



# Adding Life to Years: Comprehensive End-of-Life Care for All

April 2024

Research • Advocate • Engage  
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# Overview

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# The Government is proposing Advance Decision on Life-sustaining Treatment Bill



## What does the Bill specify?

- Individuals aged 18+ are allowed to make an Advance Medical Directive (AMD)
- Provide for **legal status of AMD and DNACPR orders**

Advance Decision on Life-sustaining Treatment Bill

C3259

Advance Decision on Life-sustaining Treatment Bill

Contents

Clause	Page
Part 1	

## What is Advance Medical Directive (AMD)?

- A written statement
- Stating what **life-sustaining treatment a person would refuse** when he/she is no longer capable of decision-making

<p>《消防條例》 (第 95 章) Fire Services Ordinance (Cap. 95)</p> <p>版本日期 Version date 15.10.2021</p> <p>經核證文本 Verified Copy</p> <p>《(法例發布條例)(第 614 章)第 5 條》 (Legislation Publication Ordinance (Cap. 614), section 5)</p>	<p>《精神健康條例》 (第 136 章) Mental Health Ordinance (Cap. 136)</p> <p>版本日期 Version date 1.7.2022</p> <p>經核證文本 Verified Copy</p> <p>《(法例發布條例)(第 614 章)第 5 條》 (Legislation Publication Ordinance (Cap. 614), section 5)</p>
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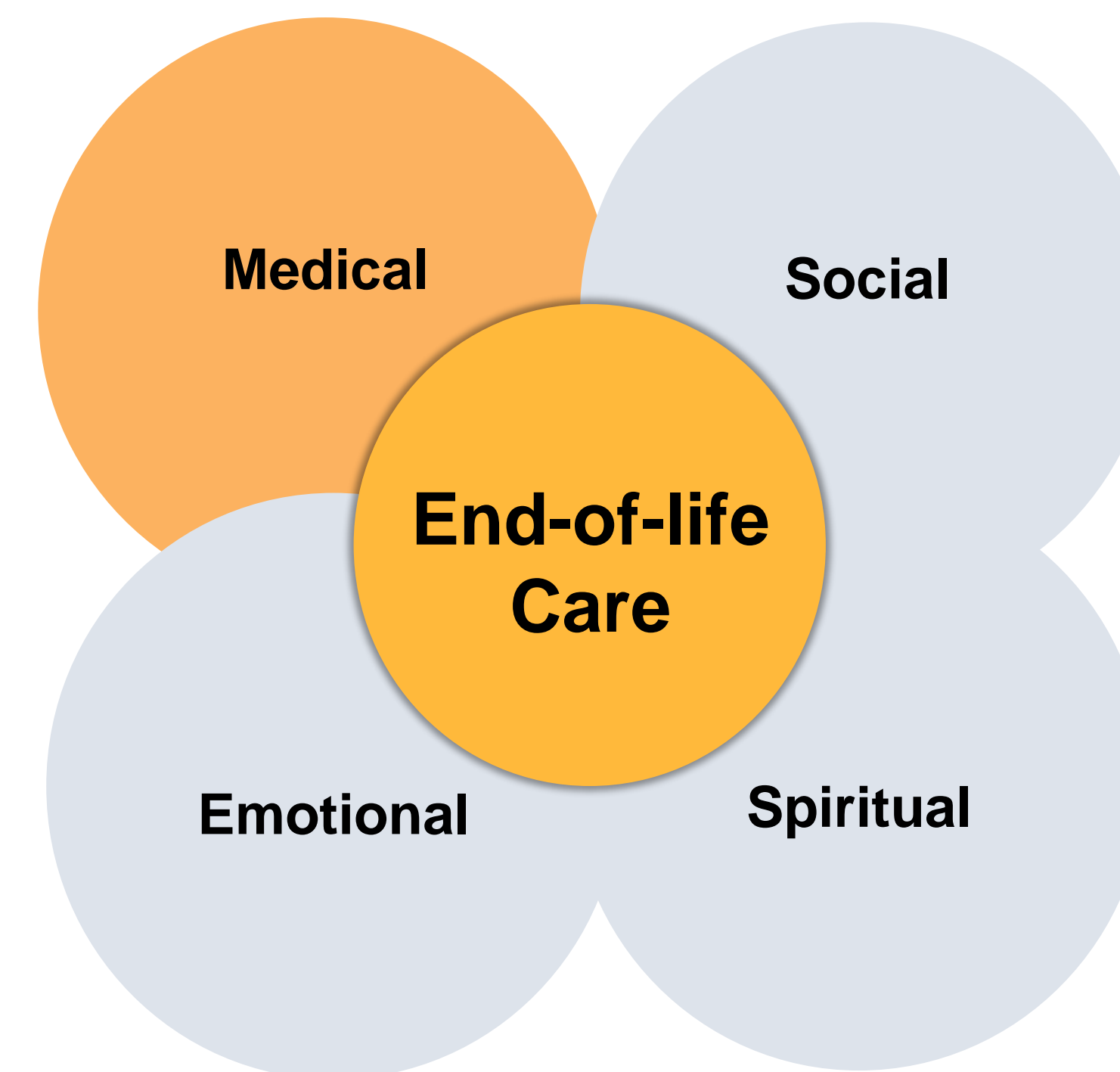
## What is different from the current arrangement?

- Provide **protection to medical professionals and rescuers**
- **Remove conflict** with AMD and DNACPR order

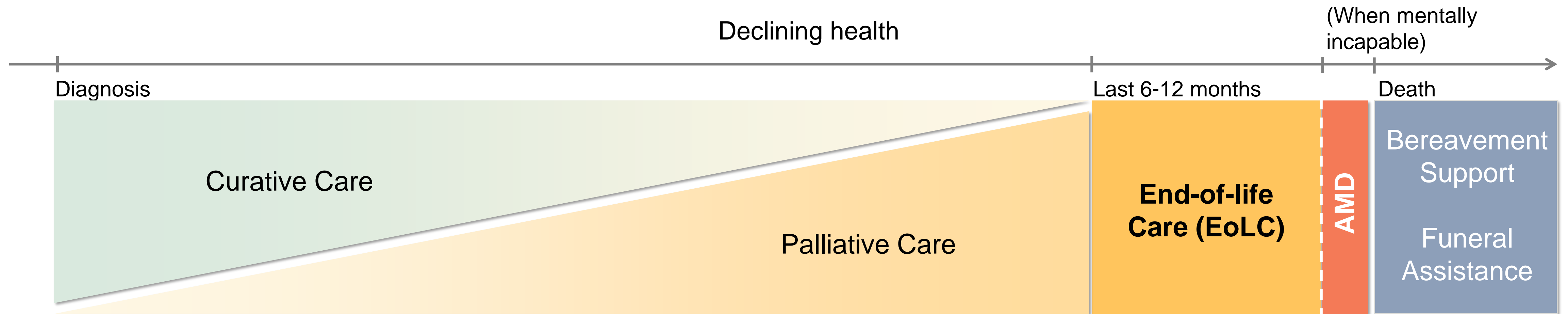
# The Bill is good but has its limitations

## The Bill alone is **not sufficient**

- 🔍 Focus on **medical** aspect of end-of-life care
- 🔍 Unable to capture full spectrum of care & individuals' wants

