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# Abandoning the dead donor rule? A national survey of public views on death and organ donation

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## ABSTRACT

Brain dead organ donors are the principal source of transplantable organs. However, it is controversial whether brain death is the same as biological death. Therefore, it is unclear whether organ removal in brain death is consistent with the 'dead donor rule', which states that organ removal must not cause death. Our aim was to evaluate the public's opinion about organ removal if explicitly described as causing the death of a donor in irreversible apneic coma. We conducted a cross-sectional internet survey of the American public (n=1096). Questionnaire domains included opinions about a hypothetical scenario of organ removal described as causing the death of a patient in irreversible coma, and items measuring willingness to donate organs after death. Some 71% of the sample agreed that it should be legal for patients to donate organs in the scenario described and 67% agreed that they would want to donate organs in a similar situation. Of the 85% of the sample who agreed that they were willing to donate organs after death, 76% agreed that they would donate in the scenario of irreversible coma with organ removal causing death. There appears to be public support for organ donation in a scenario explicitly described as violating the dead donor rule. Further, most but not all people who would agree to donate when organ removal is described as occurring after death would also agree to donate when organ removal is described as causing death in irreversible coma.

## INTRODUCTION

The dead donor rule (DDR) is a deontic constraint that categorically prohibits causing death by organ removal. This informal rule has guided the practice of organ transplantation since its inception. Brain death, the irreversible cessation of all brain function, is considered equivalent to death. Together, the concepts of brain death and the DDR form the crux of the broad medical and legal consensus surrounding organ transplantation policy and practice.<sup>1 2</sup> Despite the general consensus, the DDR and the concept of brain death have been repeatedly challenged.

Scholars have argued that 'brain death' is inconsistent with a scientific understanding of death, which is defined in terms of the basic biological concepts of homeostasis and the resistance of entropy.<sup>3 4</sup> Further, some theorists advocate abandoning the DDR.<sup>4</sup> According to this view, since brain dead patients are irreversibly comatose, they do not have any interests that can be either satisfied or frustrated, and thus, cannot be harmed by organ removal even though it causes death. Since organ

donation can benefit others, as long as informed consent is obtained, these theorists argue that the DDR should no longer guide organ transplantation practice.

Several scholars have claimed that the idea of abandoning the DDR is in opposition to mainstream public opinion. Magnus and colleagues, for example, write, 'Whatever the merits of the arguments for [abandoning the DDR] as a philosophical position, it is far out of touch with ... public opinion' (p. 3).<sup>5</sup> Bernat writes, 'I believe that ... violating the DDR is misguided ... and will result in an overall decline in organ donation' (p. 1290).<sup>6</sup> Although these opinions are plausible, there is limited empirical evidence on this question. Furthermore, there is substantial confusion among the general public on a number of key issues, including basic clinical facts about brain death, the legal status of brain death, and the fact that organ procurement takes place while the donor remains on the ventilator and the heart continues to beat.<sup>7</sup> This considerable confusion about key issues renders the existing literature largely uninterpretable, and furthermore, it provides little assistance in developing or evaluating public policy about organ donation. A clearer understanding of the public's views on this key issue is important to both sides of the debate, including those who challenge and those who endorse the DDR and the equivalence of brain death with death.<sup>7</sup>

Our aim was to evaluate public attitudes towards organ donation if it were explicitly described as causing the biological death of a patient in irreversible apneic coma. We also investigated whether those individuals who support organ donation when it is described as 'after death' would also support organ donation if it were described as causing the death of a patient in irreversible coma. Since people tend to respond differently when questions are posed concretely (eg, with respect to a specific, named person) than when similar questions are posed in the abstract,<sup>8</sup> we included both a vignette as well as more general questions regarding the DDR. Since there is documented confusion among the public about brain death and the process of organ transplantation,<sup>7</sup> we avoided possible misunderstandings by describing the vignette as hypothetical and not reflecting current medical practice, and the phrase 'brain death' was used only once at the very end of the survey in the demographics section. Finally, because the term 'death' can be ambiguous, we sought to understand how the general public construes the meaning of this term in the context of organ donation and the DDR.

