General Medical Council

Department of Health Northern Ireland consultation on Advance Care Planning Policy for Adults - GMC Response

Question 1 Ambition of Advance Care Planning (page 6) Do you agree with the ambition of the Advance Care Planning policy? (Please Tick) Yes No Please provide any further information you wish to share on your answer.

Tick: yes

1 We support the ambitions. We think they could be strengthened by referring to other policy aims mentioned later in the document:

2 To raise awareness of the benefits of Advance care planning (ACP) and thereby to increase timely uptake (although we appreciate that the term 'normalise' may imply this)

3 to ensure that ACP is carried out to a high standard, including ensuring that professionals have the opportunity to access relevant training and support. In addition, in the context of health and care planning, to make clear that ACPs must 'follow the patient' where care is delivered by multi-disciplinary teams (e.g. across health, social care, voluntary sector services).

4 To make sure systems and resources are in place to achieve this.

Question 2, What is Advance Care Planning? (page 6) Does the policy clearly explain what Advance Care Planning is? (Please Tick) Yes No Please provide any further information you wish to share on your answer.

Tick: No

5 We feel the text in the 'Introduction' section is much clearer in its explanation of the aims and the benefits of advance care planning conversations. Someone reading the

"What is Advance Care Planning?" section stand alone may have a less full understanding. It might therefore be helpful to the reader if this section was focused on explaining the particular benefits of ACP for meeting a person's health and social care needs (and the support needs of their family or other carer) as mentioned elsewhere in the policy. That would sit well with a number of important points made in this section, including the emphasis on taking a patient-centred approach and the ongoing nature of advance care planning (ACP), which should not be regarded as a one-off event.

6 We would also suggest consideration be given to making the following clarifications and amendments to this section, as it applies to advance healthcare planning:

1. Where the text says: 'and what would be important for them to prioritise in the future should they become unable to make decisions for themselves', this could be read as suggesting that ACP is limited to where a patient may lose capacity. Although potential future loss of capacity is a significant reason for having ACP discussions, you recognise in later sections of the policy that they may be valuable for people who are not necessarily expected to lose decision-making capacity but want to plan ahead (with their care providers) to put the right support in place to meet their health and/or social care needs as they change over time. This would also be consistent with our guidance at paragraph 32 of 'Decision making and consent' (in the section on looking ahead to future decisions), where we state that:

   For some patients, there are foreseeable circumstances when they will have a choice of options at a time when they might find it more difficult to make decisions – for example because:

   a. *they may be in pain, confused or afraid*
   b. *their capacity or insight may be impaired by their condition or the effects of an intervention*
   c. *a decision may need to be made quickly so there will be less time for dialogue.*

2. It may help to briefly explain the status or limits of different ACP decisions, choices or expressed preferences. With the exception of a legally binding advance refusal of treatment (see paragraphs 68-74 of our 'Treatment and care towards the end of life' guidance and noting the provisions of the MCA 2016), documented ACPs will be strong guides or recommendations for future health or care decisions that should be given significant weight.

3. We would emphasise the importance of making a record of advance care planning conversations. The current text simply states: '*If* the person wants to make a record of these conversations and share them, they should be supported to do so' (my italics). This does not adequately convey that recording ACPs is part of making sure that everyone who needs to know (including future decision makers) has a shared understanding of any relevant decisions and what matters to the patient, so that there is less of a risk of later misunderstandings or conflicts arising.

Certainly, we expect doctors to record ACP discussions. At paragraph 61 of our 'Treatment and care towards the end of life' guidance, we state that:

'You must make a record of the discussion and of the decisions made. You should make sure that a record of the advance care plan is made available to the patient, and is shared with others involved in their care (provided that the patient agrees), so that everyone is clear about what has been agreed.'

Question 3. Values & Principles of Advance Care Planning (page 7 and page 8) Are the Values and Principles stated in the policy clear, comprehensive and relevant?

