



# Palliative and Healthcare Environment: Global Community Based Palliative Care Development A progress report and way forward

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# Disclosure

- No conflicts of interest

# The need - a global perspective

- >1 million deaths/week
- >60 million need PC
  - 25.6M at EOL
- Families (at least 2-4 each)
- <10% of need for PC met, 14% @ EOL
- at least 18 million die in pain



# The need - a global perspective

A composite image where the continents of the world map are superimposed onto the features of a human face. The face has large, expressive green eyes, a straight nose, and full, slightly parted lips. The skin tone of the face is a deep blue, matching the background. The continents are rendered in various colors: North America in brown, South America in green, Europe and Africa in orange, and Asia in green. The overall effect is a global perspective on human health and medicine.

- 67% 60+ / 8.6% children
- 80% LMIC
- 93.5% NCD
- ~75% of countries no or limited delivery of PC
- only 8% of countries good integration
- 92% of morphine used by 17% of world population



# Content

- Global Need for PC – Lancet Commission & WHO
  - Serious Health Related Suffering
- Global Development of PC
- Advocacy for PC
- Community Based Palliative Care
  - Creative & Innovative Models
- Challenges and Vision for the Future of PC



# Global Need for Palliative Care

## Global Atlas of Palliative Care at the End of Life



## Global Atlas of Palliative Care at the End of Life



January 2014

## Lancet Commission Report on Palliative Care & Pain Relief

The Lancet Commissions

Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage: the *Lancet* Commission report

*Felicia Marie Knauth, Paul E Farmer\*, Eric L Krakauer\*, Liliana De Lima, Afshan Bhadelia, Xiaoxiao Jiang Kwete, Héctor Arreola-Ornelas, Octavio Gómez-Dantés, Natalia M Rodríguez, George A O Alleyne, Stephen R Connor, David J Hunter, Diederik Lohman, Lukas Radbruch, María del Rocío Sáenz Madrigal, Rifat Atun†, Kathleen M Foley†, Julio Frenk†, Dean T Jamison†, M R Rajagopal†, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group†*



# Global Need for Palliative Care

## **Global Atlas**

- 20.4 million at EOL
- 40 million total need
  - 1M children
- 18 major Dz groups
- Pain as surrogate for PC

<http://www.who.int/cancer/publications/palliative-care-atlas/en/>

## **Lancet Commission Report**

- 25.6 million at EOL
- 61.1 million total need
  - 5.3M children
- 20 major Dz group
  - Inclusion of Injury
- Suffering as surrogate
  - 15 types

[www.thelancet.com/commissions/palliative-care](http://www.thelancet.com/commissions/palliative-care)

# Need for PC in China (Lancet)

**Decedents (10,139,831)**

- 5,501,000













**Non-Decedents**




- 4,978,000

Hong Kong 22<sup>nd</sup> out of 80 on  
the 2015 EIU Quality of  
Death Index (China 71<sup>st</sup>)



# Serious Health-Related Suffering

		Categories of serious health-related suffering			
		Physical	Psychological	Social	Spiritual
Health conditions or stage of disease	End of life				
	Chronic or acute life-threatening or life-limiting disease, ill health, and injury				
	Not associated with a life-threatening or life-limiting health condition				

 Palliative care health-related interventions; described in this Report  
 Palliative care interventions primarily outside of health care; not covered in depth in this Report  
 Health conditions that generate serious health-related suffering mitigated by other health and social interventions, and preferably not managed by palliative care, yet often are in impoverished settings; not covered in this Report

**Figure 3: Serious health-related suffering, palliative care, and scope of this Report**

# Serious Health Related Suffering (SHS) – Lancet Commission Report

## **Number of deaths/patients**

1. Mortality associated with SHS (decedent)
2. Patients in need of palliative care (total, decedent and non-decedent)

## **Number of suffering days**

1. Total number of days with any suffering (sum of duration in days of each symptom) = **upper bound**
2. Number of days with symptom of longest duration (duration in days of longest lasting symptom as an “at least” estimate) = **lower bound**

# Categories & Types: Patients' Suffering

- **Physical (11 symptoms)**

- Bleeding, constipation, diarrhea, dry mouth (xerostomia), shortness of breath (dyspnea), fatigue, nausea and/or vomiting, pain (mild vs. moderate or severe), itching (pruritus), weakness, wounds

- **Psychological (4 symptoms)**

- Anxiety/worry, depressed mood, confusion/delirium, dementia



# Magnitude of the Burden of SHS

- 25.6M of 56.2M deaths experienced SHS
- 35.5M experienced SHS before year of death
- In LMIC's 10 Dx = >90% of people dying with SHS
  - Cancer, cerebrovascular, lung, injury, TB, premature birth & trauma, HIV, liver, heart disease, & dementia
- 21.2B SHS days/year for all patients worldwide
  - Cancer almost 50% of SHS
  - HIV, CVD, & COPD = ~10%
  - Pain >20% of total SHS days
- Lower bound 6 billion SHS Days





# Lancet Commission

## Essential Package of PC Services

- Medicines – all those in the WHO model list
- Medical Equipment – pressure mattress, NG tubes, urinary catheters, lock box, flashlight, diapers, O2
- Human Resources – MD, RN, SW, Psych, PT, Pharm, CHW, Support staff (clinical & non-clinical)
- Basic Needs/Social Support