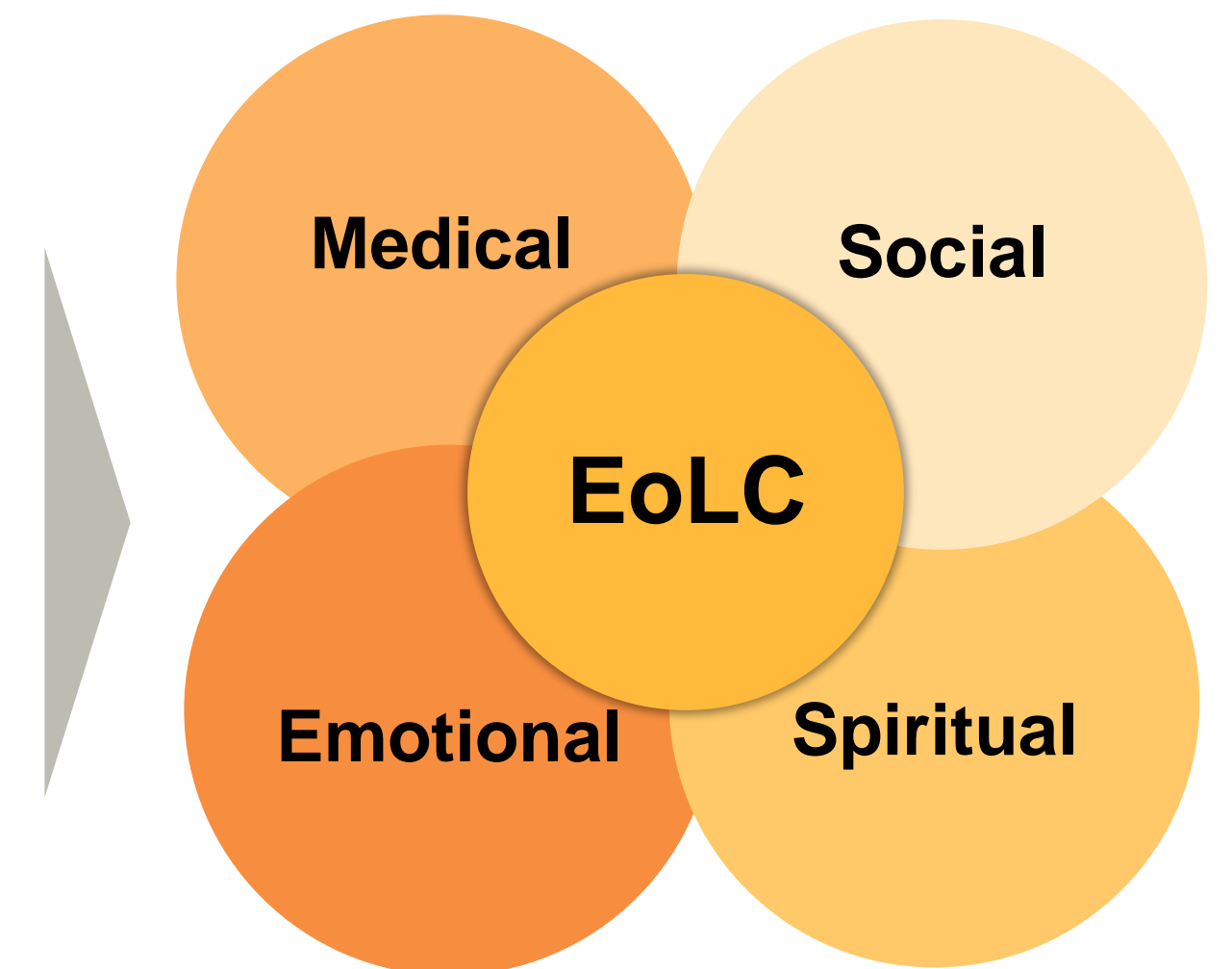


# A more comprehensive framework in End-of-life Care (EoLC) is needed



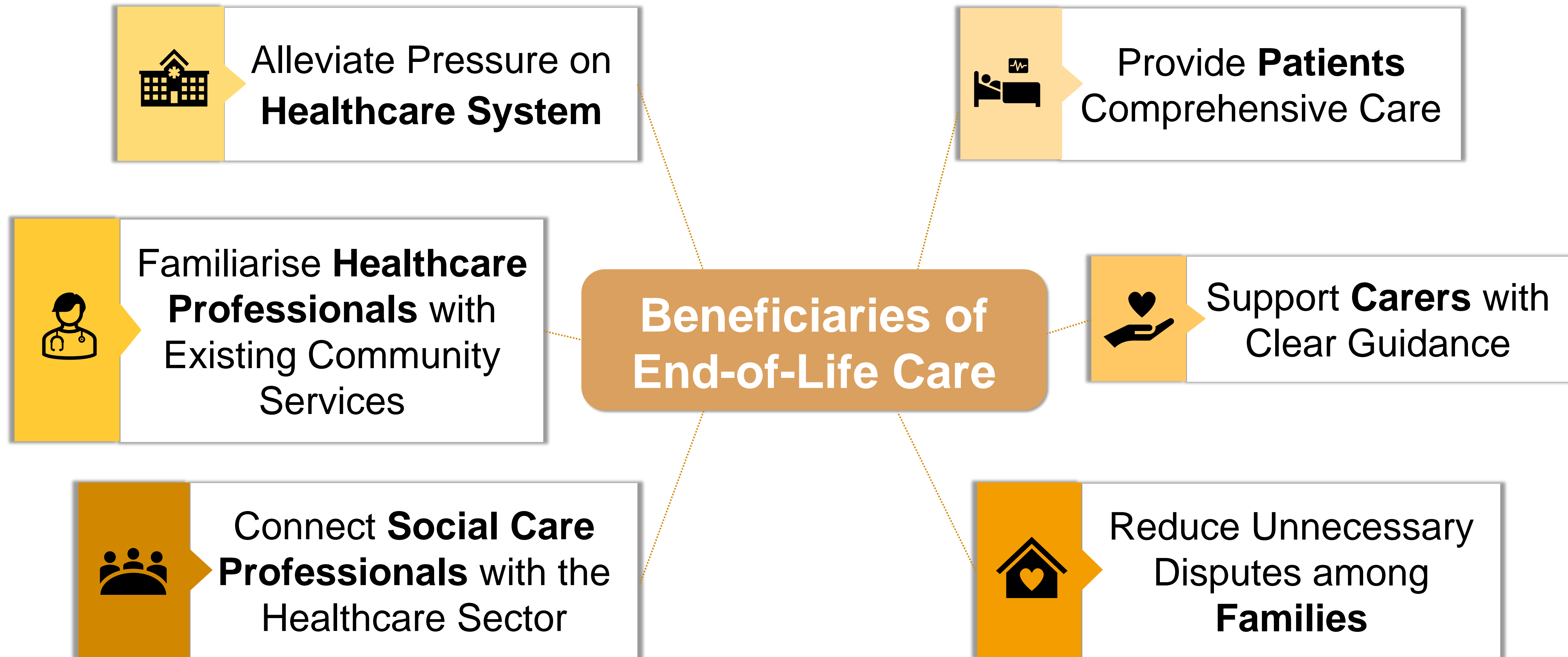
## End-of-life Care (EoLC)

- Processes of addressing the **medical, social, emotional, and spiritual needs** of people who are nearing the end of life
- Approximately the **last 6-12 months** preceding death
- May include a range of medical and social services





# Who will be benefited from EoLC?



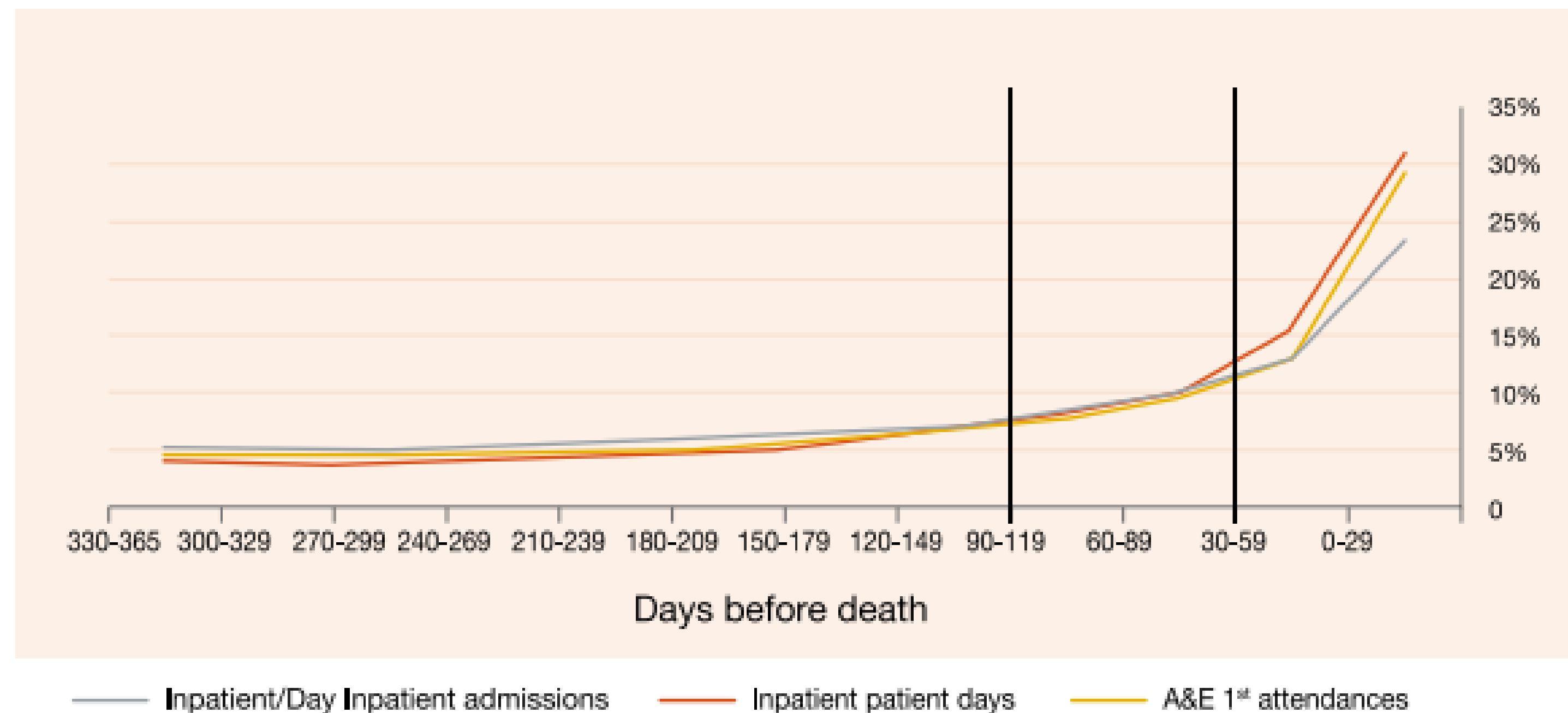
# Better EoLC benefits the healthcare system

## Medical Service Utilisation

Increases as people approach **last 6 months**, especially **last 2 months**

Considerable strain exerts to healthcare system

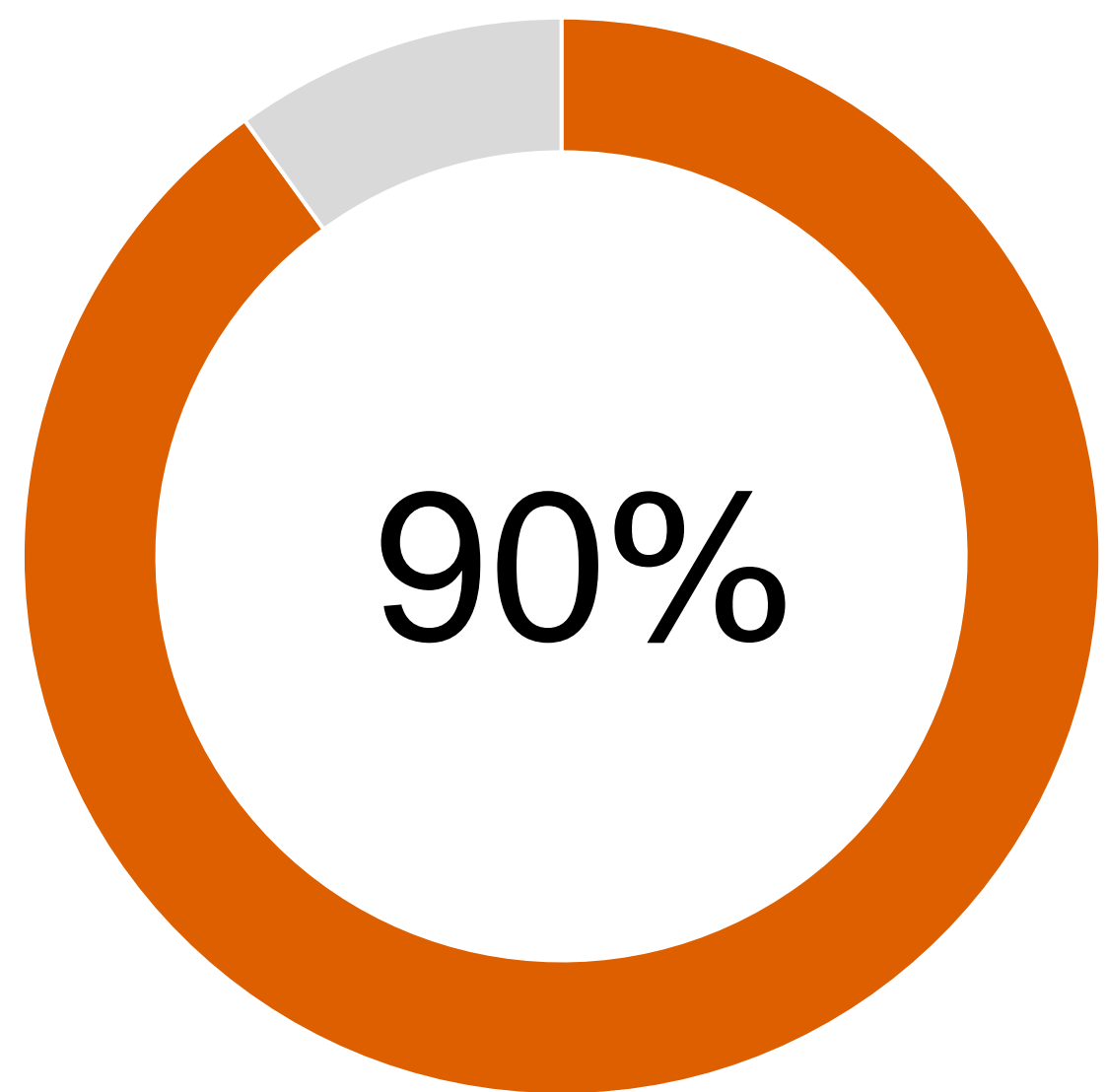
EoLC would help reduce **medical service utilisation**



