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STEP Submission on the Public Consultation on Advance Healthcare Directives

The Society of Trust and Estate Practitioners ("STEP") is the worldwide professional body for practitioners in the fields of trusts and estates, executorship, administration and related issues. STEP members help families secure their financial future and protect the interests of vulnerable relatives. STEP promotes the highest professional standards through education and training leading to widely recognised and respected professional qualifications. STEP internationally has over 17,500 members with more than 200 members in Ireland.

STEP Ireland is pleased to have been given the opportunity to participate in the public consultation on the draft General Scheme of legislative provisions for advance healthcare directives to be incorporated into the Assisted Decision Making (Capacity) Bill 2013 (the "Consultation"). STEP Ireland welcomes the Minster for Health's proposal for the introduction of a legislative framework pertaining to advance healthcare directives in Ireland.

We set out below our detailed answers to the specific questions in the Consultation.

1. **What are your views on requiring an individual to obtain professional advice e.g. clinical and/or legal) before preparing an advance healthcare directive?**

   We are of the view that it should be a requirement that clinical and legal advice should be obtained before preparing the advance healthcare directive. The benefit of this step would be, firstly to put it beyond doubt, and thereby limit challenges, that the individual had capacity, and secondly, it will provide protection where an individual is vulnerable and/or elderly.

   It appears that in some other jurisdictions, such as the US and in New South Wales, there is no requirement to obtain professional advice before preparing the advance healthcare directive but understandably, the requirement that the individual must have capacity is universal.

   In that regard, unless a professional (whether on a clinical and/or legal assessment) has certified the individual as having capacity, that issue will always be open to challenge. The Succession Act 1965 provides that a will can only be made by a person of sound disposing

mind however the validity of wills is continually challenged on the basis of lack of testamentary capacity - a medical or legal certification of capacity is not a pre-requisite to a valid will. However, when the certification does exist, there is much less scope for challenge. The benefits of having capacity assessed prior to the instrument being put in place can be seen in the Power of Attorney Act 1996 which requires a statement firstly, by a solicitor that the donor understood the effect of the instrument and there was no reason to believe there was fraud or undue duress and a secondly, statement by a registered medical practitioner that the donor had capacity. There are relatively few challenges to the capacity of donors by reason of this certification of understanding and capacity being done in advance of the instrument being put in place. We do not believe that it is enough to provide that a witness to the advance healthcare directive cannot be a beneficiary of the individual's estate. Moreover, this might result in an otherwise proper and valid advance healthcare directive being rendered invalid (because it transpires the witness is a beneficiary of the individual's estate). We are of the view that it is more appropriate to have a clinical and/or a legal certification.

Furthermore, as the individuals, for whose benefit the legislation is being put in place, includes vulnerable and often elderly individuals, there is less scope for abuse if the individual is assessed as having capacity and as understanding the effect of the document.

2. **Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed (e.g. every 2 years, every 5 years, every 10 years)?**

We do not believe that a time frame for a review should be put in place, or that this review be mandatory to the validity of the advance healthcare directive.

We are of the view that the proposed Guidelines should recommend that advance healthcare directive be reviewed regularly and certainly after important life changes to ensure the advance healthcare directive continues to reflect the wishes of the individual and those important life changes might be identified. There may be situations, as identified in Head 4, where the individual has done something clearly inconsistent with the advance healthcare directive and in those circumstances the advance healthcare directive is not valid. There are also situations where medical developments might have an impact on how and if a person wishes to be medically treated. All of these situations warrant a review by the individual but we are of the view that to make a review a statutory requirement by stating that the advance healthcare directive 'must be reviewed' could result in invalidating, otherwise valid advance healthcare directives.

3. **Should a standard format be developed for advance healthcare directives?**

We are of the view that a standard format should be developed for advance healthcare directive. The benefit of using a standard format would be to ensure that all formalities required to create an advance healthcare directive can be easily adhered to by the individual. This would mirror the approach taken in the Power of Attorney Act 1996 which provides a standard format for the creation of an Enduring Power of Attorney.

4. **If a standard format for advance healthcare directives was developed, what information should it contain?**

As provided for under Head 4 Sub-Head 4(a) we agree that an advance healthcare directive should be in writing and should contain the information prescribed at Head 4 Sub-Head 4(b).