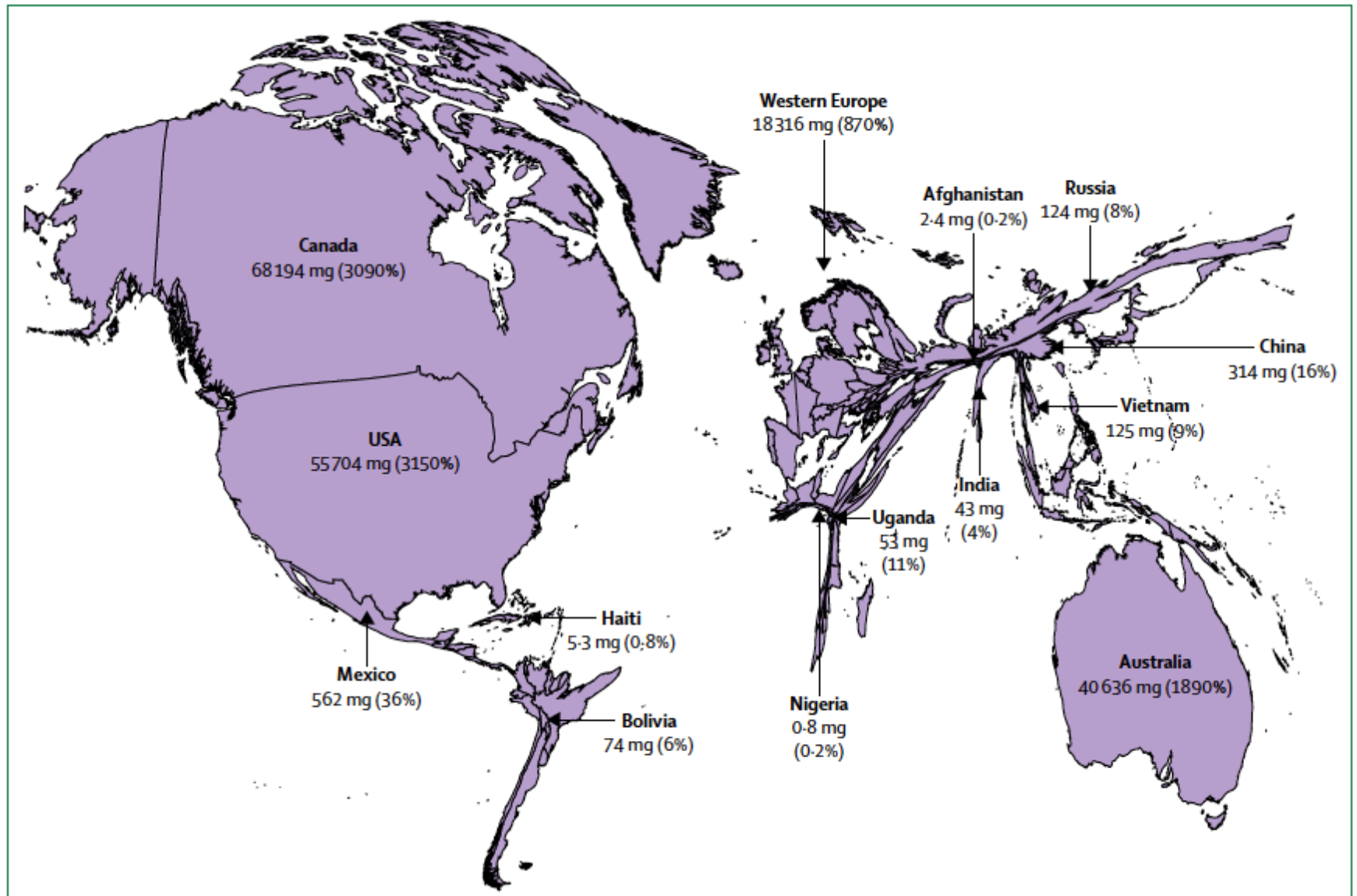
# Components of the Essential Package

Medicine
Amitriptyline
Bisacodyl (senna)
Dexamethasone
Dexamethasone
Diazepam
Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate)
Fluconazole
Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline and citalopram)
Furosamide
Haloperidol
Hyoscine butylbromide
Ibuprofen (naproxen, diclofenac, or meloxicam)
Lactulose (sorbitol or polyethylene glycol)
Loperamide
Metaclopramide
Metronidazole
Morphine (oral immediate-release and injectable)
Naloxone
Omeprazole
Ondansetron
Paracetamol
Petroleum jelly

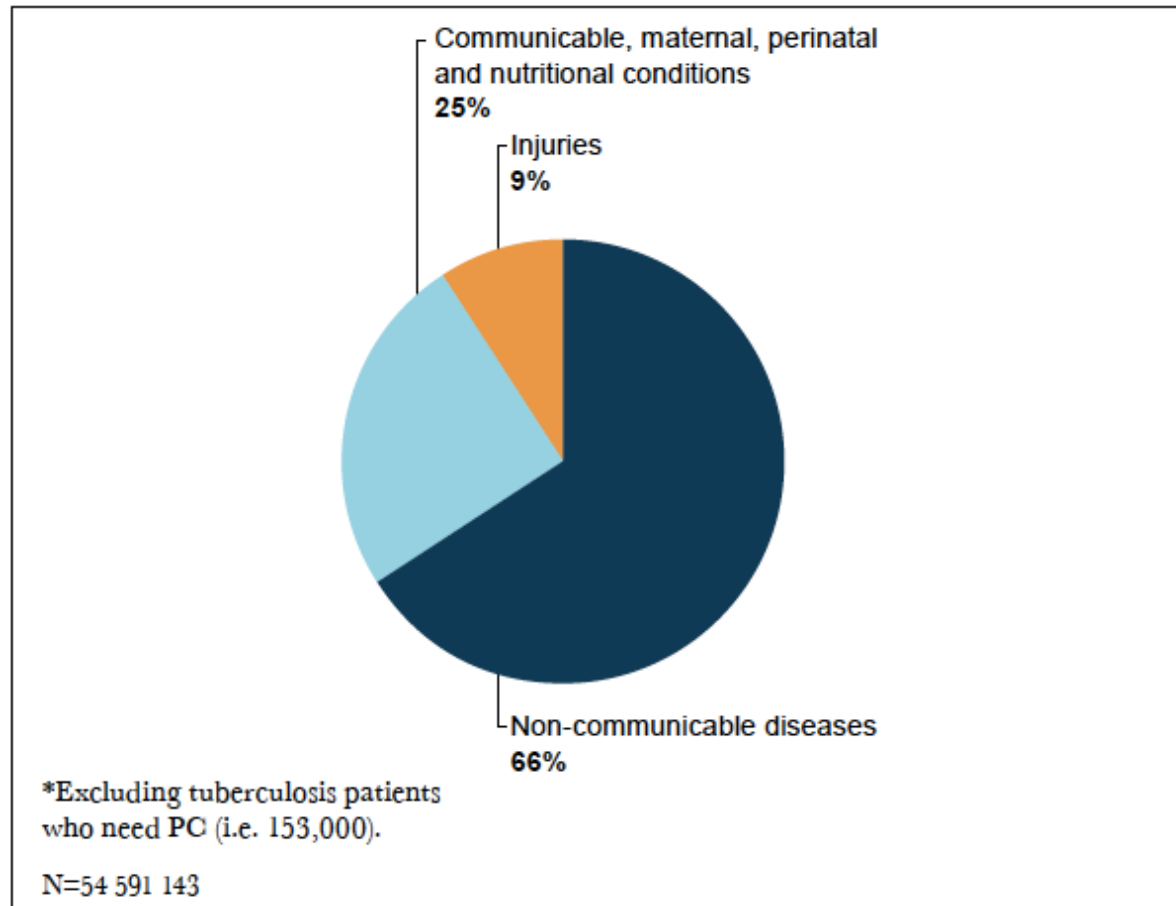
Equipment
Pressure-reducing air mattress
Nasogastric drainage or feeding tube
Urinary catheters
Opioid lock box
Flashlight with rechargeable battery (if no access to electricity)
Adult diapers (or cotton and plastic, if in extreme poverty)
Oxygen

Basic Needs/Social Support
Cash payment and housing
Food package
Funeral support
In-kind support
Transportation costs

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 (Lancet Commission Report 2017)



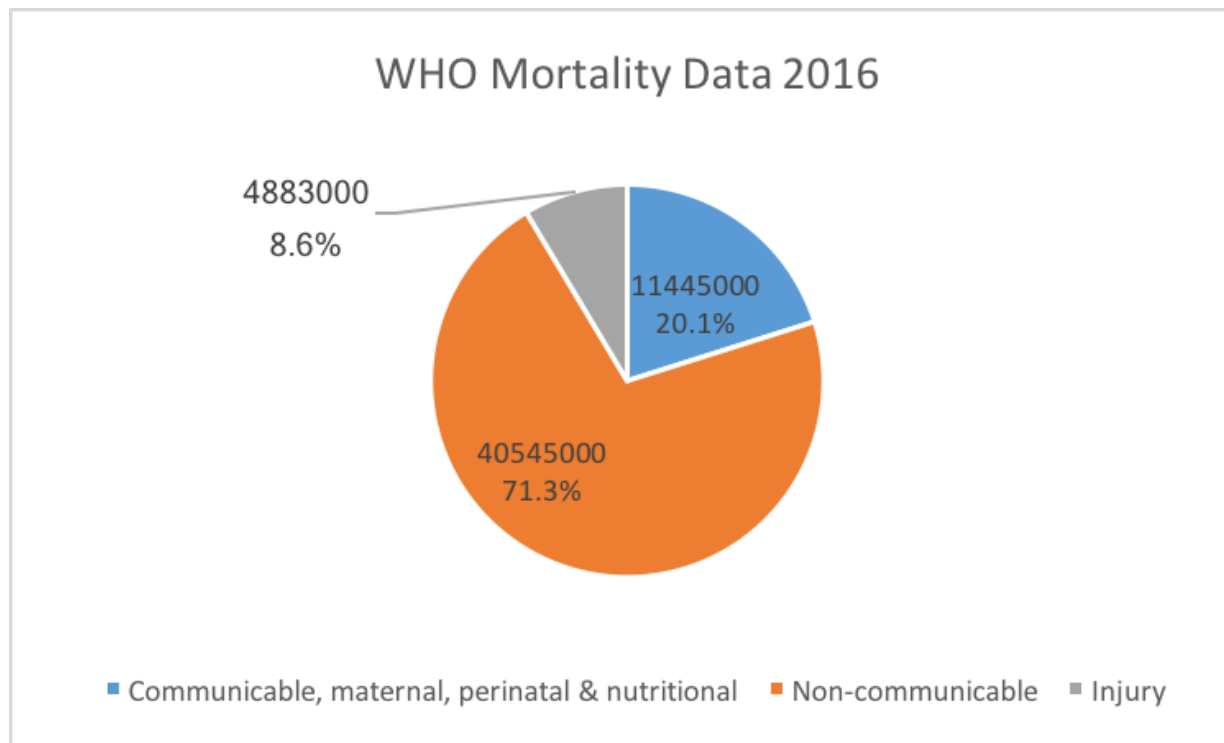
# Distribution of major causes of death worldwide (2011\*)



