Global Development of Children's Palliative Care

Prof. Julia Downing PhD
Chief Executive
International Children's Palliative Care Network

Thursday June 13th 2019

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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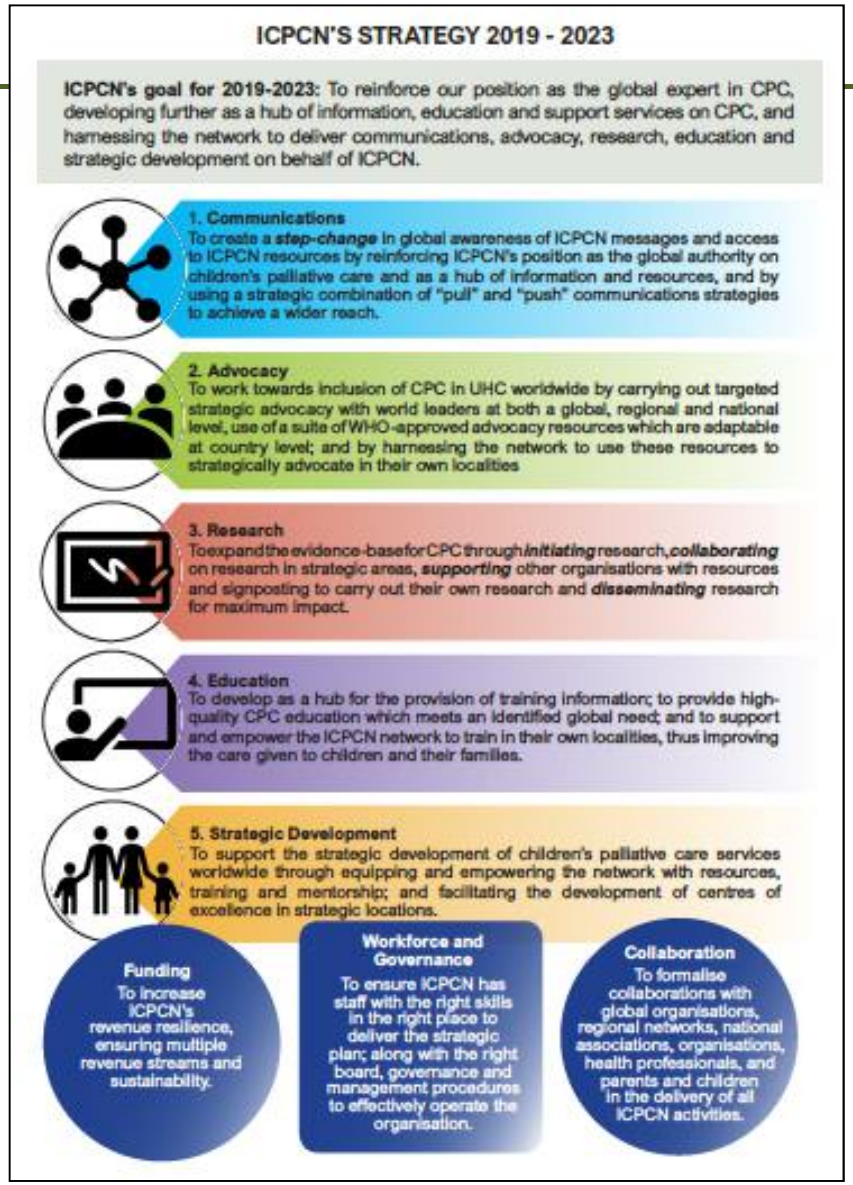
ICPCN CARES



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

- www.icpcn.org

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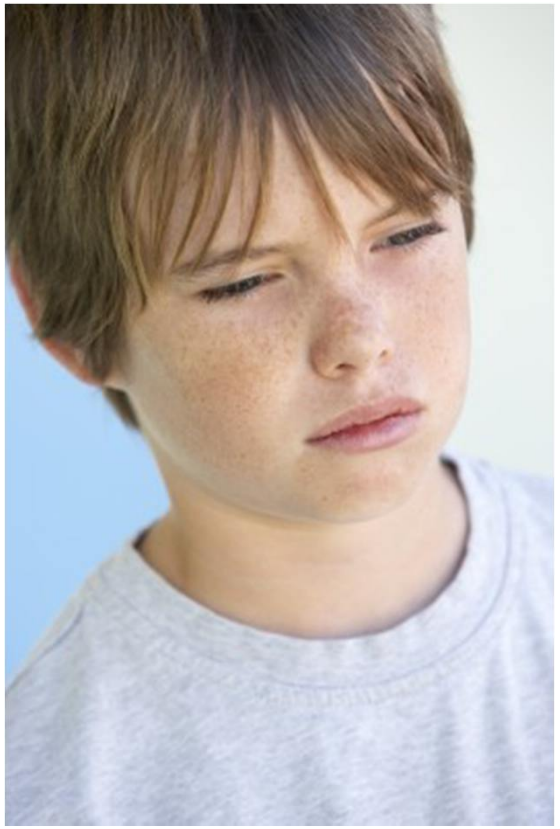
WORLD HEALTH ORGANIZATION'S DEFINITION OF PALLIATIVE CARE FOR CHILDREN

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

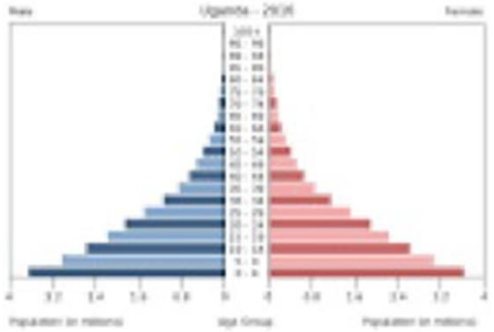


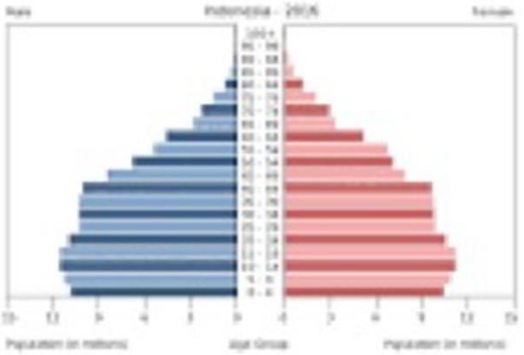
Categories of life-limiting and life-threatening conditions (Together for Short Lives) (Wood et al 2010, Downing et al 2015).

