Palliative Care for Children

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Aim of the Presentation

The aim of this presentation is to explore the global need and provision of CPC, highlighting:

- *The global health perspective*
- *Models of CPC provision*
- *The benefits of CPC*
- *The barriers to the provision of CPC*
- *Some overarching standards for CPC provision.*

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ICPCN……

- Is ***the*** global network of individuals and organisations working together to reach the estimated 21 million children with life-limiting conditions and life-threatening illnesses
- We ***believe*** that:
  - All children and young people and their families have the right of access to PC
  - That PC should begin at diagnosis and continues into bereavement
  - The family are the primary caregivers and need to be empowered
  - That CPC is about living life to the full

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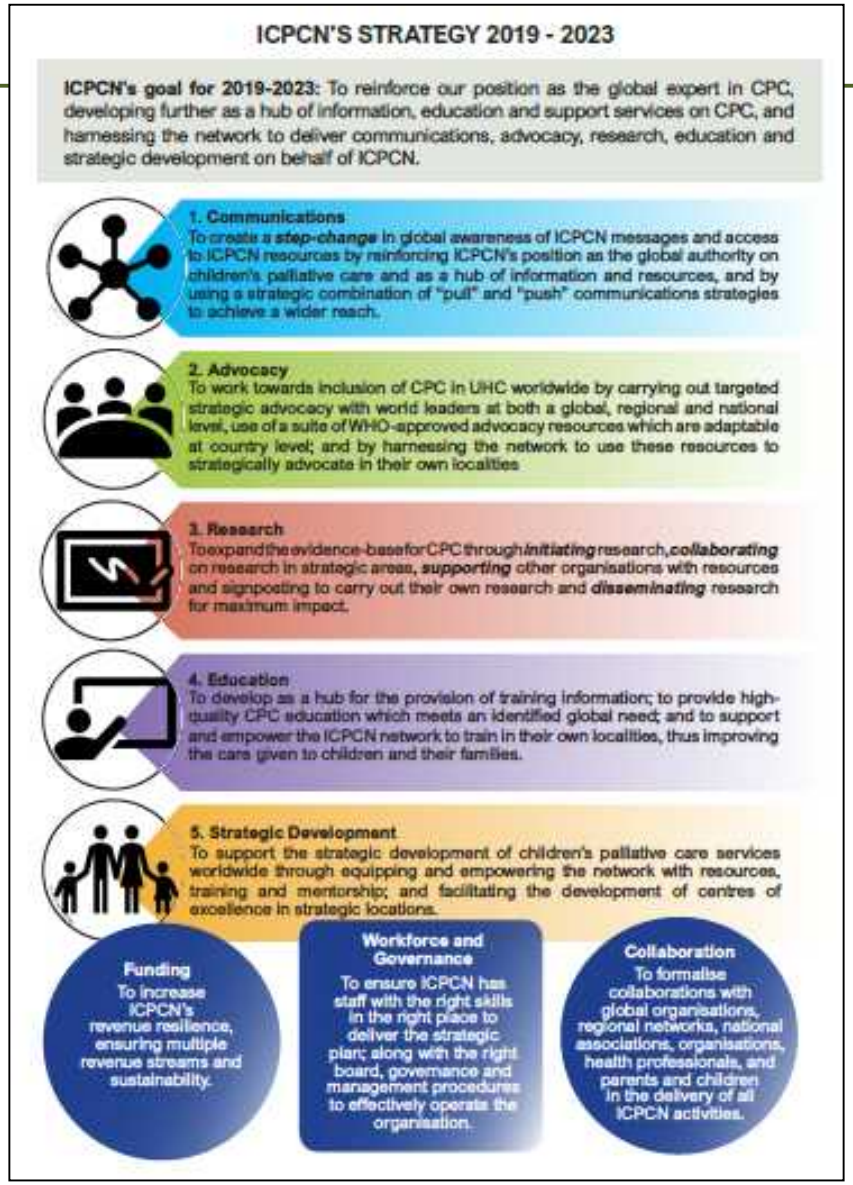
ICPCN CARES



- **C**ommunications
- **A**dvocacy
- **R**esearch
- **E**ducation and Training
- **S**trategic development

- www.icpcn.org

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WORLD HEALTH ORGANIZATION'S DEFINITION OF PALLIATIVE CARE FOR CHILDREN

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's [own] homes.

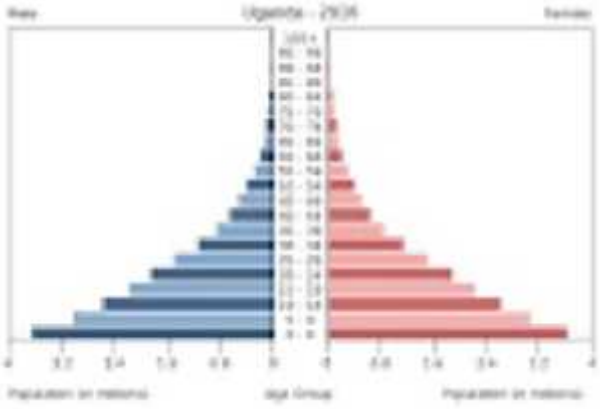
WHO 2002

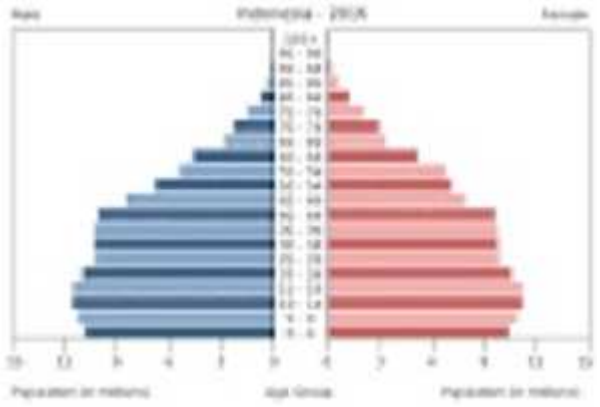
It is a *'Philosophy'* of Care

- CPC should be provided across the continuum of care
- CPC can be provided from diagnosis through into bereavement
- PC can help the child's illness and provide support for the family.
- PC ***must*** be an integral part of care not an optional extra
- PC is about living

Global Population

- 35% of the global population is < 20 years
- In 2014:
  - 26% population <15 years
  - Up to 40% in low income countries
- Despite this, the development of CPC has lagged behind development for adults





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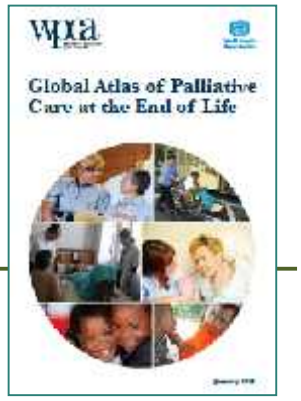
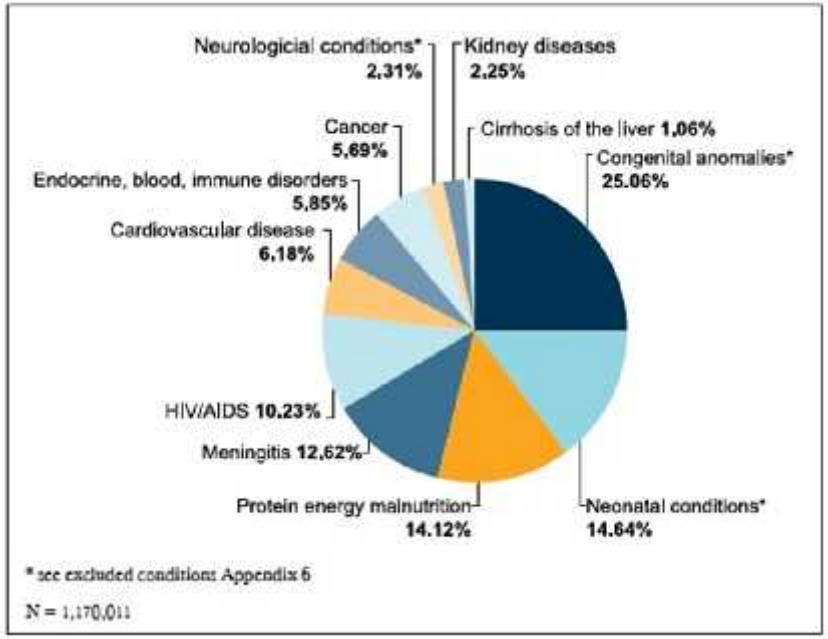
Why we need CPC?



