TOOLKIT FOR THE DEVELOPMENT OF PALLIATIVE CARE IN PRIMARY CARE 2019

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PURPOSE OF THIS DOCUMENT

This resource is to help support national leaders and clinicians in Europe and worldwide to further develop palliative care services in primary care settings. In 2014 the WHO recommended that palliative care should be integrated in all settings, and in 2018 at Astana resolved that palliative care was a key component of primary care services. This toolkit gives practical guidance on the steps required.

WHY IS DEVELOPING PALLIATIVE CARE IN THE COMMUNITY IMPORTANT?

More patients will access and benefit from palliative and end-of-life care if it is delivered in the community. For this to happen GPs and nurses working together in the community will require training and support by specialist palliative care teams, family physicians or community nurses experienced in providing palliative care in the community. They will also need adequate time, financial and practical resources, and be able to prescribe morphine and other appropriate medication.

Primary Care has a unique potential to deliver palliative care to patients with **all illnesses**, at **all times** during the illness, reach **all dimensions** of need, in **all settings** and is present in **all countries**.

A SNAPSHOT OF CURRENT ISSUES

In 2018 clinicians from 30 European nations completed questionnaires profiling palliative care services in primary care (see map).
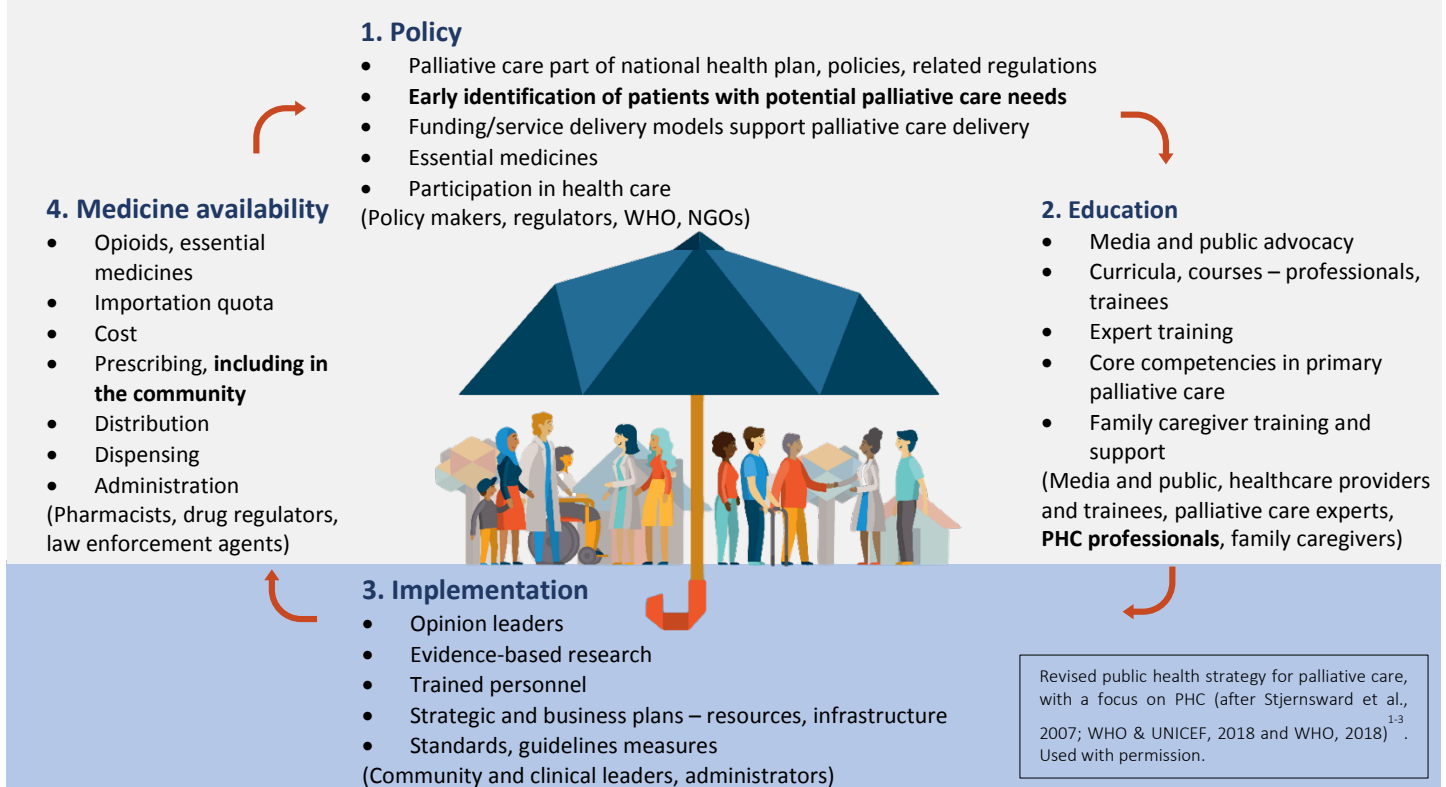
Although there is much progress in many countries due to policy, training and service delivery improvements, barriers still need to be overcome. The following barriers and opportunities were identified:

