Global Development of Children's Palliative Care

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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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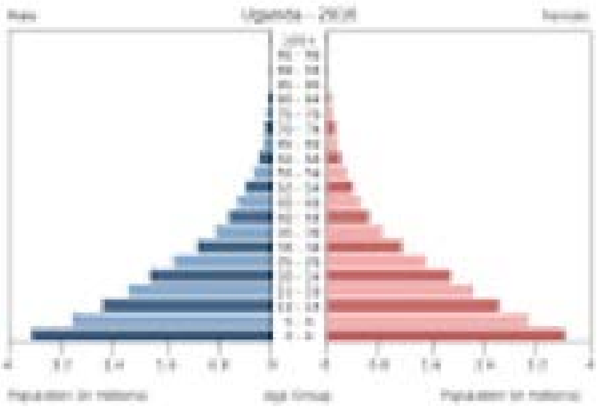
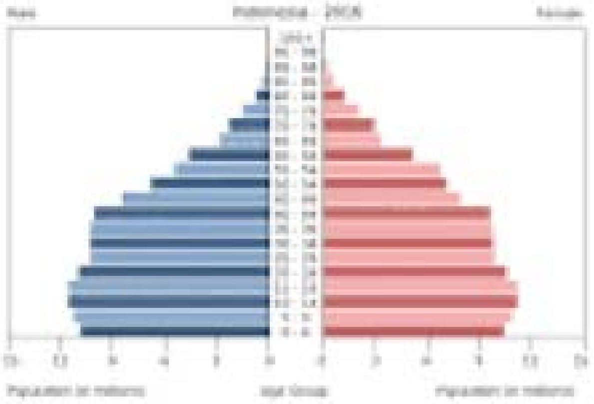
Global Population

- 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





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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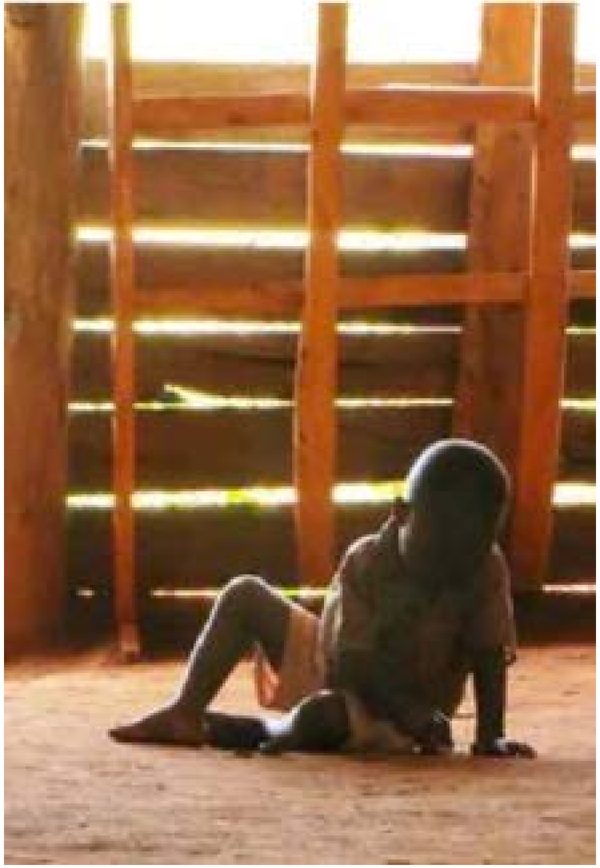
Review of CPC (2010)

