

# Perinatal Palliative Care Foundations & Experiences



## Perinatal Palliative Care Educational Perspective

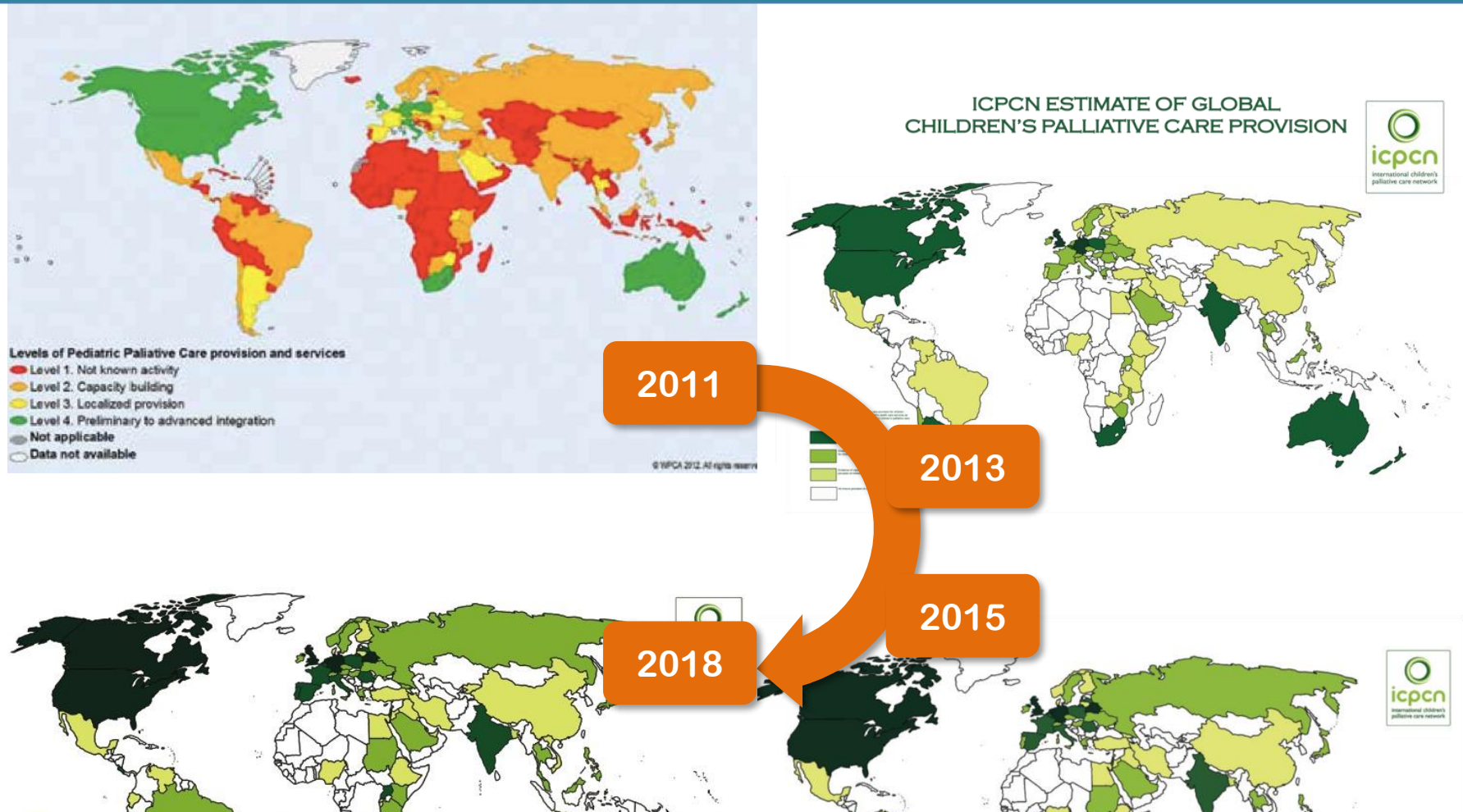
**Joana Mendes**, RN, MSc, PhD Ethics

# Portuguese journey – Can I invite you for a ride?



[https://www.google.com/url?sa=i&url=https%3A%2F%2Fsol.sapo.pt%2Fartigo%2F602670%2Fmarginal-de-cascais-volta-a-ser-cortada-devido-ao-estado-do-tempo-&psig=AOvVaw0gaiiSPnlBpg3k387ffSWf&ust=1666700852407000&source=images&cd=vfe&ved=0CAoQjRxqFwoTCMi\\_6tnu-PoCFQAAAAAdAAAAABAI](https://www.google.com/url?sa=i&url=https%3A%2F%2Fsol.sapo.pt%2Fartigo%2F602670%2Fmarginal-de-cascais-volta-a-ser-cortada-devido-ao-estado-do-tempo-&psig=AOvVaw0gaiiSPnlBpg3k387ffSWf&ust=1666700852407000&source=images&cd=vfe&ved=0CAoQjRxqFwoTCMi_6tnu-PoCFQAAAAAdAAAAABAI)

