Advance Care Directives

Submission from Irish Patients' Association March 7th 2014

"The High Court and Supreme Courts have recognised that a conscious and competent patient has an absolute right to refuse treatment grounded on the concepts of autonomy, bodily integrity and dignity, even if this refusal results in their death."

Advance Care Directives

"Everything has to come to an end, sometime."

L. Frank Baum, The Marvelous Land of Oz

Acknowledgement

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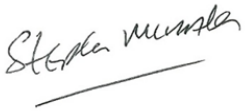

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About Dublin City University

DCU is a young, dynamic and ambitious university with a distinctive mission to transform lives and societies through education, research and innovation. Since admitting its first students in 1980, DCU has grown in both student numbers and size and now occupies a 72 acre site in Glasnevin, just north of Dublin city.

To date over 43,000 students have graduated from DCU and are now playing significant roles in enterprise and business globally. Today, in 2012, DCU delivers more than 120 programmes to over 10,000 students across its four faculties – Humanities and Social Sciences, Science and Health, Engineering and Computing and DCU Business School.

DCU's excellence is recognised internationally and it is ranked among the top 50 Universities worldwide (QS 'Top 50 under 50' 2012). In the last eight years, DCU has twice been named Sunday Times 'University of the Year'.

About the Irish Patients' Association

The Irish Patients Association is not a membership based organisation, it is an independent patient advocacy group, it works in partnership across all boundaries within the health care system, it does not lobby, it advocates. The I.P.A. cares how it conducts its business particularly with Patients, Patient Groups, its industry partners (which means all payers, policy makers and providers of health care) and the media.

We are driven by the experiences of some 500 patient contacts per annum many have had a bad encounter with the Health Care system. These encounters drive us to ensure that "Change and reform in our heath care systems must not be preceded by preventable funerals and injury to patients"

The Irish Patients Association does not advocate for "all" patients nor does it present itself as the voice for all patients; however it is uniquely placed, based on its deep experience of 16 years of helping patients, and or their families and those close to them to find closure on their particular experience and create a space for learning to occur.

This direct contact with individual and collective patient experiences and our involvement within the health care system empowers us to contribute from the patients' perspective in many areas of policy development, regarding patient safety, quality improvement, and community and patient involvement in policy formation and performance monitoring.

The IPA's mission is to continue to help build "safe" patient-centred healthcare in Ireland and share those experiences with our European and other colleagues:

- Realizing active partnerships with other patients' organizations everywhere and that by working together with, health care service providers, education institutions, medication and device manufacturers, researchers and policy makers to achieve this mission.

Pprevious successful projects such as The Global Survey of Patient Groups regarding Hospital Acquired Infections, Clean Hospital Summits I and II, Action against Counterfeit Medicines, With the Irish Department of Enterprise contributed to the EU Security call for FP Agenda items – reflected in *Topic 2010.1.3-2 Tackling counterfeit medicines and related criminal network**s*** , Academic Research on European Charter of Patients' Rights in Ireland, Academic Research on Informing Irish Patients issues direct to consumer advertising , Off label Prescribing "Safety, Patients' Rights, and off label prescribing", Pact For Patient safety for European patients by European patients. 19 Founding signatories from European patient groups - This will be launched in Q4 2014.

Opening Statements

Irish Patient's Association (IPA): Advanced Care Directives

The High Court and Supreme Courts have recognised that a conscious and competent patient has an absolute right to refuse treatment grounded on the concepts of autonomy, bodily integrity and dignity, even if this refusal results in their death.[1]The IPA welcomes this Bill in principle for providing a framework facilitating the exercise of these rights and welcomes the opportunity to share its knowledge of emerging patient needs. The IPA supports a Bill that seeks to limit the role of paternalism in health care delivery by ensuring respect for autonomy and maximizing capacity. The Bill should provide an appropriate mechanism for patients to determine what treatment is acceptable to them when they are no longer competent to make their own decisions. The Bill also provides legal clarity to clinicians about treatment refusal where clinicians had limited guidance[2] in what they perceive as a grey area.[3]Finally, the Bill is timely with an ageing population with many patients continuing to die in health care institutions rather than at home.[4]The IPA stresses that the Bill must be supported by an implementation strategy so that every patient irrespective of their economic, social, cultural, educational, linguistic or religious background can exercise his or her autonomous rights. The IPA submission contains general comments on the Bill, specific comments on particular provisions of the Bill and answers the eleven questions.

