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Centre for Ageing and Healthcare Management Research
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Submission to the Food and Health Bureau of the HKSAR Government on the public consultation of the Consultation Document on ***End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place***

By the **Centre for Ageing and Healthcare Management Research**

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1. Introduction

The Centre for Ageing and Healthcare Management Research (CAHMR) was established by School of Professional Education and Executive Development (SPEED) of The Hong Kong Polytechnic University (hereafter "PolyU SPEED") with a funding from the Research Grants Council in December 2018. PolyU SPEED is a unit under the College of Professional and Continuing Education (CPCE). The CAHMR aims to leverage on the expertise and interest among faculty members in connecting them from a diverse array of disciplines and cultivating their scholarship in the realms of health care, health services management, finance, information technology, data science, public policy, marketing and hospitality management.

It is a pleasure of CAHMR to submit views and findings from an internal survey and two focus group discussion sessions among students of PolyU SPEED in response to the "**End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place**" (hereafter "Consultation Document") released by the Food and Health Bureau of the HKSAR Government in September 2019.

2. Study Method

To gauge the responses to the Consultation Document, the CAHMR conducted a two-phase study among staff of CPCE and students who are studying at PolyU SPEED. In the quantitative phase, a questionnaire survey was conducted between September and November of 2019. The qualitative phase involves two focus group discussion sessions on 31 October 2019 and 4 November 2019 respectively.

The quantitative phase involved a questionnaire survey which used the 30 questions extracted from the Consultation Document. Staff of CPCE and students of PolyU SPEED were invited to participate in the survey through rounds of internal emails. A total of 59 responses was received.

Based on the results of the quantitative phase, a qualitative study which aimed at collecting in-depth views on selected questions of the Consultation Document was conducted in end of October and early November 2019. Among the quantitative responses to the 30 questions listed in the Consultation Document, the responses to ten questions did not show obvious majority "yes" or "no" answers. The 10 concerned questions were selected to form the question protocol of focus group discussion. In addition, Question 1 (i.e. *Do you think that the public at large is ready to accept the concept of advance directives?*) of the original questionnaire was used to start with the discussion and Question 10 (i.e. *Do you agree that both verbal and written revocation of an advance directive should be accepted?*) was also included in the question protocol since it is not easy to give a simple "yes" or "no" answer to this question. Question 13 was included to allow participants to discuss about possible hurdles when amending an AD. Hence, a total of thirteen questions was selected to form the question protocol of the two focus group discussion sessions. A total of 23 participants participated in two focus group discussion sessions. 11 informants of the first focus group comprised one man and ten women, aged 50 to 65 of years, of the Diploma in Active Ageing (DAA) programme of PolyU SPEED. Informants of the second focus group were

12 undergraduate students in Health Studies (HS) of PolyU SPEED, with seven females and five males aged from 20 to 25 years.

3. Results

1. Questionnaire Survey (Quantitative Study)

   Among the 59 responses, answers to 20 out of the 30 questions shown predominant stances. Among them, the answers to 18 questions were predominantly "yes" while those to another two questions were predominantly "no". 10 questions did not show obvious majority "yes" or "no" answers (see Appendix A).

2. Focus Group Discussion Sessions (Qualitative Study)

   Salient views collected from the two focus group discussion sessions were summarised as follows:

   1. Do you think that the public at large is ready to accept the concept of advance directives?

   DAA group: Participants generally disagreed that there was limited promotion and education about the concept. However, two participants shared that they did not even know the existence of AD until they had experienced someone closed to them were approaching death and the doctors had asked for the approval of AD.

   HS group: One participant thought the AD concept was similar to that of organ donation but the public was not familiar with it. There was no promotion and education in the public. People did not have adequate knowledge of AD.

   2. 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?

   DAA group: Participants agreed that people would understand the pros and cons of making an AD when in healthy state to avoid argument between children and relatives.

   HS group: The participants had mixed views. One student had suggested setting a limit on certain age and not all healthy individuals should be allowed to sign an AD. If all healthy people were allowed to sign an AD whenever they wanted, this would cause many problems as people's mind would change and the AD would have to be amended and updated for many times. But one student suggested that it was the right of a person to decide for his/her life.

   3. Do you agree that an advance directive must be made or modified in writing?

   DAA group: Participants agreed that AD should be made and modified in writing, just like signing the will.

HS group: AD could be in a form of verbal as long as the medical doctors agreed with it. Two participants suggested developing an electronic version of AD and accept e-signature, as in e-banking.

