Submission to UK Parliament Joint Committee on Human Rights

Legislative Scrutiny: Health Service Safety Investigations Bill

This written evidence is submitted by the Christian Medical Fellowship (CMF). CMF represents some 5,000 clinicians in a wide variety of settings across the UK and is partnered with about 80 similar organisations globally. We would be most grateful to be considered for oral evidence.

Executive Summary

We suggest four areas of health service safety for legislative scrutiny by the Committee:

1. **The complete absence of recording and auditing of decisions to withdraw clinically assisted nutrition and hydration (CANH) from patients lacking capacity, despite recommendations from the Royal College of Physicians (RCP), the British Medical Association (BMA) and the General Medical Council (GMC).[1] [2] We present evidence from FOI requests made to all NHS Acute Trusts, CCGs and the CQC.**
2. **The continuing absence of a National Register of patients with prolonged disorders of consciousness (PDOC), seven years after the RCP first made the recommendation.**
3. **Safety concerns around**
   a) **the proposal to extend the 2018 BMA/RCP guidance on CANH withdrawal to other forms of life-sustaining treatment, such as dialysis, insulin or ventilatory support**
   b) **the proposal to widen the scope of the 2020 RCP guidance. At present, this guidance applies only to a relatively small number of patients - those in prolonged disorders of consciousness known as vegetative or minimally conscious states, following sudden-onset brain injury. The proposal to widen the scope of the guidance to include those with multiple co-morbidities, frailty and neuro-degenerative disorders,[3] including dementia, would affect a very much larger number.**
4. **The 'hidden' nature of deaths following CANH withdrawal from patients with PDOC, that will hinder the work of Medical Examiners and researchers.**

We summarise recommendations to the Committee in our Conclusions

1. The safety of decisions made to withhold or withdraw nutrition and hydration from patients lacking capacity

[1] British Medical Association and Royal College of Physicians. *Clinically assisted nutrition and hydration (CANH) and adults who lack the capacity to consent:* Guidance for decision-making in England and Wales. London: BMA and RCP, 2018:44-45

[2] Royal College of Physicians. *Prolonged Disorders of Consciousness following sudden onset brain injury*: National Clinical Guidelines. RCP London. March 2020.

[3] Ref 1 ibid:14

1.1 The decision-making process for initiating and withdrawing clinically assisted nutrition and hydration (CANH) treatment in patients who lack capacity to give consent has changed dramatically over the last 30 years in England and Wales. The legal framework now emphasises that the principal requirement is to determine if it is in the best interests of the patient for treatment to be given, and the illegal nature of continuing or starting treatment if this is not the case.

1.2 'Best interests' decisions about CANH should now be made with reference to the patient's previously expressed wishes, beliefs and values with an emphasis on whether the best-case scenario for prognosis would lead to a quality of life the patient would regard as worthwhile.

1.3 Following the Supreme Court's 2018 judgement in the case of *An NHS Trust vs Y*,[4] such decisions should be made at local level without reference to the courts, except in cases where there is unresolvable disagreement. Their Lordships ruled that compliance with Art. 2 of the ECHR is dependent on the existence and practical application of a regulatory framework, such as that provided by General Medical Council (GMC) guidance.

1.4 (Their Lordships may have had in mind *Calvelli and Ciglio v. Italy* [2002][5], in which the Court confirmed that 'the positive obligations under Article 2 require States *"to make regulations compelling hospitals to adopt appropriate measures for the protection of their patients' lives" and to have in place "an effective independent judicial system to be set up so that the cause of death of patients in the care of the medical profession … can be determined and those responsible made accountable."*')[6]

1.5 The safety of this process relies on accurate diagnosis and prognosis, confident ascertainment of the person's previous wishes and the absence of any conflicts of interest or conscious or unconscious bias. Circumstances may be complex, and It can be fiendishly difficult to safeguard these decisions.

