Hong Kong Women Professionals & Entrepreneurs Association Limited
香港女工商及專業人員聯會有限公司

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

14th December, 2019

Dear Professor Chan,

Re: End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place Public Consultation Response Statement

On behalf of the Hong Kong Women Professionals & Entrepreneurs Association (HKWPEA), led by our Well-being and Health Committee, with one of our objectives of the HKWPEA being to submit timely response to the public consultation paper of the HKSAR Government on various policy issues to help build a better and healthier Hong Kong, we are pleased to see the Food & Health Bureau of the HKSAR Government is leading the community to further review and focus on the legislative aspect of improving end-of-life care of the people of Hong Kong. This has been a long-waited consultation exercise and we appreciate much the great effort led by the Food and Health Bureau to facilitate the legislative proposals on the important matters of Advance Directives and Dying in Place.

Enclosed please find our humble response paper with particular reference to the aforesaid matter, as a collective effort of our members across disciplines and sectors including our medical and legal members of the Association. Should you have any further enquiries with regard to our response, please do not hesitate to contact our Co-Chair of the Well-being and Health Committee, Dr. Janice Tsang and/or Ms Yuen-Mei Chow at 6233-5230 or email at info@hkwpea.org. Thank you very much for your kind attention.

Yours sincerely,

Rebecca Choy Yung
President, Hong Kong Women Professionals & Entrepreneurs Association

The Secretariat 秘書處 : *Unit A3, 6/F, Loyong Court, 212-220 Lockhart Road, Wanchai, HK*
香港灣仔駱克道 212-220 號洛洋閣商業大廈 6 樓 A3 室
Telephone 電話 : *(852)6233 5230* ***Email 電郵 :*** *info@hkwpea.org* ***Website 網址 :*** *www.hkwpea.org*

Response Statement for the Public Consultation End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place

Hong Kong Women Professionals & Entrepreneurs Association (HKWPEA)
(14th December, 2019)

Background of the HKWPEA

The Hong Kong Women Professionals and Entrepreneurs Association ("HKWPEA") was established as a non-profit organization in September 1996 by a group of local women professionals and entrepreneurs. We are a community of local women professionals, business executives and entrepreneurs who have been leading in their respective fields, and coming together with the following objectives: 1) to develop a strong support network; 2) to create practical and innovative learning and business opportunities for themselves and for others and 3)to promote high professional standards. Based in Hong Kong, the Association also reaches out and establishes relationship with counterparts in Mainland China and abroad. Further to the above-named objectives, ranking high on the Association's agenda also includes timely response to the consultation papers of the HKSAR Government on various policy issues to help build a better and healthier Hong Kong.

Introduction

Thanks to the advancement of economy, public health policy and the medical care and research development, Hong Kong has been ranked No. 1 city with the longest longevity globally. The Hong Kong population is indeed ageing rapidly. According to the Hong Kong Population Projections 2017-2066, the percentage of elderly population at 65 or older was 16% in 2016 and is expected to reach 34% in 2066. The number of deaths was 46,700 in 2016 and is expected to reach 98,000 in 2066. We are pleased to see that the HKSAR Government is committed to providing quality and holistic end-of-life care to persons and families to meet their preferences and needs. It has been clear that the relevant government bureaux and departments, especially the Hospital Authority ("HA") and non-governmental organizations (NGOs) have been striving the best to improve a whole range of services to support end-of-life care.

Since the public consultation paper on "Substitute Decision-Making and Advance Directives in Relation to Medical Treatment" was issued by the Law Reform Commission of Hong Kong in 2004, it has been recommended that the HKSAR Government should promote the concept of advance directives under the existing common law framework instead of by legislation, and the need to review the position in due course once the community has become more widely familiar with the concept and should consider the appropriateness of legislation at that stage. It was from

the consultation published by the Food and Health Bureau ("FHB") in 2009, entitled "Introduction of the Concept of Advance Directives in Hong Kong" to consult stakeholders on the relevant issues that the majority views received at that time being to adopt a non-legislative approach to promote advance directives in Hong Kong first, and then consider the appropriateness of legislation on this subject.

Over the years, the Hospital Authority (HA) has taken the lead to extend the "Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation ("DNACPR") to seriously ill non-hospitalized patients in 2014, and since 2012, there has been an increasing trend in the number of advance directives signed by HA patients each year from 325 in 2013 to 1557 in 2018, though this is still relatively out of proportion of the total population in Hong Kong. The education and awareness on the subject matter need to be further enhanced.