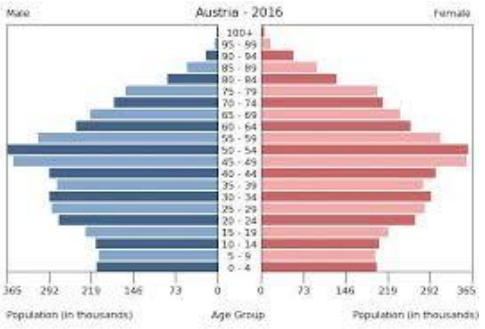
Category 1 **Life-threatening conditions for which curative treatment may be feasible but can fail**	Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. *Examples: cancer, irreversible organ failures of heart, liver, kidney.*
Category 2 **Conditions where premature death is inevitable**	There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. *Examples: cystic fibrosis, duchenne muscular dystrophy.*
Category 3 **Progressive conditions without curative treatment options**	Treatment is exclusively palliative and may commonly extend over many years. *Examples: batten disease, mucopolysaccharidoses.*
Category 4 **Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death**	*Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event of episode.*
Category 5 **Neonates with limited life expectancy** **Category 6** **Members of a family having unexpectedly lost a child from a disease, an external cause or during the perinatal period**	**Additional proposed categories (Wood et al):**

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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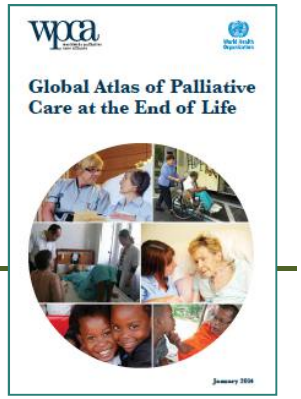
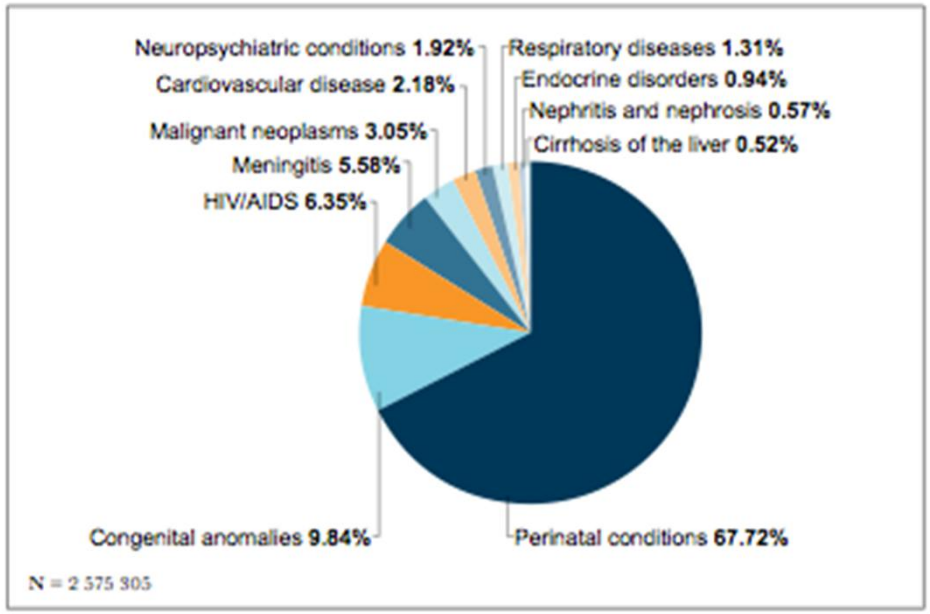
Why we need CPC?



- 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)

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Lancet Commission Report
Serious Health Related Suffering (SHS)

The Lancet Commission on Global Access to Palliative Care and Pain Relief
10 Facts about Children's Suffering and Need for Palliative Care

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UNIVERSITY OF MIAMI MILLER SCHOOL of MEDICINE

HARVARD GLOBAL EQUITY INSTITUTE HGEI

whpca

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE

CÁNCER DE MAMA TÓMATELO A PECHO

Fundación Mexicana para la Salud

1. Serious health-related suffering (SHS) is associated with illness or injury of any kind that could be ameliorated by palliative care and pain treatment[1].
2. More than 5.3 million children aged 15 years or younger experience SHS each year worldwide.
3. Children and their families have specific and intensive palliative care needs that can easily be overlooked because the absolute number of paediatric patients is low compared with adults[2].
4. Children account for 9% of patients who experience SHS, 5% of total days with SHS days, and 6% of days in pain.
5. One third of all children who died in 2015 experienced SHS.
6. Every year nearly 2.5 million children die needing palliative care and pain relief and more than 98% of these children are from developing countries.
7. Over 90% of all paediatric deaths associated with SHS in low-income countries are avoidable.
8. In low-income countries, childhood deaths account for more than 30% of all deaths associated with SHS, compared with less than 1% in high-income countries.
9. More than 50% of the burden of SHS in children in low-income countries is associated with HIV disease.
10. At best international medicine prices, the cost of covering the unmet need for opioid analgesics in all children with SHS in low-income countries is just over 1 million USD per year, which is only 63 cents per child in need.

Source: Knaul FM, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. The Lancet. 2017

http://www.thelancet.com/commissions/palliative-care

www.miami.edu/lancet

[1]The most common SHS health conditions are: atherosclerosis; cerebrovascular disease; chronic ischaemic heart diseases; congenital malformations; degeneration of the CNS; dementia; diseases of the liver; haemorrhagic fevers; HIV disease; inflammatory disease of the CNS; injury, poisoning, and external causes; leukaemia; lung diseases; cancers; musculoskeletal disorders; non-ischaemic heart diseases; premature birth and birth trauma; protein energy malnutrition; renal failure; and tuberculosis. The common SHS physical symptoms are: pain, weakness, fatigue, shortness of breath, nausea and vomiting, constipation, diarrhoea, dry mouth, itching, and wounds and bleeding. The most common psychological SHS is anxiety and worry, depressed mood, delirium or confusion, and dementia.

