

FOREWORD

Hong Kong is facing a rapidly ageing population. Not only is the number of elderly people suffering from terminal illnesses set to increase, but also the demand for end-of-life care (EoLC) will see significant growth. People have come to recognise that a good death is an important part of a quality life, while ageing in place is a preference expressed by the majority of the elderly. Yet there is insufficient service provision and a lack of care and treatment choices in Hong Kong to allow elderly people to die with dignity and comfort at the end of their life.

To address these evolving challenges, The Hong Kong Jockey Club Charities Trust initiated the Jockey Club End-of-Life Community Care (JCECC) project in 2015 with a vision to promote the quality of dying for terminally-ill seniors.

The Trust has brought together key stakeholders of the social and health care sectors to pilot five community-based EoLC service models in this multi-disciplinary, multi-institution and cross-sectoral collaboration. We hope to enhance community EoLC at three levels: at the individual level, to allow patients an informed choice of care and improve both their own quality of life and that of their caregivers during their last days; at community level, to increase public knowledge and understanding of end-of-life concepts, such as advance directives and advance care planning; and at system level, to drive systemic change in the delivery of such services by building the competence of EoLC practitioners. This will strengthen the capacity of the field as a whole, as well as establish evidence-based practices that can be used as reference for future service development.

With the concerted efforts of our partners, we are encouraged that about a quarter of all subvented elderly homes in the city have already participated in this project in the past three years. The five community service pilots have also helped make home-based care a reality for over 3,700 terminally-ill patients and their family members. We are equally encouraged that over 9,400 professionals and front-line workers have been trained under the project, with more than 560 volunteers joining hands to support EoLC.

To further strengthen the sustainable development of EoLC in Hong Kong, the Trust has extended the project for another three years, with an enhanced integrated service model and extended coverage of EoLC programmes in elderly homes.

On behalf of The Hong Kong Jockey Club Charities Trust, I would like to express my heartfelt thanks to all those involved, and particularly The University of Hong Kong for their tremendous effort in compiling this booklet. We believe that with the experience of the project implementation and evidence-based service models it documents, the booklet will further facilitate intellectual exchanges on EoLC in Hong Kong.

Ageing is a normal and natural process that everyone must undergo, and the Club would like to help make the journey more fulfilling and colourful. I believe that through our collaborative efforts, we can make our city a more caring community.

Mr. Leong Cheung

Executive Director, Charities and Community
The Hong Kong Jockey Club

FOREWORD

Hong Kong is facing a rapidly ageing population, and so end-of-life care is an important issue for our community, yet it is easily neglected owing to the traditional Chinese cultural taboo of talking about death. Because of these sensitivities, raising public awareness and scholarly understanding about end-of-life care is important if we are to provide greater care for patients and families going through this inevitable stage of life.

The Faculty of Social Sciences of the University of Hong Kong is dedicated to addressing social well-being issues in order to make a difference to society and humanity. The University is grateful to the generous support from The Hong Kong Jockey Club Charities Trust, which enabled us to work together with the Chinese University of Hong Kong and five NGO partners to launch the Jockey Club End-of-Life Community Care Project (JCECC) in 2015.

JCECC has gone through three fruitful years. This multi-disciplinary, multi-institutional and cross-sectoral collaboration has created a tremendous positive impact on the general community, and end-of-life care professionals in particular, through structured training and international wisdom sharing. The Project has also enhanced awareness of these issues and created a partnership between experts and the general public to develop a compassionate community through public education and volunteering activities.

The JCECC achievements fit perfectly with the University of Hong Kong's strategic vision: Internationalisation, Innovation and Interdisciplinarity, all converging on Impact.

This book, *"Innovation • Impact: The Foundation of Community Based End-of-Life Care in Hong Kong,"* is a testament to the impact generated by the Project on healthcare services to Hong Kong, and the first of its kind – offering valuable information to Chinese communities in Mainland China, Asia Pacific and around the world.

My sincere congratulations to the JCECC Project team and all its stakeholders who have helped make this book a reality. I hope it will stimulate academics and researchers to think more deeply about the innovative and effective advancement of healthcare services, which will generate a better quality of life for those suffering from terminal illness, and help build a more compassionate society.

Professor Xiang Zhang

President and Vice-Chancellor
The University of Hong Kong

FOREWORD

In the face of an ageing population and the prevalence of chronic diseases, the Government attaches great importance to improving end-of-life care. To provide holistic care to terminally-ill patients and their families in the public system, the Hospital Authority (“HA”) has been offering comprehensive palliative care services at all seven clusters through a multidisciplinary team of professionals. The services cover in-patient service, out-patient service, day care service, home care service, bereavement counselling, etc. In 2017, HA promulgated the “Strategic Service Framework for Palliative Care”, to guide its development of service model and system infrastructure of adult and paediatric palliative care service in the coming five to ten years.

To strengthen the provision of end-of-life care services, we need concerted efforts from both the public and the private sectors. The “Jockey Club End-of-Life Community Care Project” (“JCECC”) is a good example of enhancing the capacity of service providers in the delivery of end-of-life care, as well as raising public awareness and comprised Innovative Service, Specialised Training, Knowledge and Skill Transfer as well as evaluation of the Project.

I am very happy to learn that Phase 1 of the JCECC was a great success and Phase 2 will be launched in January 2019. I hope that the experience and insights documented in this book will encourage healthcare and social care professionals to continue their contributions to the community end-of-life care in Hong Kong.

Professor Sophia Chan

Secretary for Food and Health
The Government of HKSAR

FOREWORD

Hong Kong has the world's longest life expectancy. The latest global data collated by Japan's health, labour and welfare ministry in 2018 showed Hong Kong women live to an average of 87.66 years and men 81.70 years. However, living longer may not be a blessing to some, especially if longer life implies prolonged frailty, illnesses and most of all, physical and psychological sufferings for the patients in their final days, owing to the lack of quality end-of-life care (EoLC) in the territory.

The development of EoLC in Hong Kong is dated back to the 1960s when the Nam Long Hospital was built for cancer patients with 120 beds in 1967. More residential and home care services, as well as psychological support and bereavement services are later provided by the Hospital Authority and non-government organisations (NGOs). The Jockey Club End-of-life Community Care (JCECC) project implemented in 2015 is a proactive and timely response to the needs of our ageing population by piloting various community-based comprehensive EoLC services, either in elderly homes or at patients' own homes, along with staff training and public education programmes. By joining with two universities, five NGOs and the public and private healthcare sectors, the project has successfully taken its first step to devise feasible, cost-effective and sustainable solutions to meet the ever-increasing demand for EoLC in Hong Kong; and build professional and community capacity, which spark off more multi-disciplinary, cross-sector discussion and collaboration in society.

This book is a useful and comprehensive documentation of the work-in-progress for the JCECC. It gives an introduction of the development of EoLC in Hong Kong and showcases the innovative EoLC community services provided by the NGO partners through this project. It serves as a guideline to all industry players and also a valuable source of reference to the academia researching on the topic of EoLC.

As stated in 2018 Policy Address, the SAR Government will consult the public next year on arrangements of advance directives and the relevant end-of-life care to allow terminally-ill patients more options of their own treatment and care arrangements. It showed the SAR Government's strong determination to optimise the provision of EoLC in community. I am sure the continuation of the project for another three years goes in line with the Government's strategic intent and sheds light on how to better the EoLC in Hong Kong.

Dr. Lam Ching-choi

Member, Executive Council