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# ADDING LIFE TO YEARS: COMPREHENSIVE END-OF-LIFE CARE FOR ALL

*Ryan IP, Dicky Chow, Dorothy Yeung*, Jessie Zhang, Betty Shu*

Our Hong Kong Foundation, Hong Kong, China

Correspondence: dorothy.yeung@ourhkfoundation.org.hk

## ABSTRACT

### BACKGROUND:

End-of-life care (EoLC) plays a pivotal role in respecting an individual's desire for a peaceful death. It encompasses a comprehensive approach to address medical, social, emotional, and spiritual needs in the final 6 to 12 months of people's life. Building upon the insights from our 2019 EoLC study titled Fostering Medical-Social Collaboration in Achieving Quality End-of-Life Care, which offers an in-depth analysis of EoLC in Hong Kong, this report seeks to reconceptualize and enhance our comprehensive assessment of the EoLC landscape in Hong Kong.

### METHODOLOGY:

Employing a mixed-methods approach, this study synthesises international evidence-based policies, stakeholder insights, and analyses of local community resources, aiming to craft a robust EoLC strategy that is attuned to the needs of an ageing society.

### FINDINGS:

The study revealed that EoLC not only benefits individuals, including patients, carers, and families, but also has a positive impact on the healthcare system. The context of population ageing intensifies the need for sustained improvements in EoLC provisions. Our investigation identified several critical gaps in the system, service provision, and education.

While Hong Kong's Advance Decision on Life-sustaining Treatment Bill is commendable in promoting EoLC, this bill alone may not be sufficient to address the full range of care needs. Discussions on EoLC should not be limited to the last 6 to 12 months of one's life but should be a topic that can be discussed by citizens of all ages.

The insufficient medical-social collaboration complicates the navigation of community service systems for patients and carers. Often, it necessitates consulting multiple service providers independently, which can create a high threshold for accessing suitable services. Services should also be expanded beyond medical care to encompass the medical, social, emotional, and spiritual needs of citizens in their final stage of life, ensuring holistic care.

### IMPLICATIONS:

Acknowledging the demographic shifts and consequent healthcare challenges an ageing population poses, our study accentuates the urgent need for augmented support and strategic enhancements within Hong Kong's EoLC ecosystem. We propose six policy recommendations which span across the system, service, and education sectors, encapsulated by our strategic outline "One Framework, Two Sectors and Three Strategies". These recommendations are designed to advance the development of a person-centred, dignified, and coordinated EoLC in Hong Kong equipped for an ageing demographic.

## CONCLUSION:

This paper asserts the significant role of strategic policy and community-based support in reinforcing EoLC, ensuring it aligns with the needs and expectations of an ageing population. Such initiatives are intended not merely to enrich life quality in later stages but also to significantly reduce the healthcare system's burden. As Hong Kong's population ages, these policies provide clear, evidence-backed directions to foster a compassionate, effective, and holistic EoLC system, ensuring it is a cornerstone of healthcare strategy moving forward.