- Estimated global number of children needing PC at EoL is >7 million
- Greatest number died from perinatal conditions (67.7%)
- 49% of these children are in Africa
- 97% of children needing palliative care at the end of live belong to low and middle income groups



Connor and Sepulveda Bermedo 2014)

Lancet Commission Report
Serious Health Related Suffering (SHS)

- >5.3 million children <15 years experience SHS each year globally
- Children account for 9% of all people experiencing SHS
- 1/3rd children who died in 2015 experienced SHS
- 2.5 million children die annually needing PC and pain relief - 98% from LMICs

Global need for CPC

- **Total Need:** 21.644 Million
- **Specialist Need:** 8.163 Million
- 44.42 per 10,000 children

- Range – 21 - >100 per 10,000 children
- Important –not based on mortality figures

(Connor et al 2017)

Review of CPC (2010)

- 65.6% countries had no known CPC activity
- 18.8% had capacity building activities
- 9.9% had localised provision
- 5.7% had provision reaching mainstream providers

(Knapp et al 2011)

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Global Status of CPC - 1980

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Global Status of CPC - 1998

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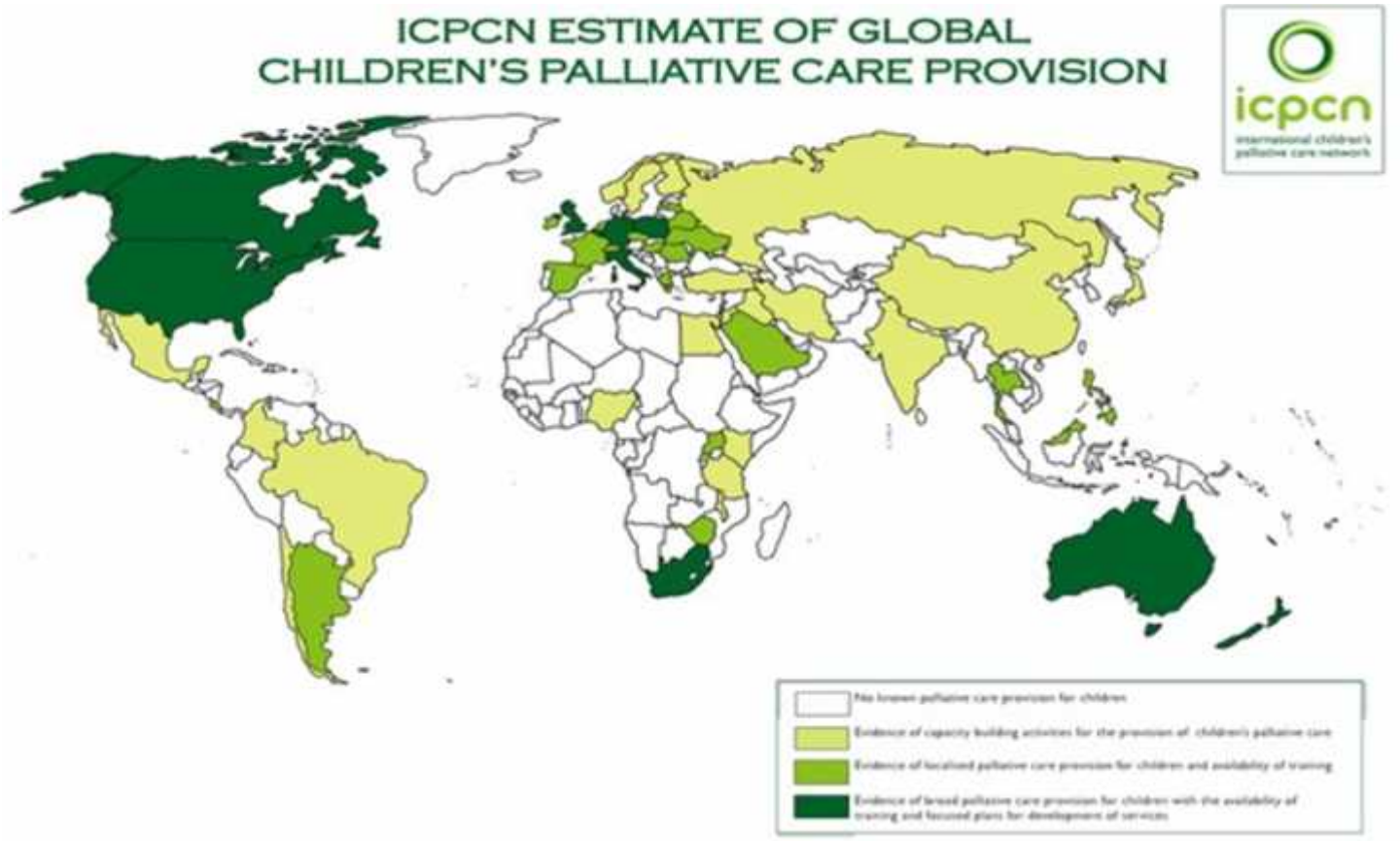
Global Status of CPC - 2011