4. ***Do you agree that both verbal and written revocation of an advance directive should be accepted?***

   DAA group: Participants disagreed with the acceptance of verbal revocation, because there would be many arguments as there would be without actual evidence to prove that it was really the will of the person concerned. Doctors should be the person to prove that the patients were physically and/or mentally capable of signing the AD for verbal revocation to be allowed.

   HS group: Verbal and written revocation should be accepted if the doctor knew and approved that the patient was fully conscious. Video tape recordings could be used as evidence to prove the patient was acting on his/her own will.

5. ***Do you agree that written revocation of advance directive need not be witnessed to avoid imposing unnecessary hurdles?***

   DAA group: One participant thought that witness should be required to avoid argument. Otherwise, stakeholders could still argue that the AD was not signed by that person. The witness should be aged 18 or above. However, witness requirement would cause hurdles to AD as it involved more than one stakeholder. It was also argued that without a witness, the signed AD was not strong enough to convince family members. Participants also discussed whether the witness should be a professional such as lawyers and doctors.

   HS group: If the AD was signed by the patient when in full conscious state and the doctor could prove that, then a witness would not be needed. The person should have clearly understood the nature of AD under the explanation by doctors when he/she signed it. There was a view that since the witness did not have the right to oppose the signed AD, so witnesses were not required. Furthermore, sometimes there was insufficient time for a witness to come and witness the process of revocation.

6. ***Do you agree that, when a single family member/carer reports that the patient has verbally revoked his/her advance directive before becoming mentally incapable, a second witness is not required before the treatment provider considers the advance directive is no longer valid?***

   DAA group: Participants viewed verbal revocation as invalid as there were chances of misunderstanding when conveying the message. Also verbal statement alone was not a proof.

   HS group: Doctors and nurses were responsible to prove the patient was in conscious state when he/she verbally revoked the AD. If time was not allowed, a second witness would not be needed. But if time was allowed, a second witness should be required.

7. ***Do you agree to the use of a model form for making advance directives, rather than a statutory prescribed form, to be legally valid?***

   DAA group: Participants were confused about the question. Some of them thought if the AD form must be legally approved by a lawyer, it would fail to achieve generalisation and cause hurdles. The current AD form provided in the hospitals was without legal power and other kind of form might be provided by other organisations of similar effect. Some participants thought both model and prescribed form should be valid.

   HS group: There should be a formal format and requirement of contents to direct people to write and sign an AD. However, when the situation was urgent, it would be time consuming to find and print the statutory prescribed form and therefore, a model form should also be legally valid.

8. ***Do you think that the proposed safeguards to ensure validity of an advance directive are sufficient?***

   DAA group: One participant thought it should be more flexible in accepting the original copy or a photocopy of AD. A central system should be developed to store the data of AD just like the current Organ Donation Register. Other option could simply be using the Hong Kong ID card and information could then be accessed. People would not carry a hardcopy AD daily but accident could always happen any time anywhere. One participant questioned the second safeguard, about the AD should not be challenged by others. He argued that the signed AD was the will of the patient and others had no right to challenge it. He also disagreed with the current policy on organ donation, in which the registered donation form would be count as invalid once the patients' family opposed the donation. Law should protect and respect the right of the person who had signed the AD.

   HS group: The original copy should not always be required as it was very inconvenient to ask people to carry the AD form all the time. There were doubts about validity of AD if the hardcopy was dirty and partly fragmented or burnt. An AD card, similar to organ donation card which could be put inside the wallet, was suggested. Also, a centralised system should be developed which allow both hospital medical team and ambulance to have access to patients' information of AD. Moreover, the AD should have a time limit. It was suggested to require a regular update of AD, depending on the kind of disease and age of the patient. Furthermore, only older age people should be allowed to sign the AD or doctors had confirmed that the patient was at the last stage of life.

9. ***Do you think that the proposed safeguards to ensure the applicability of advance directives are sufficient?***

   Both groups gave answers combining with those in question 8.

10. ***Do you agree to allow emergency rescue personnel to accept advance directives with signed DNACPR forms attached and not attempt CPR?***

    Both groups did not give clear views on this question.

11. Do you agree to the use of a model DNACPR form, rather than a statutory prescribed form?

Both groups did not give clear views on this question.

12. Do you agree to allow emergency rescue personnel to accept DNACPR form without an advance directive and not attempt CPR for the reason that there is consensus between the healthcare team and family members that this is in the best interests of the patient who is unable to make an advance directive?