## KEYWORDS

End-of-life care (EoLC), Life-sustaining Treatment Bill, Hong Kong

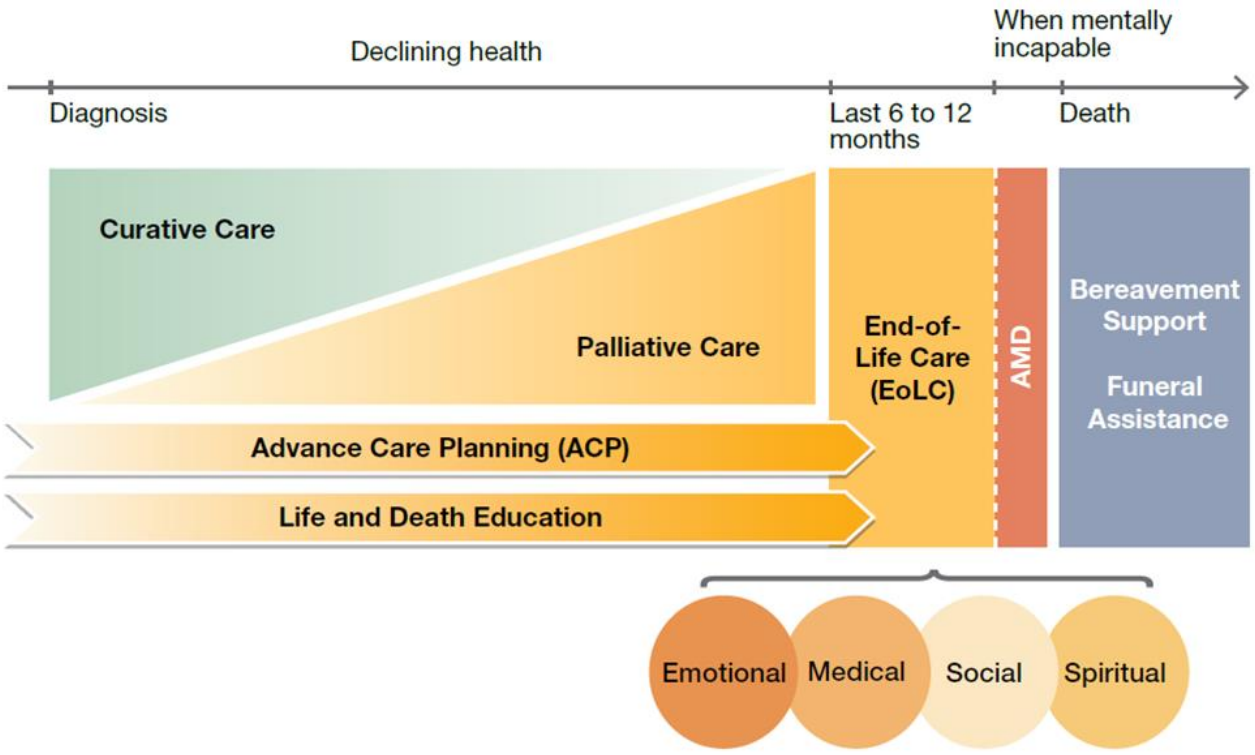

## INTRODUCTION

Under Hong Kong's Advance Decision on Life-sustaining Treatment Bill, individuals aged 18 years or above are allowed to make an Advance Medical Directive (AMD), legally supporting their choices of the medical treatments they wish to decline when no longer capable of decision-making. The associated law amendments also aim to remove existing legal barriers for healthcare professionals in following AMD [1]. While commendable, this bill alone may not be able to address the full spectrum of care needs beyond medical care. Additionally, individuals should be empowered to make informed decisions about AMD through facilitated discussions regarding individuals' needs and the available options.

### Hong Kong Demands for Comprehensive End-of-Life Care

End-of-life care (EoLC) plays a pivotal role in respecting an individual's desire for a peaceful death. It encompasses a comprehensive approach to address medical, social, emotional, and spiritual needs in the final 6 to 12 months of people's life [2].

**FIGURE 1. SPECTRUM OF CARE**



EoLC not only benefits individuals, including patients, carers, and families, but also has a positive impact on the healthcare system. Data reveals a notable surge in medical service utilisation during the last 6 months of people's life, [3], exerting a considerable strain on hospitals and healthcare resources. As hospital services are costly and highly specialised, diverting the demand for EoLC from hospitals to community can optimise resource allocation, while catering to the preference of 90% citizens to remain in community at the final stage of their lives [3-4].

## METHODOLOGY

This work builds upon the insights from our 2019 EoLC study titled *Fostering Medical-Social Collaboration in Achieving Quality End-of-Life Care*, which offers a comprehensive analysis of EoLC landscape in Hong Kong. Leveraging on the insights of diverse stakeholders across different sectors and disciplines, this report provides recommendations at the system, service, and education levels.

