16th December 2019

Professor Sophia Chan, JP
Secretary for Food and Health
Food and Health Bureau
c/o: Assistant Secretary for Food and Health (Health) 6B
19/F, East Wing, Central Government Offices 2 Tim Mei Avenue, Tamar, Hong Kong

Dear Professor Chan,

Submission of Our Hong Kong Foundation's Views on the Consultation Document 'End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place'

We would like to share our views in response to the captioned consultation document on advance directives (AD) and related end-of-life care (EoLC) arrangement in Hong Kong.

Our Hong Kong Foundation (OHKF) acknowledges the Government's continuous efforts in improving end-of-life experience in Hong Kong. To complement the Government's recent legislative proposal on this topic, OHKF has completed a study titled **"Fostering Medical-Social Collaboration in Achieving Quality End-of-life Care".** This study explored views held towards EoLC in the community, specifically through the lens of potential EoLC service end-users reached in a telephone polling exercise. The polling, commissioned by OHKF and conducted by the Hong Kong Institute of Asia-Pacific Studies at The Chinese University of Hong Kong, was executed through telephone interviews with 1,001 Hong Kong residents between 26 November and 6 December 2019 to understand public perception and practice related to end-of-life care services in local communities.[1] This submission, consolidating our survey findings and research insights, hopes not only to resonate with the Government's determination in propelling end-of-life care development in Hong Kong, but also complement the Government's plans on related service planning and modelling. OHKF believes that the Government's proposal will be largely conducive to facilitate implementation of advance directives and dying in place. Yet, an overarching policy framework and a meticulous service model for EoLC **at the community level** are equally vital for moving towards a more sustainable health system that facilitates a better, and more dignified end-of-life journey for Hong Kong citizens.

Our views are summarised into three themes as detailed below:

- Public education and advocacy
- Capacity planning
- EoLC service provision in community settings

[1] The executive summary and survey report of the study are attached in appendices of this submission.

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1. Public education and advocacy

There is limited public awareness on the concept of EoLC and thus an urgent need to reinforce related public education and advocacy. Further efforts are required to empower individuals to recognise different options for spending the last stages of their lives with quality and dignity.

1.1. High public acceptance on advance directives given adequate guidance

Consultation Question 1 Do you think that the public at large is ready to accept the concept of advance directives?	
Our Hong Kong Foundation	[✓] Agree [ ] Disagree

We agree that the general public welcomes the concept of advance directives (ADs). This has consistently been reflected in several research papers published by academics.

A recent study by The Nethersole School of Nursing at The Chinese University of Hong Kong (CUHK) and the Department of Social Work and Social Administration at the University of Hong Kong revealed that 80.2% of those who had heard about AD had made or intended to make ADs (Chan et al., 2019).

In 2017, the Food and Health Bureau commissioned the CUHK Jockey Club School of Public Health and Primary Care and CUHK Jockey Club Institute of Ageing to understand the extent of knowledge, attitudes and preferences of ADs and related EoLC concepts. The report presented similar results: 60.9% of participants would make their own ADs were they to be legislated (Chung et al., 2017).

The Hong Kong Jockey Club Charities Trust launched the three-year "Jockey Club End-of-Life Community Care Project" (JCECC) in 2015. A report published on the "Community-Wide Survey on End-of-Life Care in Hong Kong 2016" completed as part of this projects reported that 74.4% of interviewees would choose to sign an AD (JCECC, 2016).

The positive results observed in the abovementioned studies, however, were observed only when additional explanations of key concepts were provided to guide interviewees' responses, further

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discussed in paragraph 1.2.

1.2. Limited public understanding of advance directives

Consultation Question 7 Legally, there is no limitation for healthy individuals signing an advance directive. Do you agree that the public is sufficiently aware of the pros and cons of making an advance directive when healthy?	
Our Hong Kong Foundation	[ ] Agree [✓] Disagree

Despite the promising *reception* of the concept of ADs observed among the general public, in existing studies, such preferences were only revealed when further information about ADs was provided. Specifically, 81.4% (Chan et al., 2019), 85.7% (Chung et al., 2017) and 81.5% (JCECC, 2016) of respondents to aforementioned research, respectively, had not heard of ADs.

The low level of *awareness* of ADs and other end-of-life concepts is a widely recognised phenomenon in Hong Kong, triggering concerns over public knowledge of relevant decision making. According findings from OHKF's recent study, 55.1% of respondents regarded themselves to have limited, little, nil or uncertain confidence in managing EoLC and its associated arrangements; furthermore, only 33.6% felt that they understood the concept of ADs (OHKF, 2019a). These raise critical concerns over the public's ability to evaluate the pros and cons of making an AD and points to the need to further equip our citizens with required knowledge for such considerations.

Furthermore, our study revealed that 19.4% of respondents were never informed about end-of-life services available in community settings. The remaining respondents usually obtained information from scattered sources, the most popular source being medical professionals in hospitals (32.2%) (OHKF 2019a). OHKF suggests that other channels, such as medical professionals in community settings including nurses and social workers, could be further mobilised as importance sources of information for citizens. **Promoting health literacy and empowering citizens require mindful planning that shifts burden away from hospitals whilst levering upon community resources.**

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2. Capacity Planning

OHKF agrees with the principle that procedures for setting an AD need to be carefully examined to sustain the legal validity of the form. However, the resources of planning EoLC could potentially impose an immense burden on the already over-stretched health system in Hong Kong. **It will be challenging for this legislative proposal to reach its goals without a stringent capacity plan in place to facilitate pragmatic implementation.** Emphasis should be placed on an integrated approach for personnel in community settings to share respective responsibilities.

2.1 Making ADs is resource-draining

Consultation Question 9 Do you agree that an advance directive must be made or modified in writing?	
Our Hong Kong Foundation	[✓] Agree [ ] Disagree

Consultation Question 11 Do you agree that a legally-valid advance directive must be witnessed as safeguard?	
Our Hong Kong Foundation	[✓] Agree [ ] Disagree

Consultation Question 12 Do you agree to the proposed arrangement to require two witnesses for making and modifying an advance directive, one of whom must be a medical practitioner, and both witnesses should not have an interest in the estate of the person making the advance directive?	
Our Hong Kong Foundation	[✓] Agree [ ] Disagree

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OHKF agrees that a mandatory set of procedures, including a clear indication in written format (consultation question 9), the presence of witnesses (consultation question 11) and the involvement of medical professionals (consultation question 12) is essential for making ADs. These factors are understood to facilitate the decision-making process of individuals, allowing them sufficient room to thoroughly consider all consequences, reach a consensus with family members, and ensure the validity of the AD form. Such procedures would safeguard the best interests of individuals and health professionals, ultimately ensuring that an individual's end-of-life will is effectively and fully honoured without misunderstanding or doubt.

The Government's current proposal is largely aligned with international protocols for making a legitimate AD. For instance, the National Health Services (NHS) in the UK has specified that to refuse life-sustaining treatment, an AD must be written and signed by the individual and a witness (NHS, 2019). We believe that in Hong Kong, the requirement of two witnesses with one necessarily being a medical practitioner, could provide greater assistance to individuals especially considering the broadly unfamiliar concept of ADs in Hong Kong today.

Whilst the establishment of certain laws is palpably grounded, there are still practical barriers to overcome for actual realisation. In recent years, there were roughly 46,000 – 47,000 deaths per year in Hong Kong (Census and Statistics Department, 2019). Yet, statistics from the Hospital Authority (HA) showed that public hospitals handled almost 37,000 deaths in 2016/17 (Hospital Authority, 2017a), a proportion close to 80% of total cases. However, the growth rate of public hospital doctors lags behind the upsurge in service demand which contributes to the consistent overburdening of public hospitals. This was reflected in a report published by OHKF earlier this year on **the severe shortage of doctors in Hong Kong's public hospitals.** We reported that our current ratio of 1.9 doctors for every 1,000 people in Hong Kong is far below the Organisation for Economic Cooperation and Development (OECD) average of 3.4. In other words, an addition of approximately 10,000 doctors are needed in our healthcare workforce to catch up with the norm of other well-developed regions (OHKF, 2019b). Regarding this austere constraint, the capacity of current staff in public hospitals to discuss ADs with patients and co-manage end-of-life issues is uncertain.