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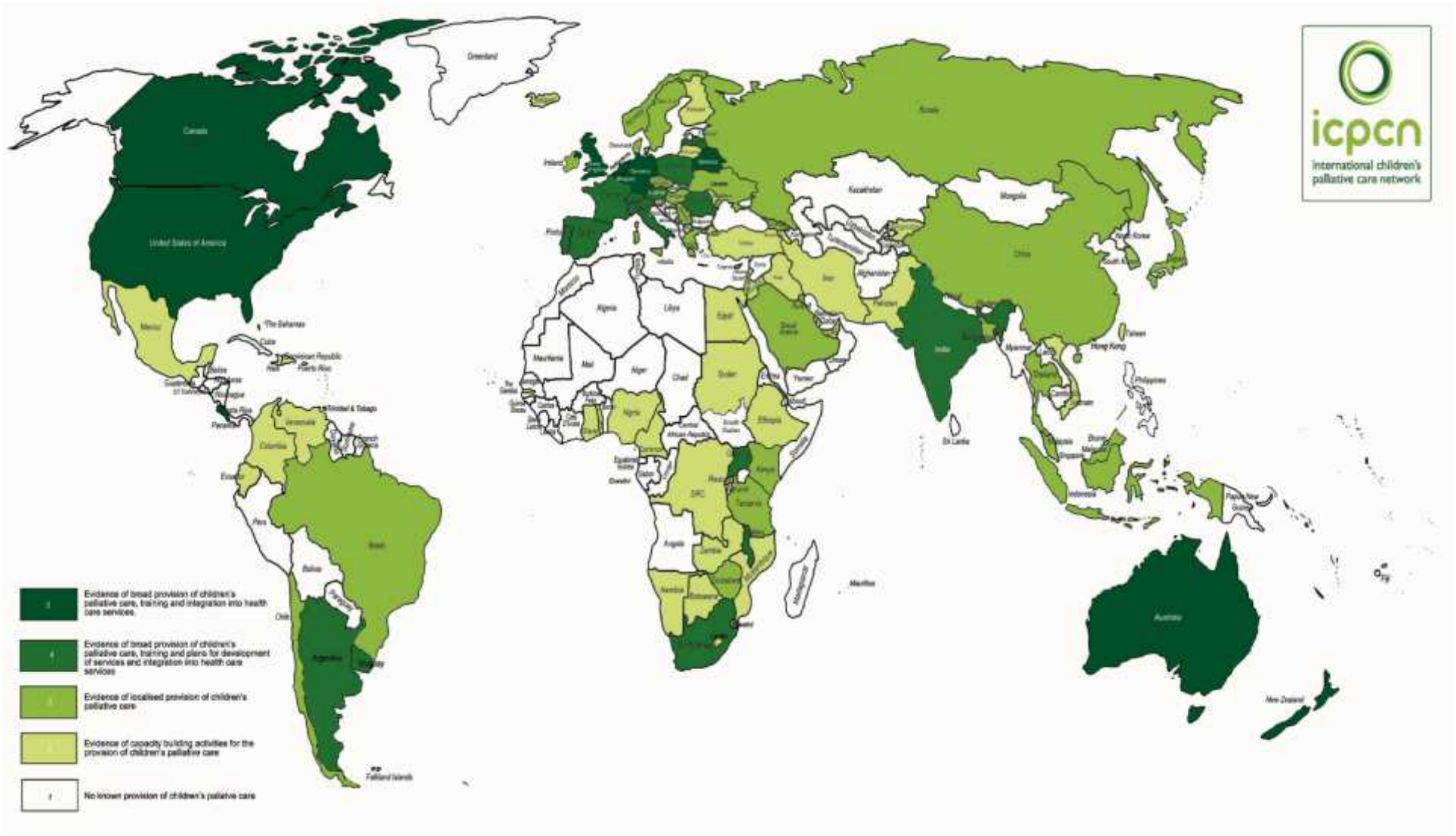
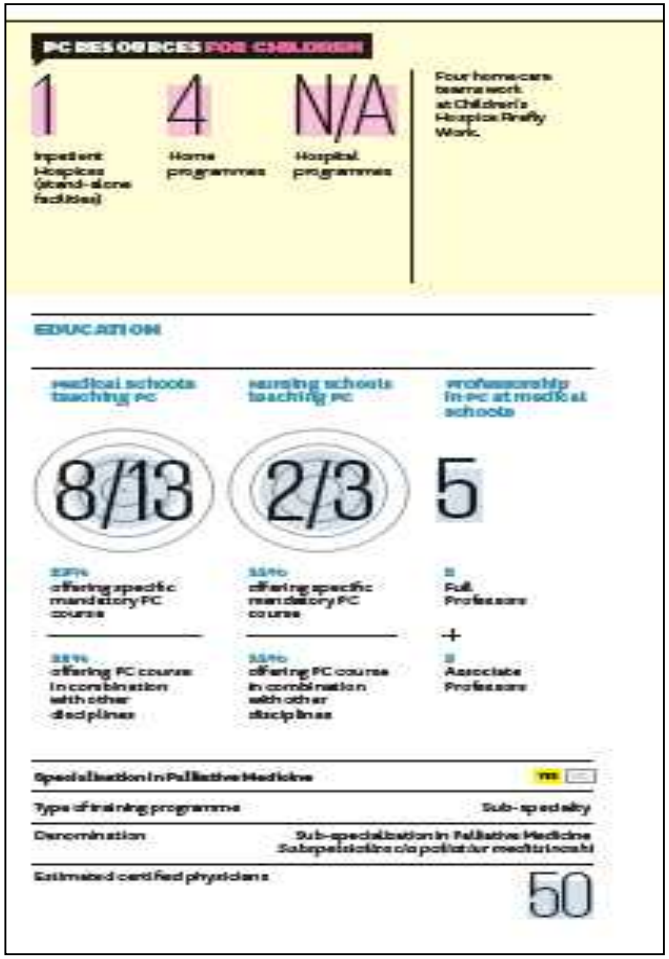
Global Status of CPC – May 2019



Georgia – EAPC Atlas (2019)



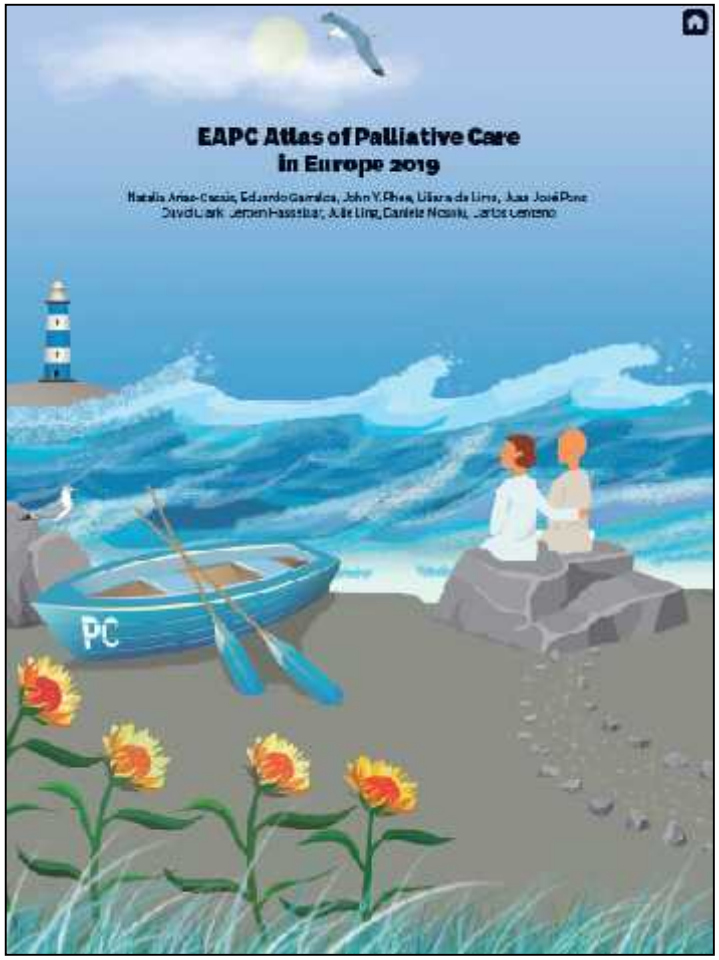
PC RESOURCES FOR CHILDREN

1	4	N/A	Four home care teams work at Children's Hospice Firefly Work.
Inpatient Hospices (stand-alone facilities)	Home programmes	Hospital programmes	

EDUCATION

medical schools teaching PC	nursing schools teaching PC	professorship in PC at medical schools
8/13	2/3	5
33% offering specific mandatory PC course	33% offering specific mandatory PC course	1 Full Professors
33% offering PC course in combination with other disciplines	33% offering PC course in combination with other disciplines	+ 1 Associate Professors

Specialisation in Palliative Medicine	YES / NO
Type of training programme	Sub-specialty
Denomination	Sub-specialization in Palliative Medicine Subespecialidad en cuidados paliativos
Estimated certified physicians	50



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Global Health Perspective: PC and SDGs

- Sustainable development goals
  - 17 SDGs and 169 targets to end extreme poverty, fight inequality and injustice, and protect our planet by 2030.

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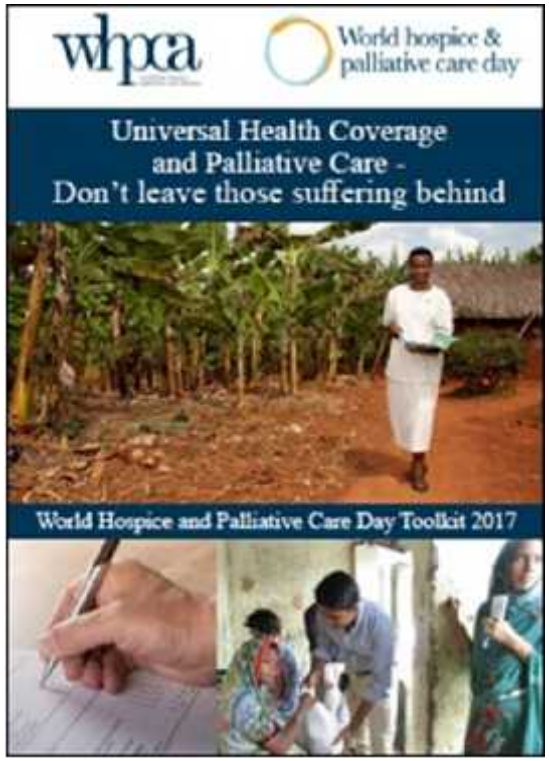
Global Health Perspective: PC and UHC