DAA group: It should depend on different situations. If the patient's family agreed and had consensus with the healthcare team, then the DNACPR could still be valid even without an AD. The healthcare team should have professional information and explain the best interests to patient's family.

HS group: When the medical team and the ambulance medical team did not know the existence of a signed AD, CPR would always be implied. Therefore, it was important to develop a system which allow medical and ambulance team to access whether that person had signed an AD.

13. 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?

DAA group: Some people were more traditional and believed that if someone died at home, then the property would be unlucky, and no one would be willing to purchase or rent it. For dying at RCHEs, adequate facilities and the hygiene issue should be carefully considered. Hospices that provide end-of-life service would be the best choice for patients who were approaching death. If new laws were implied, more hospices should be developed.

HS group: Participants suggested to amend the Coroners Ordinance as it was the patients' will to die in RCHE. One participant suggested patients' will should be followed in the first place. The doctors should confirm the last stage of condition approaching death. RCHE was a home to the patients which had no difference to a resident home. Once the final diagnosis was made at RCHE then dying in RCHE should not be different to dying at residential home. Currently, most RCHEs did not have adequate manpower or facilities such as end-of-life care rooms to facilitate dying in RCHE. One participant agreed to amend the law that once the RCHE resident had attended by a registered medical practitioner within 14 days before death, then it would not require reporting to the Coroner. However, RCHE would like to protect them by sending the patient to hospitals under urgent and critical situations.

4. Responses and Suggestions to the Consultation

4.1 ADVANCE DIRECTIVES (AD)

How do the public respond to the acceptance of AD?

- The public at large is ready to accept the concept of AD. Despite of promotion and education about the AD concept, our study shown that some of the respondents do not know the existence of AD. The public are not familiar with the concept of AD due to lack of knowledge.
- There should be clearer legal provisions for AD, and Hong Kong should continue to rely on the existing legal framework.

What are the fundamental principles?

- The CAHMR agrees with the fundamental principles of (i) respecting a person's right to self-determination; (ii) having a valid and applicable AD; (iii) a person should have the primary responsibility of keeping an AD; and (iv) sufficient safeguards should be provided to preserve lives.

Who can make an AD?

- The CAHMR suggests that an AD to be legally valid must be made by a mentally competent person who is aged 18 or above.

What can be refused in an AD?

- The CAHMR suggests that artificial nutrition and hydration should be covered under an AD and can be withheld or withdrawn according to the patient's wish.
- The primary objective of an AD should be for advance refusal of life-sustaining treatments to minimise distress or indignity when the patient faces a serious irreversible illness.

When can a person make, modify or revoke an AD?

- The CAHMR <u>is not sure</u> if the public is sufficiently aware of the pros and cons of making an AD when healthy. We suggested setting a limit on the age to sign an AD.
- We suggest that a person may revoke or modify an AD at any time.

How to make, modify and revoke an AD?

- The CAHMR suggests that an AD must be made or modified in writing, just like the will.
- We suggest to develop an electronic version of AD and accept e-signature, as in e-banking.
- We suggest that both verbal and written revocation of an AD should be accepted if a medical doctor can prove that the person is physically and/or mentally capable of signing the AD. There will potentially be many arguments with verbal revocation as the actual evidence may not be found. Video tape recordings can be considered as the evidence.
- We suggest that a legally-valid AD must be witnessed as safeguard.
- We also suggest to the proposed arrangement to require two witnesses for making and modifying an AD. One of the witnesses must be a medical practitioner, and both witnesses should not have an interest in the estate of the person making the AD.

- Regarding the proposed arrangement that written revocation of AD need not be witnessed to avoid imposing unnecessary hurdles, we opines that without the witness, the signed AD may not be strong enough to convince family members and providers.
- Regarding the proposed arrangement that when a single family member/carer reports that the patient has verbally revoked his/her advance directive before becoming mentally incapable, a second witness is not required before the treatment provider considers the AD is no longer valid, we opines that verbal statement alone is not enough to act as a proof.
- Regarding the proposed use of a model form for making an AD, rather than a statutory prescribed form, to be legally valid, we opines that, when the situation is urgent, it would be time consuming to find and print the statutory prescribed form and therefore, a model form should also be legally valid.

What should be the safeguards to ensure validity of AD?