## RESULTS

The study revealed that EoLC not only benefits individuals, including patients, carers, and families, but also has a positive impact on the healthcare system. The context of population ageing intensifies the need for sustained improvements in EoLC provisions.

Our investigation identified several critical gaps in the system, service provision, and education.

## SYSTEM LEVEL: ACP FRAMEWORK

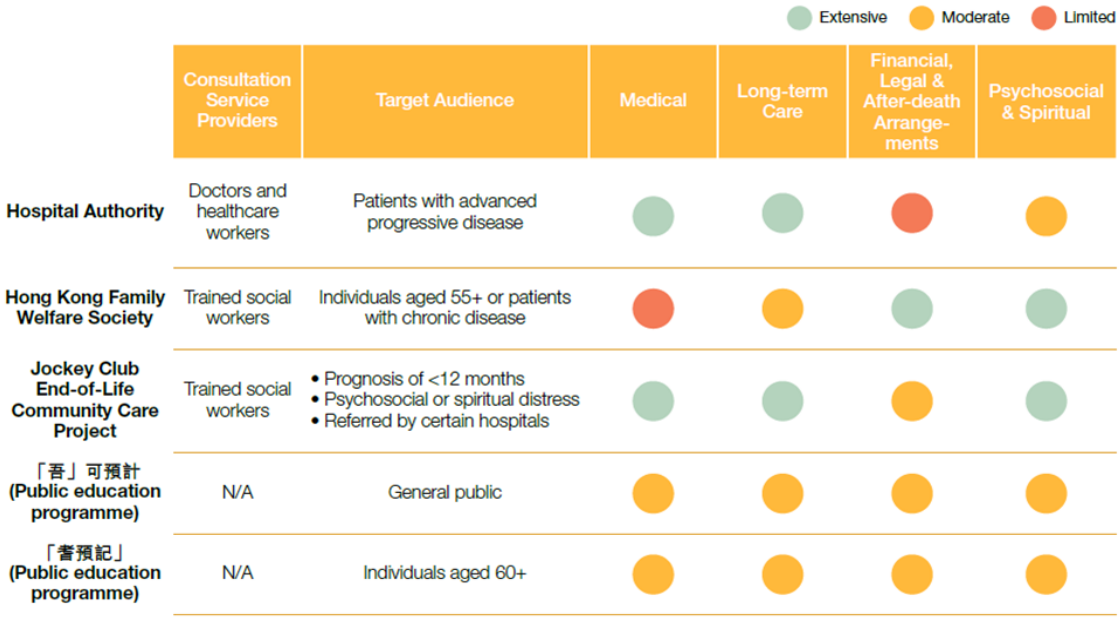
### Recommendation 1: Develop a Territory-wide Standardised Advanced Care Planning (ACP) Framework

To address the issue where AMD cannot address the full spectrum of care, a territory-wide standardised ACP framework offers a solution. While AMD is a legally binding document that focuses on medical treatments during incapacity, ACP serves as a vital communication process through which individuals can express their values, beliefs, and preferences, facilitating the creation of personalised plans for medical, personal, and social care [5].

In Taiwan, ACP consultation is mandatory before establishing an AMD under the "Patient Right to Autonomy Act" [6]. Singapore's national ACP programme, "Living Matters", effectively normalised conversations about EoLC in an Asian context, reducing cultural taboos and enhancing accessibility for ACP services in over 60 healthcare and social care institutions [7-8]. ACP enables individuals to create legally binding documents (e.g., AMD) and facilitates discussion among family members on EoLC that incorporates individuals' values and preferences.

However, ACP does not have a formal status in Hong Kong. There is a lack of standardised care focus, service providers, and target audiences in different ACP programmes [9-13], resulting in varying levels of support and coverage, as shown in Figure 2. Therefore, the Government should develop a territory-wide standardised ACP framework to guide the design of ACP programmes and set a formal status for ACP in Hong Kong.

