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JCECC

Jockey Club End-of-Life Community Care Project

JCECC Professional Training & Leadership Training

Dr. Candy Fong
Senior Training Officer, JCECC Project

策划及捐助 Initiated and Funded by:

香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER

合作院校 Partner Institution:

Faculty of Social Sciences
The University of Hong Kong
香港大學社會科學學院

The Global Aging Tsunami

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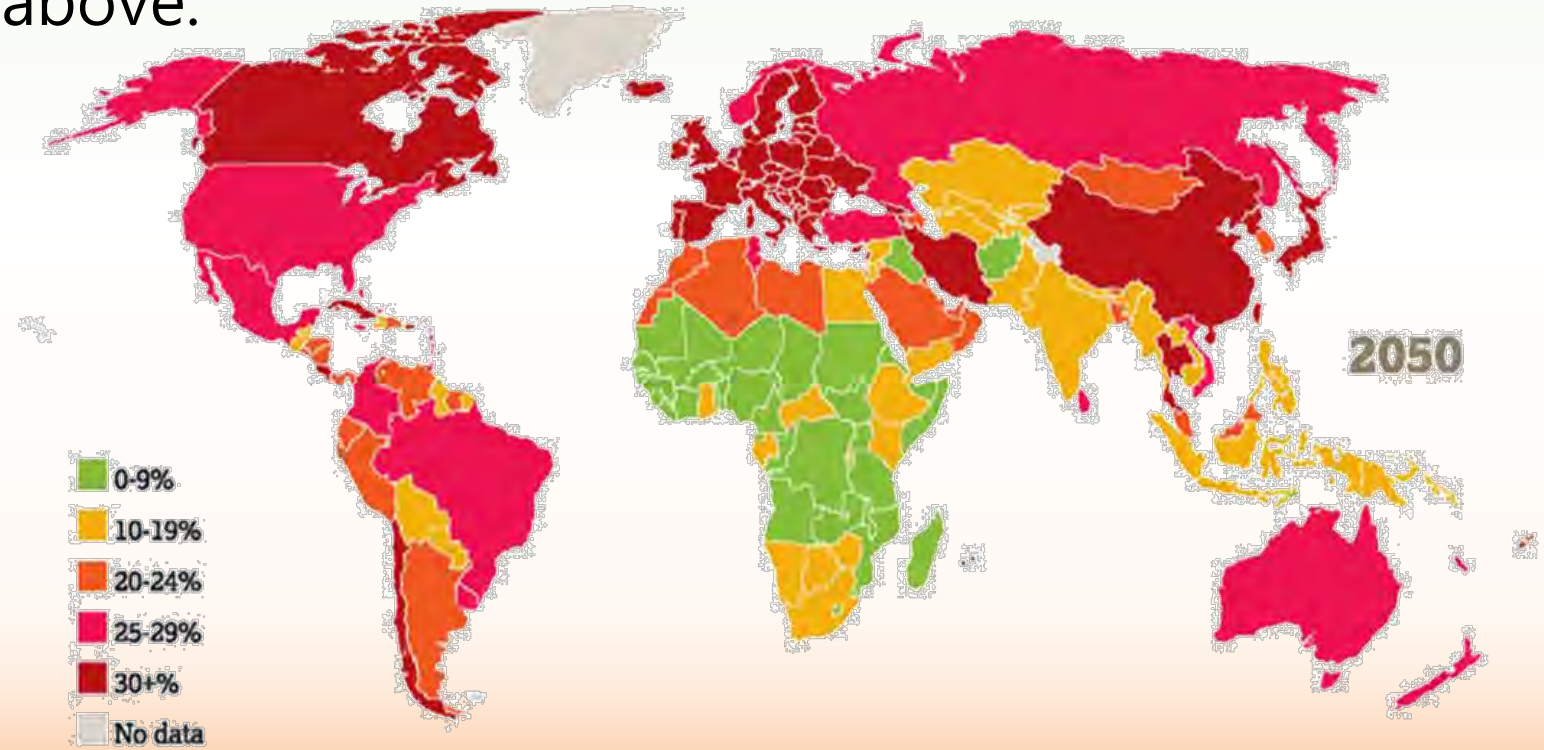
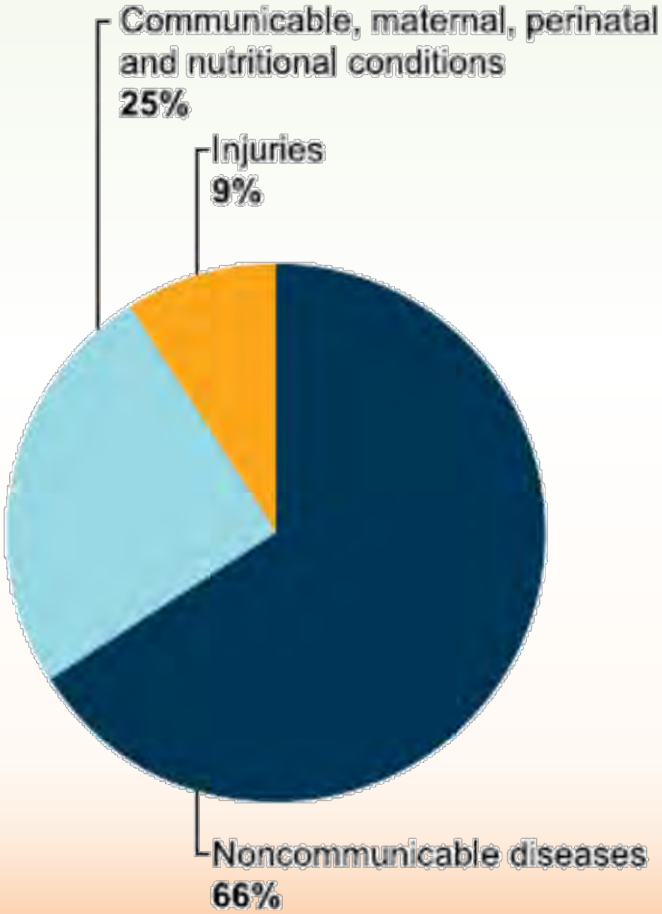
- In 2050, 22% of the population will be aged 60 and above.



Cause of Death: Global Scene



- In 2011, 54.6 million of deaths happened, and 66% due to NCDs

Global Needs for EoLC

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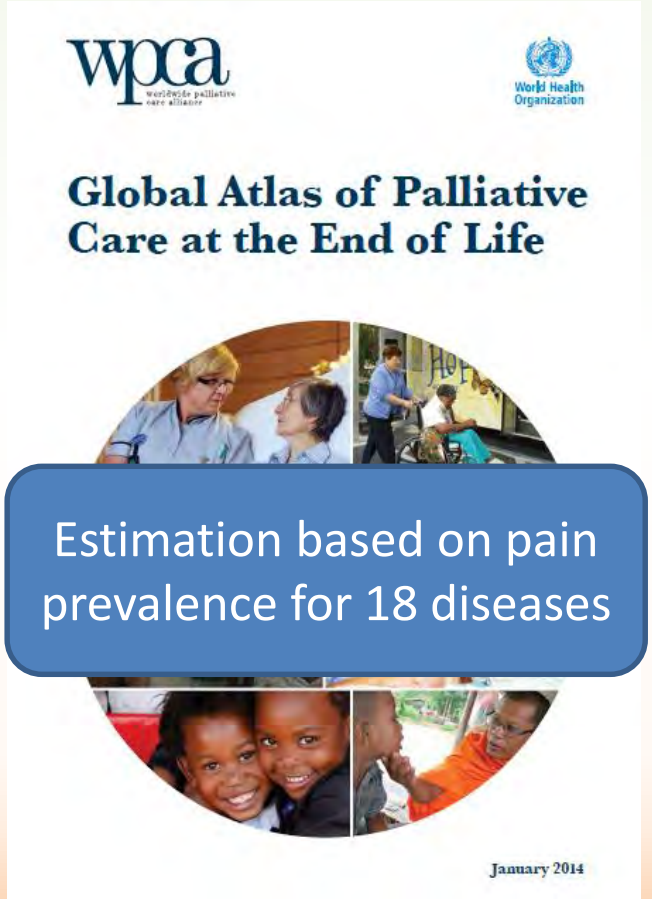
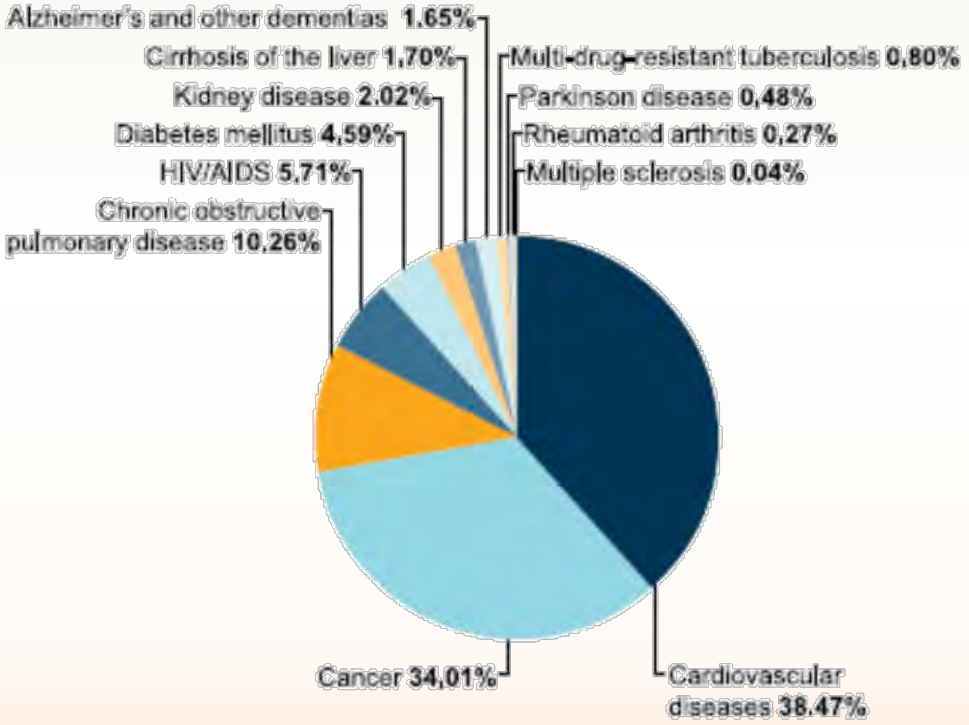