# Progress in Portugal has been substantial



**Level 2** Evidence of broad palliative care provision for children with training available and focused plans for development of services and integration into health care services.

# Facts about Perinatal Palliative Care development

Nurses are on the lead of the development of PNPC

*Education, taskforces, research, recommendations*

Recommendations exists:

*Neonatal End of Life Care (Portuguese Neonatal Society, 2014)*

*Development of paediatric palliative care (Portuguese Governement, 2014)*

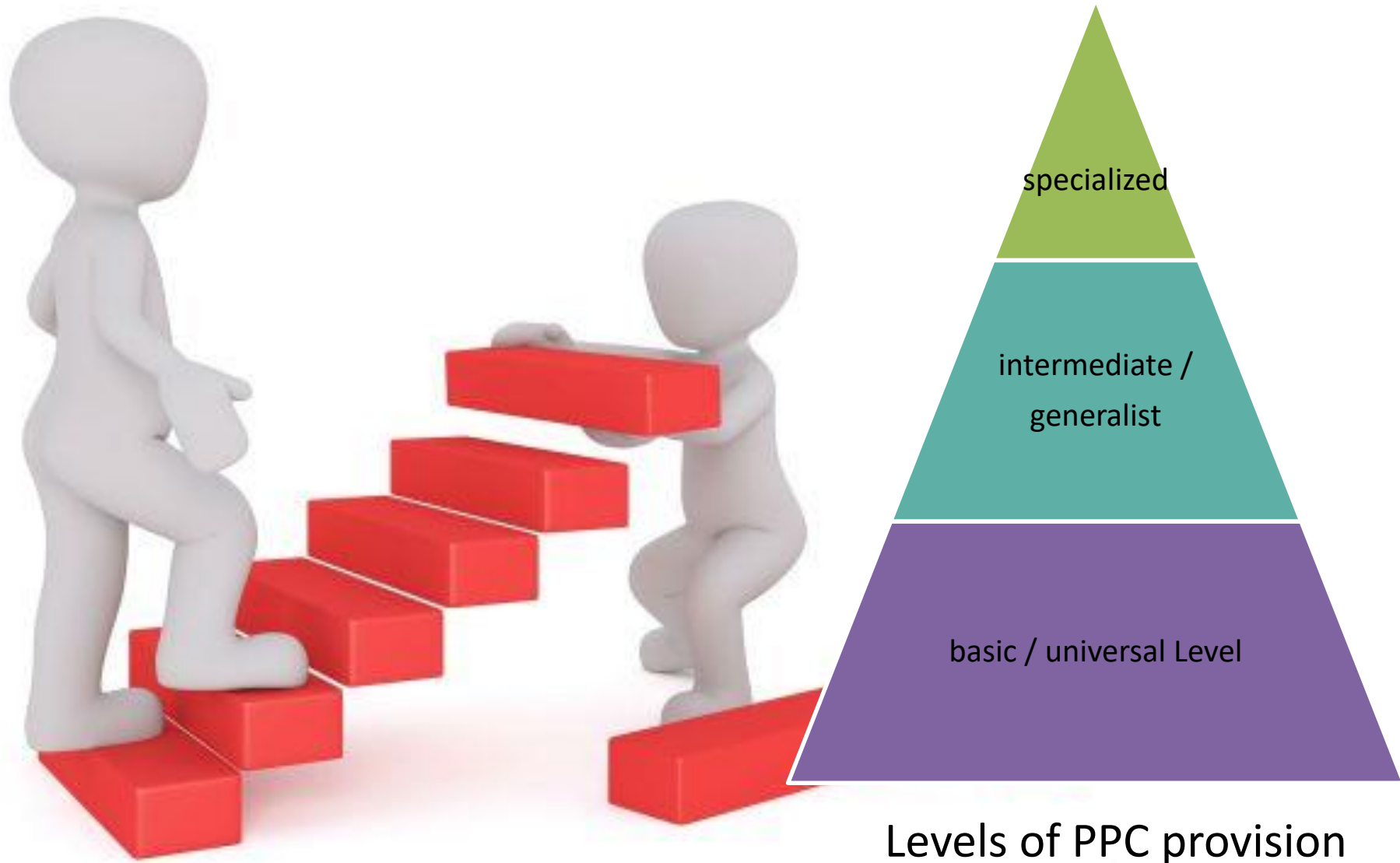
PNPC programs are spreading but still few

