowledge of palliative care in their nation.

SECTION ONE: CONTEXT OF PRIMARY PALLIATIVE CARE

Specialist palliative care services and structure: There is a great diversity in the extent and type of specialist palliative care provided. Countries might be grouped into three categories; those that have extensive, moderate or limited specialist palliative care provision.

Country	Hospice	IP Other	Hospital Teams	Home Care Serv	Day Service	Palliative Care Beds
Albania	0	0	1	5	1	0
Armenia	5	1	10	8	5	59
Belgium	0	45	150	28	6	379
Denmark	17	3	28	28	1	33
France	0	78	309	84	0	1615
Germany	185	238	56	1500	No valid data	1707
Ireland	8	2	30	34	8	171
Luxembourg	1	2	1	2	0	28
Malta	0	1	1	1	0	10
Netherlands	84	4	50	Not known	Not known	716
Norway	2	12	16	1	3	220
Poland	?	3	321	11	145	1675
Portugal	1	3	1	3	1	53
Serbia	0	0	2	3	0	Not known
Spain (Catalonia)	0 0	106 61	51 49	167 76	32 50	1186 650
Sweden	0	0	2	3	0	Not known
Switzerland	5	28	13	18	0	276
UK	158	63	305	356	257	2515
Ukraine	7	55	0	6	0	985

Table 1: Number of specialist palliative care services and palliative care beds

Palliative care teaching: Undergraduate teaching takes place in about 50% of countries, and some postgraduate teaching in all. There is a wide range of clinical and research courses, from in-service training to short courses or diplomas to Masters or PhD level although how many of these are aimed at the generalist is unclear.

Primary Care services and structure: GPs work from individually to up to large groups, and in around 50% of countries community nurses work with GPs. Various systems exist for acute



and chronic visits, and home visits are possible at night in all countries except for Albania, Armenia and Ukraine.

Country	Range GPs per practice	Average no GPs	Community nurses	Size of registered list	Pay for consultations
Albania	1-12	4	No	2500	No
Armenia	-	1 rural, 25 urb	Yes	2000	No
Belgium	1-3	2 (median 1)	Yes - practice		No not for pc
Denmark	1-9	2	Yes	1600	No
France	2-3	Unknown	No	No reg. list	Yes
Germany	1-3	2	Few	No reg. list	Yes
Ireland	1-6	2	No	800	Yes
Luxembourg	NK	NK	No	No	Yes (36E)
Malta	1 private grp practice. Otherwise, solo private GPs or GP employed by NHS in health centres	NK	Yes	No reg. list	If private yes, if NHS GP no
Netherlands	18% single, 54% group	-	No	2400	No
Norway	-	-	No formal link	-	Free up to the age of 16
Poland	1-12	2	Yes	1800	No
Portugal	4-50	20	Yes	1478	Yes
Serbia	-	1 Dr, 4 nurses for 25,000	No	2000	No
Spain	1-20	5	Yes	1200	No
Sweden	3->20	Unknown	Yes	2000	Yes
Switzerland	-	1.5	Yes	Yes but unclear	Yes
UK	1-12	4	Yes	1800	No
Ukraine	2-6	4	Yes	Regional	No

Table 2: Profile of General Practice in each country

Country	Arrangements for home visits	Arrangements for out of hours
Albania	Patient requests GP	Patient attends emergency centre at local hospital
Armenia	Phone call	Call to ambulance (emergency service 24 hours, free of charge, but unofficial payments required)
Belgium	A palliative Status gives right to a 'PalliatiefForfait' (forfaitary sum, once renewable) directly for the patient of 603,12€ (maximum 1206,24 € per patient, 9,05 mio €	Mobile teams are at disposition 24/24 and 7/7 for support of the first line GP and nurse. They support by telephone, or, rather exceptional also at home



