

# An interdisciplinary response to contemporary concerns about brain death determination

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## Abstract

In response to a number of recent lawsuits related to brain death determination, the American Academy of Neurology Ethics, Law, and Humanities Committee convened a multisociety quality improvement summit in October 2016 to address, and potentially correct, aspects of brain death determination within the purview of medical practice that may have contributed to these lawsuits. This article, which has been endorsed by multiple societies that are stakeholders in brain death determination, summarizes the discussion at this summit, wherein we (1) reaffirmed the validity of determination of death by neurologic criteria and the use of the American Academy of Neurology practice guideline to determine brain death in adults; (2) discussed the development of systems to ensure that brain death determination is consistent and accurate; (3) reviewed strategies to respond to objections to determination of death by neurologic criteria; and (4) outlined goals to improve public trust in brain death determination.

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## Glossary

AAN = American Academy of Neurology; AAP = American Academy of Pediatrics; ANA = American Neurological Association; UDDA = Uniform Determination of Death Act.

The credibility of the medical profession is dependent on public trust. Considering the finality of a determination of death, there may be nothing more injurious to the social contract between physicians and patients than inaccuracy in its determination. Recently, the legitimacy of determination of death by neurologic criteria (brain death) has been publicly questioned in a number of prominent lawsuits,<sup>1-5</sup> prompting concern that the public may develop, or already harbors, distrust in brain death determination.

While the foundations for these lawsuits are in part related to complex social, religious, psychological, and legal issues, the American Academy of Neurology (AAN) Ethics, Law and Humanities Committee, a joint committee of the AAN, American Neurological Association (ANA), and Child Neurology Society, and the AAN Practice Committee believed that it would be constructive for stakeholders in determination of brain death in the United States to convene at a quality improvement summit to address, and potentially correct, aspects of brain death determination within the purview of medical practice that may have contributed to these lawsuits. The goals of the summit were to discuss strategies to minimize perceived contemporary conceptual threats to brain death as a medical and legal determination in order to improve the public's trust, understanding, and confidence in use of neurologic criteria to determine death. Invitees included lawyers, ethicists, and physicians who represented all societies of practitioners involved in brain death determination. Attendees included adult neurologists, pediatric neurologists, intensivists, an anesthesiologist, a neuroradiologist, ethicists, and lawyers who belonged to, or represented, the AAN, American College of Radiology, ANA, American Society of Neuroradiology, Child Neurology Society, Neurocritical Care Society, and Society of Critical Care Medicine (appendix, <http://links.lww.com/WNL/A199>). The group addressed the following issues: (1) the validity of the AAN's practice guideline for brain death determination; (2) the development of systems to ensure the accurate and consistent determination of brain death; and (3) the appropriate response to family objections to the use of neurologic criteria to determine death.

## History

Due to developments in organ support that allowed ventilation and circulation to be maintained artificially for protracted periods despite devastating injury to the brain, an ad hoc committee at Harvard Medical School

introduced the first criteria for brain death in the United States in 1968.<sup>6</sup> In the following years, multiple institutions produced their own guidelines on brain death determination, all of which were variations of the Harvard criteria.<sup>7</sup>

By 1981, the medical community generally supported the concept of brain death. However, the idea that death could be declared based upon loss of brain function in an individual whose heart continued to beat was foreign to society as a whole. As a result, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (a committee composed of lawyers, philosophers, ethicists, religious officials, and physicians) was asked to consider whether death of the brain is indeed death of the person. After an extensive review, the Commission concluded that brain death should be endorsed as legal death, and produced the Uniform Determination of Death Act (UDDA), which states, "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards." When defining "accepted medical standards," the authors of the UDDA chose not to specify clinical criteria and instead declared that brain death must be determined based upon standards "accepted by a substantial and reputable body of medical men and women as safe and efficacious for the purpose for which [they are] being employed."<sup>8</sup> The UDDA, or a close approximation of it, has since been accepted as judicial or statutory law in every state.<sup>9</sup>

In response to some specific questions the Commission posed about brain death, the AAN produced guidelines on brain death determination in adults in 1995.<sup>10</sup> These were subsequently updated in 2010 and endorsed by the Neurocritical Care Society, the Child Neurology Society, the Radiological Society of North America, and the American College of Radiology.<sup>11</sup>

Guidelines for determination of brain death in pediatric patients were published by the American Academy of Pediatrics (AAP) in 1987, and then updated in 2011 by the AAP in conjunction with the Child Neurology Society and the Society of Critical Care Medicine.<sup>12,13</sup> They are similar, but not identical, to the adult guidelines.<sup>11,13,14</sup>

In 2008, the President's Council on Bioethics reevaluated the validity of determination of death by neurologic criteria. The prevailing opinion among Commission members was that

there is a sound biological and philosophical basis for brain death.<sup>15</sup>

## The validity of the AAN's practice guideline for brain death determination

The summit began with the questions of whether brain death represents death of a person and whether the AAN practice guideline is the accepted medical standard for brain death determination. While the attendees acknowledged that a minority opinion considers brain death to be a legal fiction and that death of the person does not occur until irreversible cardiopulmonary arrest, every attendee agreed that death determined by neurologic criteria is equivalent to death determined by cardiopulmonary criteria. Just as cardiopulmonary death is determined when there is irreversible loss of circulatory and respiratory function, brain death is defined by irreversible loss of consciousness and brainstem function leading to the inability to breathe independent of artificial support, and ultimately results in the demise and decay of all organ systems. Determination of death is based on loss of clinical function of the heart and lungs or the brain, and the demise of every neuron or myocardial cell is not required.<sup>16,17</sup> The attendees further agreed that the 2010 AAN practice guideline is the contemporary paragon for brain death determination, as there have been no documented cases of recovery of neurologic function after determination of brain death provided the parameter is appropriately followed.<sup>11</sup> The parameter is intentionally conservative and appropriately prioritizes specificity to avoid false-positive determinations.

