

# Attitudes of the American Public toward Organ Donation after Uncontrolled (Sudden) Cardiac Death

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**Concerns about public support for organ donation after cardiac death have hindered expansion of this practice, particularly rapid organ recovery in the context of uncontrolled (sudden) cardiac death (uDCD). A nationally representative Internet-based panel was provided scenarios describing donation in the context of brain death, controlled cardiac death and uncontrolled cardiac death. Participants were randomized to receive questions about trust in the medical system before or after the rapid organ recovery scenario. Among 1631 panelists, 1049 (64%) completed the survey. Participants expressed slightly more willingness to donate in the context of controlled and uncontrolled cardiac death than after brain death (70% and 69% vs. 66%, respectively,  $p < 0.01$ ). Eighty percent of subjects (95% CI 77–84%) would support having a rapid organ recovery program in their community, though 83% would require family consent or a signed donor card prior to invasive procedures for organ preservation. The idea of uDCD slightly decreased trust in the medical system from 59% expressing trust to 51% ( $p = 0.02$ ), but did not increase belief that a signed donor card would interfere with medical care (28% vs. 32%,  $p = 0.37$ ). These findings provide support for the careful expansion of uDCD, albeit with formal consent prior to organ preservation.**

**Key words:** Cardiac death donors, donation, public policy, transplant ethics

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## Introduction

The supply of organs for deceased donor transplantation has reached a plateau in the United States. After rising steadily during the beginning of this decade, the overall number of organ donors has increased by less than 1% between 2006 and 2007, and in 2008 actually declined (1). This plateau has occurred despite substantial efforts over the past 10 years to increase organ donation rates, including public awareness campaigns, required request legislation, and collaborative quality improvement efforts by hospitals, organ procurement organizations (OPOs) and the Health Resources and Services Administration (HRSA) (2). The main rate-limiting step appears to be consent for donation, which is provided by only 42–54% of families of potential deceased donors (3–5).

In response to the continued organ shortage, physicians have increasingly explored the use of organs from nonstandard donors, such as those who died a cardiac death. In the past, donation after cardiac death (DCD) was performed infrequently due to poor transplantation outcomes. Recently, however, improved preservation and surgical techniques have made the use of these organs an increasingly suitable alternative (6). DCD can be classified as controlled when cardiopulmonary arrest occurs in the setting of planned withdrawal of care (Maastricht type 3), and uncontrolled when cardiopulmonary arrest occurs unexpectedly (Maastricht types 1, 2 and 4) (7).

Currently, the majority of DCD donors in the United States are controlled, and they represent less than 10% of all donors (8). Although controlled DCD (cDCD) has been rapidly increasing in recent years, the potential for continued growth is low since most controlled cardiac deaths in the hospital involve the elderly and those with comorbidities that preclude solid organ donation. Uncontrolled DCD (uDCD), on the other hand, has been recommended by the Institute of Medicine (IOM) as a promising and ethically acceptable method which could nearly triple the number of organ donors (9).

Despite endorsement by the IOM, some concerns have been expressed about the whether uDCD would be acceptable to the American public (10,11). Past attempts to implement uDCD in the United States have failed in part due to negative public reactions (12,13), and there is reason to believe that any reduction in public trust could lower

rates of consent for donation even further (14). A particularly controversial aspect of uDCD involves the insertion of catheters for organ preservation prior to first person or family consent. This technique was condoned by the IOM because it enhances family autonomy to decide about donation (15). However, limited data exist measuring public attitudes regarding such details of uDCD (16,17). Therefore, the purpose of this study was to determine the public's willingness to donate in the settings of uDCD versus cDCD and DBD, and to explore public opinion regarding specific aspects of uDCD programs.

## Methods

### Study design and sample

A cross-sectional survey was conducted using a random national sample of adults age  $\geq 18$  in the Knowledge Networks panel. Knowledge Networks (Menlo Park, CA) maintains an Internet survey panel designed to be representative of the entire U.S. population. The details and validity of the KnowledgePanel™ methodology have been previously described (18). Briefly, recruitment to the panel is performed using random digit dialing of listed and unlisted numbers, and computers with internet access are provided to subjects who do not already have access. Panel members are then randomly selected and contacted by e-mail to participate in individual surveys. In this survey, Black Americans were oversampled at 35% of the entire group because they are known to view organ donation less favorably than other racial groups (19). For this reason, their attitudes are particularly important when considering an uncontrolled DCD program. Otherwise, the sampling frame represented a cross-section of the entire U.S. population. This study was approved by the Institutional Review Board of the University of Michigan.