	spent nationwide in 2007); there is also a Forfait for a nurse giving care to palliative patients (50 mio € spent in 2007)	
Denmark	GP's get a set salary per home visit and compensation for transport. The nature or the length of the home visit can in certain situations give the GP an additional financial supplement. At the moment a new agreement in some areas of Denmark allows the GP to receive specific supplements for terminal home care also in out of hours	Out of hours service are provided by a GP on call who covers a specific geographical area. The GP's in some cases chose to give their private phone number to terminally ill patients. The above mentioned agreement allows the GP to get a specific fee if they see their own patients out of hours
France	A home visit, but less than before	There is a price for night and for holidays but reimbursed 100%
Germany	Patient or carer phones practice during the day	Patient or carer phones nationwide out-of-hours number (established in 2012). The call is forwarded to the responsible regional agency. The out-of-hour service is organized by the regional association of statutory health insurance physicians, including GPs as well as specialists but no nursing services
Ireland	GPs with GMS contracts are mandated to provide home visits themselves or via a deputizing service. In reality, most GPs will restrict home visits to a minimum, but generally are very amenable to home visits to patients in need of palliative care	Variable. Most GPs are involved in local co-operative arrangements for on call, usually from an out of hours centre. Some 'co-op's provide 24hour cover, some are replaced at a certain hour e.g. 10pm by deputizing agency doctors who will do home visits. There are no out of hours visits by PHNs
Luxembourg	Only on call and only GP. Patients have to pay for home visit (between 36 to 73€ per visit) and 1.7 to 3.7€ per kilometer	Emergency call "112". 24/24 hours 7/7days availability for the palliative care team in CHL and CHEM (limited to patients who are known by the team), no visits at home (NOT allowed by the health system setting), via telephone or consultation at the hospital (patients have to come to the hospital)
Malta	GP provide house visits. If the GP is employed by the NHS, this visit is free. If the GP is in private practice, the patient pays	Patients get visits out of hours. Usually, they rely more on the NHS system for out of hours care
Netherlands	Double consultation fee per normal home visit. Intensive care visits for palliative care patients have a special fee (for day care and for care during evening, night and weekends)	Partly by out of hours services, terminal care often but not always by own GP
Norway	GPs and patients plan home visits when needed, often in co-operation with the patient's family and community nurse. The GP gets an extra fee for home visit to palliative list-patients	Out of hours are covered by GPs (and other doctors who ask for it) in a turnus covering the whole community or a larger area. We do normally not cover our own patient list out of hours, but some of the GPs will be accessible for their palliative



		patients
Poland	Home visits are provided by all GPs, there's no additional fee (for those who signed GP's personal list)	Out of hours care is a service separate from primary care. GP is obliged to hang a doorplate at the entrance to the office with clear information on OHC service available when the office is closed. When there's a need for continuity of care on weekends/holidays GP has to issue referral letter to OHC with procedures listed (e.g. injections, wound dressing). Patients or their caregivers have to arrange/make appointment to the OHC (also home visits) on their own (but it is not difficult to arrange)
Portugal	GP schedule allows designated period for home visits, established by the GP according to needs assessment. Home visits can be arranged with district nurses	Each GP practice has a limited amount for out of hours, reserved for Community Care Teams (UCC)
Serbia	Patients can be seen at home as an emergency or if they are too ill or old to visit the doctor in the out-patient clinic. In the case of an emergency the team will come within 10mins – 1 hour. Therefore seen according to need and team availability.	As before
Spain	Telephone call to contact Primary Care Health Center	Call 061/112 telephone Continuous Care Point (Primary Care) Emergency Services (Hospitals)
Sweden	Most often acute visits due to deterioration, sometimes asked for by the community nurses. They are seldom prophylactic	We have an organization for out of hours. Often these organizations do home calls only because of unexpected deaths or psychiatric acute needs
Switzerland	Extra – fee for GP's paid by insurance	Extra – fee for GP's paid by insurance
UK	Patient or carer phones practice during the day	Patient or carer phones national out-of-hours number for nurse triage at night. Some local regions have dedicated number and nurses for palliative care patients out-of-hours
Ukraine	Home visits are made to severely sick patients (post-stroke, post-MI, terminal stages of cancer, etc.). Due to the understaffing – nurses are limiting the visits themselves, and often patients are asked to pay for these visits (unofficially)	None

Table 3: Arrangements for home visits and out of hours

Place of death: Most people die in hospital, with notable exceptions such as Albania, Armenia, Switzerland and Sweden. In Spain, 50% die at home. Generally very few people die in hospices, and in Switzerland and Sweden 50% die in care homes. Most people prefer to die at home (or care home if they live there) if they (and their family) can be adequately supported there, but advance care planning is necessary.