- 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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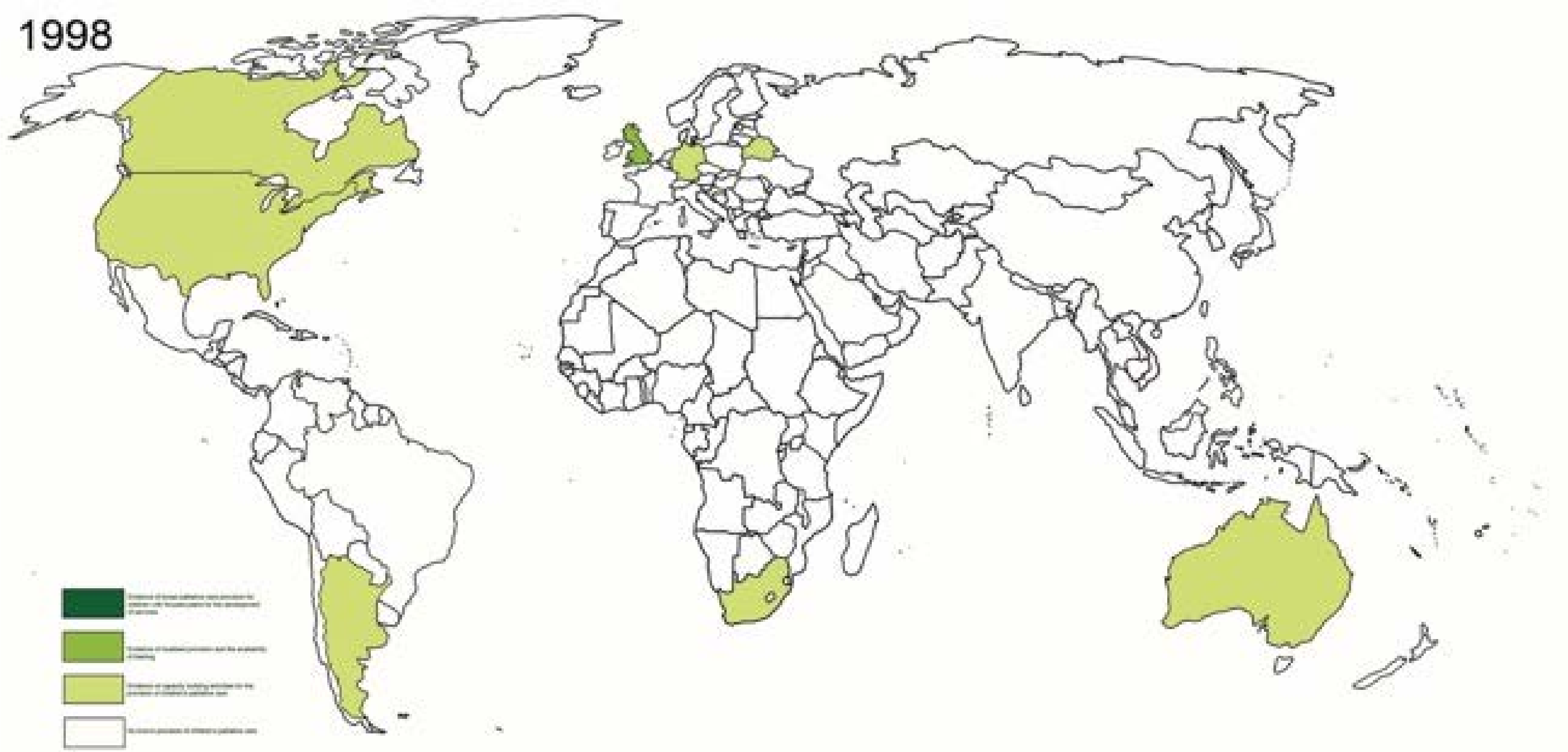
Global Status of CPC - 1998



