Bord Altranais agus
Cnáimhseachais na hÉireann
Nursing and Midwifery Board
of Ireland

14 March 2014

Nursing and Midwifery Board of Ireland Submission

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

The Nursing and Midwifery Board of Ireland (NMBI) appreciate the opportunity to contribute its view to the Department of Health's consultation on the Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013. NMBI acknowledges the significance of broad public consultation regarding the complex ethical, legal and professional healthcare issues surrounding advance healthcare directives and relied upon the expertise of the members of the Ethics Committee to draft this response.

The 11 questions posed in the DOH public consultation document frame the NMBI's submission.

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?

NMBI believes the implications of an advance healthcare directive (AHCD) are serious and long reaching, thus advice and guidance should be sought. Informed decision making by the person would best be facilitated by professional advice. It may be challenging for a person and their family to understand the consequences of preparing an AHCD and what is involved in making decisions regarding treatment and non-treatment actions. There may be differences of understanding between the lay person and the professional as to what is meant by clinical measures. An example is the term as resuscitation which may represent cardiopulmonary resuscitation (CPR) to the lay person while a professional may interpret it to include intravenous fluids and blood products for volume resuscitation, assisted ventilation in addition to CPR. As an AHCD is to be recognised as a definitive legal document, advice relating to the legal context of its application (and possible withdrawal) is necessary to fully support the person in making informed decisions for care in the event that they lose capacity. NMBI also considers that the persons serving as the patient designated healthcare representative may also need professional assistance in understanding and agreeing to serve in this important role. It is also important that the person receives advice about revising or changing an AHCD at a later point in their life if so desired. If professional advice forms part of the legal requirements for AHCDs it needs to be accessible and affordable which has resource and costing implications.

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)?

The provisions for AHCD should include a specific mandatory time period for review by the person (with notification to the patient designated healthcare representative). In considering what that designated time frame should be issues such as potential advancements in healthcare and technology developments with their associated implications, the half-life of knowledge in the field, balanced with

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the feasibility of the directions within the AHCD should be examined and discussed. Extant resources and availability of care and treatment are also influencers for the person's beliefs and consent for treatment. A minimum time period should be determined based on these issues. NMBI recognises that a person at one stage of their life may view healthcare treatment and AHCD differently at another age and providing a designated period of review supports possible changes in preferences.

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

A national standard format should be developed for AHCDs. This would give clarity and direction to those fulfilling the directive on behalf of the person, recognising the continuum of healthcare delivery settings (e.g. hospital networks, community care areas/primary care networks and the immediate/time dependent situations when it may need to be activated. Having a standard format would also make it easier to have a national digital portal where related documents, guidance and examples could be housed for all stakeholders the public and professions alike. This is especially important for education and training about AHCDs. The communication of information via other media could also be consistent if a standardised format was used.

NMBI acknowledges the significant work undertaken by the National Council of the Forum on End of Life with its *Think ahead, Speak for Yourself Form* in relation to the development of its comprehensive form addressing advance healthcare directives and other critical facets of life (e.g. legal and financial affairs, preferences for after death care).

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

There are two aspects to as to what should be contained in a standard format for AHCD. The first aspect involves the education and development of knowledge for lay persons and practitioners about AHCDs to include:

- an explanation of what is meant by AHCDs,
- reference to the relevant legislation,
- overview of the process
- benefits and important considerations for drawing up an AHCD
- eligibility determinants for making an AHCD (e.g. age and capacity)
- explanation of terms (e.g. ventilation, feeding tubes etc)

Consideration could be given to a questions and answers format for presenting these topics.
The second aspect addresses the specifics of the document information to include:

- instructions for completion with sections headings explaining the layout of the document
- standard personal and key information and containing next of kin, Patient Designated Healthcare Representative, GP, attorney (enduring power of attorney) contact details
- indications and decisions for treatment refusal
- preferences for care
- how to or where to store the document and who to inform of its existence
- review date – if mandatory and if this is prescriptive in the legislation – guidance to staff if an AHCD has not been reviewed re: expiration or invalidation concerns

NMBI recognises that the draft legislation refers to the development of a Code of Practice to accompany the scheme so it may be more appropriate to include some of the above elements in the Code in more specific detail than in the actual form for the AHCD.

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

This point needs to be debated, with consideration of the Government's e-health strategy and the *Health Identifiers Bill* and how these could contribute to a national portal. Could there possibly be a central repository for holding AHCD? Significant digital infrastructure is needed to support this. In the absence of this, other options include:

- with the person's personal documents
- included as an attachment with the person's admission/information sheet when the person enters the healthcare system – e.g. GP medical records, hospital admission, residential care facility, public health clinical notes There could be a prompter on the admission sheet asking if an AHCD exits, with copy required for records
- held by the patient designated healthcare representative
- held by next of kin/enduring power of attorney
- legal advisor
- if a national mechanism for storing was possible this should be linked with a national indicator that one exists – such notice placed in someone's home or in their wallet or purse – similar to organ donor cards.

Whatever mechanism is chosen it needs to be user friendly and maximize the potential for the information to be appropriately and confidentially stored and yet accessible as the need arises.

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?

