Global Palliative Care - working towards sustainability: Achievements and Challenges

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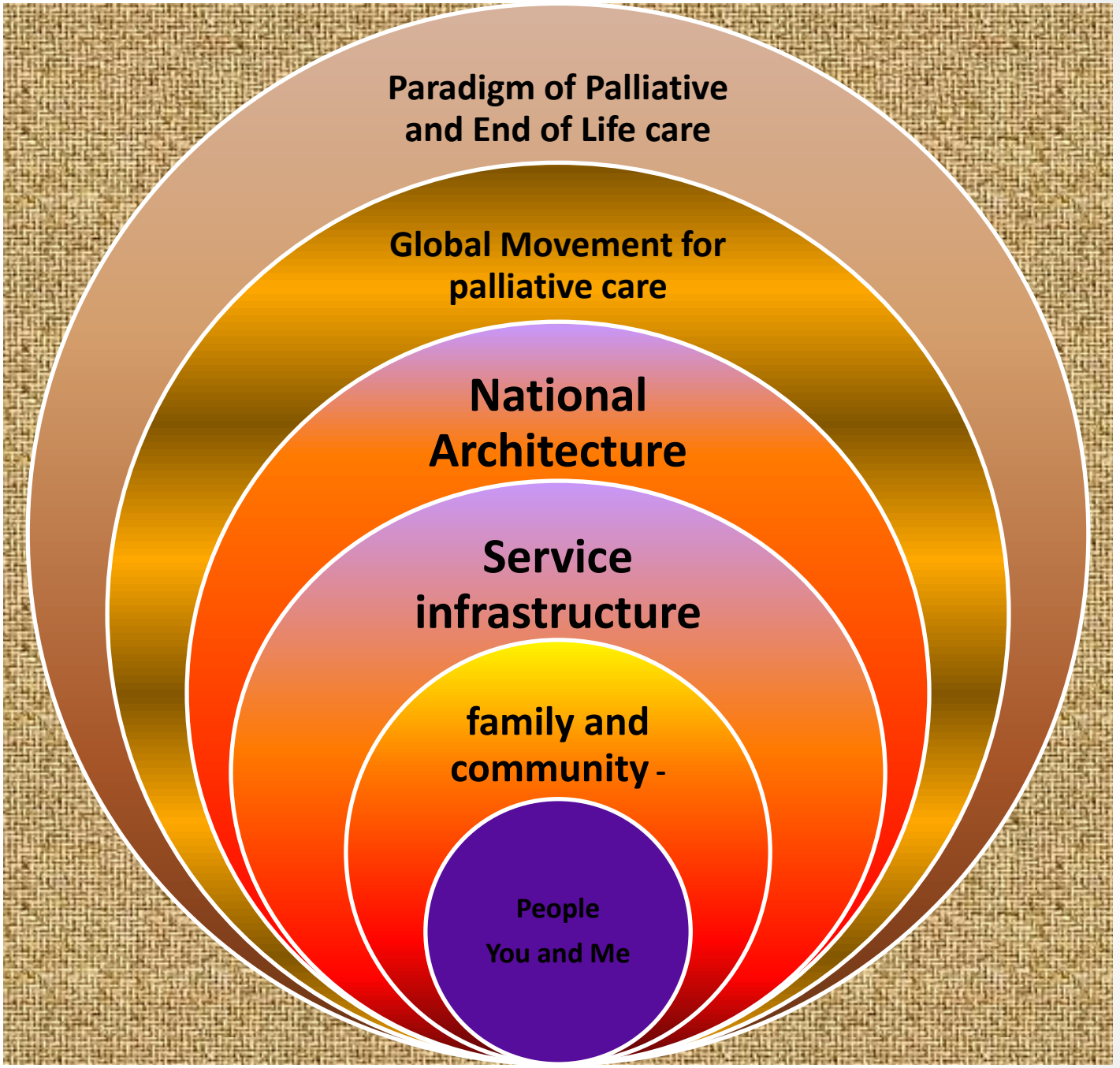
26th September 2015


Paradigm of Palliative and End of Life care
Global Movement for palliative care
National Architecture
Service infrastructure
family and community -
People
You and Me

Palliative care…..

- Never before, has there been such a global recognition for the need for palliative care and commitment to providing it.
- In the UK there has been both negative and positive media focus on palliative care
- WHO Technical Advisory Group
- Lancet Commission on Palliative Care
- International organisations:
  - International Children's Palliative Care Network (ICPCN)
  - International Association of Hospice and Palliative Care (IAHPC)
  - Worldwide Hospice & Palliative Care Association (WHPCA)

World Health Assembly

- Resolution on PC passed at the 67th WHA in Geneva in May 2014
- ***Strengthening of PC as a component of integrated treatment throughout the life course***

The Resolution

World Health Organization

- Wide and all encompassing
- Sets out definition of PC and the need
- Recognises PC is fundamental in improving QoL and is a human right
- Affirms the need for access to essential medications, including opioids
- Acknowledges PC is an ethical responsibility for health systems and providers
- Recognises need for PC across age groups, disease groups, models etc
- Welcomes the inclusion of PC in the definition of universal health coverage and the need for integrated PC.

- It urges member states 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 2014 p3)

Moving forward….

- Member states are urged to '*implement the resolution*' and to 'tear down barriers to PC and end unnecessary suffering' (WPCA 2014)

- In order to achieve this ***it must*** be sustainable

So what do we mean by sustainability?

