“Decision-making about life-sustaining treatment for patients with severe brain injury”

Summary Report by Jenny Kitzinger
of expert workshop held at
Green Templeton College 19th March 2026

Table of Contents

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Executive Summary

A workshop was organised for 19th March 2026 to bring together key experts to spend a day discussing strategies for improving decision-making about life-sustaining treatment for severely brain-injured adult patients (in the context of the law in England and Wales). The intention was to focus on how ‘clinical decisions’ were made about what treatments were on offer, and, if treatments *were* on offer, then how ‘best interests’ decisions were made – and to focus on how to ensure both forms of decision-making were robust and transparent and that there was good communication with patients’ families.

The March workshop had been planned since Autumn 2025 but turned out to be particularly timely because on the 3rd March 2026, the Court of Appeal (the highest court within the Senior Courts of England and Wales) handed down the - *Townsend v Epsom and St Helier NHS Trust* [2026] EWCA Civ 195 judgment. This prompted an explosion of interest in the medico-legal communities – particularly around the statement that ‘*There is no carve out for “clinical decisions*”.’ (para 69) and the indication that if families disagree with a decision not to offer a treatment to their relative (who lacks capacity to make decisions about their treatment) then the relevant NHS commissioning body should fund and make an application to the Court of Protection. This judgment appeared inconsistent with long-established principles of medico-legal decision-making and the workshop was rapidly adapted to engage with the Court of Appeal judgment.

The eighteen workshop participants included nine intensivists and neuro-rehabilitation consultants and five barristers and solicitors, all with extensive experience in life-sustaining treatment decision-making (in the clinic and/or in the courts) alongside participants with policy roles, social science research or personal family experience.

The discussion raised a wide range of concerns about the potential effect of the *Townsend v Epsom* judgment on the operation of the Court of Protection [CoP], on clinical practice and on families and patients.

Concerns expressed by some participants included:

- the way in which the judgment fitted, or not, with other case law and the scope of the judgment and how it had been written.
- the challenges of referring all the potentially relevant cases to CoP given the huge number of decisions clinicians make every day about what treatments are, or are not, appropriate to offer, and the pressures this would put on the legal process.
- the impact any increase in applications to the CoP would have in terms of escalating legal costs for the NHS and delays in decision-making, alongside the

additional demands on clinicians' time, and the stress for clinical teams involved.
- the potential inequalities the judgment might create between patients with and without capacity to consent to treatment
- the potential of the judgment to distort doctors' decision-making (e.g. complying with demands for more treatment in order to avoid court proceedings).
- the mismatch between the process and timescale of clinicians' decision-making at the bedside and the timescale of court proceedings, even in 'emergency applications' – particularly for patients in acute or terminal conditions.
- the questionable value of CoP intervention when the court could not, in any case, order doctors to provide a treatment they were not prepared to offer.

Although participants recognised that some families would see the judgment as empowering (and through them empowering their relative), some had concerns about possible impacts included:
- raising unrealistic hopes for families that a judge could change what treatment was on offer.
- entangling friends and relatives in legal proceedings when they could be spending precious last moments with their loved one.
- mis-leading people about the potential value of a medical intervention
- making families carry more guilt about the decision and their involvement in agreeing to, or contesting it (whether the decision was made to give/continue or withhold/discontinue life-sustaining treatments) and
- risking over-treatment of patients, and families facing the consequences of their relative left in a condition the person would not have wanted.

Some workshop participants did not view the *Townsend v Epsom* judgment as improving outcomes for patients.

Additional discussion during the day explored:
- the challenges around writing professional guidelines about life-sustaining treatments.
- the process of making and defining clinical judgement about what treatments should/should not be on offer.
- the timing of decisions to discontinue (potentially) life-sustaining interventions
- resource issues and policy decisions.
- the importance of good communication and documentation about the patient's condition, consultation about their values and beliefs, and clarity about decision-making processes
- and approaches to addressing disputes.

The full report addresses all these related issues in more depth.

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Context

Workshop development and funding

This workshop was designed to bring together legal, social science and clinical experts to focus on strategies for improving decision-making about life-sustaining treatment for severely brain-injured adult patients. It was funded as part of the Sheila Kitzinger Programme at the Green Templeton College, Oxford University[1]; with additional support from Cardiff University, Coma and Disorders of Consciousness Research Centre[2]. Plans for the day were developed by Professor Jenny Kitzinger and Professor Lynne Turner-Stokes and the bid to Green Templeton College for this event was submitted in Autumn 2025.

The original plan was for a morning focussed on how clinical decisions are made about which treatments are appropriate to offer and an afternoon focussed on how, once a treatment *is* on offer, best interests decisions are made for severely brain-injured adults who lack capacity to consent or refuse on their own behalf, taking into account the patient's values, beliefs, wishes and feelings in accordance with the Mental Capacity Act 2005. A key aim for the workshop as a whole was to clarify this distinction between (a) 'clinical decisions' about whether or not to offer a treatment and (b) 'best interests' decisions about whether or not to consent to treatments on offer and to work together to consider how to improve good practice in both forms of decision-making, share existing resources and potentially produce some additional resources to support this.

