Medical Principles May drive quality of dying in Hong Kong

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Dying well as a goal

Terminology

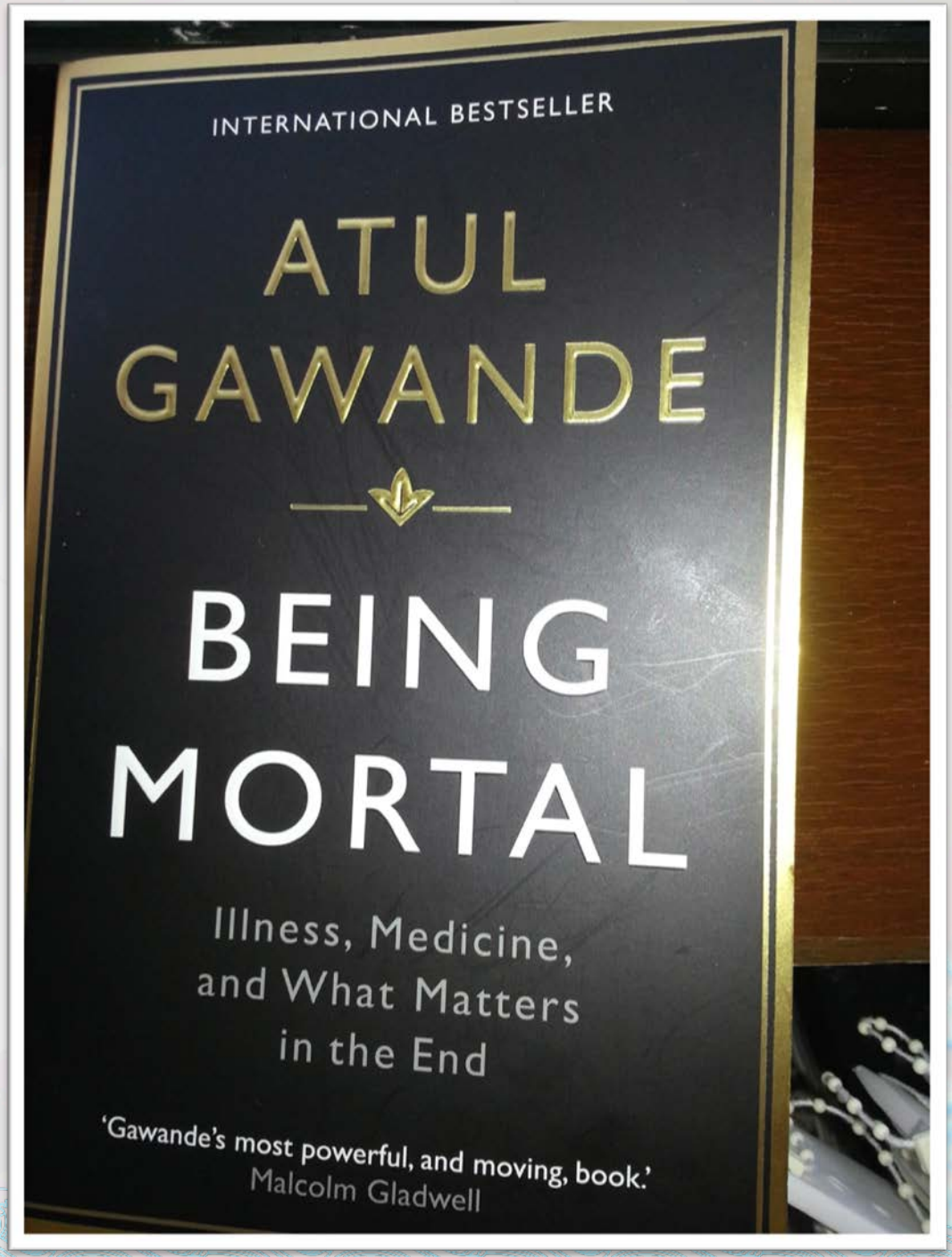
- End of life care (EOL) v. palliative care?
- Formal training of doctors: palliative medicine is a recognized specialty.
  PgDip in End of Life Care (CUHK): multidisciplinary
- EOL is a more general term that is widely adopted worldwide in relation to quality of care. Eg Quality of Death Index referred to quality of end of life care; Dying without Dignity-Parliamentary and Health service Ombudsman into complaints about end of life care

Definition of End of Life Care
General Medical Council, UK 2010

People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

The Gold Standards Framework Prognostic Indicator Guidance 2011


INTERNATIONAL BESTSELLER
ATUL GAWANDE
BEING MORTAL
Illness, Medicine, and What Matters in the End
'Gawande's most powerful, and moving, book.'
Malcolm Gladwell

Conceptual issues in elder care

- ‘As people’s capacity wane, whether through age or ill health, making their lives better often require curbing our purely medical imperatives- resisting the urge to fix and fiddle and control’

Courage

- ‘To confront the reality of mortality-the courage to seek out the truth of what is to be feared and what is to be hoped’
- ‘The courage to act on the truth we find’

