

Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care

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Abstract

Background: A multidisciplinary European Association of Palliative Care Taskforce was established 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 palliative care specialists, primary care health professionals or policymakers, service developers, educationalists and national groups more generally could use to facilitate the development of palliative care in their own country.

Design: (1) A survey instrument was sent to general practitioners with knowledge of palliative care services in the community in a diverse sample of European countries. We also conducted an international systematic review of tools used to identify people for palliative care in the community. (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 make comments. Iterations of the toolkit were then presented at international palliative care and primary care conferences.

Results: Being unable to identify appropriate patients for palliative care in the community was a major barrier internationally. The systematic review identified tools that might be used to help address this. Various facilitators such as national strategies were identified. A primary palliative care toolkit has been produced and refined, together with associated guidance.

Conclusion: Many barriers and facilitators were identified. The primary palliative care toolkit can help community-based palliative care services to be established nationally.

Keywords

Palliative care, primary palliative care, primary health care, community health services, policy, qualitative research

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What is already known about the topic?

- 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 national 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

Internationally, 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 people who are dying, 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. The World Health Assembly in May 2014 endorsed a resolution calling for palliative care to be fully integrated into health care in every setting, specifically highlighting community settings, and throughout the course of advanced illnesses.¹ The Prague Charter also calls for universal access to palliative care.² 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, the European Association of Palliative Care (EAPC) Taskforce 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 web page (available at <http://www.eapcnet.eu/Themes/Organisation/Primarycare.aspx>) drew attention to this activity and the initial work undertaken and was regularly updated. 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;³
- Start at diagnosis of life-threatening illness;⁴
- Meet all dimensions of need: physical, social, psychological and spiritual;⁵
- Provide care in clinics, care homes and at home and prevent unnecessary hospital admissions;⁶
- Support family caregivers and provide bereavement care.⁷

We thus aimed to document the barriers and facilitators for palliative care in the community and to produce a

resource toolkit so that palliative care specialists, primary care health professionals, policymakers, service developers, educationalists and national groups more generally could use to facilitate the development of primary palliative care (PPC) in various nations.

Methods

See Figure 1 for flow diagram of methods.

Step 1. Identifying barriers to and opportunities for palliative care in the community

The authors S.A.M. and E.v.R. initially 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.^{8,9} 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 services to contextualise palliative care development 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 in developing palliative care in the community and the actual practice of identifying patients in the community for palliative care. We specifically asked whether general practitioners (GPs) routinely kept a register of patients with palliative care needs and whether any care frameworks were used. Respondents were requested to respond using documented national data where available, such as national registers, or to estimate where this was unavailable. They were also asked to report any relevant research or review papers in PPC. A copy of the

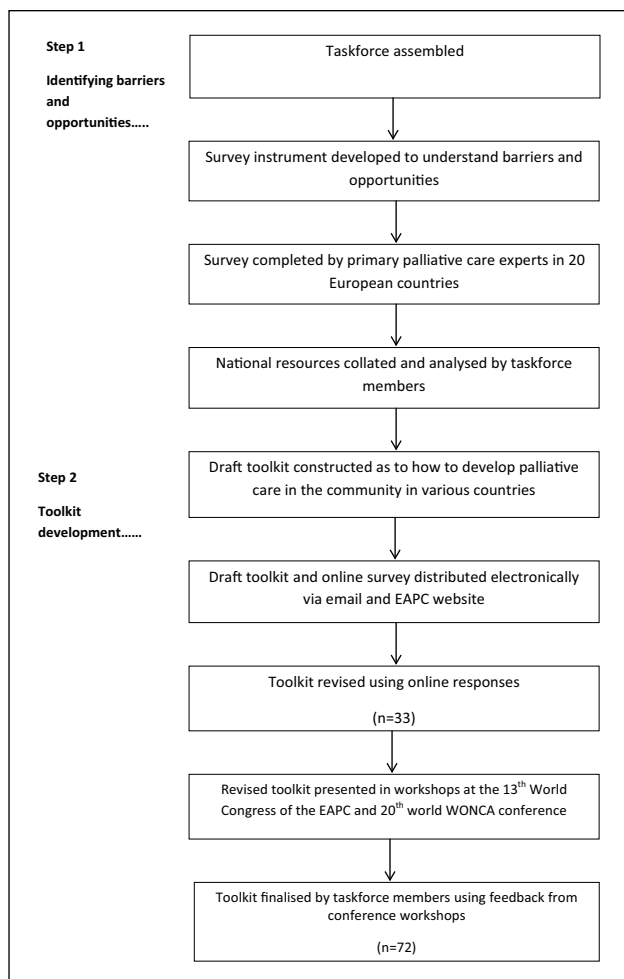


Figure 1. Process of identifying barriers and opportunities for palliative care in the community and then developing the toolkit.