## METHOD

## Participants

Participants were recruited through Survey Sampling International (SSI). The sample was selected to be reflective of the US population by age, gender, race/ethnicity, income and geographical region (for additional information on participant recruitment see the SSI website).<sup>9</sup> Upon receiving a web-based invitation (n=1482), participants who gave an informed consent (n=1329) were then directed to the online survey; 1200 participants completed the entire 15 min survey (81% completion rate). Participants were removed from the final analysed data set for failing an attention check (n=94) or taking the survey more than once as indicated by duplicate IP addresses (n=10), resulting in an analysed sample of n=1096. Based on recommendations from the American Association for Public Opinion Research, because the sample is based on those who initially self-selected for participation in the SSI panel rather than a probability sample, no estimates of sampling error can be calculated.<sup>10</sup> Table 1 shows the demographic characteristics of the analysed sample.

## Procedure

With approval from the Florida State University Human Subjects Committee, we conducted a cross-sectional web-based survey with the assistance of SSI in October and November 2013. We developed the questionnaire in five iterative steps. We carried out a thorough review of the bioethical literature on brain death and organ transplantation as well as the empirical survey literature (step 1), and developed initial survey questions (step 2). These questions were sent to four content experts (one philosopher, one legal scholar and two physicians) for comment and were revised based on feedback (step 3). A pilot was then conducted through SSI (n=38), which included the survey and additional questions regarding the readability and neutrality of the items (step 4). Based on feedback from the above sources, the questionnaire was finalised and is written at a 9th grade reading level, according to Microsoft Word (step 5).

The final survey included six modules: a vignette with associated questions, general questions not associated with the vignette, two validated scales measuring attitudes towards organ donation and towards euthanasia, open-ended questions, demographics, and five 'fact-check' questions (described below). To account for possible order effects, we counterbalanced the vignette, general questions and attitude scales. In each of the resulting six conditions (see online supplementary table S1), the fact-check questions were presented two modules after the vignette. Although some order effects were found (see online supplementary tables S2–S5), we reported the results in the aggregate, because counterbalancing should minimise the effects of order. Results from the open-ended qualitative section are not reported.

## Measures

## Vignette

In this module, participants were first instructed to read the following vignette:

Jason has been in a very bad car accident. He suffered a severe head injury and is now in the hospital. As a result of the injury, Jason is completely unconscious. He cannot hear or feel anything, cannot remember or think about anything, he is not aware of anything, and his condition is irreversible. Jason will never wake up. He also cannot breathe without mechanical support, but is on a breathing machine that keeps his lungs working. Without the machine, Jason's heart and all other organs would

Table 1 Demographics

	Survey (%)	National (%)
Gender*		
Male	49.7	49.2
Female	50.2	50.8
Transgender	0.1	–
Age*		
18–44 years	47.2	39.9
45–64 years	52.4	26.4
65+ years	0.5	13.0
Geographical region*		
Northeast	18.6	17.9
Midwest	22.8	21.7
South	35.6	37.1
West	22.9	23.3
Other	0.1	–
Race/Ethnicity*		
White, non-Hispanic	74.4	63.7
Black or African-American, non-Hispanic	11.4	12.2
Hispanic or Latino, any race	8.5	16.5
Asian/Native Hawaiian/Pacific Islander	3.1	4.8
American Indian/Alaskan Native	0.3	0.7
Multiracial	1.5	1.9
Other	0.8	0.2
Religion†		
Christian (all)	71.6	78.4
Buddhist	0.7	0.7
Hindu	0.5	0.4
Jewish	2.4	1.7
Muslim	0.3	0.6
Sikh	0.2	–
Other faiths	1.1	1.2
None/Unaffiliated	22.7	16.1
Declined to answer/Don't know	0.5	0.8
Religiousness‡		
Religion not too/not at all important	33.6	16
Religion somewhat important	21.5	26
Religion very important	44.6	56
Declined to answer	0.7	1
Political ideology§		
Conservative	27.3	34.9
Neither Conservative nor Liberal	42.1	39.1
Liberal	30	21.5
Declined to answer/Don't know	0.5	4.5
Education¶		
Less than high school diploma	1.6	12.5
High school graduate (incl. GED)	21.8	29.5
Some college or associate's degree	39.8	29
Bachelor's degree or higher	36.4	28.9

Percentages may not add up to 100 due to rounding.

\*National data from the 2010 US Decennial Census. The Census did not measure the number of individuals who identify as transgender.<sup>11</sup>

†National data from the Pew Forum on Religion & Public Life, US Religious Landscape Survey.<sup>12</sup> Pew did not report data for those who identify as Sikh.