Estimation based on pain prevalence for 18 diseases

Estimation based on Serious Health-Related Suffering for 20 diseases/ injuries

Global Needs for EoLC

- It is estimated that 70% of death (20.4 millions) are in need of palliative care in EoL each year
- 69% are aged 60+
- The number is estimated to be doubled (40 millions) and even tripled (60 millions) taking into account those who are in need of EoLC but not in last year of life



Global Needs for EoLC

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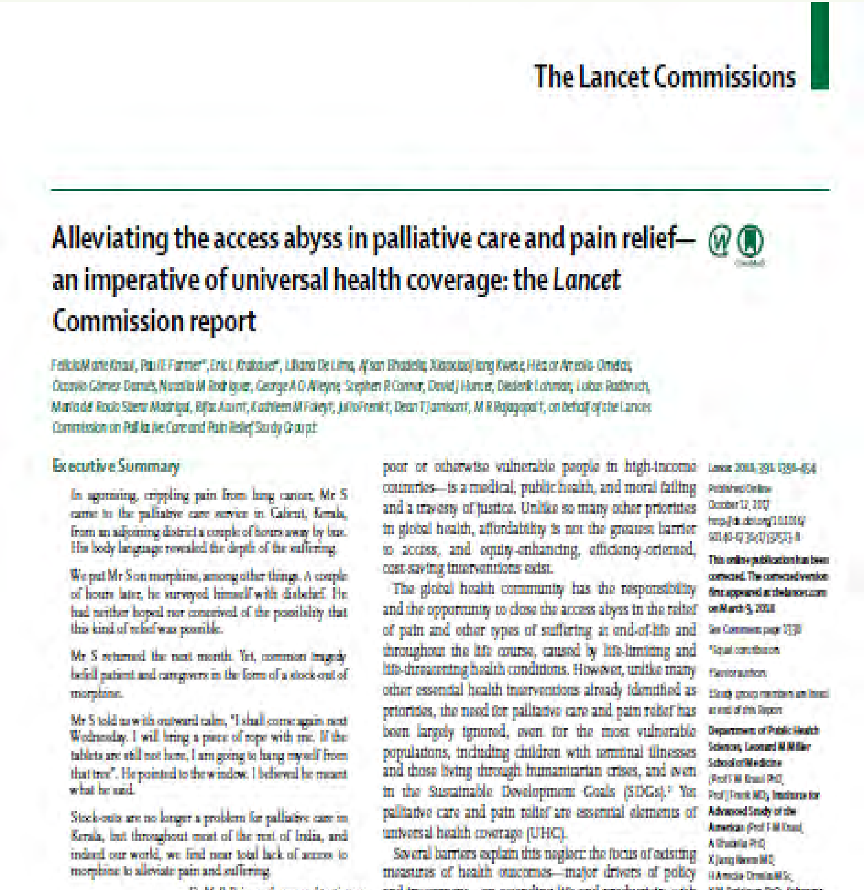

The Lancet Commissions

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

Felicia Marie Knaul, Paul E Farmer*, Eric L Krakauer*, Liliana De Lima, Afsan Bhadelia, Xiaoxiao Jiang Kwete, Héctor Arreola-Ornelas, Octavio Gómez-Dantés, Natalia M Rodriguez, 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‡

Executive Summary

In agonising, crippling pain from lung cancer, Mr S came to the palliative care service in Calicut, Kerala, from an adjoining district a couple of hours away by bus. His body language revealed the depth of the suffering.

We put Mr S on morphine, among other things. A couple of hours later, he surveyed himself with disbelief. He had neither hoped nor conceived of the possibility that this kind of relief was possible.

Mr S returned the next month. Yet, common tragedy befell patient and caregivers in the form of a stock-out of morphine.

Mr S told us with outward calm, "I shall come again next Wednesday. I will bring a piece of rope with me. If the tablets are still not here, I am going to hang myself from that tree". He pointed to the window. I believed he meant what he said.

Stock-outs are no longer a problem for palliative care in Kerala, but throughout most of the rest of India, and indeed our world, we find near total lack of access to morphine to alleviate pain and suffering.

poor or otherwise vulnerable people in high-income countries—is a medical, public health, and moral failing and a travesty of justice. Unlike so many other priorities in global health, affordability is not the greatest barrier to access, and equity-enhancing, efficiency-oriented, cost-saving interventions exist.

The global health community has the responsibility and the opportunity to close the access abyss in the relief of pain and other types of suffering at end-of-life and throughout the life course, caused by life-limiting and life-threatening health conditions. However, unlike many other essential health interventions already identified as priorities, the need for palliative care and pain relief has been largely ignored, even for the most vulnerable populations, including children with terminal illnesses and those living through humanitarian crises, and even in the Sustainable Development Goals (SDGs).[1] Yet palliative care and pain relief are essential elements of universal health coverage (UHC).

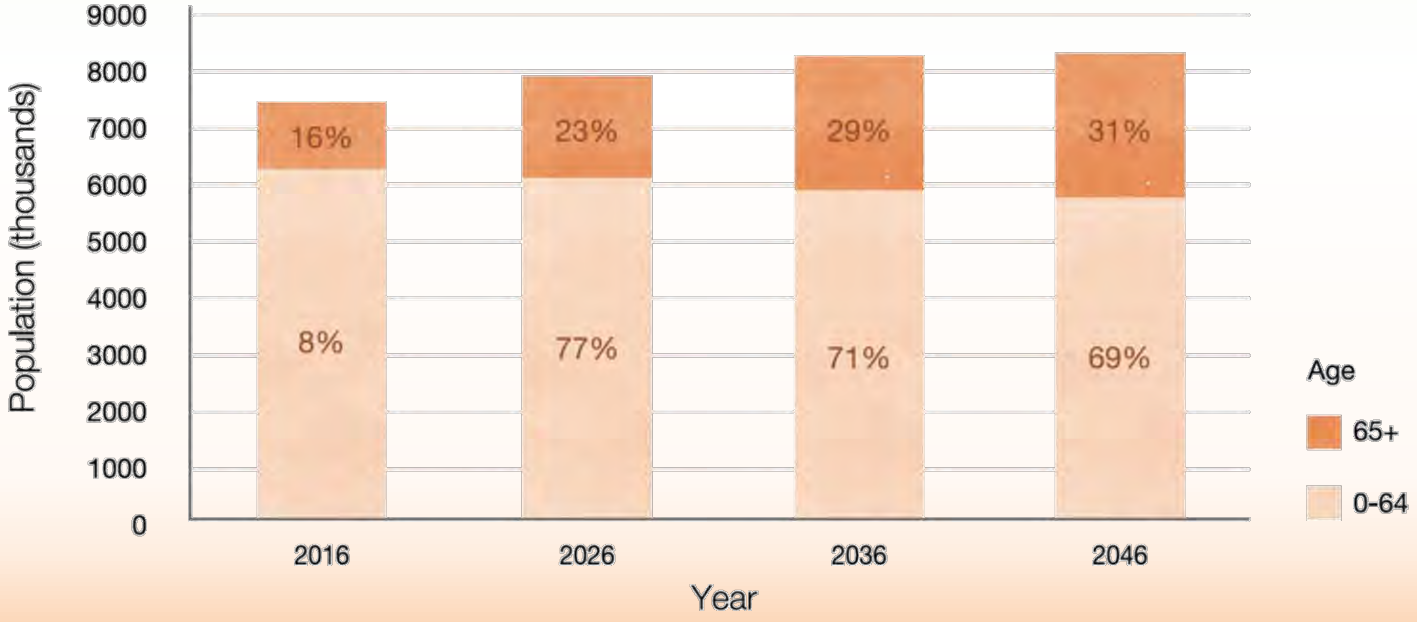
Several barriers explain this neglect: the focus of existing measures of health outcomes—major drivers of policy