Country	Hospital	Home	Hospice	Care Home	Other
Albania	5	93	0	0	2
Armenia	14	86	0	0.4	n/a
Belgium	50	23	0	24	4
Denmark	55	26	n/a	18	1
France	70-80	20-30	n/a	Unknown	Unknown
Germany	42	27	1-2	20	5
Ireland	48	25	4	20	3
Luxembourg	60	21	0	17	3
Malta	57	15	0	13	3
Netherlands	-	-	-	-	-
Norway	35	15	-	44	6
Poland	50	38	6	?	6
Portugal	61	30	-	(included in home figures)	9
Serbia	33 (cancer)	-	-	-	-
Spain	40	50	-	11	-
Sweden	38	6	5	45	6
Switzerland	34	15	<1	51	-
UK	58	18	4	17	3
Ukraine	70	26	4	2	1

Table 4: Place of death

SECTION TWO: DEVELOPMENT OF PRIMARY PALLIATIVE CARE

Development of primary palliative care: In 3 out of the 20 countries surveyed GPs keep lists of patients with palliative care needs (Spain, UK). Patients are identified as having palliative care needs through a variety of means, such as at hospital discharge or by the GP themselves. Other means included: by word of mouth or by using the surprise question. Generally no systematic way of identifying patients is evident.

The range of palliative care patients estimated to have cancer ranged from 19-95% with the majority estimating approximately 80%.

In 8/20 countries some frameworks or end-of-life care pathways are advocated for use eg. GSF, NECPAL, with variable uptake.

Specialist advice is available in nearly all the countries by telephone, outpatient referral, and in some at the patient's home or at day centre.



Availability of specialist advice in the 20 surveyed countries			
Via telephone	Outpatient Referral	Day Centre Review	Review at Patient's Home
19 – all except Ukraine	17	9	16

Table 5: Availability of specialist advice

The members of the multidisciplinary team included: palliative care physicians, GPs, oncologists, anaesthetists, paediatricians, nurses, psychologists, social workers, occupational therapists, chaplaincy and physiotherapists. The majority mentioned a doctor, nurse and psychologist.

National policies / standards / plans and developments: A variety of developments are underway as follows:

- Production of national standards (Albania, Armenia)
- Action plan by Ministry of Health (Albania)
- Development of out of hours specialist advice (Denmark)
- Legal right to palliative care in statute and 'Charter for the critically ill and the dying' in 2010 (Germany)
- National steering committee in Primary Palliative Care (Ireland)
- National Plan for Palliative Care in 2008 (Portugal), Luxemburg
- Strategy for palliative care development adopted in 2009 (Serbia)
- National strategy for palliative care moving to community care (Switzerland)
- Revised law on health care provision includes palliative care as an indispensable component of the general public health care system and statement on basic palliative care provision being approved by the Ministry of Health (Ukraine)
- National Strategy 2013-2015 (Switzerland)

Service developments

- Holidays for carers available (France)
- Appointment of GP facilitators in UK- GPs who for say 2 days per month encourage and support their local peers to undertake more and better palliative care eg. encourage roll-out of Gold Standards Framework of care.
- New tool in Belgium
- End of Life initiative in UK gives financial incentives to GPs (especially in Scotland with a Directly Enhanced Service. Regional registers to improve 24 hour communication (Coordinate My Care project, London and the electronic Palliative Care Summary, Scotland)
- Development of NECPAL project bringing systematic public health approach in districts(similar to GSF/SPICT tools) (Catalonia)

SECTION THREE: BARRIERS AND OPPORTUNITIES FOR PRIMARY PALLIATIVE CARE

Terms used for palliative or end of life care: In many countries, the terms hospice or palliative care were not widely used and as a result there is no stigma associated with them. In countries where they are used commonly, a stigma with using the term was reported. Terms such as terminally ill or incurably ill appear to be used less frequently, with terms such as supportive care or care of the critically ill or dying or simply care (as in co-ordinate my care) emerging as useful phrases.