- ***Sustain*** can mean "*maintain*", "*support*" or "*endure*"
- ***Sustainability*** – the ability to be sustained, supported, upheld or confirmed

- ***Sustainability*** is defined as a requirement of our generation to manage the resource base such that the average quality of life that we ensure ourselves can potentially be shared by all future generations. ... Development is sustainable if it involves a non-decreasing average quality of life.

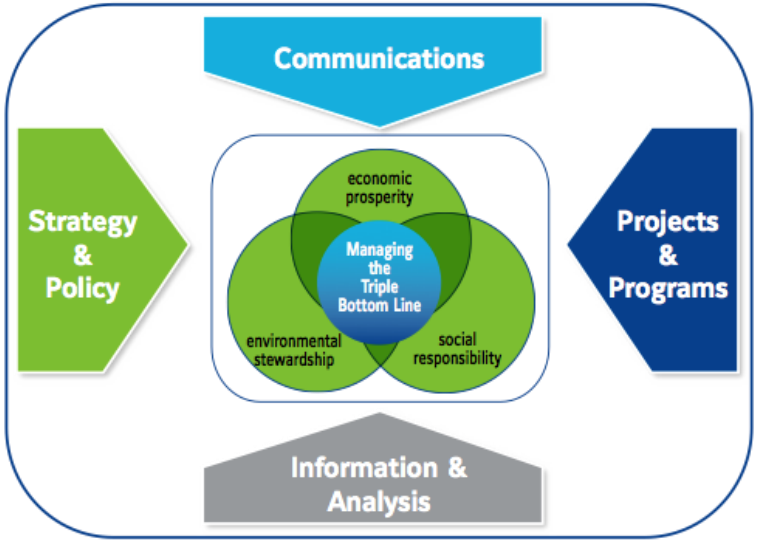
[Geir B. Asheim, "Sustainability," The World Bank, 1994]

Sustainability in healthcare?

- Sustainability could be defined as an ability or capacity of something to be maintained or to sustain itself. …… If an activity is said to be sustainable, it should be able to continue forever. *(Landlearn NSW)*

- Emerging approaches to health, care and wellbeing need to be increasingly environmentally sustainable, financially sustainable and also make far smarter use of our … social and human capital…. It also needs to help build resilience into people, families and communities….. Thus depending on supporting effective networks within communities, locally and globally, that enable the health system to provide support and services *with* people rather than just *to* people. (NHS Sustainability strategy 2014)

Building a sustainability solution



Four key steps:

1. Set strategy and policy
2. Build information and analytical platform to measure and monitor programmes
3. Develop programmes and projects to accomplish the strategy
4. Develop communications to engage with stakeholders

(Smith 2010)

So what does that mean for us when increasing global access to palliative care?

The need e.g. Cancer deaths

- 8 million people died from Cancer in 2010, 38% more than 20 years ago
- 15.1% of all deaths due to cancer

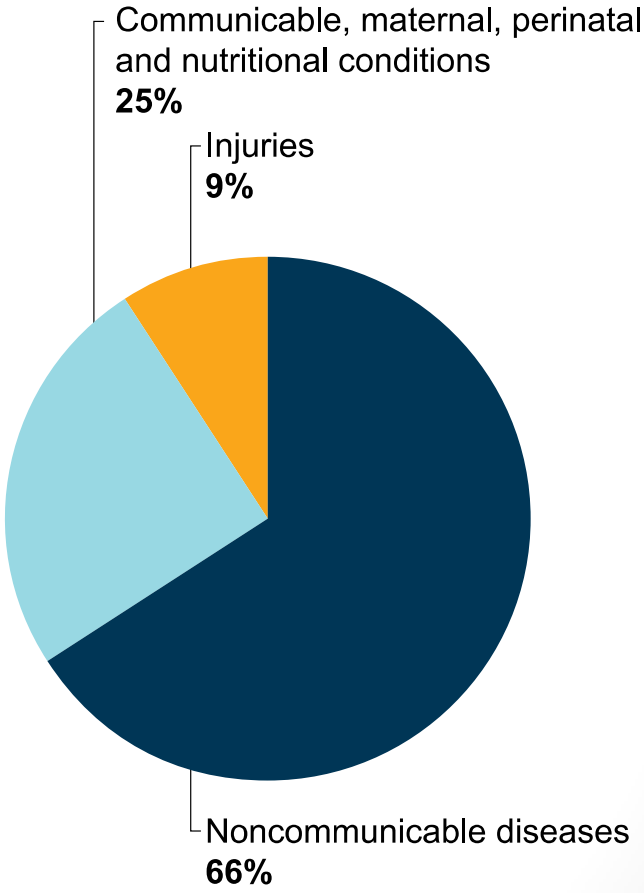
(Lozano et al 2012)

In sub-Saharan Africa

- Rates expected to grow by 400% over 50 years
- By 2020 70% of new cancer cases will be in the developing world
- Late presentation (80% advanced & incurable)
- Inadequate diagnostic and treatment facilities
  - E.g. radiotherapy