However, a couple of weeks before the workshop an unprecedented judgment was handed down by the Court of Appeal - *Townsend v Epsom and St Helier NHS Trust* [2026] EWCA Civ 195. This threw into question the entire framing of the workshop and challenged the "*established principles of medico-legal decision-making underpinned by case law, statute and guidance".*[3] So adaptations had to be made.

The Court of Appeal judgment: *Townsend v Epsom and St Helier NHS Trust*

The *Townsend v Epsom* Court of Appeal judgment concerned a previous decision made in the Court of Protection [CoP] - *Lesley Townsend v Epsom and St Helier University Hospitals NHS Trust [2026] EWCOP 14 (T3).* A daughter (Lesley Townsend) sought permission to bring an application to the CoP relating to the medical treatment of her severely brain-injured father, Robert Barnor – particularly regarding

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[1] https://www.gtc.ox.ac.uk/academic/health-care/sheila-kitzinger-programme/. Thank you to Green Templeton College, Oxford for hosting the event and particularly to Ruth Scobie for all her organisational support. Thanks also to Daniel Clark who was notetaker for the day.

[2] We are grateful to Darren Smith who raised donations in memory of his wife, Jenny Smith.

[3] This Capsticks blog goes on to state: "It had always been the case that there was a first step, which applies to all clinical decision-making for any patient with or without capacity, where a doctor exercising professional skill and judgment determines the appropriate clinical options. This approach has been supported in Supreme Court decisions such as *Montgomery v Lanarkshire Health Board*. This is not a decision taken under the MCA. The Court of Appeal's judgment does not appear to give space for any decision-making other than on a MCA best interests basis." https://www.capsticks.com/insights/clinical-decisions-versus-best-interests-the-court-of-appeals-judgment-in-townsend-v-epsom-and-st-helier-nhs-trust -

ongoing dialysis[4]. Permission to apply to the CoP was refused by Mrs Justice Theis, the Vice-President of the Court of Protection, on the ground that the medical decision-making process had concluded that dialysis was no longer on offer and the CoP is in no different position when acting as proxy for someone who lacks capacity than a person with capacity would be – the court cannot require a clinician to provide a form of treatment that is unavailable or not clinically indicated. The judge concluded that there was no option for the Court to consider and therefore the application had no prospect of success.

The Court of Appeal overturned the decision to refuse permission to apply to the CoP. The *Townsend v Epsom* judgment from the Court of Appeal states that any decision about the care and treatment of a mentally incapacitated adult, including the withdrawal of life-sustaining treatment, must be taken in the patient's best interests and that: '*There is no carve out for "clinical decisions".'* [para 69]. The Court of Appeal directed that the case be re-considered by the Court of Protection, but Robert Barnor died before this could happen.

The Court of Appeal judgment is seen by many legal/clinical commentators as having potential to '*fetter clinical discretion'*[5] and to throw out the established practice whereby a doctor exercising professional skill and judgment determines the appropriate clinical options first – and then offers those treatments to the patient.

The judgment also changes the way any dispute about a 'clinical decision' not to offer treatment might be taken to court. Previously it was considered that contested cases where a clinical decision has been made not to offer treatment should be made to the Administrative Court. The Court of Appeal judgment states that these cases for patients who lack capacity to make treatment decisions should go to the Court of Protection (for 'best interests' determination) and applications should be brought and funded by the NHS commissioning body with overall responsibility for the patient.

At the time of writing this report permission is being sought by the Trust to appeal this judgment to the Supreme Court (the final court of appeal in the UK).

Workshop participants and structure

The '*Townsend v Epsom'* judgment (as it is commonly abbreviated), handed down by the Court of Appeal on 3rd March 2026, necessarily shifted the priorities for the workshop scheduled for a fortnight later. It also meant two participants pulled out a few days before the workshop because of potential conflict of interest (due to preparations for a potential appeal to the Supreme Court). In addition, it was clearly important to invite additional participants, including, for example, from professional bodies whose guidance was affected by the new ruling: the General Medical Council

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[4] Lynne Turner-Stokes had been asked to advise the clinical team about the decision-making process in this case given her expertise as chair of the Guidelines development group for the Royal College of Physician's national clinical Guidelines for patients in PDOC. The advice she provided is detailed within the Court of Appeal judgment.

[5] https://www.capsticks.com/insights/clinical-decisions-versus-best-interests-the-court-of-appeals-judgment-in-townsend-v-epsom-and-st-helier-nhs-trust -

(GMC) and the British Medical Association (BMA). We are grateful for everyone's flexibility and willingness to clear diaries and adjust talks for the day.

The workshop opened with presentations about the shifting legal context, and reflections on current clinical and legal practice and the implications of the Court of Appeal's ruling in *Townsend v Epsom.* We then discussed the processes involved in contested and uncontested decision-making about life-sustaining treatment, including both family and clinical perspectives, and looked at professional guidelines (with a particular focus on 'clinical' and 'best-interests' decision-making).