# Our past research shows that there is a need for community EoLC services

## Place of Public's Preference to Spend their End of Life

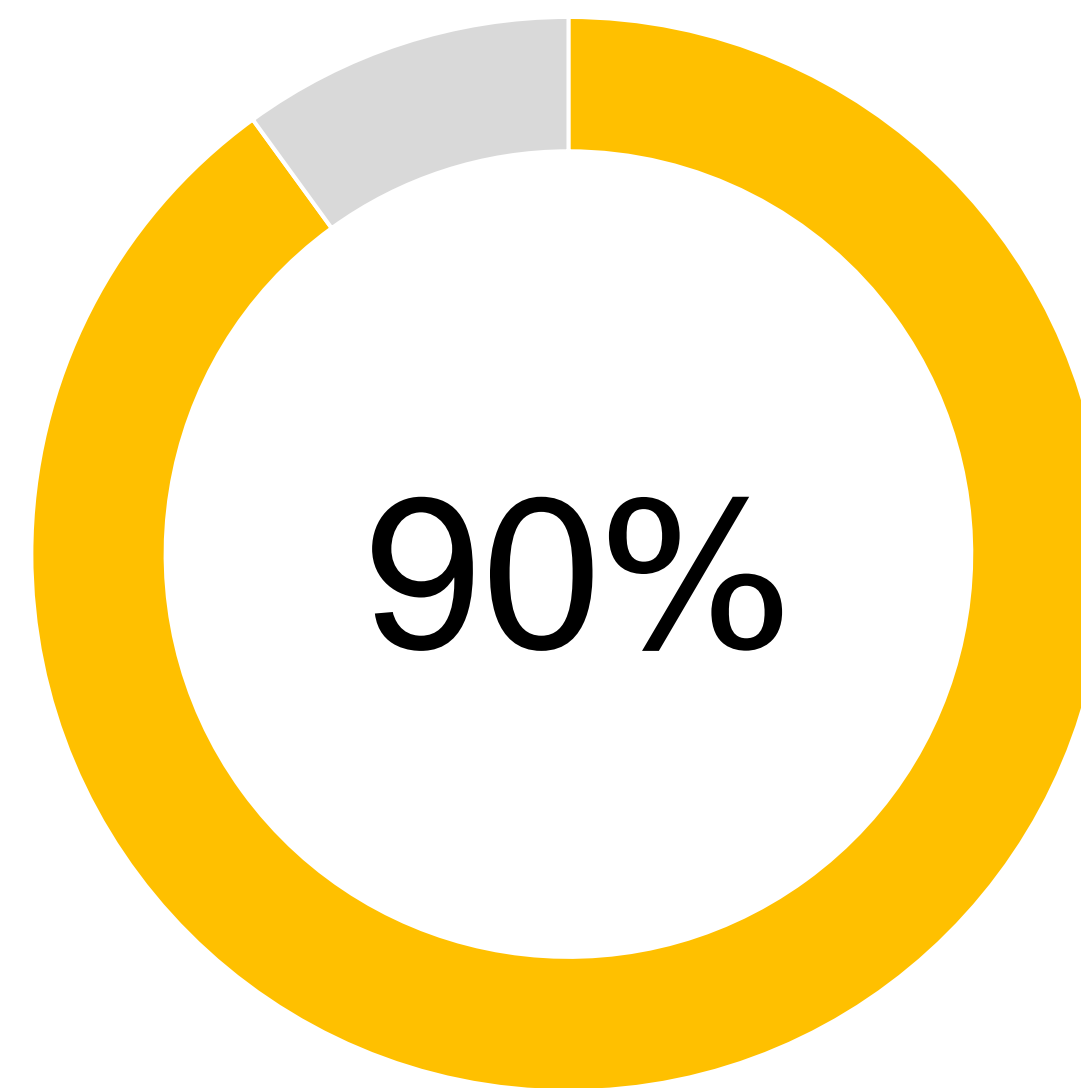
Prefer to **remain in community** at the final stage of their lives



# VS

## Places of Death

Died in **hospital**





## Other countries pay a lot more attention to community EoLC



### Singapore



- Provide home hospice care, day hospice programme, psychological support



### UK



- Nursing, emotional and personal care, as well as bereavement support at home



### Australia



- Provide information and help access to community palliative and EoLC

# Methodology and research framework

## Research Methodology



Landscape mapping on current practices



Desktop research on overseas practices

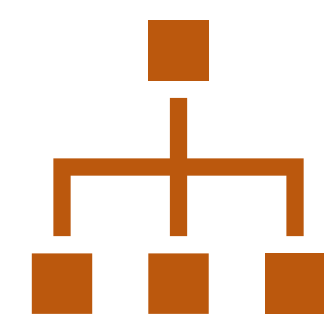


Stakeholder interview for latest insights



Qualitative analysis on EoLC development in Hong Kong

## Recommendation Direction: EoLC 123



**System**

**One Framework**



**Service**

**Two Sectors**



**Education**

**Three Strategies**





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## Part I System Level

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# Advance Care Planning is a preparatory process to supplement AMD

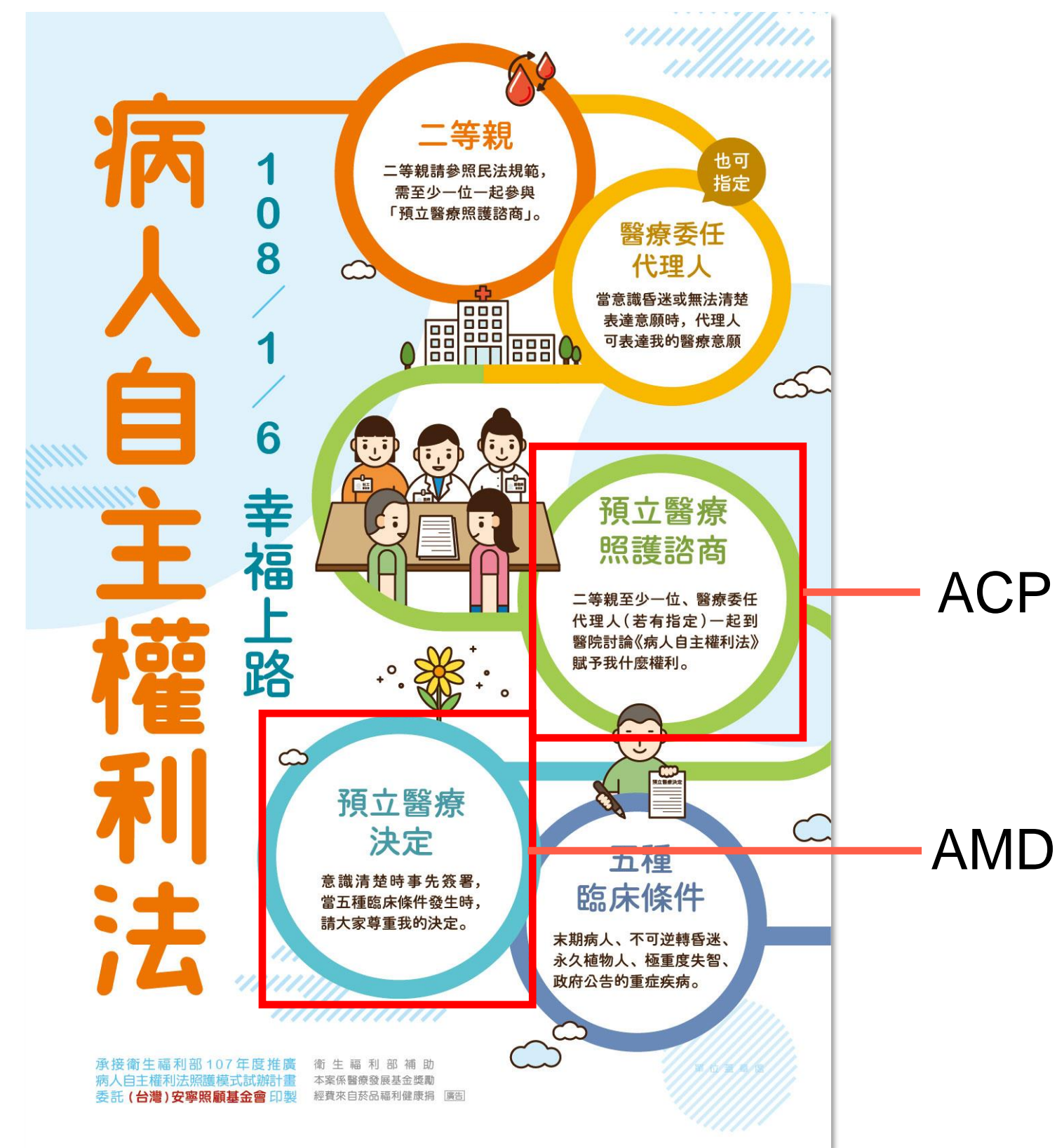
**Advance Care Planning (ACP)**

**About**

- A **communication process** through which individuals can:
  - Express their **values, beliefs, and preferences**
  - Create **person-centered plans for medical, personal, and social care**

**Benefits**

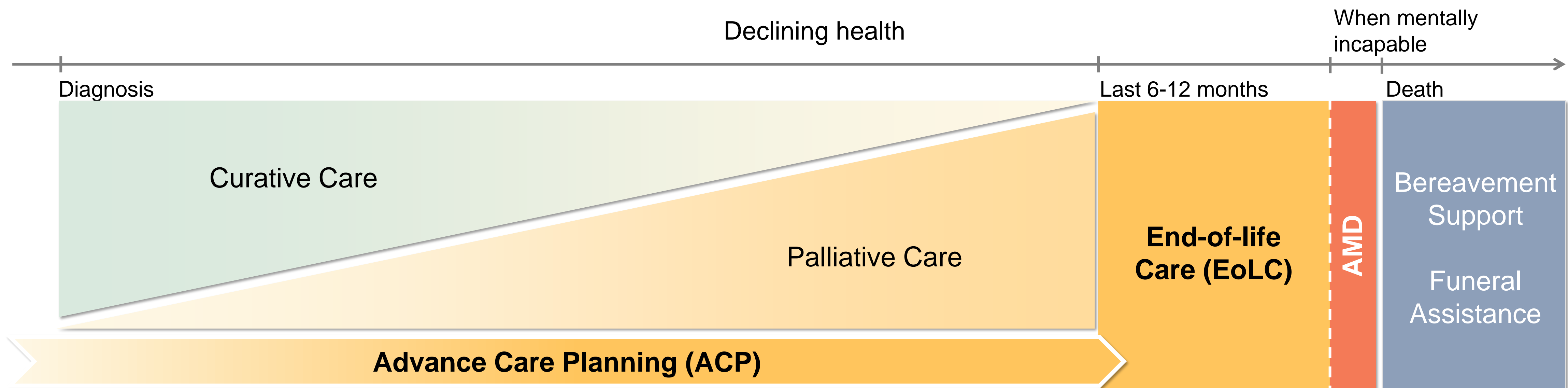
- Facilitate the **signing of legal documents (e.g., AMD)** that reflects personal preferences
- Empower family members** to make informed decision and avoid unnecessary conflicts