\*WHO Global Health Estimates Deaths by Age, Sex, & Cause



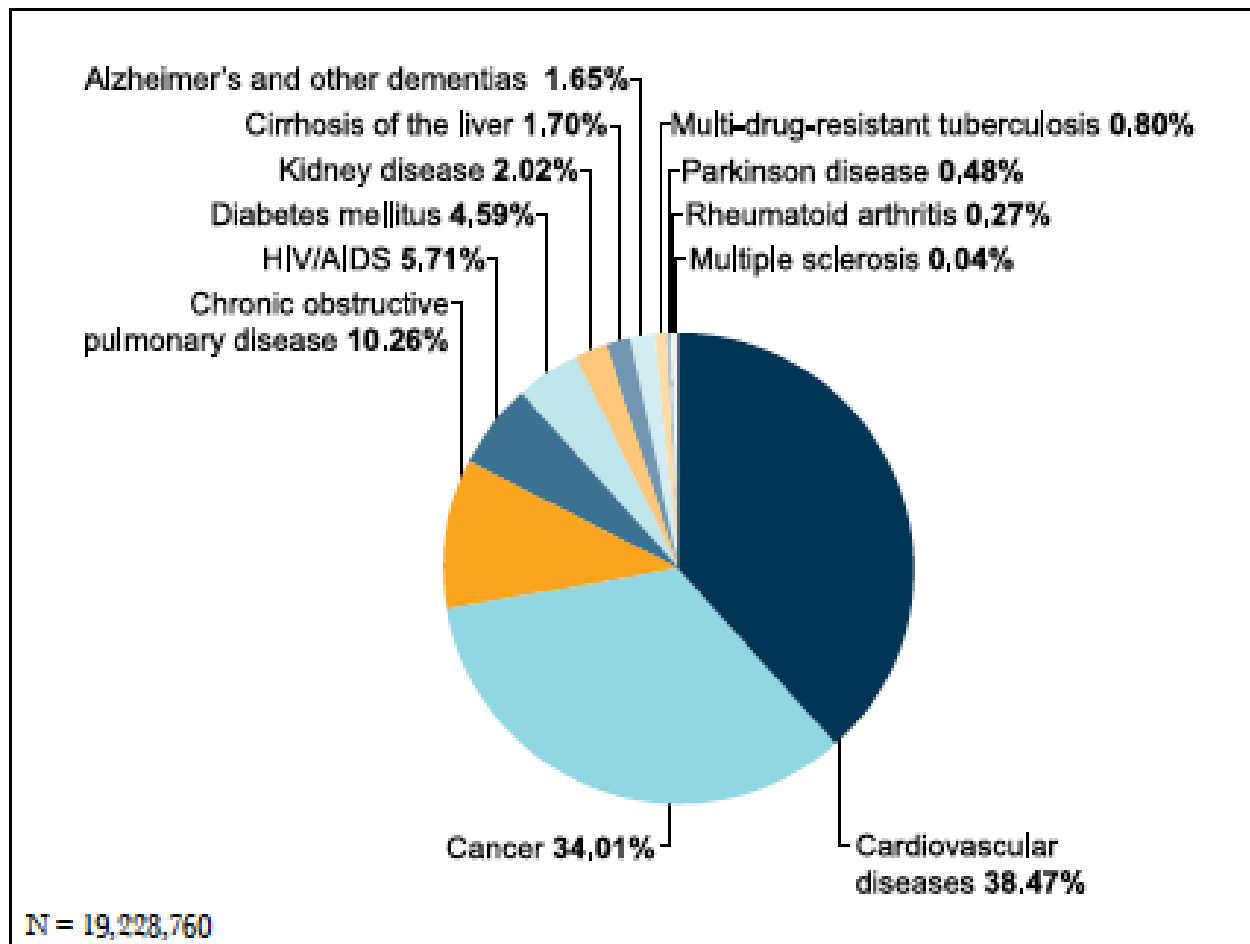
# Distribution of major causes of death worldwide (2016\*)