Further reiterating the limited capacity of hospitals to handle matters related to EoLC, current palliative care services in public hospitals are scarce with less than 400 inpatient beds available (Hospital Authority, 2017b). The HA's Strategic Service Framework for Palliative Care stated that in 2012/13, only 68% cancer patients received palliative care against the 80% threshold set by the World Health Organization (WHO) (WHO, 2007). Worryingly, a less-than-half figure (44%) was observed among end-stage renal failure patients (Hospital Authority, 2017b).

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Setting up an AD is understandably not a straightforward process that typically requires back-and-forth communication between the patient, family members and medical practitioners. Achieving the rigour of the proposed steps in setting up a legally-binding advance directive form has implications on the required time and expertise of healthcare professionals. In fact, many existing papers reflect concerns that healthcare professionals have towards establishing an AD. One common need highlighted is a cultural shift that will facilitate non-palliative staff in acute hospitals to overcome the reluctance of talking to patients and their relatives; as well as their own insecurity in discussing psychological, spiritual or religious matters deemed as areas outside of their expertise (Woo et al., 2009).

The antidote to the above resource concerns could be found in community settings. Our recent study revealed that in terms of the most trusted type of personnel for EoLC advice, citizens predominantly chose relatives and acquaintances from non-religious affiliations (55.2%), with medical professionals in community settings being the next most popular option (40.8%), even more popular than hospital-based medical professionals (39.6%) (OHKF, 2019a). This underlines a promising implication of how we could lift the burden of public hospitals through leveraging community resources in EoLC service provision.

In short, whilst OHKF concurs with the necessity of a rigorous process for making a legal AD, it would be challenging for the Government's legislative proposal to reach its goals without a **stringent healthcare manpower capacity plan** in place to facilitate implementation. . Without the readiness of required human resources and adequate training for our workforce, the sole existence of an improved legal framework will be of limited impact.

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2.2 An efficient pathway is a key motivating factor for making ADs

Consultation Question 3 Do you agree with the fundamental principles set out in paragraph 4.8?
Our Hong Kong Foundation Paragraph 4.8 (a) respecting a person's right to self-determination. [✓] Agree [ ] Disagree Paragraph 4.8 (b) patient's right to self-determination overrides treatment decisions based on treatment provider's interpretation of patient's best interest. [✓] Agree [ ] Disagree Paragraph 4.8 (c) a person should have the primary responsibility of keeping and presenting the original copy of an advance directive. [ ] Agree [✓] Disagree Paragraph 4.8 (d) sufficient safeguards should be provided to preserve lives. [✓] Agree [ ] Disagree

Consultation Question 16 Do you think that the proposed safeguards to ensure validity of an advance directive are sufficient?
Our Hong Kong Foundation Paragraph 4.24 (a) original copy of the advance directive should be presented. [ ] Agree [✓] Disagree Paragraph 4.24 (b) advance directive should be sufficiently clear and is not being challenged. [✓] Agree [ ] Disagree Paragraph 4.24 (c) advance directive must not have been withdrawn. [✓] Agree [ ] Disagree Paragraph 4.24 (d) no controversial behavior from the person which suggests a change of mind. [✓] Agree [ ] Disagree

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OHKF resonates with the legislative proposal that certain safeguards are essential to the validity of an AD. An uncontroversial and up-to-date presentation of an AD as indicated in paragraph 4.24 (b), (c) and (d) is crucial to manifest most fundamental values listed in paragraph 4.8. Yet, **there is potentially a risk that further protective measures would become over-restrictive which may eventually deter motivation in making an AD.**

For instance, the current proposal of assigning responsibilities to patients and their families for keeping and presenting the original copy of an AD would conceivably place huge expectations upon individuals. Keeping and presenting the original copy could be tiresome, is largely reliant on an individual's communication with close ones and is not necessarily efficient. Importantly, on top of the fragility of the paper form, family members may not know the storage location of the AD that could result in hindrance or failure of presentation to emergency rescue personnel. As previously discussed, there is generally low awareness and a proven lack of confidence in handling end-of-life decisions that includes making ADs. As such, it is highly perceivable for local citizens to be discouraged in pursuing all these detailed steps associated with the proposed legal framework for making an AD, conflicting with the intention of this consultation paper.

International examples have shown that an individual's responsibility to present the original AD form is not the only approach that could be taken. In the UK, although the supporting Code of Practice states that it is an individual's responsibility to take steps to ensure health professionals will be drawn to the existence of an advance decision, the following formats of presentation are accepted in addition to the original physical form (AgeUK, 2019):

- Copies in GP and hospital records,
- Copies in Summary Care Records[2],
- A physical card in wallet informing an existence of an AD, and
- Secure emergency personal record.

In another example, according to the "Medical Treatment Planning and Decision Act 2016" which took effect since March 2018 in Victoria, Australia, medical practitioners and not patients are obliged to make *reasonable efforts* to locate an Advance Care Directive (ACD) and patients' Medical Treatment Decision Maker (MTDM)' (The Parliament of Victoria, 2016). Acceptable efforts are believed to include a check of digital health records, clinical records, or contacting the

[2] Summary Care Records are an electronic record of key clinical information sourced from the GP records, used by healthcare professionals and authorized by patients to support their care and treatment (NHS Digital).

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person's primary health clinic (State of Victoria, Department of Health and Human Services, 2018). Undoubtedly, this workflow could only be enabled with an effective medical information system in place, which will be further discussed in session 2.3. It is therefore our view that an issue which could be tackled at the systemic level should not be transformed into an unnecessary barrier or demotivator to individuals or families in making end-of-life decisions.

2.3 Embracing technology in the end-of-life care model design

Consultation Question 22 Do you agree that the advance directive document may be recorded in eHRSS?	
Our Hong Kong Foundation	[✓] Agree [ ] Disagree

Consultation Question 25 Do you agree that the original advance directive document should still be required as proof of a valid advance directive, even when an advance directive record could be found in eHRSS?	
Our Hong Kong Foundation	[ ] Agree [✓] Disagree

At various public seminars organised by the Government on this consultation paper in Q4 2019, we have consistently heard the Government indicate that electronic means shall not be the solution to storage and presentation challenges of ADs. In our opinion, such views may be worthy of reconsideration.

Utilisation of technology has been a prevalent global trend, streamlining healthcare protocols and enhancing service efficiency. In our **'Fit-for-Purpose: A Health System for the 21st Century'** research report, we highlighted that "well-developed information and communication technologies and infrastructure can facilitate information exchange which further supports integrated services" (OHKF, 2018). As echoed by the WHO, palliative care providers should bear a responsibility for communication and information transfer. The seamless and efficient exchange and sharing of medical records would be the key for integrating care services between different levels and sectors of care (WHO, 2016).

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In Hong Kong, the territory-wide Electronic Health Record Sharing System (eHRSS) is essential for the smooth integration and coordination of care, and should be leveraged upon in the discussion on ADs. By uploading information on ADs to the electronic platform, timely access to this important information would also be made possible. It is indeed ambiguous to compare the possible hazard of time lag in eHRSS, as suggested by consultation question 23, to the vulnerability of keeping a paper form of an AD. Both factors present similar odds in failing to honour end-of-life wishes of individuals attributable to logistical hurdles.

As we move towards a primary care-led, person-centred, integrated health system, community resources should continuously be leveraged upon as we shift care burden from our currently overstretched hospitals into the community. In light of this, it is our view that an apt utilisation of the eHRSS is essential not only for the continuity of care between sectors, but specifically, is pertinent in facilitating EoLC service provision in community and primary care settings. Regardless of complexity, a technological challenge should be tackled technologically. Instead of taking the more anachronistic approach of resorting to a physical form, robust studies and trials should be conducted to ensure that our health system can leverage on the advancement of technology.