*First Program (2009)*

*One Perinatal Palliative Care team (2018)*

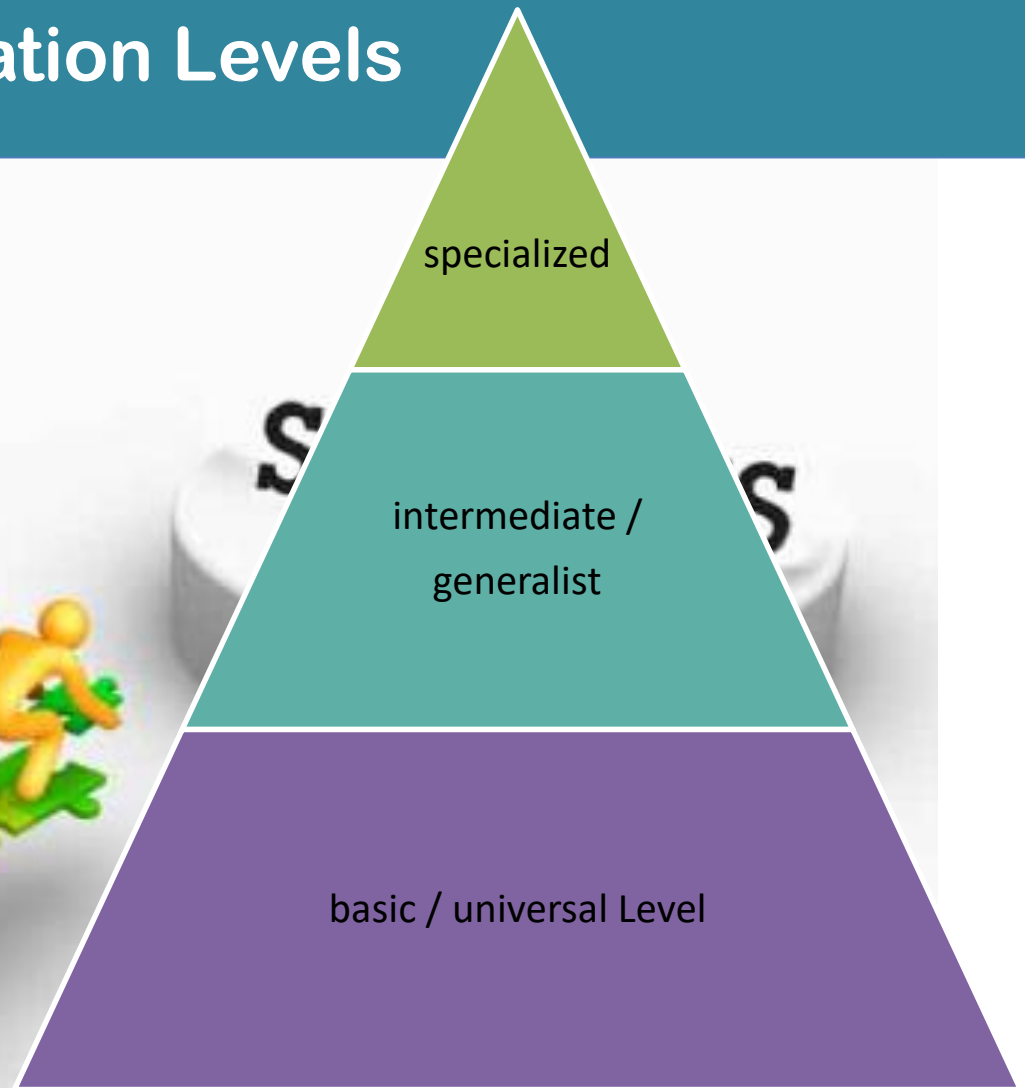
Educational plays a very important part in this development