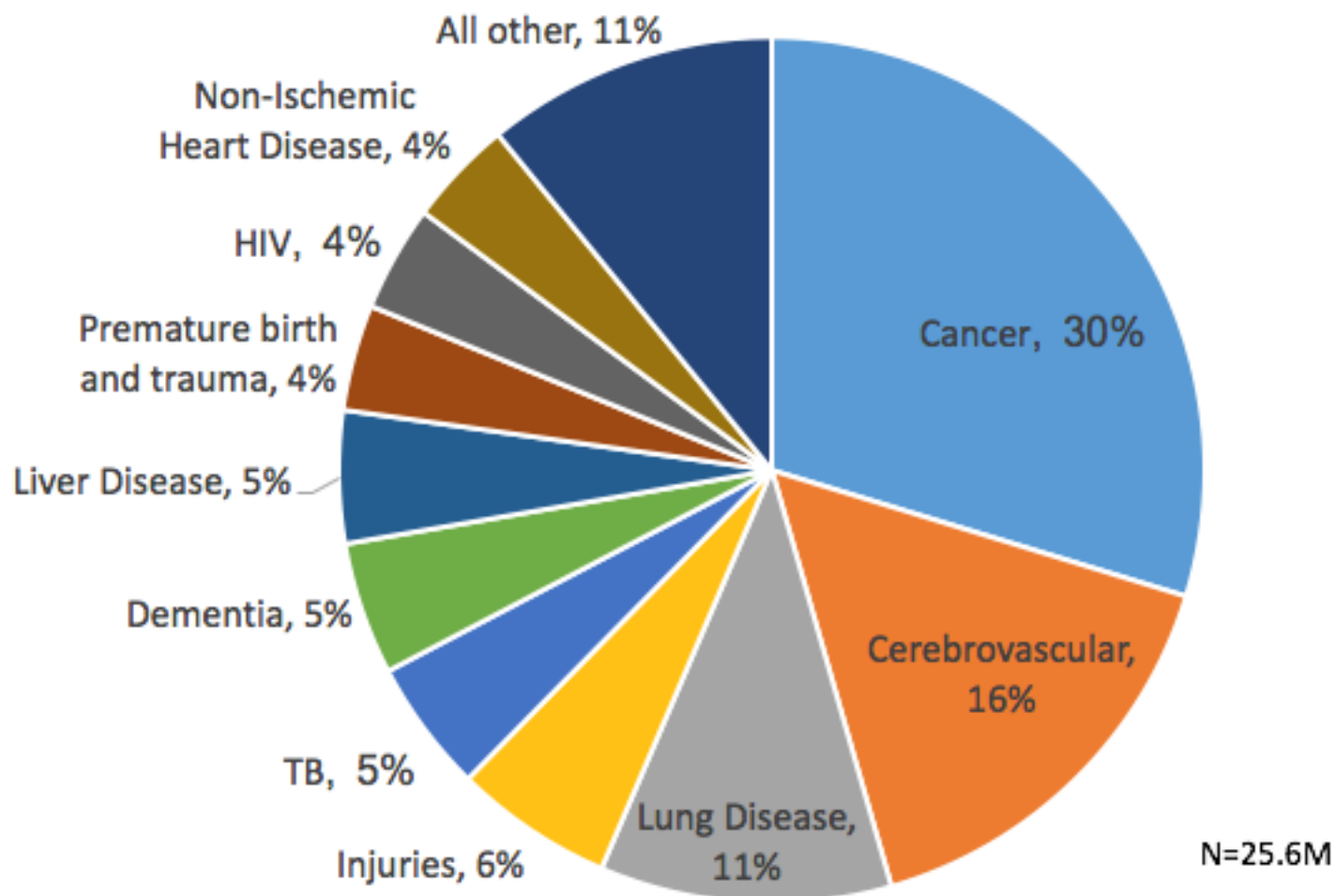
N = 56,874,000

\*WHO Global Health Estimates Deaths by Age, Sex, & Cause

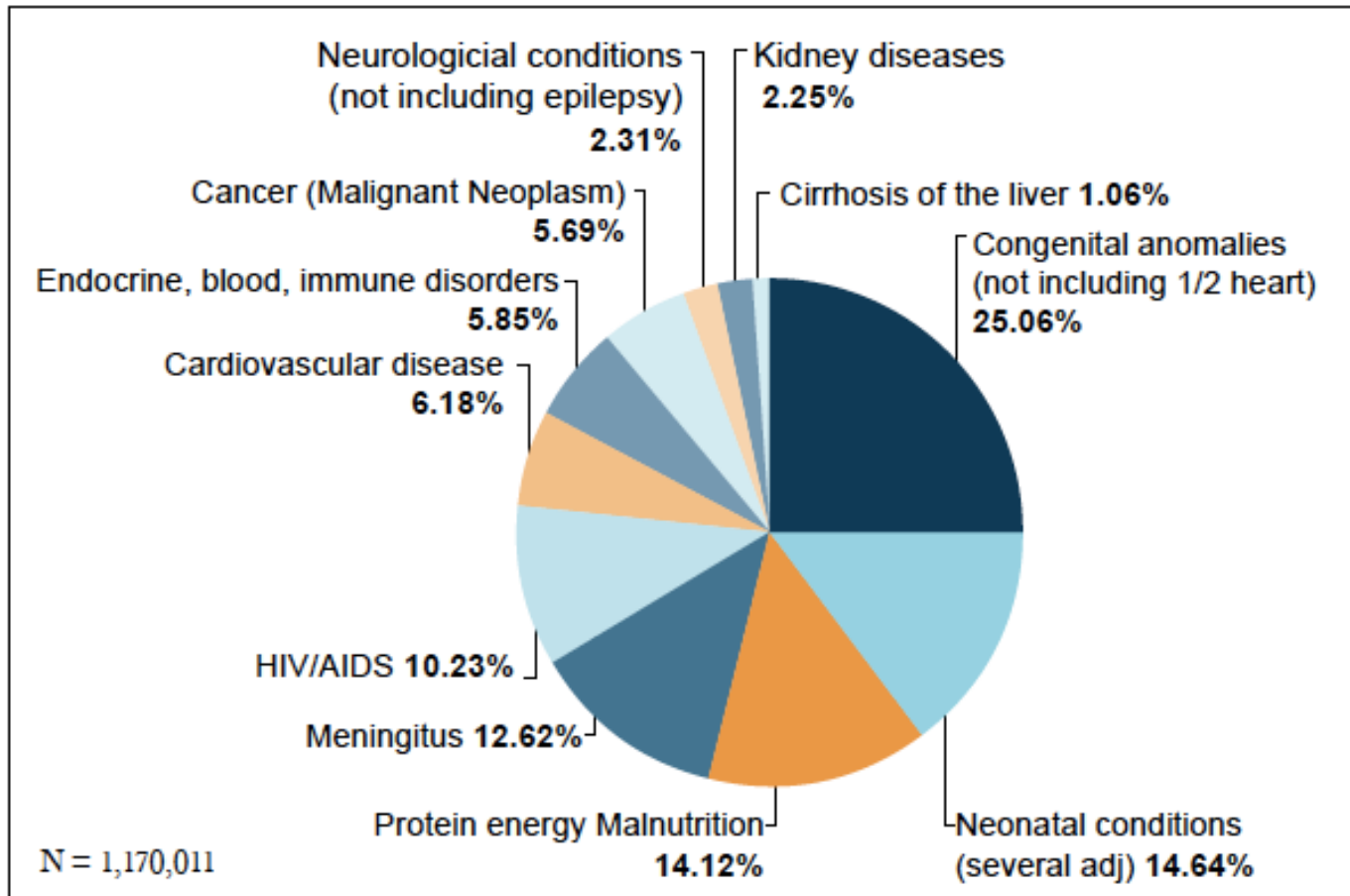
# Adult Need for PC Worldwide



## Decedent Need for Palliative Care by Diagnosis Lancet Commission Report - 2017

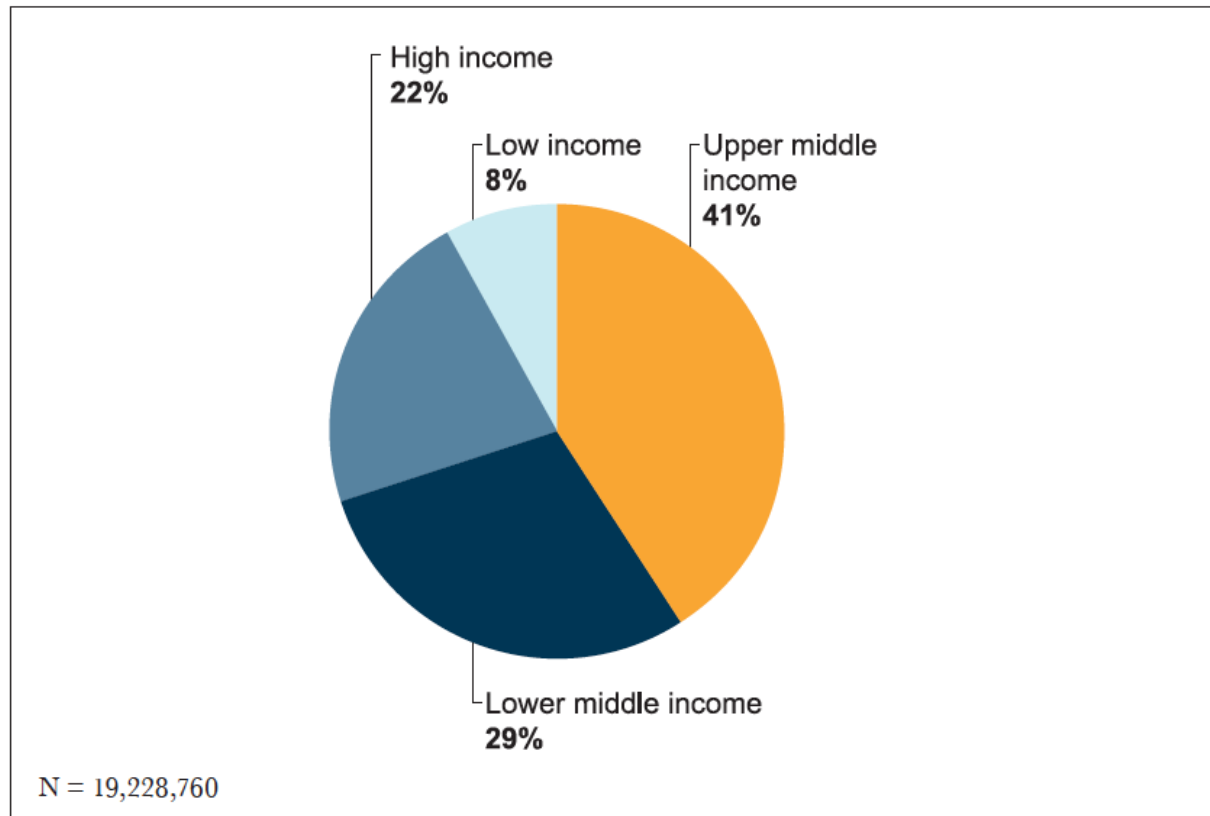


# Distribution of children in need of palliative care at the end of life by disease groups





# 80% of the need for palliative care is in LMIC's



But 80% of existing PC services are in high income countries

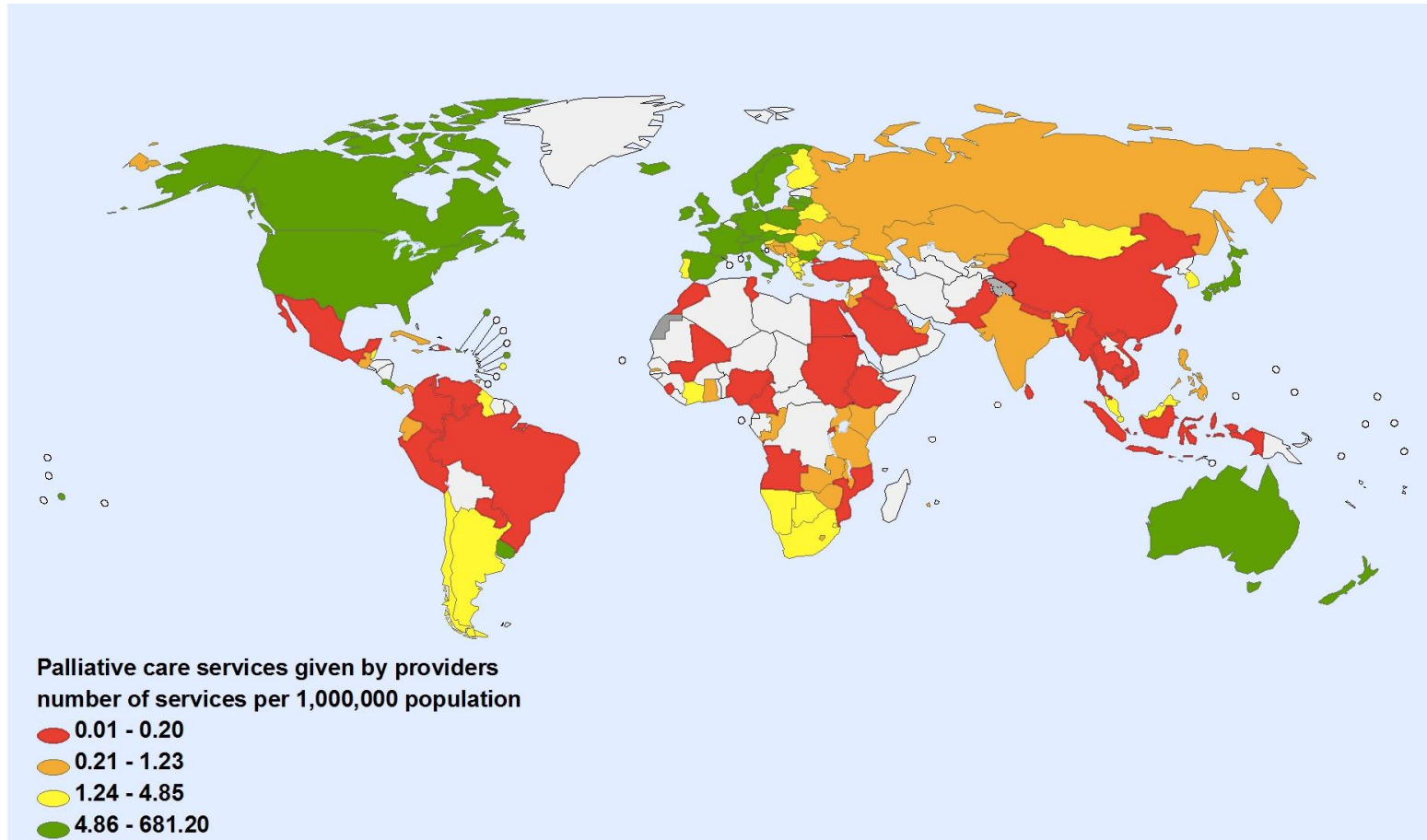