We understand that the development of the eHRSS is still in its infancy. Still, it will be conducive for our electronic health record system to become robust enough to support the provision of high-quality healthcare services across the life course, including the final stages of life, in a timely manner.

2.4 Community resources are needed to actualise dying in place

Consultation Question 29 Do you agree that, as a prerequisite to promote dying in place, the relevant provisions of the Coroners Ordinance should be amended to exempt certain deaths in RCHEs from reportable deaths?
Our Hong Kong Foundation [✓] Agree [ ] Disagree

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Consultation Question 30
Do you think that the proposed safeguard* for RCHE residents is sufficient if deaths in RCHEs may be exempted from reportable deaths? **if a resident who, before his/her death, was diagnosed as having a terminal illness, dies in RCHE, such death should remain reportable to the Coroner if there had been no registered medical practitioner who attended to him/her within 14 days prior to his/her death.*
Our Hong Kong Foundation [✓] Agree [ ] Disagree

OHKF agrees on the need to lift certain legal barriers in dying in place as we see that there is an **unequivocal preference for people to die outside of hospitals**, contrasting with the current situation. In 2016/17, our public hospitals looked after nearly 96% of all inpatient deaths (Hospital Authority, 2017a). However, a local population-based survey published in the same year discovered that merely half of Hong Kong citizens wished to pass away in hospital settings (51.8%), the other half showed preference for passing away at 'home' (30.8%) or in 'aged or nursing home/ hospice' (16.2%) (Chung et al., 2017). The stark discrepancy between people's preferences and the prevalence of death in hospitals could be attributed to factors such as the reluctance of imposing an extra burden upon family members (66.3%), and the lack of medical professional support (18.4%) (Chung et al, 2017). Furthermore, existing RCHEs had further indicated obstacles that will hinder dying-in-place in communities that include the absence of understanding and established protocols between RCHEs and HA on the timing of collaboration in advance care planning, as well as a lack of physicians to support imminently dying elders (Fang et al, 2016). **Thus, in addition to legal barriers, these hindrances to dying in place in community settings should also be addressed.**

Our recent study suggested that with sufficient support, nearly 90% of respondents of our telephone survey preferred to stay within their communities[3] until the end of their lives. (OHKF, 2019a). Correspondingly, respondents indicated "a comfortable environment" as the most imperative support at end of life (48.9%), followed by having "professional guidelines" (41.1%) and "regular community healthcare services" (38.0%) (OHKF, 2019a). This reveals public preference and readiness to receive EoLC in community settings outside of overcrowded hospital settings, and a promising opportunity to shift care burden from hospitals into the community.

[3] The term 'communities' is understood as outside of hospitals, including nursing homes and individual homes.

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Fragmented community efforts and low public engagement in current EoLC community services are vital issues that the Government need to address in order to confer confidence in the public to pass away within preferred familiar surroundings, no matter in RCHEs or at home. **An overarching policy framework tackling more than just legal barriers should be in place to enable dying in community settings become an actual option.**

3. Conclusion: EoLC service provision in community settings

We reiterate the sub-themes in this document below to encapsulate the core message of this submission:

- High public acceptance on advance directives (1.1)
- Limited public understanding of advance directives (1.2)
- Establishment of ADs is resource-draining (2.1)
- An efficient pathway is a key motivating factor for making ADs (2.2)
- Embracing technology in the end-of-life care model design (2.3)
- Community resources are needed to actualise dying in place (2.4)

Whilst OHKF welcomes the current legislative proposal on promoting advance directives and dying in place in Hong Kong, it is evident to us that a comprehensive policy and vision is yet to be devised to allow the realisation of a 'good death' in Hong Kong. This is echoed in a systematic review paper by the Chinese University of Hong Kong that covered 35 reports to summarise key features in EoLC together with implementation barriers and facilitators. "*Supportive policy and environment*", which involves legal frameworks and policies that enable the delivery of quality EoLC, is only one of eleven factors that the paper underlined across macro-, meso- and micro- levels (Threapleton et al, 2017).

The urgency to develop an apt EoLC model is further heightened by the pressing trend of population ageing highlighted by statistics indicating that Hong Kong's elderly population will increase to one million plus in the coming twenty years (Census and Statistics Department, 2017). Furthermore, our study indicated that today, already 11.2% of respondents needed to provide daily care to the elderly, or to patients with chronic conditions within their own household (OHKF, 2019a). This prevalence is set to increase with population ageing, further illustrating a rising need for well-developed, accessible and comprehensive EoLC services in Hong Kong.

Amongst the many aspects contributing to the betterment of EoLC in Hong Kong, we emphasise the importance of public education and the development of a community-based EoLC service

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provision model. Much related planning is yet to be done considering that only 8.8% of respondents in our study received EoLC-related information from medical professionals in community settings, although 40.8% of respondents preferred to get end-of-life advice and support from these professionals. (OHKF, 2019a). Our already overstretched public hospitals render it indispensable to develop the end-of-life care in community settings. The coordination of services between different levels and sectors of care is vital in ensuring that one's end-of-life needs will be attended to along the journey between hospitals and community settings.

To conclude, our health system should take on a holistic approach in health service provision so that needs of individuals are consistently met throughout the entire life course; including the final stages of life. As we move towards a primary care-led, person-centred, integrated health system, community resources should continuously be leveraged upon as we shift care burden from our currently overstretched public health system into the community. Fragmented service provision should be overcome with policies that encourage integration throughout the system to enable the provision of quality, comprehensive and continuous care throughout all stages of life as we move towards a more dignified end-of-life journey for all Hong Kong citizens.

The current legislative proposal is indeed good step forward in end-of-life care development, but will not be sufficient. We have attached the executive summary and survey report of our recent study on EoLC for your perusal. We hope that our forward-looking approach will not only serve as an affirmation to the Government's ongoing efforts to honour the end-of-life wishes of Hong Kong citizens, but will also complement the Government's dedicated vision.

Should you have any queries, please contact Pamela Tin (Lead Researcher, Healthcare & Ageing) by email at pamela.tin@ourhkfoundation.org.hk or Queenie Li (Assistant Researcher, Healthcare & Ageing) at queenie.li@ourhkfoundation.org.hk.

Yours sincerely,

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References

AgeUK. (2019). "Factsheet 72: Advance decisions, advance statements and living wills". Available at: https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs72_advance_decisions_advance_statements_and_living_wills_fcs.pdf (accessed 25th November, 2019).

Census and Statistics Department of the Hong Kong SAR. (2017). "Hong Kong Monthly Digest of Statistics: Hong Kong Population Projections for 2017 to 2066 ". Available at: https://www.censtatd.gov.hk/hkstat/sub/sp190_tc.jsp?productCode=FA100061 (accessed 22nd November, 2019).

Census and Statistics Department of the Hong Kong SAR. (2019). "The Mortality Trend in Hong Kong, 1986 to 2018". Available at: https://www.statistics.gov.hk/pub/B71911FB2019XXXXB0100.pdf (accessed 22nd November, 2019).

Chan C, Wong M, Choi K C, et al. (2019). Prevalence, Perception, and Predictors of Advance Directives among Hong Kong Chinese: A Population-Based Survey. *Int. J. Environ. Res. Public Health* 2019, 16, 265: doi:10.3390/ijerph16030365.

Chung R, Wong E, Kiang N, et al. (2017). Knowledge, Attitudes and Preferences of Advance Directives, End-of-Life Care, and Place of Care and Death in Hong Kong. A Population-Based Telephone Survey of 1067 Adults. *J Am Med Dir Assoc.* 2017 Apr 1;18(4):367.e19-367.e27. doi: 10.1016/j.jamda.2016.12.066.