The options put forward in question 5 should be considered as additional measures to facilitate healthcare professional' awareness that an AHCD exists. At a minimum, it would be important that a patient's GP and any other relevant medical teams, consultant or personnel who are likely to have a role in carrying out an AHCD should be informed in advance where and when possible. NMBI believes this is a shared responsibility between the person/patient who makes the AHCD and the patient designated healthcare representative to inform the relevant healthcare professionals. Provisions for persons travelling away from their usual local context would need attention. As suggested above, the use of an identity card/alert bracelet on the person could be considered.

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?

The decision-making process can be viewed at two junctures in time, one is at the time the person is making an AHCD and thinking about what treatments they would like in the future and the second time point occurs at the time when an AHCD is being actioned. In order for persons to fully understand treatment options and support them in their autonomy for decision-making clinical or legal guidance should be available to the person (and Patient Designated Healthcare Representative) to support them in this exercise. At the point of implementation a robust structure detailing the process of decision-making must be constructed. For example this process may include the stakeholders who should participate, the medium for the process e.g. meeting, minimum timelines and who to refer to in situations where conflict arises for treatment requests. Healthcare professionals involved in these processes should deliberate the following as it relates to the treatment requests: best available evidence based practice; available alternatives, the minimum standard of care expected (e.g. basic care). Respect of the rights and dignity of the person, their family **and** the healthcare professionals caring for the

person must remain paramount in these circumstances. Expert medical/clinical advice and legal input may be necessary to inform these decisions.

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?

NMBI believes the format and documentation used for both types of directives (mental healthcare and general healthcare) should be different to reflect the particulars of care and treatment planning. However the processes should probably be the same to reflect consistency and fairness of decisions and actions for AHCD regardless of the individual's condition and care setting. Can it be assumed that the AHCD for general healthcare is predominantly used once in general healthcare as this may not be the case with chronic or life limiting illness which may be characterized by exacerbations and possibly remissions? An example of such a condition is those suffering from chronic obstructive pulmonary disease. Circumstances where co-morbidities of mental health illness and general illness may exist should also be examined in the context of this question.

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?

The patient designated healthcare representative role should be focused on acting as the person's advocate, to represent the views and wishes of the person as denoted in the AHCD, ensuring that the AHCD is taken into account for healthcare decisions. The patient designated healthcare representative serves as a source of information for the healthcare team, most importantly notifying relevant parties of the existence of an AHCD. There should be clear guidance on the role and its limits to protect the patient and inform others (e.g. family members, significant others) of what exactly the role entails. Perhaps the proposed Code of Practice guidance will address this point.) NMBI notes that Head 7 Subheads 2 and 3 does refer to some aspects of the role. It is a difficult question as to whether the representative should have a broader role to advise about what the person's will and preferences for treatment would be. A broader role for the representative for advising about the individual's will and treatment preferences would necessitate the representative and person having comprehensive discussion about preferences. The representative could be put in the position of making subjective interpretations of the patient's decisions if such pre-emptive informed discussions did not take place and/or were time bound/outdated.

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?

Head 7 of the Scheme provides basic criteria as to who can be nominated as a patient-designated healthcare representative and includes prohibitions for this nomination (Subhead (2) (b) and (c)). Significant ethical responsibilities are represented in this role, thus it may be beneficial to give some overview of these responsibilities in the proposed Code of practice and/or as part of the guidelines for making and AHCD. This information may facilitate open discussion amongst the involved parties (e.g. patient, family, proposed representative etc) in determining suitability for this important role. Additional safeguards might involve:

- Signature of the patient-designated healthcare representative and date to be included on the AHCD which should be witnessed. Head 4 provides for general information which does not include the representative's signature.
- Requirement that the patient designated healthcare representative must be contacted
- Existing contact/relation with the person involving review of their perspective and wishes
- Regular review of for up to date contact information
- Consideration of safeguards regarding the capacity of the patient designated healthcare representative to serve in this role – given changes over time and health circumstances themselves for the representative.

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

While there is reference in the legislative provisions to the establishment of a Code of Practice it is not clear what this Code will be about. In addition, NMBI proposes that there should be greater clarity with regard to defining basic care - what does it mean to the lay person versus the healthcare professional. (This issue was previously identified with the Law Reform Commission's consultation in 2009.) And it remains a topical concern of moral distress for nurses providing care in end-of-life situations, especially in dealing with refusals of basic care. There is potential for conflict with perceived and actual professional and ethical responsibilities for respecting the autonomy of the individual with maintaining dignity and providing comfort.

In view of cross border mobility of persons and their access to healthcare the legislation should also address the issue of respecting AHCDs of individuals from other jurisdictions, provided they meet the criteria set for AHCDs in the Republic of Ireland.

Conclusion

The introduction of a legal framework for advanced healthcare directives is greatly welcomed by the NMBI. NMBI acknowledges that this topic may be ethically challenging and emotive to the public and also to healthcare professionals. The challenges and opportunities associated with the introduction and operationalisation of the proposed scheme should be openly debated with all stakeholders to ensure a robust, responsive structure is established to support the autonomy of the individual. NMBI believes that with the legislative framework being constructed for AHCDs there is a requirement to provide a comprehensive education programme to inform healthcare professionals about the legislation, the future Code of Practice(s) to develop and ensure knowledge and promote competency development. It is critical that healthcare regulatory bodies' codes of professional conduct and ethics, and regulatory guidance encompass these long awaited provisions. Thus NMBI looks forward to learning of the outcomes of this important public consultation.

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