The 18 expert workshop participants (see biographies in Appendix) were:

- five intensive care consultants: Dr Chris Danbury, Dr Sonya Daniel, Prof Dan Harvey, Dr Miriam Fine-Goulden, Dr John Gorst;
- four neuro-rehab consultants: Prof Lynne Turner-Stokes, Dr Derick Wade, Dr Andrew Hanrahan, Prof Diane Playford;
- three solicitors: Kiran Bhogal, Gavin Knox, Hannah Taylor:
- two barristers: Victoria Butler-Cole KC and Vikram Sachdeva KC.
- Veronica English (Head of medical ethics and human rights at the BMA)
- Jessica Watkin (Policy Manager – Standards and Ethics – at the GMC)
- Prof Jenny Kitzinger (co-director of Coma and Disorders of Consciousness Research Centre, Cardiff University);
- Prof Clare Elwell (Professor of Medical Physics at University College London, but participating as someone with personal experience of decision about life-sustaining treatment in relation to her husband who was severely brain-injured in 2020).

The workshop was conducted under a modified Chatham House rule - no quotes to be attributed without explicit consent but a list of participants to be published. It was not audio-recorded but detailed notes were taken by Dr Daniel Clark (Research Fellow in Open Justice at the University of Sussex) and this report summarises key themes identified from the presentations and discussion.

Key themes

Clarification of the judgment in context

Presentations and discussion examined the *Townsend v Epsom* judgment and raised a wide range of issues. Comments and questions included:

- Whether the judgment was intended to mean what it seems to mean (i.e. that all formerly 'clinical decisions' come under the scope of 'best interests') so massively extending the scope of CoP jurisdiction. For example, an intensivist highlighted the fact that there are around 300,000 admissions to ICU a year and disputes around life-sustaining treatment are common. It would be impossible, in practical terms, for applications to be made, or for the COP to deal with, the potential number of cases.
- The coherence of the judgment and the conditions under which this Court of Appeal judgment was written: *"they didn't have very long to think about it or figure out what they were going to say".*

- The ‘interesting’ interpretation of existing case law referenced in the judgment and lack of reference to other relevant court decisions which give a different interpretation of the law.[6]
- The unusual action of taking down and amending the judgment shortly after publication (to add a specification relating to *“the continuation of life-sustaining treatment”*).
- The general nature of some of the statements in the judgment, such that (even given the amendment to specify *‘continuation of life-sustaining treatment*’ in one paragraph) the implications remain very generalised (including potentially relating to decisions about care packages, treatment escalation plans and decisions about Do Not Attempt Cardiopulmonary Resuscitation).
- The status of resource policy decisions. Questions were asked, for example, about what the judgment might mean in relation to a care package or treatment that was not on offer on the basis of costs (e.g. where a Local Authority refused to pay for home care instead of a nursing home placement or where a drug was not available because it was not approved as cost-effective by NICE).
- Concern was also raised about the potential inequality created by the judgment: - it applies only to ‘mentally incapacitated’ adults; it does not give the same ‘rights’ to those with capacity to make their own decisions about treatment options.[7]

The rest of this report summarises the points raised in the workshop relating to life-sustaining treatment for severely brain-injured adults, since this was the focus of the workshop.

For the family who brought the *Townsend v Epsom* case (and for the charity, Christian Concern, which supported them) the judgment was welcome as potentially:
increasing accountability and scrutiny of decisions about life-sustaining treatment ensuring better patient-centred care; helping to protect the principle of sanctity of life; empowering families (and thereby ensuring a greater ‘voice’ for the patient).

A different perspective was evident among some of the workshop participants in Oxford. The following highlights issues raised during the day.

Implications for legal proceedings

The *Townsend v Epsom* judgment will inevitably lead to more disputes being referred to the Court of Protection. Workshop participants believed that the consequence of this could be:

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[6] A blog by Alex Ruck-Keene highlights the point that the judgment does not refer to the decision of the Court of Appeal in *AVS v A NHS Foundation Trust & Anor* [2011] EWCA Civ 7 which *“is to very different effect”,* nor does it refer to *Medmoune v France* in the Strasbourg court*, which “retained and emphasised a very clear space for clinical discretion in the context of decision-making relating to those with impaired decision-making capacity”* https://www.mentalcapacitylawandpolicy.org.uk/is-there-space-for-clinical-decision-making-in-relation-to-incapacitated-adults-the-ca-pronounces/.

[7] This point is spelled out by Alex Ruck-Keene who notes that observations made in the *Townsend v Epsom judgment* are at odds with the decision of the Supreme Court in *ACCG*, “*which made very clear that those lacking decision-making capacity should not get less, but cannot through the prism of best interests demand more, than those with decision-making capacity.”*
https://www.mentalcapacitylawandpolicy.org.uk/is-there-space-for-clinical-decision-making-in-relation-to-incapacitated-adults-the-ca-pronounces/

- delays in decision-making for the individual patient
- an increase in backlogs for access to court for other hearings before the CoP
- a knock-on impact on legal teams advising health services (‘*Do I have to double my legal team?*”).

Some participants also raised concerns about:

- Implications of the court making best interests decision in relation to a treatment that doctors are not prepared to offer (given the court can’t compel doctors to offer treatment).
- That the judgment could put the legal teams advising healthcare organisations in a difficult position: *“Lawyers need to manage what the Court of Appeal have said. If doctors have decided a treatment is not clinically on offer, what’s the point of CoP application?”*– and what impact would making an application (or not) have on all concerned?
- The implications of the CoP potentially attempting a light touch CoP review of contested clinical decisions not to offer a treatment. This was in response to a suggestion in the judgment that an *“abbreviated process”* (para 74) could be used where clinicians do not consider certain treatment options to be clinically appropriate. What would an “abbreviated process” involve, and would this really mitigate the sort of negative risks outlined above?