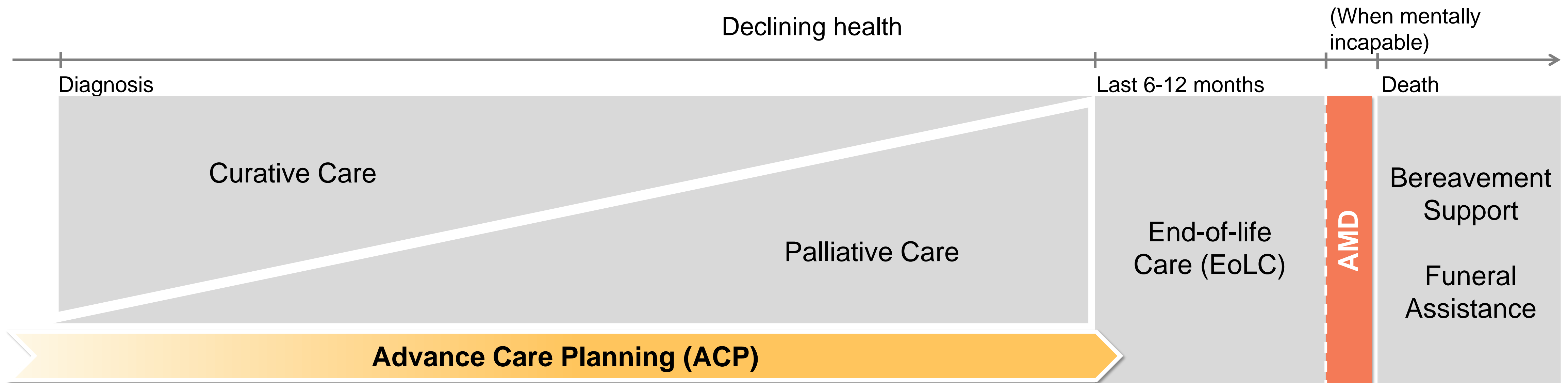
**Taiwan's Patient Right to Autonomy Act (2021):**  
Show how ACP facilitates signing of AMD



# ACP has a much broader focus and involves planning ahead of time



# ACP has a much broader focus and involves planning ahead of time



	<b>Advance Care Planning (ACP)</b>	<b>Advance Medical Directive (AMD)</b>
Definition	Communication process	Legally-binding document
Activation	Any stage of life	Mentally incapable to make healthcare decisions
Scope	Holistic (includes preferences & plans)	Medical (life-sustaining treatments to be refused only)

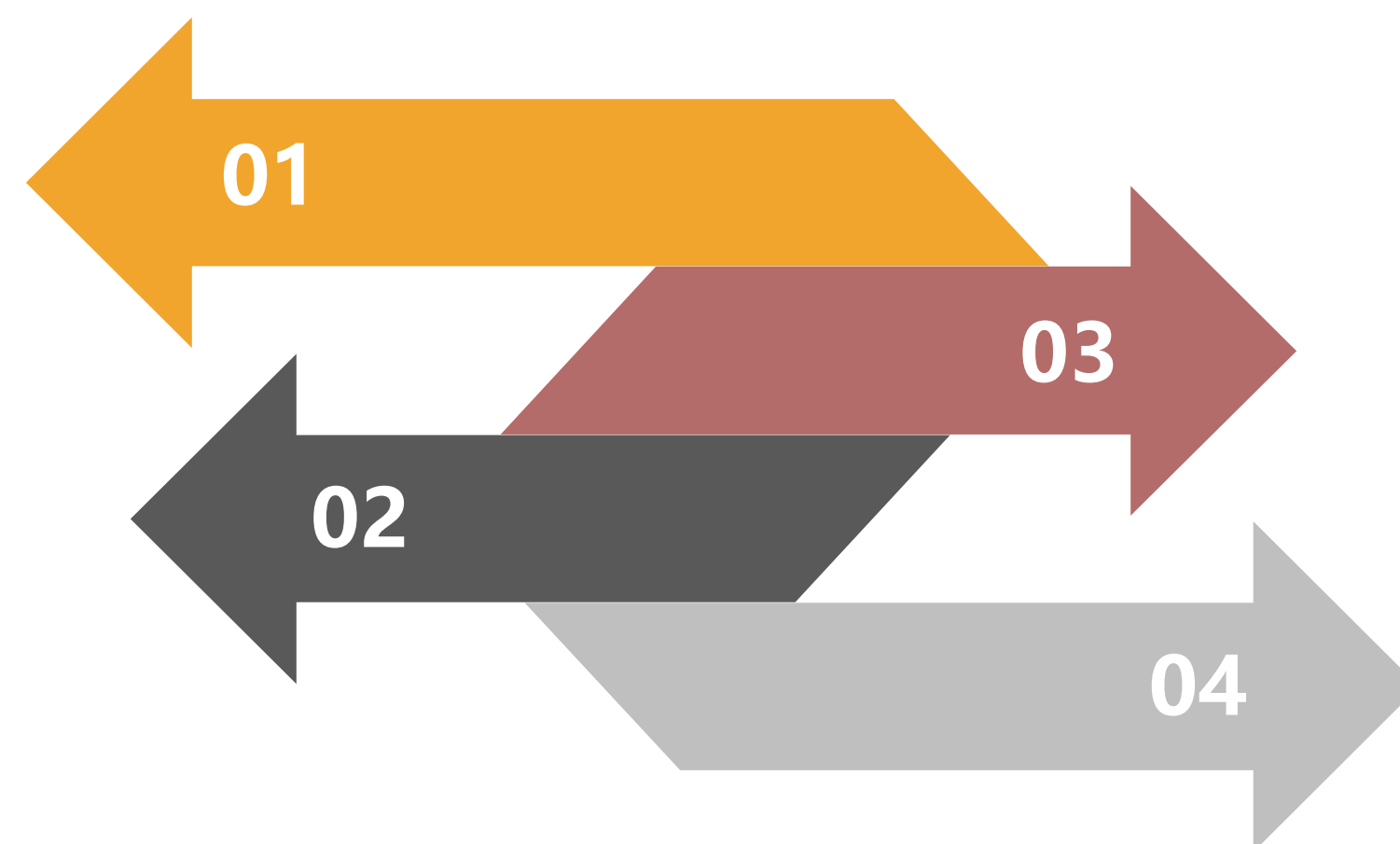


# Singapore introduced a national ACP programme

## Singapore's National ACP Programme "Living Matters"



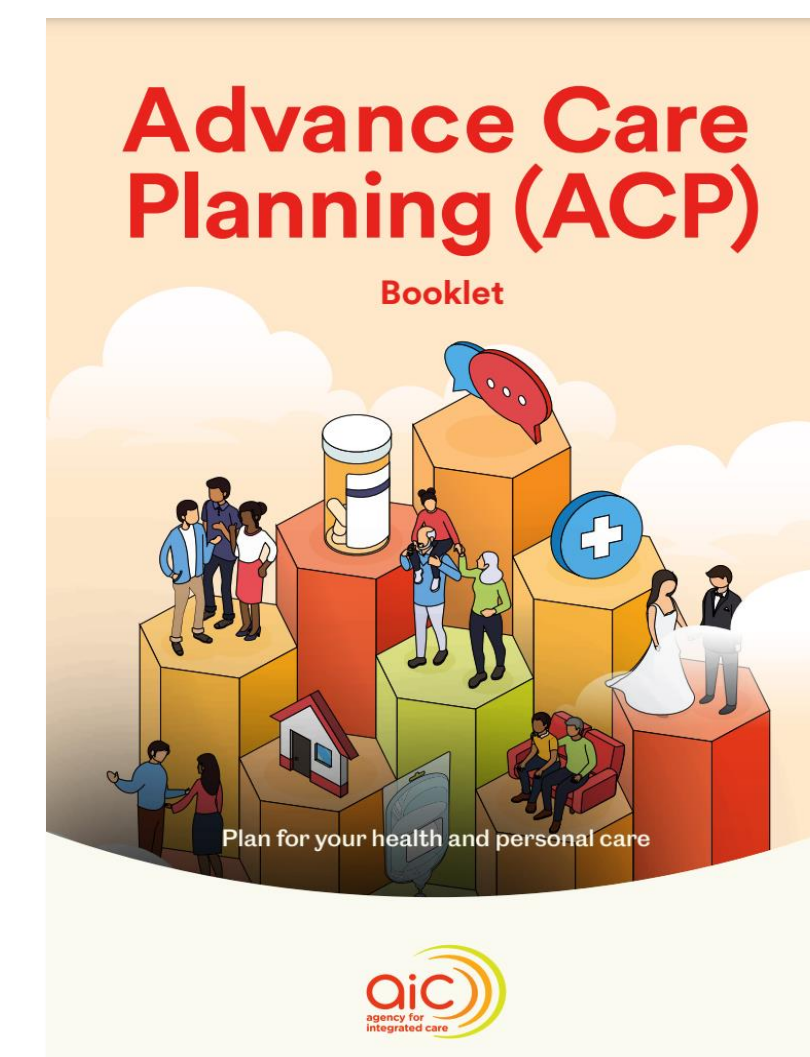
STEP 1:  
Reflect on what you want



STEP 2:  
Choose your Nominated  
Healthcare Spokesperson

STEP 3:  
Record your choices with  
an ACP facilitator

STEP 4:  
Review your ACP





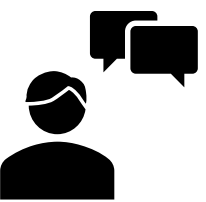


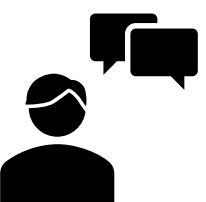


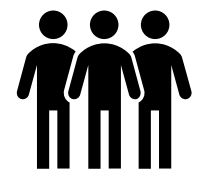




- **Simple 4 steps**
- **Improved accessibility:** Services available in 60+ health and social care institutions

### Normalised conversation about end-of-life care:

- Reduce cultural taboo
- Clearer understanding and positive attitude towards ACP compared to other Asian regions

# ACP programmes in Hong Kong have varying frameworks

	Consultation Service Provider	Target Audiences	Medical	Long-term Care	Financial, Legal & After-death Arrangements	Psychosocial & Spiritual
 <p>醫院管理局 HOSPITAL AUTHORITY</p>	 <p>Healthcare workers with a doctor as the core member</p>	 <p>Patients with advanced progressive disease</p>	●	●	●	●
 <p>家福會 HKFWS</p>	 <p>Trained social workers</p>	 <p>Individuals aged 55+ or patients with chronic disease</p>	●	●	●	●
 <p>賽馬會安寧頌 JCECC Jockey Club End-of-Life Community Care Project</p>	 <p>Trained social workers</p>	<p>Programme participants who are patients that meet the following criteria:</p> <ul style="list-style-type: none"> <li>• Prognosis of <b>less than 12 months</b></li> <li>• Indication of <b>psychosocial or spiritual distress</b></li> <li>• <b>Referred</b> by certain hospitals</li> <li>• ...</li> </ul> 	●	●	●	●
 <p>「吾」可預計</p>	<p>NA (Public education programme)</p>	 <p>General public</p>	●	●	●	●
 <p>耆預記 — 預設照顧計劃推廣行動 —</p>	<p>NA (Public education programme)</p>	 <p>Individuals aged 60+</p>	●	●	●	●

● Extensive ● Moderate ● Limited



# There is a need for a territory-wide standardised ACP framework



## Recommendation 1: Develop a Territory-wide Standardised ACP Framework

- ✓ Facilitate individuals to integrate their values, beliefs, and preferences into care plan
- ✓ Enable service providers and family members to take a holistic view to consider medical, social and personal needs

