

**Press Release****January 16, 2024****Jockey Club End-of-Life Community Care Project
Press Conference on
Public Survey on End-of-Life Care in Hong Kong 2023**

In 2022, a total of 61,557 people passed away in Hong Kong. There are various medical and care options available for the terminally ill patients. However, as patients approach the last stage of their life, they may not be in a position to make decisions or communicate their wishes; family members may not reach a consensus, which can add to the pressure and emotional distress felt.

It is important to make early preparations for care plans in order to respect patients' wishes and facilitate effective communication and discussions among the patients, family members and healthcare teams on the most suitable care plan. The Government of the Hong Kong SAR recently gazetted the Advance Decision on Life-Sustaining Treatment Bill which aims to put in place a legislative framework for providing holistic end-of-life care services for patients and their families. This includes an Advance Medical Directive (AMD), an important measure to respect patients' choices and enhance quality of life during their final days.

The Hong Kong Jockey Club Charities Trust approved funding of around HK\$520 million to initiate the "Jockey Club End-of-Life Community Care Project" (JCECC Project). Launched in 2016, the ten-year project aims to improve the quality of end-of-life care, enhance the capacity of service providers and raise public awareness. The Faculty of Social Sciences of University of Hong Kong (HKU), one of the project partners, has been responsible for evaluation of the JCECC Project and for conducting a community-wide survey on end-of-life care in Hong Kong. HKU engaged Social Policy Research Limited to conduct the survey between July and October 2023. It aimed to understand the Hong Kong citizens' knowledge, attitude and intentions regarding end-of-life care, Advance Care Planning and Advance Medical Directive. The telephone survey with random sampling interviewed a total of 1,506 Hong Kong citizens aged 18 or above. The response rate was 80.9%.

Ms. Imelda Chan, Head of Charities (Healthy Community) of The Hong Kong Jockey Club, said: "As Hong Kong's population ages, the number of elderly people suffering from terminal illnesses continues to rise, and the demand for end-of-life care services is also increasing in the community. The Government's Advance Decision on Life-Sustaining Treatment Bill should help raise public awareness on this topic. It will contribute to the future development of the JCECC Project and all end-of-life services in Hong Kong. Building a healthy community is one of the priority areas of the Club's charity strategy. The Club will continue to explore new projects, such as providing palliative care and end-of-life services to a wider variety of groups, to give the public access to better medical services."



Professor Amy Chow, Project Director of the JCECC Project and Department Head of the Department of Social Work and Social Administration of the Faculty of Social Sciences at HKU, announced the survey results. Most people are said to believe that discussing death is a taboo, yet 80% of those approached were willing to participate in this survey on life and death issues. Over 75% of the respondents felt comfortable or did not experience any discomfort during the process. Moreover, the survey revealed there is significant lack of understanding about this topic, as around 70% of respondents said they had never heard of “end-of-life care”. Additionally, the majority of the respondents had never heard of “Advance Care Planning” and “Advance Medical Directive”, respectively. Professor Chow said: “Surprisingly, after explaining these unfamiliar terms to those respondents, two-thirds of them said they would accept end-of-life care when they are facing terminal illnesses. Over 60% of them support their family members to establish an advance medical directive. Hong Kong truly needs more life and death education to prepare citizens for the future.” The prospect of end-of-life care can involve many medical decisions. The survey found that respondents are more certain about their own “Advance Care Planning” and “Advance Medical Directive”, but had more neutral opinions on their family members’ preferences. This implied a lack of understanding regarding the preferences of family members. On the other hand, many people seek various medical interventions in order to prolong the lives of family members suffering from terminal illnesses. However, nearly 70% of respondents stated that quality of life is more important than the length of life. Therefore, it is crucial to communicate with family members and understand their intentions. Only one-fourth of the respondents had communicated their end-of-life care wishes with family members. After having this conversation, not only there were no adverse effects, but it enhanced their mutual understanding (36.4%), feelings of relief (26.6%), reduce worries (22.9%) and even improved relationships (14.6%). Professor Chow emphasised that: “With ACP, worry-free!”

Among respondents who had not discussed their wishes for end-of-life care with family members, 27.4% found it difficult to start the conversation; 24% were concerned about their family members’ reactions; 16.8% believed the discussion would make them unhappy; and 14.2% stated that they lacked knowledge on this topic. Among those who did not intend to establish “Advance Care Planning”, 49.7% considered the procedure to be complicated; 38.2% perceived no immediate need; and 25% had insufficient understanding. Moreover, with relevant information provided, most people are willing to accept palliative care and Advance Care Planning. Therefore, it is crucial to have wide-ranging public education catering to different target groups; utilising various media platforms to disseminate end-of-life care information and raise public awareness about such care options in the community. At the same time, the JCECC project team will organise a series of community talks on the topic of the Hong Kong SAR Government’s gazetted “Advance Decision on Life-Sustaining Treatment Bill” between January and April 2024 to enhance public awareness.

Dr. Wong Che-keung, Associate Consultant, Medicine and Geriatric Department of Ruttonjee and Tang Shiu Kin Hospital, Hong Kong East Cluster from Hospital Authority, shared his personal experiences in discussing and establishing Advance Care Plans and Advance Medical Directives. “Advance care planning is an ongoing communication process for early preparation. It allows terminally ill patients to express their views on their future medical care and personal plans with their family members or healthcare providers in advance while they are still mentally capable. The patients can specify which life-sustaining treatments they would refuse under certain circumstances through the establishment of an Advance Medical Directive. It is very important to have adequate communication among patients and their family so they can understand their thoughts, avoid unnecessary disputes in the future and honour the patient’s wishes. By fully understanding the pros and cons of the care options, respecting patients’ autonomy and choices, patients can fulfill their wishes till their end stage of life



without regrets.”

Dr. Wong added that there are a few points that should be considered when initiating discussions on end-of-life topics.

1. Depending on the health condition and readiness of both the patient and family members, it is often easier to start with some simple topics that are related to daily life, such as relevant news articles, festivals and television programmes.
2. It is important to note that not all aspects of the discussion can be covered in a single session. Both the patient and family members need time to digest and think about it. It is recommended to have multiple discussions over time. The timing of these discussions should also take into account any changes in the patient’s health condition.

About “Jockey Club End-of-Life Community Care Project”

Hong Kong is facing a rapidly ageing population, and the number of elderly suffering from terminal illnesses has also escalated correspondingly. In view of the growing demand for end-of-life care services in the community, The Hong Kong Jockey Club Charities Trust approved around HK\$520 million to initiate the “Jockey Club End-of-Life Community Care Project” (JCECC). Launched in 2016, the ten-year project aims at improving the quality of end-of-life care, enhancing the capacity of service providers, as well as raising public awareness.

JCECC is a multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with special emphasis on the interface between social and medical systems. Service models are being developed and shaped to provide holistic support to terminally-ill elders in the community and elderly homes. The goal is to enable the city’s older people to have informed choices of care and have an improved quality of life. Please visit <http://www.JCECC.hk/>

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