Tick 'yes'

7 We support the principles set out under the 'Values and Principles' heading, which are consistent with the high-level principles in our guidance. This includes the importance of taking a patient-centred approach (see paragraph 53 of our guidance 'Treatment and care towards the end of life'), recognising the need to review discussions and decisions (see paragraph 62 of 'Treatment and care towards the end of life') and not putting pressure on patients to have conversations they may not be ready for or may not want.

8 In the section that immediately follows ('Principles of Practice'), however, the policy states that 'consent' should be addressed at every stage. It would be helpful to clarify the reason for this, to ensure there is no misunderstanding that the outcomes of ACP discussions equate to 'advance consent' (see comments under 'what is advance care planning').

Question 4. Why is it important to have Advance Care Planning Conversations? (page 8 and page 9) Does the policy clearly explain the benefits of Advance Care Planning?

Tick: yes

9 We suggest adding some additional, more practical, benefits of ACP to this section. For example, at paragraphs 50 and 51 of our 'Treatment and care towards the end of life' guidance, we explain that where care is delivered by multi-disciplinary teams ACP can ensure timely access to safe, effective care as well as continuity in its delivery. It can also help to avoid misunderstandings or conflicts (between doctors, patients or those close to them), thanks to there being greater clarity about what the patient wants/ would want.

Question 5. When should Advance Care Planning happen? (page 10) Do you agree that Advance Care Planning is important for any adult at any stage of life?

Tick: no

10 In this section, the policy states that 'Advance Care Planning is important for every adult at any stage of life and is relevant to people who are in good health as well as for those who are very unwell'. However, it's not clear how this would apply in relation to health and care decisions. Conversations about future health or care may only be meaningful or particularly relevant to the individual where they have a particular diagnosis, or they are elderly and very frail, or they are at a particular stage of a progressive medical condition. We can see some limited circumstances where it may be helpful to encourage ACP discussions with healthy patients for example conversations around organ donation or the risk relating to an hereditary condition. If this is the sort of situation the wording of the policy is intended to cover, it would help to make this explicit.

Question 6. How Advance Care Planning Conversation(s) are used (page 15 and page16) Do you understand how Advance Care Planning conversations are used?

Tick yes

~~11~~ Comment: This section is clear but reads as though the outcomes of ACP conversations are only used in situations where the adult has lost capacity or is unable to communicate. As we have outlined above, we support the view that ACP can be valuable in situations where a patient has, for example, a progressive illness but is not necessarily expected to lose capacity (see our response to question 1 above). We therefore suggest that consideration be given to rephrasing this section to reflect the broader intentions of the policy.

Question 7. Components of Advance Care Planning (page 16) Does the components model help explain the different elements of Advance Care Planning?

Tick yes

Question 8. Legal Component of Advance Care Planning Mental Capacity Act (NI) 2016 (page 19 to page 22) Is the policy clear on how mental capacity relates to Advance Care Planning?

Tick yes

12 This section clearly sets out the relevance of capacity, explaining that 'Advance Care Planning conversations, any recommendations and/or decisions will be used when the person cannot make decisions for themselves. This may be because even with support, they lack the mental capacity to make the specific decision at that time.' That said, as we have explained above, we suggest consideration be given to reminding the reader that ACP can apply to cases where people are not necessarily expected to lose capacity.

13 The section also goes into considerable detail about how to determine whether or not a person has capacity ('Aspects to consider regarding mental capacity') which, presumably, may be less relevant at the stage where advance care planning conversations are taking place (unless capacity is being assessed to determine the appropriateness of ACP conversations taking place at all) than at a future stage when particular decisions, informed by ACPs, are being made. For this reason, it may be helpful to make this clear here.

Question 9. Clinical Component of Advance Care Planning Declining Health and Unexpected Emergencies (pages 26 to page 29) Is the policy clear on:

(a) How the ReSPECT recommendations form part of Advance Care Planning?

(b) How resuscitation recommendations will be recorded on the ReSPECT form and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms will no longer be used?