# The recommended ACP framework should consider 2 aspects

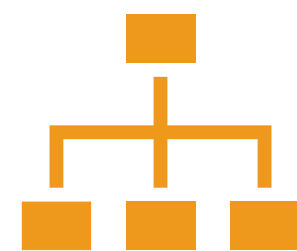
## System Infrastructure



Training of Health & Social Care Professionals



Effective Communication of ACP Information on Existing Electronic System (i.e. eHRSS for HK)



Engagement & Leadership of Organisations



Undertake Research to Establish & Improve Evidence-based Standards

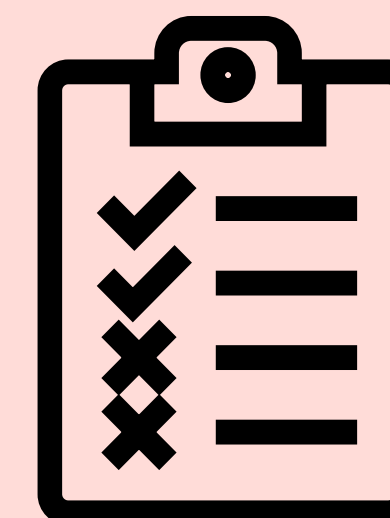
## Individual's Journey



**Territory-wide Standardised ACP Programme**

Accessing & Enactment of ACP Document

Documentation & Review of ACP Document



Public Education

Engagement

ACP Process Support



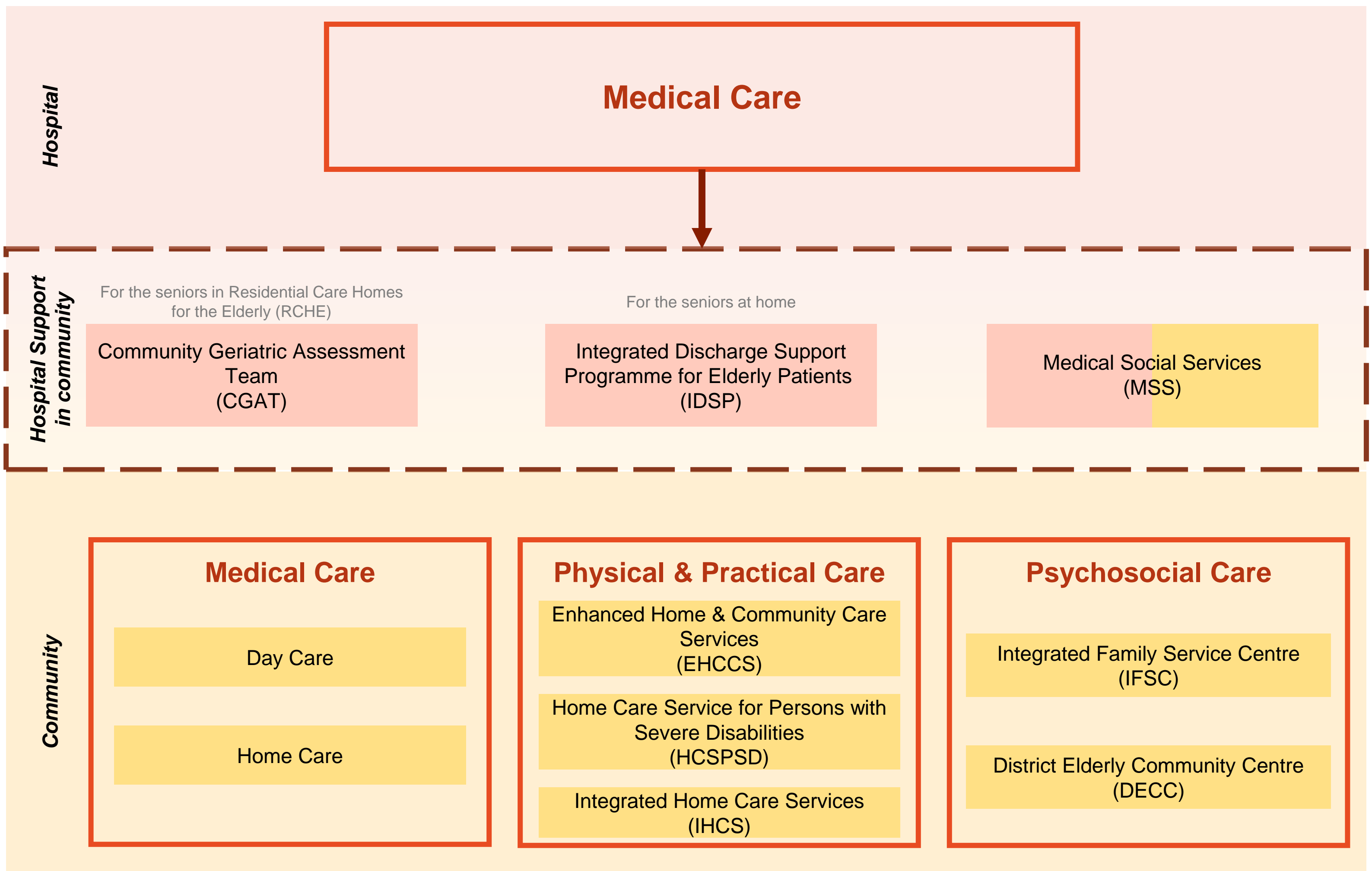



## Part II

# Service Level

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# What EoLC services are available for patients with terminal illness?



- 
- Inadequate medical-social coordination
  - Individuals may need to navigate services on their own to identify suitable ones

➔ Referral Pathway  
 □ Hospital Authority (HA)  
 □ Social Welfare Department (SWD)



# Each service provider facilitates EoLC using own resources

## Hospital Authority



- ✓ Doctors
- ✓ Nurses
- ✓ Allied health professionals
- ✓ Some social workers

## Social Welfare Department



- ✓ Social workers
- ✓ Some healthcare professionals

## Non-governmental Organisations



- ✓ Social workers
- ✓ Care assistants
- ✓ Some healthcare professionals



## Resources not efficiently shared across service providers:



### Service provider:

- Inefficiency in delivering care
- Lowered quality of care



### Individual:

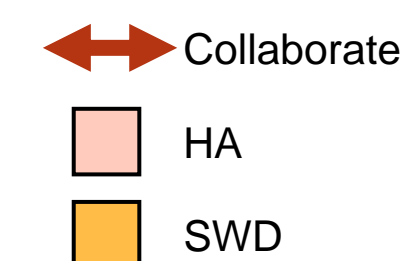
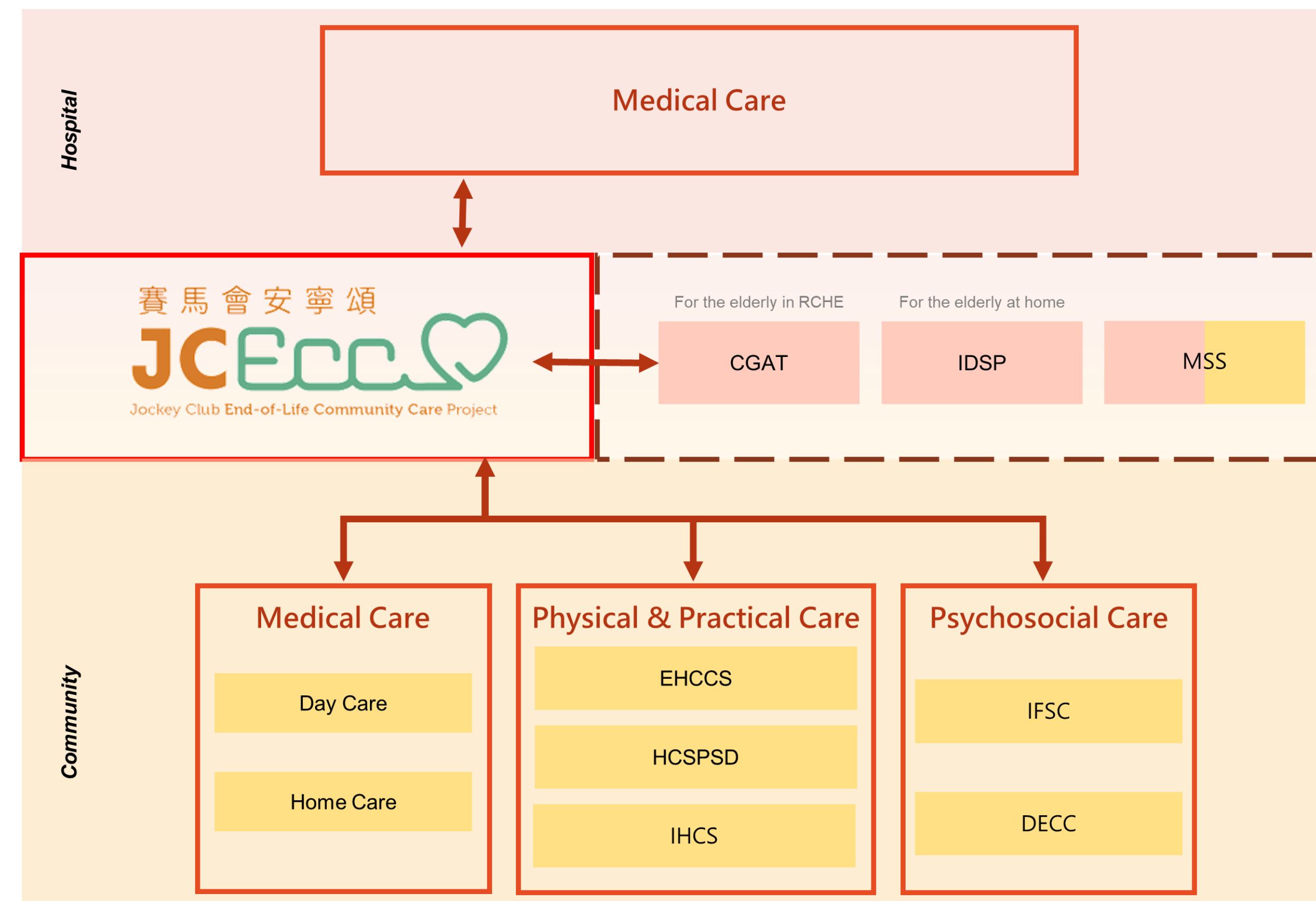
- Limited access to specialised care
- Hard to navigate complex system
- Face delay and service gap in care journey

# Projects outside the public sector bridge the gaps



## Jockey Club End-of-Life Community Care Project (JCECC)

- A 10-year project launched in 2016
- Multi-disciplinary, multi-institutional and cross-sectoral collaboration
- Provides holistic support to terminally ill seniors in the community and RCHE via two models



Note:  
**OPD:** Out-patient Department; **CGAT:** Community Geriatric Assessment Team; **IHCS:** Integrated Home Care Services; **EHCCS:** Enhanced Home and Community Care Services; **IDSP:** Integrated Discharge Support Programme for Elderly Patients; **HCSPSD:** Home Care Service for Persons with Severe Disabilities; **IFSC:** Integrated Family Service Centre; **DECC:** District Elderly Community Centre; **MSS:** Medical Social Services