EAPC: European Association of Palliative Care; WONCA: World Family Doctors Caring for People Conference.

survey instrument is available from S.A.M. 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. These included 5 countries from Eastern Europe and 15 countries from Western Europe at different stages of palliative care development. The informants were invited via email contact from a list produced by taskforce members.

The results of this survey were analysed by S.A.M., L.S. and A.F. Barriers and facilitating factors relating to the provision of palliative care in primary care settings were investigated using, as an analytical framework, the four categories of policy, implementation, education and availability of medicines from the World Health Organization (WHO) Public Health Strategy for Palliative Care.¹⁰ As the difficulty of identifying patients for palliative care was a constant theme from all countries, at the end of this stage, we embarked on an international systematic literature

review to identify instruments that we might be able to recommend in the toolkit.

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 which had been identified in the previous survey, 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.¹¹ This resulted in 33 responses to the online survey exploring the applicability of the toolkit resource across countries. S.A.M. and A.F. then analysed these findings thematically and presented them, together with the results of the stage 1 survey, to 60 delegates at a workshop at the 13th World Congress of the EAPC in May 2013 who were mostly palliative care specialists, including doctors, nurses and allied health professionals. A similar presentation was made to 12 delegates at a World Family Doctors Caring for People Conference (WONCA) in June 2013, who were multidisciplinary primary care clinicians. After the initial presentation at each of these meetings, attendees were split into small groups to discuss possible improvements. Data from these discussions were then collated and analysed by S.A.M. and A.F. who further refined the draft toolkit to contain the most useful and relevant links to resource material that would make it work as a practical document internationally. Ethics permission was granted by the University of Edinburgh. Where applicable we have attempted to follow the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines in reporting the qualitative aspects of this study.¹²

Results

Step 1

Country profiles were received and collated for the 20 European countries as sampled above (see Figure 2). The detailed collated data from these individual country reports are in the full taskforce report which can be downloaded from the EAPC Taskforce homepage at <http://www.eapc-net.eu/Themes/Organisation/Primarycare.aspx>. Summary results are provided below.

Primary care services. Some GPs work individually and others in large groups. In only 50% of countries, community nurses work with GPs, which greatly facilitates multidisciplinary palliative care. Various systems exist for acute and repeat house-calls, and home visits are possible in all surveyed countries apart from Albania, Armenia and Ukraine. Payment structures greatly influence practice of



Figure 2. Countries surveyed.

palliative care, for example, extra fees may be available for palliative care home visits in Netherlands, Norway and Denmark, whereas in Luxembourg patients have to pay directly for home visits.

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% died in care homes. Respondents reported that most people preferred to die at home if they (and their family) could be adequately supported there.

Development of PPC. In 2 of the 20 countries surveyed, GPs kept lists of patients with palliative care needs (Spain and United Kingdom): generally no systematic way of identifying patients was used. In 8 out of 20 countries, some frameworks of end-of-life care were advocated, for example, Gold Standards Framework in the United Kingdom. Despite the availability of simple and helpful tools, GPs still identified too few people for palliative care before they died. The range of palliative care patients estimated to have cancer ranged from 19% to 95%, with most estimating approximately 80%. 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 for some at the patient's home or day centre. Countries tended to fall into three groups: limited, moderate or extensive generalist palliative care provision. A large number of national developments were documented, for example, National Standards in Albania and Armenia and National strategies in Luxembourg, Switzerland and Serbia. Various service developments in the community such as 'GP Facilitators' in the United Kingdom and a Public Health and Palliative Care Project in Catalonia were also listed. Many barriers and opportunities for palliative care in the community were elicited from different countries (see Table 1 and Taskforce website).

Terms used. The term 'hospice' or 'palliative care' was 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 PPC. A number of articles relating to palliative care in the community are listed on the Taskforce website, which show encouraging recent activity in several countries.

The systematic literature review revealed that only four tools were used in primary care to identify patients nearing the end of life.^{13–16} We have published the systematic

Table 1. Barriers and opportunities for primary palliative care according to WHO framework.