## The development of systems to ensure that brain death determination is consistent and accurate

Reviews of institutional protocols have demonstrated some inconsistency with the 2010 AAN practice guideline.<sup>11,18,19</sup> Protocols have varying descriptions of prerequisites, ancillary testing, and apnea testing.<sup>18</sup> Despite significant improvements in compliance with AAN guidelines in recent years, institutional protocols still deviate from the AAN practice guideline.<sup>19</sup> Reasons for these variances should be explored and education should be provided to promote standardization in order to avoid false-positive or false-negative brain death determinations. One method to generate consistency is for an appropriate regulatory authority such as the Joint Commission to review hospital protocols, similar to that which occurs during stroke center certification.<sup>18,20</sup>

Another barrier to performance of accurate determinations is the fact that qualifications for examiners and physician awareness of the intricacies of brain death determination

vary.<sup>18,21</sup> Frequent education and reeducation is warranted. This can be accomplished through simulation sessions.<sup>21</sup> In addition, a credentialing program for physicians involved in brain death determination could help ensure that evaluations are performed consistently and accurately.

Finally, the attendees were concerned that the public trust in brain death determination could be adversely affected by the fact that criteria for determination of brain death in adult patients subtly differ from criteria for determination of brain death in pediatric patients. Guidelines for determination of brain death in pediatric patients were published in 1987 and updated in 2011 by the Society of Critical Care Medicine, the AAP, and the Child Neurology Society.<sup>12,14</sup> Pediatric guidelines require performance of 2 brain death examinations and 2 apnea tests separated by an observation period, and include criteria for use of ancillary tests during brain death determination that differ from the adult practice guideline.<sup>11,14</sup> The summit attendees resolved to work with the pediatric critical care and neurology communities to discuss these differences and facilitate, if possible, the creation of uniform criteria for determination of brain death in both children and adults. Attendees believed this could be achieved because the similarities between the criteria outweigh the differences.

## The response to objections to determination of death by neurologic criteria

Although brain death is accepted by the ethical, medical, and legal communities as legal death, families sometimes object to determination of death by neurologic criteria due to moral or religious beliefs, hope that a patient will recover, or a lack of acceptance that a determination of brain death is the legal equivalent of a determination of cardiopulmonary death. These families often attempt to have a patient transferred to another facility to avoid determination of brain death and discontinuation of organ support.<sup>17,22–24</sup> Management of these objections in both adult and pediatric patients varies by state, hospital, and practitioner.<sup>17,24</sup> Failure to manage these tensions successfully has led to a number of prominent lawsuits in the United States in recent years in which families have objected to the validity and accuracy of determination of death by neurologic criteria.<sup>1–5</sup> Although the President's Commission, in its influential 1981 report, sought to provide a template for the statutory definition of death throughout the country, defining death remains within the purview of individual states. Brain death is legally accepted as death in every state, but the language of state laws on determination of death is not uniform.<sup>25</sup> Summit attendees voiced concern that lack of uniformity in both institutional policies and practices related to brain death determination and statutory definitions of death may, along with other factors, have contributed to the recent surge in lawsuits related to determination of death by neurologic criteria. If brain death is handled inconsistently by

the medical or legal community, or handled differently from cardiopulmonary death, there could be erosion of public trust in the use of neurologic criteria to declare death.

## Discussion

Despite the fact that brain death has achieved widespread medical and legal acceptance for nearly 50 years, medical, social, and legal controversies associated with determination of death by neurologic criteria persist. In order to improve public trust in the process and outcome of brain death determination, the summit attendees resolved to work with all stakeholders in brain death determination to identify how best to accomplish the following goals:

1. Advocate for uniform policies in all US health care institutions through implementation of regulatory oversight
2. Develop and promote education initiatives on brain death determination for members of the health care community, legal community, and the public in the United States
3. Promote brain death training and credentialing programs for all physicians doing brain death assessments to ensure brain death determinations are made based on established guidelines
4. Collaborate with the pediatric community to ascertain whether a singular standard for brain death determination can be developed
5. Advocate for a consistent legal approach to brain death determination in all 50 states

This document has been reviewed and endorsed by the AAN, AAP, American College of Chest Physicians, American College of Radiology, ANA, American Society of Neuroradiology, and Child Neurology Society. The Neurocritical Care Society endorses this document as an educational tool on the topic of brain death determination.

## Author contributions

Ariane Lewis was responsible for conception and design, drafting the manuscript, and final approval of the manuscript. All other authors were responsible for conception and design, critical revision of the manuscript, and final approval of the manuscript.

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