Fang, M.S., Lou, W.V.& Kong, S.T. (2016). Overview of the Legal and Administrative Barriers to Caring and Dying in Place in Residential Care Honesfor the Elderly (RCHEs) (Policy No. 4). Hong Kong: *Faculty of Social Sciences & Sau Po Centre on Ageing, University of Hong Kong*. Retrieved from http://www.socsc.hku.hk/pp/wpcontent/uploads/2016/05/brief_4.pdf

Hospital Authority. (2017a). "Hospital Authority Statistical Report: 2016-2017". Available at https://www3.ha.org.hk/data/HAStatistics/DownloadReport/2 (accessed 22nd November, 2019).

Hospital Authority. (2017b). "Strategic Service Framework for Palliative Care". Available at https://www.ha.org.hk/haho/ho/ap/PCSSF_1.pdf/ (accessed 22nd November, 2019).

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JCECC, University of Hong Kong. (2016). "Community-wide Survey on End-of-Life Care in Hong Kong 2016". Available at: http://foss.hku.hk/jcecc/wp-content/uploads/2017/03/Population-Survey-Report_20170321.pdf (accessed 21st November, 2019).

Our Hong Kong Foundation. (2018). "Fit for Purpose: A Health System for the 21st Century". Available at https://www.ourhkfoundation.org.hk/sites/default/files/media/pdf/ohkf_research_report_digital_1201.pdf (accessed 22nd November, 2019).

Our Hong Kong Foundation. (2019a). "End-of-life Care in Primary Care". Available at: https://www.ourhkfoundation.org.hk/en/report/36/aging-society/healthcare-and-ageing-policy-research-series (accessed 21st November, 2019).

Our Hong Kong Foundation. (2019b). "Health System Capacity Constraints – The Severe Shortage of Doctors in Hong Kong Public Hospitals". Available at: https://www.ourhkfoundation.org.hk/sites/default/files/media/pdf/ManpowerPPT_20190410_full_eng.pdf (accessed 22nd November, 2019).

National Health Services. (2019). "Advance Directive (living will): End of life care". Available at: https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/ (accessed 22nd November, 2019).

NHS Digital. (2019). "Summary Care Records (SCR)". Available at: https://digital.nhs.uk/services/summary-care-records-scr (accessed 25th November, 2019).

The Parliament of Victoria. (2016). "Medical Treatment Planning and Decisions Act 2016". Available at: http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B4D3EBB66E52E98CCA25807A0014F70D/$FILE/16-069aa%20authorised.pdf (accessed: 25th November, 2019).

State of Victoria, Department of Health and Human Services. (2018) "The Medical Treatment Planning and Decisions Act 2016: information for clinicians working with young people under 18 years of age". Available at: https://www2.health.vic.gov.au/Api/downloadmedia/%7B03D70FFE-EFAD-4019-AD04-6F48EA5E74F0%7D (accessed 25th November, 2019).

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D. E. Threapleton, Chung R Y., Wong S Y.S. et al. (2017). Care Toward the End of Life in Older Populations and Its Implementation Facilitators and Barriers: A Scoping Review. *JAMDA* 18 (2017) 1000e1009. Doi: http://dx.doi.org/10.1016/j.jamda.2017.04.010.

Woo J, Lo R, Lee J et al. (2009). Improving end-of-life care for non-cancer patients in hospitals: description of a continuous quality improvement initiative. *Journal of Nursing and Healthcare of Chronic Illness* 1(3):237 - 244 August 2009. doi: 10.1111/j.1752-9824.2009.01026.x.

World Health Organisation. (2007). "Palliative Care. (Cancer control: knowledge into action : WHO guide for effective programmes ; module 5)", available at https://apps.who.int/iris/rest/bitstreams/52340/retrieve (accessed 25th November, 2019).

World Health Organisation. (2016). "Planning and implementing palliative care services: a guided for programme managers". Available at https://apps.who.int/iris/bitstream/handle/10665/250584/9789241565417-eng.pdf?sequence=1&isAllowed=y (accessed 25th November, 2019).

World Health Organisation. (2017). "Palliative Care – WHO Guide for Effective Programmes". Available at https://apps.who.int/iris/bitstream/handle/10665/44024/9241547345_eng.pdf?sequence=1(accessed 22nd November, 2019).

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Appendices

"Fostering Medical-Social Collaboration in Achieving Quality End-of-life Care"

Executive Summary

People are living longer, but not necessarily better

With a laudable life expectancy that ranks top in the world, Hong Kong's population is ageing rapidly. Greater longevity and the steep increase in co-morbidity in the elderly population has called for increased territory-wide attention on not just the quality of life, but also of death.

In 2018, Our Hong Kong Foundation ("OHKF") published the research report "*Fit for Purpose: A Health System for the 21st Century"* that advocated for the urgent need to reorient our currently hospital-centric, treatment-focused health system towards an integrated, primary care-led system (OHKF, 2018). In stressing the importance of care and not just cure, we emphasise the need to take a holistic approach in health service provision that should address the multidimensional needs of individuals throughout the entire life course; including the final stages of life.

Whilst **palliative care**, a concept that embraces **end-of-life care** (EoLC), is affirmed by the World Health Organization (WHO) as a core component of health systems (WHO, 2016), Hong Kong is clearly under-performing. In the "Quality of Death Index" launched by *The Economist* in 2015 that measures the quality of palliative care, Hong Kong was ranked 22nd of 80 selected countries, the lowest amongst its Asian counterparts including Taiwan (8th), Singapore (12th), Japan (14th) and South Korea (18th) (The Economist Intelligence Unit, 2015a). In particular, Hong Kong's score in the sub-category "community engagement" that assesses the level of discussion and awareness of end-of-life choices in communities, was below the global average of 80 countries (The Economist Intelligence Unit, 2015b).

OHKF recognises the continuous efforts of local institutions in both the public and private healthcare sectors in advancing palliative and end-of-life care services in Hong Kong. OHKF also acknowledges the Government's latest public consultation on EoLC (Food and Health Bureau, 2019) as a good effort to push end-of-life care development forward in Hong Kong.

Building on an expansive local literature in the past decade that has already revealed the palpable need to reinforce EoLC development, OHKF takes a progressive approach to explore views held towards EoLC in the community, specifically through the lens of potential EoLC service end-users reached in a telephone polling exercise. The polling, commissioned by OHKF and conducted by the Hong Kong Institute of Asia-Pacific Studies at The Chinese University of Hong Kong, was executed through telephone interviews with 1,001 Hong Kong residents between 26 November and 6 December 2019.

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Through understanding public perception and practice related to end-of-life care services in local communities, this study concludes that focusing on EoLC at a community level is vital not just for moving towards a more sustainable health system but importantly, for facilitating a better, and more dignified end-of-life journey for Hong Kong citizens.

Study Highlights (1)

A demonstrated need to enhance public education and advocacy on "end-of-life care"

Survey Questions

End-of-life care remains an ambiguous concept to most people in Hong Kong. According to the study, **55.1%** of respondents regarded themselves as having limited, little, nil or uncertain confidence in managing EoLC and its associated arrangements. Respondents also had a vague understanding of EoLC components. "Funeral assistance" proved to be the most understood component, to which **63.6%** of respondents responded positively; the other most-acknowledged EoLC parts being psychological counselling (**58%**) and social support (**43.7%**). While methodologies of EoLC have historically accentuated an integrated approach which encompasses physical, psychological, social and spiritual support. While most respondents proved to have some understanding of EoLC, most people in Hong Kong do not appear to be familiar with the vast and holistic scope of the concept. Instead, study findings point to a relatively disjointed understanding of EoLC and its individual components.

Q1

Q2

Findings also illustrate that sources of information on community EoLC services are scattered, where healthcare professionals in hospitals (**32.2%**) were found to be the most common channel of information dissemination. More concentrated efforts should be placed on public education and advocacy so that citizens will be able to understand the concept of EoLC and learn about related services in the community in a less fragmented manner.