Lancet 2018; 391: 1391–454
Published Online October 12, 2017

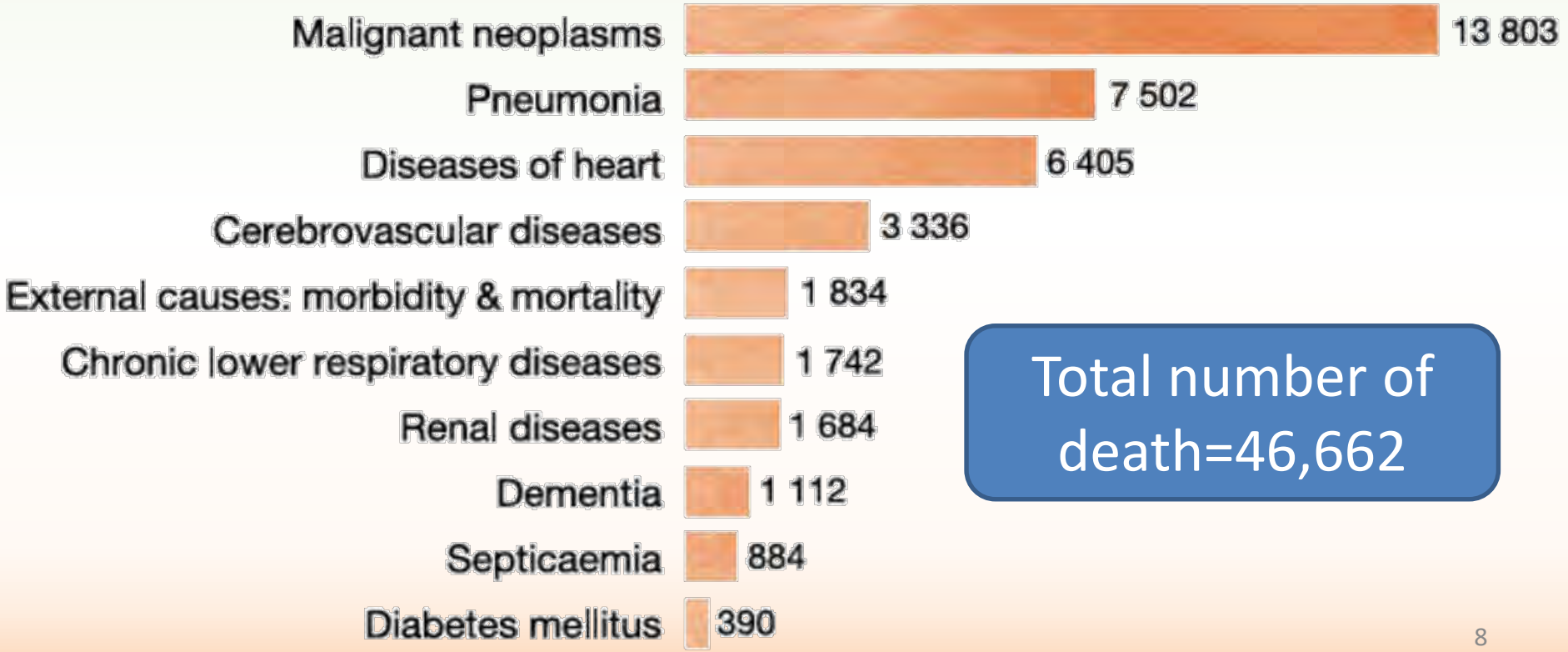
- 25.5 million people who died in 2015 are in need of palliative care (=45% of death worldwide)
- More than 61 million people experienced SHS in 2015

Aging Trend in HK

- Average life expectancy: 81.3
- Population aged 65+ will increase from 15% to 33% in 2056



Cause of Death in HK

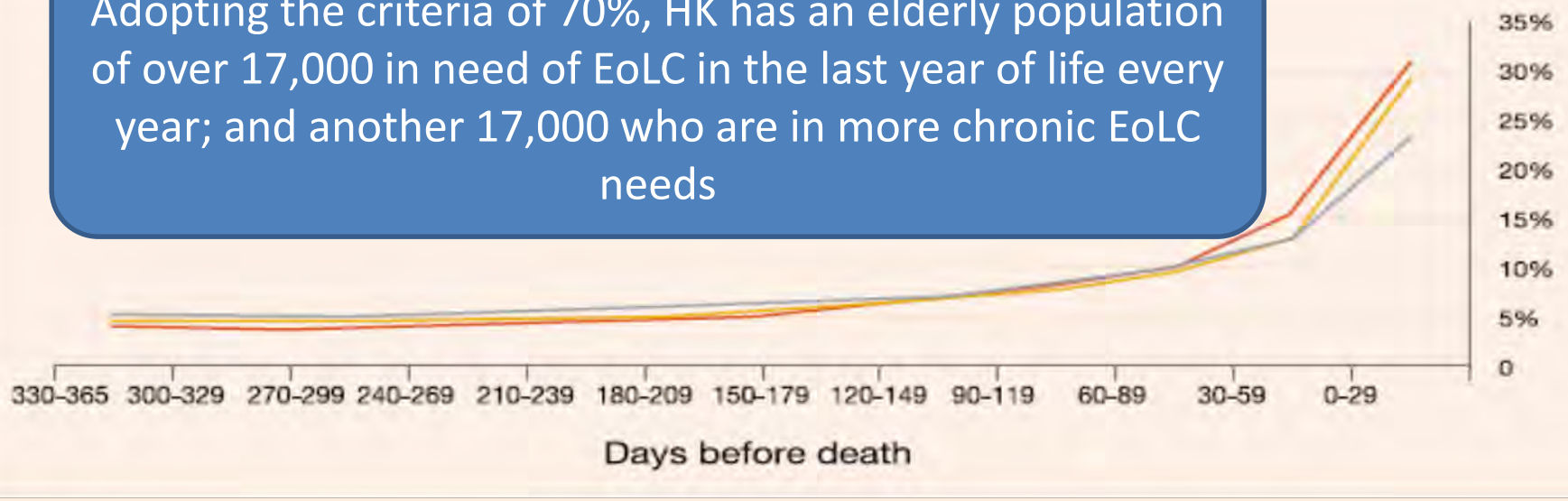


Total number of death=46,662

Local Needs on EoLC

- 75% aged 65+ are living with one or more chronic conditions
- Need for medical and social care services significantly increase in the last 6 months in life

Adopting the criteria of 70%, HK has an elderly population of over 17,000 in need of EoLC in the last year of life every year; and another 17,000 who are in more chronic EoLC needs



Palliative Care for All

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- Ottawa Charter: "health is created by caring for oneself and others, by being able to take decisions and have control over ones' life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members"
- A health promoting palliative care approach: making large scale, international effort to incorporate principle of health promotion in to EoLC, through a series of social efforts by communities, governments, state institutions and social or medical care organizations with the aim to create compassionate cities for improving health and wellbeing in face of life-limiting illnesses

Palliative Care for All

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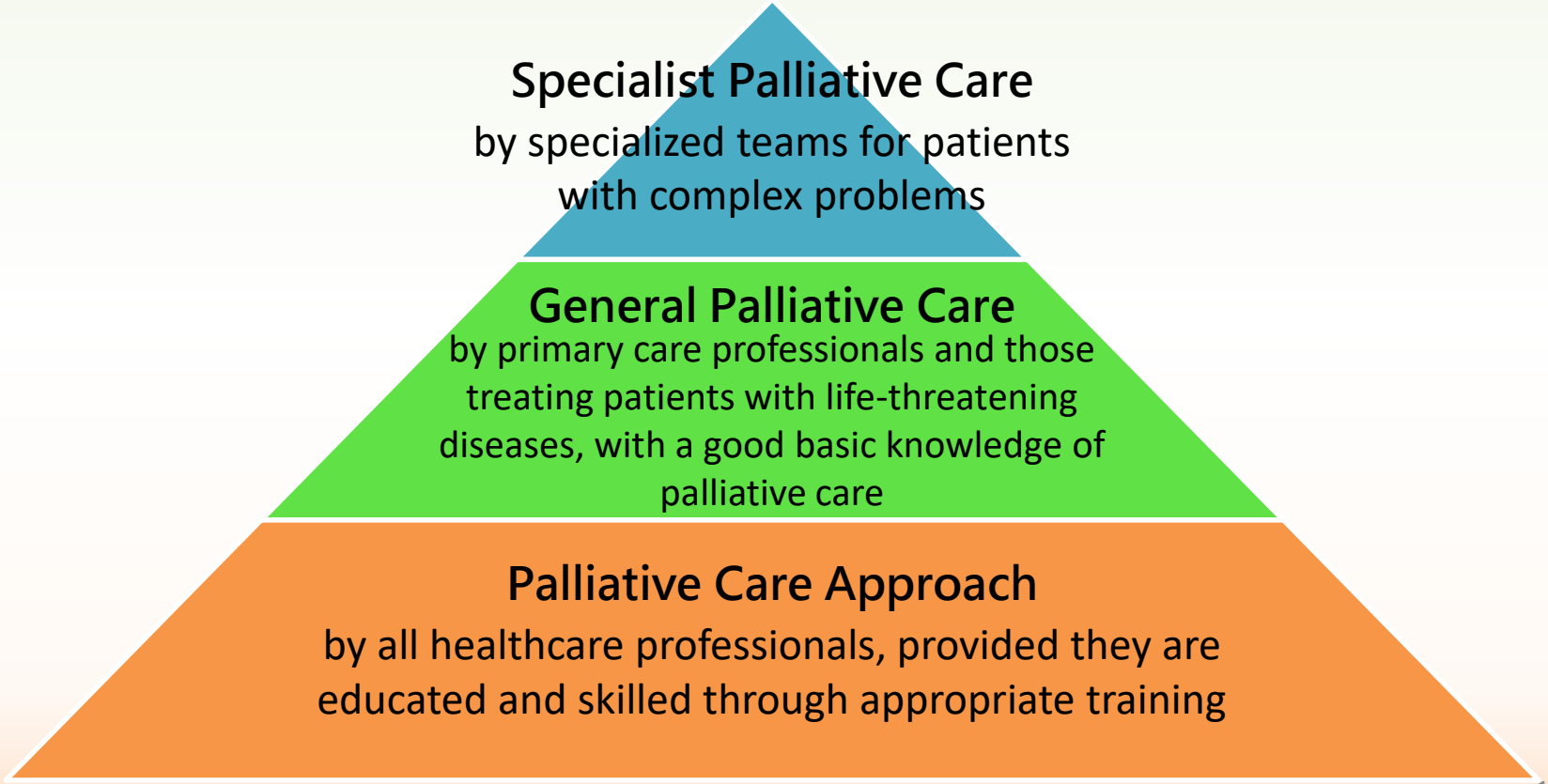

