

END-OF-LIFE CARE

Legislative Proposals on Advance Directives
and Dying in Place - Consultation Document



食物及衛生局
Food and Health Bureau

CONSULTATION DOCUMENT

End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place

Food and Health Bureau

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Appeal by the Secretary for Food and Health

Birth, ageing, illness and death are certainties in life. To most people in Hong Kong, while we acknowledge our top position in the world life expectancy ranking, death is a taboo and we avoid talking about it as much as we can, and delay the planning of it even when death is anticipated, even missing the opportunity to ensure a “good death”.

The Government, the Hospital Authority and various non-governmental organisations have been steadfastly making tremendous efforts to improve end-of-life care in Hong Kong, in areas such as service planning, delivery and quality. These efforts will continue across all fronts.

This public consultation is an integral part of these efforts, focusing on the legislative aspect to improve end-of-life care. We are contemplating new legislation on advance directives that would help uphold patient self-determination on what treatment patients voluntarily decide to refuse in advance. We also propose to remove related legislative impediments, including those that prevent patients from choosing the place where they want to receive end-of-life care instead of being confined to a hospital. As we face many challenges to achieve “dying in place”, we believe one of the first steps is to remove the legislative hurdles that are inconsistent with our policy objective to provide quality and holistic end-of-life care to persons and families to meet their preferences and needs.

Advancements in medicine have helped prolonged our life expectancy. I hope that through this consultation, we can improve the quality of life of patients right up to the last moments, and the wellbeing of their families even beyond the patients’ departure. I sincerely invite your participation in this consultation.

Professor Sophia CHAN, JP
Secretary for Food and Health

CHAPTER 1: PURPOSE OF THIS DOCUMENT

1.1 The Hong Kong population is 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 2066¹. The Government is committed to providing quality and holistic end-of-life care to persons and families to meet their preferences and needs. Indeed, the relevant government bureaux and departments, the Hospital Authority (“HA”) and non-governmental organisations have been striving to improve a whole range of services to support end-of-life care (details are at **Annex A**).

1.2 Advance directives and dying in place are important measures to respect the choice of a person who is approaching end-of-life. In view of the existing legal barriers that frustrate the development of advance directives and dying in place in Hong Kong, the purpose of this document is to consult the public on the Government’s proposals to –

- (a) codify the current common law position in respect of an advance directive and to increase the safeguards attached to it;
- (b) remove legislative impediments to implementation of advance directives by emergency rescue personnel; and
- (c) amend the relevant provisions of the Coroners Ordinance (Cap. 504) to facilitate dying in place in residential care homes for the elderly (“RCHEs”).

¹ Census and Statistics Department (2017), *Hong Kong Population Projections 2017-2066*.

CHAPTER 2: ADVANCE DIRECTIVES: BACKGROUND AND LATEST DEVELOPMENTS

2.1 An advance directive for healthcare may be described as “a statement, usually in writing, in which a person indicates when mentally competent what medical treatment he/she would refuse at a future time when he/she is no longer mentally competent”. Currently in HA, advance directives are usually made by patients with serious irreversible illnesses via advance care planning.

2.2 Advance care planning is often defined as a process of communication among a patient, his/her healthcare providers, family members or caregivers regarding the kind of care that will be considered appropriate when he/she can no longer make a decision. The person can express values, wishes and preferences for future medical or personal care, or make an advance directive to refuse life-sustaining treatments. The making of an advance directive is entirely voluntary. The person can decide whether, how and when to make an advance directive.

2.3 In 2004, the Law Reform Commission of Hong Kong (“LRC”) issued a public consultation paper on *Substitute Decision-Making and Advance Directives in Relation to Medical Treatment*. In its report issued in 2006, LRC recommended that the Government should promote the concept of advance directives under the existing common law framework instead of by legislation. It also recommended that the Government should 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.

2.4 In response to LRC’s report, the Food and Health Bureau (“FHB”) issued a consultation paper in 2009 titled *Introduction of the Concept of Advance Directives in Hong Kong* to consult stakeholders on the relevant issues. The majority of views received at the time agreed to adopt a non-legislative approach to promote advance directives in Hong Kong first, and then consider whether legislation is appropriate when there is greater awareness in society. The Government recommended at the time that guidance should be developed for the medical and other relevant professions on the making and handling of advance directives.

2.5 In 2010, HA issued the *Guidance for HA Clinicians on Advance Directives in Adults*. In its 2010 version, the scope of the HA advance directive form followed that of LRC. Upon revision in 2014, a new category “other end-stage irreversible life-limiting condition” was added (a sample HA advance directive form is at **Annex B**).

2.6 As mentioned in paragraph 2.1 above, advance directives are usually made by patients with serious irreversible illnesses via advance care planning. In 2014, HA adopted a broader definition of advance care planning by including discussion with family members of mentally incompetent or minor patients.

2.7 Also in 2014, HA extended the *Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation* (“DNACPR”) to seriously ill non-hospitalised patients. Under the latest Guidelines, a specific DNACPR form for non-hospitalised patients can be signed by doctors in charge of the patient when there is a valid and applicable advance directive refusing cardiopulmonary resuscitation (“CPR”), or when a DNACPR decision is made through an explicit advance care planning process for minors or incompetent adults without an advance directive in defined categories of seriously ill patients with end-stage irreversible diseases. A sample HA DNACPR form is provided at **Annex C**.

2.8 Since 2012², an increasing trend in the number of advance directives signed by HA patients each year has been observed, with more than four times as many advance directives made in 2018 as compared with 2013 (Figure 1 below) –

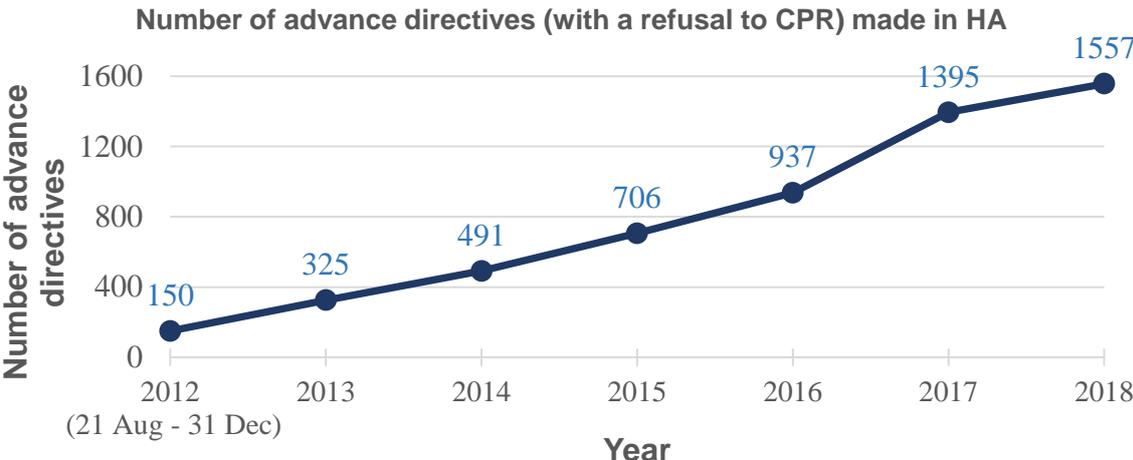


Figure 1. Number of advance directives (with a refusal to CPR) made in HA (source: HA).

² HA started to log the number of patients with advance directives in August 2012.

2.9 Local studies have found that the acceptance of advance directives among the elderly population is high. One study found that 88% of older Chinese adults residing in nursing homes in Hong Kong preferred to have an advance directive regarding medical treatment in the future³. A recent longitudinal study⁴ conducted from 2016 to 2018 also found increased awareness among both the general public and healthcare professionals. Among the general public, the awareness of advance directives increased from 18.5% in 2016 to 31.0% in 2018. As for healthcare and related professionals, including doctors, nurses and social workers, the number of professionals who had initiated advance care planning discussion with patients or their families increased from 36.5% to 46.7% over the three-year period.

³ Chu L.W. et al. (2011), Advance directive and end-of-life care preferences among Chinese nursing home residents in Hong Kong. *Journal of American Medical Directors Association* (“JAMDA”).

⁴ Chow A.Y.M. et al. (In preparation), Report of Jockey Club Community End-of-Life Care Project. Hong Kong: Faculty of Social Sciences, The University of Hong Kong.

CHAPTER 3: ADVANCE DIRECTIVES IN HONG KONG UNDER THE COMMON LAW FRAMEWORK

3.1 Currently, Hong Kong has neither statute nor direct case law on the legal status of advance directives. We are relying on the general requirement for the patient's consent to receiving medical treatment under the common law to make validly-made advance directives refusing life-sustaining treatment legally binding. However, this creates practical difficulties in the implementation of advance directives, as illustrated by the case below.

Case scenario

A 70 year-old lady with end-stage chronic obstructive pulmonary disease was admitted to the hospital for respiratory failure, where she received intubation before recovery. Upon discharge, she signed an advance directive deciding against further intubation if she developed respiratory failure again. She did not want to suffer from the discomfort of the invasive treatment and preferred comfort care. Several weeks later, she was admitted to the hospital again for respiratory failure and became mentally incompetent as a result. The patient's son strongly urged the doctor to intubate the patient despite her advance directive. His son argued that there was no legislation for advance directive in Hong Kong, and a doctor should provide emergency treatment if it was considered essential and in the best interests of the patient. The patient's daughter, however, thought that the doctor should respect the advance decision of the patient not to receive invasive treatment anymore. The doctor considered that further intubation might prolong the patient's life, but he also understood that the patient's advance directive was valid and applicable. Since there is no clear legal backing for advance directives, he was not sure whether he should override the advance directive based on the best interests principle or otherwise.