Q9

Study Highlights (2)

Current end-of-life care services in communities have room for improvement, particularly in enhancing service comprehensiveness

At the time of study administration, only **23.4%** of respondents were able to identify end-of-life care service provision points in the community; of which **30.9%** had direct experience in using related services. The average service satisfaction score among users is a moderate **3.88** out of 6 where enhancing service comprehensiveness (**65.1%**), increasing promotional intensity (**48.2%**) and improving the performance of service providers (**42.8%**) were recognised by users as key elements that would contribute to the betterment of existing community EoLC services in Hong Kong.

Q3

Q4

Q5a

In contrast, a majority of respondents who had no prior experience in using EoLC services indicated reasonable price levels (**50.7%**) and accessibility of services (**45.9%**) as major considerations for future service acquisition. In comparison, service comprehensiveness becomes the most important

Q5b

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consideration for past users of EoLC services. Reiterating the crux of this report, there is a need to review EoLC service provision at a system-level. Policies that lessen potential barriers on service acquisition and enhance the motivation of our citizens to seek appropriate care that meet holistic needs should be in place.

Crucial factors to maximize end-of-life stay in the community include an enabling environment, and accessible support for individuals and families to facilitate end-of-life journeys. Such services exist but are fragmented, and our study further affirmed that people are largely unaware of available assistance in the community.

Understanding factors that will affect decisions to seek EoLC is also important in planning the expansion of related services. Respondents expressed multi-faceted needs when facing the final stages of life. For instance, **48.9%** of respondents stressed on the importance of a comfortable environment, **41.1%** indicated the significance of professional guidance and **38.0%** pointed towards the need for regular community healthcare services. We put forward that existing community initiatives should be scaled up in meeting the all-rounded needs of our citizens in handling end-of-life related matters. Q6

Study Highlights (3)

Sufficient support could realise wishes to stay in the community towards the end of life

Up to **86.1%** of respondents stated their preference for staying in the community [Note 1] until the end of their lives. When further reiterating the availability of sufficient community support, the percentage of people willing to stay in the community reached close to **90%**. This reveals public preference and readiness to receive community-based EoLC, and a promising opportunity to shift care burden from hospitals into the community. Findings substantiate the need to expand EoLC services, particularly at the community-level so that preferences of citizens are realised and concurrently, relief is brought to overstretched public hospitals. Q7

More than half of the respondents opted for relatives and acquaintances from non-religious affiliations as their most trusted type of personnel for non-medical EoLC support (**55.2%**). Healthcare professionals in the community were the next most popular option (**40.8%**), followed closely by hospital-based healthcare professionals (**39.6%**). However, a notable mismatch exists between preferred and actual channels of information on EoLC services; this was particularly noticeable for sources of support outside of hospitals and in community settings (**40.8%** vs **8.8%** for medical professionals in the community; **24.0%** vs. **12.8%** for social workers; **16.6%** and **4.8%** for religious acquaintances; and **30.8%** vs. **21.2%** for relatives or non-religious acquaintances). This further demonstrates that our primary care system has great potential for further development and that we are yet to optimise our utilisation of community resources to meet citizens' needs and expectations. Q8 Q9

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Conclusion: a holistic capacity planning blueprint and policy framework on end-of-life care is due

Hong Kong's elderly population will increase to one million plus (Census and Statistics Department, 2017) in the next twenty years. Rapid population ageing will see an emerging prevalence of caregivers, and a rising need for EoLC services in Hong Kong. Our study indicates that today, already **11.2%** of respondents needed to provide daily care to the elderly, or to individuals with chronic conditions within their own household. The role of caregivers will become increasingly prominent and the need for EoLC services will continue to rise. Q10

OHKF welcomes the current legislative proposal on promoting advance directives and dying-in-place in Hong Kong. Concluding our study findings, however, the key development areas of end-of-life care for the Government's reflection include: the lack of education and advocacy, the low engagement level of citizens in community end-of-life care services, as well as the fragmentation of current service provision.

Most importantly, it is evident to us that a solid vision and comprehensive policy framework should be devised in order to facilitate the realisation of a 'good death' in Hong Kong. Our health system shall take on a holistic approach in health service provision so that needs of individuals are consistently met throughout the entire life course; including the final stages of life. As we move towards a primary care-led, person-centred, integrated health system, community resources should continuously be leveraged upon as we shift care burden from our currently overstretched public health system into the community. Fragmented service provision should be overcome with policies that encourage integration throughout the system to enable the provision of quality, comprehensive and continuous care throughout all stages of life as we move towards a more dignified end-of-life journey for all Hong Kong citizens.

NOTE 1: The term 'communities' is understood as outside of hospitals, including nursing homes and individual homes.

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References

Census and Statistics Department of the Hong Kong SAR. (2017). "Hong Kong Monthly Digest of Statistics: Hong Kong Population Projections for 2017 to 2066 ". Available at: https://www.censtatd.gov.hk/hkstat/sub/sp190_tc.jsp?productCode=FA100061 (accessed 22nd November, 2019).

Food and Health Bureau of the Hong Kong SAR. (2019). "End-of-life care: legislative proposals on advance directives and dying in place - consultation document". Available at https://www.fhb.gov.hk/download/press_and_publications/consultation/190900_eolcare/e_EOL_care_legisiative_proposals.pdf (accessed 22nd November 2019).

The Economist Intelligence Unit. (2015a). "The 2015 Quality of Death Index: ranking palliative care across the world - key findings infographic". Available at https://eiuperspectives.economist.com/sites/default/files/images/2015%20Quality%20of%20Death%20Index%20Infographic.pdf (accessed 22nd November 2019).

The Economist Intelligence Unit. (2015b). "The 2015 Quality of Death Index: country profiles". Available at https://eiuperspectives.economist.com/sites/default/files/images/2015%20Quality%20of%20Death%20Index%20Country%20Profiles_Oct%206%20FINAL.pdf (accessed 22nd November 2019).

Our Hong Kong Foundation. (2018). "Fit for Purpose: A Health System for the 21st Century". Available at https://www.ourhkfoundation.org.hk/sites/default/files/media/pdf/ohkf_research_report_digital_1201.pdf (accessed 22nd November, 2019).

World Health Organisation. (2016). "Planning and implementing palliative care services: a guided for programme managers". Available at https://apps.who.int/iris/bitstream/handle/10665/250584/9789241565417-eng.pdf?sequence=1&isAllowed=y (accessed 25th November, 2019).

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OHKF Phone Survey: Needs & Knowledge of End-of-Life Care in Communities

1. **Are you confident in handling end-of-life care and making end-of-life arrangements for yourself or family and friends? How would you rate your confidence on a scale from 1 (least confident) to 6 (most confident)?**

2. **Do you understand the following concepts related to end-of-life care? (can choose more than one option)**
   i. Advance directives
   ii. Dying in place
   iii. Symptom management
   iv. Psychological counselling
   v. Social support
   vi. Spiritual support (e.g. related to religion)
   vii. Funeral arrangement assistance
   viii. Do not understand any of the above

3. **Apart from hospitals, do you know where to seek end-of-life care services in the community you reside in?**
   i. Yes (jump to Q4a) ii. No (jump to Q5b)

4. **a. Have you ever engaged in or used available end-of-life care services in the community you reside in?**
   i. Yes (jump to Q4b) ii. No (jump to Q5b)

   b. Are you satisfied with your experience of end-of-life care services in your community? How would you rate your satisfaction on a scale from 1 (least satisfied) to 6 (most satisfied)?