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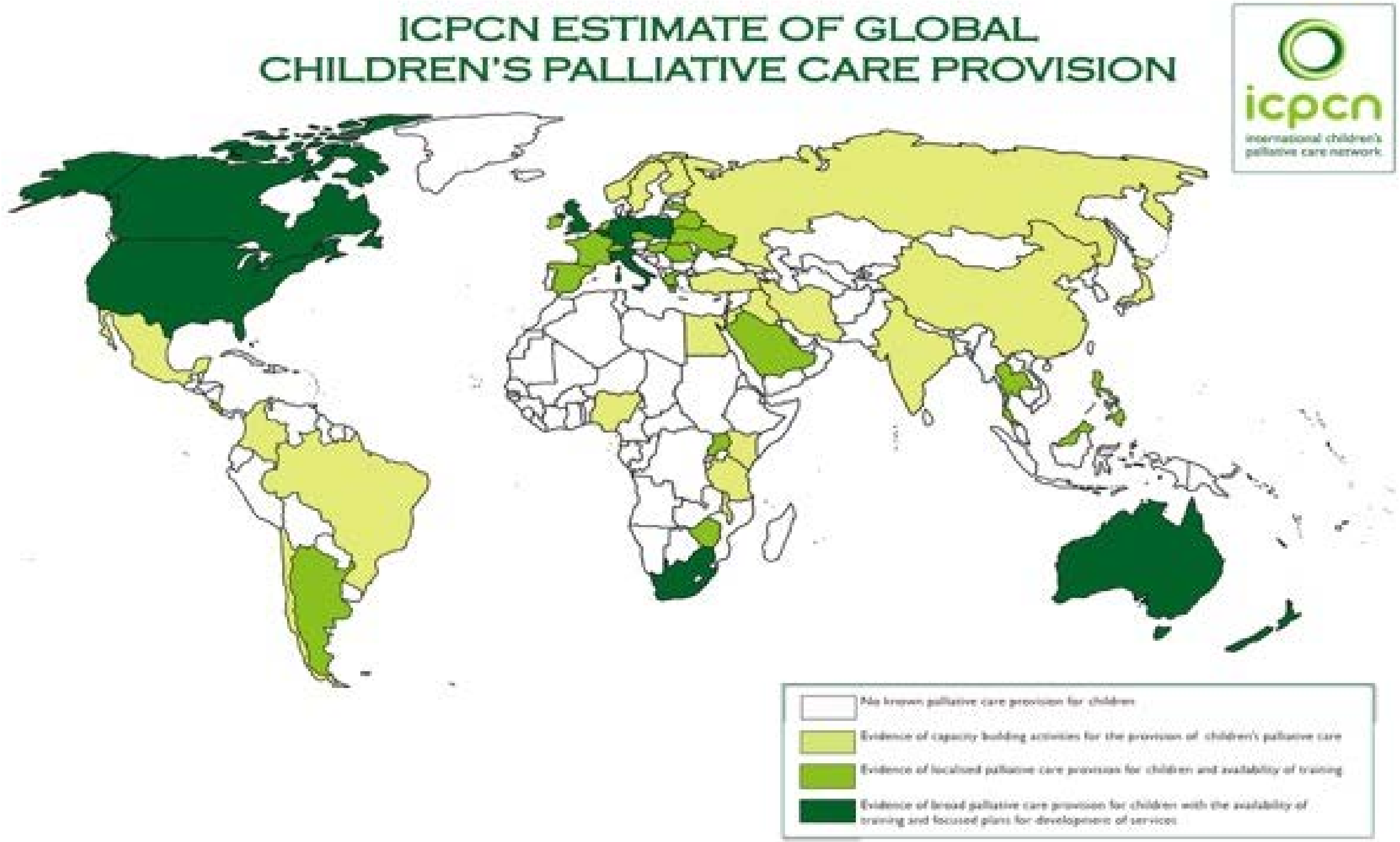
Global Status of CPC - 2011