Implementing EoLC for All

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- **Comprehensive Care**: responding to all multidimensional needs of patients and families, cancer or non-cancer conditions
- **Integrative community approach**: integrating into all services and settings and with coordination of care
- **Team-based approach**: doctors (specialty and general, depending on level of care), nurses (specialty and general), social workers and counsellors, psychiatrist, psychologist, or counsellor (depending on level of care), Physical therapist, pharmacist, Community health workers, clinical support staff (diagnostic imaging, laboratory technician, nutritionist), and non-clinical support staff (administration, cleaning)

Implications on Human Capacity Building

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For home-based care:

- 3 physicians per 100,000 population
- 12 nurses per 100,000 population
- 6 other clinical staff per 100,000 population

For inpatient care:

- 1.5 MDs for every 10 inpatients
- 15.5 nurses for every 10 inpatients
- 4 other clinical staff for every 10 inpatients

Community=???

An addition 25% administrative staff to provide leadership and to ensure compliance with regulatory and fiduciary responsibilities

Human Capacity Building in EoLC

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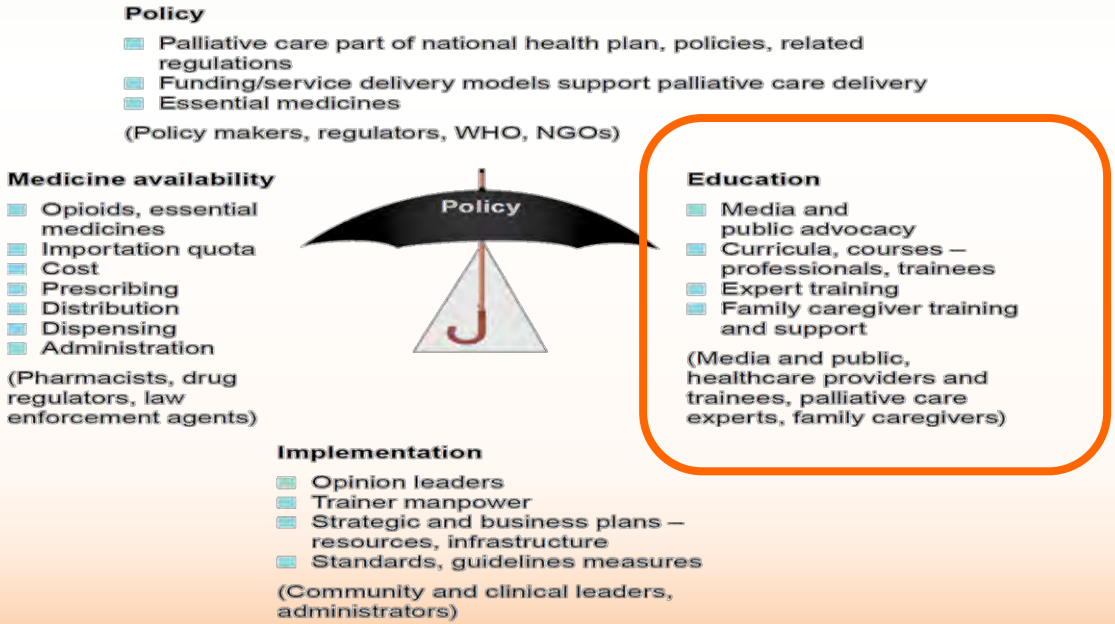
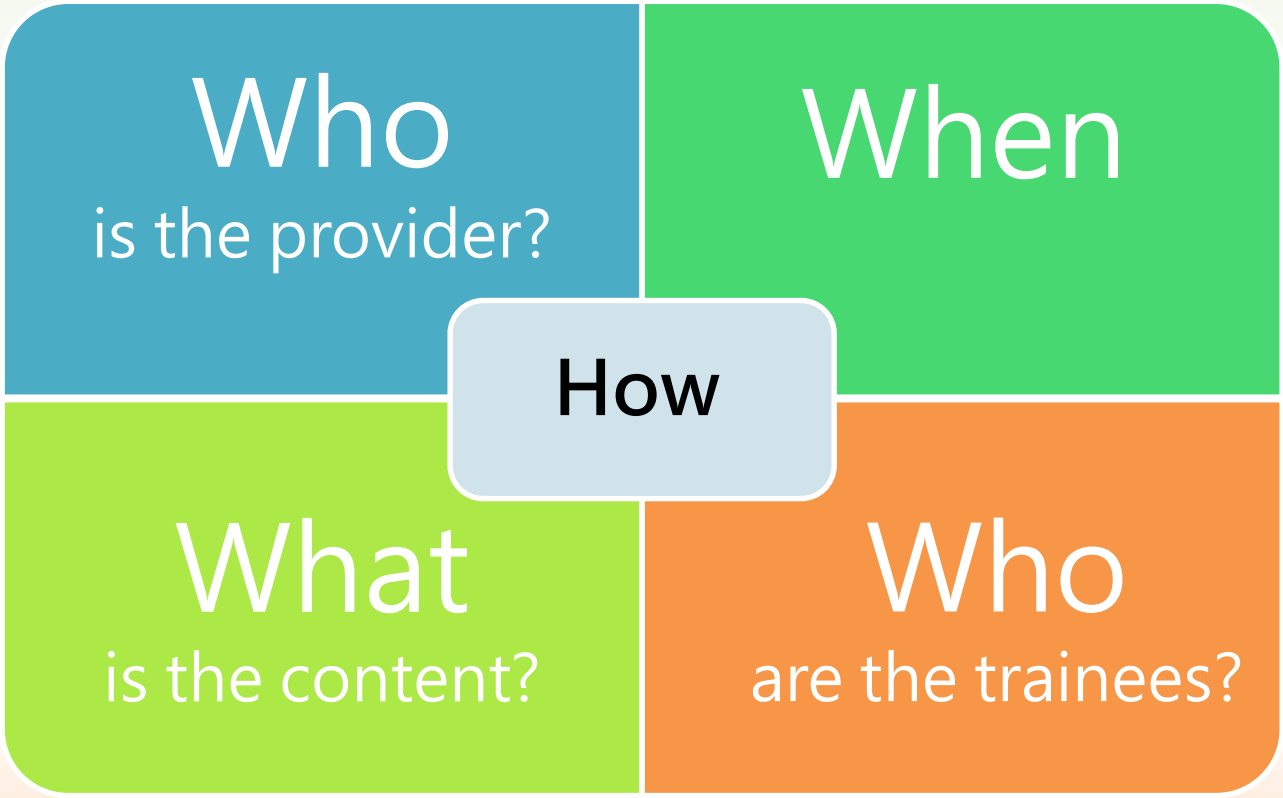
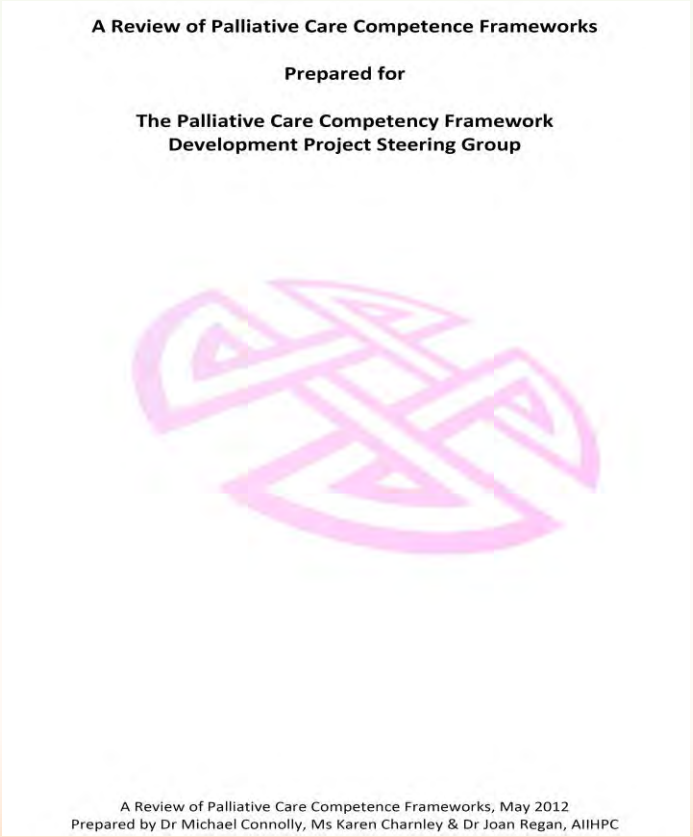
- Human resource as one of the key components of EoLC essential package, in addition to medicine and medical facilities
- Education is one of the five pillars for a public health model for EoLC