The WHO Public Health Strategy for Palliative Care highlights the need for 1) appropriate policies 2) education/training 3) availability of medicines/opioids and 4) implementation across all levels of society². This framework is used below to analyse the current situation in Europe based on the available country reports:

Barriers	Frequency of reporting	WHO Model
Lack of knowledge and skills among GPs	9	Education
Financial systems not permitting reimbursements for palliative care	9	Policy
Issues with opiate prescribing	6	Prescribing
Lack of professional or specialist support	5	Education
Poor identification of patients requiring palliative care	4	Education
Poor structures of primary healthcare teams	4	Implementation
GPs bypassed by hospital and palliative care teams	2	Education
Lack of resources	3	Policy
Lack of time	2	Policy
Poor handover to out of hours services	2	Education
Poor public awareness	1	Education
Part of the population not yet covered by a GP service	1	Implementation
Limited understanding of the English language	1	Education
GPs reluctant to talk about palliative care or death and dying with their patients	1	Education
Private medical system	1	Policy
A law regulating palliative care with euthanasia and assisted suicide	1	Policy
No national coordination	1	Implementation
GPs see only a small number of palliative care patients each year	1	Education

² Stjernsward J, Foley KM, Ferris FD. The Public Health Strategy for Palliative Care. J Pain Symptom Manage 2007;33:486-493



Opportunities	Frequency of reporting	WHO Model
Good infrastructure of primary health care	6	Policy
National strategy	6	Implementation
Increased training opportunities available	5	Education
GPs know the family well	5	Implementation
Increased political pressure	2	Policy
GPs are available to provide care	3	Education
90% of the last year of life is spent at home	1	Education
Small number of deaths per GP each year	1	Implementation
Increased awareness of importance of palliative care	1	Education
Increased knowledge of palliative care by GPs	1	Education
The majority of patients want to die at home	1	Implementation
Availability of out of hours specialist advice for GPs	1	Education
Reform of the way palliative care is financed	1	Policy
Reform of the management structures of GPs	1	Policy
Registered lists of palliative care patients	1	Implementation
New pathways for palliative care patients	1	Education
Conversations about euthanasia can be used to introduce palliative care	1	Education
Development of a palliative care network	1	Implementation

1. It is apparent from this overview that some countries are still at advocacy and national strategy development stage, while others need advocacy to promote education and training and for supportive structures in primary care and community nursing.
2. Lack of training features as a barrier while opportunities for training are mentioned in other countries.
3. Some specific service developments are happening to facilitate primary palliative care such as establishing registers and creating frameworks.
4. Issues with opiates prescribing specifically mentioned in 6 countries.

Three broad classifications are apparent from the results which allow the stages of development for primary palliative care in Europe to be understood:

A



- Limited specialist palliative care provision
- Primary care services developed but restricted opportunities for developing primary palliative care, e.g. no community nurses or home visits
- significant national barriers (policy or organisational) to integrating services, e.g. developing the infrastructure to support specialist palliative care delivery, training or opiate availability

B

- Moderate specialist palliative care provision
- Primary care services suggest some capacity to develop primary palliative care services
- National policies supporting specialist palliative care but not yet supporting primary palliative care

C

- Extensive national specialist palliative care service provision
- Primary care services becoming aware of the importance of primary palliative care and capacity and tools developed to support, but most patients still not identified for palliative care approach.
- National policies and some organisational changes supportive.