The Economist Intelligence Unit

An Economist Intelligence Unit study, commissioned by the Lien Foundation

THE 2015 QUALITY OF DEATH INDEX

RANKING PALLIATIVE CARE ACROSS THE WORLD

KEY FINDINGS INFOGRAPHIC

Ranking in Hong Kong

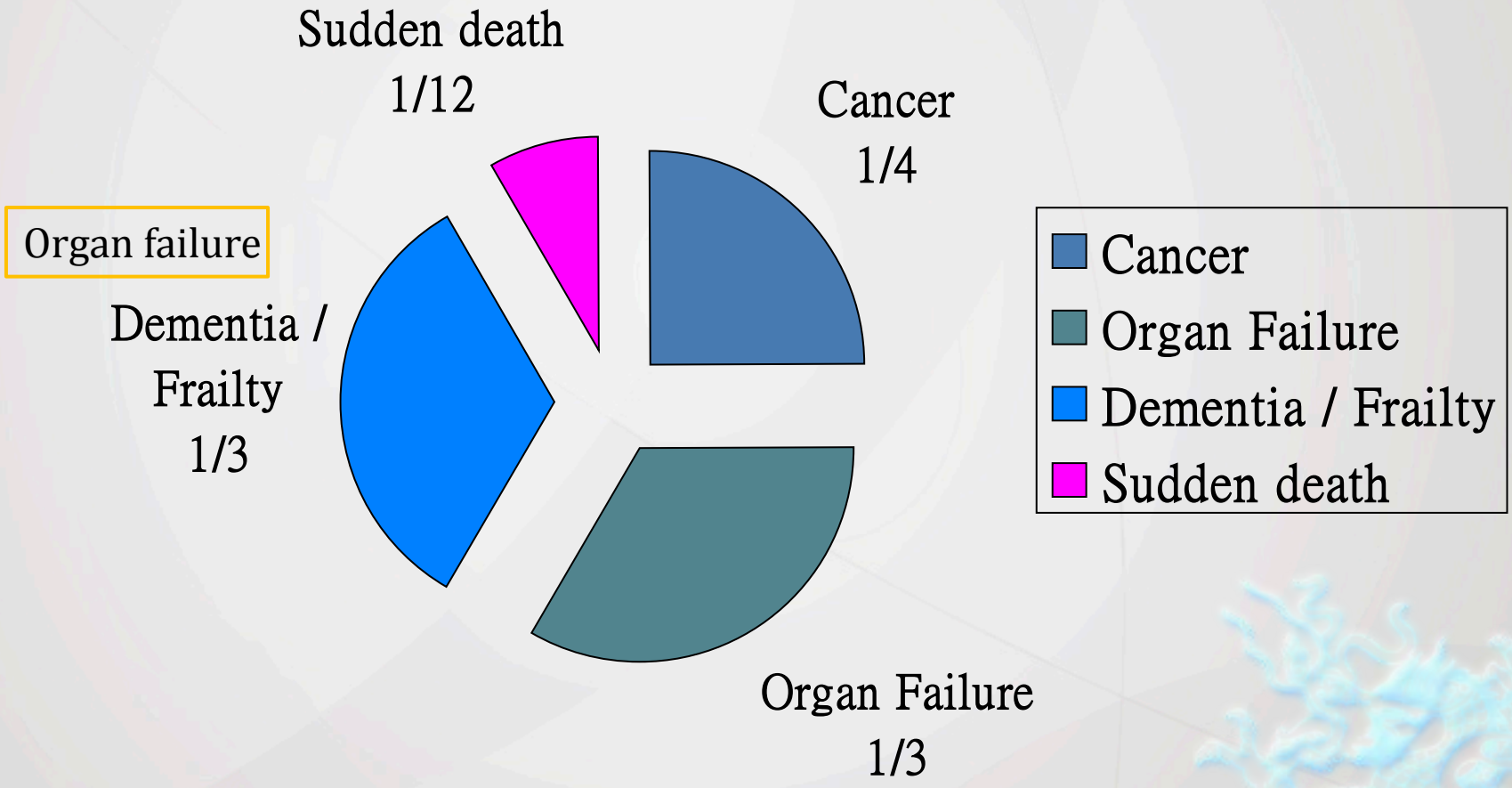
	Ranking (total 80 countries)
OVERALL RESULTS	22
Palliative and healthcare environment (20%)	28
Human resources (20%)	20
Affordability of care (20%)	18
Quality of care (30%)	20
Community engagement (10%)	38

Local scene in 2008

- Vast majority of palliative care services catered for cancer
- Little or non-existent non-cancer palliative care or end of life care
- Aggressive (and futile) therapy often applied to frail elderly patients with advanced diseases
- “Revolving door” phenomenon in last year of life