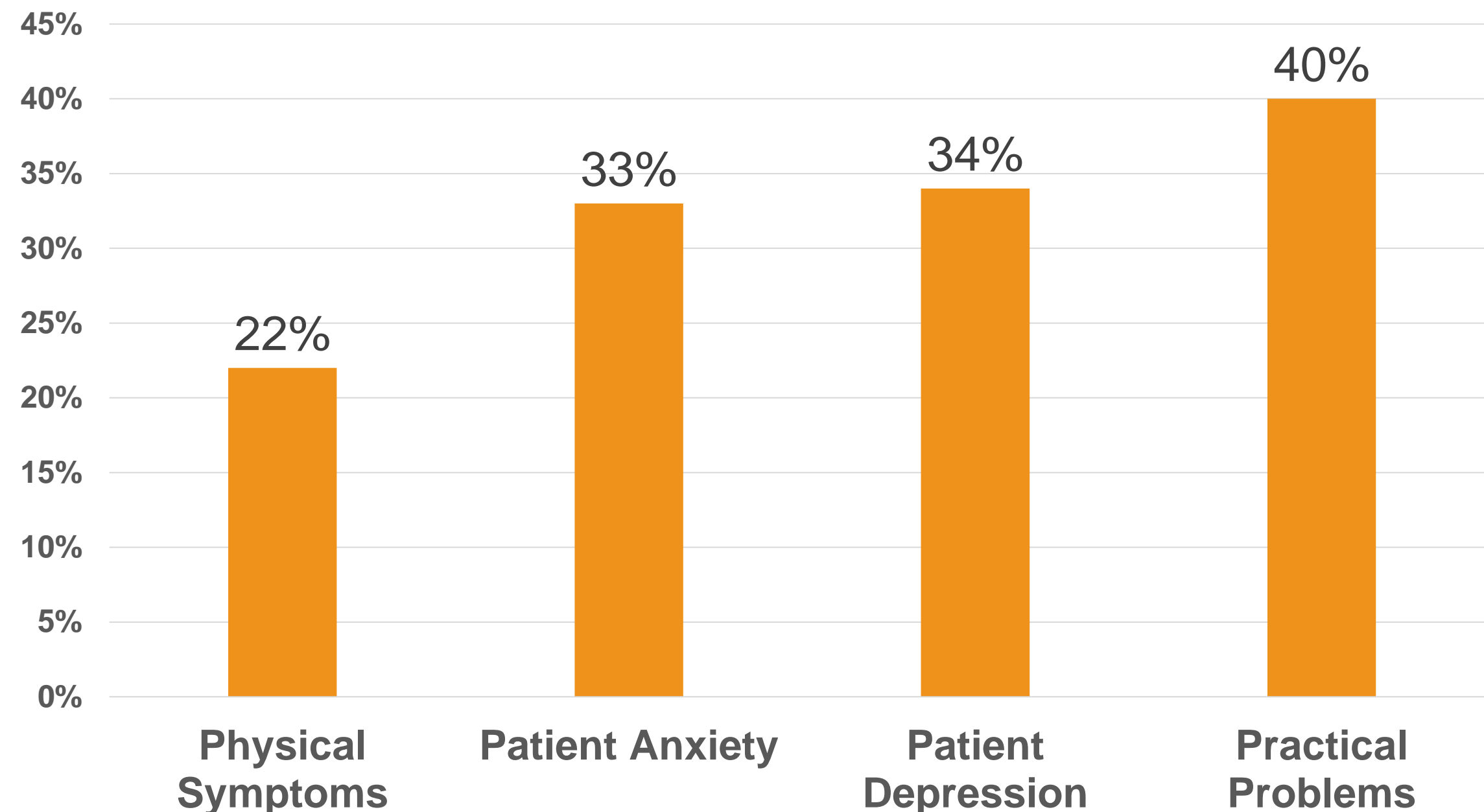


# Evaluation shows the effectiveness of JCECC model

**Evaluation of patient outcomes and medical service utilisation after using EoLC at home or in RCHes (3,700 patients and their caregivers examined)**



## Improvement in Patients' Outcomes after Three Months of Using JCECC Services



## In the last six months before they passed away...

 Hospitalisation

**15.5 days**  
fewer

 A&E admission

**0.6 times**  
fewer

 ICU admission

**0.3 days**  
fewer

...than other patients with terminal illness who did not use JCECC services

(As of September 2022)



JCECC was set to conclude in 2026, raising concerns about the future of the established medical-social network

# Singapore has a national system that integrates care services

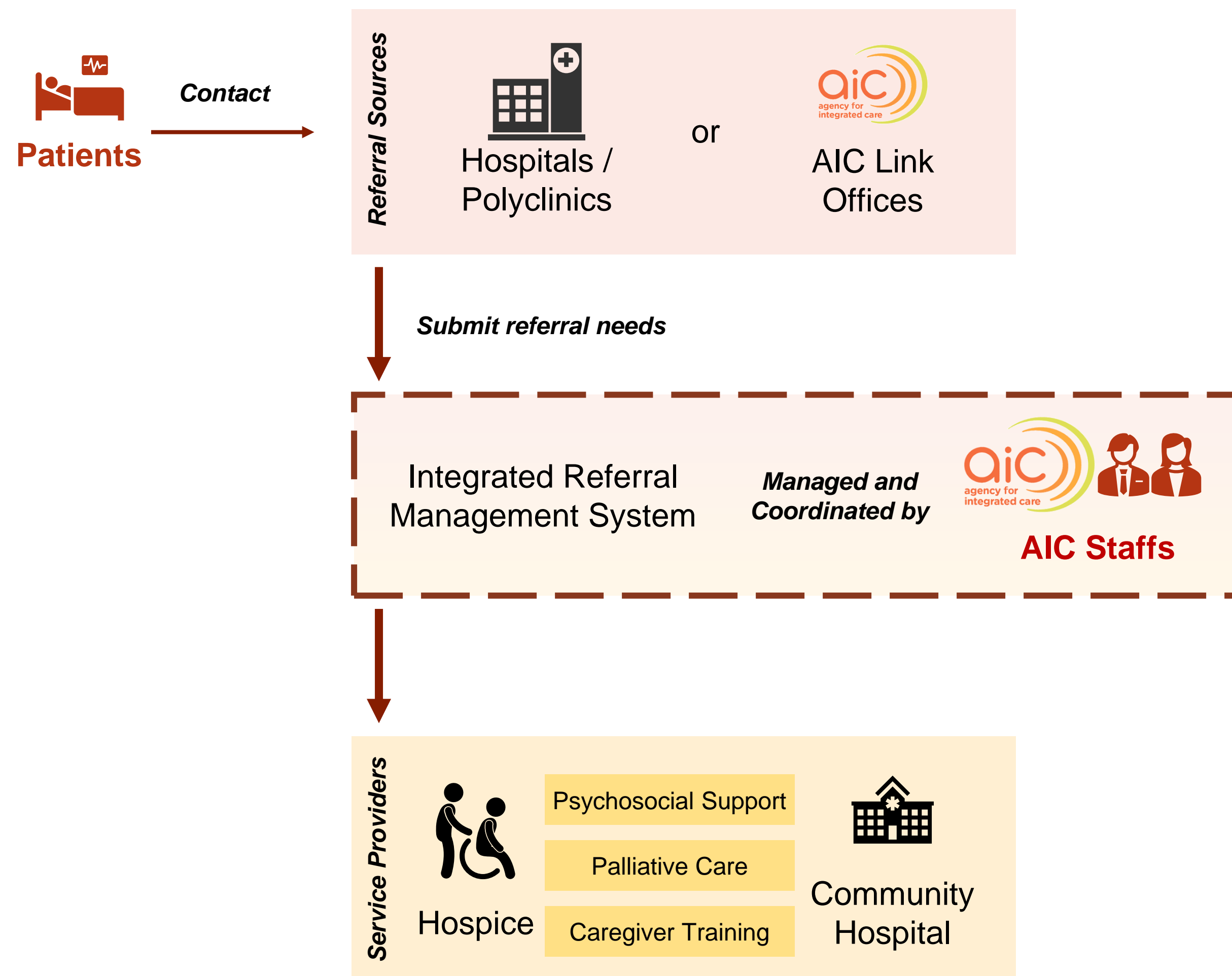


- A national care integrator set up in 2009 under the Ministry of Health
- A single agency that coordinates the delivery of aged care services, and enhances service development and capability-building across medical-social domains



- AIC as a single agency for contact and case management
- Enhance service integration and continuation

## Referral Flowchart for Hospice Home Care Service





# We need to formulate an overarching EoLC service planning

## Recommendation 2: Formulate an Overarching EoLC Service Strategy

- ✓ Explore what the framework should include based on local circumstances
- ✓ Provide **clear role delineation**
- ✓ Suggest **collaboration model** among organisations & professionals
- ✓ Involve palliative care specialists early on in care continuum for symptom relief, emotional support & raising awareness on EoLC



# We need a communication pathway to address the fragmentation

## Recommendation 3:

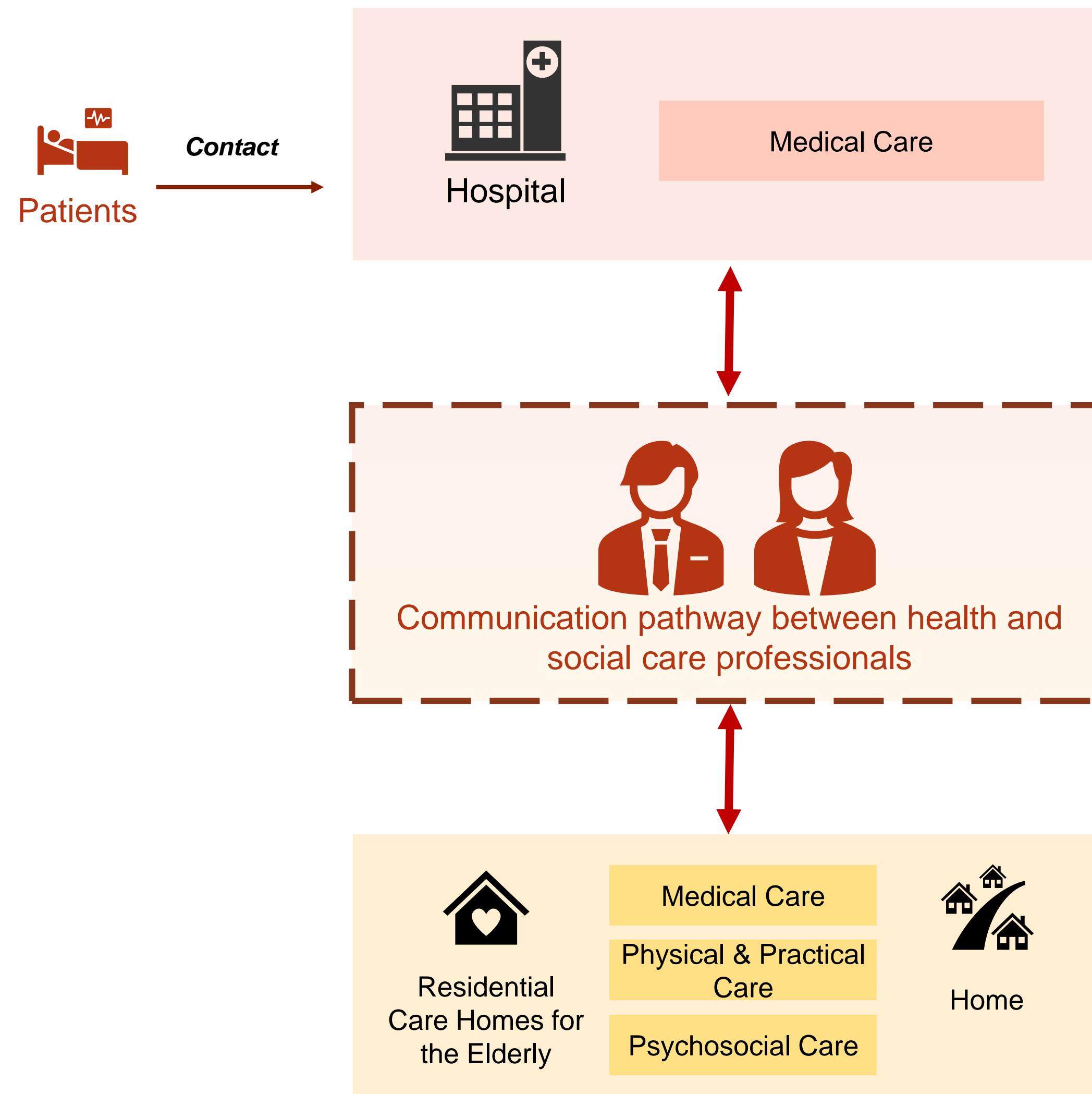
### Establish a Clear and Consistent Communication Pathway to Connect EoLC Services and Facilitate Medical-Social Collaboration