# Global Development of Palliative Care\*

- ±16,000 services
- ±3 million patients
- 6-12 million family
- ~14% of EOL need met
  - >10% of total need

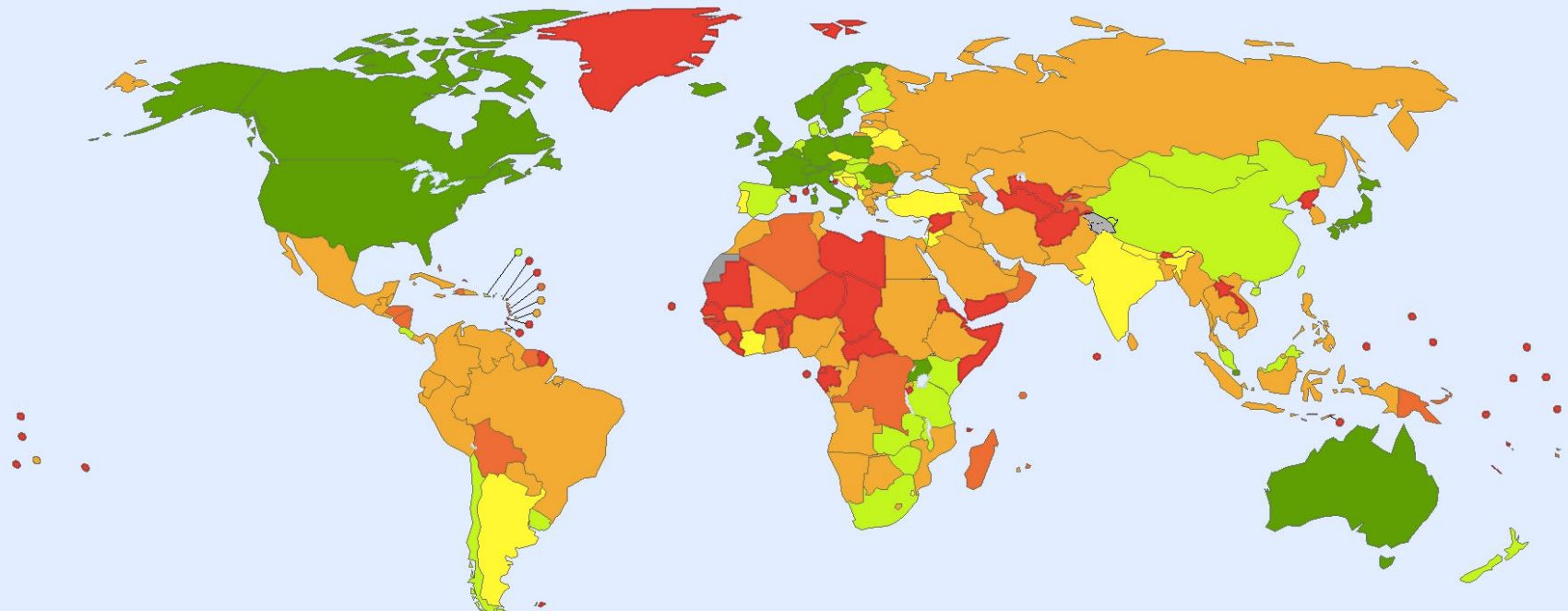
\*Global Atlas of PC 2014



# PC Services by 1M Population



# PC All Levels of Development



## Level of Palliative care Development (PCD)

- Level 1: not known activity
- Level 2: capacity building
- Level 3a: isolated provision
- Level 3b: generalized provision
- Level 4a: preliminary integration
- Level 4b: advanced integration
- Not applicable