[1] See: *In Re a Ward of Court* (No2) [1996] 2 IR 79 and *Fitzpatrick v FK* (No2) [2008] IEHC 104.
[2] See Fennell, Marcus, Saaidin, Sheikh, *"Dissatisfaction with Do Not Attempt Resuscitation orders: A nationwide study of Irish consultant physician practices*" Ir Med J (2006) Jul-Aug;99(7):208-10, see also; McNamee, O'Keeffe, "*Documentation of do-not-resuscitate orders in an Irish hospital*" Ir J Med Sci (2004) 173 2 and O'Brien Æ. O'Keeffe, "*Resuscitation decisions in Irish long-stay units*" Ir J Med Sci (2009) 178:423–425.
[3] McGlade, William Molloy, Timmons, "*Decision-Making in Incompetent Older Adults*: *Clinical, Social and Legal Issues*" (2011) 17 (2) MLJI.
[4] McKeown K, Haase T., and Twomey S, *Resources and Facilities for End-of-Life Care in Hospitals in Ireland: Report 1,* (Dublin: Irish Hospice Foundation, 2010), available at: *www.hospicefriendlyhospitals.net* [last accessed 01/03/14).

General Comments on the Bill

Do Not Attempt Resuscitation Orders (DNARs)

The Irish Patients' Association has two concerns about DNARs and the Bill. First, there is the omission of DNARs from the Bill which is surprising considering the extensive framework for DNARs in the HSE's National Consent Policy (Consent Policy)[5] and discussion of DNARS in the Law Reform Commission's Report on ACD.[6]Second, there is also the potential for conflict between ACD (Advance Care Directives) and DNARs.

ACDs allow patients to express autonomous preferences about future medical treatment, such as consenting to CPR. A DNAR can make a patient's ACD redundant where a clinical team decide that CPR is futile or may cause more harm than good.

In addition, the Bill provides that a patient request for treatment in an ACD is not legally binding. Conversely, a clinical team may decide on a DNAR where they are of the opinion that CPR is not in that patient's best interests. Therefore a clinical team could readily ignore a request for treatment in favour of a DNAR where the two are contradictory. When a DNAR is acted upon by a clinical team, the patient is inevitably doomed as nature takes it course. We are not aware of any legally binding protocols, nor have we come across any in the writings. No one necessarily advocates for the patient. It is a clinical decision made by the clinical team only, Indeed it may be the sole decision of a clinician. They need not inform the patient's family once a DNAR is ordered, however it is recommended as best practice.

[5] See: The Health Service Executive, National Consent Policy (http://www.hse.ie/eng/services/list/3/nas/news/National_Consent_Policy.pdf) as accessed 6.3.14. There has been a shift in recent years away from use of the term "do not resuscitate" and in its place, use of "do not attempt resuscitation" due to the misleading inference that may be drawn from the former that CPR will succeed which is not necessarily the case.

[6] Law Reform Commission, *Bioethics: Advance Care Directives* (LRC 94 – 2009).

The IPA believes the relationship between ACDs and DNARs must be addressed in the Bill. The Bill could adapt the approach of the Consent Policy(5) which places significant weight on the patient's preference in relation to a DNAR, as well as the likelihood of CPR succeeding balanced against the risks of attempting it. The Consent Policy requires that clinicians should consult with patients to determine their preference. Where a patient has the capacity to communicate, the patient's preference as to their family's involvement in decision-making should be respected. Where a patient is deemed to lack the capacity to make decisions, his or her previous wishes should be respected. The Consent Policy requires a patient's preferences to be weighed in the context of the associated risks and benefits of the preferred treatment. The Consent Policy does permit the senior treating clinician to make the final decision on treatment. The IPA suggests that the decision of the senior treating clinician should be reviewed by an independent clinician. Another alternative approach is to adapt the legislative approach of US states to regulate the relationship between ACDs and DNARs. The purpose of this Bill is to place the medical decisions relating to an individual in his/her hands and avoid paternalism in the delivery or non-delivery of health care. Accordingly, the Bill fails in this purpose and should be amended to prioritise the wishes of a patient as expressed under the ACD.