The **communication pathway** should:

- ✓ **Integrate** existing service referral links
- ✓ Be clear for both medical and social service providers to follow
- ✓ Be consistent to enhance the **continuity of care** for patients

**Social care service providers** to:

- ✓ **Holistically assess and provide services**
- ✓ **Communicate closely with hospitals** if medical needs are identified





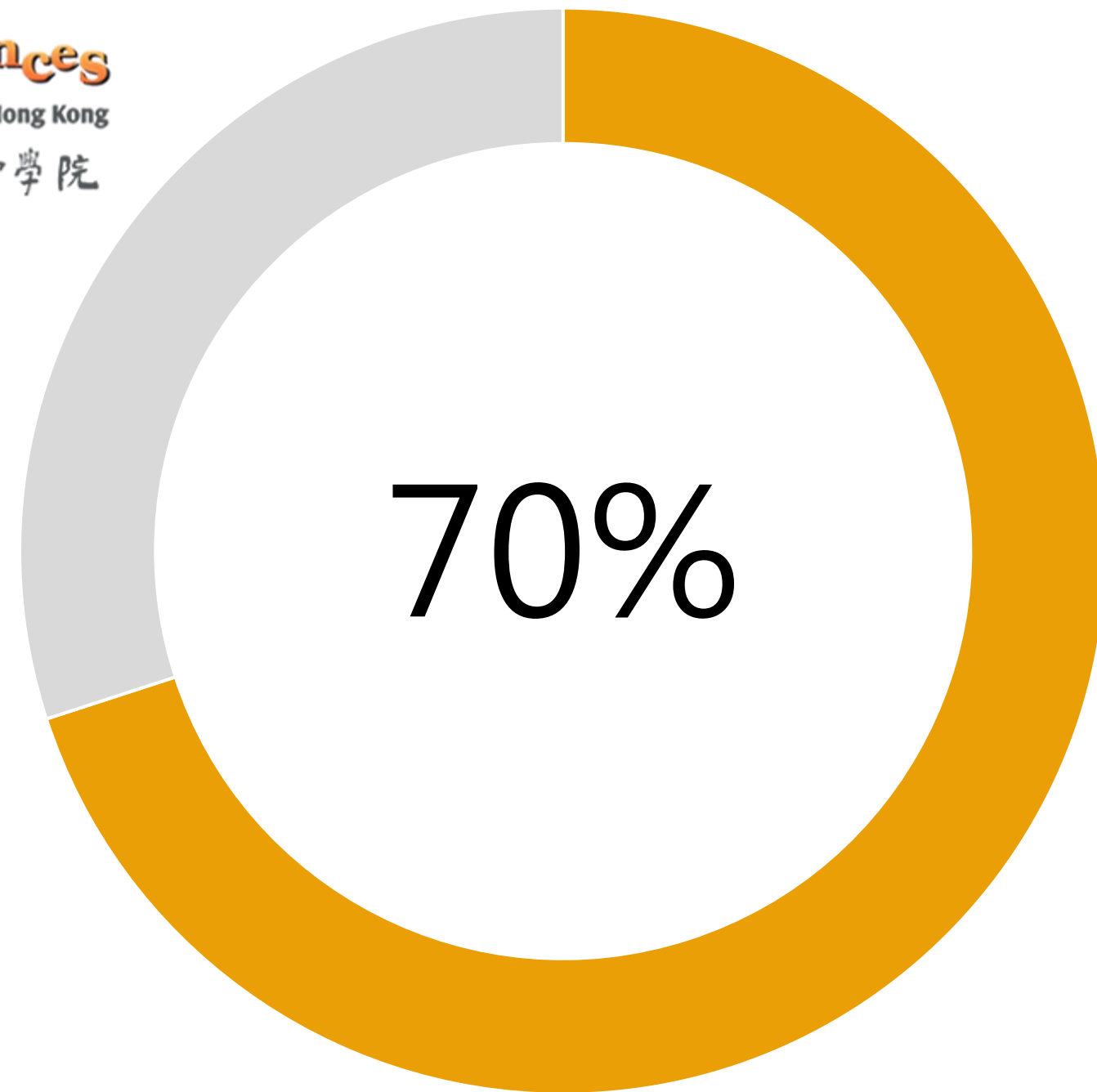
## Part III

# Education Level

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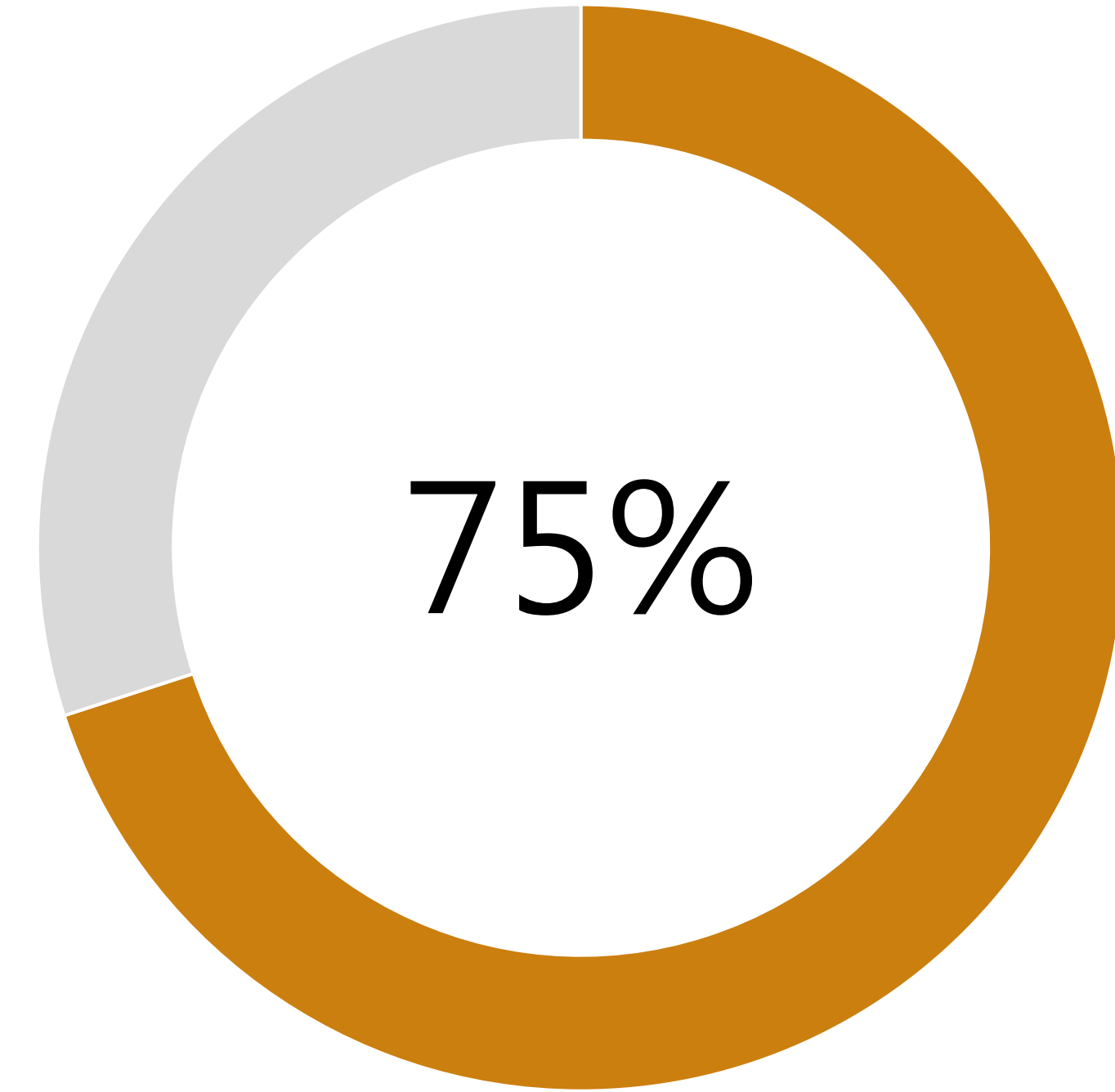
# Lack of awareness presents an opportunity

## Opportunity for promoting end-of-life care



never heard of "end-of-life care"

However...