Implications for healthcare organisations and clinical practice

Concerns discussed in the workshop included:

- The appropriateness of specifying that application should be brought and funded by the NHS commissioning body (rather than, for example, the hospital Trust) and the costs of this to the health service regardless of which part of the health service had to pay for the application
- The demands on clinical time (and effects on all patients) when clinicians have to spend time involved in court proceedings.
- The court process itself – which can at times feel adversarial and polarises different viewpoints to the extent that it can contribute to a breakdown in relationship between the family and treating team, making it very difficult to continue to offer truly patient-centred care.
- The levels of stress and intense moral distress experienced by health care providers when they are involved in giving (or disputes about) treatment that they believe should not be on offer (and the impact on staff morale, recruitment and retention). *“A single case can literally blow apart a unit…we will increasingly see it in adult intensive care”.*
- Clinicians highlighted the very high number of decisions not to offer to start or continue life-sustaining treatment that are made in the intensive care setting; one commented that “*if we went to CoP every time a family wanted to dispute a decision not to offer a treatment it would bring the NHS to its knees because as clinicians we make thousands of decisions a day”.*
- The potential of the judgment to distort doctors’ decision-making towards sometimes *not starting* life-sustaining treatment (even for ‘a trial’), rather than confront the potential difficulties of later discontinuation.
- The potential to distort doctors’ decision-making towards simply *continuing* ongoing treatment ‘as “*the path of least resistance*” (rather than having to initiate court

proceedings). "*Some clinicians will acquiesce [to family demands for treatment] or think "is it for the greater good of the intensive care unit NOT to take this to the Court of Protection?"* Clinicians gave examples where they believed this was already happening.

Some participants highlighted the mismatch between the process of clinicians coming to the decision not to offer life-sustaining treatment and how courts operate. Concerns included:

- The ability of judges to assess why clinicians might not offer a particular treatment: *"Judges have detailed knowledge of the law but little clinical knowledge".*
- The different timescales available to understand a case and ability to respond to unfolding clinical realities; as one clinician commented: "*a judge's bad decision is written in stone, it can't be undone for months; but a bad clinical decision – I can ponder it and ring the ward and reverse it."*
- the mismatch between legal procedures and the urgency and shifts in decision-making and clinical issues for patients in an acute condition or terminal phase of an illness when decisions can be particularly time sensitive. "*The court process is not fit for purpose in rapidly moving cases".*
- The risk of patients ending up with difficult and poorly manged deaths, including dying with inadequate pain relief. One neuro-rehab consultant gave two examples where legal advice was sought within 24 hours of discovering a dispute, it took 3-4 days to assemble the court bundle and elicit an external opinion: an urgent hearing was allocated, but then cases were adjourned for several weeks. Both patients died unpalliated.

Workshop participants gave accounts of the impact of some of the above factors even *'pre-Townsend'* – and anticipated that such problems would be increased by the *Townsend v Epsom* judgment, some were already involved in cases which were having to be handled differently.

Implications for families

Risks of the Court of Appeal judgment in this case identified by some workshop participants were as follows:

- Raising unrealistic hopes for families that a court will be able to ensure a treatment is given to their relative when in fact that treatment is not on offer, and the courts can not compel doctors to provide it.
- Entangling families in legal proceedings when they could be spending the precious last moments with their loved one.
- Doctors putting options on the table that previously would have been dismissed as clinically inappropriate leading to some 'over-treatment' of patients.
- Some families feeling compelled to 'accept' any treatment that is 'on offer' in order to fulfil a commitment to 'fight to the end'. Some people will assume that if a treatment is offered, then it is an option doctors might recommend. Some may feel that as the patient's mother/brother/son they are duty bound to agree to any life-sustaining treatment that is put on the table.
- If families are involved in decisions *not* to proceed with offered treatment (however tentative the offer, and however clear the disadvantages for the individual concerned), families might feel implicated in decisions (with all the guilt and burden that carries).

Implications for patients

Related to all the concerns outlined in the other sections some workshop participants did not view the *Townsend v Epsom* judgment as improving treatment decision-making and outcomes for patients.

Implications for professional guidelines

There was discussion of the range of formal processes followed for the development of different guidelines and about the way in which professional guidelines may be shaped by a variety of factors including trying to codify, defend and improve best practice and reduce unreasonable variability. One clinician suggested that updates to some guidelines can be informed by new research or contexts, and may also take into account how guidance might "*land with the public". He* commented that, given the "culture wars" around end-of-life decision-making, professional bodies may need to be sure they had the support of the Department of Health on some issues (e.g. re resource realities).

One point made was that *"if guidelines are part of the solution, then how they are produced is part of the issue".* Discussion explored the lack of time and resources to develop and update some of the professional guidelines (for example time is often given voluntarily on top of full clinical loads). This is in stark contrast to the resources that might be concentrated on a single court case.

It seems likely that some professional bodies might, in the short term, only be able to offer updated addendums to existing guidance providing interim guidance reflecting on *Townsend v Epsom*.