# Education Levels





# Education Levels



Levels of PPC provision

# Education Levels



# Facts about Perinatal Palliative Care development

Nurses are on the lead of the development of PNPC

*Education, taskforces, research, recommendations*

Recommendations on PNPC (Portuguese Neonatal Society)

Few PNPC programs- major focus in NICU, end of life, bereavement

Lack of **nursing recommendations** for PNPC (fragmented):

*Need recommendations for ratios, quality indicators of care, profile of specialized competencies, nursing pathways*



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## Neonatal Palliative Care

*Developing Consensus Among Neonatologists Using the Delphi Technique in Portugal*

Joana C. C. Mendes, PhD, MSN, RN; Lincoln Justo da Silva, PhD, MD

Assess physician readiness to build a palliative care and end of life protocol that they would accept and practice.

## Dimensions of the Protocol

1. Planning NPC
2. Prenatal Palliative Care
3. NPC Criteria
4. Working with parents
5. Medical needs
6. Pain and symptom management
7. End of life care

41% Neonatologist

Edition: International children's > Research

### Important Research from the USA replicated in Portugal

Author: Dr Joana Mendes  
19 August 2013  
Review | Research

Like 0 Tweet in G+ Email



Consensus was adopted as national guideline

# Neonatal Portuguese Society

2016-

## *Ethics and Palliative Care Commission*

Comissão de Ética e Cuidados Paliativos

Lincoln Justo da Silva (Lisboa)

Graça Roldão (Lisboa)

Joana Mendes (Lisboa)

Cármén Carvalho (Porto)



2018



## *Perinatal & Neonatal PC workshops*



2014



2016

### Perinatal Palliative Care on the agenda of the Portuguese Neonatal Society in Portugal

October 3, 2017  
Education  
Author: Dr. Joana Mendes



2017



2022

# Scientific taskforces- National

## Continuous and Palliative care - Portuguese Pediatric Society

2013 -



### Composição



#### Coordenador:

Ana Forjaz Lacerda, médica

#### Elementos constituintes:

Ana Lúcia Cardoso, médica  
Alexandra Dinis, médica  
Graça Oliveira, médica  
Joana Mendes, enfermeira  
Paula Guerra, médica  
Tânia Franco, enfermeira