# Mapping Levels of Palliative Care Development Globally

- Six Levels of Development

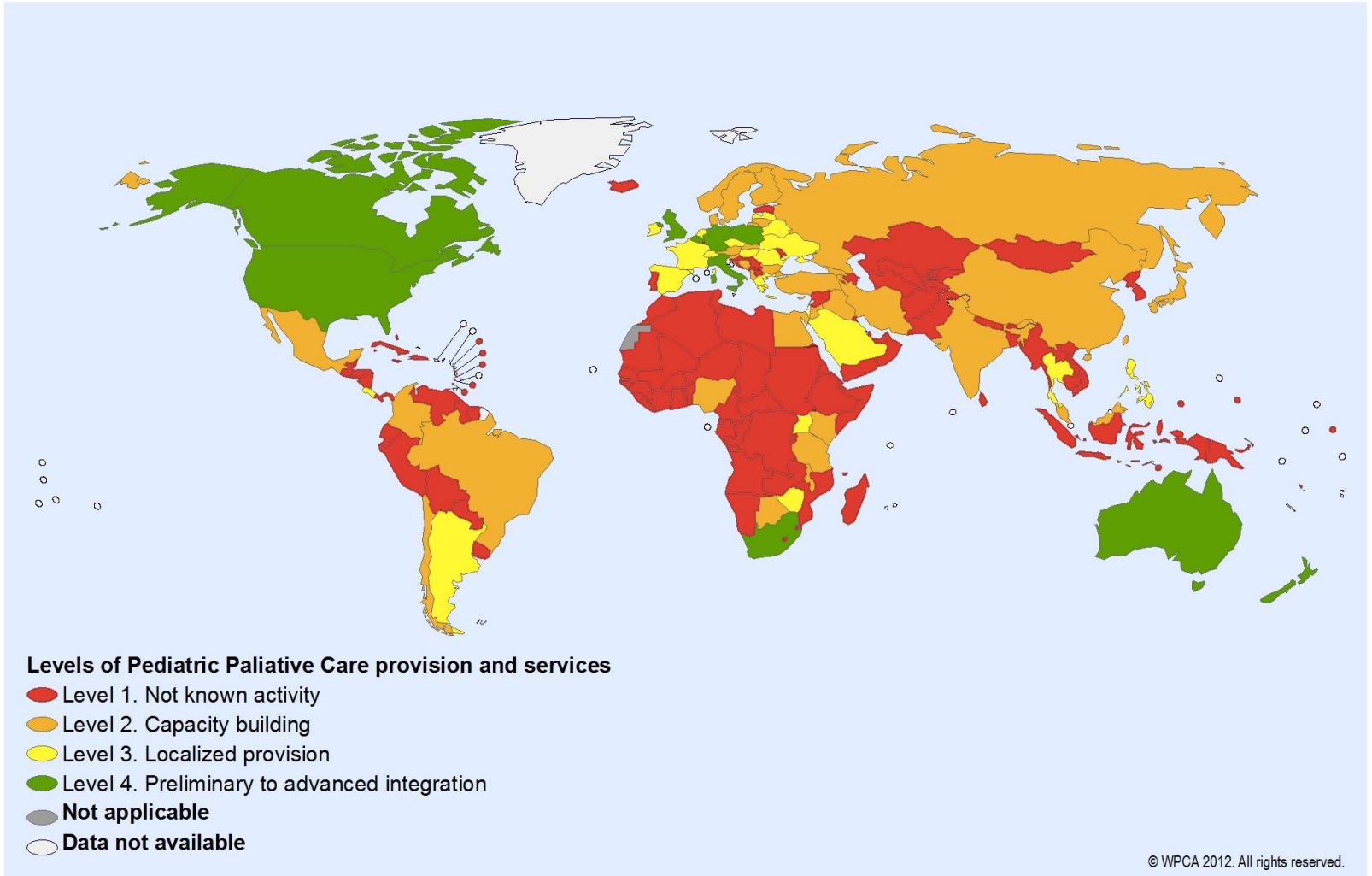
1. No interest or development	32%
2. Interest but no service provision	9.8%
3a. Isolated provision of services	31.6%
3b. Generalized Provision	7.3%
4a. Preliminary Integration	10.7%
4b. Advanced Integration	8.6%



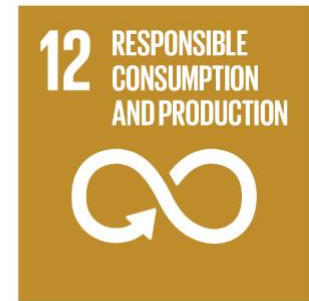
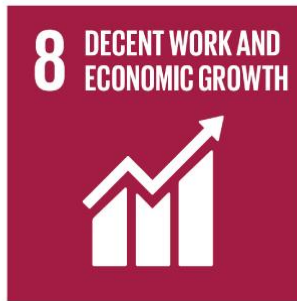
# Aging

- The Elderly Sub-Population
  - Young old 65-74
  - Old 75-84
  - Old Old 85+
- For the first time in history, people aged 65 and over outnumber children under the age of 5.
- By 2050, the U.N. estimates that the proportion of the world's population age 65 and over will more than double, from 7.6% today to 16.2%

# Children's PC All Levels of Development



# 17 Sustainable Development Goals





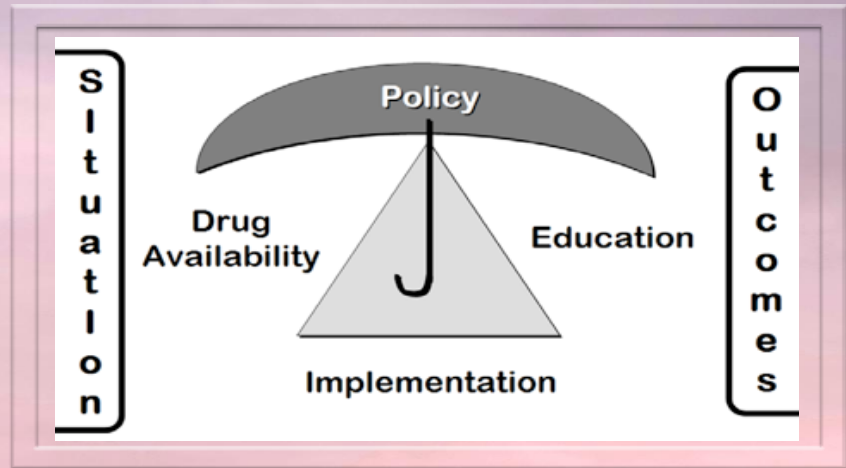
# Important Considerations

- Universal Health Coverage
- Gender & Age
- Human rights
- Disability
- Vulnerable and Marginalised Populations  
(leave no-one behind)
- Poverty Reduction

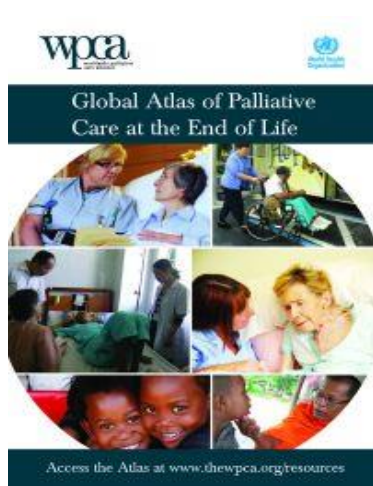


# Advocacy

- Policy
- Education
- Medication Access
- Implementation







## EVIDENCE BASED REPORTS



## DIPLOMATIC ENGAGEMENT AT THE UN



## PUBLIC ACTION



## WORLD HOSPICE AND PALLIATIVE CARE DAY

<p>whpca</p> <p>Palliative care consultation response to the draft WHO global action plan on the public health response to dementia 2017-2025</p> <p>October 15 2016</p>	
African Palliative Care Association	
Asociación Latinoamericana de Cuidados Paliativos	
European Association of Palliative Care	
Human Rights Watch	
International Association for Hospice and Palliative Care (IAHPC)	
International Children's Palliative Care Network	
UICC	
Worldwide Hospice Palliative Care Alliance (WHPCA)	

