

**POLICY FORUM: PEER-REVIEWED ARTICLE**

**Inconsistency in Brain Death Determination Should Not Be Tolerated**

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**Abstract**

Since it was proposed in 1980, the Uniform Determination of Death Act has provided the legal basis for determination of death by neurological criteria. The act contains language that allows for acceptable medical standards to be used to determine death. Since 1995, the American Academy of Neurology has provided guidelines for brain death determination (revised in 2010), but nationwide adherence to these guidelines has been incomplete. This variability could lead to misdiagnosis and erosion of public trust in this important medical practice. Physicians must work together as a profession to push for uniformity and accuracy in death diagnosis.

**Defining Brain Death**

Although the concept of death is as old as life itself, the concept of brain death is a relatively young one. Only in the mid-20th century did technology advance to the point of allowing for organ support in the event that brain function ceased. With the advent of mechanical ventilation, artificial nutrition, and the modern intensive care unit, patients who suffered an irreversible intracranial catastrophe could continue to have their other organs supported and maintained. In 1968, a committee of physicians from Harvard Medical School published a report titled “A Definition of Irreversible Coma.”<sup>1</sup> In 1980, the **Uniform Determination of Death Act (UDDA)** was proposed in order to establish a legal and uniform definition of death—determined by “acceptable medical standards”—that was “clear and socially accepted,” with the intention of its being adopted in every US jurisdiction.<sup>2,3</sup> This model statute provided the legal basis for death by neurological criteria, stating that an individual could now be determined to be dead if they had sustained “irreversible cessation of all functions of the entire brain, including the brain stem.”<sup>2</sup> What “acceptable medical standards” meant was left to be determined by the medical community, leading to the creation of societal guidelines in subsequent years.

Following the Harvard report and the UDDA, in 1995, the American Academy of Neurology (AAN) provided consensus practice parameters for the determination of death by neurological criteria in adults.<sup>4</sup> These guidelines stated that brain death has occurred when “the irreversible loss of function of the brain, including the brain stem,” has been determined by the demonstration of complete loss of consciousness (coma), brain stem

reflexes, and the independent capacity for ventilatory drive (apnea) in the absence of any factors that imply possible reversibility.<sup>4</sup> Since their introduction in 1995, the AAN guidelines for the diagnosis of brain death have been widely used; however, studies of institutional protocols for determining brain death have shown considerable variability, both within the United States and the world at large.<sup>5,6,7,8</sup> These inconsistencies in brain death protocols could sow doubt among members of the public and be a potential source of legal exposure. It is intuitively incoherent to think that a person could be dead in one US state but, according to a different protocol, not be dead in a neighboring state. We first discuss how prominent variability in determination of brain death is before discussing why variability matters and what can be done about it.

### **Variations in AAN Guideline Adherence**

The designation of “acceptable medical standards” to determine death in the UDDA allows for those standards to be set nationally, regionally, or locally.<sup>2</sup> Perhaps as a result, variability exists in protocols for brain death determination in the United States, both among leading hospitals and among all hospitals at large. While this variability seems desirable in that it allows for flexibility based on available equipment and specialists as well as changing medical knowledge, the UDDA has created a scenario in which variability in practice is possible. In 2008, a study of the top 50 hospitals in neurology and neurosurgery in the United States (according to the 2006 *US News and World Report*) showed wide variability in adherence to the current societal guidelines at the time, the 1995 AAN practice parameters.<sup>5</sup> Protocols varied from the guidelines in respect to all 3 pillars of the clinical diagnosis of brain death—coma diagnosis, absence of all cranial nerve reflexes, and apnea.<sup>5</sup> Notably, only 63% of reviewed protocols required an established cause of brain death, and only 55% specified the absence of sedatives and paralytics.<sup>5</sup> Regarding the clinical examination, only 27% of protocols specified that no spontaneous respirations should be present, and only 18% required the absence of a jaw jerk reflex.<sup>5</sup> Apnea testing had the greatest variation from the guidelines, including acceptable cut-off values for core temperature at the time of testing and whether an arterial blood gas was obtained prior to testing.<sup>5</sup> Obsolete or incompletely vetted ancillary tests were included in some protocols, including the use of unapproved tests such as computed tomography angiography and magnetic resonance imaging, and there was a lack of consensus on how many clinical examinations were required as well as the minimum wait time between exams.<sup>5</sup> Strikingly, there was also a lack of clarity regarding who could make the diagnosis of brain death, as less than half of protocols stipulated involvement of a neurosciences specialist, and, in some instances, resident physicians could make the determination.<sup>5</sup>