Transforming Legal Theory into Practical Implementation

This Bill provides a statutory framework that seeks to enhance patient autonomy. There is a risk that this framework will remain a theoretical framework unless the Bill contains statutory imperatives in relation to implementation. It is essential that every patient irrespective of their economic, social, cultural, educational, linguistic or religious background can exercise his or her autonomous rights Thus, the IPA proposes:

1. A statutory duty on the Department of Health or HSE to compile an annual report on the operation of the Act and Code of Practice so as to identify any issues arising in practice.
2. The Code of Practice should be put on a statutory footing by way of statutory instrument.
3. The Code of Practice and any standard formats for ACDs should be in plain language and different languages.
4. A statutory duty on the Department of Health and/or HSE to promote and inform patients and clinicians about ACDs and the Code of Practice.
5. A statutory duty on the Department of Health to undertake a five-year review of the Act in order to assess if the Act has enhanced patient autonomy and limited the role of paternalism in health care delivery. The same rationale underpinned the Mental Health Act 2001 which must undergo five-year reviews. However, an interim report on the 2001 Act has shown that paternalism persists.[7]
6. There should be a specialist division of High Court dealing with ACDs where judges receive specialist training because issues surrounding ACDs involve particularly emotive aspects of a person's private and family life. This training ensures that judges are well placed to make educated, experience-based, decisions if situations of conflict or confusion arise.
7. There should be specialist training and regulation for those counselling citizens/patients about their ACDs

[7] Department of health, Interim Report of the Steering Group on the Review of the Mental Health Act 2001, 27th April 2012, available at http://www.dohc.ie/publications/pdf/int_report_sg_reviewMHA_latest.pdf?direct=1 [last accessed 06/03/14.]

8. We would require that DNRS would be audited and an annual report be produced by the Department of health.
9.

Comments on specific provisions

The IPA would like to raise some issues about four specific provisions:-

1. Patient Designated Healthcare Representative: The Bill provides that a patient's designated representative may ***either*** clarify the ACD ***or*** make decisions on behalf of the incompetent patient.[8]The Bill should be amended to allow a patient's designated representative to undertake both functions, provided the patient's designated representative cannot make a decision on behalf of a patient where this decision contradicts the patient's ACD. This amendment would further enhance patient autonomy.
2. Age: The Bill restricts the right to make an ACD to persons aged 18 or over. The IPA believes that some consideration should be given to lowering this age, possibly to 16 in order to bring the Bill into line with the current age of consent to medical treatment.[9]Validly giving consent to any treatment, or lack thereof, in a correctly drafted ACD hinges on the fact that the patient has sufficient capacity to understand the implications of his or her decisions. It would, therefore, seem to follow that if adolescents aged 16 or over can consent to medical procedures, a different threshold should not be set for ACDs. The IPA believes that it would be important to include safeguards within the Bill that would ensure that an adolescent decision in an ACD was free and informed.
3. Witnesses: There is a need for the presence of two witnesses when a patient creates an ACD. It is suggested that a simpler alternative to the need for two witnesses is to require only one witness, provided this witness has no conflict of interest.
4. Accountability of Clinicians: A clinician may ignore a patient's request for medical treatment under the Bill. In the opinion of the IPA, clinicians must be accountable when they fail to give effect to an ACD. The Bill should be altered to stipulate that a clinician with the support for a second opinion would only be justified in ignoring the ACD by demonstrating that it would be the standard practice within the profession to ignore an ACD in favor of a DNAR in

[8] Head 7(3) (a)-(b), Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives.
[9] Section 23 of the Non-Fatal Offences Against the Persons Act 1997.

such circumstances. Otherwise, civil liability or professional sanction should attach to a clinician whom ignores an ACD in favor of a DNAR.

Answers to the Questions

Question 1

The IPA recognises that information is essential to a patient's decision to consent or reject treatment. A patient should consult with a clinician and a legal expert or may consult with a registered counsellor prior to drafting an ACD because there is a risk that an ACD could result in consequences neither anticipated nor wished for by the patient/citizen. Consultation with a clinician and legal expert will make it harder to challenge an ACD either in the clinical setting or court. It must, however, be noted that the cost of clinical and legal consultation may be onerous. Therefore, requiring consultation for an ACD to be valid would only be acceptable to the IPA if there is a mechanism to avoid or defray these costs.

