

# 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

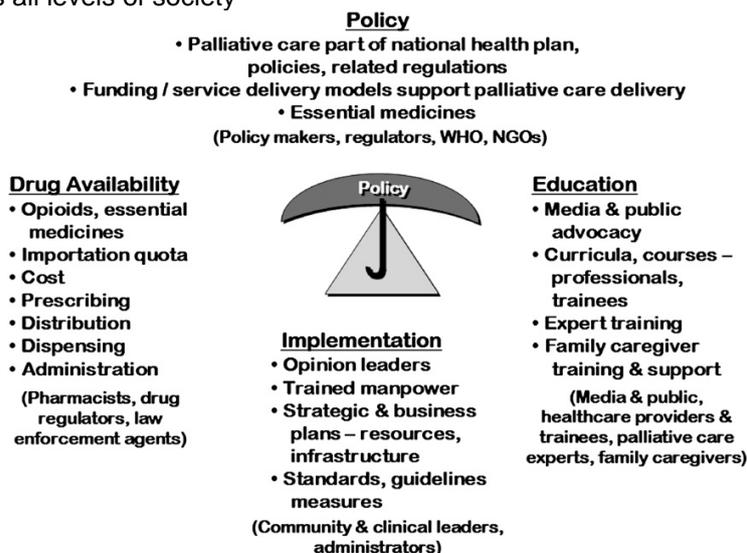
Country profiles have been collated for 20 European nations and we have identified barriers and opportunities for the development of primary palliative care. These reports, alongside data from specialist palliative care provision, demonstrate that although there are examples of excellence which can be 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 services<sup>1</sup>:

- 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.

<sup>1</sup> 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 IAHP as a preferred minimal standard but this may be aspirational at this time. We note that the advice the IAHP 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.