National Consultation
Draft Codes of Practice on Advance Healthcare Directives

Submission in respect of "*A Draft Code of Practice for Health and Social Care Professionals on Advance Healthcare Directives*" by Aisling Coffey, Siobhan Quinn and Cliodhna Beaumont, on behalf of the Irish Association of Social Workers (IASW) Special Interest Group in Ageing (SIGA)

1. Do you think the Draft Code of Practice for Health and Social Care Professionals provides sufficient information for you to apply it in practice in your work?

Yes √ No Not applicable

2. Are any aspects of the Draft Code of Practice for Health and Social Care Professionals confusing / difficult to understand? Please specify section and page number

- In the main the draft code is extremely easy to read, but please find feedback on three areas that may benefit from further clarification.

a) Section 2.1 page 20: Extract as written:
"*An Advance Healthcare Directive is a written statement made by a person who is 18 years of age or older, with capacity. It sets out their will and preferences about healthcare treatment decisions that they do not want to receive in the future, if a time comes when they lack capacity to make such decisions or cannot communicate their decision by any means*".

The section underlined "do not want" could lead the reader to interpreted that an Advanced Healthcare Directive simply sets out the directive maker's instructions as to the healthcare treatments they wish to refuse in the future, rather than documenting both the kind of healthcare treatments the directive maker wishes to accept and wishes to refuse.

b) Section 2.1 page 20 Extract as written:
"*The Advance Healthcare Directive must be in writing and must be witnessed. The person making the Advance Healthcare Directive (who is called a Directive-Maker) may set out his or her will and preferences with regard to healthcare treatment choices in an Advance Healthcare Directive and/or the Directive-Maker may appoint another individual called a Designated Healthcare Representative*."

The section underlined could lead the reader to interpret that the directive maker can appoint a Designated Healthcare Representative instead of setting out the will and preferences in an Advanced Healthcare Directive. It may be more beneficial to document the option to appoint a Designated Healthcare Representative in a separate sentence.

c) **2.4.1 Determine if the person lacks capacity page 26. Extract as written**
The burden of proof in demonstrating that the person lacks the capacity to make a decision regarding their healthcare treatment is on the Health and Social Care Professional providing the healthcare treatment

In hospital settings decisions, a common issue arising is a multidisciplinary team recommendation in relation to residential care where all options in respect of community living have been exhausted. In some cases there may be concerns about the patient's capacity to make this decision. Where a multidisciplinary team are making a recommendation it is unclear from this Code and previous guidance on the ADM Act which professional is should conduct the capacity assessment.

3. Please provide more detail on where you think the document could be improved so you can apply it in practice in your work (please specify section and page number)

Throughout the draft Code, the term Health and Social Care Professionals (HSCP) is referenced but omits to mention which professional would be most appropriately positioned in relation to certain matters or which professional should take precedence.

A key example of this matter arises in Section 3.2: which reads "*The Health and Social Care Professional should discuss the implications of the person's known medical condition and assist with whatever information is requested. He or she should explain available healthcare treatment options and risks to the Directive-Maker, including which forms of healthcare treatment may be life-sustaining treatment and the consequences of the refusal of such treatment"*

The duties outlined above would primarily be the role of a doctor as opposed to any other health and social care professional. Most health and social care professionals, apart from doctors, would not be qualified to provide this expert advice.

Some examples where HSCP is used include:

- Page 27: The HSCP should ask re Advanced HealthCare Directive (AHD)
- Page 28: The HSCP should check whether the formalities have been complied with.
- Page 52: Section 4.3 the HSCP should consult with sections (i) and (ii)
- Page 58 - if HSCP has concerns they should make a complaint to the Director of the Decision Support Service.
- Page 59 – the HSCP must consult with the rep to resolve any uncertainty as to validity or applicability of the ADH

4. Please detail any sections in the draft Code of Practice for Health and Social Care Professionals that should be further clarified / explained.

- Please find six pieces of feedback a-f below.

a) Section 2.1 page 20: Extract as written:
"The Health and Social Care Professional should also take active steps to ensure that other Health and Social Care Professionals are made aware of the existence of the Advance Healthcare Directive. Once a Health and Social Care Professional is made aware of the existence of an Advance Healthcare Directive, s/he should ensure that this is accurately recorded on all relevant medical records, for example medical and nursing notes, healthcare provider administration system, admission chart, healthcare record, National Ambulance Administration System".

Should there be a reference to **consent** being obtained by the health and social care professional prior to the professional sharing the Advanced Healthcare Directive with other healthcare professionals, all relevant medical records and the ambulance administration system?

b) Section 3.1 if the advanced healthcare directive can be recorded in "a nonwritten format, for example voice and video recording and speech recognition technologies", how is to signed by all of the relevant parties? Is there a requirement for it to be transcribed?

c) Section 3.1 page 31: Extract as written:
If the formalities have not been complied with, the Advance Healthcare Directive is not legally binding. However, if the intention of the Directive-Maker is clear and the Advance Healthcare Directive is otherwise valid and applicable, the will and preferences of the Directive-Maker should be respected.

This is ambiguous. If the legal formalities are not in place and directive is not legally binding, what does the underlined section above actually mean in practice?