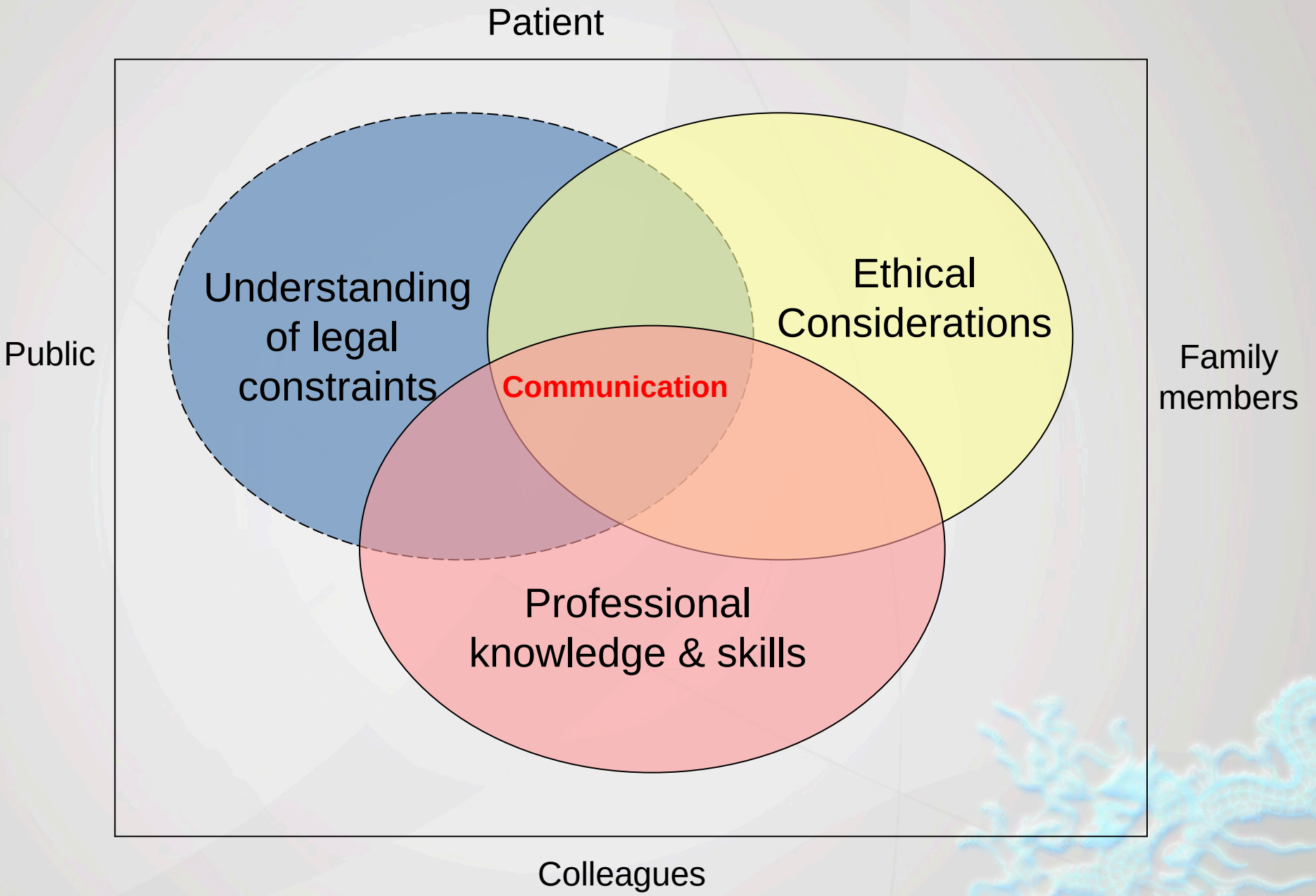
While cancer is a primary focus for palliative care, most died from non-cancer causes

Significant proportion died from organ failure



Gold standards Framework, UK, June 2006

The Modern Doctor



Differing perspectives

- HA: drugs, symptoms, care pathways
- Social: EOL care is medical
- Legal : Coroner’s ordinance governing RCHEs: deaths to be reported to the police
- Ambulance: Ordinance stipulates resuscitation without exceptions
- The person: peaceful painless death with dignity in a preferred environment; own wish regarding life sustaining treatments to be respected

- ‘The only spiritual attention that the majority pay to the dying is to go to their funeral’

Tibetan Book of the Dying. Rider. London
Rinpoche S (1992)

Ethical principles: theory versus ethnic and cultural variations

- Dying well seldom discussed as an ethical issue in the healthcare or public arena in Hong Kong
- Debates regarding whether ‘Western’ concepts are applicable to ‘Asian’ culture, especially the concept of autonomy, said to be heavily influenced by Confucianism where the family is the basic unit rather than the individual
- Academic philosophical discourse differ from views from patients and the public

Principle Based Ethics

- **Justice**
- **Autonomy**
- **Non-maleficence**
- **Beneficence**
- **Futility of treatment**
- **Informed Consent**
- **Truth telling**

Euthanasia

- Legalized in some Western European countries and some states in US; criminal offence in HK
- One survey over ten years ago suggest that the public wish to discuss this while doctors were against. Fear of suffering, of being a burden, felling of uselessness with old age, were concerns
- Lack of palliative care services, particular for non caner patients, may be a factor. End of life care ranked very low 10/12 items in HK v. 2/12 in the UK

International Comparison

	HK	UK
Treatment for children	1	1
High technology surgery	2	7
Preventive screening services	3	3
Surgery to help people carry out everyday tasks	4	4
Health promotion / education services	5	8
Psychiatric services	6	6
District nursing and community services	7	5
Long stay hospital care for elderly people	8	10
Treatment for people aged >75	9	12
Special care & pain relief for people who are dying	10	2
Intensive care for premature babies	11	9
Treatment for infertility	12	11

Physician assisted suicide

- Criminal offense
- Intense debates in Europe and the US; none in HK
- ? No individual autonomy as a concept: part of a family which has responsibility in taking care of sick/dying members
- Avoidance of discussions on dying
- Low awareness of medical ethical principles
- Distorted perception of efficacy of drugs and modern technology: the living for ever syndrome