In addition, we view that the following information should be required:

- details of any treatment decision (consent or refusal) to which the advance healthcare directive relates;

- a statement by a medical practitioner that at the time the advance healthcare directive is put in place that the individual has capacity;

- a statement by a solicitor that the individual understands the effect of the advance healthcare directive and that there was no reason to believe that there was fraud of undue influence arising;

- explanatory information in relation to the nature and effect of an advance healthcare directive and a statement by the donor that he has read the explanatory information;

- a waiver of confidentiality of medical records to enable the medical practitioner to engage freely with the designated healthcare representative as appropriate;

- a release of liability statement;

- a statement to note the location of the original advance healthcare directive;

- a statement in relation to the duration of the advance healthcare directive; and

- a statement of the donor that he/she intends the advance healthcare directive to be effective during any subsequent mental incapacity.

We have provided a specimen advance healthcare directive at the appendix to our submission which incorporates our suggestions above.

As provided for under Head 4 Sub-Head 5, we agree that the advance healthcare directive should be witnessed by two persons who have reached the age of 18 years. However, we consider that both witnesses should be independent persons and that the formalities required to execute an advance healthcare directive should be similar to the formalities provided for the execution of Wills under Section 78 of the Succession Act 1965.

5. **Where should an advance healthcare directive be kept to ensure that their existence is known about and they can be readily accessed when required?**

Given the nature of advance healthcare directives it is possible that details of same may be required urgently, for example in a road traffic accident scenario. In such cases, there may be delays arising in contacting a next of kin/general practitioner/solicitor. For this reason we would recommend that a central electronic register be created which would contain a list of advance healthcare directive executed and relevant details. Given confidentiality concerns, we would recommend that the full register should only be accessible by healthcare professionals.

Limited access to the register by password only could be provided to the individuals who create an advance healthcare directive and their solicitors. We consider that such access should be limited to the information relating to that individual's advance healthcare directive only and they should not have access to the full register.

We would also recommend that a statement detailing the location of the original advance healthcare directive should be contained within the body of the advance healthcare directive. This would facilitate any party who may have been provided with a copy of the advance healthcare directive to locate the original if required.

6. **What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?**

If a central electronic register for advance healthcare directive is created it should be possible to ensure that healthcare professionals have access as required. It would be important to ensure that healthcare professionals have easy access to the register particularly as they may require the information in urgent circumstances.

In addition, we would recommend that a copy of the advance healthcare directive be retained by the solicitor and/or the general practitioner who signed the statements on behalf of the individual at the time the advance healthcare directive was put in place. It would be helpful if details of the existence of an advance healthcare directive could be indicated on an individual's driving licence and/or organ donation card which should put healthcare professionals on notice that an advance healthcare directive has been put in place by the individual.

7. **The provisions enable an individual to make legally-binding refusal of treatment in an advance healthcare directive. However, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process.**

In our view it will be a matter for the medical professionals involved to give appropriate consideration to any requests for treatment in an advance healthcare directive, which cannot in any circumstances be legally-binding. We would presume that any such requests for specific treatment that are made contemporaneously by a patient who has capacity and is able to express his wishes, would be considered by the attending medical professionals, and we would expect that the attending medical professionals should equally take into account any such wishes that are made in an advance healthcare directive, albeit that it would appear to be much more difficult for those specific wishes to be accurately expressed in advance, without the patient necessarily knowing the circumstances in which they will find themselves. We do not see that the principle of autonomy confers a right on the individual to decide for him/herself that they should receive specific treatment, if the medical opinion is such that the treatment is unsuitable or unnecessary, and we are of the view that any wishes expressed by a patient in any circumstances on this issue should be given appropriate weight as the medical practitioners involved may determine. We agree that the Code of Practice should include guidance on how treatment requests should be handled, in recognition that they cannot in any circumstances be legally-binding.

8. **Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?**

We are of the view that it would not be preferable that separate documentation should be used for the different types of advance healthcare directive, whether dealing with mental healthcare or general healthcare. We believe that having separate documentation can lead to confusion and make the system more difficult for clients to understand. It is notable that the form of enduring power of attorney that has been broadly used since 1996, and is to a large extent the form that will be used in the future under the Assisted Decision-Making (Capacity) Bill 2013 when enacted enables donors to appoint attorneys to deal with their financial affairs and/or deal with personal care decisions, and therefore encompasses two very different forms of subject matter. We would consider that it would be appropriate for a single form of advance healthcare directive to deal with mental healthcare decisions and general healthcare decisions. This might best be dealt with through using separate

schedules or sections within the form of advance healthcare directive if a standard form is adopted and used by the individual.

