Don't Take 'No' For An Answer:
An experiment with actual organ donor registrations

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ABSTRACT

We experimentally investigate how individuals respond to an opportunity to change their actual Massachusetts organ donor registration status. Many unregistered individuals join the registry (29%) while almost all registered individuals remain (99%). How individuals are asked impacts the decision. Contrary to a popular hypothesis, a "mandated choice" frame that forces individuals to choose either yes or no does not increase registration rates over an "opt-in" frame in which people check a box to r
not to register. A second experiment suggests that "mandated choice" might also

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One potential strategy to encourage organ do

completing a survey.[12] Subjects were not informed in advance, however, that organ donation was the subject being studied.

Once they arrived at the laboratory, each subject was seated at an isolated computer terminal and provided with a consent form. The consent form indicated what subjects would do in the research study. To ensure subjects understood, the experimenter read one paragraph from the consent form aloud to all subjects. This paragraph read:

"What you will do in this research: You will (1) enter information that will be used to log you into a registry of organ and tissue donors in Massachusetts, (2) be provided with information about organ and tissue donation, (3) decide whether or not you would like to U H J L V W H U D V D Q R U J D Q D Q G W L V V X H A p p e n d i x B for D Q G F R R the full consent form.)

After signing the consent forms, subjects initiated the study by logging into the Massachusetts Organ and Tissue Donor Registry maintained by th9(Tis9nt p)-9(a)4(st)83(mnut fr)

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Figure 1: Login Screens for the Experiment (Figure 1A)
and the Massachusetts Registry of Motor Vehicles (Figure 1B)

Figure 1A: Screenshot of login page in Experiment

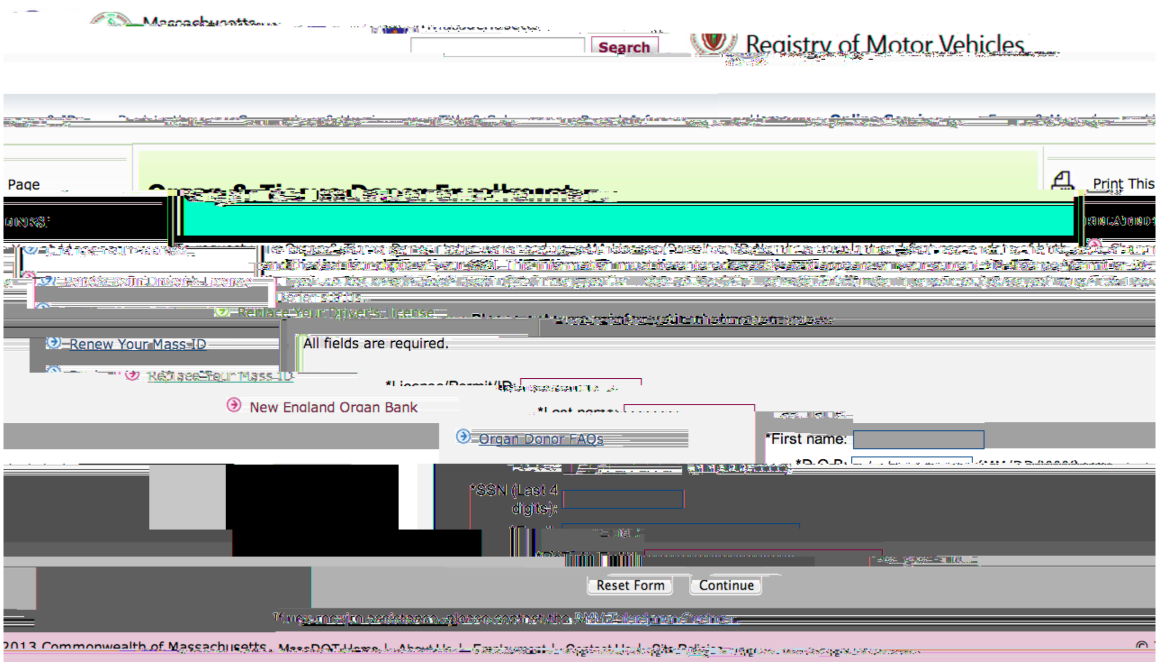

Figure 1B: Screenshot of login page on the Massachusetts Registry of Motor Vehicles Webpage that subjects did not see due to the experimental interface

Since the software interacted with the Massachusetts DOT database, we were able WR VHH WKH VXEMHFW¶V FXUUHQW GRQRU VWDWXV DQG condition based on that status. In particular, our experimental software gave each current non-donor

the opportunity to join the organ and tissue donor registry and each current donor the opportunity to remove their name from WKH UHJLVWU\ .QRZOHGJH RI WKH V status at the start of the experiment is valuable since it allows us to investigate changes in registration status in both directions (from non-donor to donor and vice versa) and it allows us investigate our experimental manipulations on both initial donors and non-donors