Advance directives and other legal issues

- Law Reform Commission proposed concept of advanced directives in 2006
- Hospital Authority drew up form in 2010: Covers cardiac resuscitation, artificial nutrition and hydration, and artificial ventilation. Allows change in choice any time.
- Little public/professional promotion or awareness.
- Wishes expressed may not be respected by family or healthcare providers
- Care of Patients with end stage dementia surrounded by many misconceptions

The Current medical scene

- Heavy emphasis on life-sustaining treatments
- Paternalistic attitude among many staff
- Avoidance of discussions relating to dying process
- Lack of training and skills in communicating with patients and relatives
- Medical ethical principles not guiding management plans

Withdrawal of life support

- Poor knowledge among family carers and the public regarding life-sustaining treatments
- Hospital Authority issued guidelines for the terminally ill in 2002:
  Emphasizes wish of mentally competent and properly informed patient to refuse life sustaining treatment, concept of futility, balance between benefit and burden of treatment, and no distinction between with holding and withdrawing of treatment. However, points to cultural difference in the interpretation of autonomy, where the opinion of family members need to be taken into consideration. 2015 modification includes dementia

Development and provision of end of life care

- Driven by population ageing, advocates highlighted the poor quality of dying among elderly patients without cancer, and started CQIs and empirical research into this area, in the past 6-7 years.
- Public education events eg Press conference, media interviews, TV programmes discussing end of life care choices and advance directives.
- Strong public interest
- Current evidence suggest inequity in healthcare distribution for this sector of the population

Facilitators and barriers to an ethical approach

- Facilitators: highlight medical ethical principles as a basis for care and changing people's mindset (public, patient, family, administrators, policy makers, health and social care professionals)
- Gulf between theory and practice
- Legal ordinances amendments
- Residential care homes setting: low level of knowledge; lack of trained staff

Future tasks

CUHK Jockey Club Institute of Ageing

End of Life Care Programme:

Capacity Building and Education on End of Life

香港中文大學
The Chinese University of Hong Kong

香港中文大學
賽馬會老年學研究所
CUHK Jockey Club Institute of Ageing

捐助機構 Funded by:
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The Hong Kong Jockey Club Charities Trust

Background:
End-of-Life Care Model by HKJC

Aims

To develop culturally-sensitive, need-based, integrated and family oriented intervention models on end-of-life care

Interventions

- Hospitals
- Long-term Care Settings
- Home-based Support
- Capacity Building
- Protocol Development
- Public Education

Present Situation

- Fragmented End of Life (EOL) care system and outdated legal framework
- Knowledge gap of medical ethics leading to wish of patients not respected, e.g.,
  - reluctance to talk about death;
  - equate EOL care with terminal care;
  - unclear interface with acute hospitals and old-age homes
- Need for cultural change, new pathways and change of healthcare service model

Proposed Framework and Approach

- **Comprehensive bottom-up approach**
  - involve acute and non-acute hospitals and residential care homes for the elderly (RCHEs) in New Territories East cluster
  - target all stakeholders: policymakers; health administrators; doctors, nurses, patients and relatives, formal and informal carers, general public

- **Synergize existing structure to maximize impact**: rotation of healthcare staff between hospitals; connection between hospitals and RCHEs through the network of Community Geriatrics Assessment Team

- Necessity to integrate medical ethics, conceptual and attitudinal change; capacity building and education to achieve cultural and systemic change

- **Complement Government initiative** to develop integrated service delivery model for elderly population including EOL care

CADENZA project in Shatin Hospital

- **Aim**: improve the quality of EOL care for non-cancer patients using a continuous quality improvement initiative: Plan-Do-Study-Act model
- **Staff education**: identify EOL patients; talks to hospital staff and role-play workshops; constant sessions to collect feedback
- **Care pathway**: develop guidelines and protocol; post-discharge support such as hotline; direct admission to non-acute wards; targeted support (acute geriatric care team in acute hospital; community geriatric nurses in nursing homes)
- **Result**: less symptoms; improved satisfaction by patients and caregivers; fewer days in hospital; survival not shortened

Topics of capacity building programmes and workshops

- Current EOL care service provisions in HK and concept of dying in place
- How to initiate discussions regarding impending death and advance care planning
- Advance Directive: its legal foundation and use in HA (do not resuscitate; withholding and withdrawing artificial nutrition and hydration; use of mechanical ventilator)
- Power of Attorney: what is it and how to enact it