5. **a. (For people with former experience) Which factor(s) contribute(s) to your dissatisfaction of end-of-life care services received in the community? (can choose more than one option)**
   i. Insufficient venues of service provision
   ii. Service hours are too short
   iii. Services are not comprehensive enough
   iv. Incompetency of service providers
   v. Over-priced services
   vi. Lack of service promotion and education
   vii. Others

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b. (For people without former experience / satisfied with current services) Which is/are the main factor(s) you will consider in your decision on whether to use end-of-life care services? (can choose more than one option)

i. Reasonable price
ii. Convenient access to services
iii. High familiarity with service providers
iv. One-stop shop service provision
v. Advice from professional personnel
vi. Fulfilling personal needs

6. What is/are the most important form(s) of support you need for you to handle end-of-life matters (for yourself or for family and friends)? (can choose more than one option)

i. Professional advice on end-of-life arrangements, e.g. making advance directives
ii. Regular healthcare services at the community level
iii. Medicine and equipment for symptom management
iv. Practical knowledge of caregiving, such as physical assistance and supporting skills
v. Psychological counselling
vi. Comfortable environment
vii. Others

7. a. If possible, would you want to maximise your time spent in the community (i.e. outside of hospitals, e.g. at home, in elderly centres) in the last stages of life?

i. Yes ii. No

b. (For those who do not wish to stay in the community as indicated in 7a) Would you want to maximise your spent time in the community in the last stages of life if there was sufficient support available?

i. Yes ii. No

8. When facing an end-of-life situation, who would you seek non-medical support from? (can choose more than one option)

i. Medical professionals in hospitals
ii. Medical professionals in communities
iii. Social workers
iv. Religious acquaintances
v. Relatives or non-religious acquaintances
vi. Others

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9. Where did you learn about community end-of-life care services? (can choose more than one option)

i. Medical professionals in hospitals
ii. Medical professionals in communities
iii. Social workers
iv. Religious acquaintances
v. Relatives or non-religious acquaintances
vi. Promotion from the Government
vii. Others

10. Are you a caregiver for elderly members or chronic disease patients within your own household?

i. Yes ii. No

Note: If there is any inconsistency or ambiguity between the English version and the Chinese version, the Chinese version shall prevail.

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團結香港基金委託香港中文大學香港亞太研究所

就市民對晚期照顧需求及社區服務認知意見調查報告

1. 抽樣方法及調查概況

調查日期：	2019 年 11 月 26 日至 12 月 6 日（晚上 6 時 15 分至 10 時 15 分）。
調查對象：	18 歲或以上、操粵語或普通話的香港居民。
調查方法：	以電腦輔助電話訪問系統（Computer-Assisted Telephone Interviewing, CATI）進行資料蒐集工作。
抽樣方法：	調查樣本包括家居固網和手機電話，號碼是以通訊事務管理局公佈的香港電訊服務號碼計劃中，已分配予電訊商的固網及流動電話號碼的前 4 個號碼為種子前置號碼，再編配 0000 至 9999 的四位數字於每個號碼後方的後置號碼，組成新的號碼庫，再從新的號碼庫框架中隨機抽出號碼，成為是次調查的樣本。家居固網方面，會先確定是否住宅單位，當成功接觸住戶後，再隨機選取其中一名人 18 歲或以上香港居民接受訪問。手機方面，先確定接聽者是否致電號碼的主要使用者及 18 歲或以上香港居民，才進行訪問。
成功樣本數目：	1,001
抽樣誤差：	以 1,001（家居固網：501；手機：500）個成功樣本數對母體進行推論，假設受推論的變項為二項分配時，其樣本標準差為 0.0158；若將可信度（confidence level）設於 95%，推論百分比變項時最大可能樣本誤差為 ±3.10 個百分點以內。
數據加權：	由於調查樣本採用了家居固網和手機電話，每人可能被抽中的機率不同，加上為了調查數據更能反映香港人口分佈的真實情況，數據在進行分析時曾作加權（weighting）處理，有關詳情參閱下一部分「有關調查資料加權的說明」。

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電話撥號結果及回應率：

致電結果	家居固網	手機
1. 最初抽樣電話號碼總數	25,000	9,500
2. **不合資格個案**	17,686	3,040
傳真號碼	544	8
無效電話（包括長鳴、服務停止）	15,702	2,565
非住宅 / 商業用電話	1,406	17
沒有合適受訪者（18 歲或以上人士香港居民）	10	408
其他（包括聲稱電話錯誤、電話轉駁等）	24	42
3. **未能界定資格個案**	6,044	5,280
線路繁忙	682	1,757
沒有人接聽	2,532	2,084
電話錄音（未確定是否住宅）	1,262	922
線路被阻 / 需輸入密碼 / 通訊障礙	29	15
語言問題	123	74
一接聽即掛線（未確定是否住宅或有合適受訪者）	1,416	428
4. **合資格個案**	770	680
被其他家庭成員拒絕（固網已確定是住宅）/ 手機拒絕（未確定是否合適受訪者）[R]	668	617
被合適受訪者拒絕（已確定合適受訪者）[R]	28	11
合適受訪者中途拒絕 [R]	24	15
合適受訪者不在家 / 在街中 [NC]	38	29
合適受訪者不適宜接受訪問（包括語言、患病）[O]	11	7
部份完成訪問 [P]	0	1
成功訪問 [I]	**501**	**500**
成功回應率（I /（I + P）+（R + NC + O）]	**39.4%**	**42.4%**

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2. 有關調查資料加權的說明

調查採用重疊的雙框（Dual frame）電話號碼取樣設計。這種方式結合了各自從家居固網電話號碼和手機號碼抽樣框架隨機抽取的電話號碼樣本，由於同時擁有家居固網電話號碼和手機號碼的人為數眾多，因而出現抽樣框架重疊的情況。為避免兩個抽樣框架重疊或其他不知名因素可能造成的偏誤估計，調查數據按以下程序加權處理：

步驟一

加權程序分兩個步驟完成。首先，由於社會上每個人擁有的家居固網電話號碼和手機號碼數目都不盡相同，如以家居固網電話號碼和手機號碼這種雙框架方式來抽樣，則不同人被抽中為訪問對象的機會率也可能會有所不同。為了剔除這種因雙框電話號碼取樣而造成的不公平影響，首個加權程序便是以每位受訪者依擁有家居固網電話號碼和手機號碼數目，對比估計全部家居固網電話及手機號碼總數，從估算被隨機抽中訪問的機會率。個人在雙框電話號碼取樣中被抽中訪問的機會率（即加權因子 1）公式計算如下：

$$\pi_i = \frac{n_L}{N_L} \times \frac{t_i^L}{e_i^L} + \frac{n_m}{N_m} \times t_i^m$$

其中，i = 第 *i* 名被抽中的人士

n_L = 家居固網電話號碼樣本數目
N_L = 全部家居固網電話號碼總數
t_i^L = 家中擁有的固網電話號碼數目
e_i^L = 住戶中合資格受訪人數
n_m = 手機號碼樣本數目
N_m = 全部手機號碼總數
t_i^m = 個人擁有的手機號碼數目

加權因子 1（$WT1_i$）之計算方式為個人被抽中訪問的逆向機會率 (inverse of probability)， 即為：$WT1_i = \pi_i^{-1}$

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步驟二

由於雙框電話號碼取樣是以固網及手機號碼為基礎的（即樣本皆為電話號碼），而不是以全港人口為本的，故為了保證調查數據更能反映香港人口分佈的真實情況，第二個加權步驟以香港政府統計處公布的 2019 年年中 18 歲或以上人口數字 [扣除外籍家庭傭工] 為基礎，來加權是次調查數據。加權因子 2（WT2）的計算方法，是把人口統計中性別和年齡組別的人口估計，除以經過加權因子 1 加權後的調查中對應組別的人口樣本。加權因子 2 的計算表列如下：

年齡組	香港政府統計處公布的 2019 年年中人口分佈		經加權因子 1 加權後的電話調查樣本人口分佈		加權因子 2	
	男 (A)	女 (B)	男 (C)	女 (D)	男 (A÷C)	女 (B÷D)
18-24	263900	253800	494323	567384	0.53386184	0.44731588
25-34	455900	486600	670884	692931	0.67955166	0.70223462
35-44	466900	570900	538217	658442	0.86749410	0.86704691
45-54	499300	617300	728209	818022	0.68565492	0.75462513
55-64	592000	624100	588940	705410	1.00519640	0.88473337
65 或以上	622000	709700	699825	888910	0.88879370	0.79839370