- Universal health coverage (UHC) means that all people and communities can use the promotive, preventive, curative, rehabilitative and ***palliative health services they*** need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

(https://www.who.int/health_financing/universal_coverage_definition/en/)



Global Perspective: Lancet Commission Report

- ‘Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage’
- 5 Key messages:
  1. *Alleviation of the burden of pain, suffering, and severe distress associated with life-threatening or life-limiting health conditions is a global health and equity imperative.*
  2. *An affordable, Essential Package of palliative care and pain relief interventions should be made universally accessible*
  3. *Publicly financing and fully integrating the Essential Package into national health systems as part of UHC, using cost-effective models is essential*
  4. *International collective action is necessary*
  5. *Effective policy making requires better evidence and priority-setting*

(Knaull et al 2017)

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Recommended PC Package for UHC

THE RECOMMENDED PALLIATIVE CARE PACKAGE FOR INCLUSION IN UNIVERSAL HEALTH COVERAGE

In order for palliative care to be included in Universal Health Coverage schemes across countries, it is important that a minimum package which is affordable, evidence based and that can be easily costed is included. The current palliative care package recommendation for inclusion in national Universal Health Coverage initiatives is based on the Lancet Commission Report on Palliative Care and Pain which aims to relieve in the most cost-effective way serious health related suffering (SHS) in Low and Middle Income Countries (LMICs). The minimum package has been developed and costed in the Lancet Commission Report [9]. In April, 2018, a global meeting of advocates, experts and direct beneficiaries of palliative care convened in Kampala, Uganda and adapted a palliative care package for inclusion in UHC, cognisant of the recommendations of the Lancet Commission Report and the WHO. A full report from this meeting is available at www.africanpalliativecare.org/resource-centre

This recommended package is presented below:

1 **Essential palliative care medicines as recommended by the 2017 WHO Essential Medicines Lists for adults [10] and children [11] and to include the following:**

- Amitriptyline
- Bisacodyl (Senna)
- Dexamethasone
- Diazepam
- Diphenhydramine (chlorpheniramine, cyclizine or dimenhydrinate)
- Fluconazole
- Hydralazine or other selective serotonin reuptake inhibitors (sertraline and citalopram)
- Furosemide
- Hyoscine butylbromide
- Haloperidol
- Ibuprofen (naproxen, diclofenac, or meloxicam)
- Lactulose (sorbitol or polyethylene glycol)
- Loperamide
- Metoclopramide
- Metronidazole
- Morphine (oral immediate-release and injectable)
- Naloxone parenteral
- Omeprazole
- Ondansetron
- Paracetamol
- Povidone iodine

- APCA Ministers meeting 17th September 2019
- Delegations from 15 Ministries of Health
- Committed to include recommended package

MOVING TOGETHER TO BUILD A HEALTHIER WORLD

UN High Level Meeting on Universal Health Coverage, 23 September 2019, New York

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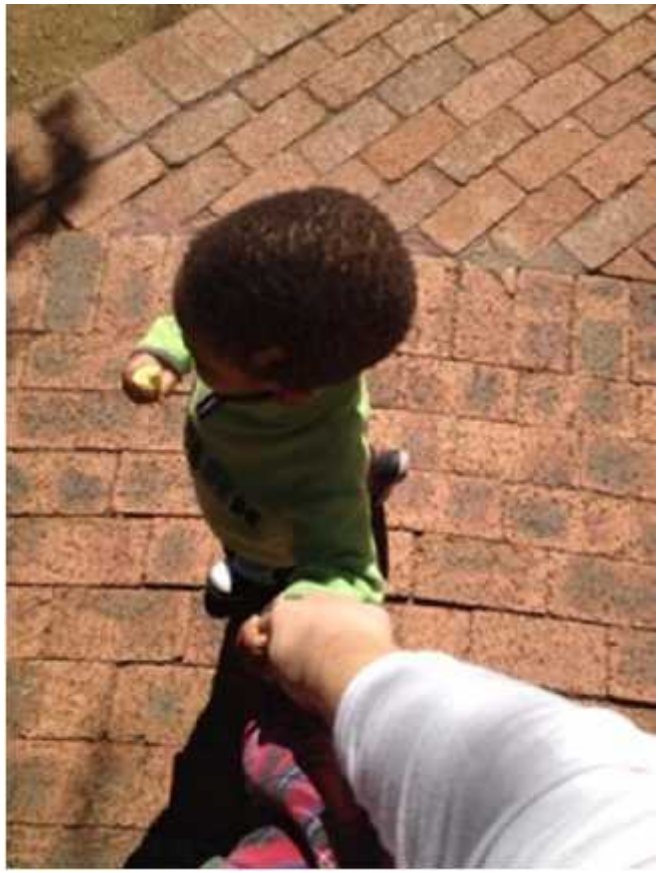
Global Health Perspective: Astana Declaration on PHC

October 2018

- *"Promotive, preventive, curative, rehabilitative services and palliative care must be accessible to all. We must save millions of people from poverty, particularly extreme poverty, caused by disproportionate out-of-pocket spending on health. …..We must address the shortage and uneven distribution of health workers."*
- *"We will prioritize disease prevention and health promotion and will aim to meet all people's health needs across the life course through comprehensive preventive, promotive, curative, rehabilitative services and palliative care."*

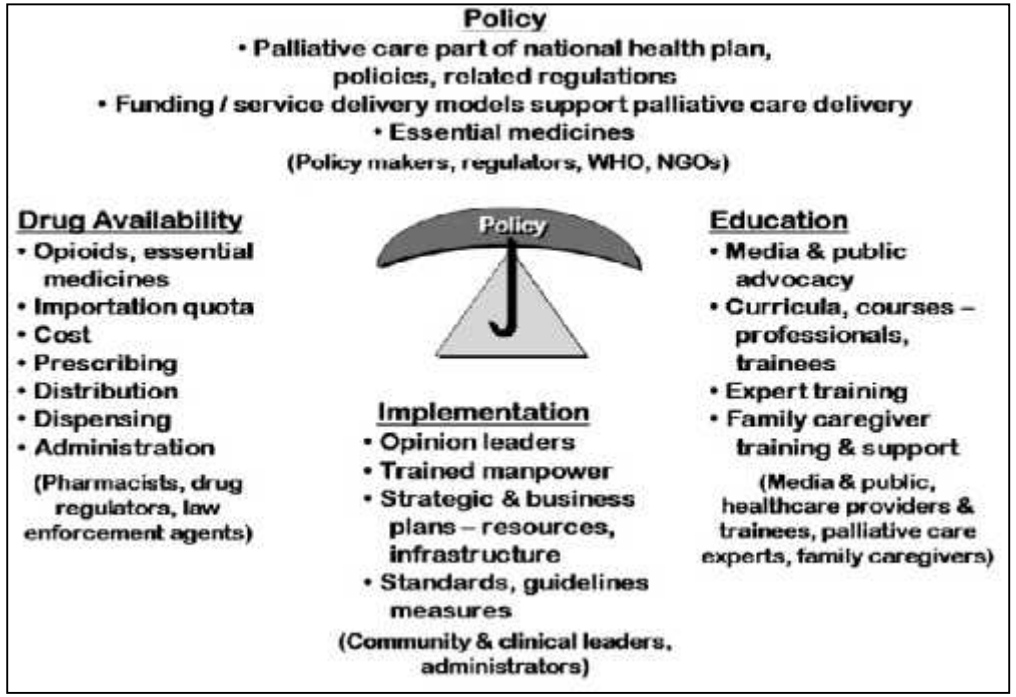
In some countries ……



- Even where cure is theoretically possible, it is often not realistic owing to:
  - Uneven distribution of services
  - Children presenting late
  - Expense
  - Awareness
  - Technical skills and expertise
- Therefore children's palliative care is even more important

WHO Foundation Measures for a Palliative Care Service:

1. Policy
2. Drug Availability
3. Education
4. Implementation
5. *Research*



(Stjernsward 2006)

(Harding et al 2013)

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1. Policy

- Needed at all levels
- PC policy and integrated into others – must included CPC
- Need data to inform policy
- Need evidence-based measures for governments to measure progress
- Bottom up and top down approaches together

- *"to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes."*

(WHA Resolution 2014)

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2. Access to Medicines

- National, Regional and International co-operation
- Need to continue to work at this – both for analgesics but also others e.g. O^2, Laxatives etc.
- Need to explore issues across the supply chain e.g. nurse prescribing
- Whenever work being done on access – ensure children's formulations are available
- Need to use the medicines we have e.g. Paed Morphine

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The Access Abyss

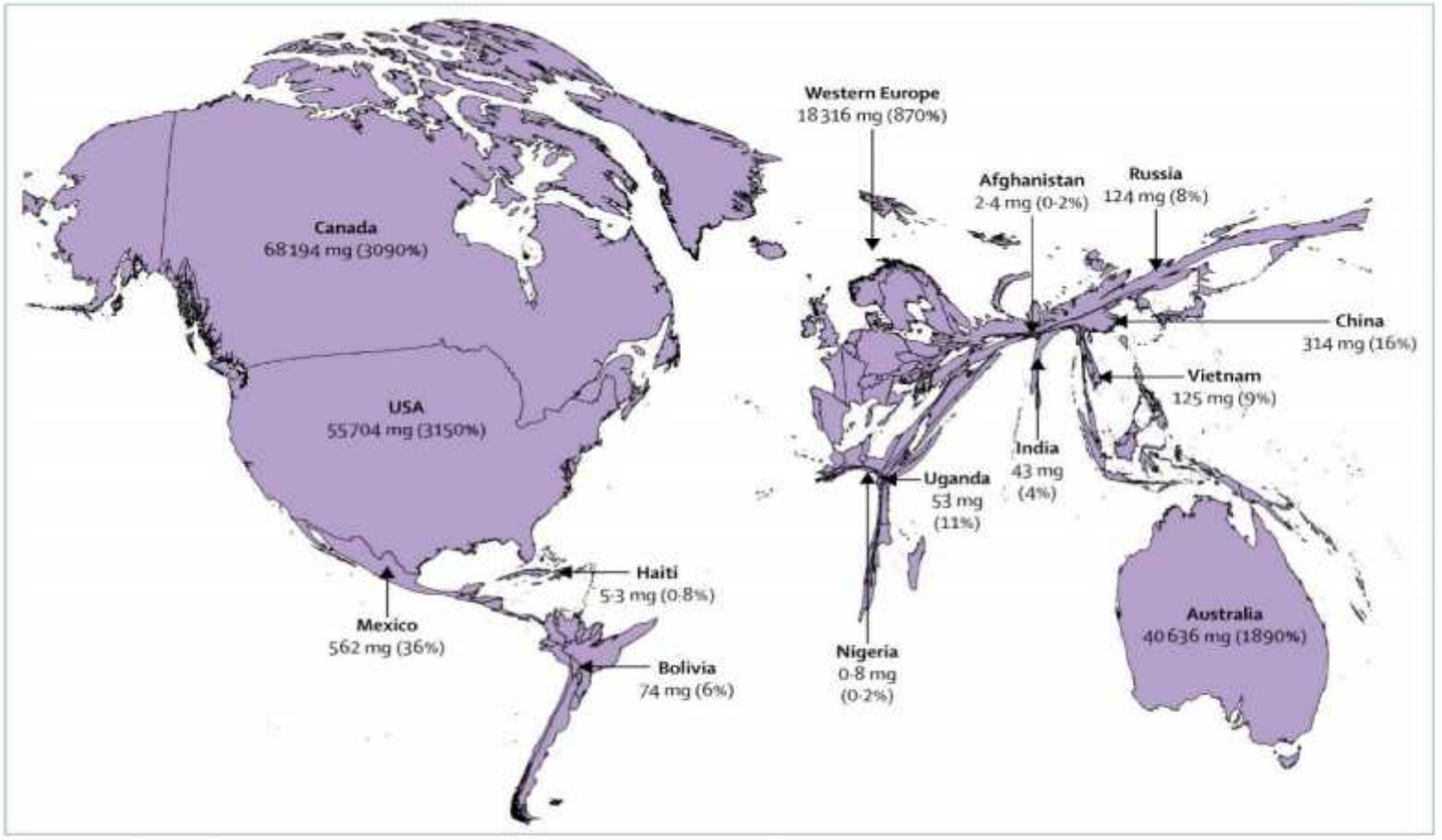

Figure 1: **Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering**
Source: International Narcotics Control Board and WHO Global Health Estimates, 2015. See additional online material for methods.

(Knaull et al 2017)

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3. Education

"to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles:

- *basic training and continuing education on palliative care*
- *intermediate training for all routinely work with patients with life-threatening illnesses,*
- *specialist palliative care training"*

(WHA Resolution 2014)

- Variety of models of delivery
- Theory and practice important
- Not just CPC skills but wider skills important
- Needs to be competency-based
- Important:
  - *To get PC into the universities*
  - *Recognition of the training by professional bodies and government*

International Children's Palliative Care Network: e-learning

icpcn elearning | English (en) | My courses | This course | Julia

Dashboard > My courses > Intro to PC

Turn editing on

NAVIGATION

- Dashboard
- Site home
- Site pages
- My courses
  - **Intro to PC**
    - Participants
    - Badges
    - Competencies
    - Grades
    - Overview
    - Introduction to Children's Palliative care
    - Final Activity
    - Where Next?
    - Evaluation Form
  - Pain
  - Communication
  - Play
  - Grief and Bereavement
  - End-of-life
  - Introduction aux SP de l'enfant
  - La douleur
  - Communiquer
  - Введение
  - More...

Introduction to palliative care in children

Your progress

Overview

This course will give you a brief introduction to children's palliative care.

It will address issues around what palliative care is, which children need palliative care, the differences between adults and children's palliative care, and the global situation of children's palliative care.

- Welcome
- Quick Navigation Guide
- Announcements

Introduction to Children's Palliative care

- Introduction to Children's Palliative care
- Which children need palliative care?
- CPC is a Global Concern
- The Global Picture
  - Reflective Activity
- Differences between children's and adult palliative care

4. Implementation

- Variety of models for CPC have evolved
- Important that they are culturally appropriate
- Can't just lift one model and put it elsewhere
- Important to understand existing models in order to scale up services
- Evidence of effectiveness has been lacking

5. Research

- Lack of robust evidence in the field
- Much of practice is based on evidence from adults or expert opinion
- Medications are used off license
- Service development based on evidence from limited number of countries
- Much of the evidence comes from the UK, Europe, USA/Canada, Australia and NZ

Research Letter

PALLIATIVE MEDICINE

A call for increased paediatric palliative care research: Identifying barriers

Emma Beecham[1,2], Briony F Hudson[1,2], Linda Oostendorp[3], Bridget Candy[3], Louise Jones[3], Vickey Vickerstaff[3], Monica Lakhanpaul[3], Paddy Stone[3], Lizzie Chambers[4], Doug Hall, Kate Hall, Thines Ganeshamoorthy, Margaret Comac[5] and Myra Bluebond-Langner[6]

SAGE

The evidence base underpinning paediatric palliative care (PPC) needs to be expanded and be made robust if advances in practice and reduction in suffering are to be achieved. While current guidance[1] emphasises the need to include children and young people (CYP), both those with good health and those with life-limiting conditions (LLCs) or life-threatening illnesses (LTIs) in decisions about health and health research,[2] it is commonly accepted that this is not easily achieved in practice. Challenges faced by researchers aiming to recruit CYP with LLCs or LTIs and their families are numerous, including small sample sizes and limited funding as well as difficulties with research ethics committees, the unpredictable nature of the illnesses and society's perceptions of the potential physical and psychological burden for participants and their families.