9. **What do you think the role of the patient-designated healthcare representative should be? Should the representative's role be limited to that of interpreting the individual's advance healthcare directive? Should the representative have a broader role to advise as to what the individual's will and preferences regarding treatment are likely to be?**

We are of the view that the patient-designated healthcare representative's authority to make decisions on behalf of an individual should be as broad or as limited as the individual executing the advance healthcare directive directs. The advance healthcare directive could be limited to merely being aware of the existence of the advance healthcare directive and making others aware of its existence. However, given the very serious implications of an authority to refuse life sustaining treatment on behalf of an individual, such an authority should be precise and explicit as to the circumstances in which it is to apply. This will provide better protection to both the individual and the patient-designated healthcare representative.

If the advance healthcare directive is specific and clear as to the particular decision and circumstances under which it is to apply and there is no doubt about the validity of the advance healthcare directive then the representative's role should be limited to notifying the healthcare professional of the existence of the advance healthcare directive and seeking compliance with the directive. If the advance healthcare directive is specific and applies to the particular circumstances in question then the representative should be prevented from overriding any such direction unless the donor's subsequent actions were contrary to this direction. The legislation should provide for criminal sanctions if a patient-designated healthcare representative knowingly contravenes an advance healthcare directive.

The representative should be granted the power to enforce the advance healthcare directive, on behalf of the patient, if the directive is subsequently challenged by a family member or healthcare professional.

It should also be included in the legislation that a healthcare professional should be obliged to liaise with and discuss the treatment options with the representative even if sufficient clarity in the directive and no question regarding validity. This should also apply regardless of how limited the representative's authority is under the advance healthcare directive. This might highlight any possible doubts surrounding the directive and any subsequent actions taken by the donor, which were contrary to the directive.

The appointment of a patient-designated healthcare representative should be strongly encouraged, if not a requirement, for the creation of a valid advanced healthcare directive. The benefit of appointing a patient-designated healthcare representative should not be overlooked. If there is any doubt or ambiguity surrounding a patient's advance healthcare directive, there is proposed provision to allow the matter to be resolved informally between the family, the healthcare professional and the representative and ultimately the Court will have to decide if agreement can't be reached. This could result in a decision being made, which is contrary to the patient's direction and original intention. However, if a patient-designated healthcare representative is appointed and given specific authority to make decisions on behalf of the incapacitated person then this will reduce or eliminate the need to make a Court application. The appointment of a representative will also be particularly relevant in relation to consideration to be given to treatment requests stipulated in a directive.

An advance healthcare directive only applies when an individual who made the directive subsequently lacks capacity to make an informed decision regarding their healthcare treatment. The functional test for capacity should be applied and consideration should be

given to extending the capacity of the patient-designated healthcare representative to that of an assisted decision maker or co-decision maker in circumstances where the patient has limited capacity and in line with the other provisions under the Assisted Decision Making Capacity Bill 2013.

If an advance healthcare directive is subsequently held to be invalid, based on procedural grounds, then there should be provision in the legislation to allow for the views of the patient-designated healthcare representative to be considered or for the Court to take into consideration the representative previously nominated, in the subsequent appointment of a decision making representative.

10. **What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?**

We agree with the proposal that the advance healthcare directive should be in writing, particularly where it includes a direction to refuse life sustaining treatment. The authority granted to a representative to refuse life sustaining treatment should be specific to ensure it is upheld and applied in the correct circumstances. The legislation should restrict a representative from being a witness to the execution of an advanced healthcare directive. The advance healthcare directive should include statements from both a legal practitioner and a healthcare professional, similar to those required for the execution of an enduring power of attorney, to ensure that they have assessed and can verify the donor's capacity to execute the directive and that there was no apparent undue influence or pressure to execute same.

If a representative is appointed under an advance healthcare directive then it should be strongly encouraged that the individual discuss his or her will and preferences with the representative. Failing which, if it is not specifically addressed in the advance healthcare directive, then the representative may have to rely on their own will and preferences in making a decision on behalf of an individual, depending on the authority given to the representative under the directive.

