NHI Submission

on

"Draft General Scheme for Advance Healthcare Directives for Incorporation into the *Assisted Decision-Making (Capacity) Bill 2013*"

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NHI is the representative body for the private and voluntary nursing home sector and speaks with a unified voice both for its members and the nursing home sector.

NHI provides a truly representative voice for the residential care sector to the Government, the Health Service Executive (HSE), Health Information and Quality Authority (HIQA), the National Treatment Purchase Fund (NTPF) and in communicating with the general public.

NHI is a professional, national organisation representing the nursing home sector at all relevant, statutory and non-statutory forums with a view to promoting the aims and objectives of the organisation and its members.

Working on behalf of small, medium and large providers, our aim is to promote high standards of care in the private and voluntary sector and create an environment in which nursing homes can deliver the high quality care that communities require and deserve.

In order to do this, NHI embraces the challenges for the short, medium and long term. NHI strives for, and is committed to, excellence in residential care within a commercially viable environment.

General Comments:

NHI welcomes the introduction of specific legislation pertaining to the making of and consideration of Advance Healthcare Directives. This is an area of increasing public importance and is a beneficial tool to enable persons to highlight their will and preferences for future healthcare decisions which may arise. This is a fundamental way to enable persons to exercise their autonomy and human rights. In addition legislating for this area will remove any ambiguity which may otherwise arise for healthcare professionals presented with a Directive.

Both the Assisted Decision-Making (Capacity) Bill and the Advanced Healthcare Directives section will require a significant change to the way in which healthcare is currently provided. Given the rights based approach and the legal requirement for presumption of capacity it is essential that both the general public and in particular health care professionals (across all care sectors) receive comprehensive dedicated information and education on the Bill to enable policy and practice change at an individual level.

The Code of Practice will be essential to ensure the Bill is interpreted and applied consistently across the health service. It is recommended that this Code is also developed within a framework which allows for public consultation and representation from all health care professionals/ sectors.

Specific Comments:

The following comments are structured as responses to the specific questions for consultation provided in the accompanying discussion paper:

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?**

NHI acknowledges that individuals now have much wider access to medical information than was previously the case as outlined in the explanatory memorandum of Head 3 Subhead 2. However there are vast differences between the sourcing and collection of medical information and the subsequent distilling and understanding of such information. It should also be noted that there are many sources of inadequate or incorrect medical information which is available via the internet. NHI therefore believes that there should be a mandatory requirement for individuals to discuss their intended Advance Healthcare Directive with their GP in the first instance. This would also assist with the test for capacity at the time the Directive was made by the individual should there be any challenge to this at a subsequent date.

Given also that there are specific provisions in the Bill which may deem the Directive to be invalid should it not be completed correctly or in full NHI would recommend that persons seek advice from a legal professional to enhance the validity of their Directive. This could be recommended in the Code of Practice but may not require to be mandatory if there is a standardised form and an unambiguous and clearly defined Code of Practice which is user-friendly and which guides individuals in the correct completion of such a form.

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)?**

In order to enhance the validity of a Directive and to ensure there is no ambiguity in the documented will and preference of an individual (who may or may not be experiencing changes to their personal health status) it is recommended that a mandatory time period be introduced. NHI believes a time period of 2 years would be too onerous for the general population whereas in a time period of 10 years the individual making the Directive may experience many changes to their health or personal circumstances which would require a review of their Directive at an earlier juncture. It is therefore recommended that a mandatory time period of 5 years would be more reasonable.

It is unclear however what would happen in the event that an individual with a Directive either has not reviewed their Directive or has lost capacity at the prescribed mandatory time period for review. It is suggested in the event that an individual has lost capacity that the most recent Directive therefore remains valid unless it can be deemed invalid by any of the other methods outlined in the Bill.

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

Yes a standard format would be beneficial both to the individual making the Directive and for health professionals who may be required to enact the Directive.

In particular for the individual making the Directive, the standardised form could provide prompts for decision making and the documentation of particular refusals of healthcare/ treatment which may otherwise not be considered e.g. if the individual intends the Directive to apply in pregnancy. A standardised form could also ensure that particular elements which are required to validate the Directive are also included hence reducing the need to seek legal advice in this case e.g. names, signatures and status of the two witnesses with a declaration to the fact that one is not a member of the person's family and are not entitled to any part of the person's estate as described under Head 4.