3.2 Specifically, the lack of legislation for advance directives in Hong Kong poses legal concerns –

- (a) given the legal uncertainties regarding advance directives in the case law of Hong Kong, healthcare professionals could be reluctant to initiate discussion of advance directives or follow advance directive directions due to concerns over the lack of legal protection;

- (b) it is not clear whether advance directive may supersede other statutory provisions when in conflict. For example –
- (i) emergency rescue personnel in Hong Kong are currently bound by their empowering ordinances to resuscitate life. For example, ambulance personnel of the Fire Services Department (“FSD”) are currently bound by the Fire Services Ordinance (“FSO”) (Cap. 95) to perform resuscitation on any person who appears to need prompt or immediate medical attention. In the absence of clear legislative provisions on the relationship between duties under the FSO and an advance directive, there is a potential conflict between a patient’s wishes expressed in his/her advance directive and emergency rescue personnel’s obligation under the FSO to resuscitate or sustain life;
 - (ii) under the Mental Health Ordinance (“MHO”) (Cap. 136), a doctor or a dentist may provide life-sustaining treatment to a mentally incompetent person without consent in urgent or non-urgent situation if the doctor or dentist considers that the treatment is necessary and in the best interests of the person⁵. This is in potential conflict with a valid and applicable advance directive which reflects the patient’s right to refuse treatment. Thus there is a need to clarify the relationship between a valid and applicable advance directive and patient’s best interests in the law.

⁵ Section 59ZF of the Mental Health Ordinance.

CHAPTER 4: ADVANCE DIRECTIVES: GOVERNMENT'S POSITION AND PROPOSAL

GOVERNMENT'S POSITION

4.1 As mentioned in paragraph 2.9 above, the awareness of the general public and healthcare professionals about advance directives has been on the rise over the years. The Government considers that it is now an appropriate time to review the Government's position in 2009 of adopting a non-legislative means to promote advance directives and to consider the appropriateness of legislation under present circumstances.

4.2 Introducing a consistent legal framework for advance directives can remove conflicts of other laws and policies and afford protection to treatment providers (including healthcare professionals and emergency rescue personnel)⁶ acting in good faith and with reasonable care.

4.3 Indeed, it is increasingly common for other jurisdictions which used to rely on common law to legislate for advance directives, including Singapore, England and Wales in the United Kingdom ("UK"), states in Australia such as Queensland and Western Australia, provinces in Canada such as British Columbia and Ontario, etc.

4.4 It should also be noted that, despite the gradual increase in awareness over the years, the concept of advance directives is still not widely familiar in the general population. For example, a telephone survey⁷ conducted in 2016 found that 86% of adults in Hong Kong had not heard of advance directives before. Enacting a new piece of legislation on advance directives should also result in raising wider public awareness.

4.5 In addition, advance directive legislation could clarify current legal uncertainties and provide protection to both treatment providers and the public. This should help strengthen society's trust and confidence in advance directives, and in turn enhance its acceptance and utilisation.

⁶ Treatment providers as referred to in this document include healthcare professionals and emergency rescue personnel.

⁷ Chung R.Y. et al. (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. JAMDA.

Consultation questions

- (1) *Do you think that the public at large is ready to accept the concept of advance directives?*
- (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?*



GOVERNMENT'S PROPOSAL

What is being proposed?

4.6 The Government **proposes** to codify and clarify the current common law position with respect to advance directives. The legal effect will be that – if an advance directive is both valid and applicable, it has the same effect as a contemporaneous refusal of treatment by a person with mental capacity, i.e. the treatment cannot be lawfully given. If given, the person or his/her estate would be able to claim damages for the tort involved, which may include battery and assault.

What is a “valid” and “applicable” advance directive?

4.7 An advance directive is considered valid if it is sufficiently clear and is not being challenged on ground of undue influence or mental incapacity, etc. (please refer to paragraph 4.24 below on the safeguards to ensure validity of an advance directive). It becomes applicable when the patient suffers from the pre-specified conditions, and is no longer mentally capable of making healthcare decisions.

What are the fundamental principles?

4.8 The Government's legislative proposal on advance directives is formulated based on the following fundamental principles –

- (a) respecting a person's right to self-determination. This means that a mentally competent adult's right to accept or refuse treatment should be respected. In case of a conflict between

the wishes of the individual and his/her family members or that of treatment providers, the individual's right to self-determination should prevail;

- (b) a valid and applicable advance directive, which has the same effect as a contemporaneous refusal of treatment by a person with mental capacity, overrides treatment decisions based on treatment provider's interpretation of patient's best interests;
- (c) a person should have the primary responsibility of keeping an advance directive and of ensuring that the original copy shall be presented to treatment providers as proof of a valid advance directive; and
- (d) sufficient safeguards should be provided to preserve lives. Under all circumstances where there are any grounds for doubt about the validity or applicability of an advance directive, treatment providers must continue to provide clinically indicated emergency life-sustaining treatments, with legal protection conferred to treatment providers acting in good faith and with reasonable care.

Consultation question

(3) *Do you agree with the above fundamental principles?*



Who can make an advance directive?

4.9 Taking into account the practice of HA and some overseas countries, the Government **proposes** that an advance directive must be made by a mentally competent person who is aged 18 or above to be legally valid. An advance directive does not require formal assessment of the person's mental capacity by psychiatrists unless circumstances suggest it.

Consultation question

- (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?*



Overseas practice

In England and Wales, individuals aged 18 or above who are mentally competent can make advance directives.

In Singapore, individuals aged 21 or above who are not mentally disordered can make advance directives.

In Queensland, individuals aged 18 or above who have the capacity to understand the nature and consequences of the directive can make advance directives.



What can be refused in an advance directive?

4.10 It is HA's current practice that a person making an advance directive may refuse life-sustaining treatments when he/she is no longer mentally competent to make healthcare decisions. According to HA Guidelines, life-sustaining treatment means any of the treatments that have the potential to postpone a patient's death and includes, for example, CPR, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection and artificial nutrition and hydration.

4.11 Regarding artificial nutrition and hydration, it means the non-oral feeding of food and fluid to a person such as through a tube or by intravenous administration. It could be given to a person who for some

reasons cannot eat or drink enough to sustain life, and thus is currently classified by HA as medical treatment, as opposed to basic care (e.g. the offer of oral food and fluid), which should not be withheld or withdrawn.

4.12 However, some people think that artificial nutrition and hydration should be considered as basic care and should not be covered under an advance directive, particularly for patients in a persistent vegetative state or a state of irreversible coma. For patients in a persistent vegetative state or a state of irreversible coma, current HA guidelines recommend that treatment providers should seek declaration from the court to withdraw artificial nutrition and hydration. The Government also noted that a recent UK court ruling in 2018 held that, with due consideration of the UK Mental Capacity Act 2005 and the UK case law, it is not a mandatory requirement to apply to the court for such declaration. The Government **proposes** that artificial nutrition and hydration should be considered a kind of medical treatment, and in certain circumstances, a kind of life-sustaining treatment, and can be withheld or withdrawn from the patient in accordance with the advance directive. Nonetheless, patients making an advance directive who wish to continue to receive artificial nutrition and hydration (if clinically indicated) may indicate so on their advance directive, until death is imminent and inevitable.

4.13 The Government also **proposes** that, modelling on HA's current practice, the primary objective of an advance directive is for advance refusal of life-sustaining treatments to minimise distress or indignity when the patient faces a serious irreversible illness. Based on this principle, the Government **proposes** that the non-statutory model advance directive form (as proposed in paragraph 4.23 below) will only provide for refusal of life-sustaining treatments when the patient is (a) terminally ill, (b) at persistent vegetative state or a state of irreversible coma, or (c) in other end-stage irreversible life-limiting condition. A patient cannot use an advance directive to refuse basic care or symptom control that is necessary for his/her comfort.

4.14 However, as proposed in paragraph 4.23 below, advance directives not made in a model form should still be accepted if the statements are clear and not ambiguous. If a patient uses a non-model advance directive form refusing all medical treatments including relatively simple maintenance medical treatments (e.g. diabetic or cardiac medication), it may raise the question as to whether the patient has been properly informed when making the advance directive. In this case, treatment providers may challenge the validity of the advance directive (as explained in paragraph 4.24(b) below).

4.15 An advance directive cannot include –

- (a) refusal of basic and palliative care that is essential to keep a person comfortable, such as nursing care, pain relief, keeping warm;
- (b) refusal of the offer of food and drink by mouth; or
- (c) anything that is against the law, such as euthanasia.

Consultation questions

- (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?*
- (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?*



Overseas practice

In England and Wales, any kind of treatment, including life-sustaining treatment and artificial nutrition and hydration, for physical or mental disorder can be refused in an advance directive unless overruled by the Mental Health Act 1983.

In Singapore, only extraordinary life-sustaining treatment in the event of the patient's suffering from a terminal illness can be refused, where extraordinary life sustaining treatment refers to "any medical procedure or measure which, when administered to a terminally ill patient, will only prolong the process of dying when death is imminent, but excludes palliative care". The law does not specify whether refusal of artificial nutrition and hydration is allowed.

In Queensland, directions about any medical treatment and health matters for a patient's future healthcare can be indicated in the advance directive, including refusal of life-sustaining measures (i.e. health care

intended to prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation such as CPR and artificial nutrition and hydration) in the specified circumstances.



When can a person make, modify or revoke an advance directive?

4.16 Currently, although patients signing advance directives within HA are limited to patients with advanced illnesses only, there is no limitation for healthy individuals to sign advance directives in the private sector or non-governmental organisations. Some people may wish to make an advance directive while healthy as a medical crisis that cannot be foreseen could leave them too ill to make their own healthcare decisions at the time. However, it is important to note that, for people without serious illness, it is not easy for them to make decisions and sign an advance directive applicable to conditions other than being in permanent severe neurological damage. As many types of diseases can progress to a terminal stage, a person would need a vast amount of complex medical information before he/she can make a meaningful directive. Moreover, a person's acceptance of disease symptoms or disability may change with his/her bodily condition. As such, it is debatable whether or not it is appropriate for healthy persons to make an advance directive other than for permanent severe neurological damage. However, discussing with the family about one's values, wishes and treatment preferences regarding the dying process at an appropriate time is helpful.

