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1st October 2025

RE: Assisted Decision-Making (Capacity) Act – Regulation for the establishment of a Register for Advance Healthcare Directives (AHD)

Dear Minister Carroll MacNeill,

Thank you for the email I received dated 19th September from your Private Secretary Eoghan Flynn in reply to letters from Safeguarding Ireland dated 24th February 2025, 1st July 2024 and 14th July 2024 (the latter two to your predecessor) in relation to the making of Regulations as respects Advance Healthcare Directives for the purposes of Section 84(12) of the Assisted Decision-Making (Capacity) Act 2015 (ADMC Act) particularly in relation to having a Register for Advance Healthcare Directives.

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Safeguarding Ireland is disappointed with the response that we have received given that no timeline is given as to when it is proposed to make the necessary Regulations. We have previously set out in our correspondence the compelling reasons why it was necessary to have an operational Register in place. The email from Mr Flynn acknowledges that '*it is essential that the wishes of people receiving healthcare are respected even when they are no longer able to make their own decisions.*' However, the State has not facilitated a person to formally record, either by way of notification to the Director or to record the making of an AHD on a register in accordance with the provisions of the ADMC Act.

Safeguarding Ireland respectfully points out that the State has been in significant delay in putting in place Regulations to facilitate the communication of a person's wishes with regard to their healthcare to those who need to know thereby not complying with either its domestic or international human rights obligations to respect a person's individual rights.

It is useful to set out the time that has been given to the consideration and enactment of the legislative framework for AHDs and to record the work that has been done to date to facilitate the making of Regulations that are provided for in the ADMC Act.

1986 - 2015

In 1986, Costello J, writing in the Irish Jurist, stated '*…there are very powerful arguments to suggest that the dignity and autonomy of the human person (as constitutionally predicated) requires the State to recognise that decision relating to life and death are, generally speaking, ones in which a competent adult should be free to make….'*

The issue of advance care treatment came into focus in the case of *In re a Ward of Court (No.2)* [1996] where there was an acknowledgement by the Supreme Court of patient autonomy and that an advance care directive may be seen as an expression of a person's wishes about their medical treatment. In fact, the Courts generally recognised the right of a person who lacked capacity to plan in advance in relation to healthcare decisions but there was no statutory provision for entering into binding agreements with regard to such decisions.

The Law Reform Commission following its work:

- on **Law and the Elderly**, (Consultation Paper in 2023)
- on **Vulnerable Adults and the Law** – **Capacity** (Consultation Paper in 2025). (In this Consultation Paper, the Commission noted that in January 2004 a draft version of the UN Convention was produced by the Ad Hoc Committee on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities).
- **Report on Vulnerable Adults and the Law** (Report published in 2006)

noted that there was no legal structure to deal with advance care directives in general and persons who wished to plan in advance for healthcare decisions should be provided with a clear legal framework.

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In 2008 the Commission published a Consultation Paper on **Bioethics: Advance Healthcare Directives** and in 2009 published its Report on **Bioethics: Advance Healthcare Directives** which recommended a legislative framework for advance care directives to deal with the advance expression of wishes of an individual in a healthcare or wider care setting and that the medical profession should be provided with a clear legal framework for the future.

In 2009 the **Council of Europe *Recommendation on Principles concerning Powers of Attorney and Advance Directives for Incapacity* September CMR/2009** was published.
Principle 1 - States should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives.

In accordance with the principle of self-determination and subsidiarity, states should consider giving those methods priority over other measures of protection.

This 2009 Recommendation was preceded by the Council of Europe *Recommendation (99)4 of the Committee of Ministers to Member States on Principles Concerning the Legal Protection of Incapable Adults* February 1999 which stated - *In relation to the protection of incapable adults the fundamental principle, underlying all other principles, is respect for the dignity of each person as a human being.* It also provided that *the previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes should be taken into account.*

In 2012, the Irish Hospice Foundation commenced its 'Think Ahead' Project with the distinct purpose *to guide people in discussing and recording their wishes and preferences in case of emergency, serious illness or death*.

In 2013, the Department of Health published a Draft General Scheme for Advance Healthcare Directives and in December 2015 the ***Assisted Decision-Making (Capacity) Act*** was enacted which included in Part 8 statutory provision for Advance Healthcare Directives taking account of the recommendations of the Law Reform Commission.

In 2014, the Council of Europe published a *Guide on the decision-making process regarding medical treatment in end-of-life situations* in Chapter 3 on the Decision-Making Process it states that advance care decisions should be available *in such a way that the doctor can access them in good time and …**they should be recorded in a national register*.**

Assisted Decision-Making (Capacity) Act 2015
Part 8 Section 83(1) provided that: *The purpose of this Part is to –*

(a) Enable persons to be treated according to their will and preferences, and
(b) Provide healthcare professionals with information about persons in relation to their treatment choices.