For lay public / patients / relatives

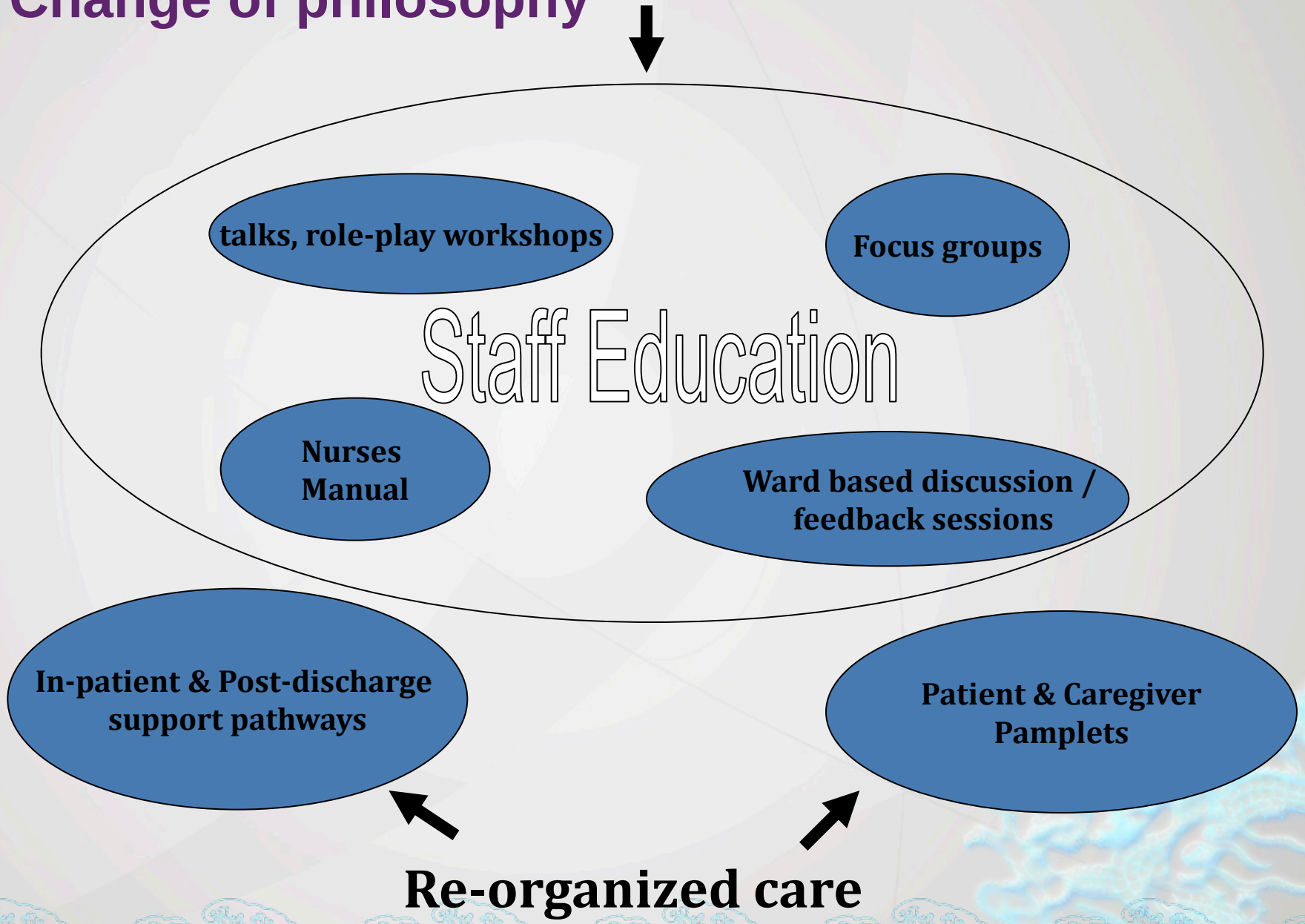
- Different life-sustaining treatments, including intended purposes and potential risks/ harms
- What happens to the body: practical guide from hospital to cremation/burial
- Putting financial affairs in order and making wills

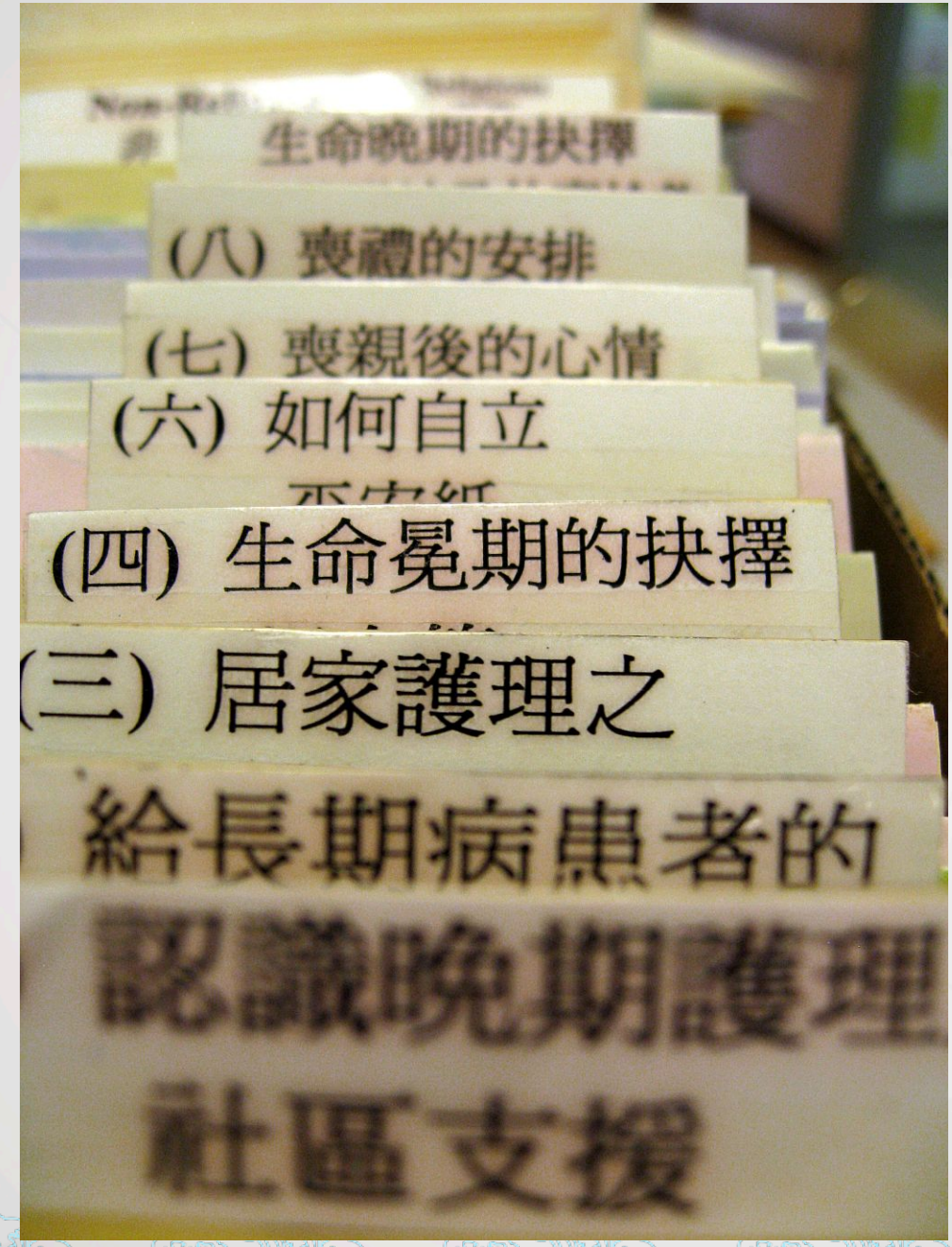
Topics of capacity building programmes and workshops