Those needing palliative care at end-of-life

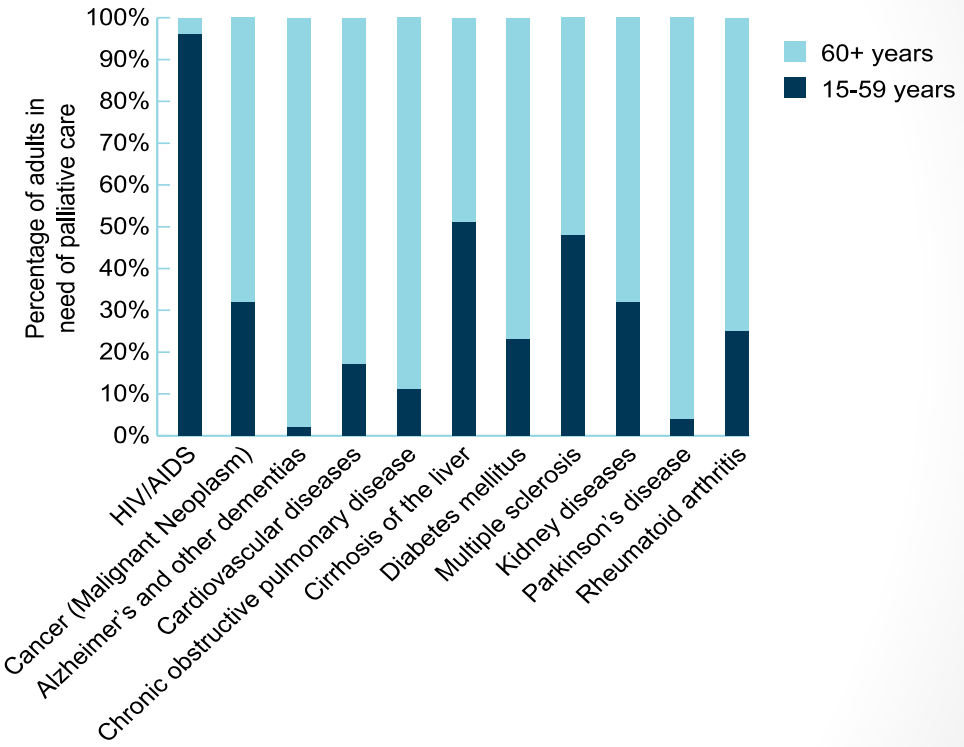
- 54.6 million deaths in 2011
- 66% due to NCDs
- >29 million died from diseases requiring PC
  - 94% adults (69% >60 years old)
  - 6% children



(Global Atlas of PC at the End-of-Life - Connor and Sepulveda Bermedo 2014)

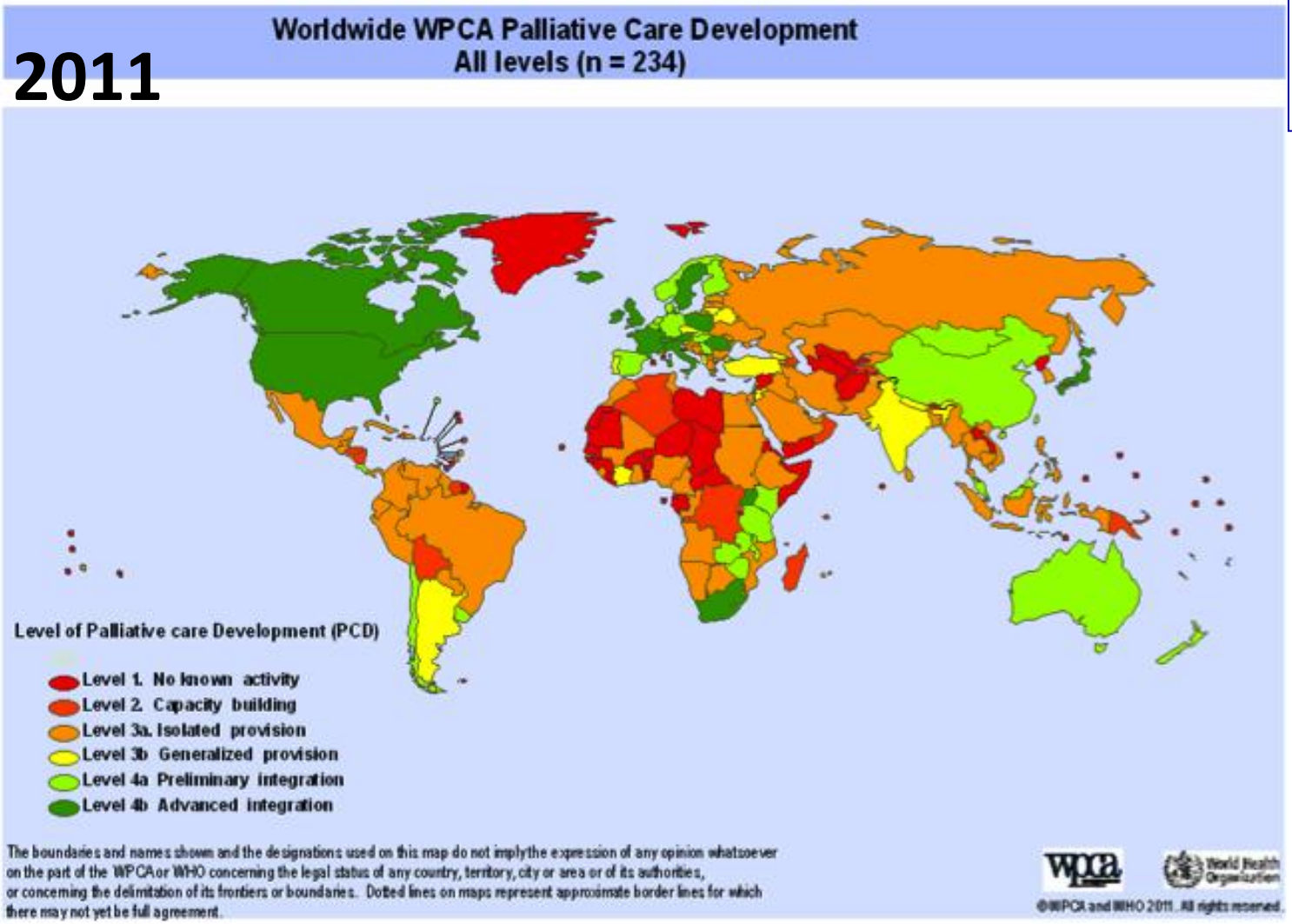
Therefore….