Question 2

The IPA believes that that the validity of an ACD should not depend on a mandatory review. There is a danger that a person may innocently forget to review an ACD and, by consequence, invalidate their ACD. This, balanced against the fact that an ACD can easily be revoked, be it in writing or orally, would suggest that imposing mandatory reviews would place too high a burden on the affected patient than is appropriate. Another possible solution is that a review is required when there is a substantial change in the patient's condition that does not affect his or her capacity. There should be clear guidelines as to the meaning or interpretation of "substantial change" and they should have the power to order such a review. Failure to follow the order would then invalidate the ACD. An ACD will also be valid if a patient reviews

the ACD after a substantial change in the patient's condition that does not affect his or her capacity and reaffirms the ACD.

Question 3

A standard format could reduce the need for consultation with a lawyer, due to the well established interpretation of a uniform document. Clinicians, Patient Advocates could also assist in the design of a standard form to ensure medically sound directives are produced. The IPA would recommend that a standard format ACD could be introduced for the common diseases and conditions. They could be crafted with a range of specialist clinicians, and other stakeholders and in conjunction with legal advisers to ensure they are fit for purpose. Outside of that, the less frequently occurring diseases could be drafted on an individual basis.

Question 4

The IPA would suggest the following information be included:

- Name of patient
- Address
- DOB
- Gender
- Name, email and telephone number of next of kin
- Name, email and telephone number of patient designated healthcare representative (if patient designates such a person)
- Relationship between patient designated healthcare representative & patient
- Name of registered medical Practioner who certified competitancy of patient (clarification this may be required because of any issues such as dementia that could be made in the future about the competitancy of the citizen at the time of

the formulation of the ACD that an assessment by a clinician was required to validate competitancy)

- Enduring power of Attorney if designated
- Name, email and telephone number of Attorney's information.
- Circumstances under which ACD will operate
    a) Medical condition
    b) Environmental conditions
- Refusal of life sustaining treatment (maybe list the treatments being refused)
- Signature of patient and witness(es).
- Date

Question 5

The IPA would propose a number of possible concurrent places of storage for the ACDs:

1. The patient carries it on their person and could be in the form of an electronic identity card, much like the newly introduced driving license.
2. It could be stored in the patient's inpatient and outpatient medical records. Notice of its existence would be highlighted by placing in a prominent position in the records and using a brightly coloured form so as not to ensure that the ACD is not missed by any treating clinician.
3. Alternatively, once the Health Information Bill is enacted, the ACD could be tied to the patient's unique health identifier.
4. The document could be stored with the patient's personal representatives.
5. The patient's primary clinician could be required to keep a copy.

Question 6

The IPA would propose three measures to ensure clinicians are aware of the existence of an ACD:

1. A registry of ACD must be established, and a duty should be placed on clinicians to check before they treat a patient.
2. The ACD could be attached to a file kept on the patient's bed.
3. A duty could be imposed on the patient representative of the patient to inform the clinicians of the existence of an ACD.

Question 7

The IPA suggests patient's requests for treatment should be legally binding unless a clinician's decision not to treat is consistent with general and approved clinical practices. A clinician cannot refuse a request to treat on the basis of economic cost of the requested treatment.

Question 8

The IPA argues it would be beneficial to have a different standard format for ACDs for mental healthcare and treatment. ACDs for mental healthcare should provide for a patient to consent to treatment that stabilises and ameliorates their mental capacity and restores capacity.

Question 9

The IPA welcomes the use of a patient representative to make treatment preferences known on their behalf where they are incapacitated. However, the IPA would not recommend restricting the scope of the powers conferred by a patient on their representative(s) It must be remembered that, in its essence, designating somebody as a healthcare representative is an action that implies complete trust in that person to carry out one's wishes and to be able to, as accurately as possible, know what the patient would have decided if they were capable of doing so. Having this in mind, restricting the powers that a patient can confer on a chosen individual would go against their personal autonomy.

Question 10

The IPA requires that a representative should not have a conflict of interest when fulfilling this sensitive role. In addition, the document appointing a representative should be signed and duly noted.

Question 11

See General Comments (supra 1-2) regarding DNARs

Broad Definition.

Cardiopulmonary resuscitation (CPR) is an emergency procedure for manually preserving brain function until further measures to restore spontaneous blood circulation and breathing in a person who is in cardiac arrest. CPR involves chest compressions at least 5 cm (2 in) deep and at a rate of at least 100 per minute to pump blood through the heart and thus the body. The rescuer may provide breaths by either exhaling into the subject's mouth or nose or using a device that pushes air into the subject's lungs;