[2]Connor SR, Bermedo MCS. Global atlas of palliative care at the end of life. Geneva: World Health Organization, Worldwide Palliative Care Alliance, 2014

- >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

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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)

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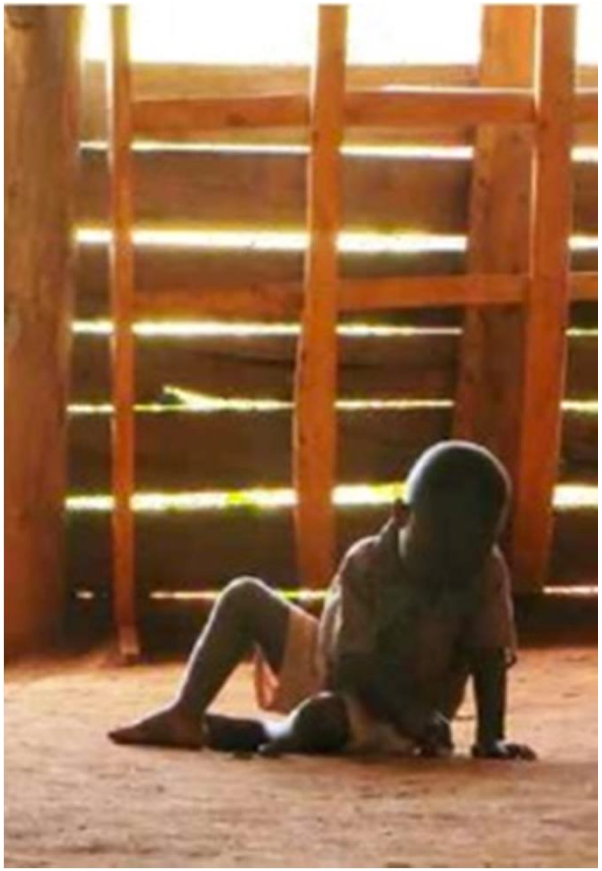
Review of CPC (2010)

- 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 2017)

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Global Status of CPC - 1980

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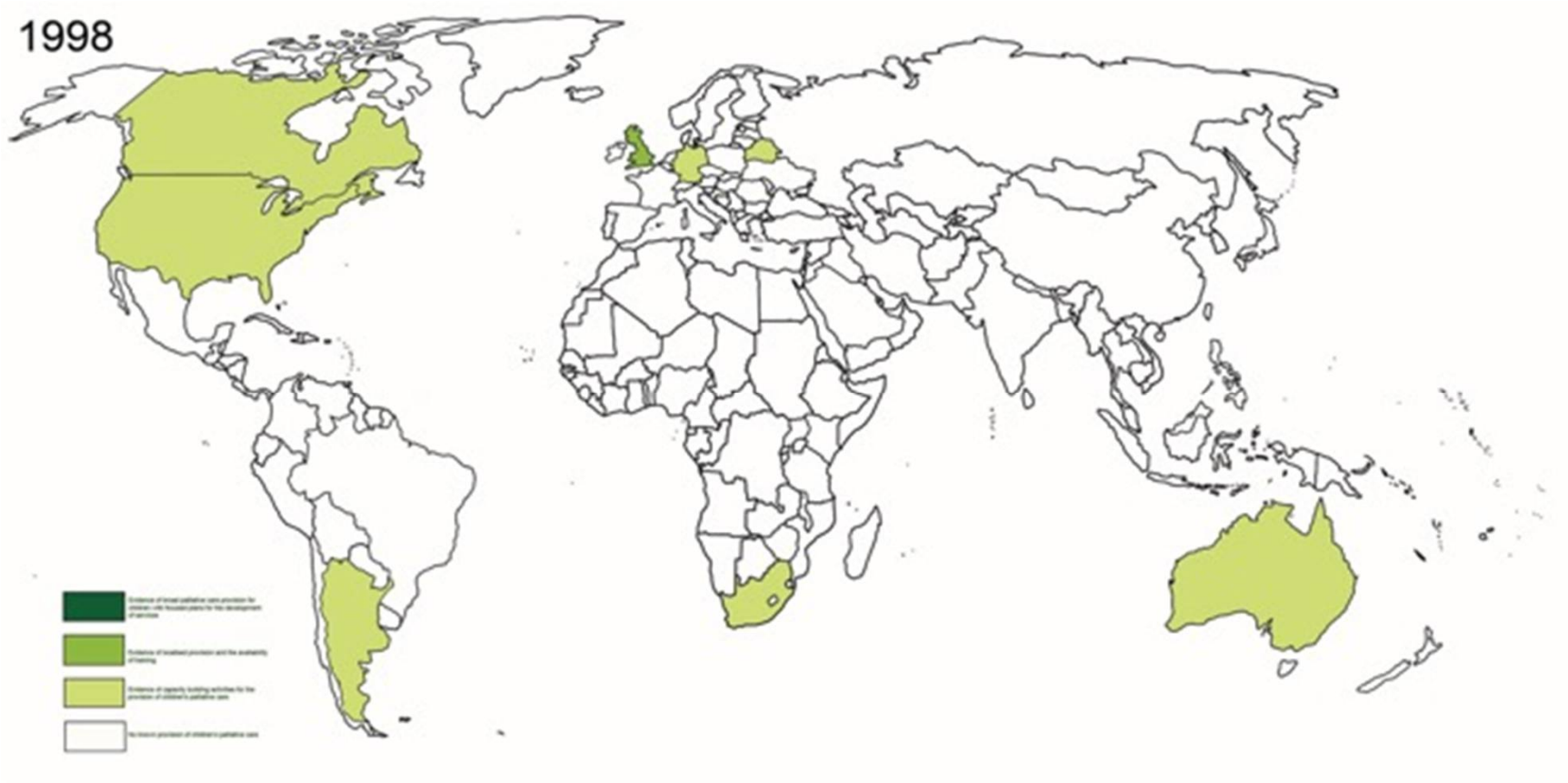
Global Status of CPC - 1998