- 377 adults per 100,000 >15 years
- 63 children per 100,000 <15 years need PC at the end-of-life



(Global Atlas of PC at the End-of-Life - Connor and Sepulveda Bermedo 2014)

What we know….

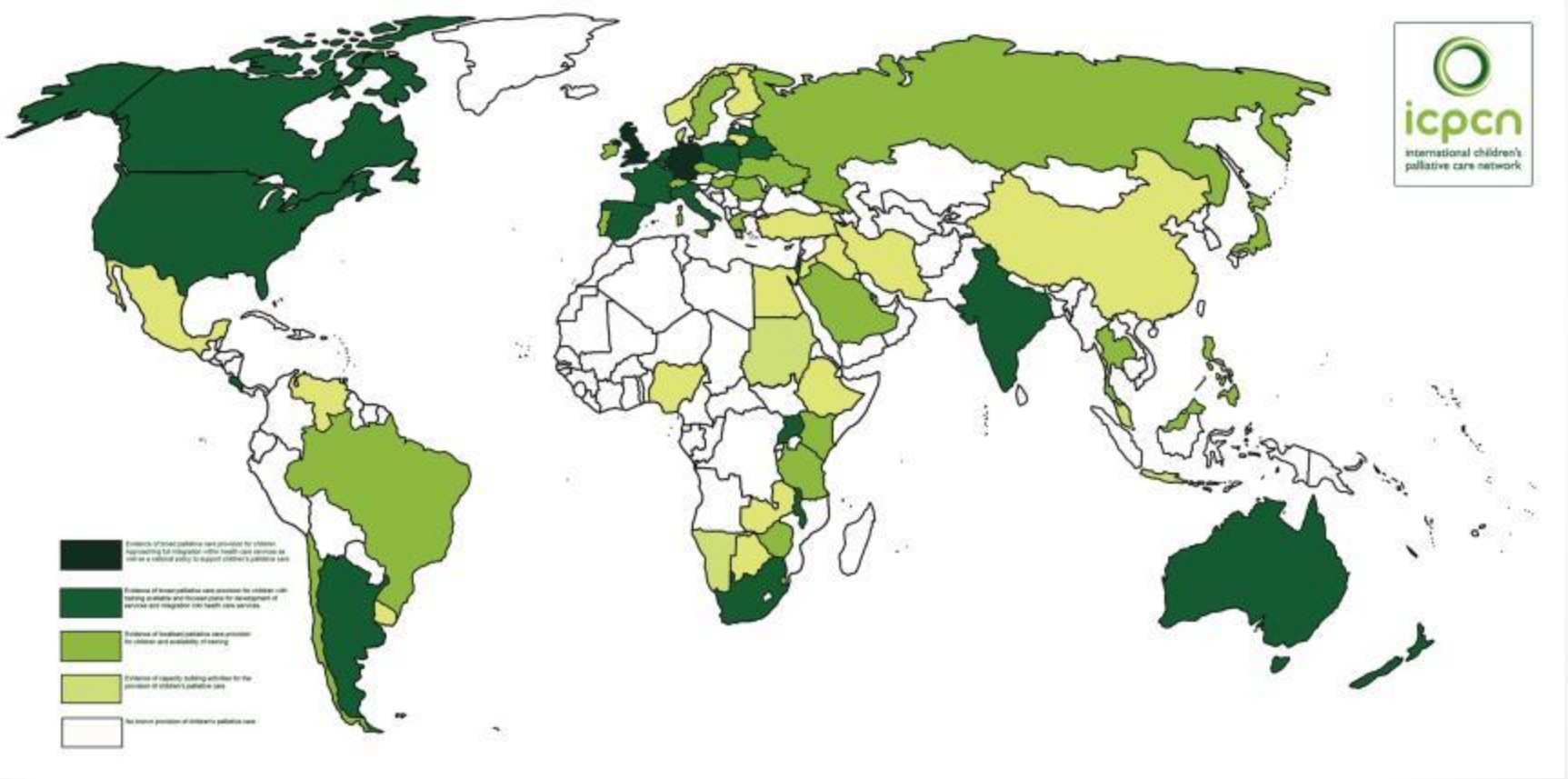


(Mapping levels of PC development: a global update. WPCA 2011)

Children's PC: A Systematic Review

(Knapp et al 2011)

Children 2014



So what???

Limitations

- End-of-life vs need
- Does not show the actual situation
- May have good PC for adults but not children and this is not reflected

However…..