Discussion in the workshop explored the way in which some guidelines might not always have contained a lot of emphasis on the established distinction between the 'clinical decision to offer' and best interests process 'to give' a treatment (or not). The reason may be because this was such an established principle and the focus had been on the starting point for best interests decision-making and how to ensure the best interests process was developed. Making such a distinction was seen as important – but also something that might have to be completely revised (especially if the appeal to the Supreme Court is unsuccessful).

The value of development of additional resources alongside guidelines (e.g. to support family/friends in understanding their role in decisions) was highlighted.

Clarity in the language used was discussed. Concern was raised by two participants about the use of terms such as 'medical best interests' in medical notes or 'clinical interests' in guidance (which do not fit with the language in the Mental Capacity Act 2005 and were seen as eliding clinical and best interests decisions even if the guidance 'taken in the round' was clear).

Although guidance needs to be consistent with the law, it may not always use the language of the law – and some terms are used because legal terminology can differ across the UK (e.g. The legal term ‘best interests’ is used in England, Wales and Northern Ireland - and ‘benefit’ is used in Scotland.)

Alongside discussion of the implications of the judgment workshop participants highlighted key issues in ongoing decision-making and as outlined below.

Definitions and understandings of when a treatment is ‘not on offer’?

The Townsend v Epsom judgment which states there is NOT a *carve out for “clinical decisions”* was seen by some as, in part, an outcome *of “a lack of conceptual work”* in the area.

> *“There’s no clear place where conceptual work is done that draws the distinction [between a decision not to offer a treatment and a decision that it is not in a patient’s ‘best interests’ to have it]. Resources are in the mix but people don’t say that. So the explanation needs to be given as to how the lines are drawn in a way that makes sense to judges who don’t know how these cases work in real life.”*

Issues highlighted included:

- The difficulty of getting a clear answer from clinicians to the question of whether or not a treatment was on offer (e.g. in previous hearings in CoP).
- Problems in how clinicians had communicated with families and written notes e.g. “*The pathway is muddled when someone says a treatment is not on offer ‘because it is not in the patient’s best interests’.”*
- The fact that CoP has in some cases made best interests decisions in situations where treatments do not actually seem to have been on offer e.g. the CoP making a judgment “*that it’s not in P’s best interests for CPR to be attempted, where evidence from doctors is that they think it’s unconscionable and unethical.”*

This led to a great deal of discussion about:

- The value of clarifying the definition of, and process involved in, decision-making
- The value of clarifying the range of reasons a treatment might not be on offer (this can include that a treatment will not deliver any clinical benefit at all, or might even hasten, death).
- The potential problems of trying to define ‘a clinical decision’ in this area so precisely as to produce just another set of guidelines that might be picked over in court in a complex medical situation in a way that was not useful or appropriate.
- Ensuring explicit clarity in communication with families/friends of the patient, and equally detailed and explicit clarity in what is written in the notes, and routinely copying detailed clinical notes to the family could help ensure consistency in the message given.

Starting/continuing, trials and timing around treatment decisions

In principle, the law makes no distinction between decision-making in relation to ‘starting’ versus ‘continuing’ treatment. Clinicians participating in the workshop were clear that, in practice, they feel different and can prompt different reactions from family/friends of the patient. The following points were discussed in the workshop:

- In intensive care settings all treatments are ‘trials’ in so far as it is often uncertain what the interventions can achieve.
- *“Inflection points”* in clinical practice are important - such as when a tube needs replacing, becomes blocked or dislodged. “*The inflection point allows space to re-consider benefits and risks. There’s no way of knowing on first admission [to ICU] what will happen.”* These ‘inflection points’ are important for how some clinicians approach decisions – *“it’s not a withdrawal, it’s a refusal to start again*” – but the point was also made that *“You can’t just rely on the fact that there needs to be a new dialysis line to make unilateral decisions”.*
- The challenges of discontinuation after a lengthy period of treatment: “*When something has been done for six months, and now doctors think it should stop, it’s harder to say why it’s not clinically appropriate anymore.”*
- The value of explicitly framing *“trials of treatment”* against a specific time scale or to be checked against events (e.g. a clinical change) (e.g. to ensure clinicians do a review and to help set family expectations).

Resource issues

Resources were highlighted as a distinct reason why a treatment might not be available.

- Workshop participants discussed the lack of a clear system for addressing the resource implications around continuing some life-sustaining interventions in certain situations (unlike the NICE oversight of cost-effectiveness for life-extending drugs for example).
- A neuro-rehab consultant made the point that many more adults are now surviving acquired severe brain injury and that: “*Keeping someone alive in PVS costs around 150-200k a year (equivalent of 20-30 hip replacements). This is not a clinician’s problem but it is for commissioners because they have finite resources”.*
- Another clinician highlighted the growing need for resources and commented on the number of severely disabled children who survive due to paediatric intensive care and now graduate to adult services.
- Another highlighted the fact that the median length of stay in ICU is about 3 days and most patients spend 5 days or less on ICU. If the Court of Protection says it needs an extra month, “*that will completely destroy critical care medicine in the UK”.*

Communications with families

Throughout the workshop, a key concern was how to improve communication between clinicians and families/friends of the patient in order to support good care for the patient, minimise distress for their family and friends, and to reduce the dangers of becoming entrenched in disagreements about treatment decisions.

