<u>Views on legislative proposals on advance directives and dying in place-</u> Submission by Our Hong Kong Foundation

Panel Members,

Our Hong Kong Foundation (OHKF) acknowledges the Government's continuous efforts in improving end-of-life care in Hong Kong. We believe that the Government's latest public consultation on end-of-life care will be largely conducive to the implementation of advance directives and dying in place. Recognizing this good effort to overcome legislative hurdles to push end-of-life care development forward in Hong Kong, we respond to the consultation document using the following themes:

- 1. **Public education and advocacy** it is our view that the public at large is ready to **accept** the concept of advance directives. This favourable reception however, is conditional upon the **awareness** and **understanding** of the concept. For instance, a local academic study conducted in 2016 by academics from The Chinese University of Hong Kong¹ revealed that 86% of study participants had not heard of advance directives but upon explanation of the concept, 61% would make an advance directive if legislated. Thus, there is a proven need to increase awareness of advance directives in the community through active public education and advocacy.
- 2. Capacity planning- making an advance directive is not simply the signage of a legal document but instead, typically involves a set of stringent procedures and a back-and-forth communication process between patients, family members and healthcare professionals. This conceivably intense process has implications on the required time and expertise of healthcare professionals. In turn, this could impose immense burden on our already overstretched health system. 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

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¹ Chung, R. Y. N., Wong, E. L. Y., Kiang, N., Chau, P. Y. K., Lau, J. Y., Wong, S. Y. S., ... & Woo, J. W. (2017). Knowledge, attitudes, and preferences of advance decisions, end-of-life care, and place of care and death in Hong Kong. A population-based telephone survey of 1067 adults. Journal of the American Medical Directors Association, 18(4), 367-e19.

required human resources and adequate training for our workforce, the sole existence of an improved legal framework will have limited impact.

3. Enhancing the role of technology in end-of-life care service model- the Government should consider electronic means of presentation and storage of advance directives. Specifically, as highlighted in our "Fit-for-Purpose: A Health System for the 21st Century" research report, the existing territory-wide Electronic Health Record Sharing System (eHRSS) is essential for the smooth integration and coordination of care in Hong Kong and should be leveraged on. By uploading information on advance directives to the electronic platform, timely access to this important information would be made possible. Furthermore, the platform will be essential to ensure continuity of care along the patient care pathway and particularly pertinent in our advocacy for shifting care from hospitals into the community.

The current legislative proposal is indeed good step forward in end-of-life care development, but will not be sufficient. In addition to submitting our views to the Government, we have also completed a **telephone polling study** to complement the public consultation. Through understanding public perception and practice related to end-of-life care services in local communities (outside of hospital settings), our study concludes that focusing on **end-of-life care at the 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.

To conclude, 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 continuously stressing the **importance of care and not just cure**, it is our view that an overarching policy framework and meticulous service model for provision of end-of-life care at the community level is vital in facilitating the realisation of a 'good death' in Hong Kong.

Sincerely,

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