- Shows great need
- Shows us great gaps

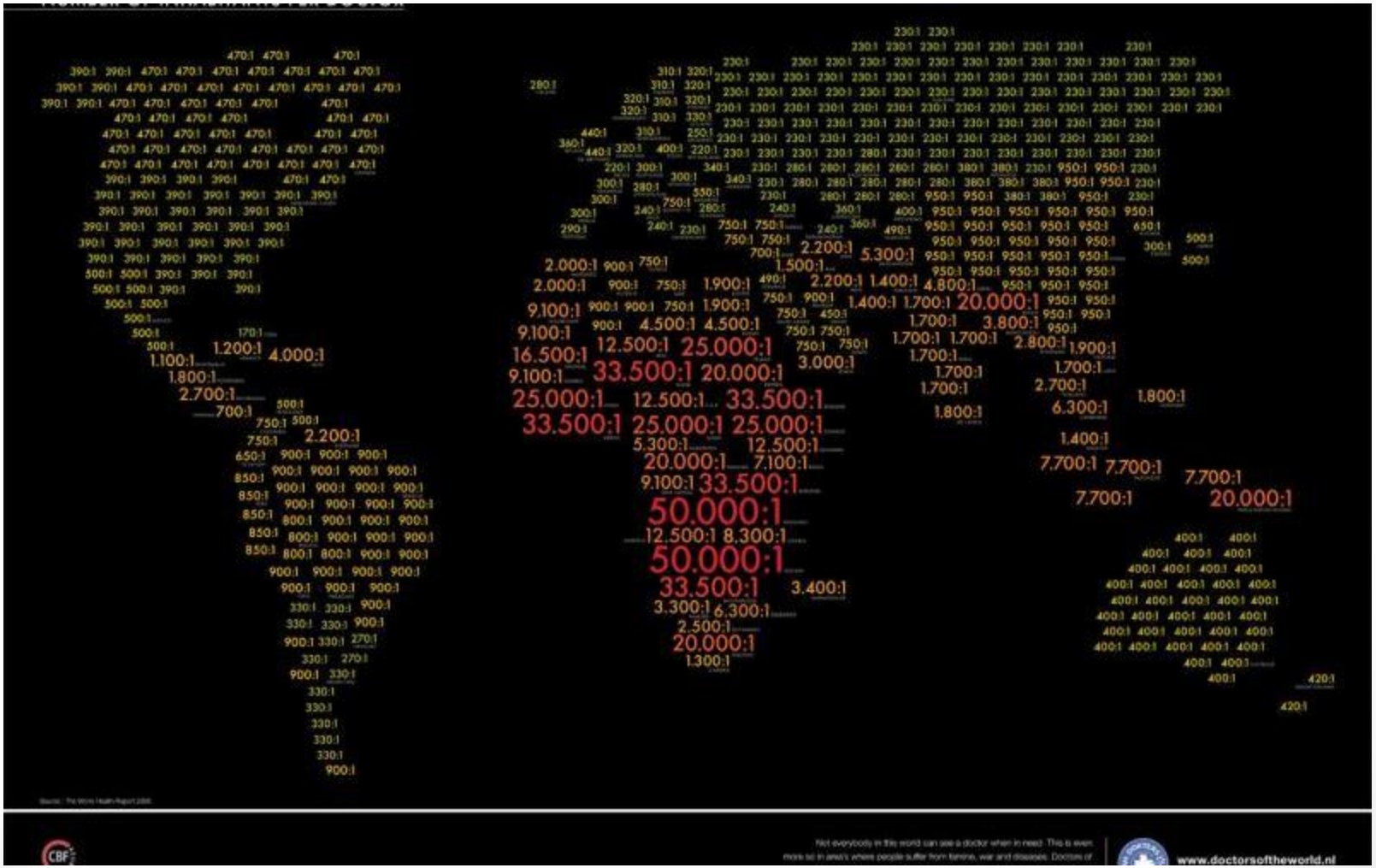
- Therefore we need to *work towards sustainability* as we develop palliative care provision

Principles to '*Developing services and working towards sustainability*'

My belief.....