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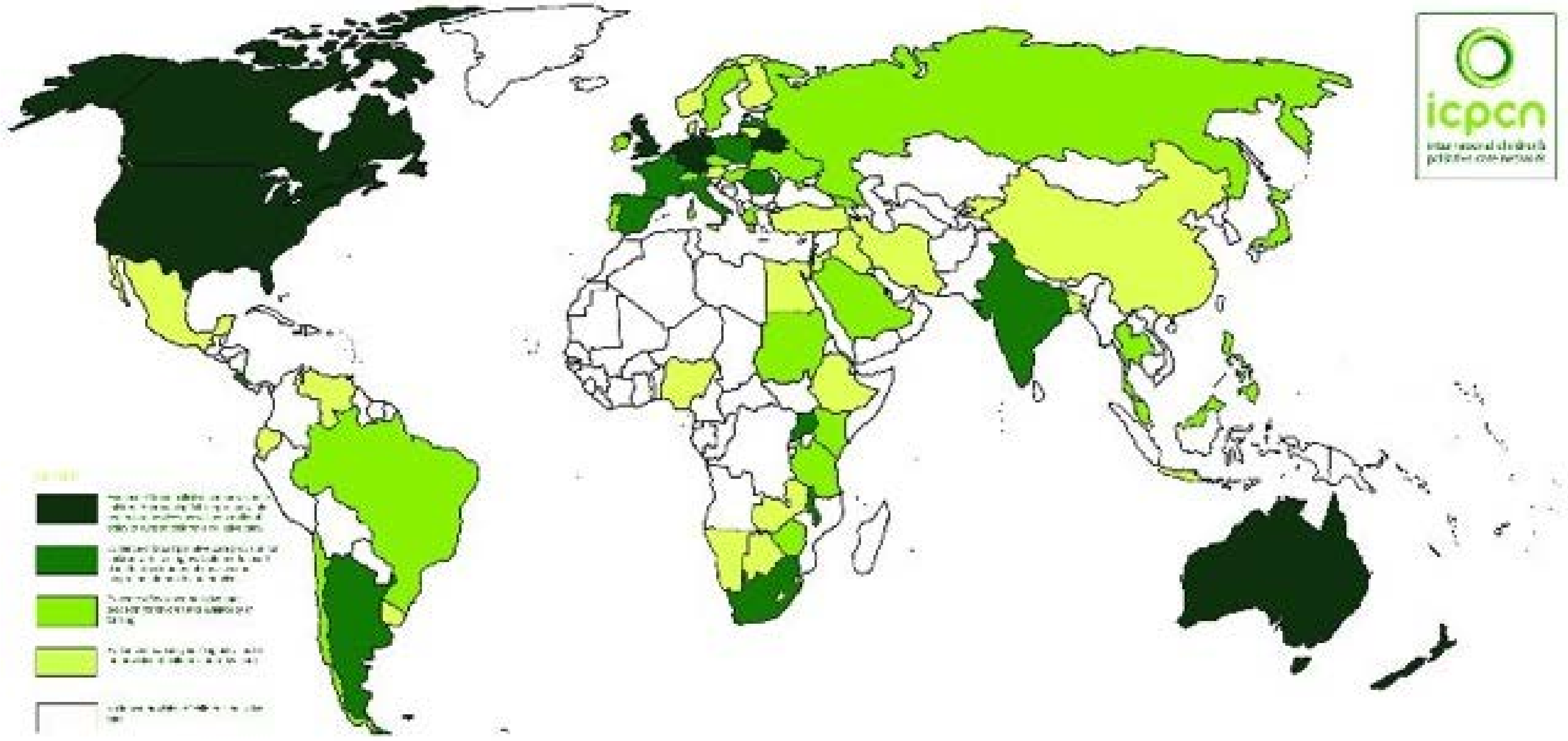
Global Status of CPC - 2018