- The following four proposed safeguards to ensure validity of an AD are sufficient: (i) The original copy of the AD should be presented under normal circumstances; (ii) The AD should be sufficiently clear and is not being challenged; (iii) The AD must not have been withdrawn; (iv) The person has not done something that clearly goes against the AD which suggests that he/she has changed his/her mind, it should be more flexible in accepting the original copy or a photocopy of AD.
- However, people may not carry a hardcopy of the AD daily but accident could happen any time anywhere. Furthermore, the hardcopy can be dirty, or partly fragmented or burnt. An AD card which can be carried inside a wallet, like the organ donation card, can be considered.
- A central system should be developed to store the data of AD just like the current Organ Donation Register. The Hong Kong Identity Card number can be used for identification and accessibility to the system.

What are the safeguards to ensure applicability of an AD?

- The "pre-specified conditions" in the proposed non-statutory AD model form should cover: (i) terminal illness, (ii) persistent vegetative state or a state of irreversible coma, and (iii) other end-stage irreversible life-limiting condition, or any conditions as pre-specified by the person.
- We <u>are not certain</u> if the proposed safeguards (i) not be applicable if the patient has the capacity to make the decision when the treatment concerned is proposed; (ii) not be applicable to treatments or conditions not specified in the advance directive; (iii) not be applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the patient and, if they had been anticipated by him/her, would have affected his/her decision; to ensure the applicability of AD are sufficient.

How to facilitate an advance directive being followed outside the hospital setting?

- We have <u>no particular view</u> on allowing emergency rescue personnel to accept AD with signed Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) forms attached and not attempt CPR.
- We have <u>no view</u> on the use of a model DNACPR form, rather than a statutory prescribed form.

- It should depend on different situations in allowing emergency rescue personnel to accept DNACPR form without an AD. The emergency rescue personnel do not attempt CPR if there is consensus between the healthcare team and family members that this is in the best interests of the patient who is unable to make an AD.
- If the family members agree and have a consensus with the healthcare team, then the DNACPR could still be valid even without an AD. The healthcare team should have the professional judgment to explain the best option to the family. Nonetheless, the emergency rescue personnel should attempt CPR when they are not certain about the existence of a signed AD.

How to facilitate treatment providers to be aware of an AD?

- The CAHMR suggests that the AD may be recorded in Electronic Health Record Sharing System (eHRSS).
- Given the possibility of a time lag between the latest status of AD and records in eHRSS, eHRSS may not contain the most up-to-date and accurate records. We suggest the proposal that storage of AD records in eHRSS should be voluntary.
- We suggest that the original AD document should still be required as proof of a valid AD, even when an AD record could be found in eHRSS.
- We suggest that it is the responsibility of the individual or family to draw the attention of emergency rescue personnel to the existence of an AD.

How to provide reasonable legal protection for treatment providers?

- The CAHMR suggests with the proposed arrangements on liability as follows: (i) a treatment provider does not incur any civil or criminal liability for carrying out or continuing a treatment if, at the time, he/she reasonably believes that a valid and applicable AD does not exist; (ii) a treatment provider does not incur any civil or criminal liability for the consequences of withholding or withdrawing a treatment from individuals if, at the time, he/she reasonably believes that a valid and applicable AD exists; (iii) a treatment provider does not incur any civil or criminal liability for carrying out or continuing CPR if, at the time, he/she reasonably believes that a valid and applicable DNACPR form does not exist.
- The healthcare 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.

What is the inter-relationship between an AD and provisions in the Mental Health Ordinance?

- We suggest that the proposed consequential change to the Mental Health Ordinance (Cap 136) to remove the potential conflict.

4.2 DYING IN PLACE - DYING AT HOME AND DYING IN RCHE

How to remove barriers to facilitate dying in place?

Should the Coroners Ordinance be amended to exempt deaths in RCHEs from reportable deaths?

- We suggest that, as a prerequisite to promote dying in place, the relevant provisions of the Coroners Ordinance (Cap 504) should be amended to exempt certain deaths in residential care home for the elderly (RCHEs) from reportable deaths.

- Currently, most RCHEs do not have adequate manpower or facilities, such as end-of-life care rooms, to facilitate dying in RCHEs. More hospice facilities should be developed.
- The proposed safeguard for RCHE residents is not sufficient if deaths in RCHEs may be exempted from reportable deaths.

Appendix A. Questionnaire Survey (Quantitative Phase)

Respondents were invited to answer 30 questions extracted from the Consultation Document. Among the answers, answers to 18 out of 30 questions, i.e. questions 1-6, 8, 10-12, 17, and 22-28, were predominantly "yes". Answers to questions 13 and 30 were predominately "no".