Education & Training for Professional Development in EoLC



Competence Frameworks in EoLC



- A review of 29 competence frameworks in EoLC
- A tailored approach to professional capacity building, specifying the aims, target, levels and methods of training and education, in accordance with the care settings, disciplines, positions, nature of work and level of involvement
- Interdisciplinary approach & discipline-specific approach

Competence Frameworks in EoLC

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- Interdisciplinary approach: common core competences

End of Life core competences and principles - overview

These common core competences underpin all levels of practice and are defined by:

- Linkages to levels defined by nationally recognised frameworks - e.g. National Occupational Standards (NOS), Knowledge and Skills Framework (KSF), National Workforce Competences (NWC), Qualifications and Credit Framework (QCF), continual professional development (CPD)
- Basic, Intermediate and Specialist Groupings – to enable further flexibility for local developments

Communication Skills	Assessment and Care Planning	Symptom management, comfort and well being	Advance Care Planning

Values & Knowledge developments

These seven principles underpin all workforce and service development, activity and delivery irrespective of level and organisation. They are:

1. Choices and priorities of the individual are at the centre of planning and delivery
2. Effective, straightforward, sensitive and open communication between individuals, families, friends and workers underpins all planning and activity. Communication reflects an understanding of the significance of each individual's beliefs and needs
3. Delivery through close multidisciplinary and interagency working
4. Individuals, families and friends are well informed about the range of options and resources available to them to be involved with care planning
5. Care is delivered in a sensitive, person-centred way, taking account of circumstances, wishes and priorities of the individual, family and friends
6. Care and support are available to anyone affected by the end of life and death of an individual
7. Workers are supported to develop knowledge, skills and attitudes. Workers take responsibility for, and recognise the importance of, their continuing professional development

Core competences for end of life care
Training for health and social care staff

Common core competences and principles
for health and social care workers
working with adults at the end of life

To support the National End of Life Care Strategy

NHS National End of Life Care Programme
Skills for Health
skillsforcare
DH Department of Health

Competence Frameworks in EoLC

End of Life Care
Core Skills Education and Training Framework

This framework was commissioned and funded by Health Education England and developed in collaboration with Skills for Health and Skills for Care.

Skills for Health skillsforcare NHS Health Education England

- 3 tiers x 14 subjects
- With learning outcomes, relevant guidance and/or legislation, mapping to relevant national standards or frameworks and additional resources

Target audience

Tier 1: Those that require general end of life care awareness, focusing on a community development, asset based approach to care

Tier 2: Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3: Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

14 Subjects	Tier 1	Tier 2	Tier 3
person-centered care	✓	✓	✓
communication	✓	✓	✓
equality, diversity and inclusion	✓	✓	✓
community skills development	✓	✓	✓
practical and emotional support	✓	✓	✓
assessment and care planning	✓	✓	✓
symptom management	✓	✓	✓
working in partnership	✓	✓	✓
support for carers	✓	✓	✓
maintaining own health and well being	✓	✓	✓
care after death	✓	✓	✓
law ethics and safeguarding	✓	✓	✓
leading services and organizations		✓	✓
improving quality through policy, evidence and reflective practice	✓	✓	✓

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Community Care Project

End of Life Care
Core Skills Education and Training Framework

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Skills for Health
skillsforcare
NHS
Health Education England

Competence Frameworks in EoLC

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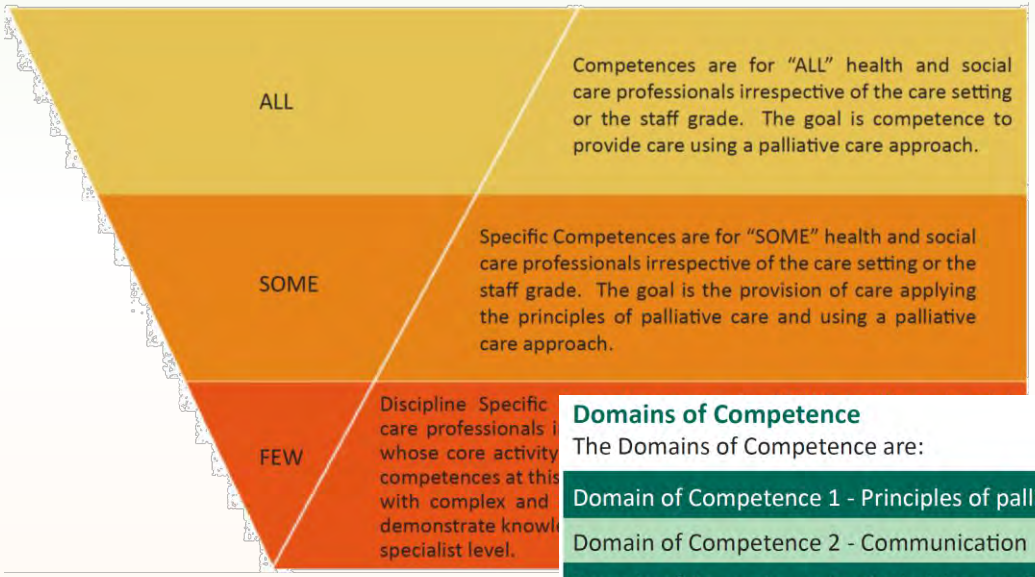
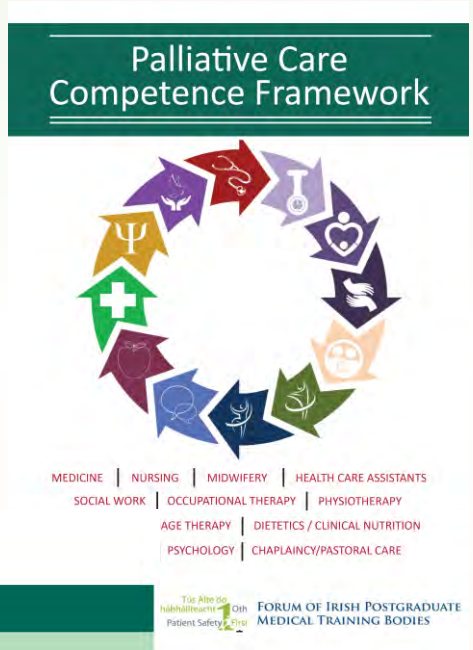
- Discipline X Competence Domains X Levels



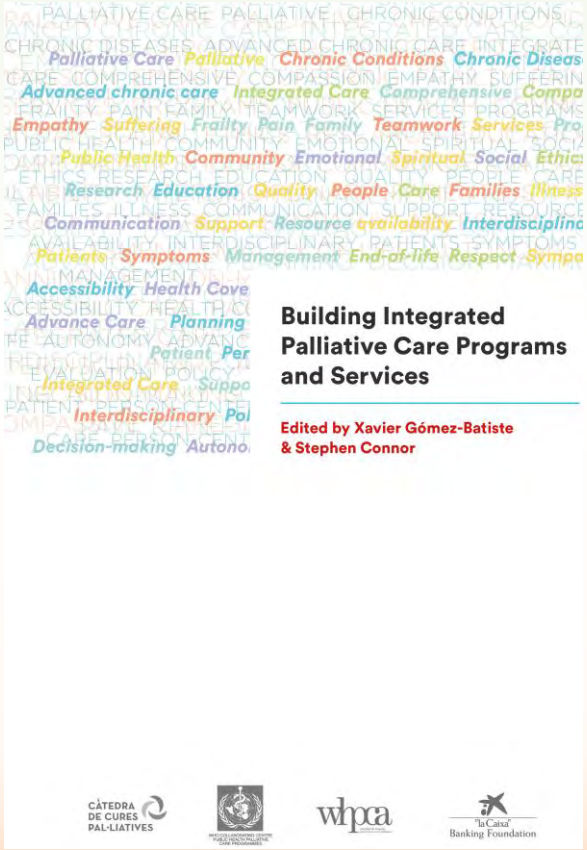
Domains of Competence

The Domains of Competence are:

- Domain of Competence 1 - Principles of palliative care
- Domain of Competence 2 - Communication
- Domain of Competence 3 - Optimising comfort and quality of life
- Domain of Competence 4 - Care planning and collaborative practice
- Domain of Competence 5 - Loss, grief and bereavement
- Domain of Competence 6 - Professional and ethical practice in the context of palliative care



Competence Frameworks in EoLC



- The aims of education have to be linked to the targets of the learning ("What do we want to change?")
- The four targets: attitudes, knowledge, skills and behaviours
- Levels: Basic, intermediate, specialist, specific training (for special situations), and specific targets