### Questionnaire

The questionnaire was developed in an iterative fashion using input from multiple experts in survey design, and pilot tested on 25 participants. The overarching design was to start with relatively generic questions on organ donation, and to move toward increasingly specific scenarios. The questionnaire began with questions about willingness to donate all or some of the respondent's own organs after his/her death. Most of the items used a 6-point response scale. Both ends of the scale were labeled, but midpoints were not labeled so as to more closely approximate a continuous measure (20). These questions were then followed by items concerning willingness to donate when deciding about a family member. In order to simulate a realistic organ donation situation, participants were asked to identify their closest family member or loved one by category (spouse, child, etc.). Forty percent chose 'spouse', 27% chose 'child', 15% chose 'parent' and 10% chose 'sibling'. The remainder chose 'other', and were instructed to type in their selection. This person's relationship was then referred to in subsequent questions. The following scenarios were provided to explain DBD, controlled and uncontrolled DCD. The order of scenarios #1 and #2 was randomly alternated to control for any possible order effects. In the uDCD scenario, extra-corporeal membrane oxygenation (ECMO) was presented as the method for organ preservation rather than cooling, since ECMO is currently the most commonly used technique worldwide (21). The term 'cardiac death' was used rather than 'circulatory determination of death' for the purposes of comprehension by the lay public.

**DBD:** *Imagine that your [family member] was in an accident, was taken to the hospital, and placed on life support. Even though the heart is still beating, the doctors inform you that their brain is dead and*

*will never recover. This is called brain death. How willing would you be to donate any of your [family member]'s organs in this scenario?*

**Controlled DCD:** *Imagine that your [family member] was in an accident and taken to a hospital. They were placed on life support, which means that a machine is breathing and pumping blood for them. Their brain is partially working, but they are not awake and their heart is not working well on its own. Your [family member] does not improve even after the doctors and the medical team do everything they can. The doctors tell you that your [family member] will never recover enough to come off of life support. After talking with the doctors, the decision is made to turn off the life support, and their heart stops beating. This is called cardiac death. How willing would you be to donate any of your [family member]'s organs in this scenario, after the life support has been turned off and the heart has stopped beating?*

**Uncontrolled DCD:** *Imagine that your [family member] was in an accident and is not breathing. The paramedics arrive quickly and try very hard, but they tell you your [family member] is dead. A second, totally separate, special ambulance with a medical team is alerted about the recent death. They arrive at the scene, restart CPR, and insert catheters, or small tubes, into blood vessels. They do this to keep blood flowing to the organs for possible donation. This is called a rapid organ recovery program, and the goal is to increase the number of available organs for donation. After all this has happened, you would then receive a call to discuss organ donation. How willing would you be to donate any of your [family member]'s organs in this situation?*

Participants were also asked whether they would prefer to donate in the setting of cardiac versus brain death, whether they would support having a rapid organ recovery program where they live, and whether family consent or a signed organ donor card should be required prior to placing catheters for cardiopulmonary bypass. Finally, we hypothesized that an uncontrolled DCD program may cause people to worry that resuscitation attempts would be halted prematurely in order to procure organs for transplant. In order to test this hypothesis, we asked participants 'Do you believe that if you sign your donor card or driver's license, the paramedics or doctors will not try as hard to save your life?' (19) and 'Please indicate how much you agree or disagree with the following statement: I have trust in the medical system as a whole' (22). Participants were randomly assigned to receive this question before or after receiving the donation scenarios, to ascertain the effect of considering uDCD on their trust in the system.