‡Survey participants selected a number from 1 (not religious) to 10 (very religious) in response to the statement: 'I view myself as ...'. National participants were asked 'How important is religion in your life ... very important, somewhat important, not too important, or not at all important'.<sup>13</sup> Based on the national report, survey participants were categorised as: 1–4 (religion not too/not all important); 5–6 (religion somewhat important); 7–10 (religion very important).

§Survey participants selected a number from 1 (very conservative) to 5 (neither conservative nor liberal) to 10 (very liberal) in response to the statement: 'Politically, I would describe myself as ...'. National participants were asked 'In general, would you describe your political views as ... very conservative, conservative, moderate, liberal or very liberal?'.<sup>14</sup> Based on the national report, survey participants were categorised as: 1–4 (conservative); 5–6 (neither conservative nor liberal); 7–10 (liberal).

¶National data from the U.S. Census Bureau, Current Population Survey, 2013 Annual Social and Economic Supplement.<sup>15</sup>  
GED, General Education Development credential.

stop within minutes. Although he will never wake up and cannot breathe without the support of the machine, Jason is still biologically alive.

Before the injury, Jason wanted to be an organ donor. The organs will function best if they are removed while Jason's heart is still beating and while he is still on the breathing machine. If the organs are removed while Jason is still on the machine, he would die from the removal of organs (in other words, the surgery would cause Jason's biological death).

Participants then rated their agreement with statements about organ donation in Jason's scenario on a 5-point Likert scale (see figure 1 for vignette questions). They were instructed to respond based only on the information in the scenario, to take everything stated in the scenario as a fact, and not to make any additional assumptions. Some statements focused specifically on Jason's situation, while others focused on whether participants would agree to donate a loved one's or their own organs in a scenario like Jason's. Participants were instructed to assume that in every case, organs would be removed while the patient was still on the breathing machine.

General questions

Participants used a 5-point Likert scale to rate their agreement with general statements such as, 'I would want to donate my organs if I was ever irreversibly unconscious, would never wake up again, and needed a machine to breathe, but was not yet biologically dead'. They responded to the question, 'In your personal opinion, how important is it, ethically, for an organ donor to be dead before organs are removed?' with a 5-point Likert-type scale in which 1=not important at all, 2=somewhat unimportant, 3=neutral, 4=somewhat important and 5=very important. Participants were also asked for their interpretation of the word 'dead':

Think back to how you answered the previous question ('How important is it for organ donors to be dead before organs are removed?'). When you considered the question, what did the word 'dead' mean to you?

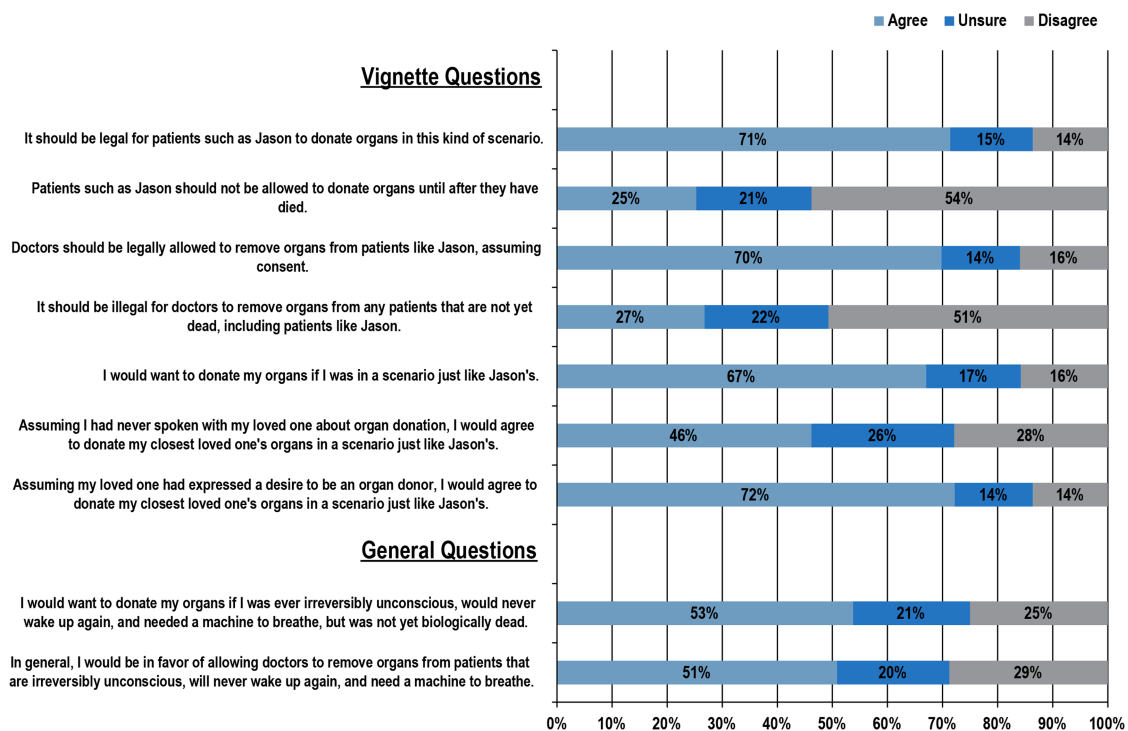
Participants could select as many answers as they wished from statements that were designed to reflect views in the bioethical literature (table 2).