Tick no to question 9a)

Tick yes to question 9b)

14 We note that the section on 'Clinical Recommendations for Cardiopulmonary Resuscitation (CPR)' talks of 'unexpected' emergencies, such as a cardiac arrest. However, patients considering future CPR decisions may be having these discussions precisely because they are at *foreseeable* risk of a cardiac arrest. As such, we suggest removing the term 'unexpected' before emergencies.

15 The section also suggests that it may be inevitable that attempting CPR would neither be successful nor appropriate at a certain stage in a person's life, which may be over-stating the situation. ('*There comes a time for everyone however, when attempting to restart the heart would either not be successful or where the risks of CPR outweigh the benefit.*'). We therefore suggest using less categorical language – and rephrasing this along the lines of: 'If a person is at foreseeable risk of a cardiac arrest and the treating clinician judges that CPR would neither be successful nor appropriate…'

16 We also suggest clarifying that a *direct* conversation with the patient (and/ or, where appropriate, those close to the patient) about future CPR should be carried out (unless the patient is unwilling to have the conversation). The current wording could be misinterpreted to suggest a conversation that is one step removed from such a direct discussion. ('*Knowing what matters to a person helps inform those providing clinical treatment to make and record specific clinical recommendations, including whether CPR would be an appropriate intervention in the event of a cardiac arrest*.')

17 In the section on 'Best interests', we suggest that there may be scope for misinterpreting the following sentence:

18 'Where there is no evidence of Advance Care Planning, ADRT or clinical recommendations for care and treatment in the event of an unexpected emergency, including cardiac arrest, the clinician who is treating the person will make a 'best interests' decision.'

19 This wording may inadvertently suggest that making a treatment or care decision which is informed by available evidence of the patient's prior preferences/decisions (e.g. an ACP) is different and separate to a 'best interests' decision where no such evidence is available. In fact, treatment or care decisions in both situations are best interest decisions – although there will be a difference in the range of available evidence to inform them. The exception is where the patient has a valid and applicable ADRT, which will be binding and is not a 'best interests' decision.

20 Under the section on 'Recommended Summary Plan for Emergency Care & Treatment (ReSPECT)', we suggest clarifying that the ReSPECT process is a type of ACP that specifically concerns emergency treatment and care recommendations and enables this information to be readily accessible to healthcare practitioners when decisions need to be made quickly. A wider ACP will include a broader range of issues.

21 We also suggest clarifying at the outset (rather than further down in this section) that: '*The ReSPECT form will be the regional form for recording all recommendations about emergency care and treatment*', given that other emergency care planning models exist and are not discussed in this policy.

22 We note that the policy signposts to a number of external sources of guidance (including NICE guidance) – and it may also be helpful to signpost to other sources, such as the RCUK website and the BMA/RCUK/RCN guidance on CPR.

23 Finally, we are currently updating our 'Treatment and care towards the end of life' guidance, which includes some substantial changes to the section on CPR. This update is due to be published after the deadline for comments to this consultation. We have worked closely with a number of stakeholders (including the RCUK) on updating it.

Question 10. Further comments

24 Our comments throughout this response are restricted to advance care planning in the context of health and care.

25 We suggest that the policy should be periodically reviewed and updated, including when additional provisions of the Mental Capacity Act NI 2016 come into force (for example, those on Lasting Powers of Attorney) and when the Organ Donation (Deemed Consent) bill is enacted and comes into force.

26 The glossary definition of 'Guidance' seems to be referring to two different types of guidance: clinical guidance (which may include guidance from NICE) and professional guidance from the regulators. We suggest making this distinction clearer to avoid any misunderstanding. The GMC guidance makes clear that doctors must be familiar with guidelines and developments that affect their work and that they must keep up to date with, and follow, the law and regulations (see paragraphs 11 and 12 of Good medical practice). However, our guidance does not provide clinical nor legal advice (although it is consistent with the law).