Open meeting of the EAPC Primary Care Reference Group

EAPC 2019
Berlin
Friday 24th May
12.55-14.15
See the website for many resources including videos, toolkit and tools, available in many languages.

https://www.eapcnet.eu/eapc-groups/reference/primary-care

**Primary Care**

Interested in learning more about this reference group? Come along to the open meeting at the 16th World Congress of the EAPC in Berlin Friday, 24 May 2013 12:45-1:45pm Room 4 (2nd floor).

 Palliative care still only reaches a minority of potential beneficiaries and is often introduced too late to prevent much distress. People with multi-morbidities and non-malignant conditions, frailty and dementia are still less likely to receive any form of palliative care than those with cancer. To gain universal coverage, a coordinated primary care and public health approach is necessary. Our vision is that palliative care is fully integrated in primary care systems internationally so that all patients have easy access to a palliative care approach in the community (in their own home and residential care facilities).

**Rationale**

Palliative care still only reaches a minority of people who could benefit from a holistic approach to care as their health declines, and is often not introduced until the terminal stage of their illness. People with multi-morbidities and non-malignant conditions, frailty and dementia are still less likely to receive any form of palliative care than those with cancer. To gain universal coverage, a coordinated primary care and public health approach is necessary.

**Almos & Objectives**

1. Promote integration of primary care as an essential element of national palliative care frameworks, and palliative care as a necessary element of national primary care frameworks.
2. Foster training and educational development in palliative care for all primary care health professionals, at both undergraduate and graduate levels.
3. Advocate that primary care practitioners providing palliative care have adequate resources and professional support to encourage safe and effective practice, and to promote health equity for people with life-threatening illnesses.
4. Provide collegiate support to primary care practitioners as they develop evidence-based approaches to high-quality primary palliative care.
5. Support and develop research opportunities in primary palliative care – across EU countries.
6. Identify mechanisms to support primary palliative care in all countries, with a specific focus on lower and middle income countries.

**How can I contribute?**

If you are passionate about improving palliative care in the community in your country, please contact our co-ordinator marie.lynch@hospicefoundation.ie to register as a member of the wider group.

**Chairs**

**Professor Scott A. Murray**

University of Edinburgh, Scotland
to contact by email please click here
Twitter: @scomurray

**Dr Sebastian Moine**

University Park, 13 Nord, Belgium
to contact by email please click here
Twitter: @Smoine

**Coordinator**

**Deirdre Shanagher**

Irish Hospice Foundation
to contact by email please click here

**Members**

Prof Geoff Mitchell
Professor Julia Downing
Dr Steffen Eychmueller
Dr Jordi Amblas
Dr Kirsty Boyd
Prof Nils Schneider
Prof Yasemin Kilic Ozturk
Small group discussion:

What are the latest and most meaningful developments in your country about palliative care in primary care?

TOOLKIT FOR THE DEVELOPMENT OF PALLIATIVE CARE IN PRIMARY CARE 2019

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 2015 in Athens 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 able to prescribe morphine and other appropriate medication.

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 development improvements, barriers still need to be overcome. The following barriers and opportunities were identified:

Barriers
- Workload of GPs and lack of time to implement palliative care
- Patients present increasingly with multiple chronic conditions rather than with a single diagnosis
- Early identification was rare
- Lack of training
- Lack of multi-professional teamwork in primary care
- Lack of specialists in palliative care
- Most patients and professional are unwilling to talk about dying

Opportunities
- GPs motivated
- Many policies and guidelines
- Educational activities and resources
- Use of specific tools to identify patients
- Advance care planning
- Development of information systems and communications including out of hours
- Developing research base
- Community Participation

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. These domains pertain to primary health care too:

1. Policy
- Palliative care as a part of national health plan, policies, related regulations
- Early identification of patients with potential palliative care needs
- Funding for service delivery models that support palliative care delivery
- Essential medicines
- Participation in health care (Policy makers, regulators, WHO, NGOs)

2. Education
- Medical and public advocacy
- Palliative care specialists - professionals, trainers
- Expert training
- Core competencies in primary palliative care
- Family caregiver training and support
- Media and public, healthcare providers and business, palliative care experts, PHC professionals, Family carers

3. Implementation
- Option leaders
- Evidence-based research
- Training personnel
- Strategies and resources - principles, methodologies, standards, guidelines, measures
- Community and clinical leaders, administration

4. Medicines availability
- Analgesic, essential
- Opioids
- Sedatives
- Dexamethasone
- Antipsychotic
- Prophylactic, including in the community
- Distribution
- Storage
- Administration
- Pharmacies, drug regulators, law enforcement agencies

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 67, 2014)
- Integrating Palliative Care and Symptom Relief into Primary Health Care (WONCA, 2018)
- The Andes Declaration on Primary Health Care (WHO, 2018)
- The Paris Declaration on Palliative Care (WHO, 2018)


How do these current national strategies 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.

A supportive national policy is an overarchingly required 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, 2015-2017)
- Ambitions for Palliative and End of Life Care (England, 2015-2020)
- Framework: Focus on Action on Palliative and End of Life Care (Europe, 2015-2021)
- Palliative Care Services, Three year Development Framework (Ireland, 2017-2019)
- Strategic Plan for the Development of Palliative Care (Portugal, 2017-2019)
- National Strategy for Palliative Care (Croatia, 2017-2020)

**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)

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
   - Evidenced-based research
   - Trained personnel
   - Strategic and business plans – resources, infrastructure
   - Standards, guidelines measures
     (Community and clinical leaders, administrators)

4. **Medicine availability**
   - Opioids, essential medicines
   - Importation quota
   - Cost
   - Prescribing, including in the community
   - Distribution
   - Dispensing
   - Administration
     (Pharmacists, drug regulators, law enforcement agents)

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

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?