Attitude scales

The Organ Donation Attitude Scale (ODAS)<sup>21</sup> is an 18-item validated scale that assesses attitudes towards organ donation. Participants responded to each statement with a 4-point Likert-type scale in which 1=strongly disagree, 2=disagree, 3=agree and 4=strongly agree. Sample statements included 'In general, I think that organ donation is a good thing' and 'I believe that organ donation is mutilation to the body' (reverse scored). Two individual items from this scale ('I am willing to donate my organs after death' and 'I have signed an organ donor card or the back of my driver's license') were used to compare willingness to donate organs when described as 'after my death' with willingness to donate organs when donation was described as causing death in irreversible coma. Participants also completed the Attitudes towards Euthanasia Scale.<sup>22</sup> Scale scores and their relationships with demographic variables are reported in online supplementary tables S6–S10.

Fact check

To verify that they were giving their opinions based on the information in the scenario, participants were asked five questions about relevant facts stated in the vignette: 'In the story you read, was Jason able to hear? Could Jason ever wake up? Was Jason able to breathe without the machine? Was Jason biologically alive or dead? Would organ removal cause Jason's



**Figure 1** Descriptive statistics of outcome variables. Participants were asked to rate their agreement with each statement on a 5-point Likert scale where 1=Strongly Disagree, 2=Disagree, 3=Unsure, 4=Agree, 5=Strongly Agree. Strongly Disagree and Disagree were combined under 'Disagree'; Strongly Agree and Agree were combined under 'Agree'. Some of the statements have been paraphrased in the figure for space considerations. Percentages may not add up to 100 due to rounding.

**Table 2** Defining 'death'

	Representative scholarly view	Frequency
I don't understand this question. <i>Dead</i> means dead, and I meant <i>dead</i> .	'Commonsense' view (cf Nair-Collins <sup>16</sup> )	465
I meant dead in a scientific sense: The body no longer functions as a whole, biologically.	Bernat <sup>17</sup>	434
I meant that the person is gone: The individual is irreversibly unconscious and will never wake up again, although the body might be technically alive in a biological sense.	Green and Wikler, <sup>18</sup> Lizza <sup>19</sup>	384
I meant legally dead: Legal requirements are satisfied, but those requirements might not be the same as what a biologist would call 'dead', and the body might not be technically dead in a biological sense.	Legal concept (cf Nair-Collins <sup>16</sup> )	195
I meant 'As good as dead': So long as the patient can't suffer and will never wake up or have thoughts and feelings again, I consider that patient dead, even if the body isn't technically dead in a scientific sense, or if there are some continuing biological functions.	Miller and Truog <sup>4</sup>	173
I meant 'morally' or 'socially' dead: Everything that made life meaningful or important for the person is gone, and it is ethically ok to do some things, like remove organs, that would not be ok to do to another person.	Veatch <sup>20</sup>	88
Other: (fill-in)*		17

A total of 725 participants (66%) chose only one answer. Of those who chose only one answer, the two most common responses were 'Dead means dead' (n=285, 26%) and 'I meant dead in a scientific sense' (n=163, 15%).

\*Among those who chose 'Other', five answers included mention of brain death.

death, if organs were removed while he was still on the breathing machine?'.<sup>2</sup>

### Analysis strategy

Responses to the vignette and general question modules on the 5-point Likert scale were collapsed into three categories of agree, unsure and disagree. Descriptive statistics (frequency and per cent) were calculated for these variables, and frequency was calculated for responses to the question about how participants interpret the meaning of the word 'dead'. For the two individual items on the ODAS that were mentioned above, we collapsed the 4-point Likert-type scale into two categories of agree or disagree and cross-tabulated them with the collapsed responses of items from the vignette and general questions modules. This cross-tabulation served as a measure of the relationship between willingness to donate organs when described as after death and willingness to donate organs when described as causing death in irreversible coma.