1.6 This was well-illustrated in the recent case of *Barnsley Hospital NHS Foundation Trust v MSP* [2020].[7] A man with a history of mental health issues and chronic gastrointestinal disease made clear to his family (and in an unwitnessed 'advance decision') his wish not to live with an ileostomy. Later, faced with the need for urgent surgery that might leave him with a stoma long term, and presumably in sepsis and pain, he consented to the operation. The surgeon was unaware of the advance decision. When the patient's wishes were made known by his family, following surgery, the hospital referred the case to the Court of Protection. Justice Hayden had to decide whether to honour the unwitnessed advance decision document, interpret consent to surgery as a change of mind by the patient, or wait for the patent to be weaned off ventilatory support and analgesia post-operatively until he could make his wishes known.

1.7 In the event, Justice Hayden ruled that the patient's best interests would be served by keeping him deeply sedated and withdrawing nutrition and hydration. MSP was not terminally ill. He lacked capacity only because he continued to receive heavy sedation following surgery. What it appears took place was essentially euthanasia by omission (of CANH) and increasing terminal sedation. MSP was made to die and did so within a few days. Even if his advance decision is accepted as reliable, this appears to amount to assisted suicide.

1.8 This case only came to light because it was brought to the attention of the Court. Whether the provisions of the 2005 Mental Capacity Act were fully satisfied is another question. It was certainly a complex and difficult case to decide and full clinical details are not available to us.

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[4] An NHS Trust & Ors v Y & Anor (Rev 1) UKSC 46, (2018).

[5] Calvelli and Ciglio v. Italy, Grand Chamber judgment of 17 January 2002

[6] Calvelli and Ciglio v. Italy (2002), p.48. Quoted in Council of Europe Human Rights Handbook on the Right to Life (2006); p.79 https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=090000168007ff4e. (Accessed 07.09.2020)

[7] Barnsley Hospital NHS Foundation Trust v MSP [2020] EWCOP 26

However, it does illustrate the need for a system of open and robust scrutiny for the many more cases that do not come to Court.

1.9 To help safeguard the process of decision-making under such complex circumstances, given that referral for judicial scrutiny is no longer a requirement, the published guidelines recommend the collection and audit of data around decisions regarding CANH withdrawal, and for this data to be included in external inspections by the Care Quality Commission (CQC)/Health Inspectorate Wales and by Medical Examiners (MEs).

1.10 Two years after the publication of the RCP/BMA guidance recommending such monitoring, Freedom of Information requests were made by us between January and March 2020 to Acute and Specialist Hospital Trusts and CCG's in England. A total of 342 were approached, which represents 95% of providers, with an overall response rate of 88.8%. The responses show that no Trust keeps a register of such deaths or has arrangements for auditing them.[8] The CQC in response to an FOI request also has stated that it does not require such information to be made available as part of its inspections.

1.11 The safety of the process to limit or withdraw CANH depends on external scrutiny. At present, such scrutiny is entirely lacking.

2. The continuing absence of a National Register of patients in Prolonged Disorders of Consciousness (PDOC)

2.1 There is a dearth of information about patients in PDOC. It is not clear how many such patients there are in the UK and there is no consistent information on long-term outcomes for such patients. Systematically collected longitudinal data is required to identify patients with PDOC, to monitor/track them through the course of their condition, and to facilitate research.

2.2 In its 2020 National Clinical Guidelines: *'Prolonged disorders of consciousness following sudden onset brain injury',*[9] the Royal College of Physicians (RCP) reiterates its 2013 recommendation to establish a national registry and agreed minimum dataset for the collection of a national cohort of longitudinal outcome data for all patients in PDOC. This recommendation was previously endorsed in the BMA/RCP/GMC guidance of 2018.[10]

2.3 **Seven years after the RCP first made this recommendation, there exists no such register**.

3. Safety concerns around decisions to withdraw other life-sustaining treatment

3.1 The 2020 RCP PDOC Guidelines note that the framework proposed for managing CANH in patients with PDOC could also be helpful when considering other life sustaining treatments such as dialysis, insulin or ventilatory support.[11] There is, however, no systematic data collection regarding deaths arising as a result of such treatment withdrawal and no recommendation for external scrutiny.