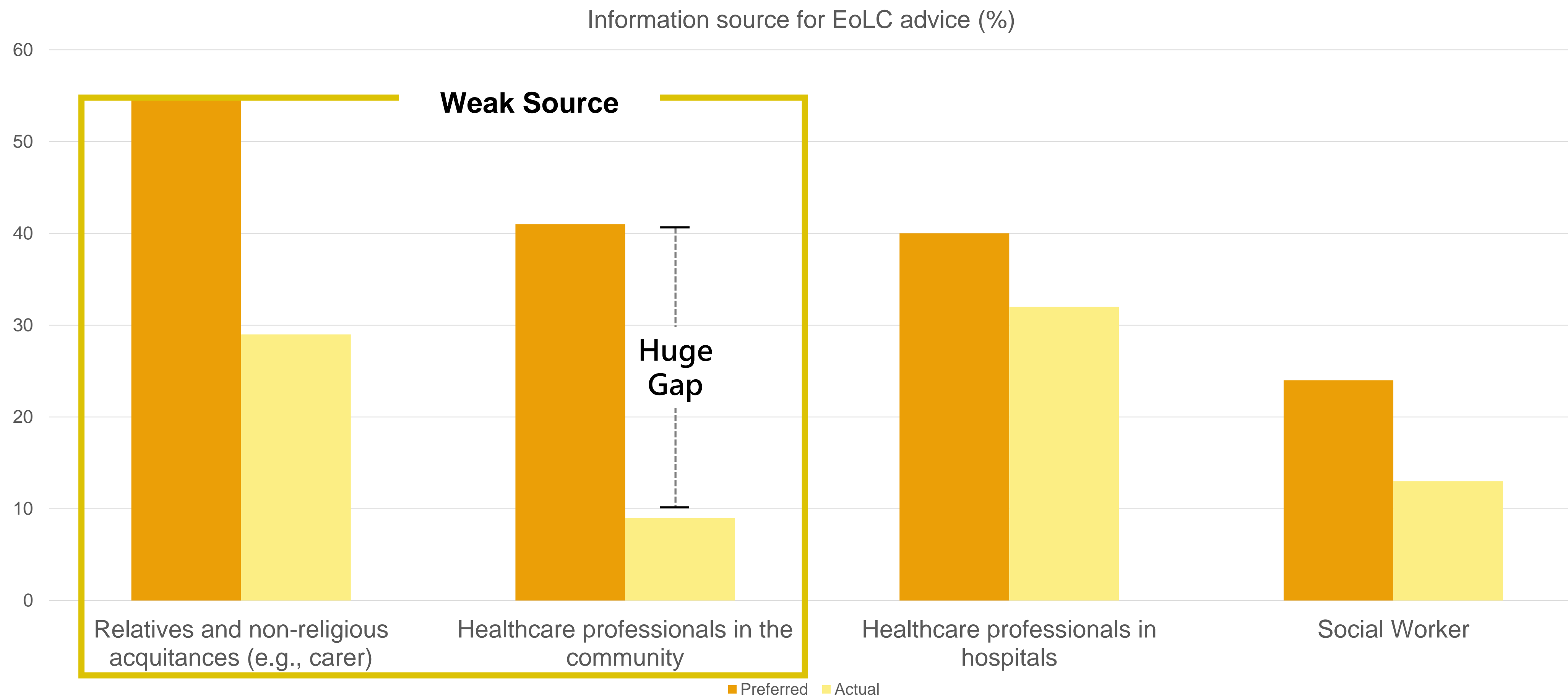


felt comfortable or did not experience any discomfort discussing life and death issues

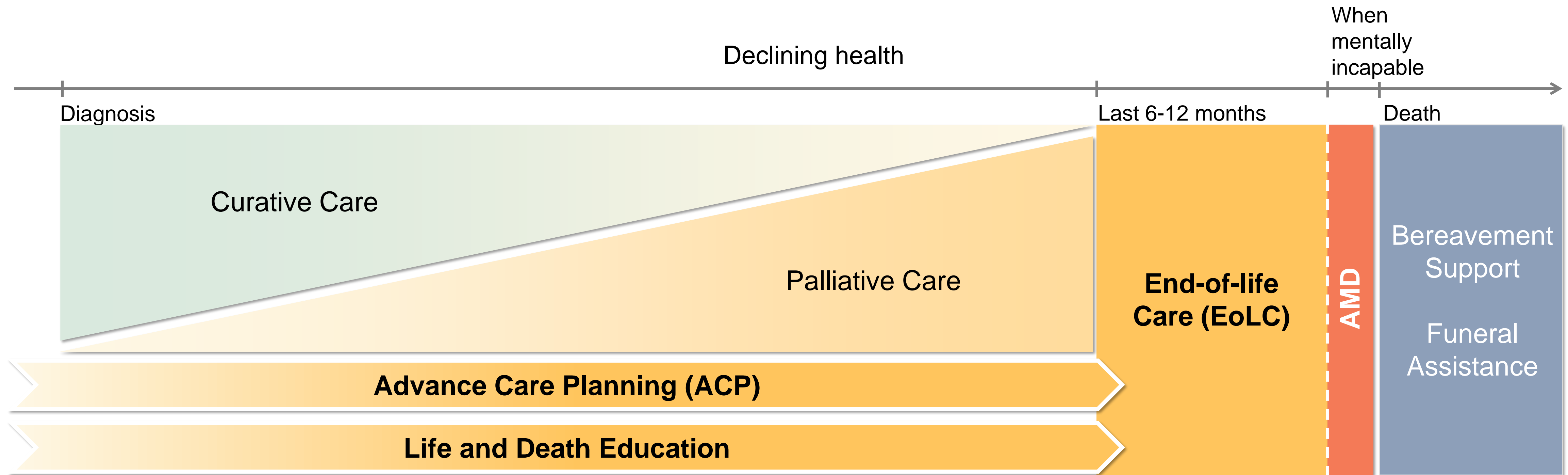


# More efforts are required to diversify information sources

## Notable mismatch between preferred and actual information source



# Life & death education is pivot to remove social taboo on facing death





# Taiwan sets an example in promoting life and death education

Service Users

“It is **compulsory** in **Taiwan** for primary and secondary school students to take life-and-death courses, with older students learning about ageing, bereavement and hospice care”



— *Dr Sam Ng Shu-sum*  
Assistant professor,  
National Taipei College of Nursing

Service Providers

## “Guidelines for Promoting Life Education Programs” (2022)

- 1 Policy Establishment**
  - Review policy development history
  - Provide administrative support
- 2 Teacher Training**
  - Organize life education in advance
  - Prompt on-job life education
- 3 Curriculum & Activity Enhancement**
  - Publish textbook for cross-generation life education
  - Set up relevant courses as mandatory subjects in primary & secondary school
- 4 Community Education**
  - Encourage teenager to voluntarily join end-of-life carer team
  - Communicate with the public through social media
- 5 Research Internationalization**
  - Collaborate with global universities

# EoLC education should be provided in advance

Service Users

Service Providers

## Service Users Public empowerment

### Recommendation 4: Promote Public Life and Death Education

#### Strategically promote for different stages

##### Raise Awareness

- Students and general public

##### Facilitate Discussion

- Citizens with declining health status and their family members

##### Take Actions

- End-of-life patients and their family members
- ACP/ AMD/ bereavement care





# US and Singapore certify diverse professional audiences on ACP training



## Respecting Choices ACP Facilitator Certification

- **Tiered courses** for providing ACP to **individuals of different health statuses**

### Intended for:

- Healthcare workers (e.g., doctors, nurses, healthcare educators)
- Social care professionals (e.g., social workers and clergy)
- Volunteers

## National ACP Programme “Living Matters” by AIC

- ACP discussion conducted by ACP facilitators
- ACP **services for different health statuses**

### ACP Facilitators (5000+):

- **Trained and certified health and social care workers** by AIC
- Could be found in **60+ health and social care organisations**



- Training to enhance ACP **services to individuals with diverse health statuses**, promoting better EoLC
- **Wide-ranging audience targeted for training**
- **Certification** to identify qualified ACP facilitators with proper training



# EoLC education should be provided in advance

Service Users

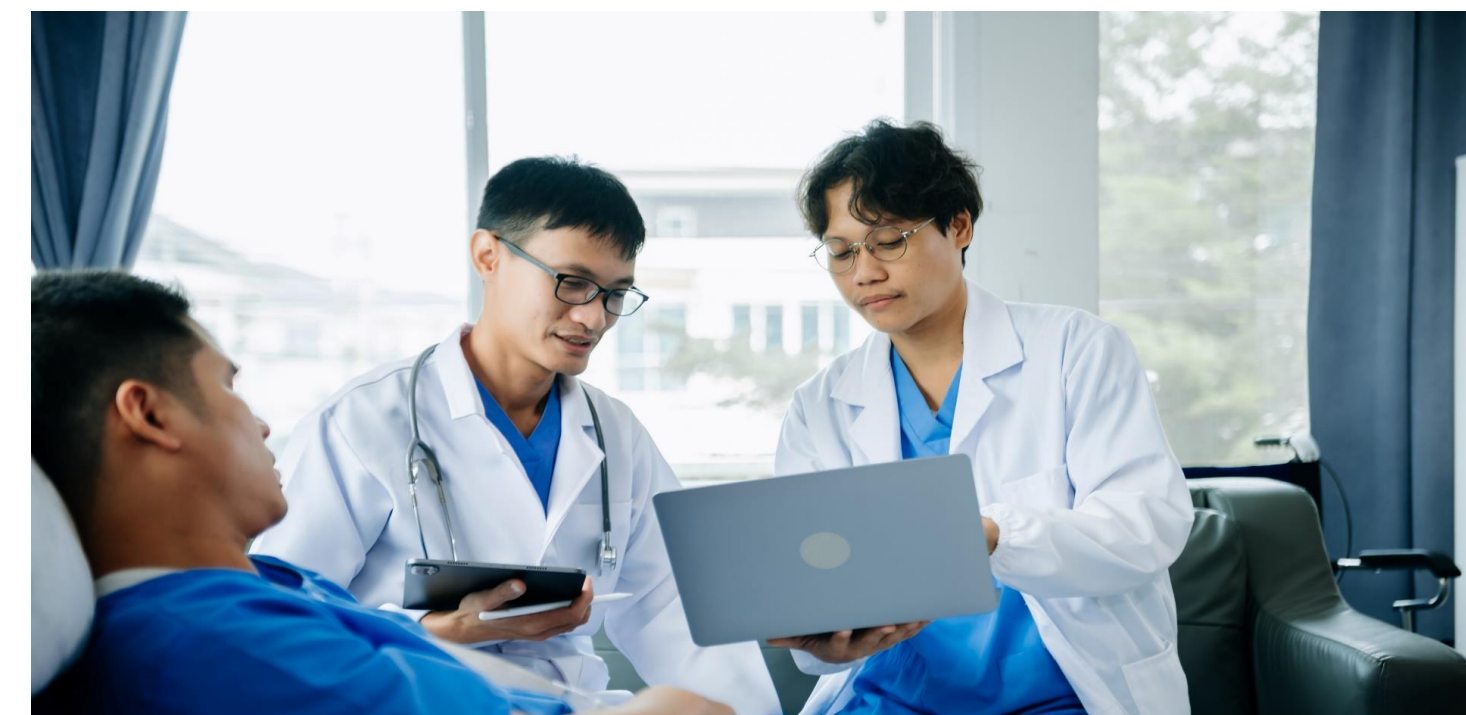
Service Providers

## Service Providers Empowerment of professionals



### Recommendation 5: Equip Community Professionals & Volunteers with ACP Training

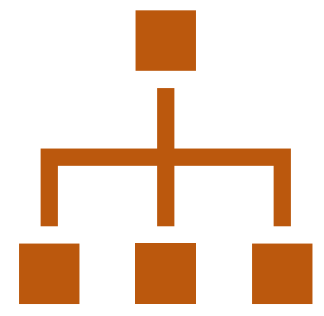
- Take reference from overseas and local examples
- Train and certify professionals and volunteers
- Facilitate the dissemination of EoLC information to the public



### Recommendation 6: Enhance University Curriculum & On-the Job Training in the Health and Social Care

- Current training tends to be fundamental
- Enhance EoLC knowledge, skills, and communication skills
- Ensure multidisciplinary team is well-equipped

# Summary



System

## One Framework

- 1. Develop a Territory-wide Standardised ACP Framework



Service

## Two Sectors

- 2. Formulate an Overarching EoLC Service Strategy
- 3. Establish a Clear and Consistent Pathway to Connect EoLC Services and Facilitate Medical-Social Interface



Education

## Three Strategies

- 4. Promote Public Life and Death Education
- 5. Equip Community Professionals & Volunteers with ACP Training
- 6. Enhance University Curriculum & On-the Job Training in the Health and Social Care



Thank you