For health and social care professionals, administrators and policy makers

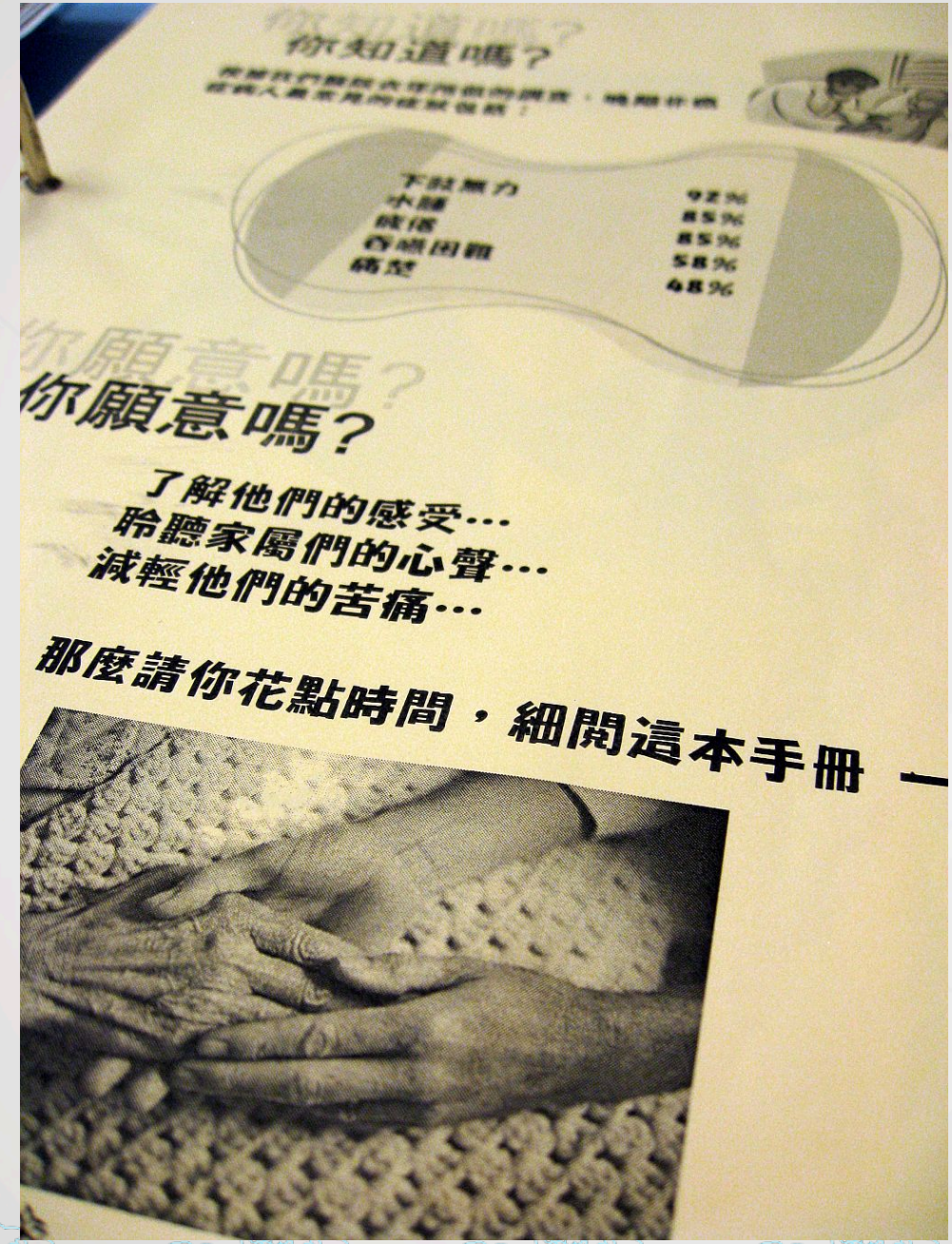
- Identifying people who are at the end of life
- Understanding the needs of the dying person and their family members, and plan management according to quality of life rather than standard disease management approach
- Ethical and legal issues: respect for autonomy, beneficence, non-maleficence, justice etc.
- Identifying and designing initiatives to overcome barriers to improving the quality of dying
- Experiences of quality EOL care in some regions and countries