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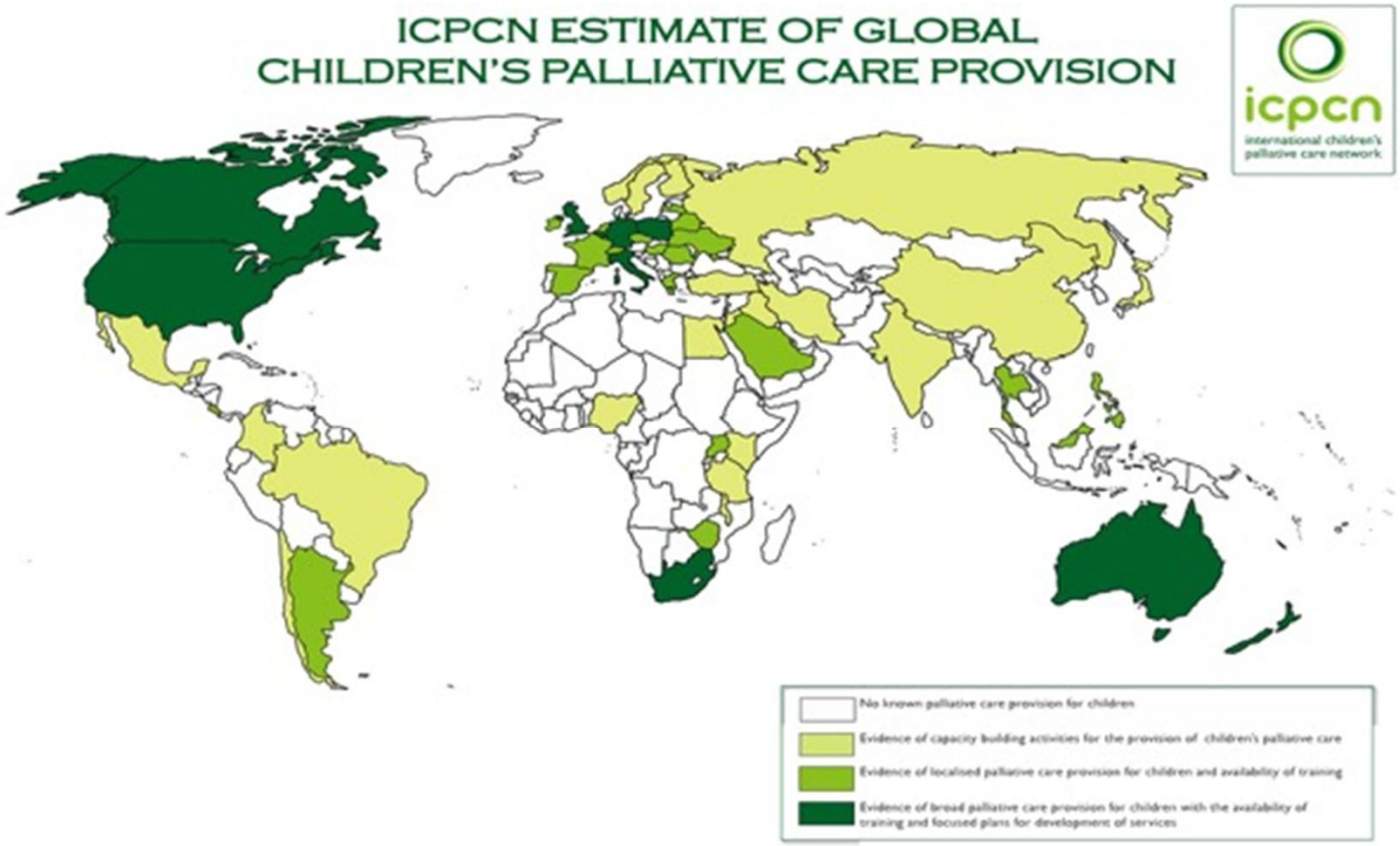
Global Status of CPC - 2011



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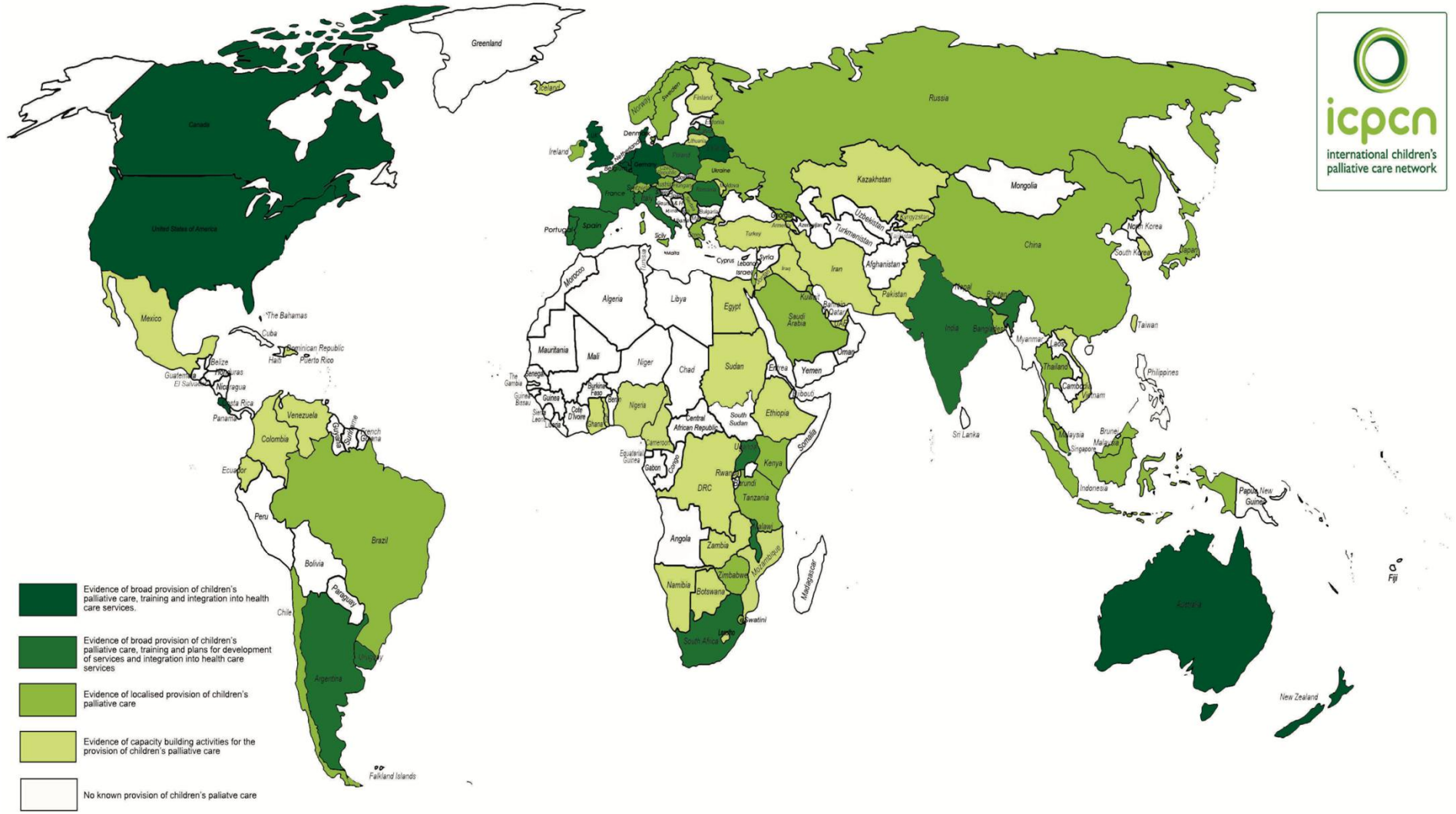
Global Status of CPC - 2018



By 2060???