4.17 Nonetheless, after making an advance directive, a person may at any time revoke or modify it as long as he/she is mentally capable and is not under undue influence.

Consultation questions

(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?*

(8) *Do you agree that a person may revoke or modify an advance directive at any time?*



Overseas practice

In England and Wales, it is up to an individual to decide when to make an advance directive, and may modify and revoke an advance directive whenever the person has capacity to do so.

In Singapore, the Ministry of Health advises that it is best to make an advance directive when there is no pressure to do so – when one is well and healthy.

In Australia, Advance Care Planning Australia recommends individuals to start planning when healthy, before there is actually an urgent need for a plan, but it also emphasises that the plan will be particularly significant towards the end of a person's life.

In the USA, Respecting Choices and the National Institute of Aging advise that planning for future medical decisions should be done over time and in relationship to one's health, so that it becomes possible to identify the relevant goals for care. It should be an ongoing process. Therefore, when adults are healthy and do not have a progressive, life-limiting condition, they recommend an individual to first select and prepare a trusted family member or friend to make health decisions if he/she cannot. A healthy person may make an advance decision regarding medical treatment in case of permanent severe neurological damage. However, it is not necessary to plan for any other medical decisions until an individual has been diagnosed with a chronic illness or serious condition that is getting worse. Finally, if an individual has a short life expectancy and is getting worse despite treatments, the individual is advised to create a specific medical plan, should hospital services such as intensive care and mechanical breathing be needed, which may prolong suffering and add little benefit.



How to make, modify and revoke an advance directive?

Should it be in writing?

4.18 The Government **proposes** that **making an advance directive** must be in writing to be legally valid. This could facilitate the assessment of the validity of an advance directive. Also, an advance directive in writing provides evidence to the existence of a prior expressed wish and that the person has intended the advance directive to apply at specified circumstances, which could reduce uncertainty and potential dispute. Since modifying an advance directive is essentially the same as making a new one, the Government **proposes** that **modifying an advance directive** must also be in writing.

4.19 As to **revocation of an advance directive**, the Government considers that we should not impose unnecessary hurdles for a person to cancel an advance directive, and hence **proposes** that both verbal and written revocation should be considered valid. The advance directive should be considered invalid if there is evidence that the patient has revoked the advance directive orally at any time before becoming mentally incompetent.

Consultation questions

- (9) *Do you agree that an advance directive must be made or modified in writing?*
- (10) *Do you agree that both verbal and written revocation of an advance directive should be accepted?*



Should it be witnessed?

4.20 Under current HA practice, as a safeguard, making an advance directive requires two witnesses, one of whom must be a medical practitioner. Neither witness should have an interest in the estate of the person making the advance directive. The requirement of a witness is not mandatory under the common law framework, but HA considers that a tighter requirement could reduce uncertainty and risk of dispute. The Government **proposes** to adopt the same arrangements as the current HA practice for **making and modifying an advance directive**. The requirement of a medical practitioner witness should help ensure that the

person making the advance directive is more likely to be properly informed of the consequences of the decision.

4.21 As to **revocation of an advance directive**, as mentioned in paragraph 4.19 above, the Government considers that we should not impose unnecessary hurdles and thus **proposes** that a witness is not required for written revocation. For any revocation (both written and verbal), we will encourage through public education that a person revoking his/her advance directive should tell his/her family members about it. Verbal revocation should be documented by his/her family member as soon as possible and with sufficient details, so as to minimise uncertainty and risk of dispute. Healthcare professionals should record any revocation (verbal or not) in the patient's record⁸. Nonetheless, the following case illustrates the possibility of dispute when a verbal revocation of advance directive does not have a second witness –

Case scenario

A patient with end-stage renal disease signed an advance directive because he knew that one of his sons did not agree to his decision not to have further life-sustaining treatment. While all other family members supported the decision of the patient, when the patient's health deteriorated, the son who disagreed raised that the patient had changed his mind beforehand through verbally revoking the advance directive. Having no other persons witnessing the verbal revocation, the other family members suspected that the son was not telling the truth, but there was no proof for that. If the doctor then provided life-sustaining treatment to the patient, it was likely to be against the actual wish of the patient.

Consultation questions

(11) *Do you agree that a legally-valid advance directive must be witnessed as safeguard?*

⁸ Based on HA's current practice, a patient may at any time revoke his/her advance directive, as long as he/she is mentally capable and is not under undue influence. The revocation of advance directive can also be made orally, and the advance directive may be considered not valid if there is evidence that the patient has revoked the advance directive orally before the deterioration. However, written, signed and witnessed revocation is the better method as it minimises uncertainty and risk of dispute.

- (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?*
- (13) *Do you agree that written revocation of advance directive need not be witnessed to avoid imposing unnecessary hurdles?*
- (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?*



Should the advance directive form be a statutory prescribed form or a non-statutory model form?

4.22 Currently, there is no requirement that an advance directive must be made in a specified format. Under HA practice, although a standard HA form for advance directive is designed for use by HA patients, advance directives not being the HA form (e.g. made overseas or in the private sector) may still be valid if the statements are clearly written and not ambiguous.

4.23 The Government **proposes** to use a non-statutory model advance directive form, instead of a statutory prescribed form. Advance directives not made in a model form should still be accepted if the statements are clearly written and not ambiguous. In other words, persons making an advance directive may opt to use their own form of directive, though we will encourage through public education the use of the model form based on clearly defined expression of wishes, which should greatly reduce the scope of uncertainty and dispute. We will also encourage persons who wish to make an advance directive without using the model form to consult a healthcare professional who can advise on specific conditions or treatments. The use of a non-statutory model form should also help retain under the common law framework the legal status of advance directives made outside Hong Kong or before enactment of the new legislation.

Consultation question

(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?*



Overseas practice

England and Wales:

Making an advance directive

In England and Wales, an advance directive only needs to be in writing if a patient wants to refuse life-sustaining treatment. If the treatment a patient wants to refuse is not life-sustaining, the patient can create a valid advance directive by telling the doctor that he/she does not want a particular treatment in certain circumstances in the future, i.e. a verbal advance directive. For patients suffering from a condition requiring long-term care, individuals have opportunities for discussion with the healthcare team over a long period. They may feel their wishes are sufficiently well known or reflected in the notes so that there is no need to write them down. In hospice or specialist palliative care settings, this form of verbal advance directive is common practice.

Also, if an advance directive does not cover refusal of life-sustaining treatment, no witness is required; if an advance directive covers refusal of life-sustaining treatment, one witness is required. Although not compulsory, the Mental Capacity Act 2005 Code of Practice states that it is very important to discuss decisions to refuse life-sustaining treatment with a healthcare professional.

Modifying or revoking an advance directive

An advance directive may be modified at any time and need not be in writing unless such modification is made to include a refusal of life-sustaining treatment. On the other hand, revocation of an advance directive (including partial withdrawal) need not be in writing. Individuals are advised to tell anybody who knew about the advance directive that it has been cancelled, and that healthcare professionals

should record a verbal cancellation in healthcare records. This then forms a written record for future reference.

Singapore:

Making an advance directive

In Singapore, an advance directive must be made in the statutory prescribed form and registered with the Registrar of Advance Medical Directives, as there is a mandatory central registry of advance directives in Singapore. Singapore requires an advance directive to be made in the presence of two witnesses at the same time, one of whom must be a medical professional.

Modifying or revoking an advance directive

In Singapore, verbal or written revocation is accepted, but must be in the presence of at least one witness. The patient or witness should then inform the Registrar of Advance Medical Directives of the revocation.

Queensland:

Making an advance directive

In Queensland, an advance directive must be written and may be made using a recommended form. An advance directive must also include a certificate signed and dated by a doctor stating that the person making the advance directive appeared to have the capacity necessary to make it. Apart from the doctor, a witness is also required, who has to be a justice of the peace or commissioner for declarations, lawyer or notary public.

Modifying or revoking an advance directive

In Queensland, only written revocation is accepted, and a witness is recommended but not required.



What should be the safeguards to ensure validity of an advance directive?

4.24 Taking reference from HA's guidelines and relevant practices from overseas, the Government **proposes** the following safeguards –

- (a) The original copy of the advance directive should be presented under normal circumstances. In the case that a valid advance directive is said to exist but the original copy is not immediately available, the treatment provider should continue to provide clinically indicated emergency life-sustaining treatment, while waiting for clarifications.

However, if the treatment provider (such as the clinical team) knows very well that a valid and applicable advance directive exists and the family members of the patient also agree that the advance directive is valid and applicable, the advance refusal of the patient should be duly respected.

- (b) The advance directive should be sufficiently clear and is not being challenged. For example, there are no claims that the person had been under undue influence at the time of making the advance directive, or there is no reason to suspect that the person was not mentally capable or was not properly informed when the advance directive was made.

If an advance directive is being challenged at the scene, the validity of the advance directive would be regarded as in doubt and the treatment provider should continue to provide clinically indicated emergency life-sustaining treatment, while waiting for clarifications.

- (c) The advance directive must not have been withdrawn.
- (d) The person has not done something that clearly goes against the advance directive which suggests that he/she has changed his/her mind, as illustrated in the following case –

Case scenario

A young man saw his friend die after a prolonged hospital treatment, thus he made an advance directive for himself which would refuse life-sustaining treatment if he was ever injured in this way. A few years

later, the man was seriously injured in a road traffic accident and became paralysed. At first he stayed conscious and gave permission to be treated and to join a rehabilitation programme. Some months later he lost consciousness. At this point somebody found his written advance directive, even though he had not mentioned it during his treatment. His actions of giving permission to be treated and joining a rehabilitation programme before his lack of mental capacity obviously went against the advance directive. Anyone assessing the advance directive needed to consider very carefully the doubt this has created about the validity of the advance directive, and whether the advance directive was valid and applicable as a result⁹.