SUPPLEMENTARY DATA

Section 1. Relevant research

Country	Relevant Research or Review Papers
Armenia	<p>A. Tadevosyan, H. Karapetyan, L. Fuortes. Starting a new Pediatric Palliative Care Program. In Proceedings of the Children's Hospice International's (CHI) 19th World Congress, November 19, 2008, San Francisco, USA</p> <p>A. Tadevosyan, Connor S., H. Karapetyan, Palliative care in Armenia: needs and perspectives. The New Armenian Medical Jurnal, 2010, vol.4, No.3. p. 142</p> <p>A. Tadevosyan, Connor S., H. Karapetyan, Palliative Care in Armenia: Needs in Professional and Public Education. In Proceedings of the 12th Congress of the European Association for Palliative Care. 18th-21st May 2011, Lisbon, p 96</p> <p>N. Movsisyan, CurrentState of Palliative Care Education in Armenia. In Proceedings of the 12th Congress of the European Association for Palliative Care. 18th-21st May 2011, Lisbon, p 186</p> <p>R. Babayan, S. Krmoyan, L. Nanushyan, A. Papikyan, The Development of the Concept of the Palliative Medical Care Introduction in Republic of Armenia In Proceedings of the 12th Congress of the European Association for Palliative Care. 18th-21st May 2011, Lisbon, p 241</p>
Belgium	'Organisation of palliative care in Belgium' (Federaal Kenniscentrum voor de gezondheidszorg, 2009)



	<p>https://kce.fgov.be/publication/report/organisation-of-palliative-care-in-belgium Evaluatierapportpalliatievezorg (Federal authority 2008, with a lot of numbers and budget): http://www.bag.admin.ch/themen/gesundheitspolitik/13764/index.html?lang=en exists also in French</p>
Denmark	<p>Who is the key worker in palliative home care? Brogaard T, Jensen AB, Sokolowski I, Olesen F, Neergaard MA. Scand J Prim Health Care. 2011 Sep;29(3):150-6. Epub 2011 Aug 23</p> <p>Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: a longitudinal cohort study. Guldin MB, Vedsted P, Zachariae R, Olesen F, Jensen AB. Support Care Cancer. 2011 Sep 4. [Epub ahead of print]</p> <p>Identifying bereaved subjects at risk of complicated grief: Predictive value of questionnaire items in a cohort study. Guldin MB, O'Connor M, Sokolowski I, Jensen AB, Vedsted P. BMC Palliat Care. 2011 May 16;10(1):9</p> <p>Cross-sectorial cooperation and supportive care in general practice: cancer patients' experiences. Lundstrøm LH, Johnsen AT, Ross L, Petersen MA, Groenvold M. FamPract. 2011 Oct;28(5):532-40. Epub 2011 Mar 22</p> <p>Preference for place-of-death among terminally ill cancer patients in Denmark. Neergaard MA, Jensen AB, Sondergaard J, Sokolowski I, Olesen F, Vedsted P. Scand J Caring Sci. 2011 Dec;25(4):627-36</p> <p>Shared care in basic level palliative home care: organizational and interpersonal challenges. Neergaard MA, Olesen F, Jensen AB, Sondergaard J. J Palliat Med. 2010 Sep;13(9):1071-7</p> <p>Associations between successful palliative trajectories, place of death and GP involvement. Neergaard MA, Vedsted P, Olesen F, Sokolowski I, Jensen AB, Sondergaard J. Scand J Prim Health Care. 2010 Sep;28(3):138-45</p> <p>Associations between successful palliative cancer pathways and community nurse involvement. Neergaard MA, Vedsted P, Olesen F, Sokolowski I, Jensen AB, Sondergaard J. BMC Palliat Care. 2009 Dec 14;8:18</p> <p>Associations between home death and GP involvement in palliative cancer care. Neergaard MA, Vedsted P, Olesen F, Sokolowski I, Jensen AB, Søndergaard J. Br J Gen Pract. 2009 Sep;59(566):671-7</p> <p>Caregivers' active role in palliative home care - to encourage or to dissuade? A qualitative descriptive study. Weibull A, Olesen F, Neergaard MA. BMC Palliat Care. 2008 Sep 16;7:15</p> <p>Palliative care for cancer patients in a primary health care setting: Bereaved relatives' experience. a qualitative group interview study. Neergaard MA, Olesen F, Jensen AB, Sondergaard J. BMC Palliat Care. 2008 Jan 15;7:1</p> <p>Cooperating with a palliative home-care team: expectations and evaluations of GPs and district nurses. Goldschmidt D, Groenvold M, Johnsen AT, Strömngren AS, Krasnik A, Schmidt L. Palliat Med. 2005 Apr;19(3):241-50</p> <p>Ongoing research is being carried out by, among others, MetteKjærgaard</p>



