Portuguese Strategic Plan for the Development of Palliative Care 2017-2018 (summary)

The Portuguese Strategic Plan for the Development of Palliative Care 2017-2018 was approved by the Secretary of State Assistant and of Health, Professor Fernando Araújo (Despacho nº 14311-A/2016, on 28th November)
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ACRONYMS

ACES – Agrupamento de Centro de Saúde (Health Centre Group)
ACSS – Administração Central do Sistema de Saúde (Health System Central Administration)
ARS – Administração Regional de Saúde (Health Regional Administration)
HHC – Hospital Healthcare
PHC – Primary Healthcare
EAPC – European Association for Palliative Care
HPCT – Home Palliative Care Team
HPCST – Hospital Palliative Care Support Team
FTE – Full-Time Equivalent
WHO – World Health Organisation
NCPC – National Commission for Palliative Care
NHS – National Health Service
NTCN – National Long-Term Care Network
NPCN – National Palliative Care Network
PC – Palliative Care
PCU – Palliative Care Unit
PCU-RNCCI – Palliative Care Unit in the Integrated Continuous Care (RNCCI)
PPC - Pediatric Palliative Care
PPCA - Portuguese Palliative Care Association
RCPC – Regional Coordinator of Palliative Care
RNCCI – Rede Nacional de Cuidados Continuados Integrados (Integrated Continuous Care)
SPDPC – Strategic Plan for the Development of Palliative Care
INTRODUCTION

The World Health Organization (WHO) estimates that more than 40 million people worldwide require palliative care (PC) per year and recognises the efficiency and cost-effectiveness of several PC organisation’s in the relief of suffering. Hence, the WHO considers the development of PC models, which are fully integrated into the national healthcare systems and continuity of all care levels, as an ethical responsibility of each State.\(^1,2\)

When integrated early, PC are beneficial for patients and caregivers, reducing the patient’s symptomatology and the family/caregiver burden\(^3,4,5\). They also reduce the hospitalisation times, readmissions, medical futility, recurrences of emergency services and intensive care, and subsequently decreases healthcare costs\(^2,6,7,8,9\).

In 2012 the Assembly of the Republic of Portugal approved the “PC Law” that confirms the right all citizens access to the PC and regulates its access. On 15\(^{th}\) June 2016, under the Ministry of Health responsibility and integrated in the Central Administration of the Health System (ACSS), it was nominated the first National Commission for Palliative Care (NCPC), responsible for the development and implementation of a functional PC network in Portugal mainland.

This document resumes the Portuguese Strategic Plan for the Development of Palliative Care 2017-2018 (SPDPC) for adult population. Recognising the high relevance of the PC for children, in 2018 the Pediatric Palliative Care (PPC), were also included under the NCPC responsibility.

Who are we?

<table>
<thead>
<tr>
<th>Board members (NCPC)</th>
<th>Regional Coordinators (RCPC) - Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edna Gonçalves (Chair) - Physician</td>
<td>North - José Miguel Lopes</td>
</tr>
<tr>
<td>Carla Reigada - Social Worker &amp; Researcher</td>
<td>Centre - Isabel Duque Martins</td>
</tr>
<tr>
<td>Fátima Teixeira - Physician</td>
<td>Lisboa e Vale do Tejo (LVT) - Ana Cristina Fryxell</td>
</tr>
<tr>
<td>Helena Salazar - Phycologist</td>
<td>Alentejo - Margarida Damas de Carvalho</td>
</tr>
<tr>
<td>Ricardo Silva - Nurse</td>
<td>Algarve - Fátima Teixeira</td>
</tr>
</tbody>
</table>
VISION AND GOALS

Our vision is that all people with a life-threatening illness residing on national territory, have access to quality PC regardless of age, diagnosis, residence, or social and economic level, from the diagnosis until death.

To ensure that all Portugal mainland inhabitants have access to qualified PC and ensure the efficient use of the available resources, the National Palliative Care Network (NPCN) should be developed in a collaborative and integrated model involving the three healthcare levels of the National Health Service (NHS - Primary Healthcare, Hospital Healthcare and Integrated Continuous Care) and two different levels of PC care:

- “PC approach” (includes the “PC approach” and the “general PC” as defined by the European Association for Palliative Care - EAPC)\textsuperscript{10} for low and medium complexity situations, which should be made available in settings not specialized in PC, at home or hospital setting, with the consultancy and support of the specialist PC teams;

- Specialist PC take care of patients with higher levels of complexity, must have advanced PC training, an interdisciplinary team approach and develop research.