### **Updated AAN Practice Parameters**

The variability found in the 2008 study prompted an update to the AAN practice parameters in 2010 in hopes of bringing about more uniformity in brain death determination—or at least in the protocols for such.<sup>9</sup> These guidelines were specifically designed to be more readily incorporated into hospital protocols, with a checklist and specific instructions on how to meticulously perform much of the cranial nerve and apnea testing.<sup>9</sup>

Despite the 2010 update, significant variability remains in hospital policies across the United States.<sup>6,8</sup> A follow-up study in 2016 reviewed 492 US hospital policies on brain death declaration.<sup>6</sup> This study again found wide variability in compliance with practice guidelines, especially in the areas of prerequisites for testing, clinical examination, and apnea testing.<sup>6</sup> Notably, this paper found that only 43.1% of policies specifically required

an attending physician to make the diagnosis of brain death.<sup>6</sup> In 2017, Wang et al analyzed protocols from the top 50 hospitals in neurology and neurosurgery in the United States (according to the 2015 *US News and World Report*) for comparison to the 2008 study.<sup>8</sup> Poor compliance with specific clinical examination techniques persisted, but overall there was improvement in concordance with the 2010 practice parameters, driven by better specification of prerequisites to testing, use of recommended ancillary testing, and performance of apnea testing.<sup>8</sup> Despite some encouraging progress, however, variability persists, which could lead to significant negative consequences.

The developments over the past half century in defining and determining brain death are summarized in the Table.

**Table.** Sentinel Publications in Brain Death Determination

Publication	Year	Key Features of Brain Death or Its Determination
"A Definition of Irreversible Coma" <sup>1</sup>	1968	<ul style="list-style-type: none"> <li>• Unreceptivity and unresponsivity</li> <li>• No movements or breathing</li> <li>• No reflexes (including deep tendon and spinally mediated)</li> <li>• Flat EEG</li> <li>• Need to exclude hypothermia and presence of central nervous system depressants</li> </ul>
UDDA <sup>2</sup>	1980	<ul style="list-style-type: none"> <li>• Defined death as "an individual with either irreversible cessation of circulatory and respiratory functions, or irreversible cessation of all functions of the entire brain, including the brain stem, is dead"</li> <li>• "A determination of death must be made in accordance with accepted medical standards"</li> <li>• Ancillary testing optional, including EEG or blood flow testing</li> <li>• Peripheral nervous system activity and spinal cord reflexes are not inconsistent with brain death diagnosis</li> <li>• Cause of the coma should be established and sufficient to account for loss of functions</li> <li>• Specifies exclusion of sedation, hypothermia, neuromuscular blockade, and shock</li> <li>• Special caution advised in determination of brain death in children</li> </ul>
AAN Practice Parameters <sup>4</sup>	1995	<ul style="list-style-type: none"> <li>• Specified brain stem reflexes to be tested and how to perform testing, including acceptable pupillary size (4-9 mm), testing for pain response in the cranium, absent jaw jerk reflex, and others</li> <li>• Specified a method for performing apnea testing</li> <li>• Recommended optional confirmatory testing (conventional angiography, EEG, transcranial doppler ultrasonography, technetium-99m HMPAO nuclear scan, and SSEPs)</li> </ul>