- Globally, 87% increase in SHS by 2060 (48mil)
- SHS will decrease among younger age groups (0–4 years, 5–14 years, 15–29 years, and 30–49 years)
- In low-income countries - 5% increase in SHS among children aged 5–14 years, between 2016 and 2060.
- SHS amongst 0–4 years will decline in all World Bank regions.

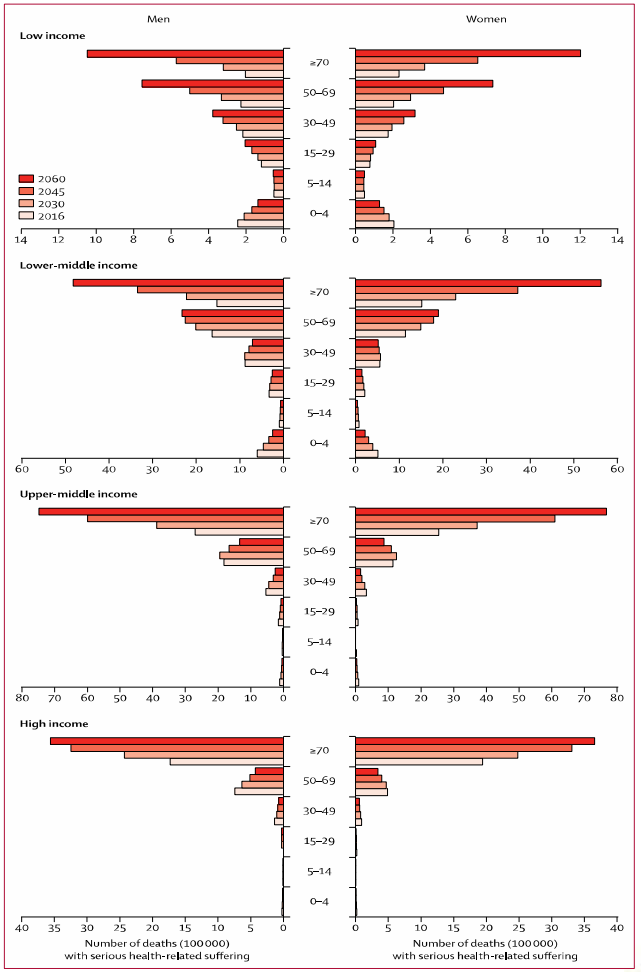


Figure 4: Changes in the number of people dying with serious health-related suffering, stratified by age group and sex, for World Bank income regions

(Sleeman et al 2019)

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Global Health Priorities: 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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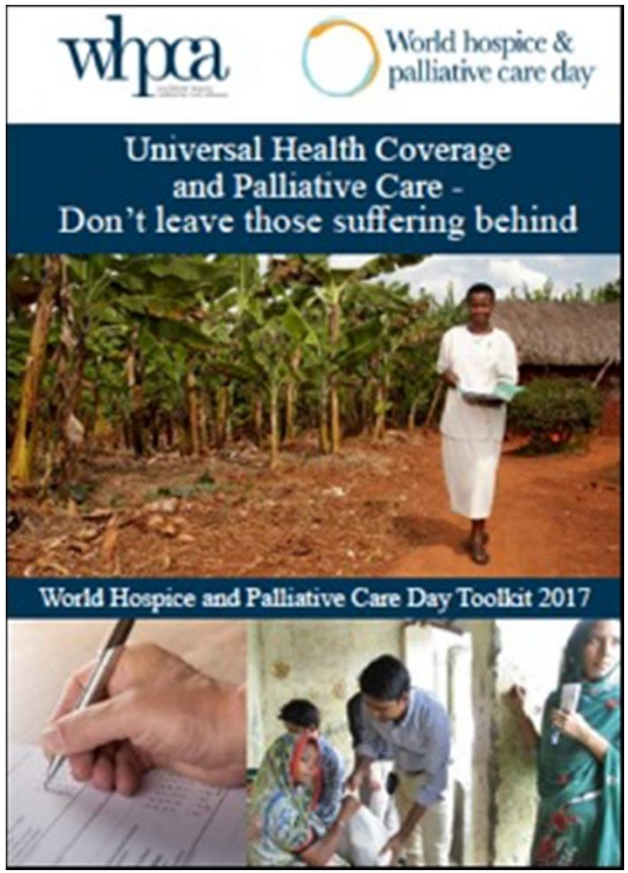
Global Health Priorities: PC and UHC

- Universal health Coverage
- *'Leaving no-one behind'*



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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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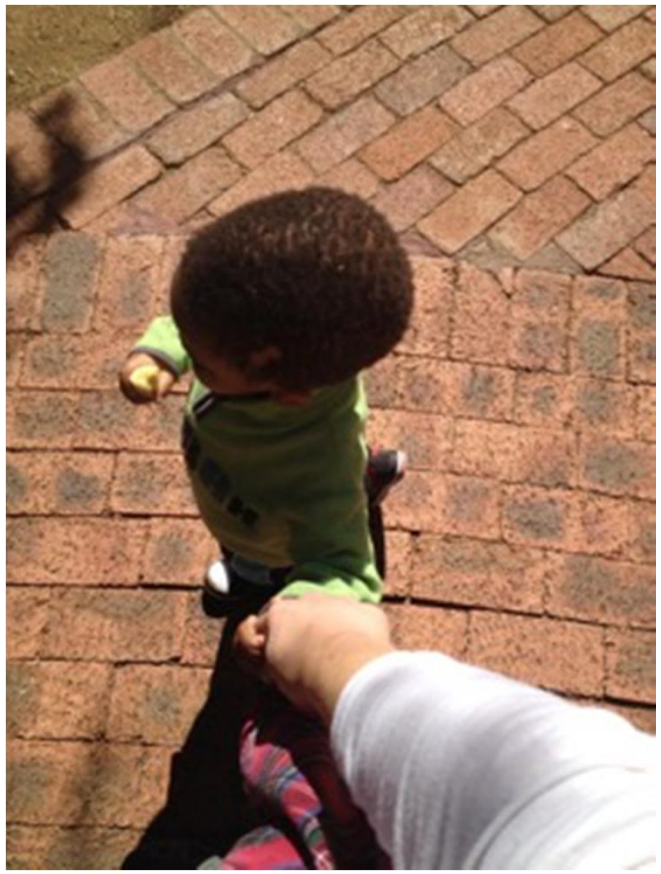
Global Health Priorities: Astrana Declaration on PHC