### Statistical analysis and power calculations

Demographics were compared between the groups randomized to receive the trust questions first versus the DCD scenarios first, using a t-test for normally distributed continuous data, Wilcoxon rank-sum test for skewed data, and chi-square test for categorical data. All reported questionnaire results and between-participant comparisons were adjusted for both panel sampling weights and study-specific sampling weights, including the oversampling of Black Americans. Questionnaire items with continuous measures were heavily skewed toward both ends of the scale in a bimodal distribution, so these measures were dichotomized at the midpoint for the purpose of analysis. Participants skipped  $\leq 1\%$  of questions, and missing data were treated as negative responses. Within-participant comparisons were performed using McNemar's test for paired data, and between-participant comparisons were performed using logistic regression (23). Multivariable logistic regression was used to determine independent demographic

**Table 1:** Participant demographics (n = 1049)\*

	Randomized to receive trust scenarios first	Randomized to receive DCD scenarios first	p- Value
	(n = 543)	(n = 506)	
Age, median (range)	50 (18–91)	49 (18–92)	0.5
Gender, % male	46%	50%	0.14
Race or ethnicity			0.03
White, non-Hispanic	53%	56%	
Black, non-Hispanic	38%	32%	
Hispanic	4%	8%	
Other, non-Hispanic	5%	4%	
Education			0.79
Less than high school	12%	12%	
High school	34%	32%	
Some college	26%	29%	
Bachelor's or higher	28%	27%	
Household income, median	\$40 000–\$49 999	40 000–\$49 999	0.31
Region			0.63
Northeast	20%	18%	
Midwest	23%	22%	
South	39%	43%	
West	18%	17%	

\*By comparison, the U. S. Census estimates median household income for 2007 to be \$50 000, 49% of the population to be male, and 27% of the population age 25 or higher to have a Bachelor's degree or higher (34).

predictors of willingness to donate. Power calculations were based upon detecting a 12% difference (50% vs. 62%) in trust in the medical system between participants randomized to receive the trust questions first versus the DCD scenarios first, for which a sample size of 374 per group was required, assuming  $\beta = 0.9$  and  $\alpha = 0.05$ . All calculations were performed using Stata v. 10.0 (Statacorp, College Station, TX).

## Results

Data collection began on December 18, 2008, and continued through January 13, 2009. The survey was sent to a total of 1631 panelists, and 1049 completed the survey for a response rate of 64%. Participant demographics are listed in Table 1, according to whether they were randomized to receive the trust questions or DCD scenarios first.

### Willingness to donate

In the overall sample, 75% (95% CI 71–79%) responded that they were more likely than not to donate their organs. Among those who would only donate some organs, the most common exclusions were eyes (n = 15), heart (n = 6), brain (n = 4), and face (n = 3). Consistent with previous studies (24), willingness to donate varied by racial and ethnic group with 59% (95% CI 52–65%) of Black, non-Hispanic participants expressing willingness to donate versus 81% (95% CI 77–86%) among White, non-Hispanic subjects, 63% (95% CI 47–78%) among Hispanic partic-

**Table 2:** Predictors of willingness to donate<sup>1</sup>

	Odds ratio	95% CI
Age (per 10 years)	1.02	0.91–1.14
Male (relative to female)	0.87	0.60–1.27
Race/ethnicity		
White, non-Hispanic	Reference	Reference
Black, non-Hispanic	<b>0.35</b>	<b>0.23–0.53</b>
Hispanic	0.58	0.28–1.21
Other, non-Hispanic	<b>0.25</b>	<b>0.09–0.67</b>
Education		
Less than high school	Reference	Reference
High school	1.22	0.70–2.13
Some college	1.70	0.94–3.19
Bachelor's or higher	<b>3.35</b>	<b>1.66–6.76</b>
Household income (per \$10 K)	1.02	0.97–1.07
Region		
Northeast	Reference	Reference
Midwest	1.49	0.81–2.72
South	<b>1.83</b>	<b>1.08–3.11</b>
West	1.10	0.58–2.10

<sup>1</sup>Adjusted for sampling weights. Statistically significant results are in bold.