## Pediatric Palliative Care - Portuguese Association of Palliative Care

2013 -



## Ethics group - Portuguese Association of Palliative Care

2018 -



Research

National  
guidelines

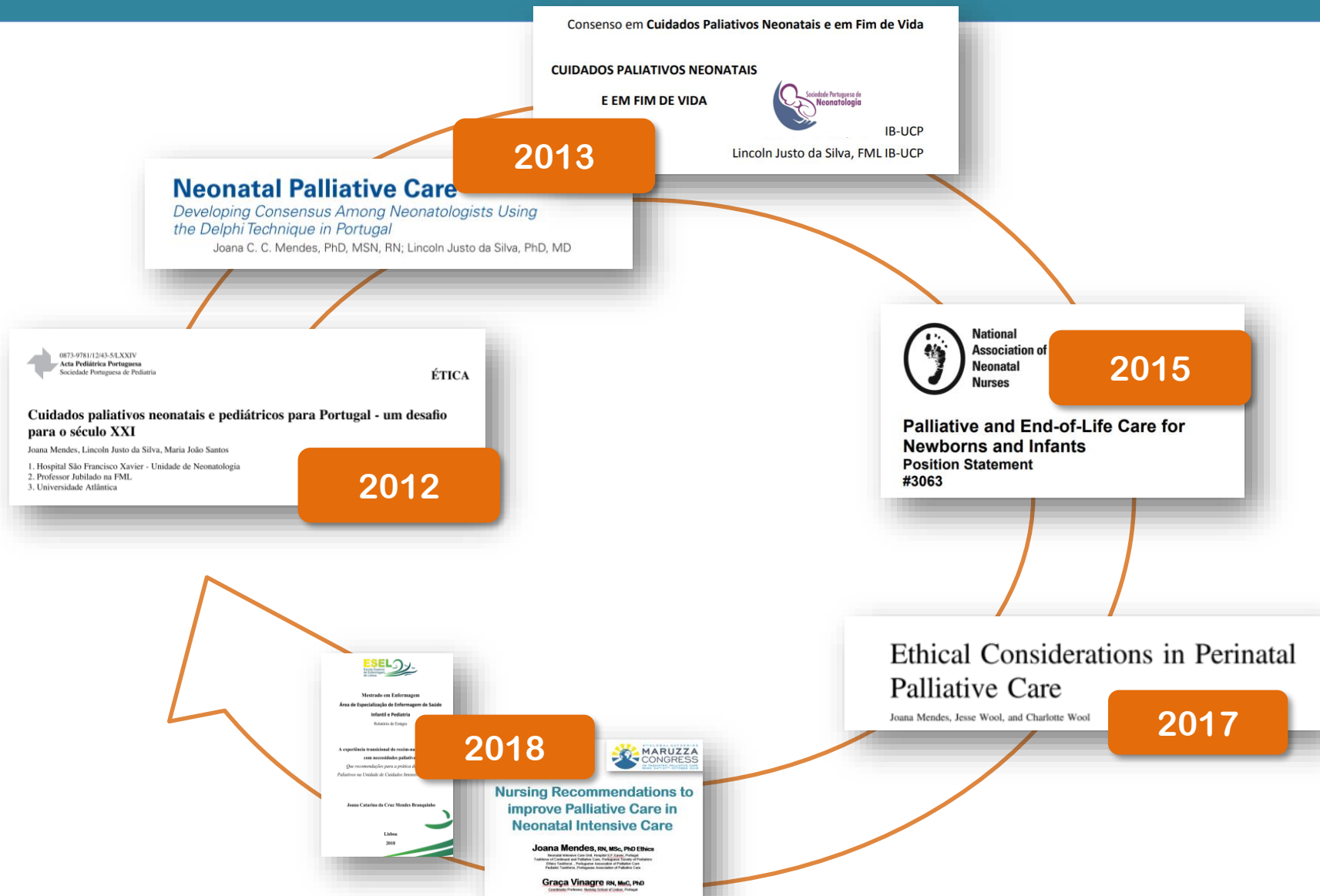
International  
collaboration

Translation  
documents

Education

GOVERNEMENT  
AWARENESS

# Gold standards and new practices



# Neonatal Palliative Care Group

2016

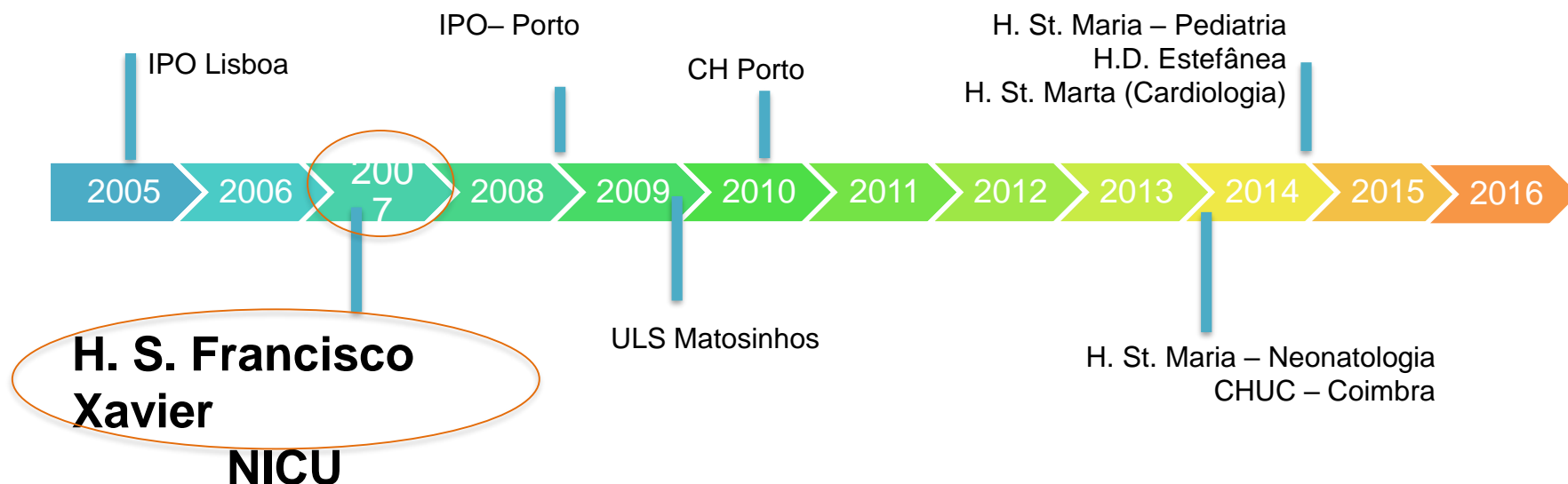


## Hospital-based Pediatric Palliative Care Programs - a National Survey.



Ana Lacerda, Alexandra Dinis, Joana Mendes

*on behalf of the Taskforces of the Portuguese Society of Pediatrics and Association of Palliative Care*





# Golden Standards

2007-2020

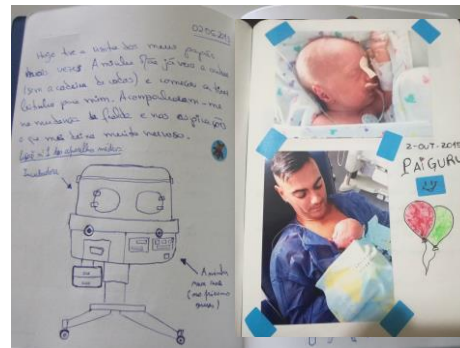


condolence cards, booklets

*bereavement*



Home away from  
home room in NICU



Memory creation  
Parent's diaries



memorial services

Some activities were replicated throughout the nation



# International collaborative work

## Raising awareness and teach how to establish/improve PPC.



2009

### Positive progress post 1st Paediatric Palliative Care Meeting in Portugal

October 13, 2015  
Author: Dr Ana Lucinda



2015

### Lisbon hosts 2nd national meeting on children's palliative care in Portugal

June 7, 2018  
People & Places  
Author: Dr Ana Lucinda



2018



2022

## Presidents of the ICPCN offered support to Portugal



Julia  
Downing

Joan  
Marston

*Ann Goldman  
Anita Catlin  
Jonathan Hellman  
Marcia Levetown  
Danai Papadatou  
Richard Hain  
Joan Marston  
Ricardo Martinez  
Eduardo Quiroga*

...