As stated in the Council of Europe Guide - advance care decisions must be accessible to healthcare professionals and they should be recorded in a national register.

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Sections 84 -90 of the ADMC set out the details for the making of an AHD to include function, scope and validity.

Section 84(12) provides:
Section 84(12) The Minister may make regulations as respects advance healthcare directives, including regulations relating to –

(a) Requiring the directive-maker to give notice of the making of an advance healthcare directive, or any revocation or alteration thereof, -
(i) to the Director, and
(ii) to other specified persons, and whether or not by reference to persons who, under this Act, are required to be notified of an application made under this Act, and
(b) …. requiring the Director to establish and maintain a register…. of advance healthcare directives and any revocations or alterations thereof, that are so notified to him or her and that are made in accordance with this section.

2016 – 2023:
In 2016 the Office of the Director of the Decision Support Service (DSS) was established and the Director of the Decision Support Service was appointed in 2017.

Section 91 of the ADMC Act provides that:
(2) *The Minister shall establish a multidisciplinary working group…to make recommendations to the Director in relation to codes of practice* for AHDs.
(3) The Director may prepare and publish codes of practice… based on the recommendations…

A National Advance Healthcare Directive Sub-Group was established in 2016 and worked over a 2-3-year period and produced a number of draft Codes to the Director including the following:

- Advance Healthcare Directives for Healthcare Professionals
- For the Maker of an Advance Healthcare Directive and
- For Designated Healthcare Representatives.

The Director engaged in a detailed consultation process on the draft Codes and final Codes of Practice were published by the Director in 2023 on the commencement of the legislation. In addition, the Director subsequently published further detailed Guidance on the making of Advance Healthcare Directive.

In 2022 the **Assisted Decision-Making (Capacity)(Amendment) Act was enacted**. This enabled a further review of the provisions of the 2015 Act including the updating of Part 8 dealing with Advance Healthcare Directives and in particular updated Section 84(12) dealing with the Register.

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Prior to, and on the commencement of, the legislation in 2023 detailed work was also done to prepare and publish templates for the making of an AHD. Three templates are now available on the websites of the Decision Support Service, Irish Hospice Foundation (ThinkAhead.ie) and the Citizens Information Board.

Safeguarding Ireland is aware that as the DSS had indicated at an early stage of its establishment that it would adopt a Digital First approach to the delivery of its service. It considered a number of different options and examined services in other jurisdictions. The DSS confirms: *Our service has been built from the ground up with efficiency, personal security, and privacy in mind.* In fact, one of the suspected delays with the commencement of the ADMC legislation was the building by the DSS of its IT system to include the setting up of the various Registers which included the establishment of a Register for Advance Healthcare Directives.

The email of 19th September acknowledges that - *The Register of Advance Healthcare Directives provided for under the Act will provide an additional means by which a person can ensure that their directive is available to healthcare professionals, including in circumstances where they* [lack] *capacity. Registration of a directive is not, however, linked to its validity, and it was not deemed necessary to establish the Register prior to the commencement of Part 8 of the Act.* Safeguarding Ireland is aware that there is no requirement for the registration of an AHD for it to come into effect, however, the Register for AHDs which was established by the DSS in time for the commencement of the Act, has not yet been operationalised (two years after the commencement of the legislation) as it is awaiting the making of Regulations as set out in Section 84 of the ADMC Act.

As indicated, substantial work has been done over a prolonged period (a period of 10 years) so it is important to ascertain, as stated in the email of 19th September, what *further work is still required on ensuring both the legal and technical requirements are in place*.

Safeguarding:
As the ADMC Act was the first statutory provision in Ireland in relation to the safeguarding of adults, (albeit limited to those whose capacity was at issue), Safeguarding Ireland wished to ascertain the focus for its public awareness campaigns given the enactment of the legislation.

In November 2022, Safeguarding Ireland commissioned Red C to survey the public on Adult Abuse in Ireland. 75% believe that there is a greater risk of abuse when others make decisions for them.

In May 2023, just after the commencement of the ADMC Act in April (a month earlier), Safeguarding Ireland carried out a further Red C survey to ascertain the awareness of the public about the legislation. 83% confirmed that either they had never heard of the Act or had heard of it but did not know what it was about.

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In October 2023, a further survey on planning ahead indicated that a very low percentage of the public had put any plan in place or were aware of such planning ahead measures contained in the ADMC Act.