Government strategies to promote public awareness of palliative care include: the National Council for Palliative Care in England, Living Wills, Dying Matters in Northern Ireland, (Good to go) in Scotland. These encourage society to be more open about death, dying and bereavement.

Video resources for public, patients and family caregivers 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 (BGP curriculum, 2016)
- Core curriculum for palliative care in family medicine (July, 2012) in Italian
- Videos on early palliative care @ University of Edinburgh, 2016
- Tools to help professionals identify patients for palliative care (Scotland, 2014)

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.

1. 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?

A good example of how a palliative care approach can be integrated in the community is the "Quid 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 SİOPAL, COCCOMOS program in Spain provides a further example of a successful implementation program incorporating education, skills development, guidelines to help clinicians identify, assess and then plan care for patients who may benefit from a palliative care approach.

Additional innovations in the last three years include:
- Essentials of the palliative approach (French National Authority for Health, 2016)
- Recommendations for a palliative approach (Italian Health Authority, 2017) in Italian
- Support services and integrated palliative care for people with advanced chronic conditions in Sweden (2018)
- The CRAMM+ Project in Italy (2018)
- Primary palliative care in Ireland (2018)
- The EAPC white paper on advance care planning
Palliative care by primary care workforce for children

Professor Julia Downing
Recruiting GPs for PPC research – Belgium

Dr Bert Leysen
PROAKTIV trial in PPC – Switzerland
Professor Steffen Eychmüller
Developments in South-East Europe

Dr Erika Zelko
WONCA and IPPCN updates

Dr Alan Barnard
# Integration of palliative care in primary care

**EAPC PPC Survey in Europe (2018)**

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification tool translated</td>
<td>Other tool translated</td>
<td>PPC Toolkit translated</td>
<td>GP Training in Primary Pall. Care (PPC)</td>
</tr>
<tr>
<td>Croatia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Romania</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Integration of palliative care in primary care

**EAPC PPC Survey in Europe (2018)**

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification tool translated</td>
<td>Other tool translated</td>
<td>PPC Toolkit translated</td>
<td>GP Training in Primary Palliative Care (PPC)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Country</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Croatia</td>
<td>✅</td>
<td>✅</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Romania</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Integration of palliative care in primary care

**EAPC PPC Survey in Europe (2018)**

<table>
<thead>
<tr>
<th></th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification tool translated</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Other tool translated</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>PPC Toolkit translated</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>GP Training in Primary Pall. Care (PPC)</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Early Pall Care video</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>PPC Pilot project</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Contact w/ regional health author.</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Contact w/ national health author.</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>PPC integrated in national pall. care strategy</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
<tr>
<td>Early identification recommended in primary care</td>
<td>✓ ✓ ✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
<td>✓ ✓ ✓</td>
</tr>
</tbody>
</table>

- **Croatia**
- **Denmark**
- **Romania**
- **Italy**
## Integration of palliative care in primary care

**EAPC PPC Survey in Europe (2018)**

<table>
<thead>
<tr>
<th></th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification tool translated</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other tool translated</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPC Toolkit translated</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP Training in Primary Pall. Care (PPC)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Pall Care video</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPC Pilot project</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact w/ regional health author.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact w/ national health author.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPC integrated in national pall. care strategy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early identification recommended in primary care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Country</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Croatia</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
</tr>
<tr>
<td>Denmark</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
</tr>
<tr>
<td>Romania</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️ ✔️</td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
</tr>
<tr>
<td>Italy</td>
<td></td>
<td></td>
<td>✔️ ✔️</td>
<td>✔️ ✔️</td>
</tr>
</tbody>
</table>

Croatia ✅ ✅ ✅ ✅ ✅
Denmark ✅ ✅ ✅ ✅ ✅ ✅
Romania ✅ ✅ ✅ ✅ ✅ ✅
Italy ✅ ✅ ✅ ✅
## Integration of palliative care in primary care

**EAPC PPC Survey in Europe (2018)**

<table>
<thead>
<tr>
<th></th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification tool translated</td>
<td>Other tool translated</td>
<td>PPC Toolkit translated</td>
<td>GP Training in Primary Pall. Care (PPC)</td>
<td>Early Pall Care video</td>
</tr>
<tr>
<td>Croatia</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
</tr>
<tr>
<td>Denmark</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
</tr>
<tr>
<td>Romania</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
</tr>
<tr>
<td>Italy</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
<td>✓✓</td>
</tr>
</tbody>
</table>
Thank you to all for your hard work and support!

We acknowledge the achievements of our representatives from Croatia, Denmark, Romania and Italy for progress in Primary Palliative Care.
New 2019 EAPC Atlas:
Primary care makes an appearance
New 2019 EAPC Atlas:
Primary care makes an appearance

Chapter 9. Integration of Palliative Care at the Primary Care level

Technological Data on the 2019 EAPC Survey on Palliative Care at the Primary Care Level

Population: 54 countries of the Europe WHO region and Liechtenstein.

Survey Details
Area explored: 5 main health indicators: identification of PC patients at the primary care level and months before death care, incentives to the identification of PC patients, official policy documents on primary PC (laws or strategies/plans/policies), primary palliative care education.

Palliative care provision in Europe only reaches a small proportion of the population and varies greatly depending on the disease, patient's stage of the illness, and geographical context.

Part of this variation in coverage could be alleviated by partnering with primary care providers, who often already see patients for primary health professionals. However, there is no clear correlation between incentives and proportion of patients in need of palliative care identified at the primary care level. In fact, up to 10/34 countries (29%) have at least some sort of incentive system in the form of economic compensation (the most common), academic curricular awards, or time off, such as free days, extra hours of leave, or early leave.
New 2019 EAPC Atlas:
Primary care makes an appearance
Next steps...