<table>
<thead>
<tr>
<th>NHS (level of care)</th>
<th>Specialist Palliative Care Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Healthcare (PHC)</td>
<td>Home PC Team (HPCT)</td>
</tr>
<tr>
<td></td>
<td>PC Consultation in the health centre</td>
</tr>
<tr>
<td></td>
<td>Advisor for nursing homes and the National Network for Integrated Continuous Care units (“RNCCI”)</td>
</tr>
<tr>
<td>Hospital Healthcare (HHC)</td>
<td>Hospital PC Support Team (HPCST)</td>
</tr>
<tr>
<td></td>
<td>Inpatient PC Unit (PCU)</td>
</tr>
<tr>
<td></td>
<td>Home care Consultation team (while there aren’t HPCT in the primary healthcare centre)</td>
</tr>
<tr>
<td>Integrated Continuous Care (“RNCCI”)</td>
<td>PCU-RNCCI (patients with low to moderate complexity needs)</td>
</tr>
</tbody>
</table>

Fig. 1 – Portuguese Palliative Care Network – Organisational model
PC training
Based on the EAPC recommendations, the European Commission and the Portuguese Association for PC (PAPC) we recommended three levels for PC training:

<table>
<thead>
<tr>
<th>Level of Care</th>
<th>Health Services</th>
<th>Professionals</th>
<th>Training Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Approach</td>
<td>Basic</td>
<td>PC methods and procedures applied in a non-specialist environment</td>
<td>All healthcare professionals</td>
</tr>
<tr>
<td></td>
<td>Generalist</td>
<td>Often assist patients with palliative needs but PC is not the main focus of their professional activity</td>
<td>Family doctors; Oncology; Haematology; Internal Medicine; RNCCI; other</td>
</tr>
<tr>
<td>(Specialist)</td>
<td>(Specialist)</td>
<td>PC is the main activity and take care of patients with complex needs</td>
<td>HPCT HPCST PCU</td>
</tr>
<tr>
<td>Palliative Care</td>
<td></td>
<td></td>
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</tbody>
</table>

Research
PC should be evidence-based to contribute to the excellent management, organisation, specialisation, implementation, and assessment of resources without forgetting particularities and ethical limitations required by this particular area of care. For that reason, it is fundamental to have a strict articulation between the PC services and academic departments to carry out scientific projects and to increase funding research opportunities in Portugal.

In Portugal, the PC research should be based on four central fields / areas:
1. The patient and family (cancer and non-cancer diseases);
2. Service organisation/PC development;
3. Healthcare professionals;
4. Society.
**PALLIATIVE CARE SITUATION IN PORTUGAL (June/2016)**

In Portugal, PC emerged in the early 1990s, with the Fundão Unit for Chronic Pain (in 1992), the PCU of the Portuguese Institute of Oncology - Porto (in 1994) and the Home Palliative and Long-Term Care Team in Odivelas Healthcare Centre (1997)\(^1\).

The Portuguese Association for Palliative Care (PAPC) was founded in 1995\(^2\) and in 2001, took place the first National Congress of PC. The 12\(^{th}\) EAPC Congress took place in Lisbon, in 2011 and counted on more than 2000 participants.

In 2000, the Faculty of Medicine of the University of Lisbon (FMUL) started the first postgraduate course in PC in Portugal and in 2004, the Directorate-General of Health issued the first National PC Programme. *The National Network for Integrated Continuous Care* created in 2006 (designated “RNCCI”) to provide long-term healthcare and social support, contributed to the development of PC structures in Portugal, but gave rise to the notion that PC was limited to the long term-care. This view changed in 2012 with the publication of the “PC Law”. In November 2013, the Portuguese Medical Association approved the Palliative Medicine as a medical skill ("*Competence in Palliative Medicine*"") and the Nurses’ Association is developing the Nursing Speciality on People in Chronic and Palliative Situations.

According to the Statistics Portugal institute in 2015 the mainland of Portugal had about 9.840 million inhabitants. Based on the methodology defined by Murtagh and Higginson, we estimated that 71,500 to 85,000 patients needed PC and the following ratio of palliative care resources were recommended:

- Hospital Palliative Beds (HPCB): 40-50 beds per 1 000 000 inhabitants;
- Home PC Teams (HPCT): 1 team per 100 000 to 150 000 inhabitants;
- Hospital PC Support Teams (HPCST): 1 team per hospital or hospital centre.