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		<ul style="list-style-type: none"> <li>• Provided a standard for documentation of testing in the medical record</li> <li>• Recommended a repeat neurological examination; discussed that 6-hour waiting period between repeat neurological examination is reasonable but that interval is arbitrary</li> </ul>
AAN Practice Parameters <sup>9</sup>	2010	<ul style="list-style-type: none"> <li>• SSEPs no longer recommended as an ancillary test</li> <li>• Provided a checklist to diagnose brain death</li> <li>• Provided in-depth instructions for performance of each step of clinical examination and apnea testing</li> <li>• Provided more guidance on documentation (eg, time of death is the time arterial Pco<sub>2</sub> reached target value)</li> </ul>

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Abbreviations: AAN, American Academy of Neurology; EEG, electroencephalogram; HMPAO, hexamethylpropyleneamineoxime; SSEP, somatosensory evoked potentials; UDDA, Uniform Determination of Death Act.

### Why Variation Matters

Variability in the diagnosis of brain death has the potential to lead to misdiagnosis. Even in the clearest circumstances, families may have difficulty accepting a diagnosis of brain death when they see their loved one’s heart still beating and feel their body warm to the touch. Public trust in the process of brain death determination is integral to enabling physicians to bridge the gap between diagnosis and perception and to help families understand what it means for their loved one to be not only brain dead, but also legally dead with no hope for recovery of any brain function. If the medical profession cannot achieve rigorous, disciplined brain death testing in accordance with accepted guidelines for the determination of brain death on a national scale, confusion and doubt may ensue, leading to **erosion of public trust**. In the event of organ donation, lack of public trust becomes even more ethically concerning. If we cannot promise robust and 100% accurate diagnosis of brain death, we cannot in good faith counsel families about organ donation, as to do so would violate the dead donor rule.<sup>10</sup> It should be noted, however, that there have been no legitimate, unconfounded false positive cases of a patient declared dead by neurological criteria according to the practice parameters put forth by the AAN.<sup>9</sup> Conversely, failing to diagnose a patient as brain dead (who is dead) might give family members false hope that the patient might recover, prolong their grief, and cause undue pain to all involved. In any case, in order for brain death testing to be effective, the guidelines must be followed.

### Recommendations

A variety of reasons may exist as to why the AAN practice parameters have not been uniformly incorporated into hospital protocols nationally. First, the wording of the UDDA allows for determination of death to be based on medically acceptable standards at a national, regional, or local level, which provides legal room for variations in policies and procedures. Second, a significant time investment must be made by clinicians at all hospitals to champion updating practices to meet accepted standards of care and to help train clinicians in the most modern techniques and approaches. Third, without the pressure of regulatory bodies, the calculus at many of these institutions may be that the protocols currently in place are appropriate and sufficient, or “good enough.” In light of this unfortunate reality—and until outside pressures change—the burden of **responsibility falls on practitioners** to push their own institutions to adopt guidelines for best practice in order to ensure a uniformly accurate diagnosis of brain death.

Efforts are underway to outline the differences that exist in brain death determination both in the United States and worldwide and to develop clearer and more unified practice parameters to ensure correct determination as close to 100% of the time as possible. These efforts include new practice parameters from the AAN, currently under development, which will merge adult and pediatric guidance into one document. National accreditation bodies could be a key ally in ensuring that proper policies are in place at the hospital level, and even revision of the UDDA might be a necessary step. Such a revision would optimally address what are the appropriate medical standards; clarify what is meant by “all functions of the entire brain, including the brain stem”<sup>2</sup>; address the issue of whether consent for testing is necessary; and address how to handle objections to termination of organ support after brain death determination.<sup>11</sup> Finally, ensuring that proper determination of brain death is occurring will require in-depth and meticulous efforts by hospitals. The Neurocritical Care Society has developed a Brain Death Toolkit,<sup>12</sup> which includes a sample brain death policy (including a checklist) that can be amended for use in an individual hospital, as well as a new training and certification course, which will help ensure that the practice of brain death determination is sound. Combating our current complacency with variability will require these and other ongoing local, national, and global efforts to ensure that the medical community moves toward more uniform and consistently accurate diagnosis of brain death.

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