*Discussion*

The majority of cases (88%) were deemed clinically justified although only 33 (66%) fell into disease category 1, 2 or 3.

For those 11 cases which did not fall into category 1,2 or 3 but were assessed overall as clinically justified, there was uniform agreement among the assessing consultants that overnight treatment was clinically justified for certain conditions, namely hyperviscosity with severe symptoms and renal vasculitis /SLE with associated DAH. These formed a relatively high proportion of the cases (6/11). Other cases were either extremely rare (for example methemoglobinaemia) or there was less consensus.

For cases deemed not to be clinically justified, there was unanimity among the three consultants regarding one case (NMDA encephalitis). For the other cases, only a maximum of two consultants offered an opinion but were mainly in agreement.

Since this review was undertaken the ASFA guidelines have been updated and the new version published in July 2016.

*Audit Recommendations*

1. Update the TAS on call manual to include additional diagnostic categories where there is general consensus that overnight treatment is or may be clinically justified.
2. Extend analysis of data to include identification of authorising consultant as TAS or non-TAS consultant and assess if there is any difference in decision-making between the two groups.
3. Discuss with TAS consultants a mechanism for capturing and collating out of hours referrals which are not accepted for overnight treatment.
4. Review assessments against new ASFA guidelines.
5. Circulate report to all NHSBT patient facing consultants.
6. Present final report at biannual NHSBT patient-facing consultants meeting.
7. Submit report for publication.
8. Undertake extended audit to include all out of hours referrals.

An audit of all out of hours procedures is now in the planning stages.

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## Explaining Death Confirmed Using Neurological Criteria to Families

In 2013, in preparation for the launch of the new National Deceased Donation Simulation Course for Intensive Care Trainees, I emailed many colleagues in the UK to see if they were aware of any documents to help guide intensive care doctors in how to explain 'brain death' to families. Surprisingly, very little has been done in this area.

While there is research evidence to support the belief that explaining 'brain death' well to families, and at a pace commensurate with their emotional needs, is positively associated with consent for deceased organ donation, the exact words to use remain quite opaque.[1] This is not to say good work has not occurred in this area. It is for example becoming increasingly common for clinicians to offer families the chance to witness the second set of brainstem tests as this is felt to be beneficial for their understanding and acceptance of the tragic reality of their loss.[2]

There is no official validation or research for the below but it does reflect how I conceptually understand death determined by using neurological criteria and how I approach communicating this to the families of patients under my care. I would welcome your feedback.

### Essential Messages

- Death is suspected
- Tests to confirm death

The essential messages I try to communicate is that death is suspected to have already occurred and that tests are required to confirm or refute this suspicion.

Key points I like to communicate are:

1. The brain injury is so severe that death is suspected to have already occurred.
2. There is a plan to carry out a set of tests to see if the patient will ever regain any consciousness or ever breathe again.
3. The tests will be done carefully by two senior doctors.
4. If the tests confirm that these essential brain functions are permanently lost; this will mean the patient has died.
5. The tests will not hurt the patient.
6. The tests will be done at the bedside by examining the patient and as part of the tests the patient will be removed from the mechanical ventilator to see if the patient can breathe.

7. The tests will be done twice.
8. There is an opportunity for family to observe the second set of tests if desired.
9. If the tests do not show the presence of any of the essential brain functions, it will confirm that the patient has died.

It is vital that family reaction and understanding is assessed as the information is relayed and working with my bedside nurse and specialist nurse for organ donation we always try to pace the delivery according to the family's needs. If there are points of confusion or distress, or the information is too overwhelming, then further explanation or time is given before proceeding.

Accepting that individual styles may vary (even when I am doing the speaking) and regurgitating quotes of any text would appear forced and unnatural, I offer as way as illustrative example the below paragraph. The imagined case is for Margaret a middle-aged woman who had an overwhelming subarachnoid haemorrhage, who is in intensive care awaiting testing to determine death using neurological criteria.