In July 2016, the Portuguese NHS had (Fig. 2):
- 18 HPCT (14 if we consider teams per Health Centre Group)
- 31 HPCST (North=12; Centre=2; LVT=13; Alentejo=3; Algarve=1)
- 26 PCU (362 beds), twenty-two of which (278 beds) were in the RNCCI (PCU-RNCCI), corresponding to 77% of all PCU beds (*one PCU had five beds in RNCCI and 4 acute PC beds).

<table>
<thead>
<tr>
<th>Health Regional Administration (“ARS”)</th>
<th>PCU in NHS hospitals</th>
<th>PCU-RNCCI</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Unit</strong></td>
<td><strong>Beds</strong></td>
<td><strong>Unit</strong></td>
</tr>
<tr>
<td>North area</td>
<td>2</td>
<td>52</td>
<td>3</td>
</tr>
<tr>
<td>Centre area</td>
<td>1</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>LVT</td>
<td>0</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Alentejo*</td>
<td>2</td>
<td>12</td>
<td>3*</td>
</tr>
<tr>
<td>Algarve</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Portugal mainland</td>
<td>5</td>
<td>84</td>
<td>22</td>
</tr>
</tbody>
</table>

- Hospital Palliative Beds (HPCB): 40-50 beds per 1 000 000 inhabitants;
- Home PC Teams (HPCT): 1 team per 100 000 to 150 000 inhabitants;
- Hospital PC Support Teams (HPCST): 1 team per hospital or hospital centre.
According to the 2015 RNCCI monitoring report, most PCU-RNCCI had a high median of time from the reference to the admission (LVT=25 days; North=13.0 days; Centre and Alentejo=9.9 days; Algarve=2.0 days). The mean length of stay in the PCU-RNCCI was 36 days but 10.6% of admissions had exacerbations requiring the resort to a hospital emergency department. Almost 77% of patients admitted died in the PCU-RNCCI and less than 5% were discharged to home.

Fig. 2 – Geographic distribution of the Portuguese Palliative Care in 2015
STRATEGIC PLAN OVERVIEW

With the aim of ensuring that all citizens residing in mainland Portugal have adequate access, in due time, to quality PC and that the available resources are efficiently used - as provided in the National Health Plan (NHP) - eight general strategic lines and three priority areas of intervention were defined, as well as the actions to be carried out for each one of them.

General strategic lines

1 - Organisation and Coordination
National coordination (NCPC) in close collaboration with the regional coordinators (RCPC) in the Health Regional Administrations.

2 - Improvement and generalisation of the basic PC level – “Palliative Approach”
Improving the 'palliative actions' carried out by all healthcare professionals and enabling professionals working in services with high prevalence of patients with palliative needs (RNCCI, oncology, internal medicine, emergency department, primary healthcare, among others) to carry out quality "Palliative Approach".

3 – Specialised PC resources adequacy
Adequate cover of PC teams should be implemented, mainly with support teams (community and hospital) and PCU in the NHS hospitals for patients with complex PC needs, promoting equal access throughout the country regardless of the patient’s age or diagnosis. The PC teams articulate among each other as well as with other NHS teams, ensuring the continuity of care.

4 - Training and qualification of healthcare professionals
Encouraging specific PC training (theory and practice) on undergraduate and postgraduate levels and qualifying healthcare professionals who will work in specific PC teams.

5 - Monitoring and certifying PC-specialist teams
Since PC is a clinical expertise over which there are still wrong conceptions, and which was insufficiently regulated, it’s necessary to certify the quality of the provided care and monitor the existing teams.

6 – Improvement of the information systems
There are several information systems in the NHS and it’s necessary to introduce specific PC information into these systems to streamline communication between different care providers and to enable the monitoring of provided care.

7 - Information and awareness of the population
Disseminate and improve information about PC in the general population and encourage PC volunteering as well as promote patronage.

