Citizens Information Board
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Advance Healthcare Directives Consultation on draft Codes of Practice
Citizens Information Board Response

The Citizens Information Board (CIB) is the statutory body responsible for the provision of information, advice and advocacy on social services and has a particular remit to provide advocacy for people with disability. CIB supports and funds the National Advocacy Service (NAS) for people with disabilities[1]. The Board welcomes the opportunity to respond to this consultation on the Advance Healthcare Directives respective draft codes of practice.

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

The introduction into Irish law of Advance Care Planning is a welcome development. In general, it is considered that advance care planning reduces invasive life-sustaining treatment, increases the use of palliative and hospice care, prevents hospitalisation and overall there is an increase in patient and family satisfaction and a reduction in family stress anxiety and depression (Tripkin et al., 2018; White et al., 2014). In addition, crisis decision making is avoided and opportunities to enable difficult conversations are facilitated (Cornally et al., 2015).

This proposed code of practice is a very thorough and considered document and usefully discusses the implementation of Advance Care Directives from a number of perspectives.

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 general, the document is not confusing and health and social care professionals should have no difficulty in understanding the concepts and issues outlined. The glossary of terms provides a useful reference point.

[1] NAS is making a separate response to this Consultation.

However, use of the word 'healthcare' in the title 'designated healthcare representative' has the potential to cause confusion because it could be interpreted that the designated person should or could be a healthcare professional.

While the terms of "directive maker", "co-decision maker", "decision-making assistant", "decision-making representative" and "directive-maker" are not confusing in themselves, their use and application in the context of the Assisted Decision-Making Act 2015 is new and potentially confusing at least during the implementation period. Therefore, it is suggested that an illustrative easy-reference guide which outlines the definitions and clear differentiation between the terms could be helpful both for professionals themselves and also for use by professionals in their discussions with patients/service users and families.

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) ☒

Recognition of the role of independent advocates and a definition of the advocacy role could usefully be included in the Code as health and social care practitioners will encounter advocates who will be assisting people with expressing their will and preference in cases where capacity issues arise.

While compliance with patient/service user issues is an important standard of good practice for health and social care professionals, the liability issues outlined on page 29 of the code have the potential to cause some concern for practitioners. More detail and discussion on these points could allay these concerns.

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

More clarity is required with regard to situations where a patient/service user has nominated two or more designated health care representatives for different aspects of his/her care but there is an overlap in decision making. For example, where a proposed surgery or course of drug treatment for a physical condition could negatively impact on some other aspect of health such as mental health. ☒

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

Yes **No**

The vignettes provide useful illustrations of how advance care directives could operate in practice. The explanatory notes at the end of the vignettes are also very useful and illustrative. ☒

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

The vignettes are generally well constructed, provide clear explanations and address multiple issues in a helpful way.☒There is a need to further illustrate cases where capacity is at issue and include guidance for healthcare professionals on assessing capacity in line with the functional approach envisaged in the ADM Act.

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

Additional vignettes could provide further illustration and assistance to professionals as they tease out the issues in a busy environment that is rarely clear-cut or straightforward. What happens in the absence of an AHD could be illustrated in a vignette outlining what kinds of difficulties arise.

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) ☒

As noted above the introduction into law of advance care planning is welcome and increases patient/service user and family satisfaction with healthcare and end-of-life care. Advance care planning also assists health professionals in decision-making. Notwithstanding the positive implications of advance healthcare directives and while the code is clear and thorough, it must be noted that the application of advance care planning in practice is complex, time consuming and requires considerable skill on the part of health and social care professionals.

The attitudes and beliefs and practical considerations of health professionals have been shown to influence the uptake of Advance Care Directives. The first factor is the time required to effectively implement care planning. A number of studies have shown that patients are unlikely to consider or complete advance care directives unless the discussion is initiated by their doctor (Tripkin et al., 2018; Lovell & Yates, 2014). However, in the Irish context, doctors in primary care and in hospital settings continually report unmanageable demands on their time. Thus, they may postpone or avoid introduction of this sensitive topic due to time pressures.

Furthermore, as outlined in the code a 'functional approach to capacity' should be adopted by those delivering health and social care. This is good practice and in line with standards and requirements for health and social care professionals. However, it must be acknowledged that assessment of capacity is a skilled task and as advance care planning is a dynamic, iterative and multi-stage process (Tripken et al., 2018; Lovell & Yates, 2014) it will take time and expertise to perform assessment evaluations on a regular basis. Additional factors which add complexity for health and social care professionals include fluctuating capacity, evolving health care needs and advances in medical treatments or interventions. In the current

context of a very pressurised health service in Ireland, and in light of the growing numbers of residents in long-term care with cognitive impairment (Cornally et al., 2015), advance care planning will certainly pose challenges for health and social care professionals.

Health professional discomfort with the introduction of the emotive subject of loss of capacity and end-of life decisions has also been shown to adversely affect uptake and consequently such discussions may occur too late for the person to actively engage in the care planning process thereby missing opportunities to make informed choices about their own care (Lovell & Yates, 2014).