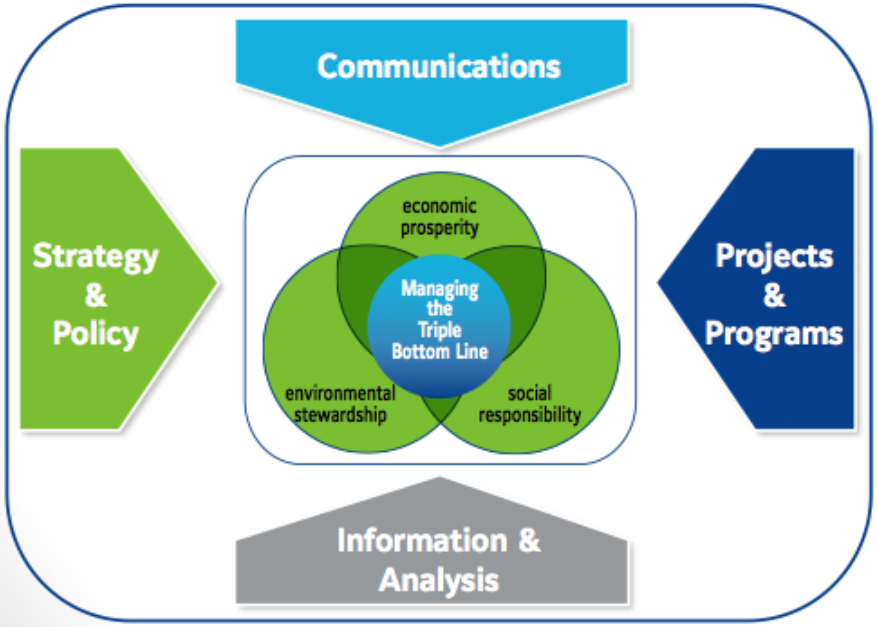
Nurses and PC in Africa……

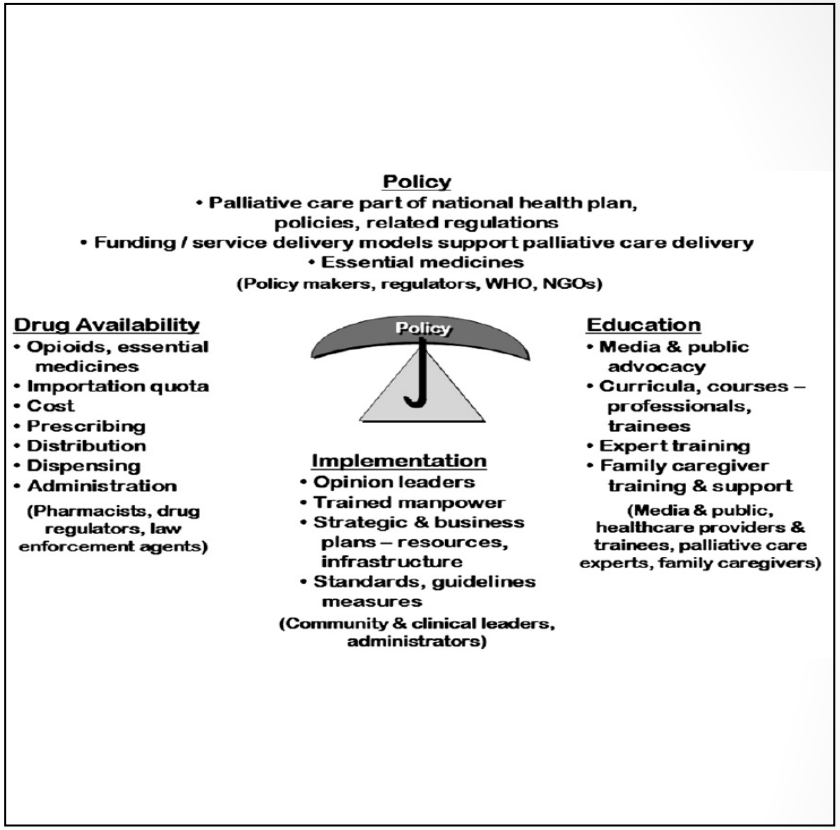
Number of inhabitants per Doctor.....



(Doctors of the World, September 2007)

Public health model for palliative care





+ Research

(Stjernsward et al 2007, Harding et al 2013)

So how do we increase global access to palliative care whilst working towards sustainability?

(Achievements - Examples)

Advocacy – How many children need PC??

- UNICEF and ICPCN Study
- Need numbers for advocacy purposes
- No accurate figures

unicef
unite for children

icpcn
international children's palliative care network

The study….

Estimates of children reached

- 1,257 Children Reached
  Need: 120.05 per 10,000 children

< 1%

- 5,438 Children Reached
  Need: 180.63 per 10,000 children

4.64%

- 14,501 Children Reached
  Need: 151.92 per 10,000 children

4.76%

unicef
unite for children

icpcn
international children's palliative care network

Initial results of the global study…

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

- Range – 21 - >100 per 10,000 children
- Therefore providing evidence that we need sustainable models of PC service provision in order to meet the need

Uganda - Policy

- A lot has happened in Uganda
- Now getting a policy
- Once the policy is in place, other issues that enhance sustainability will be put in place e.g.:
  - PC positions
  - Budget and workplan
  - National indicators
  - Standards etc.