Research from within the Louis Dundas Centre for Children's Palliative Care has highlighted how attitudes and experiences of working with CYP with LLCs or LTIs can influence if, when and how clinicians introduce the prospect of research participation to families of children with LLC or LTI.[3] Indeed, even when participants are successfully recruited, the lack of detailed, standardised reporting of how recruitment was achieved hinders our ability to decipher the applicability of research to our own populations of interest.

In light of these challenges, and to help to pinpoint what

attempted our questions, n = 76 (out of approximately 80 in the room, estimated by the Louis Dundas Centre researchers who handed out and collected the surveys). The international delegates included researchers and a range of healthcare professionals including clinicians, nurses and psychologists working in a variety of settings including hospitals, universities and hospices.

Delegates' responses were categorised into four themes which were derived from the data; time and other resources, clinician's attitudes towards research, clinician's perceptions of patients and their families and the ethical approval process (Table 1).

Over half of the delegates (42) reported that time and other resources were a barrier to their research with CYP with LLCs or LTIs. This is perhaps not surprising, given that the majority of delegates were clinicians. It is well known that the demands and pressures on PPC clinicians are heavy and high. This was demonstrated through comments such as *'Limited resources – team teams with limited capacity to take on additional work'*.

Safety responses pertain to a lack of experience and confidence in conducting research among participating delegates (*'No one in my organisation seems to have any interest/desire ... to start (a) project'*). In addition, many delegates made reference to what they saw as a

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What are the Benefits?

1. Improved QoL
2. Across the Continuum of Care
3. Pain and Symptom Management
4. Emotional Support
5. Social Issues
6. Spiritual Issues
7. End-of-Life Care
8. Transitions
9. The family and significant others
10. Financial issues
11. …..

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Barriers and Challenges to CPC Development

- Lack of recognition of the need for CPC
- Palliative care not a priority
- Lack of policies
- Lack of integration into health services for all ages
- Lack of access to:
  - *Education*
  - *Treatment*
  - *Trained professionals*
  - *Medicines*
    - Fear of the use of opioids
    - Lack of prescribers
- Lack of resources

(Downing et al 2017)

Opioid Crisis……

Some unique characteristics of CPC

- Children are not small adults – they think and behave differently
- Children are developing and maturing all the time
- Diverse conditions
- Medications and dosages are more complex
- One size does not fit all
- Death in childhood is not seen as normal

35

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Things to consider when working with children….

- Communication with children changes as they mature and develop
- Children's understanding of death and dying differs according to age and developmental stage
- Ethical dilemmas may be different and more difficult
- Families of dying children have different social roles
- Experiences of bereavement change with age
- Subtly different challenges face professionals dealing with dying children
- Children tend to have a broader range of people involved in their care

Generalist vs Specialist CPC

- Need for specialist PPC will be individual to each child
- Some will never need specialist services and others will depend on it
- Often mix of the two

PPM provision	Competencies
Level IV	Skills expected of doctor fully trained in specialist PM in children e.g. PPM consultant
Level III	Specialist skills expected of someone trained in children and with a special interest in PM
Level II	Generic PM skills expected of any doctor trained in paediatrics
Level I	Generic PM skills expected of any professional

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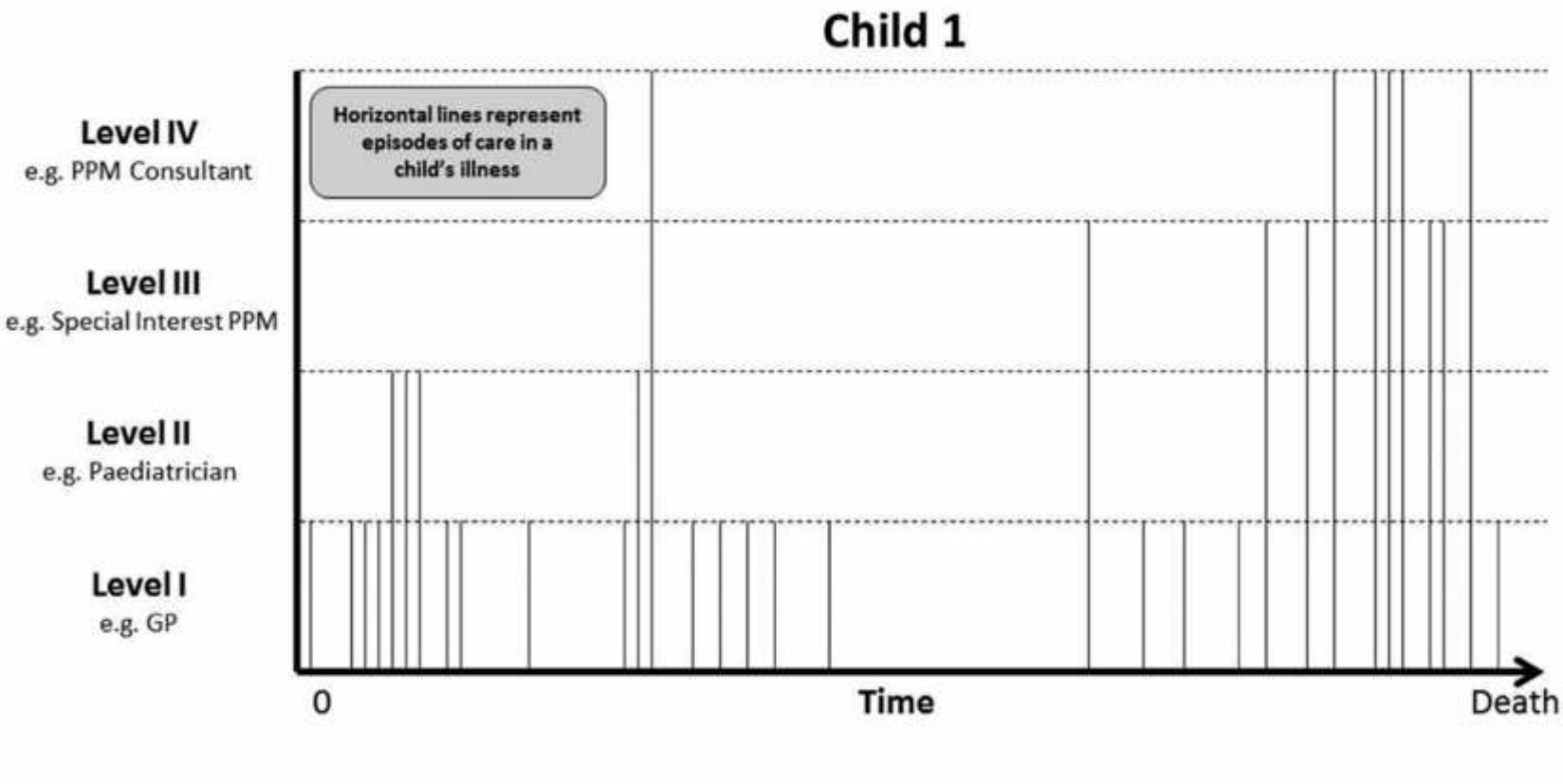

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Key Elements of an Effective CPC Programme

- Clear and strong leadership
- Focused on the vision
- Linked to what makes the programme unique
- Different components of care
- Holistic approach to care
- Clear strategy
- In touch with changes in the environment
- Adaptable (but not losing focus)
- Consistency in approach
- Acceptance by the community and collaboration
- Access to a variety of education programmes

(Downing et al 2017)