Consultation question

(16) *Do you think that the proposed safeguards to ensure validity of an advance directive are sufficient?*



What are the safeguards to ensure applicability of an advance directive?

4.25 Even when an advance directive is validly made, it will be applicable only when the person suffers from the pre-specified conditions in the advance directive form and is no longer mentally capable of making healthcare decisions.

4.26 Modelling on HA's advance directive form, the Government **proposes** that the "pre-specified conditions" in the non-statutory 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, and the treatments to be refused cover life-sustaining treatment.

4.27 By limiting the pre-specified conditions to less controversial situations in the advance directive model form, this should help minimise difficulties in reaching consensus between treatment providers and the patient's family members. It should, however, be noted that a patient may still choose to adopt other advance directive forms with other additional

⁹ This case scenario has been adapted from the Mental Capacity Act 2005 Code of Practice.

pre-specified conditions (re paragraph 4.23 above). If a patient uses a non-model advance directive form specifying conditions which are not irreversible life-limiting conditions, it may raise question as to whether the patient has been properly informed when making the advance directive. In this case, treatment providers may challenge the validity of the advance directive (as explained in paragraph 4.24(b) above).

4.28 An advance directive will not be applicable –

- (a) if the patient has the capacity to make the decision when the treatment concerned is proposed;
- (b) to treatments or conditions not specified in the advance directive; or
- (c) 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.

Consultation questions

(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?*

(18) *Do you think that the proposed safeguards to ensure the applicability of advance directives are sufficient?*



Overseas practice

In England and Wales, there are no particular restrictions on the content of the advance directive, in terms of the conditions to which an advance directive is applicable and/or treatments to be refused under such conditions. The only requirement is that an advance directive must specify what treatment is to be refused and may specify the circumstances to which the refusal should apply. It is therefore recommended that people who are thinking about making an advance directive get advice from healthcare professionals or an organisation that

can provide advice on specific conditions or situations.

In Singapore, the law only allows “extraordinary life-sustaining treatment” to be refused when a person suffers from a “terminal illness”, and each term is defined specifically by law. In addition, for an advance directive to be applicable, an agreement of three medical practitioners is required to confirm that the patient is terminally ill.

In Queensland, the law lists out specified types of “health care matters” that can be included in an advance directive. It also lists out additional conditions to which a patient must fulfil in order for an advance directive involving life-sustaining treatment to be applicable (e.g. persistent vegetative state, permanently unconscious).



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

4.29 An important concept that is relevant to the implementation of advance directives outside the hospital setting is the DNACPR form. A DNACPR form is a written direction by the doctor not to perform CPR on a person, made in advance when cardiac arrest is anticipated.

4.30 In an advance directive, a person may make an advance decision to refuse CPR when he/she falls into some pre-specified conditions. When the advance directive legislation is in place, a valid and applicable advance directive refusing CPR has clear legal status and has to be respected by treatment providers, including emergency rescue personnel outside the hospital setting.

4.31 However, in an emergency situation, when an unconscious patient with impending cardiac arrest is seen by emergency rescue personnel, it could be difficult for them to tell whether a patient is in conditions specified in the advance directive, e.g. whether a chronically ill patient is terminally ill or not, and whether a comatose patient is having irreversible coma or not. Hence, there will be great difficulty for emergency rescue personnel to make an immediate assessment at the scene about the applicability of a valid advance directive presented by the patient or his/her family members.

4.32 To overcome this difficulty, HA has developed guidelines and a DNACPR form for non-hospitalised patients in 2014. Doctors signing the

DNACPR form certify that the advance directive is valid and that the patient already falls into the condition specified in the advance directive which becomes applicable. The DNACPR form attached to the advance directive of the patient would then facilitate the emergency rescue personnel to respect the advance decision of the patient.

4.33 As mentioned in paragraph 3.2(b)(i) above, emergency rescue personnel are currently bound by their empowering ordinances to protect life or prevent injury to life. In particular, ambulance personnel of FSD are bound by the FSO (section 7(d)) to perform CPR and other related resuscitation, even if an advance directive or a DNACPR form for a non-hospitalised patient is presented to them.

4.34 The Government **proposes** that, after legislating for advance directives, emergency rescue personnel shall respect a valid and applicable advance directive presented to them. This would enable adults with a valid and applicable advance directive to have their expressed wishes respected by the emergency rescue personnel, despite their statutory duty to resuscitate life as required under their empowering ordinances. As mentioned in paragraph 4.32 above, the DNACPR form attached to the advance directive of the patient would facilitate emergency rescue personnel to respect the advance decision of the person.

4.35 The DNACPR form also serves another important purpose. For minors and incompetent adults without an advance directive and suffering from advanced irreversible illnesses, the healthcare team may discuss and build consensus with family members of an incompetent adult or parents of a minor, via advance care planning, as to whether it is in the best interests of the patient to perform CPR if the patient develops cardiac arrest. If there is consensus that CPR is not in the best interests of the patient, doctors can then sign a DNACPR form for non-hospitalised patients to certify that CPR is not in the best interests of the patient and thus should not be performed. In an emergency situation, the DNACPR form would then facilitate the emergency rescue personnel to avoid performing futile CPR not in the best interests of the patient.

4.36 To facilitate emergency rescue personnel to avoid performing futile CPR which is not in the best interests of the patient or against the expressed wish of the patient, the Government **proposes** to amend the relevant empowering ordinances (such as the FSO), where necessary, so that the duty to resuscitate or sustain life will be subject to a valid advance directive with a refusal of CPR, DNACPR form or any valid instrument certified by a registered medical practitioner that CPR should not be performed. Similar to the proposed arrangements for advance directives

outlined in paragraph 4.23 above, the Government **proposes** to use a non-statutory model DNACPR form, instead of a statutory prescribed form. Detailed guideline on how advance directives (attached with a DNACPR form) and DNACPR forms should be implemented would be developed for use by emergency rescue personnel. The guideline will note in particular that emergency rescue personnel should not rely on an advance directive alone.

Consultation questions

- (19) *Do you agree to allow emergency rescue personnel to accept advance directives with signed DNACPR forms attached and not attempt CPR?*
- (20) *Do you agree to the use of a model DNACPR form, rather than a statutory prescribed form?*
- (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?*



Overseas practice

In the USA, in addition to legislating for advance directives, some states have separately legislated for Physician Orders for Life-Sustaining Treatment (“POLST”), which is a legal document signed by a physician for people with advanced illnesses that specifies the type of care a person would like in an emergency medical situation. It is complementary to an advance directive. Any emergency and non-emergency medical personnel are legally obligated to follow the instructions of the POLST.

In England and Wales, although there is no separate legislation for DNACPR, national and local guidelines have been developed such that there is a clear policy for emergency personnel in implementing DNACPR. The legal backing for DNACPR is indirectly inferred from the Human Rights Act 1998, as healthcare professionals (which include emergency rescue personnel) must be able to show that their decisions are compatible with the provision in the Act, including the right to be free

from inhuman or degrading treatment. For patients with an advance directive, it is recommended to have the DNACPR form placed together with the advance directive, but it is not essential.



How to facilitate treatment providers to be aware of an advance directive?

4.37 Currently in HA, a flagging alert in the HA Clinical Management System (“CMS”) has been set up to facilitate communications. The flagging points to the date and occasion when an HA doctor witnessed the making of the advance directive, and to the medical record where a copy of the advance directive was filed. When an advance directive is presented to the HA clinical team, it may be cross-checked with the information available in CMS flagging and hard copy in medical record. It should be emphasised that flagging in the CMS is not an advance directive registry as such. Even with flagging alert, there is a chance that a patient has subsequently revoked or modified an advance directive made (and flagged) earlier on. Hence, the information contained in flagging alert can only be used as reference for ascertaining the patient’s wish. If a mentally competent patient informs the HA clinical team that an advance directive has been signed outside HA, HA doctors are advised to consider advising the patient to sign an advance directive in HA in order to reduce ambiguity.

4.38 To facilitate treatment providers to be aware of an advance directive made in the public and private sectors, the Government **proposes** to consider the feasibility of leveraging the existing Electronic Health Record Sharing System (“eHRSS”) to store and allow access by designated healthcare professionals to the advance directive records. Same as the existing arrangements for eHRSS, storage of the records of advance directives should be voluntary.

4.39 As storage of the records of advance directives is proposed to be voluntary, the relevant records will only be for reference purpose and the eHRSS should not be treated as a central registry. The record of advance directives stored in eHRSS should only act as an alert to facilitate communication between treatment providers and patients, and to allow information sharing between treatment providers of the public and private sectors. The original advance directive document should still be required as the only proof of a valid advance directive since the keeping of advance

directive records in eHRSS would be voluntary. Also, there is always the possibility of a time lag between the latest status of advance directives and in eHRSS (e.g. verbal revocation of advance directives).

4.40 While emergency rescue personnel (including ambulance personnel) are expected to follow a patient's advance directive (attached with a DNACPR form) or DNACPR form, given the different settings in an ambulance as opposed to a hospital, it may not be practicable to require emergency rescue personnel to first find out the eHRSS record of advance directives for alert while carrying out resuscitation at the same time. As such, emergency rescue personnel would have to rely on the production of the original advance directive document attached with a signed DNACPR form or a signed DNACPR form by the patient or the patient's family. Patients may wear specific items (e.g. bracelet, necklace) to alert emergency rescue personnel.

Consultation questions

- (22) *Do you agree that the advance directive document may be recorded in eHRSS?*
- (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?*
- (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?*
- (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?*



Overseas practice

In Singapore, a statutory central registry exists. An advance directive is only valid when it is registered with the central registry. The register of advance directives will be kept confidential and will be only disclosed to individuals authorised by the patient in writing. If the patient's doctor

has reason to believe that the patient is terminally ill and incompetent in making his/her wishes known, the doctor can check with the Registrar on whether an advance directive has been made.