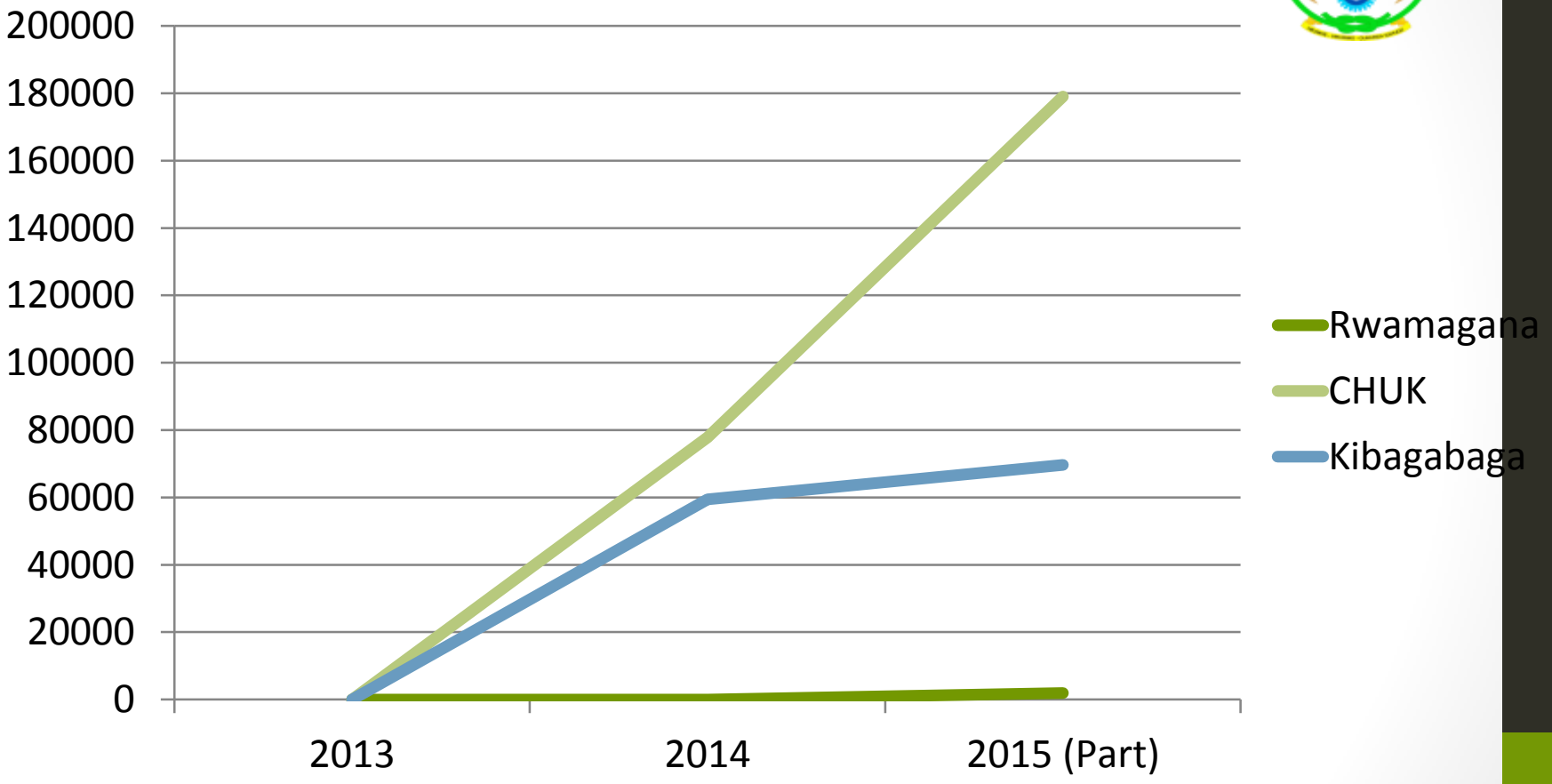
Access to medications including opioids

- Patchy – poor in many countries especially developing countries (Global State of Pain Treatment Access to medicines and palliative care. HRW 2011)
- Much advocacy being done

Collaboration…..

- Essential
- Key component of sustainability
- Range of national, regional and international organisations:
  - IAHPC, WHPCA, WHO TAG, APCA, EAPC, APHC etc etc.

Access to medication



PARTNERSHIPS FOR GLOBAL HEALTH

THE UNIVERSITY of EDINBURGH
Global Health Academy

MAKERERE PALLIATIVE CARE UNIT

African Palliative Care Association
APCA
Relieving Pain and Suffering

Access to medication

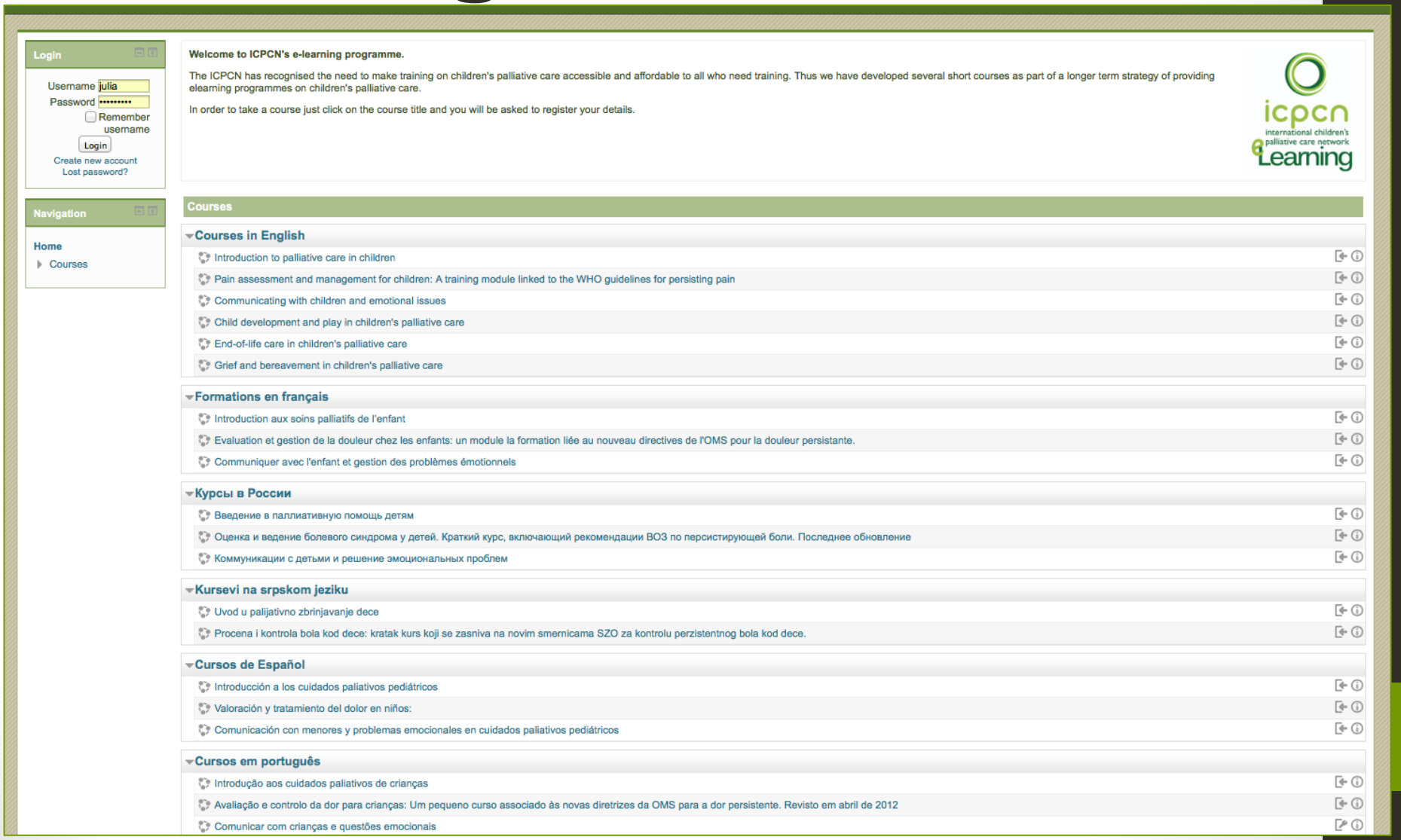
- *"We now have access to oral morphine – our patients are no longer in pain – the wards are quiet"* (Nurse)