8 - PC research
Encourage and boost PC research promoting the cooperation between specialised PC teams and national and international research centres.
<table>
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<tr>
<th>Priority Areas of Intervention</th>
<th>Actions to be carried out</th>
</tr>
</thead>
</table>
| **I- Healthcare quality assurance and organizational definition** | Define the reference terms for contracting with PC teams in Primary Healthcare (HPCT) and NHS Hospitals (HPCST and PCU)  
Define indicators to evaluate PC teams  
Develop standards for reference to/from PC teams  
Adapt the NHS information systems to improve communication between different care providers  
Establish criteria for monitoring, certifying, and accrediting PC teams  
Initiate accreditation of PC teams |
| **II- Accessibility to PC on all healthcare levels** | **A) Improvement and generalization of the Palliative Approach**  
(Undergraduate and postgraduate degrees; development and update of technical standards and guides to good practice in PC; articulation of PC teams with other teams)  
**B) Adapting PC assistance resources**  
Check for compliance of the number of professionals and of the respective working hours within the PC teams (table A)  
Implementation of HPCT  
Promote HPCST with PC Outpatient clinic in all NHS hospitals  
Implement PC services with PCU, HPCST and Outpatient clinic in all NHS hospitals included in E and F funding group (university hospitals and oncologic institutes)  
Conversion of PCU-RNCCI installed in NHS hospitals into acute PCU  
Define the PCU-RNCCI admission criteria |
| **III- Training and Research** | **C) Social Support, Family Assistance, and Community**  
Develop Centres of reference in PC at the NHS hospitals in E and F funding group (university hospitals and oncologic institutes)  
Work with professional associations to define PC specialists profile  
Manage the rate of inclusion of PC content on undergraduate degrees  
Create a Consortium of Strategic Partners for the qualification of PC teams  
Educate the HPCT and HPCST on the use of tools for identifying patients with palliative needs at an early stage  
Carry out B level PC Courses (90 h each) provided by the NHS  
Draw up a Roadmap of the professionals with PC specialised training  
Promote the cooperation between specialist PC teams and national and international research centres |
Table A - Minimum staff per PC resource and goals for 2017-2018

<table>
<thead>
<tr>
<th>PC Resource</th>
<th>Location</th>
<th>Staff (minimum recommended)</th>
<th>2017-2018 Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>HPCT(^1)</td>
<td>Primary Healthcare (&quot;ACES&quot;) and RNCCI (While the ACES do not have ECSCP, hospital PC teams can make domiciliary consultation)</td>
<td>Physician – 1.5 FTE Nurse – 2 FTE Psychologist – 0.5 FTE Social Worker – 0.3 FTE</td>
<td>1 CPCT/ACES until the end of 2018 (adviser for other primary care and RNCCI professionals and direct assistance to complex patients)</td>
</tr>
<tr>
<td>(1) (team for 150 000 inhabitants)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPCST with Outpatient Clinic(^2)</td>
<td>NHS Hospitals (advisor for all clinical services)</td>
<td>Physician – 1 FTE Nurse – 1.5 FTE Psychologist – 0.25 FTE Social Worker – 0.3 FTE</td>
<td>1 HPCT/Hospital until the end of 2017</td>
</tr>
<tr>
<td>(2) (professionals for 250 beds)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCU(^3)</td>
<td>NHS Hospitals (8-20 beds/PCU)</td>
<td>Physician – ≥0.15 FTE per bed Nurse – 1.2 FTE per bed Psychologist – 0.5 FTE/12-20 beds Social Worker – 0.55 FTE per 12-20 beds Operational Assistant – 0.7 FTE per bed</td>
<td>1 PCU / Hospital in E and F funding group (university hospitals and oncologic institutes) until the end of 2018</td>
</tr>
<tr>
<td>(3) (professionals per bed)</td>
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FTE = Full Time Equivalent - 1 FTE for Physician = 40 hours/week; 1 FTE for another professionals = 35 hours/week

1- HPCT: Indicated staffing does not include PC appointments in the ACES
2- HPCST – In hospitals > 250 beds, staffing increases in proportion to the number of beds
3- PCU opening encouraged in all hospitals >200 beds and/or with Oncology Services

Hospitals <200 beds, without Oncology Services, should decide the opening of PCU on a regional level.

Other professionals such as a spiritual assistant, nutritionist, physiotherapist, occupational therapist, and others should be included in PC teams based on the needs of each situation.

By the end of 2018, there should be a PC team of reference (ideally a HPCT) for all RNCCI teams and units without PCU-RNCCI.
ACKNOWLEDGMENTS

Responsible for the SPDPC, the NCPC would like to thank the cooperation of the RCPC, the four PC experts invited (Barbara Gomes, Isabel Galriça Neto, Maria Aurora Matias, Paula Sapeta) and the Portuguese Palliative Care Association (PPCA), as well as those who sent comments or suggestions at the stage in which it was under public discussion.
REFERENCES


