IRISH MEDICAL ORGANISATION
Ceardchumann Dochtúirí na hÉireann

Irish Medical Organisation

Submission to the Department of Health on

The Draft General Scheme for Advance Healthcare Directives for Incorporation in to the Assisted Decision-Making (Capacity) Bill 2013

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Introduction

The Irish Medical Organisation is pleased to make a submission on the Draft General Scheme for Advance Healthcare Directives for Incorporation in to the Assisted Decision-Making (Capacity) Bill 2013 to the Department of Health as part of consultation activities for the preparation of legislation. The IMO acknowledges that the government intends to develop the law on assisted decision making and accepts the invitation to submit our views regarding the issue.

While advance care-planning is an important part of overall care, and recognized as such both in practice and the ethical guidelines of the Medical Council, there has been increasing professional concern over the utility of advance care directives[1] , described by the majority of ICU staff in one US study as 'useless'[2]. Indeed it is quite likely that for the vast majority of patients who are likely to develop impaired capacity sufficient to interfere with even supported decision-making that **it will never be possible to legislate for – or to legislate away – the enormous complexity of individual decision-making as the end of life approaches, and there is a real risk that legally-binding directives may serve as an obstacle rather than a support to good end-of-life planning.**

An advance care plan, on the other hand, can provide valuable insights into their pre-morbid views and wishes at a time of great distress for the patient and their family. The Medical Council[3] supports this by stating that:

An advance treatment plan has the same ethical status as a decision by a patient at the actual time of an illness and should be respected on condition that:

- *The decision was an informed choice, according to the principles of informed consent.*
- *The decision covers the situation that has arisen, and*
- *The patient has not changed their mind.*

However, the manner in which an advance care plan is created is also an issue that needs consideration. It is essential that a patient is fully informed of the consequences of their actions and is clear on exactly what advanced wish they are creating.

It is very important to stress that the creation of an advanced healthcare plan is a complex procedure. It is dangerous to assume that merely transcribing an agreement will be sufficient. In certain situations, advance care directives may only offer limited benefit as there are some decisions that are unforeseeable. The potential danger with many formalized advance care plans is that they are generally negative in nature tending to focus on non-treatment options. Patients who only focus on the non-treatment options may misjudge all the choices available to them and fail to grasp the complexity of late-life care.[4] As such, persons wishing to create an advance care directive should be made aware of all options available to them.

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[1] Fagerlin A, Schneider CE. Enough. The failure of the living will. Hastings Cent Rep. 2004 Mar-Apr;34(2):30-42. http://www.thehastingscenter.org/pdf/publications/hcr_mar_apr_2004_enough.pdf

[2] Gutierrez KM. Advance directives in an intensive care unit: experiences and recommendations of critical care nurses and physicians. Critical care nursing quarterly 2012; 35: 396-409

[3] https://www.medicalcouncil.ie/News-and-Publications/Publications/Information-for-Doctors/Guide-to-Professional-Conduct-and-Ethics-for-Registered-Medical-Practitioners.pdf Accessed 03/03/14

[4] O'Neill, "Towards Realistic and Flexible Advance Care Planning", The Irish Medical Journal, February 2014, Vol. 107 (2)

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?**

The IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive. Informed consent is a key principle of medical practice and patient-centred care as laid out in the Medical Council Guide to Professional Conduct and Ethics for Registered Medical Practitioners and in the HIQA National Standards for Safer, Better Healthcare.

Under Head 3 Purpose and Guiding Principles - "An advance healthcare directive should be made on the basis of informed decision making" is also a key principle that will apply to this Act. As such it is essential that an individual obtains advice from a medical professional before preparing an advance healthcare plan. Therefore it is important that advanced care plans:

a) are planned at a point where the patient has some experience and knowledge of the likely conditions;
b) are developed with a healthcare professional who has in-depth knowledge of the relevant conditions - Given that the most likely scenario for impaired decision-making capacity in clinical practice arises from the two key illnesses of later life, dementia and stroke, ideally the healthcare professional should have some specific training in gerontology and dementia care;
c) include the possibility to request positive, pro-active care as well as treatment refusal;
d) that the patient is offered the possibility of making the advance care plan in conjunction with a trusted family member or friend.

GPs and other doctors may not have the necessary expertise to carry out such a role. Specific training will be required both as part of undergraduate training and as part of on-going CPD arrangements. In addition the preparation of an advanced care plan will require substantial practitioner time and resources.