A patient-designated healthcare representative might be in a better position to make an informed decision on behalf of the patient, taking into consideration any advances in medical treatments that may not have been available at the time the directive was executed. The legislation should contain a proviso that the patient-designated healthcare representative can only act to the extent that the patient would have been expected to act in that particular circumstance, if the patient had capacity at that particular time.

11. **Are there any other issues relating to advance healthcare directives that should be included in the legislative provisions?**

The proposed legislation provides for the presumption of capacity on execution of an advance healthcare directive, however, the legislation should include safeguards to ensure that capacity is assessed and verified at the time of execution of the advanced healthcare directive by a suitably qualified healthcare professional. This assessment of capacity should also be extended to the revocation and/or alteration of an advanced healthcare directive.

The formality for the execution of an advanced healthcare directive should not be any less than that for the valid execution of an enduring power of attorney, particularly given the serious implications of a decision to refuse life sustaining treatment.

An individual with capacity is entitled to make an informed decision and consent or refuse medical treatment. If there is no requirement under the legislation that an individual take medical advice to ensure their decision under an advanced healthcare directive is an

informed one then this may lead to the subsequent doubt about the validity of the advance healthcare directive. Without the benefit of medical advice the directive might also be unclear or ambiguous, which could ultimately lead to the High Court having to make a decision on behalf of the incapacitated patient, which is contrary to the individual's right to autonomy. The format of the directive could also influence whether or not it is subsequently held to be valid and therefore, we are of the view that a standard format for an advance healthcare directive should be developed.

Finally, it is noted and agreed that a healthcare professional should not incur any civil or criminal liability if acting in good faith he or she was unaware of the existence and content of a directive. However, we are of the view that this provision should include a caveat that the healthcare professional will not incur civil or criminal liability, provided they have taken reasonable steps and/or made reasonable enquiries to establish if a directive exists, except in emergency situations.

Kind regards

Sent by email and accordingly bears no signature

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WF-8040002-1

APPENDIX – SPECIMEN ADVANCE CARE DIRECTIVE

DECLARATION OF ADVANCE CARE DIRECTIVE

I, _____ of _____ on _____ appoint _____ of _____ as my designated healthcare representative to make any and all healthcare decisions for me as set out in the Advanced Healthcare Directive executed by me on [ ] attached at Schedule 1 hereto.

I appoint _____ of _____ to act as my designated healthcare representative if my designated healthcare representative dies or is unable or declines to act or is disqualified from acting as my designated healthcare representative.

I intend this power to be effective during any subsequent mental incapacity of mine.

SIGNED

by [THE DONOR]

in the presence of: _____ Signature

_____
First Witness (Signature)

_____
Print name

_____
Print address

Dated this day of 20[ ]

Second Witness (Signature)

Print name

Print address

Dated this day of 20[ ]

I [the designated healthcare representative] of _____
understand my duties and obligations as designated healthcare representative.

SIGNED

by [the designated healthcare representative]

in the presence of: Signature

Witness (Signature)

Print name

Print address

Dated this day of 20[ ]

I [the alternate designated healthcare representative] of _____
understand my duties and obligations as designated healthcare representative.

SIGNED

by [ ]

in the presence of: _____
Signature

_____
Witness (Signature)

_____
Print name

_____
Print address

Dated this day of 20[ ]

STATEMENT BY REGISTERED MEDICAL PRACTITIONER

I, [ ], a registered medical practitioner, of [ ] hereby state that in my opinion at the time this document was executed, the donor [ ] had the mental capacity, with the assistance of such explanations as may have been given to the donor, to understand the effect of the advance care directive.

Signed _____

Dated this day of 20[ ]

STEP Ireland

STATEMENT BY SOLICITOR

I, [ ], of [ ], hereby state that after interviewing the donor, [ ], I am satisfied that s/he understood the effect of creating the advance care decision.