### RESULTS

A majority of participants were in favour of organ donation when it was explicitly described as causing the biological death of a donor in irreversible apneic coma (figure 1). This opinion held when the question was posed as a general query, when it was posed with respect to a particular patient and scenario, when it involved donating their own organs, and when it involved donating a loved one's organs who previously expressed a desire to donate. The one exception was when participants assumed they had never spoken with their loved one about organ donation. In this case, 46% (n=504) responded that they would agree to donate organs in this scenario, while 26% (n=284) were unsure and 28% (n=304) disagreed. As expected, there was more support for organ donation when the questions were posed with respect to a particular scenario, rather than as a general query. There was also greater agreement when statements were phrased in the affirmative versus the negative, which likely reflected acquiescence bias.<sup>23</sup> A few small correlations were found between outcome variables and selected demographic variables. In general, participants who described themselves as more politically conservative and more religious were slightly less in favour of organ donation in the scenario described (the absolute values of  $r$ 's range from 0.07 to 0.17;

see online supplementary tables S11–S13 for relationships between demographic variables and outcome variables).

When asked explicitly, 'In your personal opinion, how important is it, ethically, for an organ donor to be dead before vital organs such as the heart and lungs are removed?', 69% of the sample (n=755) agreed that it was somewhat or very important, while 20% (n=220) responded 'neutral' and 11% (n=121) responded that it was somewhat unimportant or not important at all. This seems inconsistent with other results in which, for example, 71% stated that it should be legal for patients such as Jason to donate organs even though doing so would cause his biological death. One possible explanation of this discrepancy is that many participants believe that the death of the donor is important, but also believe that the need to save lives through organ donation is more important, and thus are willing to consider organ donation in scenarios like Jason's. A second and not mutually exclusive possibility is that there is ambiguity in the meaning of the term 'dead' in the context of irreversible coma. For example, when asked how they interpreted the meaning of the word 'dead', 384 participants selected 'The person is gone: The individual is irreversibly unconscious and will never wake up again, although the body might be technically alive in a biological sense', whereas 434 selected 'Dead in a scientific sense: The body no longer functions as a whole, biologically'. Since participants could select multiple items, percentages were not calculated (table 2).

Consistent with other surveys,<sup>24</sup> the public's support for organ donation (when described as 'after death') was quite high. For example, 85% of the sample (n=915) agreed that they were willing to donate their organs after death on the ODAS, and 61% (n=653) indicated that they had signed an organ donor card. Furthermore, willingness to donate organs after death correlated positively with participants' willingness to donate their own or a loved one's organs in the scenario of irreversible apneic coma with organ removal causing death ( $r$ 's range from 0.32 to 0.53; see online supplementary table S14).

When responses to individual items on the ODAS and individual items on the vignette and general questions modules were cross-tabulated, we found that most but not all participants who agreed that they were willing to donate organs after death were also willing to donate organs in irreversible coma. Of the 85% of the sample (n=915) who agreed that they were willing

to donate their organs after death on the ODAS, 76% (n=691) agreed that they would donate organs in a scenario like Jason's. Of this same group, 62% (n=569) agreed with the general statement that they would donate their organs if they were irreversibly unconscious but not yet biologically dead. Of the participants who indicated on the ODAS that they had signed an organ donor card (n=653, 61% of the total sample), 81% (n=530) agreed that they would donate their organs in a scenario like Jason's and 69% (n=449) agreed with the general statement that they would donate their organs if irreversibly unconscious but biologically alive (see online supplementary table S15 for further details).

Finally, 50% of participants (n=548) passed all five fact-check questions, 26% (n=285) passed four of five, and 24% (n=263) passed three or fewer. The most common incorrect responses were to the questions, 'Was Jason biologically alive or dead?' and 'Was Jason able to hear?'. A few significant differences were found in responses to the outcome variables in the vignette and general questions modules between those who passed the fact-check questions and those who did not. In general, those who responded correctly were more in favour of organ removal in irreversible coma than those who responded incorrectly (Cohen's *d* ranges from 0.21 to 0.91; see online supplementary figure S1 and tables S16–S18).