It appears at odds with section 3.4 page 35 " An alteration to an Advance Healthcare Directive is of no effect unless it is signed and has two witnesses".

d) Section 3.2 Witnesses to an Advance Healthcare Directive. Extract as written:
"*It is a matter for each Health and Social Care Professional to decide whether or not to agree to act as a witness" and "The mere act of witnessing an Advance Healthcare Directive by a Health and Social Care Professional does not require the Health and Social Care Professional to undertake a capacity assessment to determine whether the person has the capacity to make an Advance Healthcare Directive*"

What is written above in relation to healthcare staff witnessing the signing of documentation and the need to ensure capacity when witnessing such documentation is at odds with current HSE Guidelines on Will Making by Older People in Residential and Day Services. In the aforementioned guidelines, in relation to witnessing a will it

states "*Only in exceptional circumstances where time is of the essence and subject to ones' line manager's approval may a unit employee act as a witness, for example near or imminent death*" (section 10.0 page 10) and in respect of capacity the guidelines state: "*The witness may be called to give evidence as to the older person's capacity at the time of signing the will if a legal dispute arises*" (section 10.1 page 10).

e) Section 3.2 witness to an Advance Healthcare Directive. Extract as written:
"*The mere act of witnessing an Advance Healthcare Directive by a Health and Social Care Professional does not require the Health and Social Care Professional to undertake a capacity assessment to determine whether the person has the capacity to make an Advance Healthcare Directive. However, if a Health and Social Care Professional, notwithstanding the presumption of capacity, is concerned that a person may not have the capacity to make an Advance Healthcare Directive, s/he should not witness the Advance Healthcare Directive*"

This paragraph is slightly ambiguous and could be considered contradictory. If a health and social care professional witnesses an advanced healthcare directive, they are operating under the presumption that the person had the capacity to make the Advance Healthcare Directive, and there were no reasonable grounds to believe that the person did not have the capacity.

f) Section 4.1.2 Doing something inconsistent with the Advance Healthcare Directive while having capacity needs further explanation. Extract as written:
"An Advance Healthcare Directive is not valid where the Directive-Maker acts in a manner or makes decisions that clearly are inconsistent with the relevant decisions in his or her Advance Healthcare Directive". This section proceeds to provide a vignette where Ms Daniels acted inconsistently thereby invalidating that aspect of the AHD but she still was not given ventilation because of her husband's interpretation of her will and preference? This is unclear and open to challenge and interpretation. This is unsafe when the matter involves healthcare treatment.

5. Do the vignettes help with your understanding of how an Advance Healthcare Directive can be applied in practice?

Yes √ No

Overall the vignettes were helpful and outlined how Advance Healthcare Directive can be applied in practice.

6. Please provide details on how the vignettes could be improved (please specify vignette number and page number)

Vignette 10 ends prematurely and would benefit from guidance on where Ms Ryan could take her concerns as in reality the matter would have been quite contentious. The public will require education of the fact that a next of kin has no legal status when it comes to healthcare treatment decision-making.

In relation to all of the vignettes, they would be easier to follow if they simply referred to "the doctor", "the surgeon", "the Consultant", etc, rather than giving these categories of person titles such as Dr Brody. The titles are unnecessary and add complexity to reader trying to follow the case study. Vignette 2 simply refers to his GP and is easier to read.

7. Is there any issue which is currently not covered by a vignette which you think would benefit from a vignette?

There is no apparent issue as yet, but advanced healthcare directives are not in operation so one is attempting to foresee potential issues.

8. Do you have any other views on the Draft Code of Practice for Health and Social Care Professionals? (please provide as much detail as possible)

- **Please find three points a-c below**

a) In order for the Code of Practice to be clear, effective and fair, there needs to be the **infrastructure in place to support its implementation**. A key piece of infrastructure is the Register of Advance Healthcare Directives, allowing all directives, their various amendments, revocations, etc, to be stored securely in one central location, which is easily accessible to the HSCP if required.

It is unsafe to expect a HSCP to ascertain if there is an advanced healthcare directive. The HSCP may not be able to glean that information from the service user or their family. The HSCP may be provided with an Advanced Healthcare Directive that has since been amended or revoked. Given the most serious health related implications of these directives, a register in the DSS is a most necessary prerequisite.

Similarly the Code refers to the HSCP checking whether the formalities for the making of the Advance Healthcare Directive have been complied with – that is, it is signed by the Directive-Maker, by the Designated Healthcare Representative (if such has been appointed) and by two witnesses on the same date (at least one of whom should not be a family member), etc. Surely ensuring the formalities have been complied with should fall to the DSS when the Advanced Healthcare Directive is registered. A responsible HSCP will also check this matter but primary responsibility for ensuring the formalities of a legal instrument should not fall to the HSCP.

b) It would be helpful to have **further guidance** on:

- how and when healthcare facilities should seek advanced healthcare directive
- how and who refers matters to the Court
- what an advanced healthcare directive will look like / what form it may take

c) Section 6.4 Advance Healthcare Directives and Pregnancy

Will these restrictions continue to apply if the 8th amendment is removed from the Constitution?