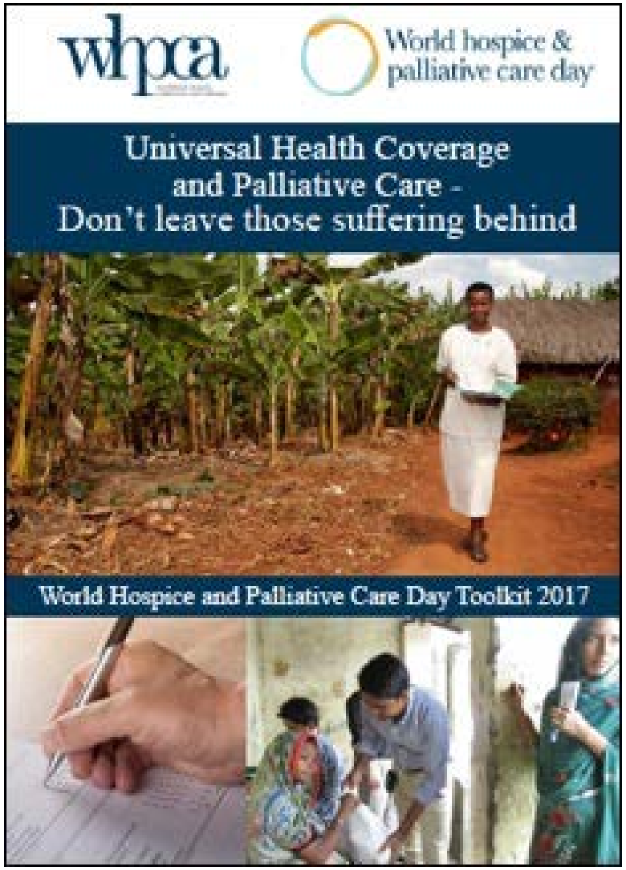


Global Health Priorities – PC and SDGs

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

Global Health Priorities: PC and UHC

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


whpca

World hospice & palliative care day

Universal Health Coverage and Palliative Care - Don't leave those suffering behind

World Hospice and Palliative Care Day Toolkit 2017

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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Direct Stakeholder Voice

- Ensure children are included at every stage of advocacy and development
- Involvement of children and parents is essential
- Stakeholder voice e.g. Palliative Care Voices (Lucy Watts)
- Utilising different media e.g.:
  - *Social media such as twitter*
  - *Blogs/ ehospice*
  - *Face-to-face/ skype*

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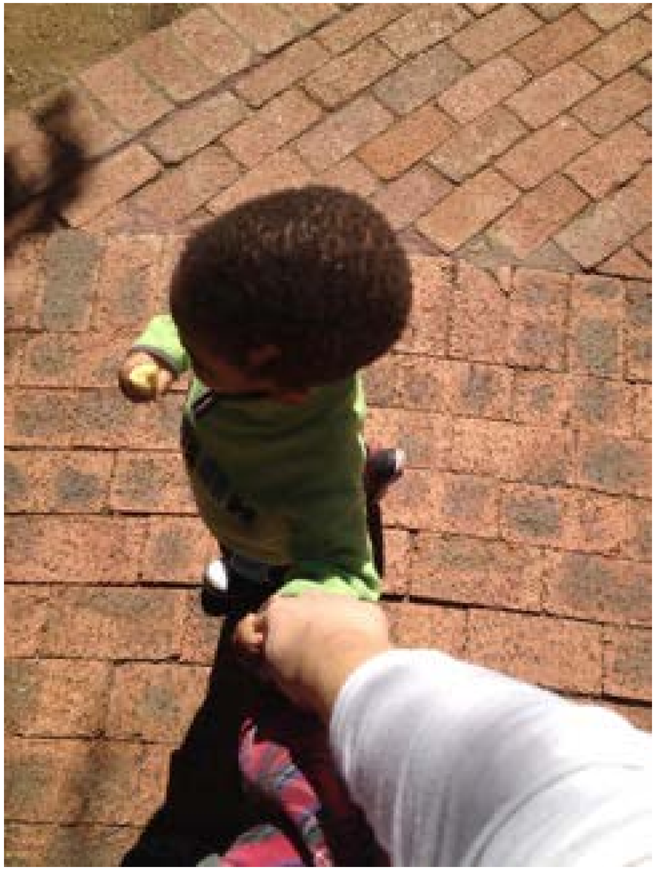
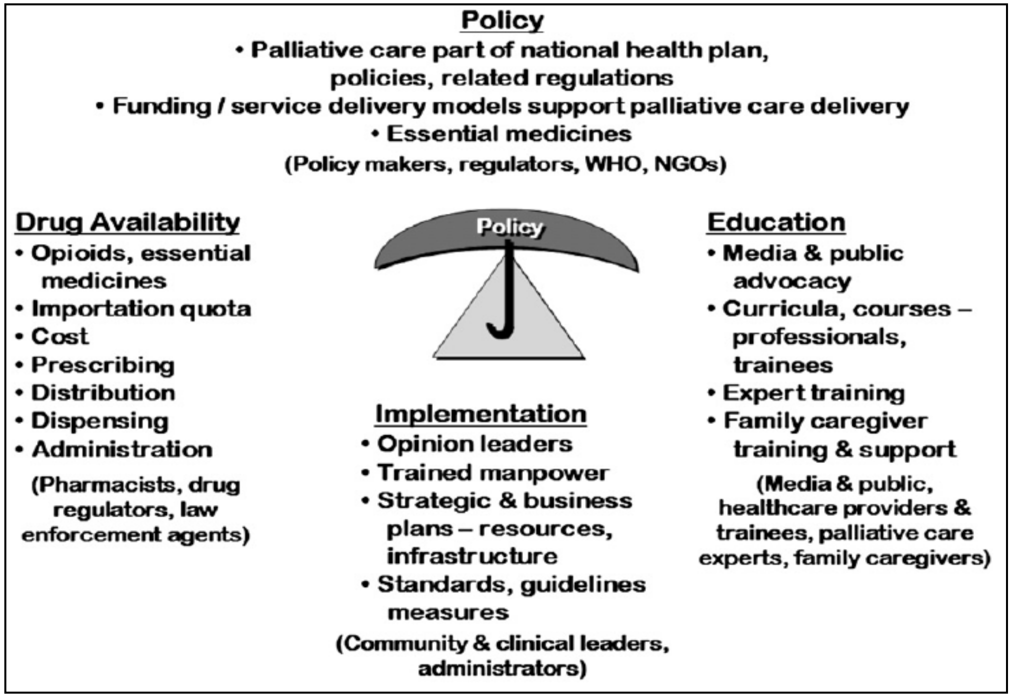
In some countries ……