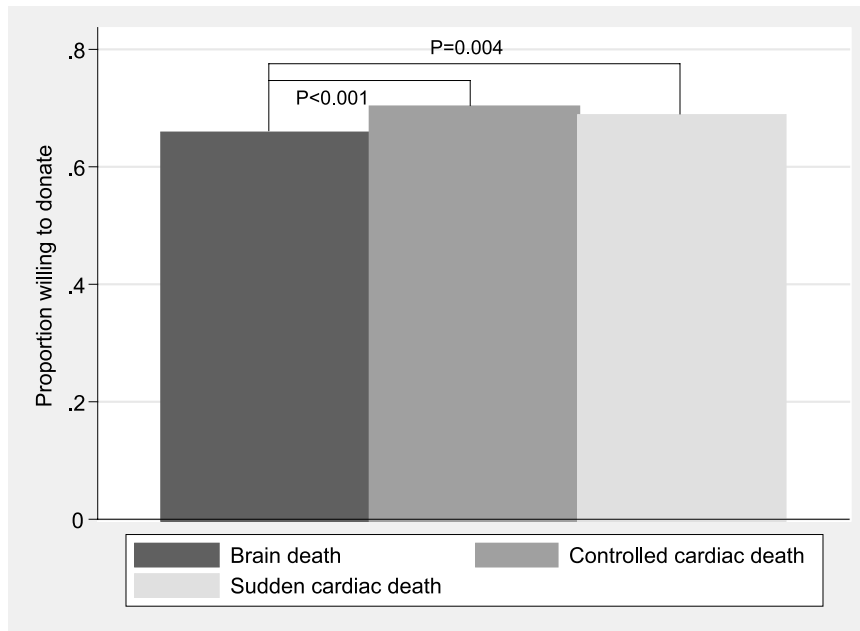
ipants, and 58% (95% CI 33–83%) among Other, non-Hispanic participants. Participants living in the South, and those with lower levels of education were also less willing to donate, as shown by the multivariate analysis in Table 2. As hypothesized, participants were slightly less willing to donate when deciding for a family member than when deciding for themselves: 75% of participants expressed willingness to donate their own organs after their death, but only 71% (95% CI 67–76%) would agree to donate for their family member ( $p = 0.005$ ).

### Donation after brain death versus cardiac death

Participants expressed slightly more willingness to donate their family member's organs in the setting of cardiac death compared to brain death, as shown in Figure 1. In the brain death scenario, 66% indicated a willingness to donate (95% CI 62–71%), compared to 70% (95% CI 66–75%) and 69% (95% CI 65–73%) in the controlled and uncontrolled DCD scenarios, respectively. Although these differences were small, they were statistically significant ( $p < 0.001$  for DBD vs. controlled DCD, and  $p = 0.004$  for DBD vs. uncontrolled DCD). There did not appear to be any interactions on willingness to donate between the type of death and race/ethnicity (data not shown). When participants were asked directly in which setting they would prefer to donate, 9% (95% CI 6–12%) chose brain death, 15% (95% CI 12–19%) chose cardiac death, 51% (95% CI 46–55%) would be equally likely to donate in either context and 25% (95% CI 21–29%) would not donate at all.

### Support for a rapid organ recovery program

As shown in Table 3, participants expressed strong support for a rapid organ recovery program, with 80% (95% CI 77–84%) expressing willingness to have such a program where they live. This support did not vary significantly by



**Figure 1: Proportion of Americans expressing willingness to donate the organs of their family member, in the context of brain death, controlled cardiac death and sudden (uncontrolled) cardiac death.**

race or ethnicity, at 81% (95% CI 77–85%) among White, non-Hispanic participants, 76% (95% CI 71–81%) among Black, non-Hispanics, 67% (95% CI 52–82%) among Hispanics and 78% (95% CI 58–99%) among Other race, non-Hispanic. Despite this strong support, there were some caveats. First, only 17% (95% CI 13–20%) of participants felt that it was appropriate for catheters to be placed for cardiopulmonary bypass prior to obtaining family consent or a signed organ donor card. Second, the idea of such a program did seem to induce feelings of mistrust in some participants. Among participants who were randomized to receive the trust question before the donation scenarios, 59% (95% CI 53–65%) expressed trust in the medical system, while among those who received the questions in reverse order, only 51% (95% CI 44–57%) expressed trust

in the system (odds ratio 1.35,  $p = 0.02$ ). However, the idea of a rapid organ recovery program did not significantly increase fears that signing an organ donor card would make doctors not try as hard to save their life. Among participants randomized to receive this question before the donation scenarios 28% (95% CI 23–33%) expressed belief in this idea, while among those receiving this question in reverse order 32% (95% CI 26–38%) expressed belief in this idea (odds ratio 1.19,  $p = 0.37$ ).