**FIGURE 2. THE FRAMEWORK OF EXISTING ACP PROGRAMMES IN HONG KONG**





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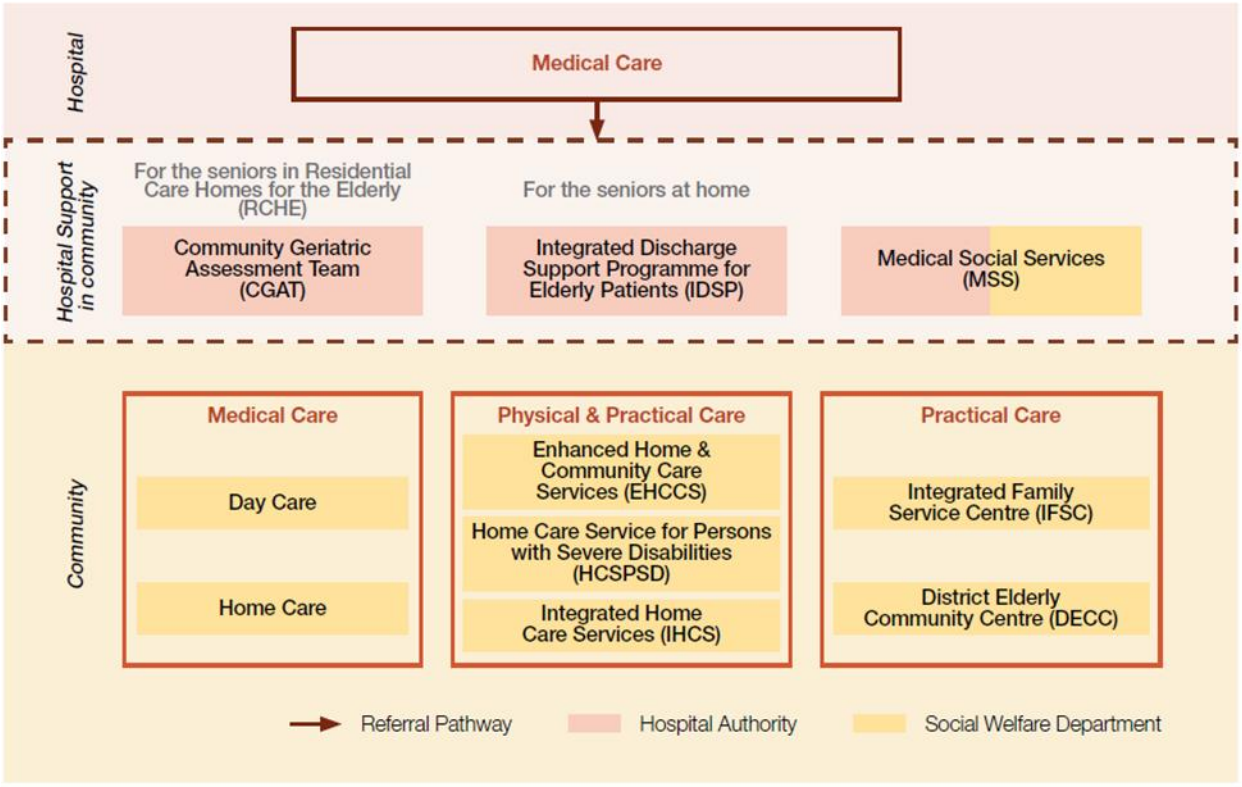
Drawing from successful models in the United Kingdom, Singapore, and Australia [14-17], the recommended ACP framework should consider both system infrastructure and an individual's journey. System infrastructure should incorporate the training of professionals and the inclusion of ACP information in the existing electronic health record system (i.e. eHRSS for Hong Kong), while the individual's ACP journey should encompass public education, active engagement, proper documentation, and regular review and implementation of ACP documents. The documentation of ACP should be effectively communicated with different units in hospitals, especially the Accident and Emergency Department, and other health and social care institutions.