- 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**



Policy
- Palliative care part of national health plan, policies, related regulations
- Funding / service delivery models support palliative care delivery
- Essential medicines

(Policy makers, regulators, WHO, NGOs)

Drug Availability
- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration

(Pharmacists, drug regulators, law enforcement agents)

Education
- Media & public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Family caregiver training & support

(Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

Implementation
- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures

(Community & clinical leaders, administrators)

(Stjernsward 2006)

(Harding et al 2013)

1. Policy

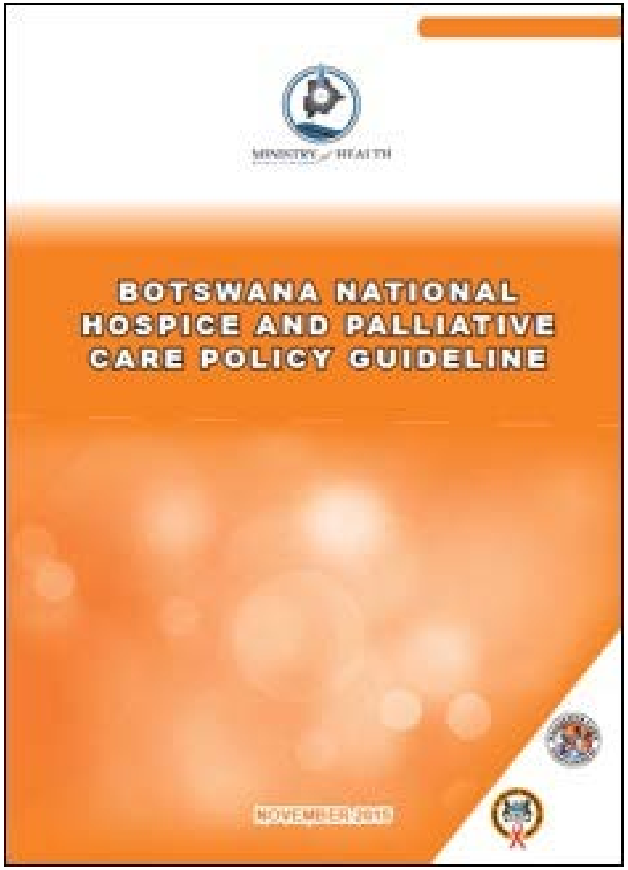
- Needed at all levels
- PC policy and integrated into others – must included CPC
- Need data to inform policy
- Need evidence-based measures for governments to measure progress
- Bottom up and top down approaches together