In England and Wales, no central registry exists. It is the responsibility of the person making the advance directive to make sure his/her decision will be drawn to the attention of treatment providers when it is needed.

In Queensland, no central registry exists. It is the responsibility of the individual to keep the original document and share copies to important others such as family members, close friends, general practitioners and local hospitals. Patients are advised to send a copy of all pages of advance care planning documents (including advance directive) to the Queensland Office of Advance Care Planning for review, and to add to their electronic health record, under a system called “My Health Record”. The system also allows removing such advance care planning documents at any time if wishes change. Patients can also manage or limit who can see their advance care planning documents using the access control mechanism in the system.



How to provide reasonable legal protection for treatment providers?

4.41 To provide reasonable legal protection for treatment providers which should help encourage them to initiate discussion of advance care planning and advance directives with individuals and their family members, the Government **proposes** that 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.

4.42 The Government also **proposes** that 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.

4.43 As mentioned in paragraph 4.35 above, emergency rescue personnel should follow a valid DNACPR form (where there is no advance directive) that CPR should not be provided. Hence, the Government also **proposes** that 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. Similarly, a treatment provider does not incur any civil or criminal liability for the consequences of withholding or withdrawing CPR from individuals if, at the time, he/she reasonably believes that a valid and applicable DNACPR form exists.

Consultation questions

(26) *Do you agree with the proposed arrangements on liability?*

(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?*



Overseas practice

In Singapore, exemption is granted for specified categories of personnel only (namely a medical practitioner, or a person acting under the instructions of a medical practitioner). Such personnel shall not be subject to civil or criminal liability or discipline for professional misconduct for a decision made by him/her in good faith and without negligence under specified scenarios.

In England and Wales, a person carrying out or continuing the treatment incurs liability if he/she is satisfied that a valid and applicable advance directive exists to the treatment. On the other hand, a person withholding or withdrawing treatment from a person does not incur liability if he/she reasonably believes that a valid and applicable advance directive exists. Disciplinary proceedings are not specified.

In Queensland, a health provider is protected and not affected by an adult's advance directive if the health provider does not know the adult has an advance directive. Moreover, a health provider does not incur any liability, either to the adult or anyone else, if the health provider does not act in accordance with the directive if he/she believes that the directive is uncertain or inconsistent with good medical practice or that circumstances have changed.



What is the inter-relationship between an advance directive and Continuing Powers of Attorney for medical and healthcare treatments?

4.44 The Department of Justice (“DoJ”) conducted a public consultation in 2017/2018 to seek views on the proposed continuing powers of attorney (“CPA”) legislation in Hong Kong. The CPA Bill aims to provide a statutory framework for the creation of CPAs, under which the donor confers on the attorney authority to act for the donor on any matters relating to the personal care, and property or financial affairs, of the donor.

4.45 Under the consultation draft of the CPA Bill, “personal care matters” include matters relating to the donor’s healthcare, but exclude any decision to give, refuse or withdraw life-sustaining treatment for the donor. In light of the responses received from the public consultation, DoJ may consider modifying the proposal concerning life-sustaining treatment to provide flexibility, such as allowing the donor to expressly empower the attorney to make such decision for the donor in the prescribed CPA form. Based on the fundamental principle of respecting a person’s right to self-determination, it is proposed that an advance directive shall take precedence over a CPA. In the case where the donor has made an advance directive and a CPA, the donor’s decision made in the former will override that of the attorney. In the case where the donor has not made an advance directive but has a CPA, it is proposed that the attorney should not be empowered to make an advance directive on behalf of the donor.

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

4.46 As indicated in paragraph 3.2(b)(ii) above, under the MHO, a doctor or a dentist may provide life-sustaining treatment to a mentally incompetent person without consent in urgent or non-urgent situation if the doctor or dentist considers that the treatment is necessary and in the best interests of the person. This gives rise to a potential conflict between the patient’s expressed wishes through an advance directive made when mentally competent and the doctor’s judgment of what is in the patient’s best interests. As the relevant MHO provisions are currently silent in respect of the treatment of advance directives, the Government **proposes** to make specific provisions to state that a valid and applicable advance directive made by the relevant person shall prevail. A registered doctor or dentist or an appointed guardian cannot override a validly made advance directive.

Consultation question

(28) *Do you agree with the proposed consequential change to the Mental Health Ordinance to remove the potential conflict?*



CHAPTER 5: DYING IN PLACE

BACKGROUND

5.1 Currently, the enrolment in elderly homes is about 62,000 residents¹⁰. We acknowledge that end-of-life care for elderly patients living in RCHEs should be enhanced, and that providing the choice of “dying in place” is one important measure.

5.2 Dying in place usually means spending the final days at the place of choice of the patient, be it at home, in RCHE or nursing home, and not necessarily a hospital. Home or home-like environment (such as RCHE) where the elderly patients used to reside before they succumb to terminal illnesses are often the natural choice for dying in place. They can live and die in a familiar environment and in the company of family members. According to the outcome of a survey study¹¹, over 80% of the elderly persons who are expected to die in a year preferred their homes or RCHEs/nursing homes/hospice as the place for end-of-life care, as compared to 17% choosing hospitals¹².

5.3 However, the usual practice of RCHEs is to send elderly residents with terminal illnesses to hospitals when they are unwell, often resulting in repeated admissions and discharges, and it is common that elderly residents living in RCHEs die in hospitals. In 2017, more than 96% of elderly patients (aged 65 and above) died in hospitals and about 40% of hospital death cases lived in elderly homes (including RCHEs and nursing homes)¹³.

DYING AT HOME AND DYING IN RCHE

5.4 Under the Coroners Ordinance, when a person dies at home due to natural cause, there is no requirement to report to the Coroner, if he/she was diagnosed as having terminal illness before his/her death or if he/she was attended to by a registered medical practitioner during his/her last

¹⁰ Figure as at end-February 2019 by Social Welfare Department.

¹¹ The study was conducted by the Jockey Club School of Public Health and Primary Care, Faculty of Medicine, The Chinese University of Hong Kong (the JC School of Public Health and Primary Care), as commissioned by the Health and Medical Research Fund.

¹² The survey revealed that 58.4% of surveyed elderly persons preferred their homes as the place of end-of-life care when they are expected to die in a year, 23.7% chose RCHEs/nursing homes/hospice and 17.0% chose hospitals. When the elderly persons only had “days” left, some 33.8% chose homes, 15.5% chose RCHEs/nursing homes/hospice and 49.5% chose hospitals.

¹³ According to the report produced by the JC School of Public Health and Primary Care in August 2017.

illness within 14 days prior to his/her death¹⁴. On the other hand, if a person without a terminal illness dies at home without being attended to by a registered medical practitioner within 14 days prior to death, the death then needs to be reported to the Coroner by law.

5.5 However, the requirements of reportable deaths for deaths in RCHEs are currently inconsistent with those for deaths at home. For cases of deaths due to natural causes in RCHEs, all such deaths must be reported to the Coroner via the Police, irrespective of whether the person had been diagnosed with terminal illness or whether the person had been attended to by a registered medical practitioner during his/her last illness within 14 days prior to his/her death. If necessary, an investigation by the Police and forensic pathologist and a post-mortem examination will follow¹⁵. Failure to report “reportable deaths” to the Coroner is a criminal offence. While these requirements are important safeguards for RCHE residents, they also pose a serious disincentive for RCHEs to allow elderly residents to die in their premises. Very often, when RCHE staff see a patient’s health is deteriorating, they will call an ambulance to take the patient to the accident and emergency department of hospitals.

How to remove barriers to facilitate dying in place?

5.6 It is the Government’s policy to promote dying in place, either at home or any residence choice including a RCHE, so as to allow elderly patients to spend their final moments in a familiar environment with dignity and privacy. Indeed, we expect that more and more people will want to spend their last days in RCHEs.

5.7 We acknowledge that there are different factors rendering dying in place difficult, including social taboo, fear of depreciation of property value if a person died at home, inadequate medical support to take care of dying persons at home/RCHEs, etc. We nonetheless believe that, as a prerequisite, consideration should be given to revising the relevant legal provisions to provide more options in the place of care for an ageing population.

¹⁴ The Births and Deaths Registration Ordinance (Cap. 174) provides that, in case of death of a patient, it is the doctor attending the patient during his last illness who shall sign a death certificate, in which the cause of death should be stated.

¹⁵ According to Schedule 1 to the Coroners Ordinance (Cap. 504), any death of a person where the death occurred in any premises in which the care of persons is carried on for reward or other financial consideration (other than in any premises which comprise a hospital, nursing home or maternity home registered under the Hospitals, Nursing Homes and Maternity Homes Registration Ordinance (Cap. 165)) is a reportable death.

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

5.8 The Government **proposes** to consider amending the Coroners Ordinance to provide that if a RCHE resident (regardless of whether he/she was diagnosed as having a terminal illness) who was attended to by a registered medical practitioner within 14 days prior to death and a medical practitioner had made a final diagnosis and determined the cause of death, the reporting requirements to the Coroner should be exempted. This aims to remove a major hurdle for RCHE operators to facilitate dying in RCHEs for their elderly residents. However, unlike a person dying at home, the Government **proposes** that if a resident who, before his/her death, was diagnosed as having a terminal illness, dies in RCHE, such death should remain reportable to the Coroner if there had been no registered medical practitioner who attended to him/her within 14 days prior to his/her death. This will serve as a crucial safeguard for RCHE residents.