Research was presented about family members’ view of their role in intensive care; how relatives of PDoC patient look back at the treatment decision-making process, one participant presented on her personal family experience of a best interests decision to discontinue life-sustaining treatment and a clinician presented on ways to minimise conflict.

In the context of severe brain injury workshop participants emphasised the importance of three areas: (1) good overall communication, (2) clarity about roles, and (3) good documentation of how decisions were reached.

Good overall communication – discussing the patients' clinical condition, treatment options and the patient as an individual.

Discussion around this theme included an emphasis on:

- Ensuring family/friends are consulted, listened to and asked questions about the person. "*My approach is to say I know the medicine, you know the person; so I'll tell you about the medicine and you tell me about the person."*
- Being honest about uncertainty and avoiding excessively black-and-white prognostication. As one lawyer noted – *"Doctors told them the [patient] would die within two weeks, four weeks later I picked it up. There was already distrust… could there be more emphasis on uncertainty in medicine. When a prognosis is given, should there be stress on biological systems being uncertain?"*
- Being clear about the spectrum of likely outcomes and specific about what a predicted severe cognitive impairment might mean (e.g. for memory, dressing, social interaction, talking), alongside sharing information about how people can adapt to living with profound disabilities.
- Addressing the burdens of treatment – "*Not mentioned very often is what the person is experiencing in terms of pain or distress. I often read the nursing notes to see what this is like. Sometimes nursing notes will say someone is in a lot of pain but the medical notes make no reference to it."*
- Understanding family experience: "*As lawyers we know it's difficult, but we don't appreciate how difficult it is because we're wrapped up in getting it moving. We parachute in and parachute out".*

Workshop participants also highlighted that it was useful to:

- Flag up potential withdrawal of life-sustaining treatment early: "*we don't need to talk about it now"* but saying it means they've heard it and you've documented it. "*At the early stages, also make clear some treatments won't be considered. It prepares the family for what might be coming."*
- Set the scene prior to significant meetings so families are prepared and informed for the discussion.
- Avoid jargon and provide clear accessible resources for families (including those with different levels of literacy and education, and addressing language and cultural diversity).
- Check in regularly with families. One lawyer noted that in their experience the question sometimes asked by clinicians of relatives - *'What do you understand'* - could backfire and leave a family thinking that the doctor doesn't know the patient. *"Clinicians often ask questions that they know the answer to …. But this doesn't land well with families who think the doctor just hasn't read the notes."*
- Consider the long-term prospects for a patient and foreground what they valued, rather than just focussing on small changes in diagnosis/prognosis which might not be significant for that person. One clinician commented:

> *"There's enthusiasm about moving from the vegetative to the minimally conscious state – everyone gets terribly excited … but often that's a million miles away from where the person would want to be… but we don't have those discussions...We need to be clear that "there are limits to what we can do in medicine".*

Clarity about the role of family/friends, clinicians and the courts.

There was a lot of discussion about how families could be misled about their role, for example, a clinician commented:

> "*Unless family hold Lasting Power of Attorney (covering* life-sustaining treatment*) it's not their decision. When you ask for agreement, the burden is placed on family. So, I ask what the person's view on quality of life would be, and that's all I need to know from the family. Thereafter it's my clinical decision".* She added *"We muddy the water by saying 'it's not your decision' but then asking people to agree".*

- There was criticism of the way the NHS perpetuates the idea of 'next of kin' when this really means just the primary person to contact and has no legal status in decision-making, and the public are left confused about this.
- One clinician also highlighted the problem of *"colleagues who talk about family making decision - one despairs when one's own colleagues don't know what the law is".* This consultant also said he'd seen other colleagues "*fudge"* the process as "shared decision-making" in an attempt to look for consensus *"but then re-assert themselves as decision-maker when consensus doesn't come."*
- Clear and accurate information about when the *courts* might become the location of decision-making was agreed to be vital. (The presentation about personal experience included an example of being inaccurately informed that a court hearing would be necessary and that the family member would have to make the application).

High quality documentation of decision-making.

The legal and clinical experts at the workshop highlighted the importance of good documentation for clinical and legal reasons as well as supporting good communication with families. The value of this was also underlined by the workshop participant whose husband died following a best interest decision about life-sustaining treatment.

- She emphasised the value of such documentation not only for those who attend a best interest meeting but also as "*an objective record"* to "*arm me so I can manage what is happening outside the room"* and help the extended family understand what is going on.
- Careful documentation also helps in the longer term – several years after her husband's death, the best interest documentation is still useful as family members live with, and review, what happened and its aftermath.
- This workshop participant also made the point that *"the responsibility on what might be seen as a primary relative is so enormous because the conversations happening around you are that 'he's a fighter'…If there's something that can back a primary relative up then that is very important".*

- Access to high-quality information about brain injury and *c*areful and well-documented decision-making, alongside good palliative care, had been crucial and allowed for a positive way forward to the extent that:

  > *"the anniversary of his accident is traumatic, but the anniversary of his death is not. What I'm left with five years on is extreme gratitude for the clinical and legal framework that enabled him to have a peaceful and dignified death.*" [Permission to use these attributable quotes has been given]

Disputes between families and clinicians

Ensuring good communication (such as outlined above) was seen to be positive in a wide range of ways and also to reduce the chances of intractable disputes over treatment options. However, where a dispute is developing workshop participants also emphasised points such as:

- Double-checking that information from family/friends had been taken on board by the clinical team, and that family/friends have had their say, and what they've said has been taken into account.
- The importance of working to maintain trust, ensuring transparency and *"barn door openness".*
- Training in mediation skills - *"these are useful even if you are not a trained mediator"* alongside access to independent mediation. Although the point was also made that mediation may be more useful in care/welfare decisions, but less useful when there's a binary decision – *"you can't really mediate that, it's a yes or a no"* (e.g. to life-sustaining treatment).
- The importance of following a clear process to find out whether other clinicians are willing to offer the treatment (that is commensurate with the urgency and nature of the decision).
- Ensuring that legal advice is sought early on and that, for example, for any second opinion sought, there is a clear letter setting the specific questions or issues for the second opinion to address
- The importance of the second opinion being clearly independent - *"When the second opinion simply comes from the hospital next door, people lose trust."*
- The value of signalling, early on, possible court avenues for addressing disputes (being careful this does not come over as a threat, or as something families would need to initiate).
- The valuable role of solicitors, including as "*a lightning rod for being hated".*
- Establishing 'parity of arms' – supporting families accessing a lawyer as appropriate. "*It might encourage people to access support if a list of lawyers and how to access pro bono scheme was created by neutral third party and could be presented to families."*

Looking forward

The timing of this workshop – immediately after the *Townsend v Epsom* judgment – meant it became an important forum for discussion and exchanging ideas in relation to that judgment, especially in the light of the need for ongoing decision-making about patient care and given the potential for an appeal to the Supreme Court. (At the time of writing this report the application for permission to appeal has been submitted, but the outcome of that is not yet known).

It was also useful to address the continuing challenge of improving best interests decision-making and to share strategies to increase understanding (between everyone involved) and try to reduce conflict around life-sustaining treatment decisions.

Consideration is being given to organising a second workshop after any Supreme Court appeal about *Townsend v Epsom*. Informed by the outcome of that appeal, the hope is to contribute to training resources for healthcare professionals and the creation of further support and information for families.

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Appendix: Workshop participants' biographies

Kiran Bhogal heads Hill Dickinson LLP's national Healthcare and Public Law team and was appointed in 2005 as a Deputy District Judge on the SE Circuit. Kiran has more than 32 years of experience in NHS and public sector work, is ranked as a leader and expert in her field and known for her depth of experience in all aspects of healthcare-related law including medical ethics and the court of protection (serious medical treatment cases). She was the lead lawyer in *Re N v A CCG* (2017) and *Re AA* (2024) both of which were cited in the recent Townsend Court of Appeal judgment.

Victoria Butler-Cole KC specialises in health and social care. Her work includes public law, community care, Court of Protection, medical treatment disputes involving babies and children, inquests, human rights claims, and regulatory appeals. She is the co-founder with Alex Ruck Keene of the 39 Essex Mental Capacity Report, and is past Chair of the Court of Protection Bar Association.

Dr Daniel Clark was notetaker for the day. Daniel recently completed his PhD, in which he argued that older people are an oppressed social group. He is currently Research Fellow in Open Justice in the School of Law at the University of Sussex. His research focuses on gaps in access to, and knowledge of, courts and tribunals. He is an experienced observer of cases in the Court of Protection.

Dr Chris Danbury is a Consultant in General and Neuro Intensive Care Medicine at University Hospitals Southampton. He was the founding Chair of the Legal and Ethical Policy Unit of the Faculty of Intensive Care Medicine (FICM), has honorary academic medicolegal posts, and has been commended by FICM for sustained services to the specialty of Intensive Care Medicine. He has been awarded an Honorary Fellowship of the Faculty of Forensic and Legal Medicine for his academic medicolegal work.

Dr Sonya Daniel is a Consultant in Intensive Care Medicine at the University Hospital of Wales and represents Wales on the Legal & Ethical Policy Unit at the Faculty of Intensive Care Medicine. She sits on the health board's Clinical Ethics and Consent Committees and is the departmental medical law and ethics lead. She is in the final year of an LLB, with academic interests in the legal aspects of clinical decision-making.

Professor Clare Elwell is Professor of Medical Physics at University College London (UCL). She is Director of the Near Infrared Spectroscopy Research Group at UCL, developing optical technologies to monitor and image the brain. Her research projects include studies of acute brain injury on neurointensive care. She also has personal experience of life-sustaining treatment decisions in relation to her husband who was catastrophically brain injured in 2020.

Veronica English is head of medical ethics and human rights at the British Medical Association and led on the development of the joint BMA/RCP guidance on CANH and adults who lack the capacity to consent and accompanying resources.

Dr Miriam Fine-Goulden is a consultant in Paediatric Intensive Care at the Evelina London Children's Hospital and South Thames Retrieval Service for Children and is Lead for Child Death at Guy's & St.Thomas' Hospital NHS Foundation Trust. She is on the NHS England Clinical Reference Group for Paediatric Critical Care and is a member of the UK Paediatric Critical Care Society (PCCS) Council. As Council representative, she is a member of the Professional Advisory Group for the National Child Mortality Database (NCMD) and on the Executive Committee of the Association of Child Death Review Professionals (ACDRP). She was part of the group reviewing paediatric evidence for the updated 2025 Academy of Medical

Royal Colleges (AoMRC) Code of Practice for the diagnosis and confirmation of death, and is currently on the working group revising the 2015 Royal College of Paediatrics and Child Health (RCPCH) guidance on decisions to limit treatment in children at the end of life. She is currently undertaking a Master's in Medical Ethics and Law at King's College London.