2024 – to date:
As already noted in our letter of 1 July 2024, Safeguarding Ireland welcomed the publication, in May 2024, by your Department of **'Digital for Care: A Digital Health Framework for Ireland 2024-2030'** and notes in particular Principle 3 which provides:

> ***Digitally Enabled and Connected Care:*** *We will drive future investment and make architectural decisions based on the ability of systems to share clinical information and deliver connected care. We will make it possible for healthcare professionals, and others who support delivery of care, to be able to access the information they need about their patients when and where they need it, regardless of where those patients were treated previously.*

The availability of a National Register for Advance Healthcare Directive is surely an important element to achieving this aim.

In June 2024 Safeguarding Ireland's as part of its public awareness campaign on adult safeguarding focussed on making people aware of the need to make of an advance healthcare directive having established that less than 23% of the public were aware of an AHD and only about 4% had one. In addition, a RedC survey had indicated that less than 4% of healthcare professionals had enquired from a patient if they had made an AHD.

The HSE Consent Policy was updated in 2024 and sets out the functions and duties of a healthcare worker to ascertain if a person has made an advance healthcare directive and if so what steps should be taken to read and follow same. The ADMC Act also provides that an AHD must be in writing. It is therefore important that there is a reliable record that can be readily accessed by healthcare workers to ascertain the existence of an AHD.

For persons who are resident in long term care, it is particularly important that there is a formal accessible record as to their wishes particular for end of life care/palliative care.

The email of 19th September states – *While a person isn't legally obligated under the Act to notify anyone of their directive, they are strongly advised to give a copy of their directive to their GP and other healthcare professionals.*
Safeguarding Ireland notes the Department's view on this and is also aware that the DSS and HSE websites, in the absence of a national register, currently encourage the maker of a directive to give copies to families, a Designated Healthcare Representative (if a person appoints one) and GPs. However, this is far from being optimal or sufficient and is not practicable in many cases.

- Many older people, (and a growing number of them) do not have close family members or a trusted person that is readily available if they are unable to make

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healthcare decisions at a particular time, but they do wish to provide for such eventualities, to record their health wishes in advance and ensure that those wishes are available at a future time when they lack decision-making capacity.

- Many GPs/healthcare professionals will not agree to act as a repository for AHDs. Also, in many cases, the relationship of a person in the community and a GP ceases when a person is admitted to long term care. In other cases, the interaction with a healthcare professional may be a 'once-off'. Moreover, GP's may not be accessible out of hours when an emergency occurs and there is a need to access the AHD.
- People are admitted to hospital/care without notice e.g. emergency situation or at the time of admission may lack decision-making capacity and are not in a position to indicate that they have made a directive or where it is located.
- It is clear that AHDs do not 'travel' with a person from nursing home to hospital or from one care centre or community service to another.

There is significant cost to the State in not encouraging the making an advance healthcare directive or if made, not having them available to communicate a person's wishes and choices with regard to their healthcare. The lack of planning for healthcare can be both human and financially resource intensive. For example, in a hospital/care setting when it is necessary for a healthcare professional to obtain consent for treatment and it is not available, critical time and effort may be necessary before consent becomes available and it may not become available. In some cases, it may be necessary to make an application to the court, for the court to make a decision or to appoint a third party to do so and it is usually the HSE that has to bear the cost of such applications. The Department will be very aware of the increase in the number of applications to the Circuit Court in relation to the ADMC Act (where there has been no planning in advance) and many of the applications relate to healthcare issues. These are critical policy issues that require efficient and cost-effective administration of both healthcare and justice. A court application should be a last resort.

Safeguarding Ireland regards the making of an Advance Healthcare Directive as an important safeguarding tool to prevent abuse.
In 2025, in the past number of months, Safeguarding Ireland has engaged directly with healthcare professionals, first in making them aware of the provisions for AHDs in the legislation and the need to encourage patients to plan in advance. In out interaction with healthcare professionals the accessibility to patient's directives has been raised repeatedly.

The State has a public duty obligation to fully implement the legislation and to support and facilitate a person to appropriately record their advance healthcare directive so that it is readily accessible no matter what the circumstances are. This will be achieved by having access to a National Register.

If there are outstanding issues that need to be addressed for the making of Regulations to operationalise the Register for Advance Healthcare Directives, Safeguarding Ireland is willing to engage with officials in your Department to identify what needs to be done. The Register is essential to enable a person to record their health/social care wishes and choices and to

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communicate that important information to healthcare professionals at the time they need that information. This is now an urgent matter.

Yours sincerely



Patricia Rickard-Clarke
Chair

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