Barriers		Opportunities
Workload of GPs and lack of time to implement palliative care	Most frequent	**GPs motivated**
Patients present increasingly with multiple chronic conditions rather than with a single diagnosis		**Many policies and guidelines**
Early identification was rare		**Educational activities and resources**
Lack of training		**Use of specific tools to identify patients**
Lack of multi-professional teamwork in primary care		**Advance care planning**
Lack of specialists in palliative care		**Development of information systems and communications including out of hours**
Most patients and professional are unwilling to talk about dying	Less frequent	**Developing research base**
		Community Participation

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INNOVATIONS AND BEST PRACTICE APPROACHES

The WHO Public Health model for Palliative Care highlights the need for developments in 4 domains as a framework for improving palliative care services[1]. These domain pertain to primary health care too:

Primary health care (PHC) is a critical foundation for universal health coverage

1. Policy
- Palliative care part of national health plan, policies, related regulations
- **Early identification of patients with potential palliative care needs**
- Funding/service delivery models support palliative care delivery
- Essential medicines
- Participation in health care

(Policy makers, regulators, WHO, NGOs)

4. Medicine availability
- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing, **including in the community**
- Distribution
- Dispensing
- Administration

(Pharmacists, drug regulators, law enforcement agents)

2. Education
- Media and public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Core competencies in primary palliative care
- Family caregiver training and support

(Media and public, healthcare providers and trainees, palliative care experts, **PHC professionals**, family caregivers)

3. Implementation
- Opinion leaders
- Evidence-based research
- Trained personnel
- Strategic and business plans – resources, infrastructure
- Standards, guidelines measures

(Community and clinical leaders, administrators)

Revised public health strategy for palliative care, with a focus on PHC (after Stjernsward et al., 2007; WHO & UNICEF, 2018 and WHO, 2018)[1-3]. Used with permission.

Recently, a number of key international statements have encouraged countries to adopt policies, practices, research and training supporting palliative care in all countries:

- World Health Assembly Resolution 67.19 (WHA, 2014)
- Integrating Palliative Care and Symptom Relief into Primary Health Care (WHO, 2018)
- The Astana Declaration on Primary Health Care (WHO, UNICEF, 2018)

1. POLICY INITIATIVES

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 these examples could inform local policy.

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A supportive national policy is an overarching requirement to facilitate palliative care provision in the community. Several countries have succeeded in developing national end-of-life care strategies which incorporate a primary care focus. The following are some examples of useful policy initiatives in Europe since 2014 that can provide an effective foundation for comprehensive palliative care provision covering all sectors of the health and social care systems.

- National Strategy for Palliative Care (Switzerland, 2013-2015)
- National Plan for the Development of Palliative and End of Life Care (France, 2015-2018)
- Ambitions for Palliative and End of Life Care (England, 2015-2020)
- Strategic Framework for Action on Palliative and End of Life Care (Scotland, 2016-2021)
- Palliative Care Services. Three year development framework (Ireland, 2017-2019)
- Strategic Plan for the Development of Palliative Care (Portugal, 2017-2018)
- National Strategy for Palliative Care (Croatia, 2017-2020)

[1]Stjernswärd J, Foley KM, Ferris FD, et al. The public health strategy for palliative care. J Pain Symptom Manage 2007; 33: 486–93.
[2]WHO, UNICEF. *Declaration of Astana. Global Conference on Primary Health Care. Astana, Kazakhstan, October 25–26, 2018*. Geneva, New York: WHO, UNICEF, 2018.
[3]WHO. *Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers*. Geneva: WHO, 2018.

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2. EDUCATIONAL INITIATIVES

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?

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Government strategies to promote **public awareness** of palliative care include: the National Council for Palliative Care in England; Living Matters, Dying Matters in Northern Ireland; Good life, Good death, Good grief in Scotland. These encourage society to be more open about death, dying and bereavement. Video resources for public, patients and family carers to help facilitate conversations include How to Live and Die Well.

Undergraduate teaching resources including PowerPoints and discussion documents are available.

Postgraduate training resources include:
- EAPC Primary Care Reference Group
- Clinical modules in end of life care (RCGP curriculum, 2016)
- Core curriculum for palliative care in family medicine (Italy, 2012) *in Italian*
- Videos on early palliative care (University of Edinburgh, 2018)
- Tools to help professionals identify patients for palliative care (Scotland, 2016)
- Daffodil Standards (Marie Curie, RCGP, 2019)

GP training curricula have 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.

3. IMPLEMENTATION FRAMEWORKS IN THE COMMUNITY

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?