Competence Frameworks in EoLC

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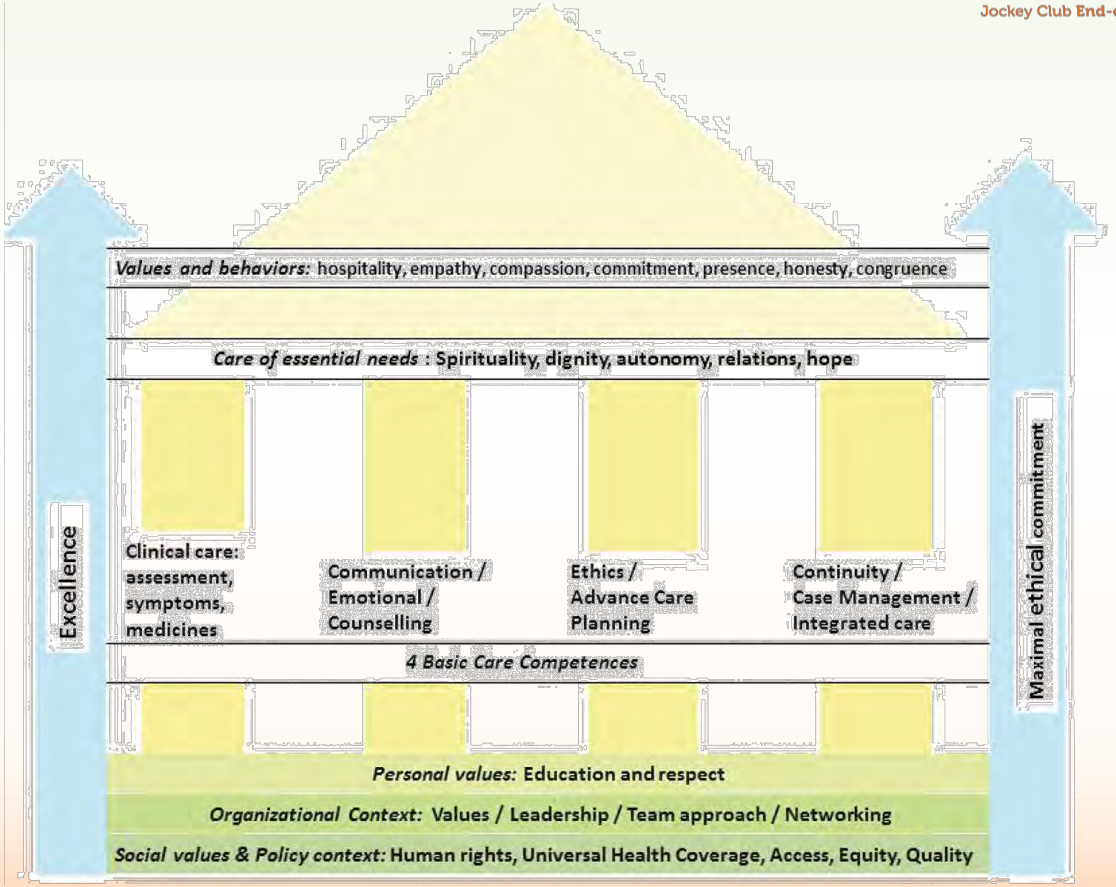

Competence Frameworks in EoLC

Level	Targets	Aims & Competences	Preferred method	Preferred time
Special targets	Clinical and organizational palliative care leaders	Leadership, managerial issues, training for trainers, research, planning, evaluation, quality assessment and improvement	Organizational stages, workshops, and courses	Crucial in the initial phases, and/or when required
Specialist	Professionals willing to work in specialist services, and reference professionals	Knowledge and skills to response to complex situations	Specialty formal 3-year fellowship, sub-specialty 1-year fellowship after training in other related specialties, and master degree	Postgraduate as any other specialty, after other specialties
Inter-mediate	Professionals dealing with high prevalence of patients in need, in chronic care specialties, long term care facilities, and reference professionals	Knowledge and skills to response to common and specific situations	Fellowship in specialist service, intermediate and postgraduate courses, and workshops	Training specialty period
Specific training (for special situations)	Professionals dealing with impact situations (policemen, firemen, rescue, etc)	To response to specific issues	Workshops, courses, and short stays	When required
Basic	All care professionals	Attitude and basic knowledge	Basic courses, sessions in services and online materials	Postgraduate or any time after

Time and Strategic Planning in EoLC Professional Training

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	AIMS	TARGETS	METHODS	ACTIVITIES	EXPECTED OUTCOMES	COMMENTS
	Start the process Create a core nucleus of national, organizational,	Decision-makers Policymakers Clinical leaders	Advocacy, awareness Attitudes Showing experiences	Meetings Basic and introductory courses: clinical, leadership,	National plan approved and going on	Pre-graduate training not a priority at this stage

0-2 years

- Mobilize key stakeholders
- Train up leaders
- Set up education framework & reference services

2-5 years

- Consolidation & expansion of service models and education framework
- Integration of EoLC professional training in formal curriculum

5+ years

- Full coverage EoLC professional training in pre-/post-graduate levels, for all professionals and specialties

8 Steps in Designing Education Plan

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Step 1: Conducting situational analysis

Step 2: Select and conduct initial activities

Step 3: Identify and train national, clinical and organizational leaders

Step 4: Build a solid nucleus of reference services

Step 5: Establish methods to provide training support, follow up and accompany the leaders

Step 6: Design and develop the strategy of implementation at short-, mid- and long-term

Step 7: Define the National Educational Standards based on national and international consensus

Step 8 Identify specific targets, barriers and resistances and design specific strategies to face

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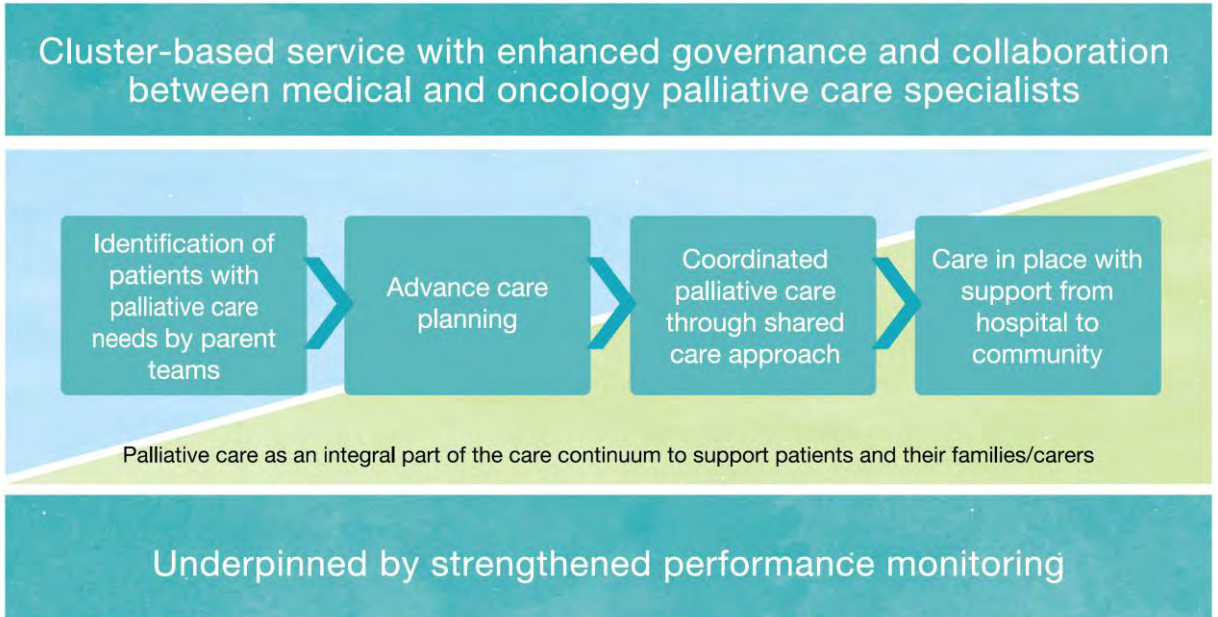
Situational Analysis:

- Aging trend and health conditions
- Regional strategies for EoLC



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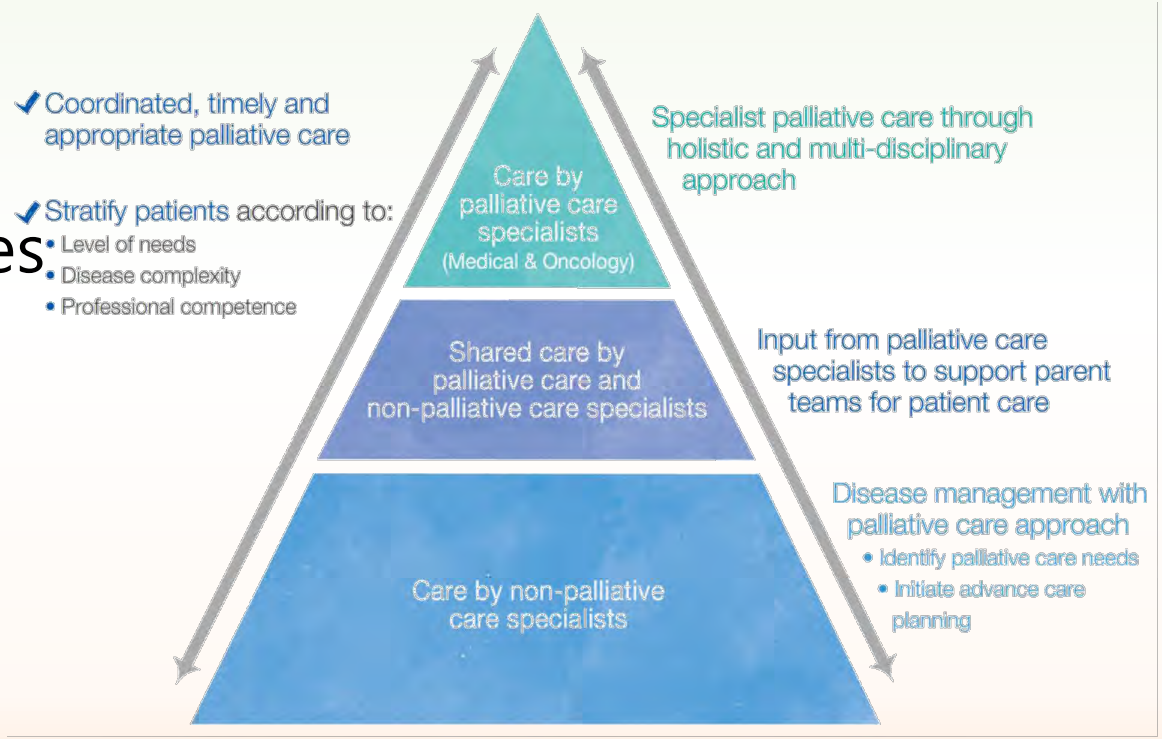

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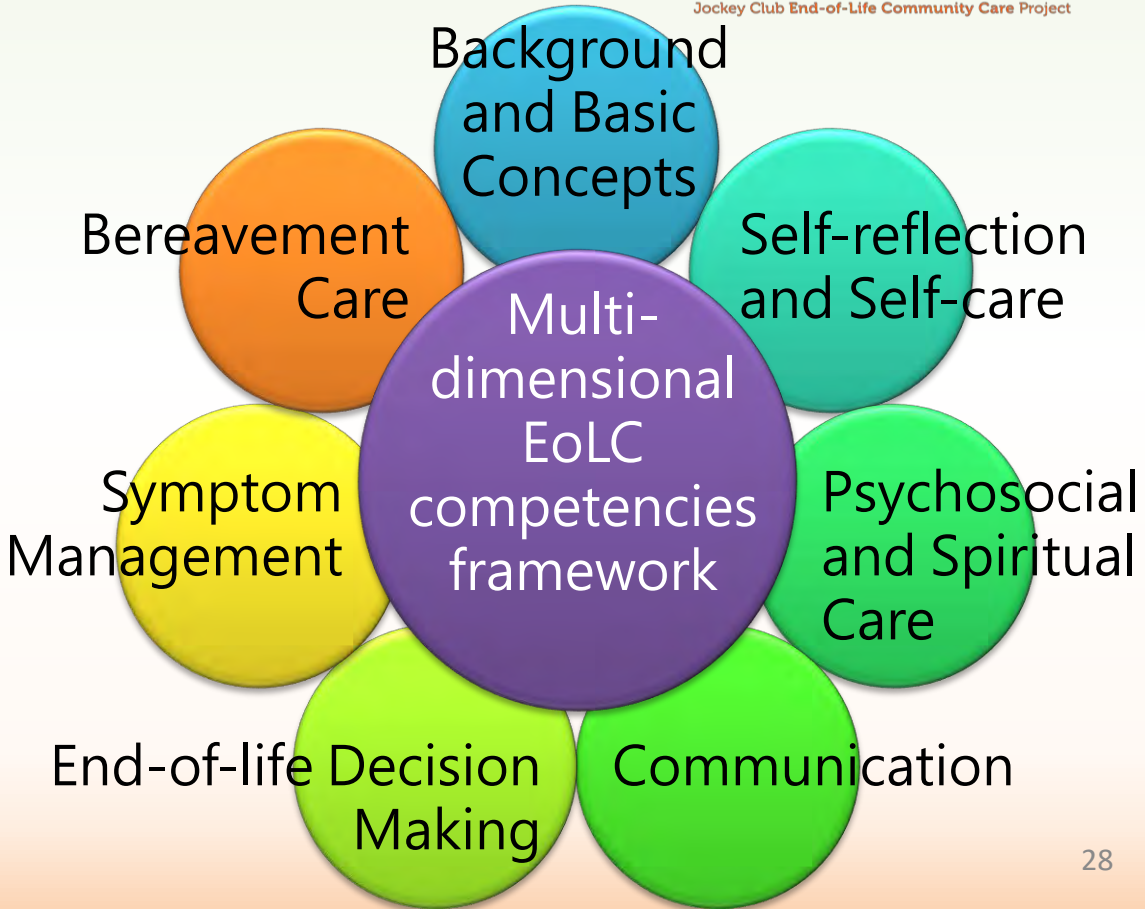
Select and conduct initial activities:

- Competence based: establish competences



The JCECC Project

Select and conduct initial activities:

- Need based: Identifying the training needs among professionals in EoLC

The JCECC Project

Select and conduct initial activities:

- Target based: identify targeted groups for training and appropriate strategies
  - Leaders: policy and administrative leaders, organizational leaders and clinical leaders
  - Health and social care professionals working in elderly and EoLC field
  - All health and social care professionals

Overview of JCECC Professional & Leadership Training

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International Conference

Specialized training workshops & seminars

Fundamental Training Course in EoLC

Leadership Training Programme

Policy roundtables & Executive Forums

Publications: Books, Guidelines, Game Cards

Health and social care professionals

Organizational & clinical leaders

Policy and administrative leaders

International Conferences

- 2017: 390 participants
- 2018: 620+ registered

Policy roundtable & Executive Forums

- A platform to facilitate proactive engagement in EoLC from different stakeholders
- Up-to-date development, challenges and barriers and possible solutions

Leadership Training Programme 2016

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- One year training programme with 24 clinical leaders who are providing EoLC services in community settings
- Format: 3 full-day lectures+9 study groups (monthly sessions)
- Study groups: presentations on specific topics and case discussion
- Topics includes: evidence-based psychosocial care in EoL, preventing professional burnout in death-work, community engagement in EoLC, Contrasting EoLC for cancer and non-cancer, communication between families & professionals, EoLC for patients and families with severe mental illness, family dynamics at EoLC, anticipatory grief and ACP and legal issues

Leadership Training Programme 2017

- One year training programme with organizational leaders
- Screening: nominated by supervisor, relevant working experience, area of interest and person statement
- 34 applicants and 24 were selected





Leadership Training Programme 2017

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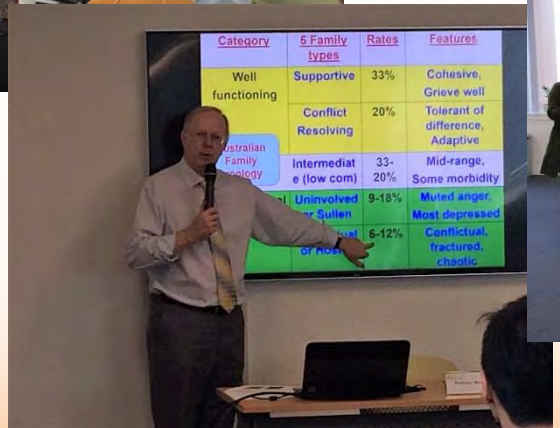
Leadership Training Programme 2017

End of Life Care Project for People with Mental Disability	Project Compassion
Advance Care Planning Project for Persons with Dementia	My Wishes: An End-of-Life Platform for Record Keeping
Preparing for a Better Future That Includes Ageing Parents – East Programme	Dysphagia diet for frail elders
Communication of ACP with Mentally Disabled Persons	Good Death Movement: Everyone in the Church Can Play a Role
Communicating Advance Care Planning with Older Married Couple	Evaluation of Spiritual Needs in Chinese Patients and Caregivers under Palliative Care in Hong Kong
Dying in Place	An introduction of JCCRC: what we are doing here in the last 10 years
Promotion Death in Nursing Home	Family-based programme as a caring intervention for the elders with terminal illness and their families in community
Advance Care Plan Programme: Promoting Advance Care Planning for Older Adults in Nursing Home	Life Story Photography
The Implementation of Advance Care Planning in the Residential Home for the Elderly	See Life Message in Horticultural Therapy
Development Programme for Staff in Residential Home for Elderly on Advance Care Planning	An Evaluation Study On the Effectiveness of “Be-with” Service to Alleviate the Grief of the Bereaved
Building Capacity for Eolc in home	Fadeless Love
Unleash the Lucky Bag	