# Government awareness

## Landmark PPC Meeting held in Lisbon, Portugal

July 15, 2013  
Author: Dr Ana Forjaz de Lacerda



2013



Meeting  
report

## Ministry of Health Taskforce- National recommendations PPC



Cuidados Paliativos Pediátricos

Relatório do Grupo de Trabalho  
do Gabinete do Secretário de Estado Adjunto do Ministério da Saúde  
(despachos 8286-A/2014 e 8956/2014)

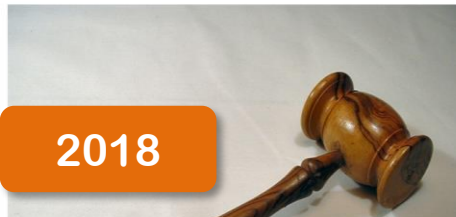
2015

## National stakeholders meeting

## Government in Portugal mandates the creation of paediatric palliative care teams in all hospitals

Author: Dr Ana Lacerda  
08 March 2018  
News | Policy

2018



2016

Regulatory Documents

Government committees formed and regulatory documents  
developed

# Government awareness

2015



## Cuidados Paliativos Pediátricos

Relatório do Grupo de Trabalho  
do Gabinete da Secretária de Estado Adjunta do Ministro da Saúde  
(despachos 8286-A/2014 e 8956/2014)

dezembro 2014

*All high level NICU should have palliative care teams  
Palliative care should also include perinatal palliative care*

## Hospital PPC teams :

2019-2020

### PLANO ESTRATÉGICO PARA O DESENVOLVIMENTO DOS CUIDADOS PALIATIVOS

Biénio 2019-2020

Comissão Nacional de Cuidados Paliativos (CNCV)  
paliativos@acss.min-saude.pt

● Specialized teams (5)

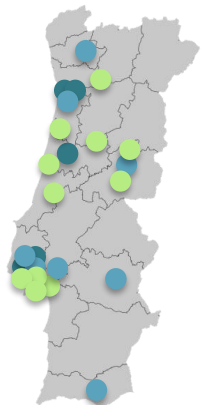
● Non specialized (7)

● Others (+11)

**Medicine, nursing, psychology, social  
worker**

Education, clinical trained PC specialist

Recommendation: one with neonatal training



# Pediatric Palliative Care hospital based team CHLO

2018-2020

HATS AND MASKS ON FOR  
CHILDREN'S PALLIATIVE CARE



Friday 9 October 2020



Pediatric palliative care team of centro  
hospitalar de lisboa ocidental gearing up for  
[#HatsOn4CPC](#)





# EDUCATION

## PPC multiprofessional modules started:

**Medical & Nursing schools**  
**Specialization nursing courses,**  
**Pos-graduate/master programs**



### Portugal introduces first diploma in paediatric palliative care

November 13, 2013  
Education  
Author: Ana Maria Lacerda

e hospice  
Palliative care news,  
views and inspiration  
from around the world



2013-

2019

**Catholic University (Lisbon) started  
a post-graduate training certificate  
program**

### ARSLVT trains professionals in Pediatric Palliative Care



2017-

CURSO BÁSICO  
CUIDADOS PALIATIVOS  
PEDIÁTRICOS

***Courses in palliative care, developed by  
the Regional Administrations of Health,  
with the support of the National  
Commission for Palliative Care, started  
a pediatric module***

# Academia: New challenges



2022-



Nursing Pediatric Department- Lisbon Nursing School

Undergraduate  
awareness

Pos graduate  
awareness

Research

Society  
awareness

National and  
International  
Collaborative  
work



# Facts about Perinatal Palliative Care development

Perinatal Palliative Care is still a priority on the development of

Nurses are on the lead of the development of PNPC

*Education, taskforces, research, recommendations*

Recommendations on PNPC (Portuguese Neonatal Society)

Few PNPC programs- major focus in NICU, end of life, bereavement

Educational plays a very important part in Portuguese development  
of PNCP