- *"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)

Examples of Policies

- PC Policies in a variety of countries e.g. Uganda, Swaziland, Botswana etc.
- Variety policies in UK e.g.:
  - *DoH: Strategic Development of Children's Palliative Care Networks for Better Health and Care Outcomes through Improved Commissioning.*
  - *Joint commission of palliative care services for children and YP*



MINISTRY of HEALTH

BOTSWANA NATIONAL HOSPICE AND PALLIATIVE CARE POLICY GUIDELINE

NOVEMBER 2015

2. Access to Medicines

- National, Regional and International co-operation
- Developing networks, relationships and key messages
- Looking at the whole supply chain
- Nurse Prescribing??

The Access Abyss

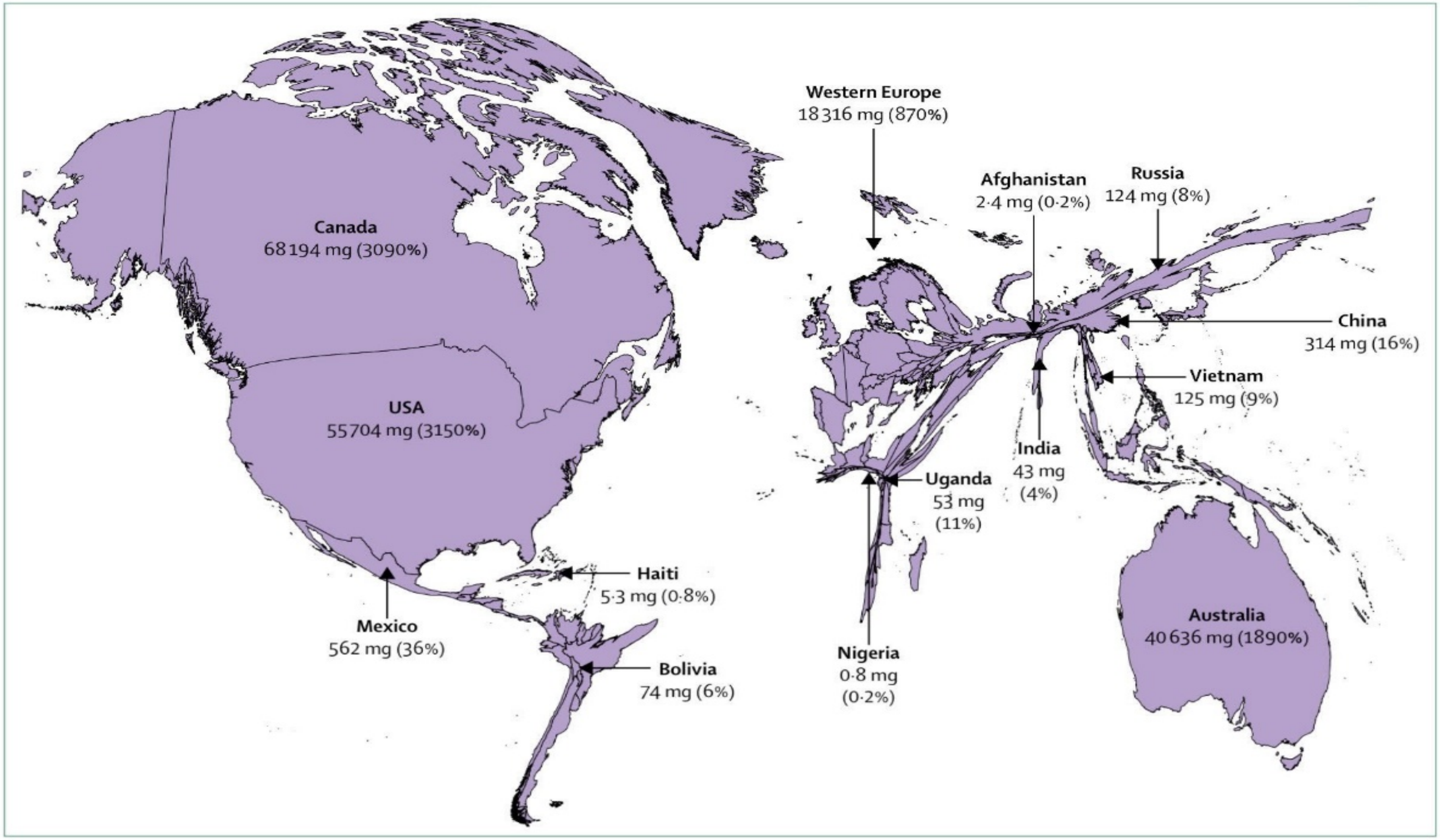


Figure 1: Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering
Source: International Narcotics Control Board and WHO Global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

(Knaull et al 2017)

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Lancet Commission

- *"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."*

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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Dashboard ❯ My courses ❯ Intro to PC

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.