Professional Training workshops



Professional Training workshops

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By Key Domians	Number of Events held	Total Enrollment	Background of Enrolled participants												Appropriate Target Estimation (%)	Attending %
			Social worker	Counsellor	Nurse	Physician	Education (in healthcare)	Volunteer	Family/ caregiver	Student (Social Sciences / healthcare)	Student (Others)	Religious practitioner	Other healthcare worker	Others		
			Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)	Freq. (%)		
Psychosocial and Spiritual Care	15	740	319	16	86	5	72	5	0	82	17	32	79	25		
			43.30%	2.26%	12.36%	0.74%	8.99%	0.69%	0.00%	11.21%	1.83%	4.32%	11.24%	3.06%	74.22%	72.31%
Communication	11	326	143	9	68	1	20	2	0	29	1	15	30	8		
			44.58%	2.66%	21.30%	0.34%	5.61%	0.62%	0.00%	7.49%	0.30%	4.79%	9.73%	2.59%	83.41%	79.01%
Bereavement Care	5	274	124	10	33	2	36	0	0	24	4	5	27	9		
			44.52%	3.66%	13.30%	0.91%	13.16%	0.00%	0.00%	7.46%	1.82%	1.62%	8.67%	4.86%	72.68%	71.76%
Self Competence in End-of-life Care	5	207	73	6	37	6	18	0	0	28	2	8	26	3		
			33.22%	2.73%	17.31%	2.61%	8.99%	0.00%	0.00%	14.54%	1.38%	4.51%	13.51%	1.19%	73.90%	63.74%
End-of-life Decision Making	4	140	70	2	35	1	9	0	0	10	2	1	9	1		
			47.00%	1.71%	35.99%	1.15%	8.95%	0.00%	0.00%	9.86%	2.00%	1.04%	8.92%	1.04%	83.61%	79.80%
Symptom Management	3	80	38	4	12	0	9	0	0	1	1	3	11	1		
			47.44%	4.35%	15.73%	0.00%	11.32%	0.00%	0.00%	1.47%	1.09%	3.64%	13.49%	1.47%	84.65%	69.69%
All Events	51	2366	959	51	398	39	209	13	45	194	69	73	220	94		
			40.64%	2.19%	17.89%	2.07%	8.74%	0.47%	1.45%	8.16%	2.89%	3.26%	9.61%	3.84%	74.97%	73.10%

JCECC Publications

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Building reference services

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- Professional Competency Model專業效能模式
- Volunteer-based Model義工支援模式
- Residential home care model
  院舍照顧模式
- Assisted family-care model
  家庭協作模式
- Community-care model
  社區照顧模式
- Non-cancer model
  非癌症照顧模式

Training Evaluation Framework

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Education Domains

- Background & Basic Concepts
- Psychosocial and Spiritual Care
- Communication
- End-of-life Decision Making
- Symptom Management
- Bereavement Care
- Self-Reflection and Self-Care

Evaluation Domains

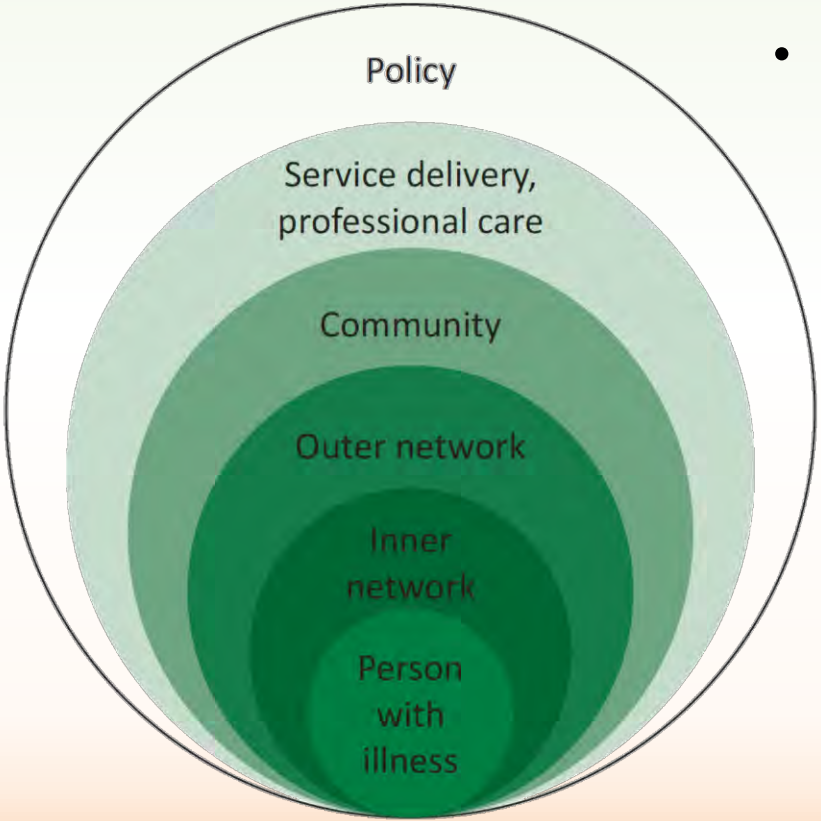
- Overarching Values and Knowledge
- Community End-of-Life Care Support
- Psychosocial and Spiritual Care
- Communication Skills
- End-of-life Decision Making
- Symptom Management, Maintaining Comfort and Wellbeing of Patients & Families
- Bereavement Care
- Self Competence in End-of-Life Care

End-of-Life Care Educational Objectives

Rethinking about…

- Who is professionals?
  - Patients: expert of their own health conditions and preferences
  - Caregivers: expert of patients' daily life and care
  - Neighbors/ community members/ volunteers: expert of social support and community resources
- A de-professionalized approach to EoLC

Circles of Care



- Building resilient networks
  - an inner network contains two to five people who take care of physical care, accompaniment,
  - emotional support or attention to symptom control issues
  - Family, friends, neighbors, community members or caring professionals forms an outer network to support the inner circle through supporting tasks of life such as washing, cooking, cleaning, walking the dog and working on the garden

All of us are professionals!

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Tier 1 — Those that require general end of life care awareness, focusing on a community development, asset based approach to care.

This tier outlines the knowledge and skills that will support individuals accessing end of life care, as well as their family, friends and carers, to ensure they are making the most of the support on offer and are able to plan effectively for their own current and future care needs. This tier is also relevant to those working in health and social care who have limited contact with individuals approaching the end of life.

A community development, asset-based approach to care encourages individuals to look beyond traditional care provision, ask 'what is important to me?' and how this could be achieved alongside care and support from health and social care professionals. This might include: the strengths and abilities of individuals approaching the end of life; the strengths and abilities of their family, friends, loved ones and carers; and the potential of the community to provide care and support.

The tier will be relevant to you if:

- You are a member of the public
- You have been diagnosed with a life limiting condition
- You support someone with a life limiting condition
- You work in the adult health and social care sector but have limited contact with anyone approaching the end of life. For instance, you might deliver care and support in ophthalmology or physiotherapy, or may be in a role that doesn't deliver care and support such as administration or maintenance.

JCECC efforts to Community Engagement

心安·家寧

有您幫助的堅持

承諾·踏行

JCECC efforts to Community Engagement

JCECC efforts to Community Engagement

Future Directions & Implications

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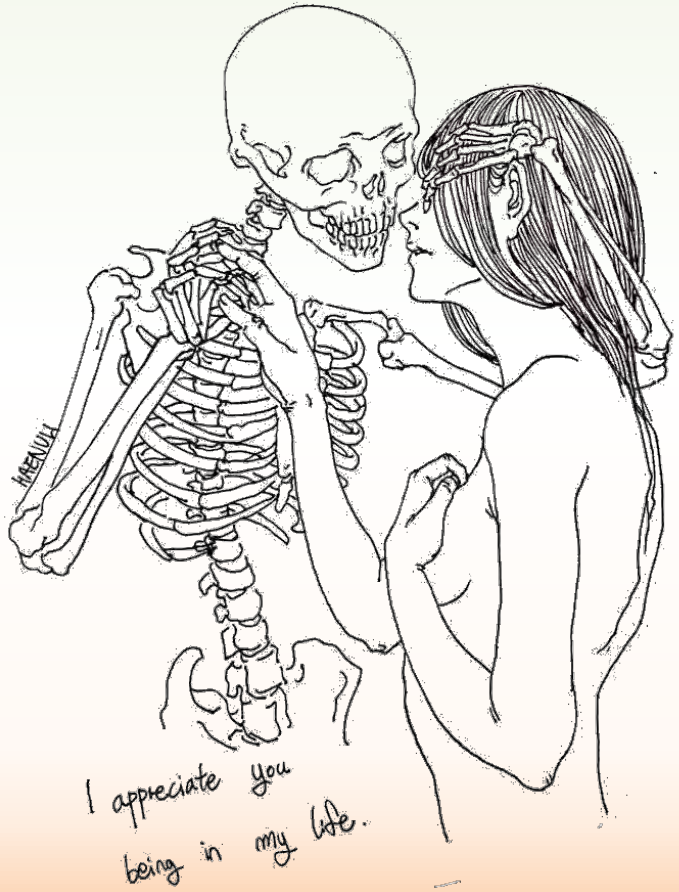
- Consolidating and benchmarking the initial experience in building referencing models through protocols and training
- Train the trainers, empowerment of leaders
- Setting up formal curriculums for CPD, undergraduate and post-graduate training, and accreditation system
- Make good use of ICTs
- Systemic evaluation
- Sustainable development



Thank you!

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