### Discussion

This nationwide survey demonstrates that the American public is at least as willing, if not more willing, to donate organs in the setting of cardiac death than brain death. Furthermore, the majority of people expressed strong support for a rapid recovery program to procure organs after sudden cardiac death. This support was widespread, and was not limited to Caucasians. Although we had expected that this unfamiliar form of donation would create public dismay (10,25), our results instead suggest that uDCD has the opportunity to gain widespread public support if it is implemented in a sensitive manner. These unexpected findings may in part reflect people’s discomfort with the idea of brain death, since newspaper and television reports contain numerous inaccuracies (26) and only 34% of subjects in one single-state study believed that someone with brain death is legally dead (27). In other words, the public may prefer donation after cardiac death because it resonates more closely with popular conceptions of the dying process.

Despite this generally positive attitude, we did identify some latent concerns about donation. Participants who

**Table 3: Support for a rapid organ recovery program**

	Proportion	95% CI
Willing to have a rapid organ recovery program where they live	80%	77–84%
Feel that cardiopulmonary bypass may be initiated prior to family consent or signed donor card	17%	13–20%
Express trust in the medical system		
Received trust questions first	59%	53–65%
Received DCD scenarios first	51% <sup>1</sup>	44–57%
Believe that signed donor card makes doctors not try as hard to save life		
Received trust questions first	28%	23–33%
Received DCD scenarios first	32% <sup>2</sup>	26–38%

<sup>1</sup> $p = 0.02$  for the difference in trust between those receiving trust versus DCD questions first.

<sup>2</sup> $p = 0.37$  for the difference in this belief between those receiving trust versus DCD questions first.

first received our donation scenarios consequently expressed less trust in the medical system than those who responded to the trust questions before learning about specific donation scenarios. Thus, while the American public has generally positive attitudes toward donation, the potential exists for implementation of uDCD to erode their trust in the medical system. These findings suggest that uDCD programs need to be conducted in a careful manner. A strict separation needs to be maintained between the medical care team and the transplantation team. Furthermore, if uDCD is to be performed in the United States, it should be done as part of a demonstration study which carefully investigates and reports the impact on donor families. Currently, there are federally funded studies of uDCD underway in New York and in Michigan.

Another caveat is that most participants indicated familial informed consent or a signed donor card should be required prior to insertion of catheters for organ preservation. Our study thus did not confirm the cautious support for this practice identified in prior small studies (9,16). Differences between studies may relate to the method of organ preservation presented (ECMO vs. organ cooling), or may simply reflect differences in study sample size. Our results coincide with anecdotal reports from prior attempts at uDCD in the United States, in which families were angered by invasive procedures being performed prior to their consent (12). Clearly, obtaining rapid family consent in the setting of an unexpected cardiac arrest would pose many logistical and ethical challenges. Therefore, future uncontrolled DCD programs in the United States may be limited to those on a donor registry, or those with signed drivers licenses or organ donor cards.

Our study was limited by the fact that no sample can ever be perfectly representative of the American public. The Knowledge Networks panel excludes people without a fixed address or telephone number, and it is possible that people who agree to be in the survey panel are somehow different from other Americans. Additionally, although the response rate was reasonably good at 64%, the possibility of nonresponse bias still exists. Despite these limitations, demographics of the participants in our study compare similarly to figures from the U.S. Census, as shown in Table 1. In the field of public opinion research the Knowledge Networks panel is recognized as state of the art (28,29), as evidenced by publication of Knowledge Networks surveys in major journals (18,30,31). In fact, several studies have demonstrated that estimates from the Knowledge Networks panel compare favorably to estimates from telephone surveys and large national face-to-face surveys such as the General Social Survey (32,33). Finally, it is possible that participants in this study could have been swayed more by the wording of the specific donation scenarios than their underlying beliefs. For example, participants were not instructed that a person with brain death is legally dead, nor was the time frame between declaration of death and organ procurement specified for

the DCD scenarios. Conversely, however, the inclusion of more controversial methods in the uDCD scenario (such as ECMO rather than organ cooling) may have actually biased participants against uDCD.

In conclusion, Americans do not appear to hold serious reservations about donation after cardiac death. In fact, the American public is slightly more willing to donate in the setting of cardiac death than brain death, and seems generally supportive of rapid organ recovery programs for donation in the setting of unexpected cardiac death. We believe that these findings provide support for ongoing demonstration studies of uDCD, albeit with consent obtained prior to invasive procedures for organ preservation. Such studies should include systematic analyses of the impact of uncontrolled DCD on potential donor families, especially on their trust in the medical system. For without trust, organ donation and transplantation would cease to exist entirely.

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