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- 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

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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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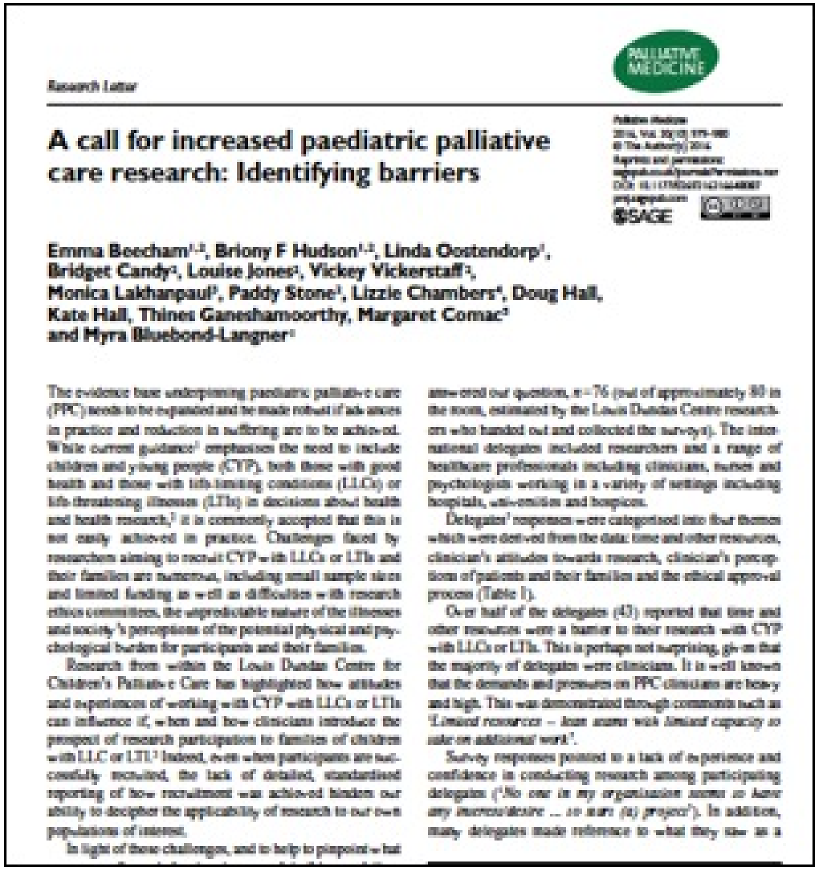
Challenges to Implementation

- Lack of financial resources
- High Disease Burden: (Ebola crisis)
- Lack of other resources
  - People who allocate resources are not sensitised to the PC concept
  - Failure to collaborate
  - Medical supplies
  - Not knowing (what you have from year to year)
- Palliative care not a priority
  - Competes with other needed health services
  - Poor integration with the formal health services
- Staffing
  - Education
  - Changes in leadership
  - Difficult to compete with private sectors

(Downing et al 2017)

5. Research
Call for more Research on CPC

- 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

SAGE

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

Now………

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

MEDECINS SANS FRONTIERES

PAEDIATRIC DAYS • DAKAR 2017 •

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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

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Thank You!

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