- *"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

Barriers and Challenges to CPC Development

- Lack of recognition of the need for CPC
- 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

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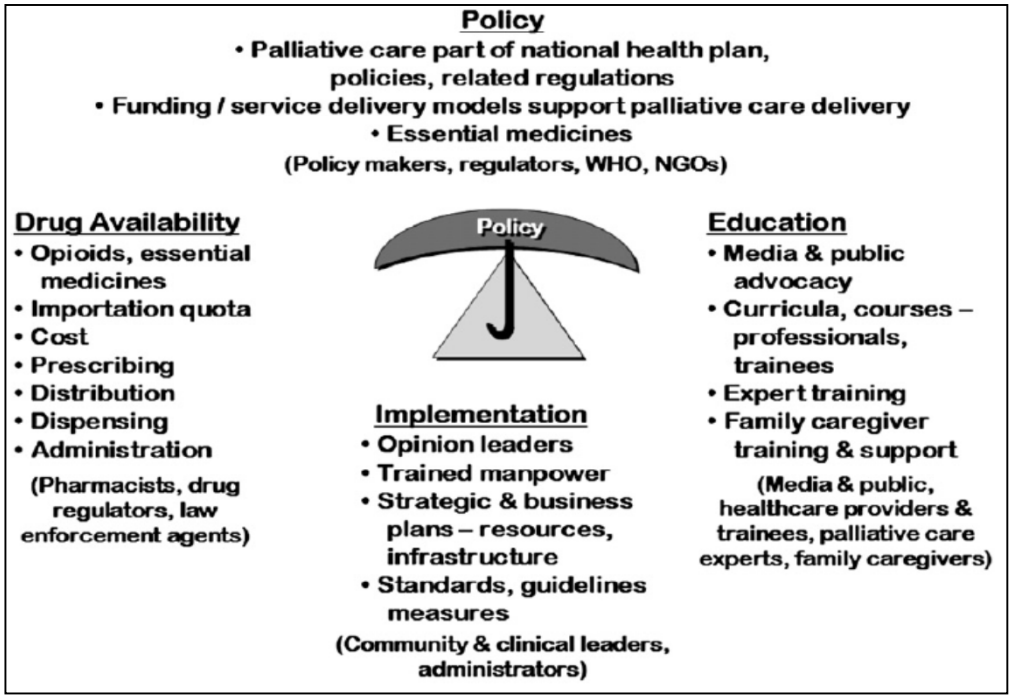
WHO Foundation Measures for a Palliative Care Service:

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

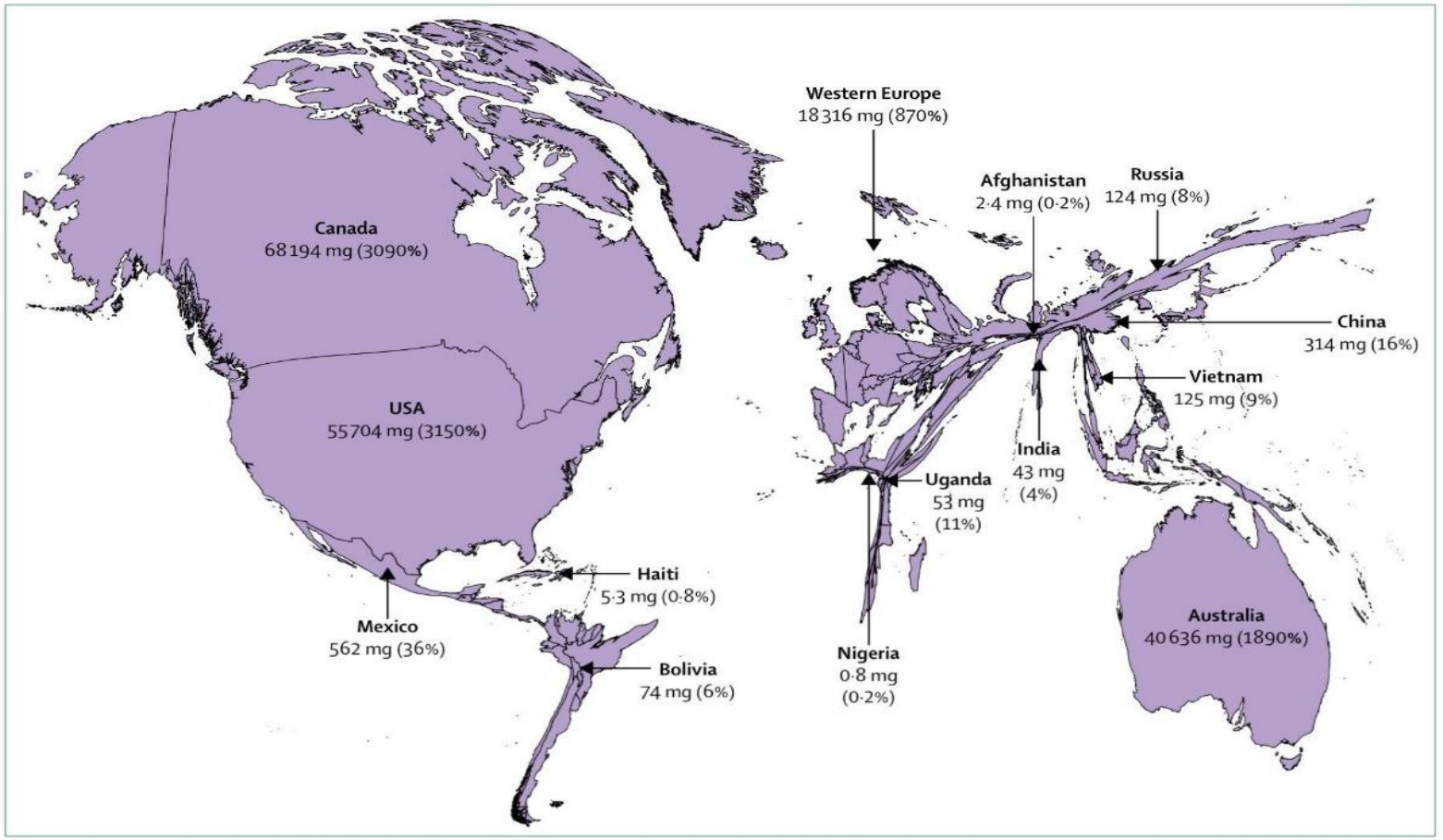

***Figure 1*: Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering**

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*

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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