Signed _____

Dated this day of 20[ ]

STEP Ireland

SCHEDULE 1

ADVANCE HEALTHCARE DIRECTIVE

STEP Ireland

INFORMATION CONCERNING THE ADVANCE HEALTHCARE DIRECTIVE

PART A: EXPLANATORY INFORMATION

An Advance Healthcare Directive is an important legal document. Before signing the Advance Healthcare Directive you should know these important facts:

[We view that "Part A: Explanatory Information should explain provide comprehensive information to the donor creating the Advance Healthcare Directive in a manner similar to the information provided in Part A of the Prescribed Form of Enduring Power of Attorney. We would envisage this to include the following:

- the effect of creating an Advanced Healthcare Directive to note that a person may be nominated to act on behalf of the donor as their designated healthcare representative;

- a clear statement that an Advanced Healthcare Directive will only operate in the event of the subsequent mental incapacity of the donor and that any medical decisions taken by the donor whilst the donor has mental capacity will take precedence;

- the operational extent of the Advanced Healthcare Directive which should note the scope of medical treatments which may be consented to or to which consent may be refused. In this regard we would view that it would be appropriate to include a specific statement that the Advanced Healthcare Directive cannot be utilised for procedures which accelerate the end of life (euthanasia), assisted suicide or abortion;

- a statement to note that any express wishes of the donor for a treatment request are not legally binding but such requests will be considered by their physician;

- explain the role of the designated healthcare representative and that the designated healthcare representative should be a person whom the donor trusts. Where any persons are specifically precluded from acting as a designated healthcare representative this should also be detailed;

- information for the donor on appointing an alternate designated healthcare representative;

- information for the designated healthcare representative to outline the extent of their role and duties;
- information on how the Advanced Healthcare Directive may be amended or revoked;
- information on who may not act as a witness to the Advanced Healthcare Directive; and
- any other relevant explanatory information.]

PART B: ADVANCE HEALTHCARE DIRECTIVE

1. Appointment of designated healthcare representative(s)

I, [the donor], of [ ] born on [ ] appoint:

Name: [ ]

Relationship: [ ]

Address: [ ]

Telephone No: [ ]

as my designated healthcare representative with

*general authority to act on my behalf to make any and all health care decisions for me

or

*with authority to do the following on my behalf.

2. Limitations

Limitations on the authority of my designated healthcare representative are as follows:

[ ]

3. **Treatment Decisions [additional treatment decision sections to be included as appropriate]**

   In the following circumstances:

   _____

   _____

   I consent / refuse consent [one option to be struck out as appropriate] to the following treatment:

   _____

   _____

4. **Waiver of Confidentiality of Medical Records**

   [We view that a statement should be included to the effect that in the event of the subsequent mental incapacity of the donor that his/her physician is authorised to release any information relating to the health and treatment of the donor to the designated healthcare representative subject to any limitations contained in the Advanced Healthcare Directive].

5. **Release of Liability**

   [We view that it may be appropriate to include a release of liability for the designated healthcare representative, physician, medical institution, or any other party which may be involved in carrying out the wishes set out in the Advance Healthcare Directive provided that they at all times acted in good faith and had taken all reasonable steps to adhere to the wishes of the donor where practicable].

6. **Appointment of alternate designated healthcare representative(s)**

   If my designated healthcare representative is unable or declines to act or is disqualified from acting to make health care decisions for me, I designate the following person(s) to serve as my designated healthcare representative to make health care decisions for me as authorised by this document, who shall serve in the following order:

First designated healthcare representative:

Name: [ ]

Relationship: [ ]

Address: [ ]

Telephone No: [ ]

Second designated healthcare representative:

Name: [ ]

Relationship: [ ]

Address: [ ]

Telephone No: [ ]

7. Location of Documents

An original of this document is kept at [ ].

8. Duration

I understand that this Advance Healthcare Directive exists indefinitely from the date I execute this document unless I establish a shorter time or revoke this Advance Healthcare Directive. If I am unable to make health care decisions for myself when this Advance Healthcare Directive expires, the authority I have granted my designated healthcare representative continues to exist until the time I become able to make health care decisions for myself.

9. Statements of the Donor

I have been provided with a Disclosure Statement at Part A of the Advance Healthcare Directive explaining the effect of this document. I have read and understand the information contained in the Disclosure Statement.

I intend this power to be effective during any subsequent mental incapacity of mine.

I sign my name to this Advance Healthcare Directive on this the [ ] day of [ ]

Donor Signature

SIGNATURE OF FIRST WITNESS

Witness Signature: [ ]

Print Name: [ ]

Date: [ ]

Address: [ ]

SIGNATURE OF SECOND WITNESS

Witness Signature: [ ]

Print Name: [ ]

Date: [ ]

Address: [ ]