5.9 However, we recognise that even with the proposed exemption from the reporting requirements under the Coroners Ordinance, many RCHEs may not possess the required capacity in terms of manpower, physical space and supporting infrastructure to facilitate dying in place. Also, whether dying in place in RCHEs would be widely adopted depends on such other equally important considerations such as the readiness of the elderly residents and their family members, as well as public acceptance. In this regard, the relevant bureaux and departments, HA and non-governmental organisations have been making effort in providing a more facilitating environment for dying in place, including –

- (a) starting from September 2017, subvented and contract RCHEs under planning are required to provide an end-of-life care room, in which a dying resident may pass away peacefully;
- (b) since 2015-16, HA has been strengthening the Community Geriatric Assessment Team (“CGAT”) service to enhance end-of-life care and support (including advance care planning, symptom control and psychosocial support) for elderly patients living in RCHEs with terminal illnesses. CGATs are working in partnership with the palliative care teams and RCHEs to improve medical and nursing care and support service for those patients in RCHEs, and to provide training for RCHE staff. The end-of-life care and support service provided by HA in RCHEs has been rolled out to all CGATs for the initial phase since 2018-19;

- (c) more will be done to raise public awareness and knowledge about end-of-life care;
- (d) in view of the growing demand for end-of-life care services in the community, the Hong Kong Jockey Club Charities Trust launched the First Phase of the Jockey Club End-of-life Community Care Project in January 2016.

The Project calls for multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with emphasis on the interface between social and medical systems. Building upon the outcome of the First Phase, the Second Phase of the Project was launched in January 2019, with a view to further enhancing end-of-life care training for medical professionals and frontline and managerial staff, expanding coverage of end-of-life care services, raising public awareness and knowledge to improve the overall quality of care for terminally ill or patients approaching end of life in Hong Kong, and exploring the feasibility of different service models; and

- (e) there will be further expansion of medical-social collaboration in the coming years with a view to providing better support for terminally ill patients living in RCHEs and improving quality of end-of-life care through enhanced training for RCHEs.

Consultation questions

- (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?*
- (30) *Do you think that the proposed safeguard for RCHE residents is sufficient if deaths in RCHEs may be exempted from reportable deaths?*



CHAPTER 6: SUMMARY OF CONSULTATION QUESTIONS

ADVANCE DIRECTIVES

- (1) Do you think that the public at large is ready to accept the concept of advance directives?
- (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?
- (3) Do you agree with the fundamental principles set out in paragraph 4.8?
- (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?
- (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?
- (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?
- (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?
- (8) Do you agree that a person may revoke or modify an advance directive at any time?
- (9) Do you agree that an advance directive must be made or modified in writing?
- (10) Do you agree that both verbal and written revocation of an advance directive should be accepted?
- (11) Do you agree that a legally-valid advance directive must be witnessed as safeguard?

- (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?
- (13) Do you agree that written revocation of advance directive need not be witnessed to avoid imposing unnecessary hurdles?
- (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?
- (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?
- (16) Do you think that the proposed safeguards to ensure validity of an advance directive are sufficient?
- (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?
- (18) Do you think that the proposed safeguards to ensure the applicability of advance directives are sufficient?
- (19) Do you agree to allow emergency rescue personnel to accept advance directives with signed DNACPR forms attached and not attempt CPR?
- (20) Do you agree to the use of a model DNACPR form, rather than a statutory prescribed form?
- (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?
- (22) Do you agree that the advance directive document may be recorded in eHRSS?

- (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?
- (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?
- (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?
- (26) Do you agree with the proposed arrangements on liability?
- (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?
- (28) Do you agree with the proposed consequential change to the Mental Health Ordinance to remove the potential conflict?

DYING IN PLACE

- (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?
- (30) Do you think that the proposed safeguard for RCHE residents is sufficient if deaths in RCHEs may be exempted from reportable deaths?

CHAPTER 7: INVITATION OF VIEWS

7.1 Your support and constructive views to the proposals for improving end-of-life care in Hong Kong are much needed. We will consolidate and analyse the views received for this public consultation exercise before deciding the way forward. Your views will be taken into account when the Government formulates relevant legislative and administrative measures.

7.2 Please provide your written submission on the consultation issues or complete the Questionnaire (**Annex D**) and return to us on or before **16 December 2019** through one of the channels below –

Online Consultation Paper and Questionnaire: https://www.fhb.gov.hk/en/press_and_publications/consultation/190900_eolcare/index.html



Address: Food and Health Bureau
19/F, East Wing, Central Government Offices
2 Tim Mei Avenue, Tamar
Hong Kong
(Attn: Assistant Secretary for Food and Health (Health) 6B)
(Re: End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place)

Fax: 2840 0467

Email: eolcare@fhb.gov.hk

7.3 FHB may, as appropriate, reproduce, quote, summarise or publish the written documents received, in whole or in part, in any form, without seeking permission of the contributing parties.

7.4 Names of the contributing parties and their affiliations may be referred to in other documents that FHB may publish and disseminate by different means after the consultation. If any contributing parties do not wish their name and/or affiliations to be disclosed, please expressly state so when making your written submission. Any personal data provided will only be used by FHB and/or other governmental departments/agencies for purposes which are directly related to the consultation.

7.5 Thank you for taking part in the consultation exercise.

Food and Health Bureau
September 2019

EXISTING SERVICES SUPPORTING THE PROVISION OF PALLIATIVE AND END-OF-LIFE CARE

Palliative and end-of-life care is provided to people who have an incurable and progressive illness to improve their quality of life. The World Health Organisation defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. While palliative care is applicable in the earlier stages of chronic diseases or life limiting illness, the term end-of-life care is used to describe palliative care delivered at a later stage when patient is approaching end-of-life. Therefore, palliative care is not limited to end-of-life care, but embraces end-of-life care.

2. In Hong Kong, palliative care service is mainly provided by the Hospital Authority (“HA”) under a comprehensive service model for patients with life limiting diseases and their families including in-patient, consultative service, outpatient, day care and home care services and bereavement service through multi-disciplinary teams of professionals including doctors, nurses, medical social workers, clinical psychologists, physiotherapists, occupational therapists, etc. The palliative care service embraces end-of-life care as death approaches. A description of the range of palliative and end-of-life care services and proposed improvements can be found in this Annex.

3. Palliative care has been used interchangeably with the term hospice care in Hong Kong in the past, though the HA is aiming to standardise the term as palliative care.

4. Defining the end-of-life phase of a patient in terms of exact time frame has been difficult. In Hong Kong, HA defines the terminally ill as patients who suffer from advanced, progressive and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy of days, weeks or a few months (*HA Guidelines on Withholding and Withdrawing Life Sustaining Treatment*). In UK, the General Medical Council and the National Council for Palliative Care say that people can be said to be “approaching the end of life” when they appear likely to die within the next 12 months.

Promotion of Advance Care Planning

5. Advance care planning is an integral part of a comprehensive palliative and end-of-life care. Usually advance care planning is a process of communication intended for mentally competent patients. Participation of family members is encouraged. The patient can express preferences for future medical or personal care, or make an advance directive refusing life-sustaining treatments. In HA, the process of advance care planning extends beyond communication with mentally competent adult patients to include that with family members of the mentally incompetent and minor patients. Decision making regarding the patient's future medical or personal care should be by consensus building among members of the healthcare team and the patient's family, based on the best interests of the patient.

6. HA has recently published its *Guidelines on Advance Care Planning* in June 2019, which have been developed to provide practical guidance and standardise HA forms to facilitate advance care planning in clinical operation. Furthermore, HA is also considering extending advance care planning to specialties looking after seriously ill patients beyond palliative care, oncology and geriatric patients.

Palliative and End-of-life Care

7. HA published an overarching *Strategic Service Framework for Palliative Care* in 2017 to guide the development of palliative care services in the next five to ten years. It outlines the strategies and key enablers for building up the service model and system infrastructure to address existing issues and improve service quality. The document also highlights the stratification of patients according to their level of needs, their disease complexity, and the shared care model for provision of appropriate palliative care to patients in need¹⁶.

8. HA palliative care in-patient services are mainly for terminally ill patients with severe or complex symptoms and needs. Besides, if necessary, some terminally ill patients admitted to other specialties and in need of palliative care services can also receive treatment from the palliative care teams. If necessary, HA will follow up the condition of discharged patients by arranging palliative care outpatient services.

¹⁶ For details of the Strategic Service Framework for Palliative Care, please refer to: https://www.ha.org.hk/visitor/ha_visitor_index.asp?Content_ID=224128&Lang=ENG&FontSymbol=al

9. To enhance care for terminally ill patients, HA has set up a number of Palliative Day Care Centres to provide day care services to strengthen different modalities of physical and psychosocial support for patients and their families.

10. Palliative care home service is particularly important to support patients in the community and reduce unnecessary hospitalisation. Palliative care home care teams collaborate closely with in-patient units of hospitals to provide symptom management and monitoring, psychosocial and spiritual care, advance care planning, care coordination, counselling and bereavement support in order to provide continuing care for discharged patients.

11. In 2018-19, HA enhanced palliative care by strengthening palliative care consultative service in hospitals, improving palliative care home care service through nurse visits and strengthening the competence of nursing staff supporting terminally ill patients beyond palliative care setting through training.

12. Since 2015-16, HA has been strengthening the Community Geriatric Assessment Team (“CGAT”) service in phases to enhance end-of-life care and support for elderly patients living in the residential care homes for the elderly (“RCHEs”) facing terminal illness. CGATs are working in partnership with the palliative care teams and RCHEs to improve medical and nursing care and support service for those terminally ill patients in RCHEs, and to provide training for RCHE staff.

Training and Development of Healthcare Professionals

13. Another crucial component to providing quality palliative and end-of-life care and engaging in meaningful advance care planning discussions is that healthcare providers are well-trained to handle the subject of death with sensitivity and facilitate meeting individuals’ needs and preferences.

14. Currently, a number of institutions provide professional training and development to healthcare professionals on palliative and end-of-life care.

15. HA provides commissioned training for palliative care professionals of various disciplines to update their skills and knowledge. Basic training for all healthcare staff across all disciplines and specialties to raise their general knowledge and awareness of palliative care in HA is also provided. HA will continue to provide advanced training for non-palliative care teams working directly with patients who are suffering from life-threatening or life-limiting illnesses to build up their competency in implementing the shared

care model. The HA Institute of Advanced Nursing Studies provides a specialty Nursing Program on Palliative Care for post-graduate nurses.