## SERVICE LEVEL: HOLISTIC EOLC SERVICES

In the current service landscape, as shown in Figure 3, while providing medical care in public hospitals, the Hospital Authority (HA) extends support for the patients to the community level through programmes such as "Enhanced Community Geriatric Assessment Team for EoLC in Residential Care Homes for the Elderly" (Enhanced CGAT), Integrated Discharge Support Programme for Elderly Patients (IDSP) and Medical Social Services (MSS). These services aim to connect patients to community-level services provided by the Social Welfare Department (SWD) and community partners, covering medical care, physical and practical care, and psychosocial care.

**FIGURE 3. CURRENT SERVICE DELIVERY PATHWAY IN HONG KONG**




Although both HA and SWD provide various medical-social transition support for patients and their carers, the lack of coordination leads to service fragmentation. Individuals may need to navigate the community service system by themselves and consult multiple service providers separately, resulting in a high threshold for accessing suitable services.

Nevertheless, this service gap is now bridged by community efforts. Jockey Club End-of-Life Community Care Project (JCECC) was launched in 2016 to improve the quality of EoLC. It introduced two community-based EoLC models, the Integrated Community End-of-Life Care Support Teams (ICEST) and EoLC in Residential Care Homes for the Elderly (RCHEs). These models foster collaboration between public hospitals, RCHEs, and different sectors, promoting holistic support for terminally ill patients in the community.

JCECC has presented significant impact. Patients who had the EoLC at home or in RCHEs services for three months experienced both physical and mental improvements, accompanied by fewer hospital bed days and A&E attendances[18]. Nonetheless, JCECC was set to conclude in

2026, raising concerns about the future of the established medical-social network.

In Singapore, a national care integrator called Agency of Integrated Care (AIC) was established in 2009 under the Ministry of Health. As a single agency, AIC manages referrals, coordinates aged care services, and enhances service development and capability-building across the medical-social domains. By fostering medical-social collaboration, AIC enhances service accessibility and continuity of care [19].

### Recommendation 2: Formulate an EoLC Service Strategy

To better coordinate EoLC services, it is imperative to establish a clear role delineation and collaboration model among organisations and professionals. An EoLC service strategy that connects existing medical and social services is therefore crucial to ensure coordinated and comprehensive EoLC.

Drawing from examples in the United Kingdom and Australia [20-22], the Government should consider common themes present in overseas models, including the emphasis on ACP, holistic care, care coordination and utilisation of technology.

To better deliver EoLC in a coordinated manner, it is crucial to expand the focus beyond the last 12 months of life to encompass palliative care (PC). Incorporating elements of early PC into curative care can ensure that individuals receive holistic care, including symptom relief and emotional support, while still pursuing curative treatments.

A local study featured a structured ACP programme introduced by a hospital PC unit in collaboration with various specialties. It reduced acute admission and length of stay of patients by 35% and 39% respectively, while ensuring the concordance of patients' wishes with end-of-life and funeral arrangements [23]. Better incorporating early PC into the care continuum can raise awareness towards EoLC and facilitate patients in making informed decisions, ensuring that their wishes are respected and fulfilled.

By formulating an EoLC service strategy that incorporates these elements, Hong Kong can work towards establishing coordinated services that cater to the diverse and evolving needs of individuals requiring EoLC.

*"Many doctors and medical social workers outside Palliative Care Unit are not fully aware of community EoLC resources."*
*- Consultant of palliative care in a public hospital*

### Recommendation 3: Establish a Clear and Consistent Communication Pathway to Connect EoLC Services and Facilitate Medical-Social Collaboration

To provide patients with integrated medical-social care, it is crucial to establish a clear and consistent communication pathway to connect EoLC services between hospital and community, facilitating medical-social collaboration. This communication pathway should integrate existing service referral links, streamlining the process of connecting patients with suitable services.