## DISCUSSION

In this national survey of public views on organ donation, we described a scenario that explicitly violates the DDR. In general, the American public was largely in support of organ removal even though it causes death in this scenario. Furthermore, those who are already in favour of organ donation when described as 'after death', mostly remain in support of organ donation when described as causing the death of a patient in irreversible coma. This survey challenges the assertions of scholars who claim that proposals to abandon the DDR are out of touch with mainstream opinion.<sup>5 6</sup>

However, it is also important to note that 19–38% of people willing to donate their organs 'after death' were either unsure or unwilling to donate their organs in the circumstance of irreversible apneic coma with organ removal causing biological death (this numerical range is derived from the cross-tabulations reported above). If the scientific criticisms of 'brain death' are correct,<sup>3 4</sup> then it is likely that some people who become heart-beating organ donors would not have agreed to do so, had they had a more nuanced contextual understanding of the circumstances of organ removal. This raises a concern about the legitimacy of some consents to donate organs.

In a recent review of the empirical evidence on public attitudes towards brain death and organ transplantation, Shah and colleagues argued that the existing survey literature demonstrates considerable confusion among the public about both brain death and the process of organ procurement, rendering the interpretation of existing data problematic. They argued that there is an urgent need for new empirical research that provides meaningful, interpretable data on the public's views about organ donation.<sup>7</sup> The data reported here substantially contribute to the project envisioned by Shah and colleagues. We sought to avoid the problem of public misunderstanding by refraining from using the phrase 'brain death' anywhere in the body of the survey, by stating that the vignette is hypothetical and does not reflect current medical practice, and by instructing participants to take everything as stated in the vignette as a fact and not to make any additional assumptions. Yet despite these efforts, only half of the participants responded correctly to

all five fact-check questions. This may reflect continued misunderstanding about organ transplantation, but it may also be a result of participant fatigue or other factors. Nonetheless, differences in responses to outcome variables between those who passed and those who did not pass the fact-check questions, where they were found, generally showed that those who responded correctly were more in favour of lethal organ removal in irreversible coma than those who responded incorrectly (see online supplementary figure S1 and tables S16–S18).

This research also illustrates several critical methodological issues that must be considered in developing and evaluating future research aimed at understanding the public's views about organ donation. In addition to the problem of public misunderstanding, future research efforts must take into account acquiescence bias,<sup>23</sup> the abstract/concrete distinction,<sup>8</sup> and the effect of the order of presentation of questions or vignettes. Each of these phenomena likely influenced the results of this survey. For example, there was a 19 percentage point difference between the vignette question of whether doctors should be legally allowed to remove organs from patients like Jason, and the general question of whether doctors should be allowed to remove organs from patients in irreversible apneic coma (figure 1). This difference is likely a result of the abstract versus concrete wording of the question.<sup>8</sup> Within the vignette module, there were similar differences in responses to questions that were phrased in the affirmative versus the negative (figure 1), likely a result of acquiescence bias.<sup>23</sup>

Furthermore, researchers must phrase questions in a way that provides relevant information. For example, in their oft-cited survey of the residents of Ohio, Siminoff *et al*<sup>25</sup> described 'a 22 year old' or 'a 70 year old' in a hospital or nursing home with varying degrees of brain injury, and then asked, 'Would you be willing to donate this person's organs?'. Responses to this question provide little information on the more relevant questions of whether participants would be willing to donate their own organs, or the organs of a loved one, in these scenarios. Nor do these questions address the more relevant issue of whether participants believe that physicians should be legally allowed to remove organs under such conditions.

It should be noted that our sample was somewhat more liberal, more educated, less religious and younger than the general US population (eg, persons of age 65 years and older were under-represented; see table 1). However, associations between these demographic variables and the outcome variables, where they were found, were small in magnitude (see online supplementary table S11). Thus, although our sample differed slightly from the general US population, it is unlikely that responses from a more reflective sample would differ greatly from the responses reported here.

The results of this survey should be interpreted in light of the above mentioned influences; however, as a first step towards a more adequate understanding of public views, this survey has important implications for public policy as well as the academic debate on brain death and organ transplantation. Many scholars argue that the current system of organ transplantation is flawed because of its lack of transparency.<sup>4 26 27</sup> There is a legitimate scientific dispute among experts as to whether 'brain dead' donors are truly dead, and this information is not routinely disclosed. Although some scholars have suggested that the idea of abandoning the DDR is out of touch with mainstream opinion, the results of this survey challenge this claim. At the very least, it seems clear that the public is ready for an honest and forthright conversation on these issues.

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