步驟三

最終加權因子透過以下公式計算：

$$WT\_F = WT1 * WT2$$

而： WT_F = 最終加權因子

WT1 = 加權因子 1

WT2 = 加權因子 2

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3. 受訪市民社會經濟背景變項的頻數表【經加權】

【由於數據經加權處理，樣本數可能出現進位的關係，樣本總計或不等於 1,001，而百分率相加後的總計亦未必等於 100%。】

性別

	頻數	百分比	有效百分比
1. 男	471	47.1	47.1
2. 女	530	52.9	52.9
總計	1001	100.0	100.0

有效樣本 1001　　缺值樣本 0

年齡「請問你屬於以下邊個年齡組別呢？」【讀出1-6】

	頻數	百分比	有效百分比
1. 18 至 24 歲	84	8.4	8.4
2. 25 至 34 歲	153	15.3	15.3
3. 35 至 44 歲	169	16.8	16.8
4. 45 至 54 歲	181	18.1	18.1
5. 55 至 64 歲	198	19.7	19.7
6. 65 歲或以上	216	21.6	21.6
總計	1001	100.0	100.0

有效樣本 1001　　缺值樣本 0

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教育程度「請問你嘅教育程度去到邊呢？」【讀出1-6】

		頻數	百分比	有效百分比
1.	無受教育或幼稚園	14	1.4	1.4
2.	小學	108	10.8	11.0
3.	初中（中一至中三）	99	9.9	10.0
4.	高中（中四至中七）	319	31.9	32.5
5.	大專非學士（包括文憑 / 高級文憑 / 副學士等）	110	10.9	11.1
6.	大專學士或以上（包括大學學士 / 碩士 / 博士等）	334	33.3	33.9
9.	拒絕回答	18	1.8	缺值
	總計	1001	100.0	100.0

有效樣本 983　　缺值樣本 18

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就業狀況「請問你現時係唔係在職人士呢？」

		頻數	百分比	有效百分比
1.	非在職：學生	61	6.1	6.1
2.	非在職：主理家務	114	11.4	11.6
3.	非在職：退休	226	22.6	22.9
4.	非在職：失業 / 待業	30	3.0	3.0
5.	在職人士	557	55.7	56.4
9.	拒絕回答	13	1.3	缺值
	總計	1001	100.0	100.0

有效樣本 988　　缺值樣本 13

收入「請問你個人每個月嘅收入大約有幾多呢？」【讀出1-5】【此題只問在職受訪者】

		頻數	百分比	有效百分比
1.	一萬以下	40	4.0	7.4
2.	一萬至二萬以下	141	14.1	26.3
3.	二萬至三萬以下	171	17.1	31.8
4.	三萬至六萬以下	131	13.1	24.3
5.	六萬或以上	46	4.6	8.5
8.	收入不定	9	0.9	1.7
9.	拒絕回答	18	1.8	缺值
0.	不適用	444	44.3	缺值
	總計	1001	100.0	100.0

有效樣本 539　　缺值樣本 462

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居住地區「請問你係住緊十八區議會邊一區呢？」

	頻數	百分比	有效百分比
11. 中西區 [港島]	31	3.1	3.2
12. 灣仔區 [港島]	9	0.9	0.9
13. 東　區 [港島]	93	9.3	9.5
14. 南　區 [港島]	26	2.6	2.6
21. 油尖旺 [九龍西]	57	5.7	5.8
22. 深水埗 [九龍西]	32	3.2	3.3
23. 九龍城 [九龍西]	37	3.7	3.8
31. 黃大仙 [九龍東]	51	5.1	5.3
32. 觀　塘 [九龍東]	92	9.2	9.5
41. 荃　灣 [新界西]	45	4.5	4.6
42. 屯　門 [新界西]	90	9.0	9.2
43. 元　朗 [新界西]	65	6.5	6.7
44. 葵　青 [新界西]	69	6.9	7.0
45. 離　島 [新界西]	25	2.5	2.6
51. 北　區 [新界東]	37	3.7	3.8
52. 大　埔 [新界東]	54	5.4	5.6
53. 沙　田 [新界東]	96	9.6	9.9
54. 西　貢 [新界東]	66	6.6	6.8
99. 拒絕回答	25	2.5	缺值
總計	1001	100.0	100.0

有效樣本 976　　缺值樣本 25

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4. 主要問題變項的頻數表【經加權】

【由於數據經加權處理，樣本數可能出現進位的關係，樣本總計或不等於 1,002，而百分率相加後的總計亦未必等於 100%。】

Q1「你有冇信心喺你人生晚期，或面對親友過身時，能夠處理到晚期照顧同善終安排呢？如果 1 分代表『非常無信心』，至 6 分代表『非常有信心』，1 至 6 分，你會俾幾多分呢？」

		頻數	有效百分比
1.	1 分（非常無信心）	73	7.3
2.	2 分（幾無信心）	133	13.3
3.	3 分（稍無信心）	287	28.7
4.	4 分（稍有信心）	215	21.5
5.	5 分（幾有信心）	151	15.0
6.	6 分（非常有信心）	84	8.4
7.	普通 / 一半半	7	0.7
8.	唔知道 / 好難講	51	5.1
	總計	1001	100.0

有效樣本 1001　　缺值樣本 0　　平均分 (mean)：3.52；標準差 (S.D.)：1.361

註：計算平均分時，「8. 唔知道 / 好難講」的樣本不包括在內，故計算平均分時的有效樣本為 950。

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Q2「當提及晚期照顧時，你覺得了唔了解以下嘅服務呢？」【逐一讀出 1-7，可選多項】

	頻數	以有效樣本數為基數之百分比
1. 預設醫療指示	336	33.6
2. 在居離世	387	38.7
3. 徵狀控制	251	25.1
4. 心理輔導	580	58.0
5. 社交支援	437	43.7
6. 靈性討論（如宗教信仰）	406	40.6
7. 殯儀協助	636	63.6
8. 以上皆不包括（或以上皆不了解）	134	13.4
總計	3167	316.8

有效樣本 1000　　缺值樣本 1

* 該百分比是答案數目（即頻數）除以有效樣本人數（即 1,000 人）得出的。此外，由於容許受訪者給予多於一項答案，故百分比總計將超過 100%。

Q3「除咗醫院以外，你知唔知喺你住嘅社區邊度有提供晚期照顧服務呢？」

		頻數	有效百分比
1.	知道 【續問 Q4】	234	23.4
2.	唔知道【跳問 Q5b】	767	76.6
	總計	1001	100.0

有效樣本 1001　　缺值樣本 0

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Q4a「咁你有冇曾經喺你住嘅社區內，接觸或者使用過晚期照顧服務呢？」

【此題只問 Q3 回答 1 的受訪者】

		頻數	百分比	有效百分比
1.	有 【續問 Q4b】	72	7.2	30.9
2.	沒有【跳問 Q5b】	162	16.1	69.1
.	不適用	767	76.6	缺值
	總計	1001	100.0	100.0

有效樣本 234　　缺值樣本 767

Q4b「請問你滿唔滿意曾接觸或使用過嘅社區晚期照顧服務呢？如果 1 分代表『非常唔滿意』，至 6 分代表『非常滿意』，1 至 6 分，你會俾幾多分呢？」【此題只問 Q4a=1 的受訪者】

		頻數	百分比	有效百分比
1.	1 分（非常唔滿意）【續問 Q5a】	1	0.1	1.3
2.	2 分（幾唔滿意）【續問 Q5a】	6	0.6	8.2
3.	3 分（稍唔滿意）【續問 Q5a】	22	2.2	30.1
4.	4 分（稍滿意）【跳問 Q5b】	15	1.5	20.4
5.	5 分（幾滿意）【跳問 Q5b】	19	1.9	25.8
6.	6 分（非常滿意）【跳問 Q5b】	5	0.5	6.8
8.	唔知道 / 好難講【跳問 Q5b】	5	0.5	7.4
.	不適用	929	92.8	缺值
	總計	1001	100.0	100.0