## TARGETTED COLLABORATIVE ACTION



## BUILDING PARTNERSHIPS AND CO- PRODUCING SOLUTIONS AND ACTION

# Collaborative Global Advocacy Highlights

2005 – First World Hospice Palliative Care Day

2008 – UN Special Rapporteur on right to health report includes palliative care as neglected issue to UN GA

2011 – PC in Non-Communicable diseases global plan, UN political declaration and first PC indicator in WHO global monitoring framework

2013 – PC included in Universal Health Coverage definition

2014 – First Global Atlas on End of Life Care (WHO/WHPCA)

2014 – WHA palliative care resolution adopted

2017 – Palliative care included in Global Action Plan on Dementia and WHA cancer resolution





# Community Based Palliative Care Development – Innovative Models

## Three Examples

1. Neighborhood Network in PC – Kerala, India
2. Compassionate Communities – Korail Slum, Dhaka, Bangladesh
3. Kibera Community Self-Help Program – Nairobi, Kenya



# Model Palliative Care Programs Globally - Kerala

- Neighborhood Network in Palliative Care









# Compassionate Korail



- Mindful Awareness & Intention
- Attunement to Self and Others
- Kindness & Courage
- Knowledge & Skills
- Wisdom & Fortitude for Presence and Action

- Between Family Members
- Between Patient-Caregiver
- Between Team Members
- Between Organizations
- Between Systems

**Compassionate  
Individuals**

**Compassionate  
Relationships**

**Connectedness & Shared Humanity**

**Compassionate  
Communities**

**Compassionate  
Organizations**

- Solidarity
- Social Attitudes
- Shared Values
- Sense of Belonging
- Interoceptivity

- Policy & Structure
- Leadership & Governance
- Guidance & Accountability
- Economic Sustainability

# Kibera Community Self Help Program - KICOSHEP

- Grafting palliative care into a CBO



# Decent Care Values in PC

## Individual

- **Agency**
- **Dignity**

## Social

- **Interdependence**
- **Solidarity**

## Systemic

- **Subsidiarity**
- **Sustainability**









# What have we learned from low & middle income countries?

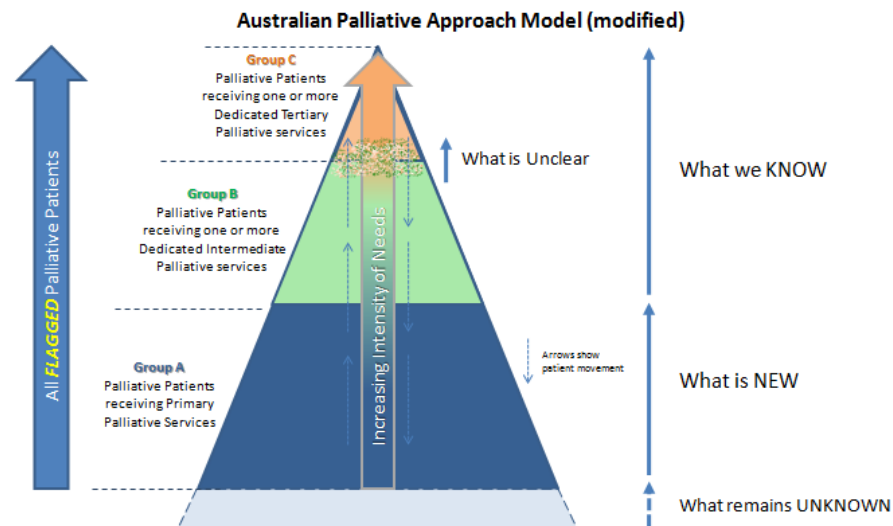
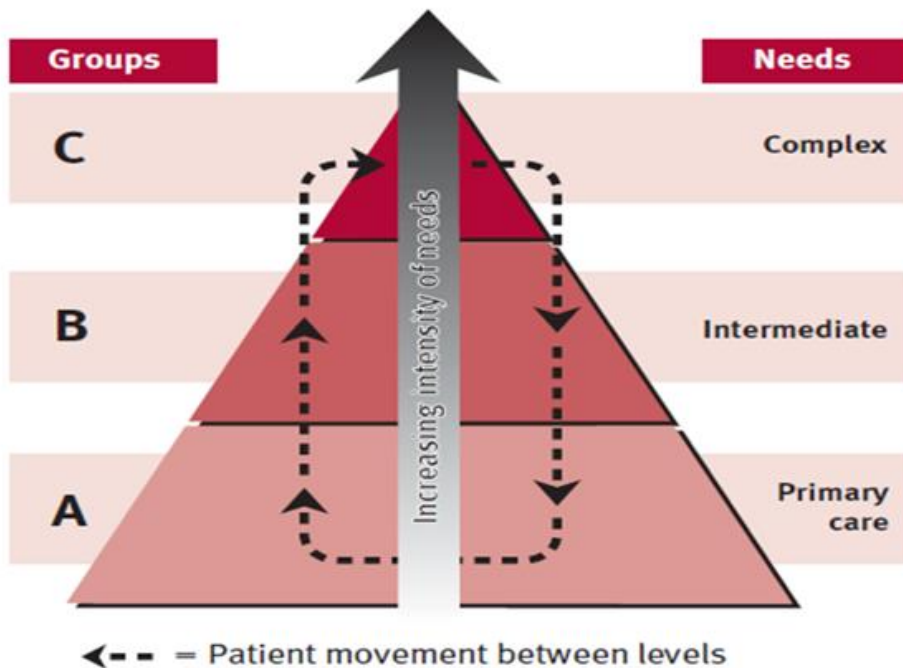
- Community Involvement/owners
- Home based care focus
- Task shifting
- Continuity of caring
- Our barriers are universal and mostly self-created
- Top down & bottom up



# Community based palliative care development

- What do these models have in common?
  - Importance of leadership
  - Focus on home based care
  - Community Health Workers
  - Volunteerism
  - Community Ownership
  - Family Caregiver Training/Empowerment
  - Professional Back Up
  - Compassionate Communities

# Australian Population-based Palliative Approach Model



- What We Flagged - using database flags to identify all various palliative type patients
- What we Know - patients already receiving one or more dedicated palliative services & providers
- What is New - previously unknown palliative patients now picked up by flags
- What is Unclear - remains to be decided what dedicated services best fit in Group B or Group C
- What is Unknown - patients who died but no palliative flags or services. Not know if need for HPEOL



# Challenges and Vision for the Future of Palliative Care

- Challenges

- 75% of countries have severely limited access to opioids
- The world has two opioid crises
- 42% of countries had no PC services
- Over 61 million need PC but less than 10% receive it
- 80% of this need is in resource limited settings
- Children are less likely to receive PC services than adults
- Slow progress in educating and retaining workers
- Lack of public awareness of hospice & PC





# Challenges and Vision for the Future of Palliative Care

## How do we get to a more integrated model of palliative care?

- Increasing the capacity of primary care providers to integrate palliative care (PC) into practice
  - Increased PC education for all health professionals
  - Shifting existing resources from acute to primary palliative care – advanced illness management
  - Increased capacity to deliver home based care
  - Available, accessible, and affordable medicines



# Challenges and Vision for the Future of Palliative Care

## How do we get to a more integrated model of palliative care?

- Integration of specialized PC into existing health care delivery structures, not stand alone
- Better continuity of care between levels of care
- More community involvement/ownership and volunteerism
- Palliative care as a model for the health care system of the future