	<p>Nielsen (Family caregivers in palliative care trajectories) http://pure.au.dk/portal/en/persons/mette-kjaergaard-nielsen(05fa3b7d-5cf0-4c04-965e-89638e6a049b).html</p> <p>And Mai-Britt Guldin (complicated grief and bereavement) http://pure.au.dk/portal/en/persons/maibritt-guldin(d4164724-4519-4f76-9755-f9ef0cf52590).html</p>
Germany	<p>Ongoing studies:</p> <p>Schneider N, Hummers-Pradier E, Bleidorn J. End-of-life care for frail older patients in family practice. Study carried out by Hannover Medical School, funded by the Federal Ministry of Education and Research, 2012-2015.</p> <p>Papers:</p> <p>Seger W et al. Comparison of survival under domestic or institutional care: the Hannover morbidity and mortality long-term care study [in German]. Deutsche Medizinische Wochenschrift 2011;136:28-29.</p> <p>Schneider N, Mitchell GK, Murray SA. Palliative care in urgent need of recognition and development in general practice: the example of Germany. BMC Family Practice 2010, 11:66</p> <p>Schneider N, Buser K, Amelung VE. Attitudes of Family Doctors on Health Care for Incurable Patients at the End of Life – Results from a Survey in Lower Saxony. [in German] Z Allg Med 2006; 82:298-304.</p> <p>Schneider N, Engeser P, Behmann M et al. Specialized outpatient palliative care. The expectations of general practitioners [in German]. Schmerz 2011, DOI 10.1007/s00482-011-1037-0</p> <p>Bleeker F, Kruschinski C, Breull A et al. Characteristics of Palliative Care Patients in General Practice [in German]. Z Allg Med 2007;83:477–482</p>
Ireland	<p>Phase 2 of PPC project underway to implement findings of initial report Unpublished research by Kiely in Cork re Out of Hours arrangements for palliative care patients at home</p>
Italy	<p>An observational study on the application of a palliative home care integrated model. The study features the collaboration of the National Agency of Health Services and is backed by the Italian Ministry of Health. The objectives are: Identify patients with palliative care needs in early stages able to be candidates for a palliative care path, evaluate in structured and homogeneous manner needs and preferences of these patients and their relatives, recognize among these patients the ones that needs basic and specialist palliative care, analyze the elements characterizing basic/specialist palliative care processes from the organizational, managerial, professional point of view, evaluate the results of the palliative home care integrated organizational model with relation to: GP activity, UCP functioning, palliative care network. This Research Project started in January 2014. We hope results will be helpful for both the Programmer and Italian Institutions to favor the integration of those operators who are independently rotating around the patient without coordination today.</p>
Luxembourg	<p>1. No research until 2010 2. First research actions in the CHL: - 2010: Clinical audit on “Quality of end of life care in a general hospital in Luxemburg”, Poster Discussion Session, French Congress on Palliative Care</p>