有效樣本 72　　缺值樣本 929　平均分 (mean)：3.88；標準差 (S.D.)：1.177

註：計算平均分時，「8. 唔知道 / 好難講」的樣本不包括在內，故計算平均分時的有效樣本為 67。

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Q5a「你唔滿意曾接觸嘅社區晚期照顧服務嘅原因係乜呢？其次呢?」

【半開放式問題】【此題只問 Q4b=1/2/3 的受訪者】

	頻數	以有效樣本數為基數之百分比
1. 服務地點示不足	7	24.0
2. 服務時間太短	5	18.3
3. 服務不夠全面	19	65.1
4. 服務者不夠專業 / 服務者能力不足	12	42.8
5. 服務價錢太高	11	39.0
6. 服務推廣和教育有待加強 / 宣傳不足	14	48.2
總計	68	237.4

有效樣本 29　　缺值樣本 0

* 該百分比是答案數目（即頻數）除以有效樣本人數（即 29 人）得出的。此外，由於容許受訪者給予多於一項答案，故百分比總計將超過 100。

Q5b「你認為以下邊方面係你接受晚期照顧服務的主要考慮因素呢？其次呢?」【半開放式問題】

	頻數	以有效樣本數為基數之百分比
1. 價錢合理	507	50.7
2. 服務獲取方便	459	45.9
3. 熟悉服務提供者	286	28.6
4. 一條龍服務	418	41.8
5. 專業人士建議	358	35.7
6. 自身支援需要	272	27.2
7. 其他【註明】	11	1.1
8. 唔知道 / 好難講	45	4.5
總計	2357	235.5

有效樣本 1001　　缺值樣本 0

* 該百分比是答案數目（即頻數）除以有效樣本人數（即 1001 人）得出的。此外，由於容許受訪者給予多於一項答案，故百分比總計將超過 100%。

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	【其他答案】	頻數	百分比	有效百分比
11.	其他：服務質素	3	26.2	26.2
12.	其他：服務地點是否近住所	1	8.9	8.9
13.	其他：服務是否符合自身需要	0	4.0	4.0
14.	其他：殯儀服務是最重要考慮因素	1	6.4	6.4
15.	其他：長者是否喜歡該服務 / 患者意願	4	32.6	32.6
16.	其他：患者是否接受自己很快離世	1	4.5	4.5
17.	其他：服務提供者有否認可資格	2	17.4	17.4
	總計	11	100.0	100.0

有效樣本 11　　缺值樣本 0

Q6「喺人生晚期，或面對親友過身時，你認為以下邊方面嘅支援係最重要呢？其次呢?」

【先讀出 1-7 選項，依重要性排列次序；可選多項】

		頻數	以有效樣本數為基數之百分比
1.	臨終安排上的專業指引，例如協助設定預設醫療指示	412	41.1
2.	喺社區獲得定期嘅健康護理	381	38.0
3.	徵狀控制嘅藥物和設備	359	35.8
4.	照顧病情嘅實際知識，例如扶抱技巧	371	37.0
5.	心靈輔導	379	37.8
6.	舒適環境	490	48.9
7.	其他【註明】	15	1.5
8.	唔知道 / 好難講	46	4.6
	總計	2451	244.8

有效樣本 1001　　缺值樣本 0

* 該百分比是答案數目（即頻數）除以有效樣本人數（即 1001 人）得出的。此外，由於容許受訪者給予多於一項答案，故百分比總計將超過 100%。

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	【其他答案】	頻數	百分比	有效百分比
11.	其他：對那些要照顧臨終人士的輔導	7	46.5	46.5
12.	其他：家人如何面對臨終者 / 臨終人士子女如何面對	3	19.9	19.9
13.	其他：一條龍服務，可以查詢有關晚期照顧的問題	1	5.8	5.8
14.	其他：如何令病人舒服些	1	6.0	6.0
15.	其他：如何令病人抱積極態度	0	3.1	3.1
16.	其他：財政支援	2	15.1	15.1
17.	其他：對病情的了解	1	3.6	3.6
18.	其他：對那些要照顧臨終人士的輔導	7	46.5	46.5
	總計	15	100.0	100.0

有效樣本 15　　缺值樣本 0

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Q7a「如有可能，你想唔想喺人生晚期，儘量留喺社區（即醫院以外，如院舍或家中）呢？」

		頻數	百分比	有效百分比
1.	想 【跳問 Q8】	862	86.1	86.1
2.	唔想【續問 Q7b】	62	6.2	6.2
8.	唔知道 / 好難講【跳問 Q8】	77	7.7	7.7
	總計	1001	100.0	100.0

有效樣本 1001　　缺值樣本 0

Q7b「如果喺社區（即醫院以外，如院舍或家中），有以上提及過嘅充足支援，你想唔想喺人生晚期儘量留喺社區呢？」【此題只問 Q7a=2 的受訪者】

		頻數	百分比	有效百分比
1.	想	25	2.5	39.9
2.	唔想	30	3.0	48.1
8.	唔知道 / 好難講	7	0.7	11.9
.	不適用	939	93.8	缺值
	總計	1001	100.0	100.0

有效樣本 62　　缺值樣本 939

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Q8「喺人生晚期，或面對親友過身時，如有需要，你會搵以下邊類人士以獲得醫療治療外嘅支援呢？」

【讀出 1-選項，可選多項】

		頻數	以有效樣本數為基數之百分比
1.	醫院醫護人員	397	39.6
2.	社區醫護人員（如家庭醫生，社區護士）	409	40.8
3.	社工	240	24.0
4.	宗教人員或教友	166	16.6
5.	親屬或非教會朋友	553	55.2
6.	其他【註明】	2	0.2
8.	唔知道 / 好難講	28	2.8
	總計	1794	179.2

有效樣本 1001　　缺值樣本 0

* 該百分比是答案數目（即頻數）除以有效樣本人數（即 1001 人）得出的。此外，由於容許受訪者給予多於一項答案，故百分比總計將超過 100%。

	【其他答案】	頻數	百分比	有效百分比
11.	其他：精神健康輔導	2	100.0	100.0
	總計	2	100.0	100.0

有效樣本 2　　缺值樣本 0

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Q9「你曾經得到過嘅社區晚期照顧資訊來源係乜呢？」【可選多項】

		頻數	以有效樣本數為基數之百分比
1.	醫院醫護人員	322	32.2
2.	社區醫護人員（如家庭醫生，社區護士）	88	8.8
3.	社工	128	12.8
4.	宗教人員或教友	48	4.8
5.	親屬或非教會朋友	290	28.9
6.	政府宣傳	239	23.9
7.	其他【註明】	57	5.7
8.	唔知道 / 好難講	194	19.4
	總計	1367	136.5

有效樣本 1001　　缺值樣本 0

* 該百分比是答案數目（即頻數）除以有效樣本人數（即 1001 人）得出的。此外，由於容許受訪者給予多於一項答案，故百分比總計將超過 100%。

	【其他答案】	頻數	百分比	有效百分比
11.	其他：新聞 / 傳媒	24	2.4	41.5
12.	其他：工作上認識	9	0.9	15.2
13.	其他：學校 / 課堂	3	0.3	5.8
14.	其他：書本 / 雜誌	1	0.1	1.4
15.	其他：網上曾看過 / 自己上網搜尋資料	6	0.6	10.5
16.	其他：屋企附近的社區中心 / 老人中心	2	0.2	3.4
17.	其他：社福團體	1	0.1	1.4
18.	其他：屋企有老人家 / 有家人晚期人士 / 自己經驗過	8	0.8	13.2

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19.	其他：講座 / 論壇	1	0.1	1.9
20.	其他：展覽 / 街站	3	0.3	5.7
	總計	57	100.0	100.0

有效樣本 57　　缺值樣本 0

Q10「你屋企有冇家人因年紀大或疾病，而需要人特別照顧佢嘅生活起居呢？」

		頻數	百分比	有效百分比
1.	有	117	11.7	11.7
2.	冇	882	88.1	88.3
9.	拒絕回答	2	0.2	缺值
	總計	1001	100.0	100.0

有效樣本 999　　缺值樣本 2

[完]

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