Barriers	Opportunities in some countries
<p><i>Education:</i> lack of knowledge and skills within primary care</p> <p><i>Implementation:</i> financial systems not permitting reimbursements for palliative care</p> <p><i>Policy and availability of medicines:</i> problems with opiate prescribing</p> <p><i>Implementation:</i> lack of professional or specialist support structure</p> <p><i>Education:</i> poor identification of patients requiring palliative care</p> <p><i>Education:</i> limited public understanding of palliative care</p>	<p><i>Education:</i> training opportunities available in some countries</p> <p><i>Implementation:</i> examples of established multidisciplinary primary care infrastructure and financial incentives</p> <p><i>Policy and availability of medicines:</i> national strategies supporting palliative care and access to medicines</p> <p><i>Implementation:</i> developing clinical networks and referral pathways</p> <p><i>Policy and implementation:</i> GP accessibility to all patients</p> <p><i>Policy:</i> increasing political support and public advocacy campaigns</p>

WHO: World Health Organization; GP: general practitioner.

review already.¹⁷ However, three other tools were identified through the stage 1 survey as also having been developed to aid identification of this cohort.^{18–20} During the iterative feedback process in stage 2, it was revealed that specialists and GPs in Italy had done considerable work in palliative care education in the community, but that this was unfortunately hidden from international literature as the training manuals and procedures were published in Italian.

Step 2. Development of a toolkit for the advocacy and development of PPC

A toolkit to give practical guidance and to signpost interested parties to documents and examples of practice was drafted and refined through the process above, and 105 individuals had input in refining the draft toolkit (see Appendix 1). 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 four-page hyperlinked document utilises the four domains of the WHO Public Health Strategy for Palliative Care to highlight examples of innovations and best practice in various European countries.¹⁰

The resources identified by the previous country surveys were grouped and incorporated on the basis of their potential use in the diverse countries in which it is hoped that this toolkit will be used. It was restricted to a manageable four pages.

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, for example, GP, pharmacy, community nurse organisations and 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 and conducted a literature review when we found it was necessary. Based on this information, we developed a resource toolkit and gained feedback on it from many individuals and at two international meetings. The four 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 competencies 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.²¹

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 details on specialist services.²² 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. The toolkit was considered to have international relevance and had valuable input from specialists and generalists. Rather than conduct a complete mapping of this emerging field, we utilised our scarce resources to profile a range of European countries (around

50%), to understand their barriers and facilitators and to undertake an iterative process of toolkit development. This methodology did not allow the COREQ guidelines to be rigidly applied, and we would have missed some developments happening in unsurveyed countries.

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 PPC services across member nations, and this study provides both information and suggested actions.²⁰ Toolkits of this type have been produced elsewhere with excellent examples from the African Palliative Care Association (APCA)²³ who also have produced a variety of resources that different African countries are using to promote policy developments and services. 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 have a wide focus in incorporating both primary and secondary services in their guidance.²⁴

Implications for clinical practice and research

We have produced a toolkit highlighting some excellent innovative national strategies and developments that have been undertaken throughout Europe. The country profiles which we collected and the content of the EAPC Atlas also highlight the considerable work that is still to be done. All four domains of the WHO Public Health Strategy for Palliative Care are best developed simultaneously, and there is clear need for work to define the core competencies and service configurations required for the delivery of PPC. Increased recognition of the need for community-based palliative care services to be established alongside specialist provision is vital in order to ensure adequate population coverage if the vision set out in the Prague Charter is to be realised.² 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.

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Declaration of conflicting interests

The authors are all advocates for palliative care in the community.

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Appendix



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](#))

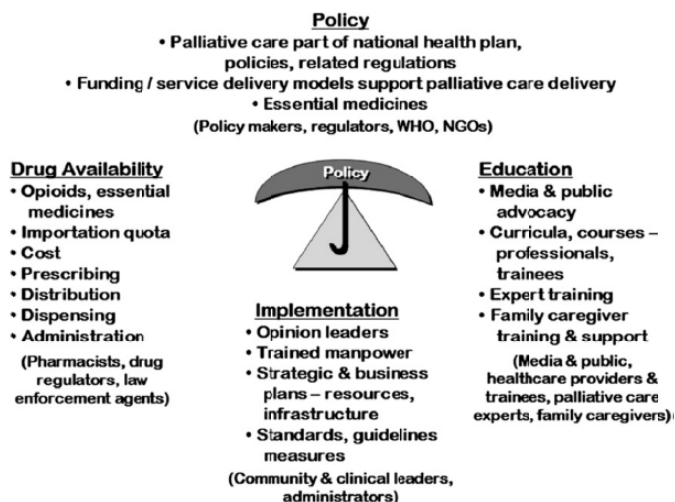
Major barriers and opportunities include:

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)
- Revised law on health care provision includes palliative care as an indispensable component (Ukraine)

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.