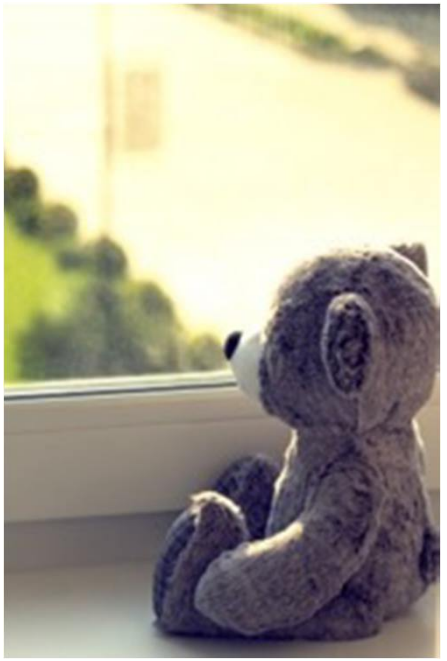
- Introduction to Children's Palliative care ☑
- Which children need palliative care? ☑
- CPC is a Global Concern ☑
- The Global Picture ☑
  - Reflective Activity ☐
- Differences between children's and adult palliative care ☑

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

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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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 answered our question, $n = 76$ (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 (43) 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 – busy teams with limited capacity to take on additional work'*.

Survey responses pointed 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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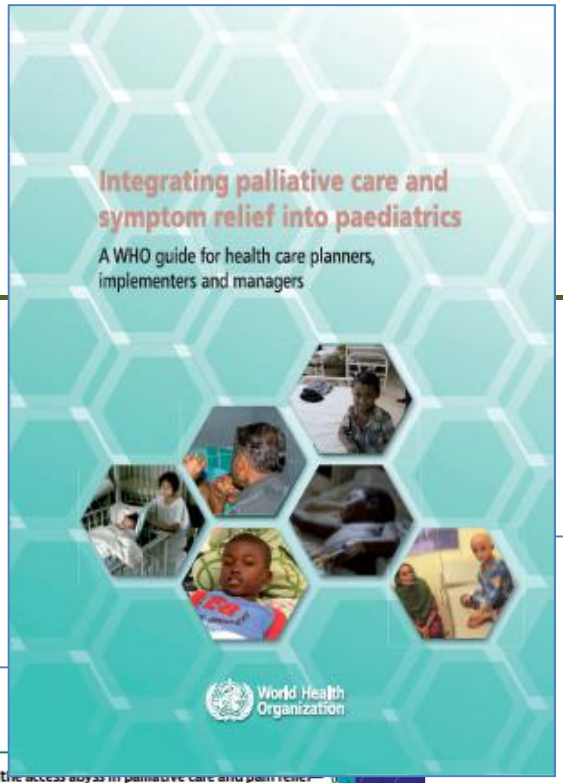
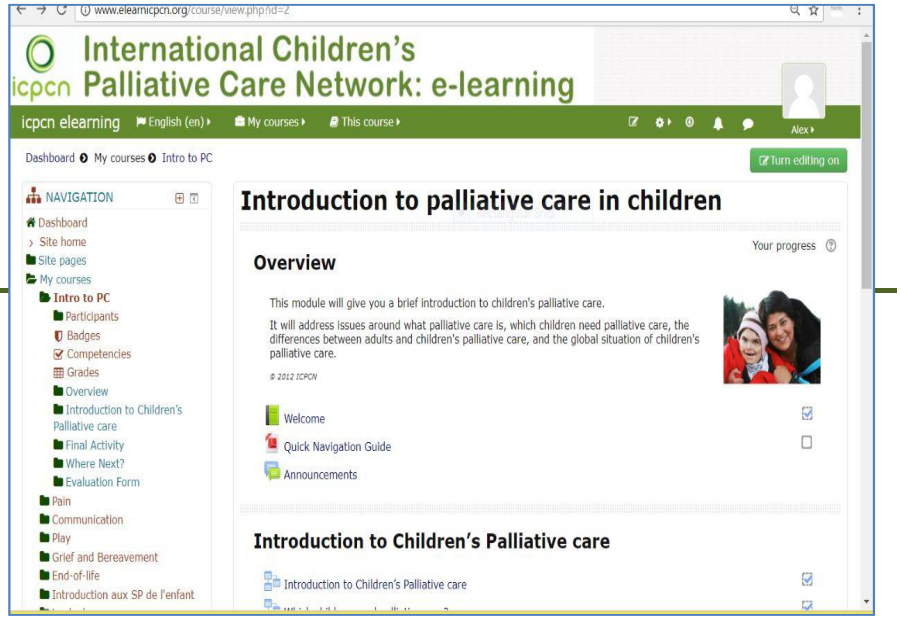
Current Issues ……..

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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International Children's Palliative Care Network: e-learning
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English (en)
My courses
This course
Alex
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
Introduction to palliative care in children
Your progress
Overview
This module 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.
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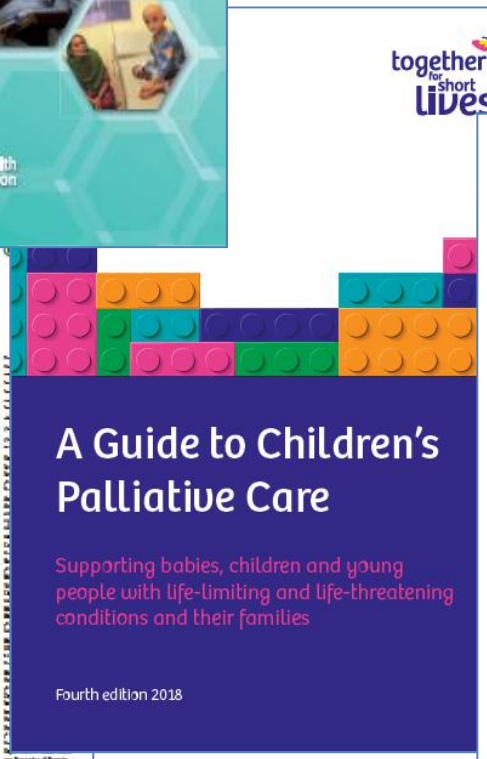
Welcome
Quick Navigation Guide
Announcements
Introduction to Children's Palliative care
Introduction to Children's Palliative care


Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report
Executive Summary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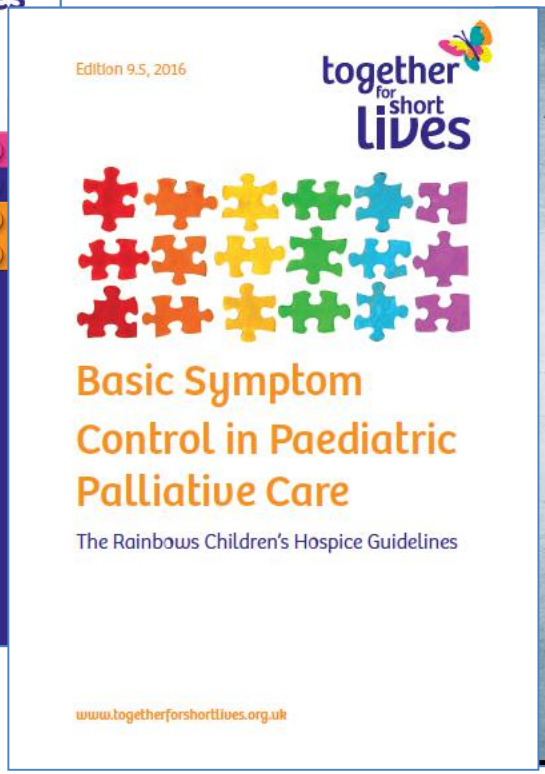
A Guide to Children's Palliative Care
Supporting babies, children and young people with life-limiting and life-threatening conditions and their families
Fourth edition 2018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Basic Symptom Control in Paediatric Palliative Care
The Rainbows Children's Hospice Guidelines
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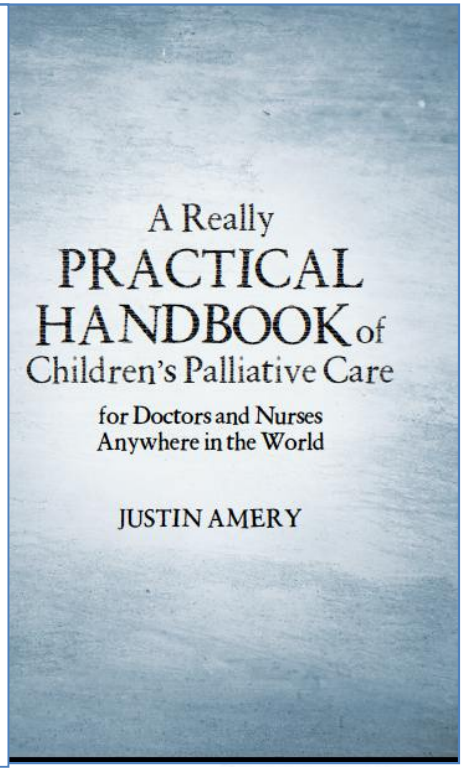
A Really
PRACTICAL
HANDBOOK of
Children's Palliative Care
for Doctors and Nurses
Anywhere in the World
JUSTIN AMERY

Developments & 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
- Exciting to hear about what is happening in Austria

icpcn
international children's palliative care network

Thank You!

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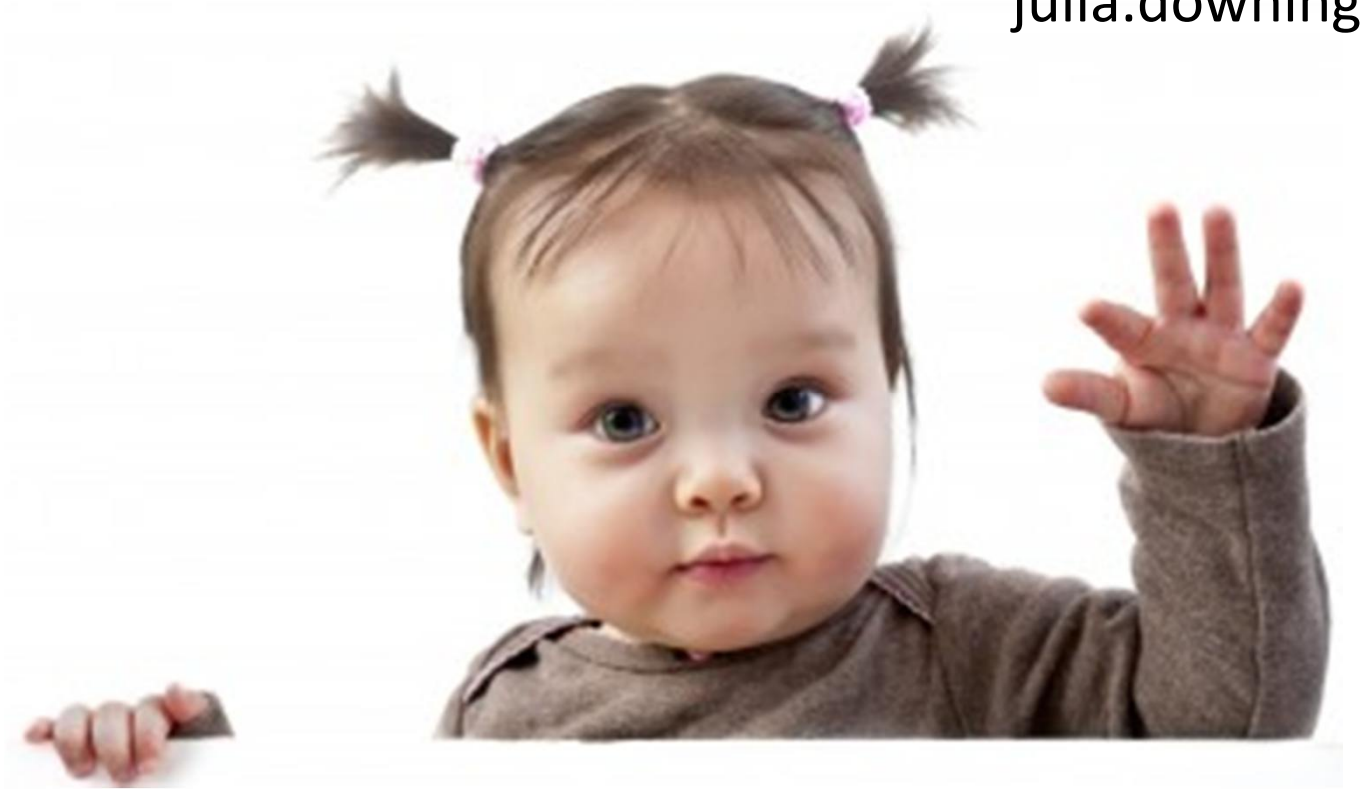

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