Change of philosophy

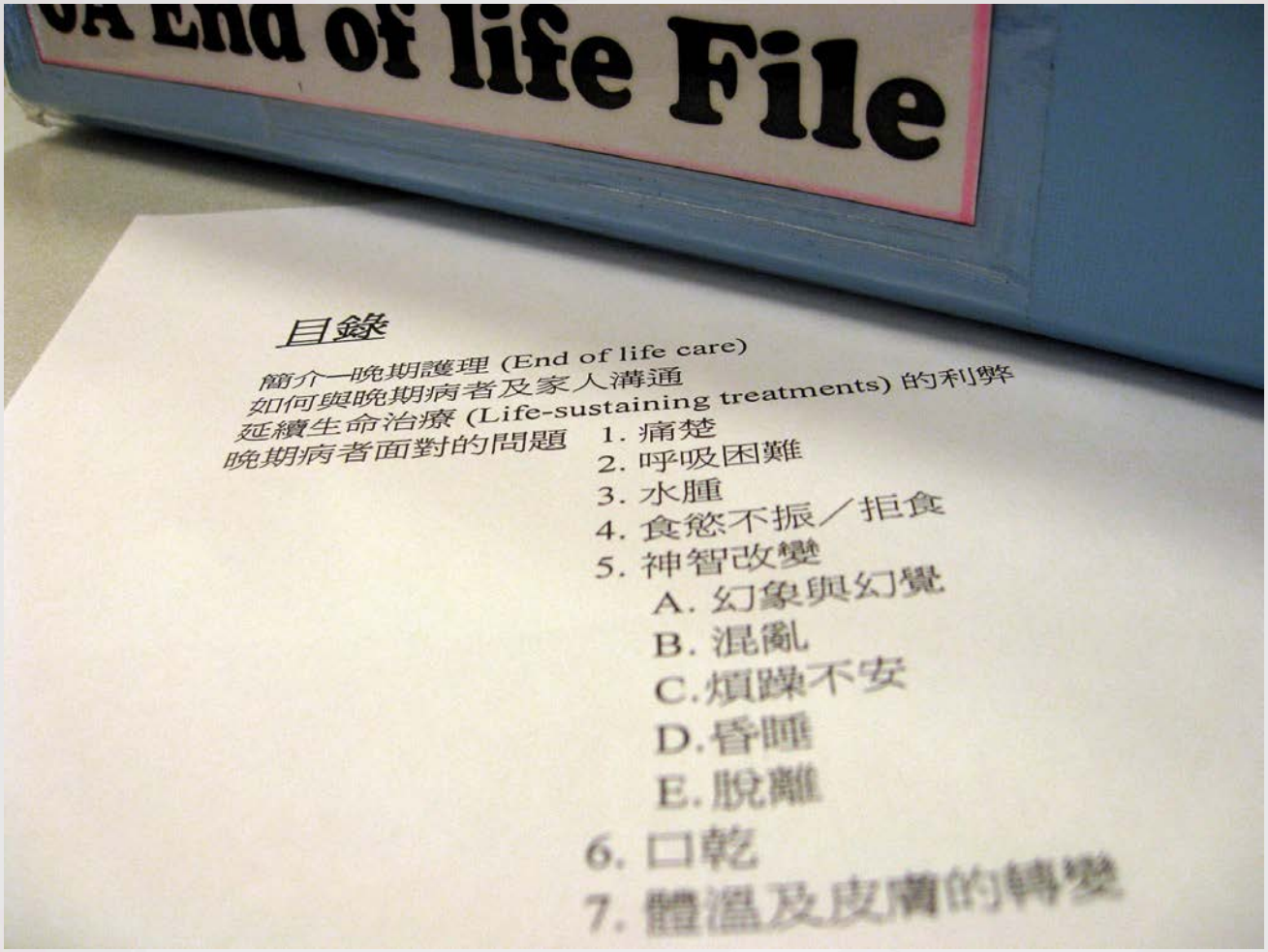




Helping
to
Make Choices



Changing Philosophy

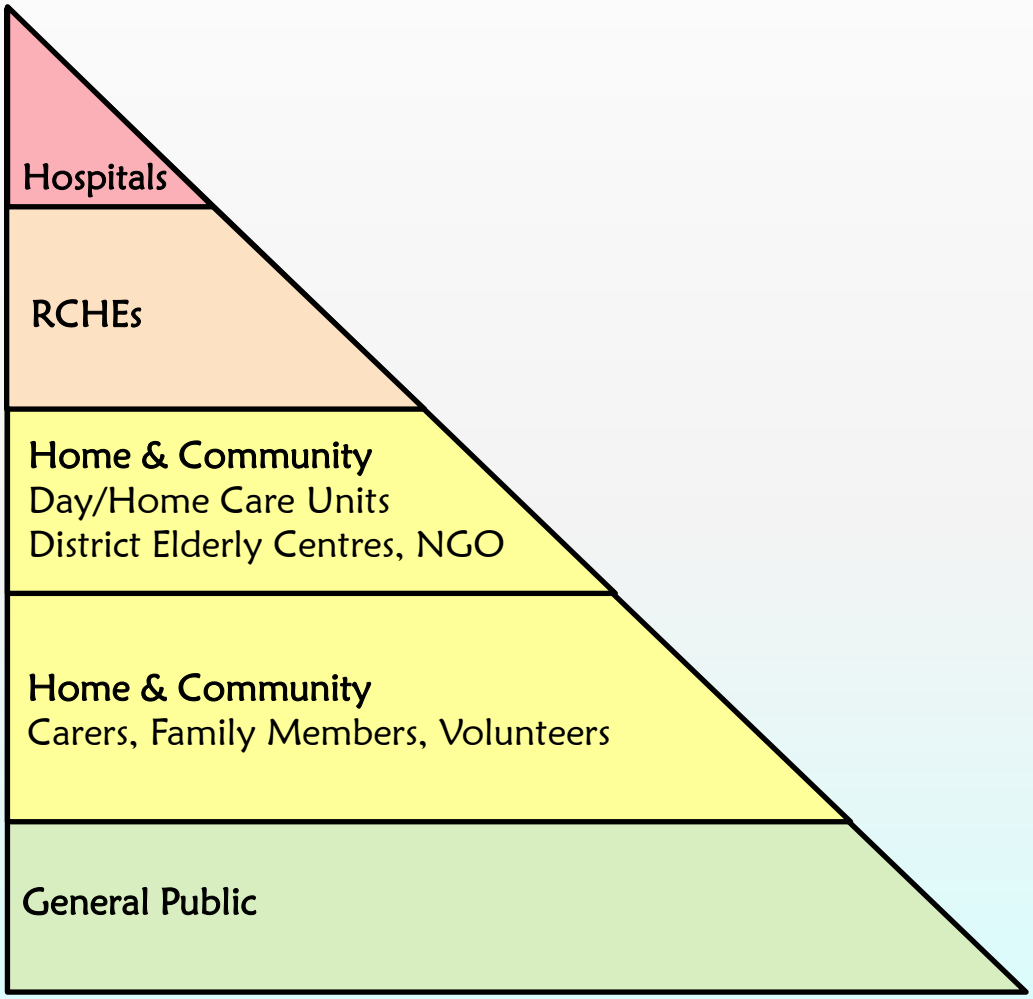


Re-focusing Care

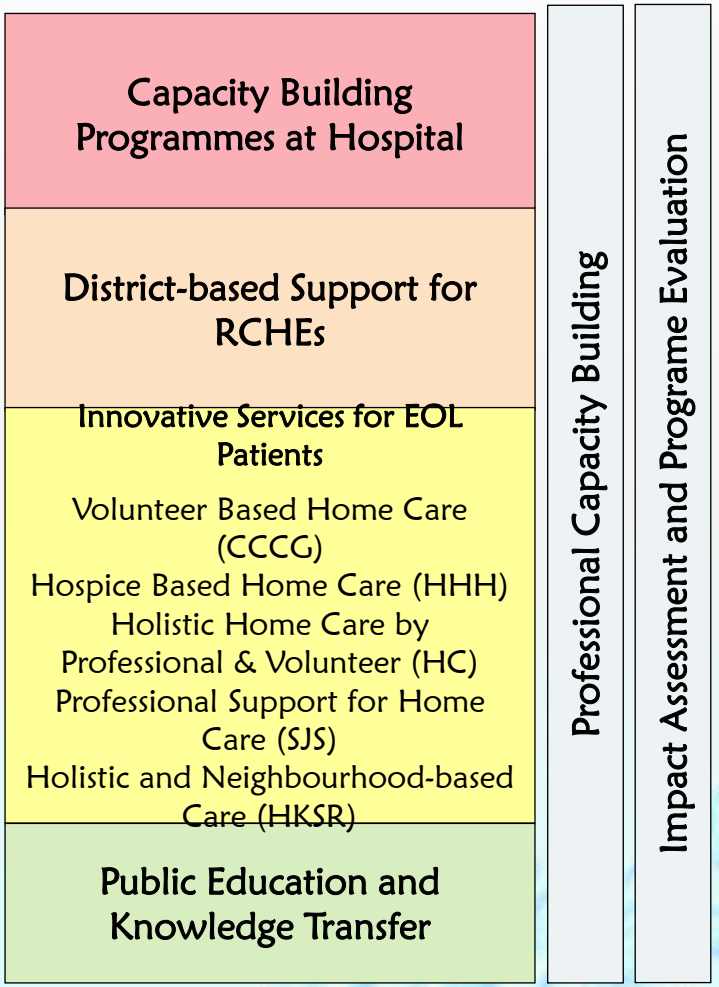
Deliverables and Impact

- Over 200 capacity building programme /workshops and seminars / public forums /information sessions in 3 years
- About 8,000 beneficiaries in 3 years
- Dedicated website as resource hub of EOL care
- Stimulus to further systemic change to government policy and healthcare system
- Cultural change to healthcare community and general public
- Synergies to implement together with the Age-friendly city movement

EoLC Systems



Project Components



Conclusion

- Population aging in HK is accompanied by increasingly poor quality of care in the dying process.
- Raising awareness of the reality of dying among the public and professionals, changing culture of care underpinned by medical ethical principles, may provide a suitable momentum to drive quality improvements.
- Centre for Bioethics and the Institute of Aging will work closely together to achieve the above objectives.