Drawing references from the examples of JCECC and AIC in Singapore, the Government should put in place a mechanism to coordinate with hospitals, holistically assess patients' needs, match them with existing social services, and follow up regularly. This can ensure that patients receive integrated EoLC across hospitals and the community.

## EDUCATION LEVEL: STRATEGIES TO RAISE AWARENESS

There is a palpable disparity in awareness and information dissemination among the population. Although a substantial percentage of individuals (75%) felt comfortable or did not experience any discomfort discussing life and death issues, a staggering 70% lacked awareness of EoLC, underscoring the opportunity to enhance education in this domain [24].

Furthermore, it has been observed that citizens prefer to receive EoLC information from relatives and non-religious acquaintances (e.g., carers) (55%), healthcare professionals (HCP) in the community (41%), and HCP in hospitals (40%)[3]. It is concerning, however, that the actual flow of information does not align with these preferences—most information is transmitted through hospital-based healthcare professionals (32%), while fewer individuals receive guidance from their preferred sources, — only 29% and 9% of individuals receive information from relatives and non-religious acquaintances (e.g., carers) and HCP in the community respectively.

Therefore, it is crucial to provide EoLC education strategically. For EoLC service users, promoting life and death education should be prioritised, while for EoLC service providers, the Government should empower health

and social care professionals through enhanced university curriculum and on-the-job training, as well as ACP training.

"We should empower doctors across specialties, as well as health and social care professionals, to initiate difficult but necessary conversations, making EoLC more accessible."
- Professor engaged in EoLC training and education

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

Hong Kong can strategically promote public life and death education by adopting a three-step approach targeting individuals at different stages of life and with varying levels of preparedness, which involves raising awareness, facilitating discussion, and taking actions.

To enhance awareness among students and the public from an early age, the Government may draw reference from Taiwan's approach of integrating life and death education into school curriculum. Taiwan's initiative serves as a comprehensive model that emphasises policy establishment, teacher training, enriching curricula with relevant activities, and extending education into the community [25].

For individuals facing deteriorating health conditions and their families, health and social care professionals should provide information on ACP, tailored to the severity of health conditions and preparedness level. This can encourage patients and their families to participate in discussions related to EoLC and take action in ACP and AMD for the later stage. Additionally, terminally ill patients and their families should actively participate in ACP and AMD, as well as receiving bereavement support when needed.

"The Government should strategically plan for life and death education targeting citizens of different ages and care needs."
- Programme director of community care service

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

Community professionals and volunteers who are delivering services to individuals with declining health should be incentivised to undertake ACP training and become ACP facilitators. Through providing ACP to all age groups across different service settings by these trained personnel, EoLC information can be disseminated to a wider population. This is also aligned with people's preference, considering that HCP in the community, and relatives and non-religious acquaintances (e.g., carers) are preferred as the top two EoLC information sources.

Such training should extend beyond working professionals to include volunteers and laypeople. This practice is also evident in the "Respecting Choices" model in the United States, which offers a robust training protocol for participants of different backgrounds. This model is comprehensive, encompassing an array of ACP skills tailored for different health statuses [26]

Moreover, Singapore's national ACP programme "Living Matters" also illustrates the benefits of training ACP facilitators for both clinical and social care settings [27]. A network of over 5,000 certified and proficient ACP facilitators has been created to effectively disseminate accurate and compassionate EoLC information to the public [28]. The Government may reference these models in promoting ACP training in Hong Kong.

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

Currently, university curriculum and on-the-job training for healthcare professionals in EoLC tend to be fundamental, which may only include hospice visits. This may not fully prepare them for the complexities of providing comprehensive and quality EoLC, sometimes leading to a greater emphasis on curative treatments which may come at the expense of a patient's overall quality of life. Hence, the relevant institutions should enhance EoLC elements in the curriculum and training, emphasising the importance of striking a balance between disease management and improving a patient's quality of life.

