

Agenda item:	3
Report title:	Clinically Assisted Nutrition and Hydration (CANH) and adults who lack capacity to consent
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Action:	To consider

Executive summary

New guidance co-authored by the BMA and RC Physicians (RCP), on decisions about '*Clinically-assisted nutrition and hydration (CANH) and adults who lack capacity to consent*', is due to be published on 19 November 2018. We were a member of the BMA-led expert group which developed the draft guidance. We are asked to endorse the final guidance in a statement to be included in the text.

It is unusual for the GMC to endorse third party guidance beyond stating that, we are satisfied the particular guideline is consistent with our own standards. In this case, the BMA and RCP prefer a more explicit endorsement. We see strong arguments in favour of this, and some choice about the terms in which this could be expressed. The guidance meets a pressing need for up to date advice, following recent judgements in the English courts. It provides good, practical advice, to support the shift of decision-making responsibility from the courts to professionals, in some cases where CANH is the primary life-sustaining treatment for an adult who lacks capacity to decide whether it should be withdrawn. Endorsing the guidance will mean that we can delay developing up-dated GMC guidance on CANH, until about Q2 of 2019.

However there are reputational risks; if we endorse guidance on professional practice in an area of decision-making which is often seen as contentious. We anticipate strong public criticism by some campaign groups.

Recommendations

The Executive Board is asked to:

- a** Consider the background to the development of the joint guidance and our role in the process.
- b** Note key provisions of the guidance and its relationship to GMC professional standards.
- c** Consider the arguments in favour and risks for the GMC in endorsing the final guidance.
- d** Agree to endorse the joint guidance, in terms that make clear we are not according it the same status as GMC issued guidance.

The need for joint guidance

- 1 Late in 2017 a succession of court judgements in England overturned a longstanding requirement to seek a court ruling on all proposals to withdraw CANH from adult patients in persistent vegetative and minimally conscious states (PVS/MCS). In England and Wales, there is no longer a need to go to court in cases where:
 - a professional clinical guidance has been followed and
 - b the healthcare team and those close to the patient agree that it's not in the patient's best interests to continue with CANH.
- 2 This rapid shift of responsibility from the court to clinicians raises questions about whether current professional guidance adequately protects the interests of patients in PVS/MCS. Thousands of patients and their families are affected by this change. And the resulting pressure for national bodies to issue up-to-date advice grew when the Court of Protection withdrew a related Practice Direction in December 2017.

Our role in developing the joint guidance

- 3 In November 2017, the BMA and RCP set up a small expert group to lead a short-life project to develop up to date guidance. The aim was to:
 - a build on existing good practice published by the BMA, RCP and GMC
 - b incorporate learning from recent court judgements
 - c set out current clinical practice standards for managing patients with a prolonged disorder of consciousness (PDOC) which includes PVS/MCS.
- 4 We joined the group to help our understanding of the practical implications of the court judgements, and to evaluate the need for any urgent revision to our own guidance on CANH decisions.
- 5 It quickly became clear that comprehensive up to date guidance is needed and could not be delivered before mid-2018. This was going to leave an unhelpful gap for families and carers who were seeking urgent review of CANH decisions for their loved ones. And it wouldn't meet the pressing needs of the professionals, Trusts, Boards and CCGs involved in these cases. We decided to issue interim guidance, to bring together in one document relevant key principles and key standards of good practice drawn from existing guidance. This joint interim guidance was approved and published in December 2017. We advised Council about this in the February 2018 Chief Executive report.
- 6 The expert group has been working intensively since the start of the year. This includes delivering three stakeholder consultative workshops, a targeted

profession/public consultation in England and Wales, and preparation of guidance supporting materials.

- 7 The guidance sets out general principles for good decision-making with families and carers, in healthcare teams, with clinicians providing second opinions, and with staff at Trust/Board/CCG level responsible for the care of patients in PDOC. It covers in some depth the standards for good clinical care of PDOC patients and includes recommendations for service delivery to support good practice. As many of the areas covered fall outside the GMC's remit, we do not intend to become co-signatories to the final guidance. However, the BMA and RCP consider that it would be helpful for the final guidance to include an endorsement from the GMC.