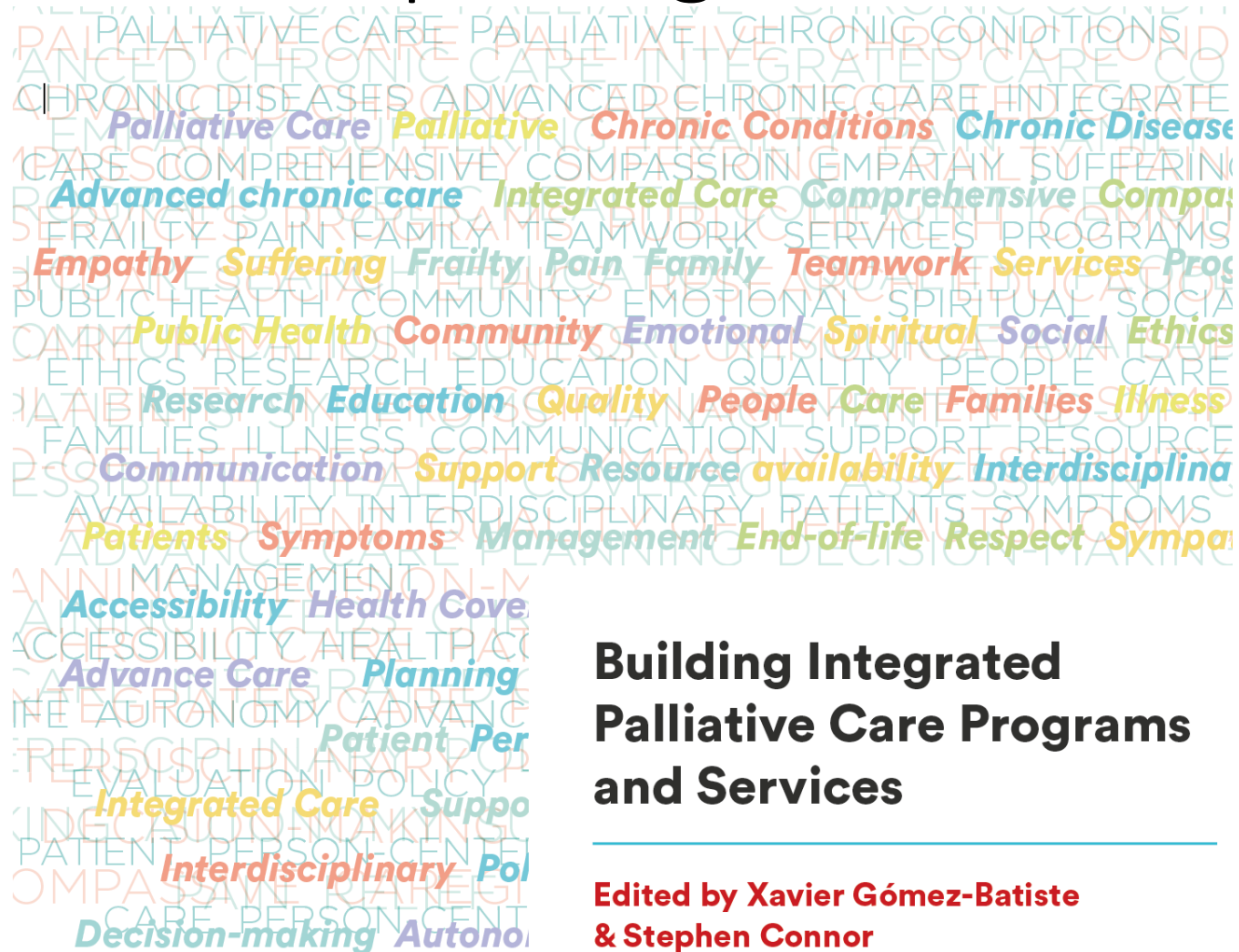


# Challenges and Vision for the Future of Palliative Care

- Vision for the future
  - Opioids for palliative care patients are available in all countries
  - Public financing for palliative care extends to all LMIC's
  - Palliative care is included in all country Universal Health Coverage schemes by 2030
  - Palliative care indicators & evidence measure the impact & value of palliative care in health care systems
  - All who need palliative care receive at least the essential package integrated into existing health care by 2030



Free to Download  
[www.thewhpc.org/resources](http://www.thewhpc.org/resources)

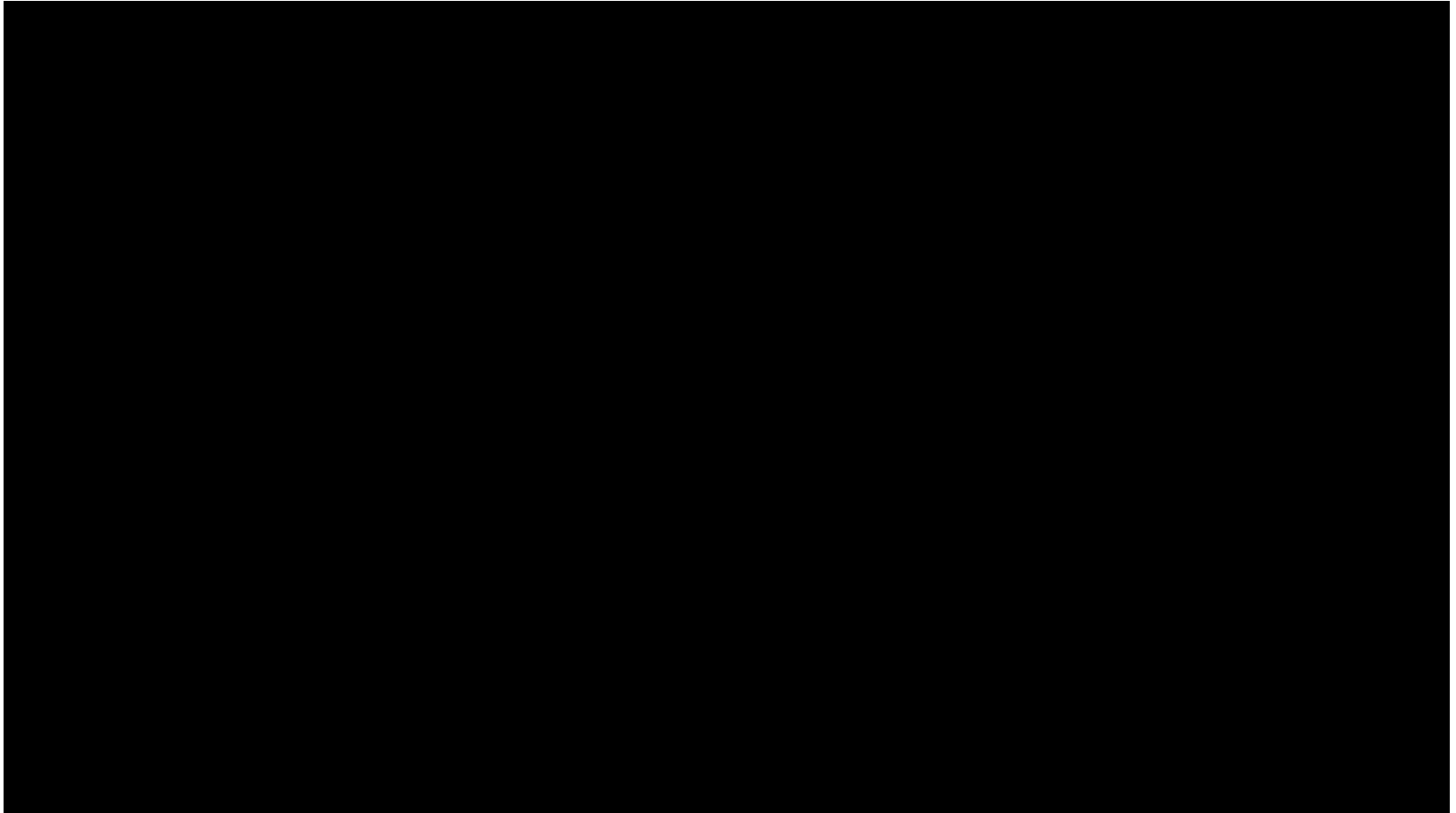


## Building Integrated Palliative Care Programs and Services

Edited by Xavier Gómez-Batiste  
& Stephen Connor



# Lucy's Story – Public Engagement by Direct Stakeholders





# Thank you!

**For questions about this presentation contact me at  
[sconnor@thewhpca.org](mailto:sconnor@thewhpca.org)**