The HKWPEA, in response to the recent public consultation on "Legislative Proposals on Advance Directives and Dying in Place" led by the Food and Health Bureau of the HKSAR Government, in an attempt to further enhance and improve better quality end-of-life of the general public, has charged the Well-being and Health Committee to also lead an internal consultation exercise among our members who are professionals and entrepreneurs across sectors and vintage, yet all being leaders in their respective profession and sectors.

This response paper is the collection of the comments and response from the HKWPEA members with the final paper endorsed by the Executive Committee Members of the Association. The following are our comments and response to the subject matter for "a good death" for everyone with particular reference to the matters of "Advance Directives" as well as "Dying in Place" and highlights of some of the concerns with regard to some of the potential issues in the Questionnaire:

1. The HKWPEA members **appreciate the extra effort and leadership of the Food and Health Bureau** to publish this timely consultation paper with latest update of the background and development of the issue of "Advance Directives", the "Advance Directives" in Hong Kong under the common law framework, the Government's position and proposal, as well as the discussion and proposal of "Dying in Place". This has reflected the FHB's determination and respect of quality holistic care of the people of Hong Kong from birth till death, and to **promote and facilitate a "good death"** despite the intrinsic Chinese culture that death is a taboo.

2. Despite there has been an increasing trend of Advance Directives over the years at the Hospital Authority, the number is relatively small (1557 in 2018), and this is relatively out of proportion of the total population of Hong Kong. **The public at large is still a**

relatively conservative body, with an increasing population of elderly citizens who tend to hold entrenched conservative positions, further **complicated by the historical and traditional cultural taboo** to discuss the "death" or "dying" subjects. It is recommended that **wide population-based public health education campaigns and education activities need to be endorsed** and promoted, and **holistic education with collaboration with the Education Bureau** to enhance the life and death education programme for our students of Hong Kong, from primary to secondary and tertiary education.

3. Any horizontal and vertical public education programmes with the aim to **raise the public awareness on Advance Directives and Dying in Place** are urgently needed, in order to facilitate the ultimate achievement that the public at large is ready to accept the concept of advance directives. This unmet need and knowledge gap is seen by the 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 (Chung R.Y.N. et al, Journal of American Medical Directors Association, 2017)

4. We **agree** that at this time of the year, **there should be clear legal provisions for** advance directives though it is appreciated and understood from other countries that this is a subject developed over a relatively long period of time across decades. Unless clear legal provisions are available, potential conflicts of interests from any unscrupulous stakeholders may still arise.

5. We do agree that an advance directive must be made at least by a mentally competent person who is aged 18 or above to be legally valid, though **whether the chronological age equals or reflects the maturity of any individual to decide on this matter is unknown and is questionable** and there are still individual differences among values, and beliefs.

6. At the moment, it seems that **so far there has not been any evidence of any community-wide public debate on the pros and cons of making an advance directive when healthy**, and much attention is needed for all stakeholders and the whole Hong Kong population to review this process. Thus, even if legally that there is no limitation for healthy individuals signing an advance directive, **we have reservation if the current public is sufficiently aware of the actual pros and cons** of making such an advance directive when healthy.

7. While we **agree that an advance directive must be made or modified in writing** to

avoid any potential future disputes**, the revocation of the advance directive would be more easily deemed to be valid with minimal risk of potential dispute if any verbal revocation could be accompanied by a written statement or affidavit** to legally confirm the verbal statement and to project all potential stakeholders, the patient and the medical personnel, and to ensure that the decision of advance directive of any individual is well respected.

8. **Whether a legally-valid advance directive must be witnessed as safeguard, there seems to be a split even among our members with regard to revocation** at the HKWPEA. While we have members volunteered the necessity of an independent witness as safeguard to confirm the mental fitness of the owner of the advance directive to revoke, we have relatively equal input from members expressing and questioning the witness for any revocation if it comes clearly and directly from the patient concerned and to ensure the individual decision of revocation is respected especially when it comes to more acute life-threatening issues of the existing condition. Indeed there should never be any case where persons are not saved when they struggle to inform someone that they no longer wish to die without medical intervention, but the law does not recognize it because there is no witness. After all, it is any individual's right, and on a matter as important as this, **the individual should be granted the liberty at all times to revoke without requiring any witness, provided the revocation is clearly documented such as any signed written document or the process and decision is video-taped** with the informed consent of the individual.