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 IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive. Given the extensive literature on change among patients who make advance care plans, the IMO believes that there should indeed be suggested periods within which an advance care plan ought to be reviewed and the factors to be taken into account by health care professionals where it has not been reviewed regularly. As such, it is advisable that patients review their advance care plans periodically. The maximum time frame in which an advance care plan should be reviewed is every 2 years. However in certain common conditions the level of capacity will alter in the intervening period of the recommended two year review - rendering the review document subject to question .

The whole process of capacity will have to be completed on each review - not merely reviewing the original advance care plan. Thus a whole new document / process may have to be completed each two years or whatever interval is deemed necessary. Again this may require substantial practitioner time and resources.

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

The IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive. Given the relatively unformed state of science of operationalizing advance care plans, and the fact that there are already a number of instruments available to support the making of advance care plans, the IMO recommends that this area should be studied closely in the coming years with a view to teasing out common elements that would inform best practice. It is necessary that any advance care directive is as clear and precise as possible but also allows for innovations in care, signals of resistance to the planned care from the patient, and unexpected circumstances not envisaged in the care plan.

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

The IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive. Should a patient wish to create a legally binding agreement a standard format should include the following essential elements that should be signed by the patient:

a) As with a consent form the patient must be required to sign a form agreeing that they understand their options and that the decision made by the patient was voluntary. Doctors are required to include in their patient records the options outlined to the patient as well as any documentation given. This should also be included in the consent form;
b) Similarly if the patient chooses to involve a trusted family member or friend, he/she should be encouraged to sign the form agreeing that they understand their options and that the decision made by the patient was voluntary.;
c) That the advance care directive was valid at the time of writing and exempting the physician from liability if the directive is altered or revoked without informing the physician;
d) Given that a treatment refusal in an advance healthcare directive is intended to be legally-binding, it is essential that the directive state in clear and unambiguous terms the specific treatments to which the refusal(s) relates and also the situations in which the treatment refusal(s) is intended to apply. It is advisable that patients review their advance directives periodically. In order for this to be successful, the IMO would like to stress the importance of the public being made, and kept, aware of this legislation.
e) A mandatory time limit for review.

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

The IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive. The IMO believes that an advance healthcare plan should be kept with the GP, circulated to treating specialists, and a copy with the next of kin, attending doctor – or residents file in a Nursing Home, in order to ensure the safekeeping and ease of access of the document.

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 IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive. It is not clear that a central registry would be a practicable option for advance care plans. Linking up of electronic patient records may facilitate transmission of advance care plans.

Again a copy of the advance care plan should be kept with the next of kin, attending doctor – or residents file in a Nursing Home.

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 IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive and should provide for patients to make specific positive informed treatment requests provided they are clinically indicated for that patient. However clear guidance will be required in the event that requested treatments are not available for reasons such as cost or suitability, although such decisions should be similar in nature to those with patients with preserved capacity.

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?

The IMO would advise patients to make an advance care plan rather than a legally-binding advance care directive.

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 role of the patient-designated healthcare representative should be limited to that of interpreting the individual's healthcare plan. Where the care of the incapacitated patient falls outside the scope of the plan, doctors will act in the best interest of their patient and in consultation with the patient-designated healthcare representative. The promotion of the concept of a co-decision-maker is preferable to that of a health-care proxy, as a subtle but important emphasis is placed on assisted decision-making, which extends autonomy.[5]

[5] O'Neill, "Towards Realistic and Flexible Advance Care Planning", The Irish Medical Journal, February 2014, Vol. 107 (2) - Even in late dementia, a patient may make preferences clear by pulling out a tube or line, or by insisting in drinking despite a swallow disorder which means that liquids may spill into the lungs: what is most important is that the care staff know how to interpret and support these decisions.

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?

A situation may arise where a patient designated healthcare representative contests the decision made in the advanced care plan – contesting either the capacity of the patient to make that decision at that time or they may contest that the patient changed their decision. To avoid such situations the advanced care plan should be prepared where possible and desired in conjunction with the patient-designated-healthcare representative. Again it is essential that the plan is as clear and precise as possible but also allows for innovations in care, signals of resistance to the planned care from the patient, and unexpected circumstances not envisaged in the care plan.

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

Physicians and healthcare providers must be protected from liability in the case above where a patient designated healthcare representative contests the decision made in the advanced care plan – contesting either the capacity of the patient to make that decision at that time or they may contest that the patient changed their decision.

Clear guidance for both physicians, patients and patient designated healthcare representatives is required.