**"As you know Margaret has had a very bad bleed in her brain. As you saw, she lost consciousness almost immediately and the paramedics had to put the breathing tube in because she was no longer breathing for herself. Since coming to hospital we have not seen her breathe and many of her brain functions appear to have ceased.**

**"The scan of her brain is very abnormal and devastating. My fear is that the damage Margaret has sustained to her brain, is so severe, that she may have already died.**

**"Another senior doctor and I are planning to carry out some tests on Margaret to see if she will ever regain any consciousness or ever breathe again. If the tests confirm that these essential brain functions are permanently lost, this will confirm to us, that she has died.**

**"The tests won't hurt Margaret. One of these tests will be to shine a light in her eyes to see if her pupil gets smaller, much as the nurses have already been doing in the Intensive Care Unit. We will also take her off the ventilator to see if she can breathe by herself.**

**"The tests will be done twice. We'll do the first set of tests shortly but we'll give you the chance to watch the second set of tests if you wish. Some families find this helpful, to see for themselves.**

**"I'm very sorry; but I expect the tests will confirm that Margaret has already died."**

### *Brain Death or Brainstem Death or just Death?*

It might appear strange to the reader that in the above example I did not use the term 'brain death' or 'brainstem death' even once. I find these terms confusing and unhelpful. The term brain death is loosely used by the media, often conflating persisting coma with brain death. Neurologists in the USA have also been shown to have an inconsistent rationale for accepting 'brain death' as death.[3] Is it any wonder then that a public survey carried out in 2013 in Northern Ireland found that nearly 50% of those surveyed thought that maybe you could, or didn't know if you could, recover from brain death.[4]

More compelling to me is that nearly a decade ago the Academy of Medical Royal Colleges (AoMRC) Code of Practice (2008) for the Diagnosis and Confirmation of Death abandoned the terms and instead refers to the 'Diagnosis and Confirmation of Death in a Patient in Coma.'[5]

'Brain death' and 'brainstem death' are terms that are therefore poorly defined, widely misunderstood, difficult to explain and abandoned by the authority who gives us our Code of Practice in the UK for confirming death. The time has surely come for health professionals to withdraw the term brain death from their lexicon and allow it to historically die; especially when we are explaining how we know someone has died to families.

*Actors representing family from the Nottingham Deceased Donation Simulation Course.*

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**References:**

1. National Institute for Health and Clinical Excellence. (2011) *Organ Donation for Transplantation: Improving Donor Identification and Consent Rates for Deceased Organ Donation* https://www.nice.org.uk/guidance/cg135

2. Reid M. (2013) *The presence of relatives during brainstem death testing in an intensive care unit.* JICS 14(4): 324-9.
3. Joffe A.R., Anton N.R., Duff J.P. and DeCaen A. (2012) *A survey of American neurologists about brain death: understanding the conceptual basis and diagnostic tests for brain death.* Annals of Intensive Care 2:4.
4. HSC Public Health Agency. (2013) *Organ donation: Public attitudes and stakeholder engagement in Northern Ireland 2013.* https://www.organdonationni.info/sites/organdonationni.info/files/publications/organ%20donation%20report.pdf
5. Academy of Medical Royal Colleges. (2008) *"A Code of Practice for the Diagnosis and Confirmation of Death"* http://www.aomrc.org.uk/publications/reports-guidance/ukdec-reports-and-guidance/code-practice-diagnosis-confirmation-death/


## The ATTOM Study


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### *Introduction*

The Access to Transplantation and Transplant Outcomes Measures (ATTOM) study is a National Collaborative Research Programme funded by the National Institute for Health Research (NIHR). The programme was launched in 2011, with the overarching aims of improving equity in access to renal transplantation and maximising the benefit and cost-effectiveness of renal transplantation in the UK. ATTOM is the first and largest study of its kind, having recruited around 7000 dialysis, waiting list and transplant patients from all UK renal units as part of a truly national prospective cohort study. The interdisciplinary and collaborative approach of the ATTOM study has enabled implementation of a high quality and relevant research programme, putting the UK at the international forefront of clinical research in transplantation.

### *Importance of the Study*

Kidney transplantation is widely regarded as the best treatment for end-stage renal disease (ESRD). When compared with dialysis, transplantation leads to a two- to three-fold increase in life expectancy and, it is often believed a better quality of life. However, while the success of transplantation has led to an exponential rise in demand, there has not been a corresponding increase in the availability of donor organs. This has led to increasing challenges in access to and allocation of this scarce resource. Furthermore, the changing demography of patients with ESRD with an older population and more significant comorbidity, has added further complexity to treatment decisions at an individual patient as well as societal level. It is currently unclear what constitutes best practice with regards to appropriate and equitable