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A good example of how a palliative care approach can be integrated in the community is the Gold Standards Framework, a systematic evidence based approach to optimising the care for patients in the last months of life being delivered by GPs and nurses in the community. The NECPAL CCOMS-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, assess and then plan care for patients who may benefit from a palliative care approach.

Identify ▸ Assess ▸ Plan

IN THE COMMUNITY

Additional innovations in the last three years include:

- Essentials of the palliative approach (French National Authority for Health, 2016)
- Recommendations for a palliative approach (Danish Health Authority, 2017) *in Danish*
- Comprehensive and integrated palliative care for people with advanced chronic conditions in Europe (2017)
- Improving palliative care provision in primary care in the Netherlands (2018)
- The ARIANNA Project in Italy (2018)
- Primary palliative care in Ireland (2018)
- The EAPC white paper on advance care planning

Development of tools and resources to aid in the identification of patients is vital. Find out what is happening locally, and consider how these developments might be implemented. A recent systematic review 2013 has identified a handful of approaches that have been established to date:

- GSF Proactive Care Indicator Guidance
- Supportive and Palliative Care Indicators Tool (SPICT)
- NECPAL Tool (in Catalan / in Spanish)

4. MEDICINES AVAILABILITY

How do the prescribing arrangements and availability of opioids and other medications in your country compare to the ideals described below? **??**

A detailed review of opioid 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 EAPC. The major recommendations include:
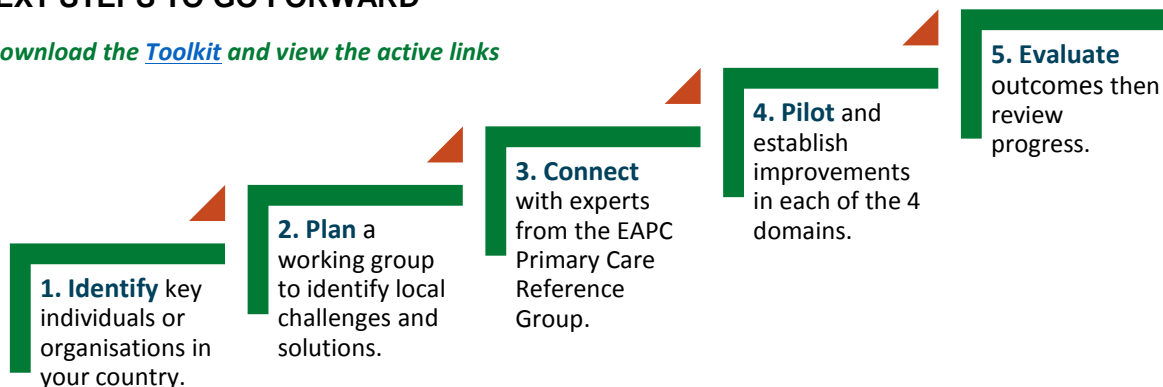
1. **Formulary restrictions:** The minimal formulary should include immediate release morphine, controlled release morphine tablets, injectable morphine and oral codeine. Governments should not approve controlled release morphine, fentanyl or oxycodone without first guaranteeing widely available immediate release oral morphine.
2. **Regulatory restrictions:** Governments should repeal excessive restrictions that impede good clinical care of severe pain. Issues identified in our recent survey include prescribing restrictions and relate to length of time or how medicines are prescribed e.g.
   - *Slovenian GPs have to write prescriptions in an opioid book*
   - *in Macedonia, prescriptions must come from hospital or hospice*
   - *in Iceland prescriptions need a double signing*
   - *In Romania only oncologists can prescribe opioids free of charge*
   - *in Croatia some opioids can be prescribed only under recommendation from oncologist*
3. **Emergency prescribing:** Provision should be made for emergency prescriptions of opioids for patients in severe pain who cannot obtain a physical prescription. Emergency prescription by telephone or facsimile to the pharmacist should be considered. The pharmacist must ensure the veracity and validity of the prescription before dispensing the controlled substance and the prescriptions must be transcribed to a hard copy by the pharmacist and retained.
4. **Special prescription forms:** The requirement for special prescription forms is not considered onerous in itself. The process of procuring them must not be excessively burdensome.
5. **Dispensing:** Pharmacists must have the authority to correct technical errors in consultation with the prescribing physician

Further resources:
- EAPC Blog **on the 'Access To Opioid Medication in Europe' (ATOME) project**
- The 10-point plan **of the 'Global Opioid Policy Initiative' (ESMO)**

NEXT STEPS TO GO FORWARD

Download the Toolkit and view the active links

1. Identify key individuals or organisations in your country.

2. Plan a working group to identify local challenges and solutions.

3. Connect with experts from the EAPC Primary Care Reference Group.

4. Pilot and establish improvements in each of the 4 domains.

5. Evaluate outcomes then review progress.

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