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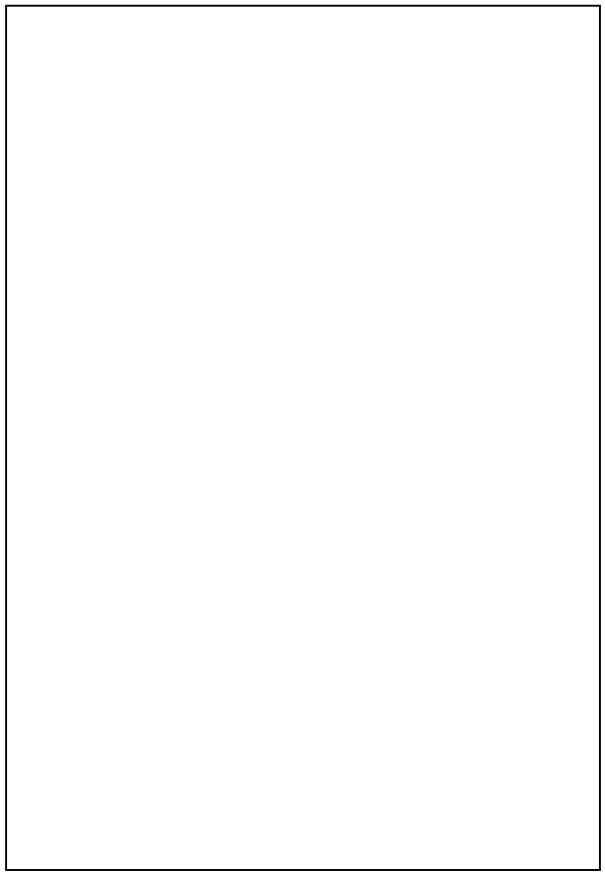
IMPaCCT Standards

- Provision of care
- Unit of care
- The care team
- Care co-ordinator
- Symptom management
- Respite care
- Bereavement
- Age-appropriate care
- Education and training
- Funding
- Euthanasia
- Ethics and legal rights



(EAPC 2007)

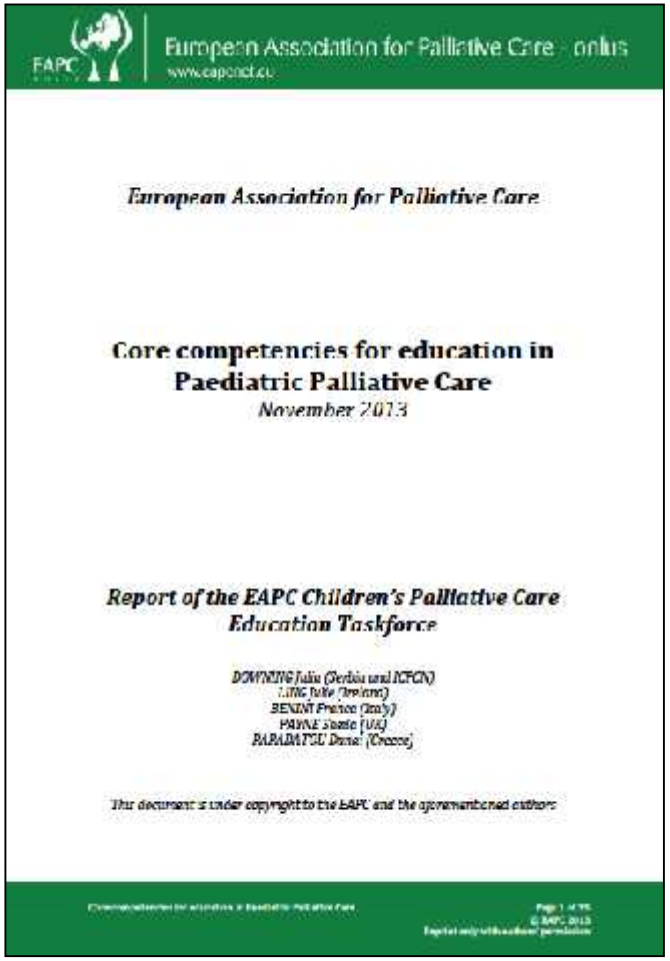
APCA Standards

(APCA 2010)

Principle 3: CPC

1. Holistic care provision
2. Pain & symptom management
3. Psychosocial care
4. End-of-Life care
5. Bereavement care
6. Ethical care, human rights and legal support

CPC Education



European Association for Palliative Care onlus
www.eapcnet.eu

European Association for Palliative Care

Core competencies for education in Paediatric Palliative Care
November 2013

Report of the EAPC Children's Palliative Care Education Taskforce

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PARAMATOU Dana (Greece)

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Table 2. The five key competency domains at the specialist (third) level of paediatric palliative care, and their sub-domains[6]

Domain	Sub-domains
The caregiving relationship	• Philosophy and practice of paediatric palliative care • Communication with the child and their family • Psychosocial and spiritual care • Bereavement support • Self- and team care
Clinical care	• Pain assessment and management • Assessment and management of other symptoms • End-of-life care
Collaboration and interprofessional practice	• Teamwork • Networking
Leadership	• Leading and developing services • Advocacy
Professional practice	• Research • Evaluation of services • Policy • Training and education

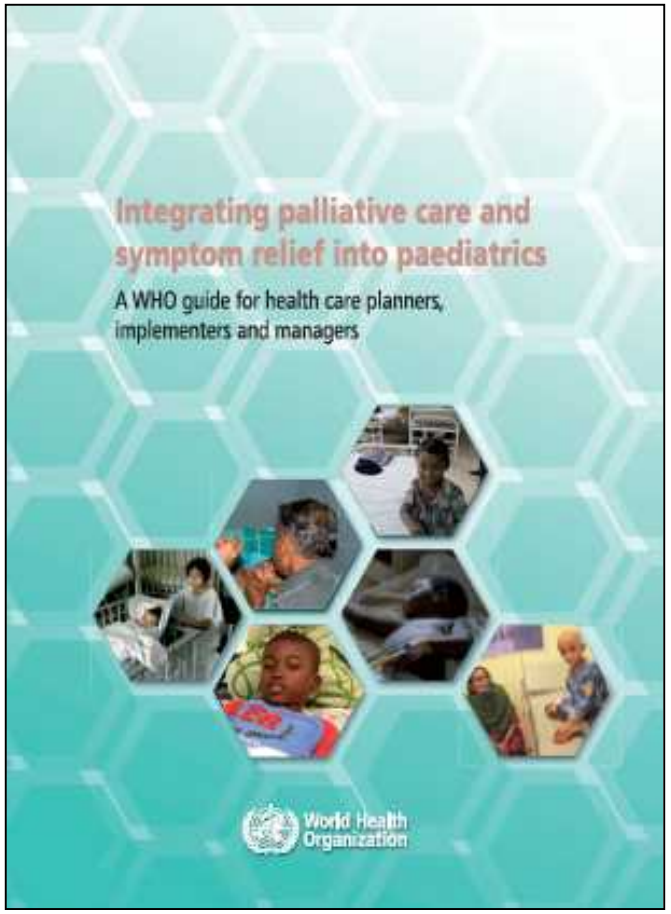
3 Levels:

(Downing et al 2014)

- *PC approach*
- *General PC*
- *Specialist PC*

WHO Handbook

1. What is CPC
2. Access to PC and symptom relief
3. PC and symptom relief as part of comprehensive CPC
4. Essential package
5. Implementing CPC and symptom relief
6. Ensuring access to essential medicines
7. Integration to strengthen health care systems and UHC
8. Research and quality improvement

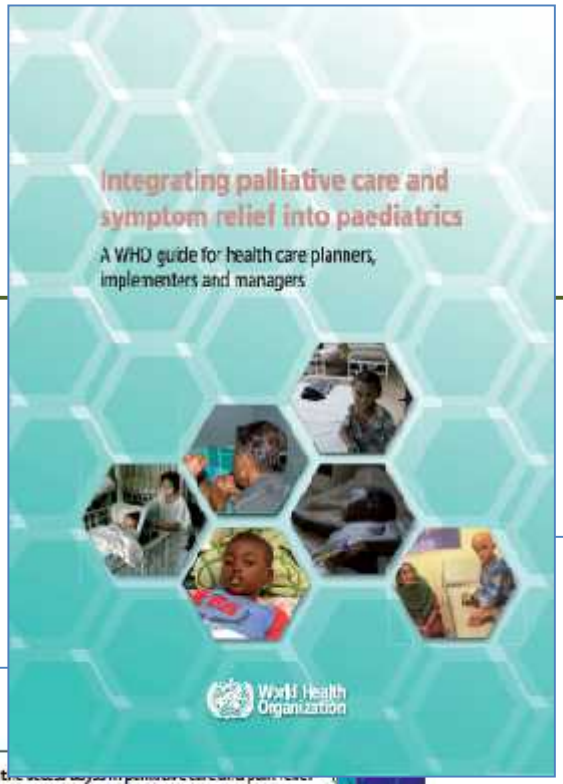


(WHO 2018)

Current Issues ……..