I. Questions having predominantly "yes" as the answers:

Questions	**Yes**	**No**
(1) Do you think that the public at large is ready to accept the concept of advance directives?	43	13
(2) Do you think that there should be clear legal provisions for advance directives, or Hong Kong should continue to rely on the common law framework?	45	10
(3) Do you agree with the above fundamental principles (respecting a person's right to self-determination; a valid and applicable advance directive; a person should have the primary responsibility of keeping an advance directive; sufficient safeguards should be provided to preserve lives)*?*	57	1
(4) Do you agree that an advance directive must be made by a mentally competent person who is aged 18 or above to be legally valid?	49	7
(5) Do you agree that artificial nutrition and hydration should be covered under an advance directive and can be withheld or withdrawn according to the patient's wish?	45	13
(6) Do you agree that the primary objective of an advance directive should be for advance refusal of life-sustaining treatments to minimise distress or indignity when the patient faces a serious irreversible illness?	53	5
(8) Do you agree that a person may revoke or modify an advance directive at any time?	54	4
(10) Do you agree that both verbal and written revocation of an advance directive should be accepted?	42	11
(11) Do you agree that a legally-valid advance directive must be witnessed as safeguard?	55	3
(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?	47	10
(17) Do you think that the "pre-specified conditions" in the proposed non-statutory advance directive model form should cover (a) terminal illness, (b) persistent vegetative state or a state of irreversible coma and (c) other end-stage irreversible life-limiting condition, or any conditions as pre-specified by the person?	52	6
(22) Do you agree that the advance directive document may be recorded in eHRSS?	49	6
(23) Given the possibility of a time lag between the latest status of advance directives and records in eHRSS, eHRSS may not contain the most up-to-date and accurate records. Do you agree to the proposal that storage of advance directive records in eHRSS should be voluntary?	46	12

(24) 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?	42	16
(25) Do you agree that it is the responsibility of the individual/family to draw the attention of emergency rescue personnel to the existence of an advance directive?	45	13
(26) Do you agree with the proposed arrangements on liability (a treatment provider does not incur any civil or criminal liability for carrying out or continuing a treatment if, at the time, he/she reasonably believes that a valid and applicable advance directive does not exist; a treatment provider does not incur any civil or criminal liability for the consequences of withholding or withdrawing a treatment from individuals if, at the time, he/she reasonably believes that a valid and applicable advance directive exists; a treatment provider does not incur any civil or criminal liability for carrying out or continuing CPR if, at the time, he/she reasonably believes that a valid and applicable DNACPR form does not exist)*?*	47	10
(27) Do you think 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?	49	8
(28) Do you agree with the proposed consequential change to the Mental Health Ordinance to remove the potential conflict?	52	6

II. Questions having predominantly "no" as the answers:

Questions	**Yes**	**No**
(13) Do you agree that written revocation of advance directive need not be witnessed to avoid imposing unnecessary hurdles?	17	41
(30) Do you think that the proposed safeguard for RCHE residents is sufficient if deaths in RCHEs may be exempted from reportable deaths?	12	44

III. Questions having neither predominantly "yes" or "no" as the answers:

Questions	**Yes**	**No**
(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?	22	36
(9) Do you agree that an advance directive must be made or modified in writing?	34	21
(14) Do you agree that, when a single family member/carer reports that the patient has verbally revoked his/her advance directive before becoming mentally incapable, a second witness is not required before the treatment provider considers the advance directive is no longer valid?	21	37
(15) Do you agree to the use of a model form for making advance directives, rather than a statutory prescribed form, to be legally valid?	29	28
(16) Do you think that the proposed safeguards (The original copy of the advance directive should be presented under normal circumstances; The advance directive should be sufficiently clear and is not being challenged; The advance directive must not have been withdrawn; The person has not done something that clearly goes against the advance directive which suggests that he/she has changed his/her mind) *to ensure validity of an advance directive are sufficient?*	25	32

(18) Do you think that the proposed safeguards (not be applicable if the patient has the capacity to make the decision when the treatment concerned is proposed; not be applicable to treatments or conditions not specified in the advance directive; not be applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the patient and, if they had been anticipated by him/her, would have affected his/her decision) *to ensure the applicability of advance directives are sufficient?*	23	33
(19) Do you agree to allow emergency rescue personnel to accept advance directives with signed DNACPR forms attached and not attempt CPR?	34	21
(20) Do you agree to the use of a model DNACPR form, rather than a statutory prescribed form?	24	33
(21) Do you agree to allow emergency rescue personnel to accept DNACPR form without an advance directive and not attempt CPR for the reason that there is consensus between the healthcare team and family members that this is in the best interests of the patient who is unable to make an advance directive?	30	28
(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?	29	28