16. For specialist doctors, the Hong Kong College of Physicians and the Hong Kong College of Radiologists provide the subspecialty of Palliative Medicine in their formal training curriculums.

17. The Nursing Council of Hong Kong has set a minimum of 16 training hours on the subject “oncology nursing and palliative care” in its pre-registration general nurse training.

18. There are several training curriculums provided by various societies, e.g. the Hong Kong Anti-cancer Society, the Federation of Medical Societies of Hong Kong in collaboration with Hong Kong Society of Palliative Medicine and Hong Kong Palliative Nurses Association, and the Society for the Promotion of Hospice Care also provide palliative care training for healthcare professionals including nurses. Amongst them, the Society for the Promotion of Hospice Care has several structured palliative and end-of-life care training programmes provided to healthcare workers working in various settings.

19. Hong Kong Society of Palliative Medicine, Hong Kong Association of Gerontology and the Hong Kong College of Gerontology Nursing also organise certificate courses regularly to healthcare professionals about palliative care, psycho-spiritual support of patients and families including older persons when facing life limiting disease and during end of life.

20. A number of education institutions also offer training in the subject. For example, the HKU SPACE offers a diploma in Oncology and Palliative Care for Healthcare Professionals and the Chinese University of Hong Kong provides palliative and end-of-life care training in postgraduate diploma or workshop format. The Vocational Training Council offers a Higher Diploma in Community Healthcare for Senior Citizens covering palliative and end-of-life care.

21. On-the-job training is available for healthcare providers. For example, staff of the Elderly Health Service of the Department of Health (“DH”) have attended seminars/courses related to life and death education, palliative and end-of-life care and advance care planning organised by non-governmental organisations and universities. Nurses have also undertaken in-house training delivered by clinical psychologists in the preparation of health talks on life and death education to the community.

Facilities in Hospitals and RCHEs

22. Besides human resources to improve palliative and end-of-life care, a wide range of “hardware” are being planned and implemented to augment an improvement in service delivery. For instance, facilities such as a comfortable family or solace room to allow for family gathering during the dying process, overnight accompanying beds for close families during the final days, etc., are being developed in hospitals and RCHEs, subject to physical and other constraints.

23. For hospitals, the HA *Strategic Service Framework for Palliative Care* highlights that physical design for facilitating the delivery of palliative care will be incorporated into the hospital development and redevelopment projects in HA where appropriate. For instance, single rooms, interview rooms and family areas could be included, with design features to foster a caring environment and meet the needs of patients at the end-of-life and their families/carers. The design of mortuaries will also be improved taking into account the operational workflow and perception of patients’ families/carers.

24. For RCHEs, with a view to strengthening the planning of premises, the Social Welfare Department (“SWD”) has completed a review of the Schedule of Accommodation (“SoA”) for RCHEs. Starting from September 2017, an end-of-life Care Room has been included as a standard provision in the SoA for subvented and contract RCHEs under planning, which could be used by the severely sick or terminally ill residents and their families.

Public Education on Ageing, End-of-life and Death

25. The Government has been making effort in raising the awareness and understanding of the public in end-of-life care through public education.

26. For example, the Education Bureau attaches great importance to nurturing students’ positive values and attitudes. In schools, the elements of life education, such as “understand life”, “cherish life”, “respect life” and “explore life”, have already been incorporated into different learning themes under the comprehensive school curriculum. For example, in Health Management and Social Care at the senior secondary level, various stages of life including elderly and their needs as well as the care for elderly are included. Students are expected to understand “death” as one of the crucial examples of life events, the positive responses to different life events and culturally diverse ways of dealing with eldership and death. Besides, schools are encouraged to organise diverse learning activities,

such as visiting old age homes, to cultivate students' positive values of caring for others (including the elderly).

27. Another example is the Elderly Health Service of DH, which conducts regular public education on ageing, end-of-life and bereavement via its multi-disciplinary team of nurses and allied health professionals. Health talks are arranged in RCHEs, elderly centres in the community and Elderly Health Centres under the Elderly Health Service. Take the “Life and Death Education” talk as an example, it aims to guide elders to express their wishes regarding advance care to their families. The content of the talks will be reviewed and enhanced to align with future developments on this aspect of care. On the other hand, fact sheets and articles on relevant topics are posted on the Elderly Health Service website for public access.

Patient Transfer Service

28. To support the terminally ill or patients approaching end of life who choose to stay in the community, timely and adequate transfer service for sub-acute and non-emergency service between hospitals and the individual’s residence is essential.

29. Currently, the Non-emergency Ambulance Transfer Service (“NEATS”) provides non-emergency ambulance transfer service for patients on discharge, transfer, and attending medical appointment to or from a HA institution in groups. The competence of the crew, equipment on board the vehicles and service hours are specific to the target group of patients. Terminally ill or patients approaching end of life can use the NEATS if the mode of service matches their needs. HA will monitor the workload of NEATS and adjust the resources of the service. In recent years, the overall number of transfers provided through NEATS has been increasing and exceeds 500 000 per annum. The Auxiliary Medical Service and Hong Kong St. John Ambulance also provide patients with similar services.

After-Death Arrangements

Mortuary Services

30. With a growing ageing population, the Government anticipates an increased demand for mortuary service. The current availability of mortuary places can barely handle 40 000 deaths per annum. Among the 40 000 annual deaths, about 11 000 were reportable to the Coroner. DH’s

public mortuaries handled about 8 000 of these Coroner cases, while the remaining Coroner cases were handled by HA's hospital mortuaries (which also handled non-Coroner hospital deaths in HA hospitals).

31. To satisfy the anticipated demand in public mortuary services for handling deaths that are reportable to the Coroner for the next two decades, DH is currently embarking on two public mortuary re-provisioning projects, namely the Re-provisioning of Fu Shan Public Mortuary and Re-provisioning of Victoria Public Mortuary in which the former is tentatively expected to be commissioned by 2022. The Government will continue to explore opportunities to further expand public mortuary facilities to cater for longer term need.

Other After-death Services

32. Beyond end-of-life care, the various after-death arrangements from registration of death to funeral and cremation or burial can be daunting to the family and friends during a time of grief and agony. Since 2010, the Food and Environmental Hygiene Department ("FEHD") has published *A Guide to After-Death Arrangements* to provide handy information on after-death arrangements such as death registration, disposal of bodies and ashes, and the holding of funerals to facilitate the bereaved in handling funeral matters.

33. The list of FEHD's after-death services can be accessed from its website, including cremation services, deposit of ashes in public niches, scattering of ashes, coffin/urn burial and temporary storage facility for ashes. E-forms and the list of licensed funeral parlours and undertakers of burial are also available.

34. In addition, a number of charitable organisations and non-governmental organisations in Hong Kong, such as the Tung Wah Group of Hospitals and the Society for the Promotion of Hospice Care, support family members of the deceased in handling funeral and after death arrangements, and provide emotional support services.



醫院管理局
HOSPITAL
AUTHORITY

ADVANCE DIRECTIVE¹

Please Use Block Letter or Affix Label

SOPD / Hospital No.:

Name:

ID. No.: Sex: Age:

Dept.: Team: Ward/Bed:

Section I : Personal details of the maker of this advance directive

Name : (please use capital letters)

Identity Document No.:

Sex : Male / Female

Date of Birth : / /
 (Day) (Month) (Year)

Home Address :

.....

Home Tel. No. :

Office Tel. No. :

Mobile Tel. No. :

Section II : Background

1. I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, or in other specified end-stage irreversible life limiting condition, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.
2. I understand that euthanasia will not be performed, nor will any unlawful instructions as to my medical treatment be followed in any circumstances, even if expressly requested.
3. I, (please print name) being over the age of 18 years, revoke all previous advance directives made by me relating to my medical care and treatment (if any), and make the following advance directive of my own free will.
4. If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state or in other specified end-stage irreversible life limiting condition as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my directives in relation to my medical care and treatment are as follows:

(Note: Complete the following by ticking the appropriate box(es) and writing your initials against that/those box(es), and drawing a line across any part you do not want to apply to you.)

¹ The Form was proposed by the Law Reform Commission on 16 August 2006; amended as in Food and Health Bureau Consultation Paper on 23 December 2009; modifications made and footnotes added by the Hospital Authority in May 2010 and in June 2014.

(A) **Case 1 – Terminally ill**

(Note: In this instruction –

"Terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death, and

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.)

I shall not be given the following life-sustaining treatment(s):

Cardiopulmonary resuscitation (CPR)

Others: _____

Save for basic and palliative care, I shall not be given any life-sustaining treatment². Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.

However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.

(B) **Case 2 – Persistent vegetative state or a state of irreversible coma**

(Note: In this instruction -

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration³. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.)

I shall not be given the following life-sustaining treatment(s):

Cardiopulmonary resuscitation (CPR)

Others: _____

Save for basic and palliative care, I shall not be given any life-sustaining treatment⁴. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.

However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.

² Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

³ Note that to withdraw artificial nutrition and hydration (ANH) in a non-terminally ill patient who is in a persistent vegetative state or a state of irreversible coma (PVS/IC) can be contentious even in the presence of an advance directive. For patients presenting with such a directive and in PVS/IC, advice should be sought from the HCE/CCE and HAHO to consider whether an application to the Court is required. A patient wishing to make a directive to withdraw ANH, or to withdraw all life-sustaining treatments under this Section, should be alerted about this special caution.

⁴ Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

(C) **Case 3 – Other end-stage irreversible life limiting condition, namely:**

(Note: In this instruction -

"Other end-stage irreversible life limiting condition" means suffering from an advanced, progressive, and irreversible condition not belonging to Case 1 or Case 2, but has reached the end-stage of the condition, limiting survival of the patient. Examples include:

- (1) patients with end-stage renal failure, end-stage motor neuron disease, or end-stage chronic obstructive pulmonary disease who may not fall into the definition of terminal illness in Case 1, because their survival may be prolonged by dialysis or assisted ventilation, and
- (2) patients with irreversible loss of major cerebral function and extremely poor functional status who do not fall into Case 2.