Benefits of endorsing the joint guidance

- 8 The Supreme Court made a ruling in July 2018 which confirms that the requirements for reaching a best interests decision - set out in the Mental Capacity Act 2005 (MCA) - apply to all adults who lack capacity to give consent. There is no additional requirement to seek court review solely because the patient is in PDOC and CANH is being withdrawn. The judgement doesn't set out any fundamentally new decision-making principles. However it includes helpful statements about the importance of carefully applying the requirements of the MCA, and about the role of second opinions in safeguarding the interests of patients in PDOC cases. The joint guidance reflects and builds on the outcomes of this case.
- 9 We need to update our guidance on CANH decisions, to reflect the Supreme Court judgement. This involves more than small changes to the text. Since our End of Life Care (EOLC) guidance (in which our CANH advice sits) is scheduled for review from Q2 of 2019, it would be better to wait until 2019. If we delay; we will need to be able to answer questions on key CANH issues in the intervening period. The BMA/RCP guidance addresses second opinions, and other questions arising from the judgement. If we endorse the guidance; we can refer doctors to it as a reliable source of advice on these matters.
- 10 We are content that the general principles and standards in the joint guidance are consistent with current GMC guidance. Additionally, the BMA/RCP guidance provides substantial practical advice that we believe will help doctors to meet our standards in the range of settings in which patients in PDOC are being cared for. Specifically the guidance:
 - a explains in detail how the MCA 'best interests' decision-making framework should be applied to CANH decisions
 - b sets out a proportionate approach to obtaining 'independent' second opinions for assessment of a patient's condition and review of best interests evaluations

- c** describes the steps that can be taken to address known operational barriers to following good practice, including the shortage of PDOC specialists and the need for nationally recognised and auditable PDOC/CANH documentation
 - d** sets out how professionals who have conscientious objections to withdrawing CANH from patients in PDOC should act in such cases
 - e** advises on the complexities around certifying the cause of death and reporting deaths to the coroner
 - f** summarises relevant case law for the benefit of those who may be advising the healthcare team, the patient's family and carers, or the Trusts/Boards/CCGs
- 11** The BMA engagement and consultation process enabled us (the expert group) to hear from professionals, families and advocates, care home staff, legal advisers to Trusts/Boards/CCGs, Continuing Care teams, and faith-based campaign groups. Consultees were clear that, even where they do not fully support the advice given, practical advice of this kind is urgently needed. If we endorse the guidance; it will provide added reassurance for these interest groups that the standards are recognised as good practice by key national bodies.

Risks of endorsement

- 12** In the case of third party guidance; we usually only confirm that the principles and standards are consistent with those in our own guidance. Going further than this may give the impression that, in case of a complaint to the GMC, we will use the guidance as a starting point to judge the doctor's actions and decisions. There are a number of factors that make this a low risk.
- 13** The joint guidance explains our advisory role in its development, and in a number of places references GMC guidance as the standard for good practice (eg obtaining second opinions). The opening section makes clear that:
- This guidance does not provide a simple set of instructions or define rules which must be followed without reflection, but is a tool to inform and aid decision making. It does not provide easy answers, but offers an approach through which an appropriate decision may be reached.*
- 14** Where the standards describe 'best' practice, the guidance acknowledges that in some localities it may take a long time for staff and service providers to be able to ensure that all patients in PDOC and their families/carers are supported in line with best practice. For example, the second opinion safeguards require specialist PDOC assessment of the patient. As there is a UK shortage of PDOC specialists, the guidance discusses the use of video consultations, and the creation of regional clinical

networks to share knowledge and provide an outreach service in response to local demand.

15 A carefully worded GMC statement can make clear that, we support the guidance as helping doctors to practice within the law and in line with GMC standards. We welcome the sort of initiatives set out in the guidance, where they help to improve local service provision, enhance the support available to those involved in caring for PDOC patients, and create the conditions needed to ensure that health and care professionals can meet relevant standards. However our support for the guidance does not confer on it the same regulatory status as our own guidance on end of life care and CANH decision-making.

16 As an example; we endorsed the Academy's guidance for doctors and nurses in *Responsible Consultant/Clinician roles* through an accompanying statement:

A key recommendation from the Francis report was for every patient admitted to hospital in England to have a named, identifiable clinician assigned to them. They are known as a responsible consultant or clinician. We support this initiative, which will help to make sure care is properly coordinated and that patients and those close to them know who to speak to if they have questions or concerns about their treatment. [2014]

17 We will table a draft statement at the 29 October 2018 meeting.

18 Clearly, the stronger our endorsement of the guidance, the stronger might be the tone of any public criticism directed at us by those who object to certain aspects of the guidance.

19 A number of mainly faith-based organisations consider that, irrespective of the Supreme Court's ruling, it is wrong on moral grounds to permit CANH to be withdrawn where a patient is in a PDOC state and does not have capacity to consent. Some consultees consider that the courts are wrong to shift responsibility for the final CANH decision back to clinicians and families – they would prefer to see an alternative statutory form of independent review. Some of those who have concerns about the court judgement view the guidance on conscientious objection as insufficient, to shield them from any duty to engage in treatment withdrawal or from criticism for expressing objections to a patient's healthcare team and family.

20 If we limit our support to confirming that the guidance is consistent with our standards, we don't believe this will deflect public criticism from these groups. A more specific statement (along the lines of paragraph 16) can make clear that we think the guidance supports doctors to act within the law and continue to practice in a way that serves the interests of patients.

- 21** In conclusion; we recommend GMC endorsement of the BMA/RCP guidance, to be expressed in terms that make clear the guidance does not have regulatory status.