For the health professionals who may be required to enact a Directive, NHI suggests that a standardised format would assist in the recognition of a valid Directive and would enable greater understanding of the circumstances in which the decisions documented are to be followed.

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

It is suggested that the contact telephone number be added to the details required for the person's general practitioner and any nominated patient-designated healthcare representative/advocate? or attorney so that healthcare professionals in an emergency situation can make contact immediately.

i. the name, date of birth and address of the person making the advance healthcare directive,
ii. the name, address ***and contact telephone number*** of that person's general practitioner or other healthcare professional,
iii. the name, address ***and contact telephone number*** of any nominated patient-designated healthcare representative and/or any attorney appointed through an enduring power of attorney.

In addition the following information is recommended to be included:

iv. A section to document Treatment Refusals (to include information such as decisions on Do Not Attempt Resuscitation; Artificial nutrition and hydration; Artificial Ventilation, etc (not an exhaustive list) and the particular circumstances in which these refusals are intended to apply)
v. A section to document Treatment Decisions
vi. A section to indicate whether it is intended that the Directive applies should a woman become pregnant including an area to highlight specific deviations from previously documented decisions
vii. The power conferred on the patient-designated healthcare representative

viii. The name, address and contact number of any alternate patient-designated healthcare representative

ix. The name, date of birth, address and signatures of each of the two witnesses to the Directive

x. A section for any alteration to the Directive including the name, date of birth, address and signatures of each of the two witnesses to the alteration.

In order to enhance the use of Directives and not impact on the validity and applicability of documented decisions outlined in the explanatory memorandum head 4: subhead 4 it is recommended that any proposed standardised form or Code of Practice is reviewed by the National Adult Literacy Agency with a view to achieving plain English approval.

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

It is recommended that the original Directive be held by the person making the Directive with a copy held by both the person's General Practitioner and Patient-Designated Healthcare Representative.

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?

There could be a requirement placed on General Practitioners to alert local acute services where they are aware a Directive exists or if a Directive is altered. This could be performed on a continual basis or at the point of referral to acute services.

There may be merit in establishing a central registration system which places the onus on the person making the Directive to register that one exists. This could then be checked by health care administrative staff should the person requiring healthcare treatment not have capacity/ the ability to communicate.

7. The provisions enable an individual to make a 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?

A section could be included on a standardised form for this information or as an appendix to a standardised form (which includes that this information is not 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?

Given that there is a presumption of capacity for persons making a valid Directive this should apply to persons with or without a mental illness and as such their documented will and preferences should not be differentiated. There is a provision under Head 4 to clearly specify the treatments to be refused and the circumstances in which the treatment refusal is intended to apply – this would therefore provide clarity for mental healthcare refusals where documented.

Furthermore there may be some situations where the refusal of physical healthcare as documented in a Directive may not have the consequences envisaged and therefore lead to the same situation presenting at a subsequent date. It is therefore presumed that the Directive should remain valid on this subsequent occasion.

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?

It is suggested that the patient-designated healthcare representative's role should be to interpret the Directive only. Having a broader role may put un-necessary stress on the representative at an already emotive/ stressful time particularly where the designated representative is personally involved or related. Their emotional attachment in this case may skew their decision making ability and this therefore may not adequately reflect the will and preferences of the person concerned.

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?

Other motives may exist which could influence the designated representative's decision making ability such as an entitlement to the person's estate or a change in the relationship. Having a prescribed timeframe for the review of Directives which includes the need to review the designated representative may assist in this process.

The Code of Practice should also recommend that the person making the Directive clearly explains the intent behind his/ her documented decisions.

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

Given that there is a presumption of capacity the legislation should clearly outline the test(s)/ evidence required to make a Directive invalid, particularly where the Directive

was made in the absence of a health professional/ legal advice who could attest to capacity.

Where an individual revokes their Directive verbally, the process for the witnessing and documenting of this in that individual's healthcare record should be outlined in the legislation.

It is currently unclear if the patient-designated healthcare representative and an attorney appointed under an enduring power of attorney can be one and the same person.

We thank you for the opportunity to make our submission on the draft guideline.

Nursing Homes Ireland
7th March 2014