In addition, there is a need to enhance communication skills among health and social care professionals, particularly in conveying prognosis and conducting sensitive EoLC discussions. Ethical training for healthcare professionals should prioritise the shift of focus from treating diseases to considering the patient's overall well-being, promoting a more compassionate and patient-centred approach. Extending trainings beyond healthcare professionals to other social care professionals is equally critical, to ensure that a multidisciplinary team is well-equipped to provide holistic care, engage in meaningful discussions about death, and meet the unique needs of patients and their families who face end-of-life issues.

## DISCUSSION

The implementation of the Advance Decision on Life-Sustaining Treatment Bill in Hong Kong marks a significant step forward in empowering individuals to make informed choices about their medical treatment preferences. However, our findings highlight the critical need to expand the focus of EoLC beyond just medical decisions. A holistic approach that encompasses medical, emotional, social, and spiritual dimensions is essential for truly respecting individuals' wishes during their final stages of life.

Our study underscores the multifaceted nature of EoLC needs. The preference for community-based care over hospital settings does not only aligns with patients' desires but also presents an opportunity to alleviate strain on healthcare resources. This is particularly crucial in the context of Hong Kong's ageing population.

The identification of systemic gaps in EoLC delivery is a key finding of our research. The absence of a standardised ACP framework in Hong Kong emerges as a significant barrier. Establishing a territory-wide ACP framework could facilitate more meaningful discussions between patients, families, and healthcare providers, ensuring that individual values and preferences are prioritised in care planning.

Service fragmentation across medical and social domains presents another challenge. While initiatives like JCECC have made progress in bridging these gaps, their limited duration raises concerns about long-term sustainability. Our recommendation for a comprehensive EoLC service strategy aims to address this by promoting sustained collaboration between hospitals and community services. The stark contrast between individuals' comfort in discussing life and death issues and their lack of awareness about available EoLC options highlights a significant gap in public knowledge. Our proposed strategic public education initiatives, drawing inspiration from successful models in Taiwan, could foster a more informed community capable of engaging proactively in ACP discussions.

The need for enhanced training for healthcare professionals is another crucial finding. Our recommendations focus on improving communication skills, ethical considerations, and understanding of palliative care. By integrating EoLC training into university curricula and ongoing professional development, we aim to equip healthcare providers with the tools to navigate the complexities of end-of-life discussions and provide more compassionate, person-centred care.

Our six policy recommendations are designed to create a cohesive framework for EoLC in Hong Kong, addressing immediate care needs while adapting to the evolving landscape of an ageing society. By emphasizing system-level changes, service coordination, and educational enhancements, we believe we can build a robust EoLC ecosystem that respects individual preferences and optimises resource allocation.

While our study offers valuable insights into EoLC in Hong Kong, it is essential to highlight areas for future research and refinement. While we addressed various cultural and spiritual considerations, future studies could explore these complex factors in greater depth. Furthermore, the implementation of our recommendations may encounter practical challenges, such as resource allocation and necessary systemic adaptations, which are common hurdles in healthcare innovations.

Despite these limitations, our study provides valuable insights into the current state of EoLC in Hong Kong and offers a roadmap for improvement. While we touched on cultural and spiritual aspects, future research could delve deeper into these nuanced factors, exploring how they influence EoLC preferences and outcomes across different communities in Hong Kong. Additionally, future research could focus on implementation science, examining the success factors in translating policy recommendations into effective practice, ultimately leading to more effective and culturally sensitive care practices.

## CONCLUSION

In conjunction, these recommendations support the vision where EoLC is delivered in a person-centred, dignified, and coordinated manner in Hong Kong. The implementation of policies and programmes at all levels—system, service, and education—would create synergy and contribute to the development of comprehensive EoLC. This ensures EoLC is well-integrated into the care continuum, respecting and responding to people's preferences and rights to compassion and care at the final stage of life.

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