9. Do you want to provide feedback on the other Codes of Practice?

Yes, the Draft Code of Practice on How to Make an Advance Healthcare Directive ☒

Yes, the Draft Code of Practice for Designated Healthcare Representatives

No ☒

10. Do you think the Draft Code for Making an Advance Healthcare Directive provides sufficient information for you to make an Advance Healthcare Directive? ☒
Yes
No

The document is thorough, clear and well considered. However, due to its length and terminology it may not be accessible to all. Tripken et al., (2018, p.73) quote a nationwide study in the US which found that "*more than 78% of adults did not know what palliative care was and that awareness and understanding of end-of-life terms are low."* Similarly, Sudore et al., (2007, p. 165) consider that limited literacy negatively impacts on information exchange, decision-making and communication of treatment preferences and that these factors can jeopardise decision-making and choice of treatment options.

Thus, it is proposed that an 'easy read' version of this guide is developed to improve accessibility for all groups. Other communication options could also be considered such as explanatory films or video guides. In devising information tools for communicating information about advance care planning, the needs of different groups will need to be considered. These groups include (but are not limited to) those with intellectual disabilities; people with mental health issues; people with dementia; people for whom English is not their first language; and others.

10. Please provide more detail on where you think the document could be improved so you would be able to make an Advance Healthcare Directive (please specify section and page number).

As noted with regard to the previous survey, use of the word 'healthcare' in the title 'designated healthcare representative' is confusing because it could be interpreted that the designated person should or could be a healthcare professional.

While the terms of "directive maker", "co-decision maker", "decision-making assistant", "decision-making representative" and "directive-maker" are not confusing in themselves, their use and application in the context of the Assisted Decision Making Act 2015 is new and potentially confusing at least during the implementation period. Therefore, it is suggested that an illustrative easy-reference guide which outlines the definitions and clear differentiation between the terms could be helpful both for professionals themselves and also for use by professionals in their discussions with patients/service users and families.

11. Please detail any sections in the draft Code for Making an Advance Healthcare Directive that should be further explained.

See comments above with regard to accessibility. Sudore et al., (2007, p.172) found that advance directives that were designed to meet the literacy levels of most adults were more useful than a standard form. In addition, they recommend clear layout; the inclusion of culturally diverse text-enhancing graphics with expanded values clarification and treatment preferences sections. Similarly, Tripken et al., (2018) recommend that in order to increase engagement with advance care directives terminology should be carefully considered because the terms that health care professionals use are often not aligned with what the general public uses and understands.

Thus, it is suggested that these factors are considered throughout this draft code with a view to enhancing clarity and explanation of all points.

12. Are there any other issues you would like to see covered by a vignette? (please provide details) ☒

Additional vignettes could provide further illustration for people of instances where fluctuating capacity may be at issue and scenarios of what can happen in the absence of a Directive as well as being able to to alter a Directive.

13. Do you have any other views on the Draft Code for Making an Advance Healthcare Directive? (please provide as much detail as possible) ☒

Notwithstanding the issues with literacy outlined above, studies have shown that there is a low rate of planning for the future in general. The sensitive and taboo nature of death is a key barrier in discussing advance care directives (Lovell & Yates, 2014). For example, a recent survey (2017) claims that seven out of ten people in Ireland have not made a will (https://www.royallondon.ie/). Given that White et al.,

(2014) found that in Australia respondents who had made a will were 2.5 times more likely than non-will makers to have an advance care directive in place, it seems likely that a large majority of the population in Ireland will be slow to engage with advance care planning.

Many people may have concerns about formalising an advance care plan and these will need to be specifically addressed. Lovell and Yates (2014) cite studies that identified fears that treatment may be withdrawn too soon or that formalising their preferences may prevent changes in their advance care plan later. According to Billings (2012) a further concern is that doctors can sometimes err on the side of withholding life-sustaining treatments when a patient has indicated in their advance care directive that they do not wish to receive aggressive or intrusive treatments.

It will also be important to bear in mind the influence of socio-economic differences when considering how to increase the uptake of advance care planning opportunities. Literacy skills have already been discussed. It is interesting to note that in the study conducted by Tripken et al., (2018) significant differences in familiarity of terminology and the rate of completion of advance care directives was noted between two economically diverse communities despite the fact that no difference was found in attitudes and beliefs about end-of-life issues. This suggests that in Ireland care must be taken to tailor information campaigns in varied and diverse ways to ensure that the needs of different groups are adequately addressed.

Do you want to provide feedback on the other Codes of Practice?

Yes, the Draft Code of Practice for Health and Social Care Professionals ☒

Yes, the Draft Code of Practice for Designated Healthcare Representatives

No ☒

The following questions apply to the Draft Code of Practice for Designated Healthcare Representatives ONLY. In your response, where applicable, please specify the section, page and line number to which you are referring.

Do you think the Draft Code for Designated Healthcare Representatives provides sufficient information for someone to be able to carry out the responsibility, functions, duties and restrictions that apply to the role?

Yes

No

The comments in relation to the draft code for making an advance healthcare directive are all applicable to this code. As designated healthcare representatives will likely be members of the general public, this code also needs to be accessible to people from all socio-economic groups and of all literacy levels.

References

Billings, J., (2012) ***The need for safeguards in Advance Care Planning*** Journal of General Internal Medicine 27(5):595–600

Cornally N., McGlade C., Weathers E., Daly E., Fitzgerald C., O'Caoimh R., Coffey A., Molloy D. (2015) ***Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: staff perspectives*** BMC Palliative Care 2015, pp1-10.

Lovell, A., Yates, P., (2014) ***Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012***. Palliative Medicine 2014, Vol. 28(8) pp 1026–1035.

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