Dr John Gorst is a jobbing consultant in intensive care medicine and anaesthesia at Swansea Bay University Health Board, having recently 'retired' as clinical director. Clinical interest in assessing neurological prognosis following out of hospital cardiac arrest, including service improvements to ensure evidence-based provision of treatments and investigations across the region. Previous experience with Court of Protection application as key hospital professional witness. Hospital clinical ethics committee member. Expert witness practice in civil, coronial, and criminal proceedings.

Dr Andrew Hanrahan is a Consultant in Neurorehabilitation at the Royal Hospital for Neuro-disability, Putney and works in the Brain Injury Service and Neurobehavioural Service. He is also the clinical Lead for Neuropalliation and end of life care. He has served as expert witness to the CoP and is on the RCP national guideline development group for Prolonged Disorders of Consciousness.

Professor Dan Harvey is a consultant in intensive care medicine at Nottingham University Hospitals NHS Trust. He was a previous chair of the Intensive Care Society’s Legal and Ethical Advisory Group, and the lead author of the Faculty of Intensive Care Medicine’s Management of perceived devastating brain injury after hospital admission guideline. He is National Lead for Innovation and Research in Organ Donation for NHS Blood & Transplant.

Professor Jenny Kitzinger is co-director (with Prof Celia Kitzinger) of the Coma and Disorders of Consciousness Research Centre at Cardiff University. As well as conducting academic research in the field she has co-developed an online resource for families (including sections on family role in best interests decision-making) and developed an online training resource for healthcare professionals addressing law, ethics and life-sustaining treatment decisions.

Gavin Knox is Manager of the Complex Patient Team advising the NHS in Wales on all issues related to Mental Capacity, Mental Health, Court of Protection and Inquests. He is an experienced advocate in the High Court and Court of Protection representing Health Boards throughout Wales and advises on All Wales policies.

Professor Diane Playford is Professor in Neurological Rehabilitation, Warwick Medical School, Warwick University. She has been involved in developing national standards through guideline development, including chairing the NICE Clinical Guideline on Stroke Rehabilitation, Vice Chair for the Royal College of Physicians Prolonged Disorder of Consciousness guidance, and three for the British Society of Rehabilitation Medicine.

Vikram Sachdeva KC is a former medical doctor who specialises in Administrative & Public Law, Civil Liberties & Human Rights, Healthcare, Commercial Law, Regulatory & Disciplinary, Tax, Media Law, and Costs & Litigation Funding. He has taught law at university, and is known for creatively pushing the boundaries of the law, and has appeared in a number of important cases including in the Supreme Court. He is co-founder and past Chair of the Court of Protection Bar Association, and also past Chair of the Constitutional and Administrative Law Bar Association. He was one of the three barrister members appointed to the Independent Review of Administrative Law.

Hannah Taylor is partner in the Health & Care Regulatory team at Bevan Brittan law firm. She specialises in the legal frameworks engaged in commissioning and providing health, social care, education and housing to vulnerable adults, young people and children. She has experience in representing clients at inquests, Tribunals, in the Court of Protection, the Inherent Jurisdiction of the High Court and in the criminal courts in the regulatory jurisdiction. She regularly advises organisations on serious/catastrophic incidents and the parallel processes arising out of these, including; HSE investigations and prosecutions, police investigations and CPS prosecutions for corporate and gross negligence manslaughter, complex inquests, NHS England/CCG reviews, CQC inspections and the interface between enforcement agencies.

Professor Lynne Turner-Stokes is a consultant in rehabilitation medicine and Director of the Regional Hyper-acute Rehabilitation Unit, Northwick Park. She has a special interest in the management of patients with prolonged disorders of consciousness. In her academic role as Northwick Park Professor of Rehabilitation Medicine, King's College London, she chairs the Guidelines development group for the Royal College of Physician's national clinical Guidelines for patients in PDOC. She has also been extensively involved with the legal aspects of clinical and best interests decision-making, working with multiple clinicians and legal teams, as well as acting as an expert witness in court proceedings.

Dr Derick Wade, Consultant and Professor in Neurological Rehabilitation, Oxford OX2 6TN derick.wade@icloud.com. I have specialised in neurological rehabilitation since 1981, been a consultant since 1986, and been acting as an expert for the courts in cases of people in a prolonged disorders of consciousness since 1994 or 1995, when I was asked by the Official Solicitor to see several cases. The second one was not in a vegetative state, despite assertions to the contrary by the two national experts' opinions. I have seen 500-1000 clinically and several hundred as part of the legally required clinical process. I have appeared in court 20-30 times. I have written 16 papers, my first being with a member of the Official Solicitor's office, and contributed to three national guidance documents. I have written several webpages and blog posts: https://rehabilitationmatters.com/clinical-rehabilitation/pdoc-an-introduction-and-history/

Jessica Watkin is Policy Manager (Standards and Ethics), GMC and was involved in updating the GMC guidance Treatment and care towards the end of life – the updated version of which was published in 2022.