- *"Oral morphine is now being provided through the MoH system – before, when we had to rely on donations, supply was sporadic, now we can receive it regularly and the system is sustainable as it is utilising normal government systems."* (Doctor)

Education

Adolescenti
• Vršnjaci igraju važnu ulogu u životu adolescenta
• Prihvatanje od strane vršnjaka direktno utiče na
samopouzdanje adolescenta. Oni imaju potrebu
da se uklope i budu deo grupe
• Kod teško bolesnog adoles
povećanje telesne mase
određenih lekova mož
ove pojave dodatn

Increasing access.....



In Serbia.....

Razvoj palijativnog zbrinjavanja u Srbiji
Projekat finansira Evropska unija

Oxford Policy Management

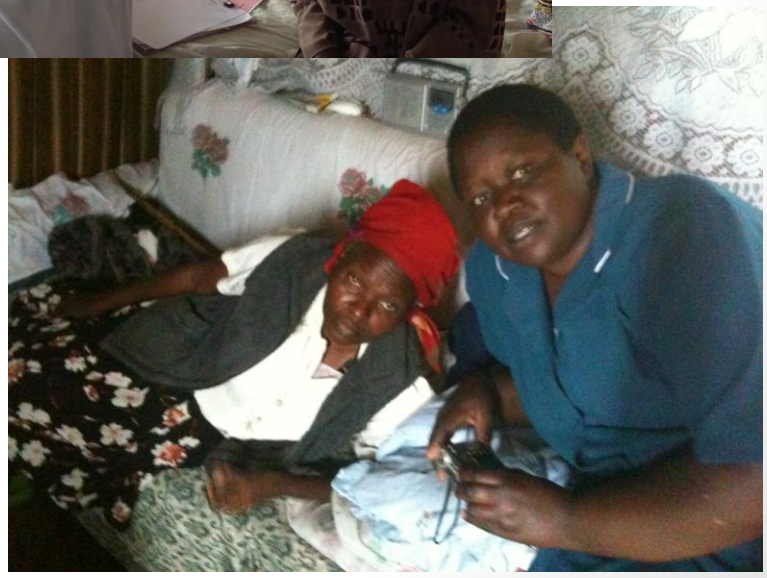
Mentorship & Supervision

- Essential
- Adds towards sustainability as skills are embedded in practice
- Often not part of regular training and the value of mentorship and modelling is not always appreciated

- *"Our leaders involved us, and the mentorship gave us inspiration"* (CHUK)

- *"the mentors showed us how to do it, it was through their experiences that we learnt"* (Kibagabaga)

Models of PC Delivery



Integrate Project

- Strengthening & integrating PC into national health systems
- Integrated into:
  - Systems
  - Policies
  - Practice
  - Communities

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MAKERERE PALLIATIVE CARE UNIT

African Palliative Care Association APCA Relieving Pain and Suffering

Link-nurse programme

- To improve palliative care provision within Mulago hospital
- Being extended to other hospitals in Uganda and surrounding countries

Patient care

- What it is all about!

- Palliative care and pain control is a human right:
  - *Whoever we are*
  - *Wherever we live*
  - *Whatever our race*
  - *However old we are*
  - *Regardless of our illness*

Challenges to increasing access to PC and working towards sustainability (1)

1. Socio-cultural
2. Governmental, legalistic and national context
3. Service provider
4. Service user level

- *Clarifying the definition of palliative care in accordance with the WHO definition is key (2002)*

Challenges (2)

- Meeting the complex needs of those needing palliative care
- Limited resources:
  - Lack of health and social professionals
  - Lack of funds
  - Lack of specific training
  - Lack of recognition of our role as nurses, social workers etc.
  - Lack of recognition of palliative care

Challenges (3)

- High burden of disease
- Need for different models of care
- Child headed households
- Conflict situations
- Fear of providing PC for children
- Ensuring PC is within policy

So why do we need to work towards sustainability?

Can we increase global access to palliative care and work towards sustainability?

If you want something in your life you've never had, you'll have to do something, you've never done.
~ JD Houston
www.Dailyinspirationalquotes.in

"We too must not just talk the talk, But, like her, we must walk the walk, And stay the course, and continue the task of changing the world."

(Robert Twycross speaking about Dame Cicely Saunders March 2006)