	<p>in Lyon and EAPC Congress in Lisbon, Leader: Dr. Fogen Frederic - 2011: Clinical trial on reflexology in supportive care, Leader: Dr. Fogen Frederic, Poster discussion session at the French Congress on Palliative Care in Strasbourg in June 2012</p>
Netherlands	<p>Tools to early identification of pall care patients (Thoonsen, Engels, Vissers) Systematic and proactive care planning (Thoonsen, Engels, Vissers) Spiritual care (Vermandere, BJGP) Pall Care for non cancer (Willems) Case management (Philipsen)</p>
Poland	<p>Buczkowski K, Krajnik M, Budzyński J, Chlabicz S. Znajomość zasad leczenia opioidami bólu nowotworowego wśród lekarzy rodzinnych województwa kujawsko – pomorskiego i podlaskiego. [Knowledge of opioid treatment principles in family physicians in Kujawy-Pomerania Voivodship region] Pol Med Paliat 2004;3:335-342</p> <p>Buczkowski K, Krajnik M, Budzynski J, Chlabicz S. Management of Cancer Pain in Primary Care in Poland. Adv Pall Med (formerly Pol Med Paliat) 2007;6:17-22</p> <p>Krajnik M, Muszalska M, Rogiewicz M. Is the palliative medicine specialist unique among medical practitioners? A comparative study of the personality of specialists in palliative medicine, surgery, anaesthesiology and general practice. Adv Pall Med (formerly Pol Med Paliat) 2007;6:63-68</p> <p>Adamczyk A, Buczkowski K, Jagielski D, Krajnik M, Rogiewicz M. Opieka Paliatywna. WydawnictwoLekarskie PZWL, Warszawa 2009. (Palliative care handbook for Family Physicians[GPs])</p> <p>Buczkowski K, Krajnik M, Adamczyk A. Opiekanadpacjentemterminalniechorym (Palliative care – part of the multimedia educational platform for Family Physicians at www.docedu.klrwp.pl)</p>
Portugal	<p>Capelas ML. Palliative Care: a Proposal for Portugal (2007), available in URL: http://www.apcp.com.pt/uploads/manuel_luis_capelas_1.pdf</p> <p>Oliveira JE. Caring in end-of-life: perception of GP's (2011) – MSc research project – a sound qualitative study exploring views and barriers for Portuguese GP's involvement in General Palliative Care</p> <p>Ongoing study by Fatima Teixeira – MSc Project – exploring benefits of a Portuguese Home Palliative Care Team in health costs and use of health services (ER visits, hospital admissions...)</p>
Spain (Catalonia)	<p>The NECPAL Project: validation of the tool, prevalence study, prognostic study</p>
Switzerland	<p>English: National Strategy for Palliative Care 2010-2012 Summary Federal Office of Public Health (FOPH)/Swiss Conference of the Cantonal Ministers of Public Health</p> <p>Ongoing: Community end of life care – is health care at the end of life going home in Switzerland? Project national research fund – ongoing application</p>



<p>UK</p>	<p>Ongoing studies: Campbell C, Murray SA et al. Identifying patients who would benefit from palliative care, irrespective of diagnosis: the development and feasibility testing of a primary-care based intervention. <i>Marie Curie Cancer Care</i>, April 2012.</p> <p>Papers: Harrison N, Cavers D, et al To what extent are primary care teams in the UK formally identifying patients for palliative care before they die? <i>BJGP</i> in press. Sheikh A. End-of-life care in the UK: a wider picture of service provision and initiatives. <i>European Journal of Palliative Care</i>. 2008;15:272-275. Boyd K & Murray SA. Recognising and managing key transitions in end of life care. <i>BMJ</i> 2010;341:c4863</p>
<p>Ukraine</p>	<p>Needs assessment in palliative care – grant from OSF/IRF to Caritas Ukraine Palliative care costing analysis comparing in-patient care with mobile teams and with standard care that patients receive now - grant from OSF/IRF to Ivano-Frankivsk Hospice and team of researchers from Kyiv-Mohyla Academy, School of Public Health Study on access to controlled medications (opioids) and consumption rates vs the need – individual PhD research N. Datsjuk – has been recently selected as International Pain and Policy Fellowship recipient.</p>

Section 2. General comments

	<p>Other comments</p>
<p>Albania</p>	<p>A Basic handbook is being translated into Albanian. A plan to develop a curriculum for Nurses. Development of a sub specialization training for Drs. An Albanian Dr has been accepted for specialist training in US. The active National Assoc of Pall Care is a big asset.</p>
<p>Belgium</p>	<p><u>1. Palliative Care Services:</u> depends on what is counted as 'a service': Home care: 28 Mobile teams, 2 specialized teams for children, 6 Day Centra; 45 Palliative or inpatient Units in hospitals; 150 Palliative Support teams in the Hospitals: SUM > 231 services for 10.000.000 inhabitants... (36-45-150 = 15,6 % - 19,5 % - 64,9 %)</p> <p><u>2. Pediatric Resources:</u> two palliative care university teams for children (working 20 years on other funding) are recently financed by the government (University of Ghent and University of Leuven).</p> <p><u>3. Palliative Care Beds:</u> at least 379 in Hospitals (palliative units)</p> <p><u>4. PC physicians?</u> at least: > 65 GPs for mobile teams at home; > 36 PC physicians in the Palliative Units (not Full-time) + 114 extra (150-36, same physician responsible for unit and support team) in the hospital support teams (not Full-time) SUM > 215 physicians for 10.000.000 inhabitants = 1 PC physician per 46.500 inhabitants</p> <p><u>5. Publications in scientific journals?</u> The End-of-life-care group of the Vrije Universiteit Brussels (prof. Luc Deliens) is European top in the number of relevant publications, after Kings College London. There are also the publications of the University of Ghent, of Antwerp and Leuven.</p>