More understanding of the need for CPC in specific groups e.g.:

- Perinatal/Neonatal Palliative Care
- Adolescents and Young People
- Transitions
- Children in situations of humanitarian crisis


Integrating palliative care and symptom relief into paediatrics
A WHO guide for health care planners, implementers and managers
World Health Organization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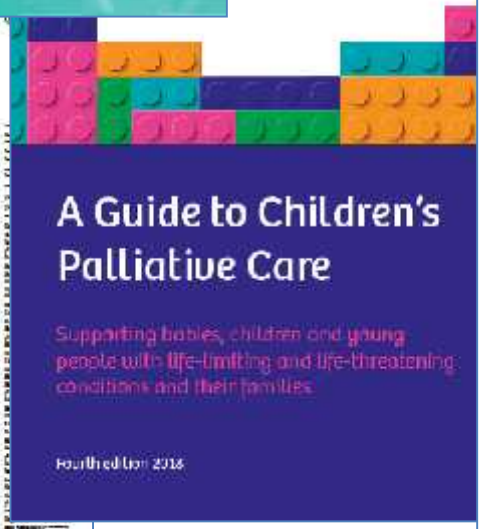
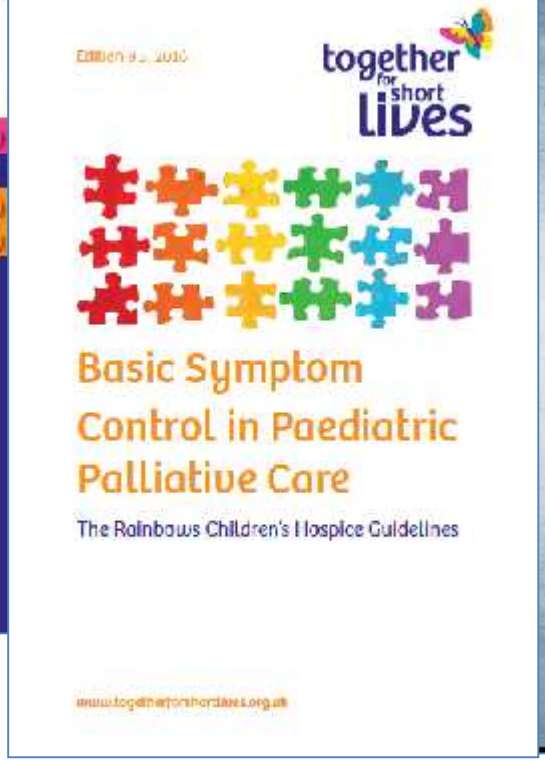
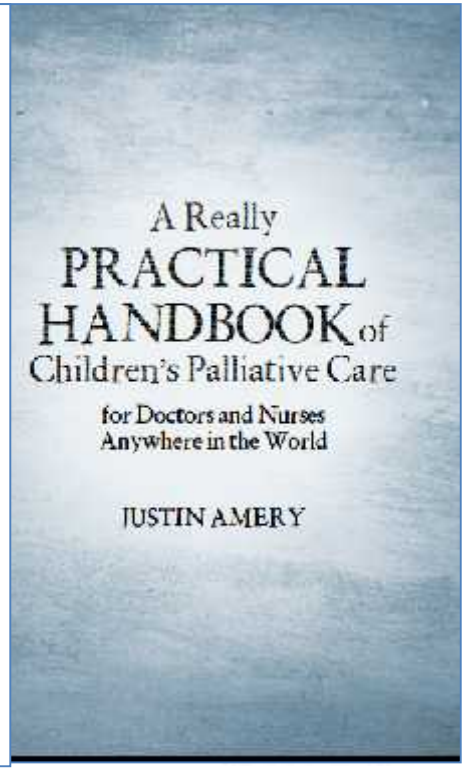
Overview
Introduction to Children's Palliative care

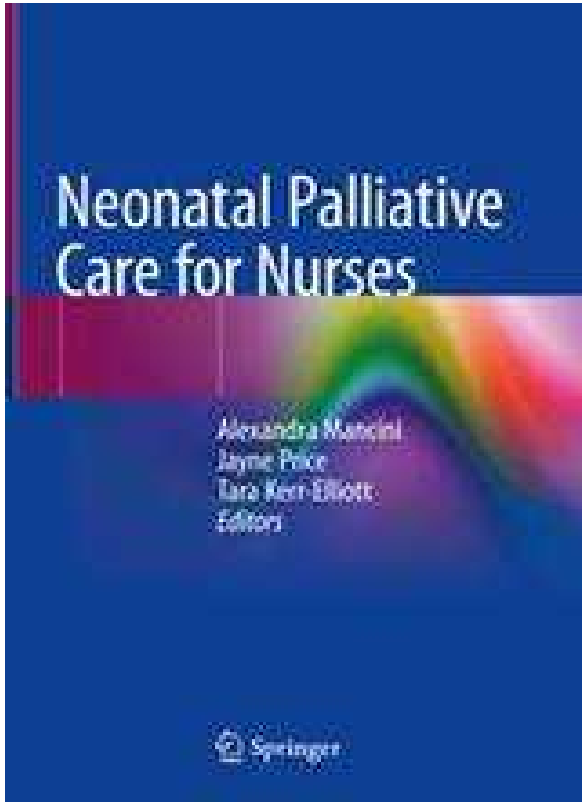

an imperative of universal health coverage: the Lancet Commission report

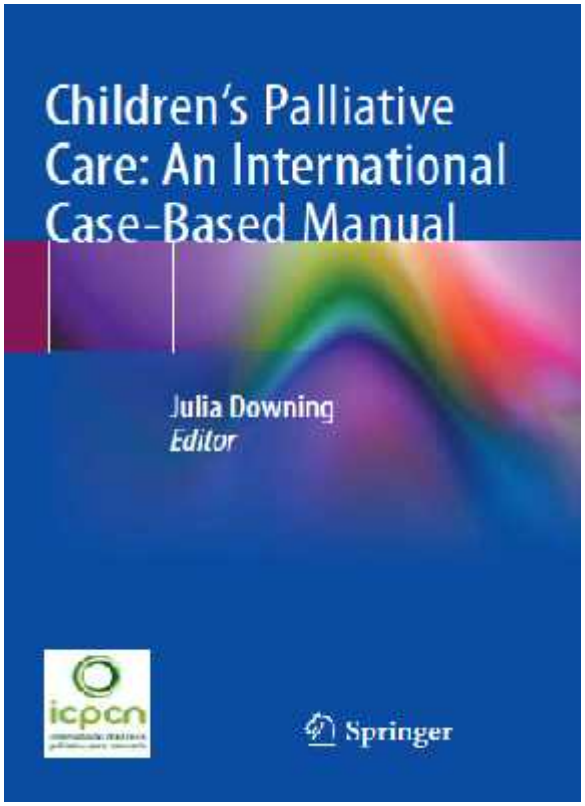

together for short lives
A Guide to Children's Palliative Care
Supporting babies, children and young people with life-limiting and life-threatening conditions and their families
Fourth edition 2016


Edition 3 2010
together for short lives
Basic Symptom Control in Paediatric Palliative Care
The Rainbows Children's Hospice Guidelines
www.togetherforshortlives.org.uk


A Really
PRACTICAL
HANDBOOK of
Children's Palliative Care
for Doctors and Nurses
Anywhere in the World
JUSTIN AMERY

New Resources Out Soon…..





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Developments and the Future

Still a long way to go but:

- The time is right
- The Lancet Commission and Universal Health Coverage are opportunities
- Stakeholder engagement is key
- Collaboration is essential – need to learn from each other

Thank You!

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