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.)

I shall not be given the following life-sustaining treatment(s):

Cardiopulmonary resuscitation (CPR)

Others: _____

Save for basic and palliative care, I shall not be given any life-sustaining treatment⁵. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.

However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.

5. I make this directive in the presence of the two witnesses named in Section III of this advance directive, who are not beneficiaries under:

- (i) my will; or
- (ii) any policy of insurance held by me; or
- (iii) any other instrument made by me or on my behalf.

6. I understand I can revoke this advance directive at anytime⁶.

Signature of the maker of this advance directive

Date

Section III : Witnesses

Notes for witness :

A witness must be a person who is not a beneficiary under –

- (i) the will of the maker of this advance directive; or
- (ii) any policy of insurance held by the maker of this advance directive; or
- (iii) any other instrument made by or on behalf of the maker of this advance directive.

⁵ Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

⁶ A written revocation can be directly signed on the advance directive form, or written and signed on a separate piece of paper and attached to the advance directive form.

Statement of Witnesses

First Witness

(Note: This witness must be a registered medical practitioner, who, at the option of the maker of this directive, could be a doctor other than one who is treating or has treated the maker of this directive.)

- (1) I, _____ (*please print name*) sign below as witness.
 - (a) as far as I know, the maker of this directive has made the directive voluntarily; and
 - (b) I have explained to the maker of this directive the nature and implications of making this directive.
- (2) I declare that this directive is made and signed in my presence together with the second witness named below.

Signature of 1st witness

Date

Name:

Identity Document No. / Medical Council Registration No.⁷:

Office Address:

Office Tel. No. :

Second Witness

(Note: This witness must be at least 18 years of age)

- (1) I, _____ (*please print name*) sign below as witness.
- (2) I declare that this directive is made and signed in my presence together with the first witness named above, and that the first witness has, in my presence, explained to the maker of this directive the nature and implications of making this directive.

Signature of 2nd witness

Date

Name:

Identity Document No.⁸:

Home Address / Contact Address :

Home Tel. No. / Contact No. :

⁷ It is not necessary for HA staff to provide the Identity Document No. / Medical Council Registration No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 1st witness.

⁸ It is not necessary for HA staff to provide the Identity Document No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 2nd witness.

(Please fill in either English part or the Chinese part)

 醫院管理局 HOSPITAL AUTHORITY	<p>Do Not Attempt CPR (DNACPR) Form for Non-Hospitalized Patients 非住院病人「不作心肺復甦術」 文件</p>	Please Use Block Letter or Affix Label SOPD / Hospital No. : Name: I.D. No: Sex Age..... Dept: Team:..... Ward/Bed: /.....
<p>I. Diagnosis:</p>		
<p>II. On the date of signing Part IV of the Form, we, the doctors of the certifying healthcare team (Please fill out either paragraph (A) or paragraph (B) below):</p>		
<p>(A) <u>For an adult with an advance directive (AD):</u> <u>have ascertained that</u> the AD with a refusal of cardiopulmonary resuscitation (CPR) signed by this patient on _____(date) is valid, and <u>hereby certify that</u> this patient’s clinical condition is that specified in the AD namely (please tick), he/she <input type="checkbox"/> is terminally ill, <input type="checkbox"/> is in irreversible coma or persistent vegetative state, <input type="checkbox"/> has other end-stage irreversible life limiting condition: _____, and <u>according to the AD</u>, if this patient’s condition falls within the circumstances under the AD and he/she suffers from cardiopulmonary arrest, neither artificial ventilation, external cardiac compression, nor defibrillation should be given.</p>		
<p>(B) <u>For a mentally incompetent adult without a valid AD or a minor:</u> <u>certify that</u> this patient (please tick) <input type="checkbox"/> is terminally ill, <input type="checkbox"/> is in irreversible coma or in a persistent vegetative state, <input type="checkbox"/> has irreversible loss of major cerebral function and extremely poor functional status, <input type="checkbox"/> in the case of a minor, has other end-stage irreversible life limiting condition, <u>and that</u> this patient’s current clinical condition and advance care planning (ACP) have been discussed: (please tick) <input type="checkbox"/> between the healthcare team looking after this patient and the family of this patient (who is a mentally incompetent adult) <input type="checkbox"/> between the healthcare team looking after this patient and the parent(s) of this patient (who is a minor) <u>and that</u> agreement has been reached that if this patient suffers from cardiopulmonary arrest, it would be in this patient’s best interests that neither artificial ventilation, external cardiac compression, nor defibrillation should be given. The family (or parents) of this patient confirms the agreement with the DNACPR decision (for paragraph (B) only). Signature: _____ Date: _____ Name: _____ Relationship with patient : _____</p>		

DNACPR FORM FOR NON-HOSPITALIZED PATIENTS HA9614/MR



**Do Not Attempt CPR
(DNACPR) Form
for Non-Hospitalized Patients**
非住院病人「不作心肺復甦術」
文件

Please Use Block Letter or Affix Label
SOPD / Hospital No. :
Name:
I.D. No: Sex Age.....
Dept: Team:..... Ward/Bed: /.....

III. Reminder:

1. Before withholding CPR, the Accident and Emergency team attending to this patient should ascertain that the decision to withhold CPR remains valid and unchanged, and that this patient's condition when presented to the team falls within this form. If in doubt (e.g. whether or not CPR is still in this patient's best interests), or if foul play, accident or untoward event is suspected, CPR should be given to this patient.
2. The original form should be kept with the patient and presented to the Accident and Emergency team.

IV. Signatures of the certifying healthcare team doctors (signatures of both doctors are required):

<p>Doctor:</p> <p>_____</p> <p align="center">(Doctor's name)</p> <p>_____</p> <p align="center">(Signature)</p> <p>Date: _____</p>	<p>Specialist doctor:</p> <p>_____</p> <p align="center">(Doctor's name)</p> <p>_____</p> <p align="center">(Signature)</p> <p>Date: _____</p>	<p>Department: _____</p> <p>Hospital: _____</p> <p>Hospital/Department Chop: _____</p>
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V. Reviewed & endorsed by (the form will be ineffective if not endorsed within the review period):

	Review date	Doctor's name	Signature	Department / Hospital
Review period* 6 months, or less at ___ months				

* If a review period shorter than 6 months is indicated, please cross out "6 months" and fill in the period in the space provided.

QUESTIONNAIRE

To help us collect your opinion on Advance Directives and related End-of-Life Care Arrangements as set out in the consultation document we would appreciate if you would take a few minutes to complete this questionnaire. Please tick the box that best represents your views .

Name: _____ Telephone: _____

Email Address: _____

Organisation: _____

		Agree	Disagree	Remarks
Advance Directives				
1.	Do you think that the public at large is ready to accept the concept of advance directives?			
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?			
3.	Do you agree with the fundamental principles set out in paragraph 4.8?			
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?			

		Agree	Disagree	Remarks
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?			
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?			
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?			
8.	Do you agree that a person may revoke or modify an advance directive at any time?			
9.	Do you agree that an advance directive must be made or modified in writing?			
10.	Do you agree that both verbal and written revocation of an advance directive should be accepted?			

		Agree	Disagree	Remarks
11.	Do you agree that a legally-valid advance directive must be witnessed as safeguard?			
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?			
13.	Do you agree that written revocation of advance directive need not be witnessed to avoid imposing unnecessary hurdles?			
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?			
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?			
16.	Do you think that the proposed safeguards to ensure validity of an advance directive are sufficient?			

		Agree	Disagree	Remarks
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?			
18.	Do you think that the proposed safeguards to ensure the applicability of advance directives are sufficient?			
19.	Do you agree to allow emergency rescue personnel to accept advance directives with signed DNACPR forms attached and not attempt CPR?			
20.	Do you agree to the use of a model DNACPR form, rather than a statutory prescribed form?			
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?			

		Agree	Disagree	Remarks
22.	Do you agree that the advance directive document may be recorded in eHRSS?			
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?			
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?			
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?			
26.	Do you agree with the proposed arrangements on liability?			
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?			

		Agree	Disagree	Remarks
28.	Do you agree with the proposed consequential change to the Mental Health Ordinance to remove the potential conflict?			
Dying in place				
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?			
30.	Do you think that the proposed safeguard for RCHE residents is sufficient if deaths in RCHEs may be exempted from reportable deaths?			

Other views:

THANK YOU FOR YOUR FEEDBACK.

Please provide your written submission on the consultation issues or complete the Questionnaire and return to us **on or before 16 December 2019** through the contact below:

Address: Food and Health Bureau
(Attn: Assistant Secretary for Food and Health (Health) 6B)
19/F, East Wing, Central Government Offices
2 Tim Mei Avenue, Tamar
Hong Kong
(Re: End-of-life Care: Legislative Proposals on Advance Directives and Dying in Place)

Fax: 2840 0467

Email: eolcare@fhb.gov.hk

PERSONAL DATA COLLECTION STATEMENT

1. It is voluntary for any member of the public to supply his/her personal data upon providing views on the consultation document. Any personal data provided with a submission will only be used for this consultation exercise. The submissions and personal data collected may be transferred to the relevant Government bureaux, departments or agencies for purposes directly related to this consultation exercise. The relevant parties receiving the data are bound by such purposes in their subsequent use of such data
2. The names and views of individuals and organisations which put forth submissions in response to the consultation document (senders) may be published for public viewing after conclusion of the consultation exercise. FHB may, either in discussion with others or in any subsequent report, whether privately or publicly, attribute comments submitted in response to the consultation document. We will respect the wish of senders to remain anonymous and / or keep the views confidential in relation to all or part of a submission; but if no such wish is indicated, it will be assumed that the sender can be named and his/her views be published for public information.
3. Any sender providing personal data to FHB in the submission will have the right of access and correction with respect to such personal data. Any request for data access or correction of personal data should be made in writing to the contact specified above.