3.2 **In our opinion, it would be entirely inappropriate to widen the scope of such decisions to other treatments before a robust monitoring system is in place for CANH, its results monitored, and the process strengthened as necessary.**

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[8] Gray A, Sturman SG. 'Withdrawal of Clinically Assisted Nutrition and Hydration (CANH) and Other Treatments – Absence of Monitoring or Scrutiny is Cause for Concern'. London, CMF, May 2020

[9] Ref 2 ibid:64.

[10] Ref 1 ibid:55

[11] Ref 2 ibid:115

3.3 The 2018 BMA guidance extends CANH withdrawal to groups of patients other than those with PDOC. Specifically mentioned are patients with multiple co-morbidities, frailty and neuro-degenerative disorders,[12] cumulatively a far larger number than those with PDOC. Best interests decision-making can be influenced by individual philosophy and institutional culture, conflicts of interest and conscious or unconscious bias. Robust external scrutiny is therefore essential to reassure society that this is a safe and humane process. Presently, that scrutiny does not appear to exist. **We believe it unwise to consider extending CANH withdrawal to new groups of patients before an effective system of monitoring is in place for its withdrawal in patients with PDOC.**

4. Recording deaths following CANH withdrawal

4.1 A new Medical Examiner (ME) system is being rolled out across England and Wales. MEs will provide independent scrutiny of all deaths not referred to the coroner and provide a point of contact for bereaved families to raise concerns about the care received by their loved ones prior to death.

4.2 As part of their role, MEs will audit data surrounding decisions to withdraw clinically assisted nutrition and hydration (CANH) from patients with Prolonged Disorders of Consciousness (PDOC). Together with the Care Quality Commission/Health Inspectorate Wales, they will monitor the effect in practice of the 2018 Supreme Court ruling (in *An NHS Trust vs Y)* that removed the legal requirement for cases where CANH withdrawal is under consideration to be brought before the Court, provided there is agreement upon what is in the patient's best interests and that the provisions of the MCA 2005 are followed and the relevant guidance observed.

4.3 **The safety of the 2020 RCP PDOC Guidelines in practice depends upon robust independent scrutiny and easy access to relevant information by those conducting the audit. The withdrawal of CANH (or other life-sustaining treatments (LSTs), such as dialysis or ventilatory support) is not presently recorded on the Medical Certificate of Cause of Death (MCCD). It would enable external scrutiny by MEs, as well as data collection by researchers, if there was some obligatory, formal and easily accessed mechanism to record when a death had occurred following withdrawal of CANH or other life-sustaining treatment.**

4.4 According to the Council of Europe's Handbook on Article 2, the European Court of Human Rights has held that 'Article 2 imposes a "positive obligation" on States to investigate deaths that may have occurred in violation of this article.'[13] Perhaps an additional clause in the HSSI Bill should amend the Coroners and Justice Act 2009 to require that any circumstances indicating that deaths may have occurred in violation of Article 2 - **including details of any withdrawals of LSTs preceding a death** - are formally recorded and explicitly drawn to the attention of the ME/senior coroner.

4.5 We suggest this simple step would help to protect the human rights of people lacking capacity and ensure the safety of the RCP Guidelines in practice.

Conclusions

[12] Ref 1 ibid:14

[13] https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=090000168007ff4e, page 7.

1. **We recommend that the accurate recording and internal audit of data relating to deaths following the withholding or withdrawal of CANH from persons who lack capacity be made a statutory responsibility of NHS Acute Trusts and CCGs. We further recommend that responsibility for external scrutiny of these processes be included in the statutory duties of the CQC/Health Inspectorate of Wales.**
2. **We courteously suggest that seven years is an excessively long period to wait for a national register of patients with prolonged disorders of consciousness. Without the ability to identify this cohort of patients, it is impossible to track treatment outcomes and safeguard 'best interests' decision-making.**
3. **We recommend that the withdrawal of other life-sustaining treatments from a wider group of persons who lack capacity be expressly forbidden until a robust monitoring process is in place for CANH withdrawal from those with PDOC, and that process has been in operation long enough to reveal if changes need to be made.**
4. **We recommend there be some obligatory, formal and accessible mechanism by which to indicate when a death has occurred following withdrawal of CANH or other life-sustaining treatment. This would facilitate external scrutiny by Medical Examiners and data collection by researchers.**