	<p><u>6. Belgium (Flanders)</u> has the highest rate in attending palliative congresses.</p>
France	<p>The situation is different depending of the GP ,the place and the local organization</p>
Germany	<p>GPs in Germany have, on an average, 250 patients contacts per week which is much more than in other countries, e.g. Norway, Sweden, Netherland and the UK where GPs have 80-130 patient contacts per week.</p> <p>In an international comparison the median time per patient contact in Germany is the lowest with a median of 9.1 minutes. For example, in the UK it is 13.3 minutes, in the Netherlands 15 minutes and in Sweden 28.8 minutes.</p> <p>Source: Koch K, Miksch A, Schürmann C et. al. The German Health Care System in International Comparison: The Primary Care Physicians' Perspective. DtschArzteblInt 2011; 108: 255-61</p>
Luxembourg	<p>Please notice that Luxemburg has 39 palliative care identified beds, but only 28 beds are official recognized and powered by the Ministry of Health. For this report, I only indicated all the different actors who are official recognized (units, hospice, home care service...).</p> <p>Please notice that Luxemburg official depenalised euthanasia and assisted suicide in 2009 (following the NL and BE). There's only one law (at all 16 pages) regulating palliative care, euthanasia and assisted suicide! Palliative care and euthanasia are presented as the two end of life models. "So make your choice!"</p>
Malta	<p>In Malta there are two parallel systems of GP going on. One is private, the other is NHS. The latter is free, available 24\7 but lacks continuity of care. The former has continuity of care but is dependent just on solo GPs, who get paid by patients for their service</p>
Poland	<p>Primary care in Poland is planned to be based on the family medicine specialists (GPs) and their team. Since the specialty is just 15 years available – the training and re-training procedure is not completed. Some 60% of primary care physicians are trained FM specialists. The rest are mainly internists and pediatricians.</p> <p>Palliative care is separate specialist care, part of secondary and tertiary healthcare. Palliative care medical specialty is a secondary specialty, available for most of the basic clinical specialist. GPs trained in palliative care are minority. Mostly palliative care specialist are hospital doctors – anesthesiologists, oncologists, neurologists and others.</p> <p>There are no perspectives and plans/visions to change the model of palliative care in our country. Most of the institutions (and particularly patients) struggle with bureaucracy and financial problems, as the framework for the care is established by centralized National Health Fund.</p> <p>Patients who are not 'typical cases' have to fight and struggle with lots of procedural obstacles to receive the care. This is another condition when GP is involved in palliative care – someone has to help the patient until specialist care is available.</p> <p>Amid the 'procedural' problems, professional cooperation between GPs and</p>



	<p>palliative care specialist is satisfying. Majority of palliative care specialists are highly motivated individuals, open and ready to support GPs when their help is needed.</p> <p>In areas where availability of palliative care is low, GP is the only available physician to manage palliative care patients.</p>
Portugal	Portugal has awakened very late for Palliative Care. Nevertheless, in recent years huge steps have been taken which have boost confidence for growing a broad accessible system for the Portuguese population and for reaching the standards achieved in other European countries.
Serbia	There is currently an ongoing three year project funded by the EU to develop palliative care services in Serbia.
Spain (Catalonia)	Most of full time palliative care doctors (220) are GPs and/or geriatricians
UK	<p>Palliative care specialist nurses and doctors could play a much greater role in training and supporting generalists</p> <p>For one palliative med specialist doctor, there are 70 GPs and 70 hospital doctors, and similar stats for specialist nurses.</p>

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