9. Yet, **the majority of our members disagree that any written revocation of advance directive need not to be witnessed** to avoid imposing unnecessary hurdles, as we are obliged to balance the pros and cons and to also be mindful about **potential risk from any revocation without any written documentation**. As any unwitnessed revocation can be used by any **potential unscrupulous stakeholders**.

10. With the same argument, **we are also inclined a second witness be required before the treatment provider considers the advance directive is no longer valid when any single family member/carer reports** that the patient has verbally revoked his/her advance directive before becoming mentally incapacitated, again to protect the owner of the advance directive and to prevent any potential unscrupulous act with any potential hidden agenda.

11. In terms of storage of the advance directive, while it is valid and encouraged for the owner to keep the original copy of the advanced directive, it is **also rather unrealistic to**

require the production of the original copy of the advance directive at all times, and we agree that it should be uploaded to the Electronic Health Record Sharing System

(eHRSS) for authorized access, and this may include those who have signed their advance directive outside the Hospital Authority. **A central registry for the Advance Directive may be more useful** to have better awareness about the decision among each of the owner with informed consent of the owner, the use of technology, and smart living and smart working, could perhaps **facilitate "smart dying" with territory-wide eHRSS which is essential for smooth integration and coordination of quality end-of-life care** in Hong Kong.

12. Furthermore, at this time of the year, we would **prefer a statutory form** which is more defined and provides less room for any potential arbitration nor unscrupulous act. Of course, we do understand, and from what we have learnt from other countries, **there will always be a transition from the use of model form to the statutory form** for making the advance directive legally active and this **depends very much on the awareness, understanding and acceptance of the community at large** with time.

13. With regard to the **allowance granted to emergency rescue personnel** to accept advance directives with signed DNACPR forms attached and not attempt CPR, **we do agree that the emergency rescue personnel should be able to accept** this as the advance directive and the DNACPR forms have been signed off with witness by an individual registered medical practitioner.

14. Overall, we do agree that **medical professionals should also be exempted from disciplinary proceedings** for professional misconduct for a decision made by him/her in good faith and with reasonable care **if the advance direct by any individual or owner has been made valid in the proper and formal manner as proposed**.

15. With regard to **dying in place**, **which has been longed for by many individual especially senior citizens**, especially those who are residing in the residential care homes for the elderly ("RCHEs**"), much needs to be done as it involves another set of initiatives and determination not only by the HKSAR government**, but all the related **stakeholders** such as the RCHEs owners, their employees, medical, nursing and paramedical and rescue personnel, as well as the family and significant others of the senior citizens, and most importantly, **a holistic well-rounded public education and awareness enhancement of the matter**, against the myths, and traditional and cultural taboos.

16. The **proposal to amend the relevant provisions of the Coroners Ordinance** (Cap. 504) to facilitate dying in place in RCHEs **needs further public engagement and promotion** to all stakeholders in the community and the macroscopic and microscopic capacity

planning to achieve the goal.

17. Last but not least, it is apparent that **the majority of the general public**, whether the healthy or the seriously ill, even with terminally ill patients and their families are **not familiar with the current community support for end-of-life care**, access to palliative care and NGOs and the support by community hospice care and bereavement support.

The Way Forward

Indeed, the HKWPEA does appreciate the bold step forward with the lead of the Food and Health Bureau to initiate this current round of the public consultation is timely to further facilitate better end-of-life care for the community. Equal access to "good death" is as important as equal access to medical treatment as this is the basic of human rights and one's decision on his or her own death with due respect. Continuous public health education and engagement, promotion of a dignity of good death with dignity and free from unnecessary pain and invasiveness and the respect of quality end-of-life care should continue to be part of the public campaign led by the HKSAR Government, and meanwhile, the facilitation with various appropriate legislative proposals as presented in the consultation paper with the pros and cons of any move to be further discussed and reviewed across sectors, all stakeholders and further public consultation.

We understand that the end of this consultation is not the end, but just the end of the beginning and we look forward to seeing the further follow up of this important issue, and will continue to contribute our humble part to work hand-in-hand with the HKSAR government to help build a better and healthier Hong Kong, and to achieve better deaths for everyone in our community with humanistic care.