After logging into the registry, all subjects²

heart (for valves), heart with connective tissue, kidneys, liver or iliac vessels, lungs,

preceded by a bullet. See Figure 3 for screenshots of the control conditions (3A and 3B) as well as the list conditions (3C and 3D).[15]

After subjects made their organ donor registration decision, they completed a 40 question survey.

and from Massachusetts Registry of Motor Vehicles (Figure 3E)

Figure 3A 6 F U H H Q V K R W R I ([S H U L P H Q W U H´ J L V W U D W L R Q W S D J

´ W U H D W P H O W

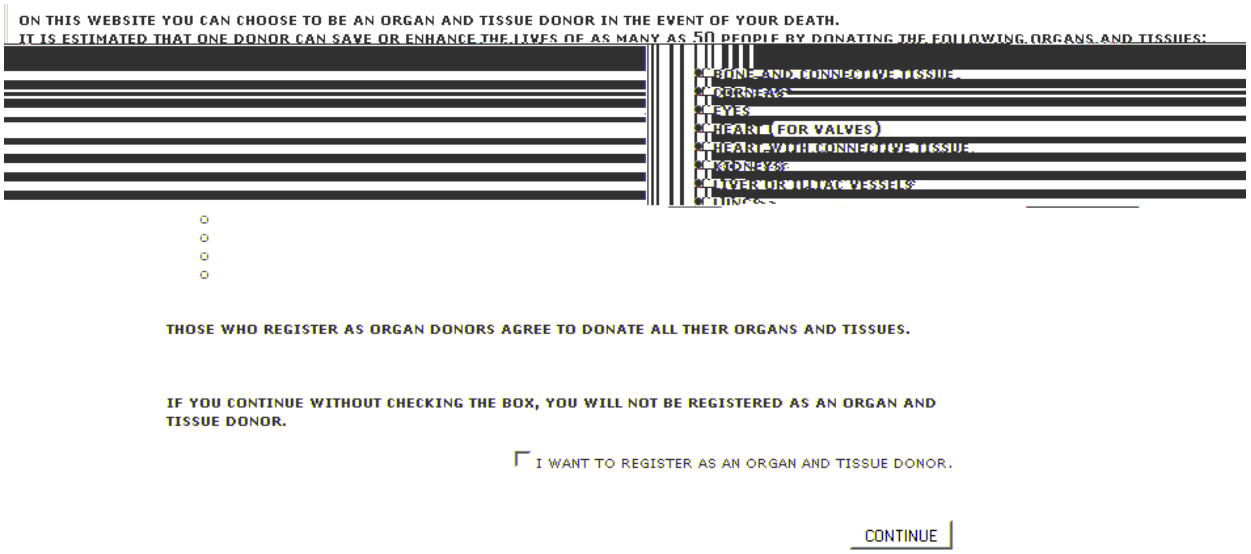

Figure 3& 6 F U H H Q V K R W R I ([S H U L P H Q W U D W L R Q S D

Figure 3' 6 F U H H Q V K R W R I ([S H U L P H Q W

Figure 3E: Screenshot of Massachusetts Registry of Motor Vehicles registration page that subjec3hTCteeeeeeee

III.

III.1 Asking again for organ donation

Table 1 provides demographic information about the 368 subjects who participated in the study as collected in the survey conducted after the registration decision. For each demographic breakdown, we show the percentage of those subjects who were donors before they entered the lab and those who were donors when they left. In the "PR test p-value" column, we denote the p-value associated with a two-sample test of proportions and indicate whether the change in percentage of registered (ted)] TJ ET BT 1 0 044 299.1

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Result 2: People who are given the opportunity to change their organ donor registration status overwhelmingly add themselves to the registry and do not remove themselves from the registry.

The increase in the number of donors highlighted in Result 1 was driven by both: (1) previous non-donors adding themselves to the registry and (2) previous donors keeping themselves on the registry. When given the opportunity to change their organ and tissue donor registration status, current donors were very unlikely to remove themselves from the registry (the 1.3% probability of removal from the registry is not statistically significantly different from 0; two-sided *t*-test, $p > 0.1$). Previous non-donors, however, were quite likely to add themselves to the organ and tissue donor registry (the 28.8% probability of joining the registry is statistically and economically significant). These results suggest that the intention to register as a donor appears to be stable, while the intention not to register appears to be less stable.

These results are relevant for policy in that they suggest that an individual being listed on a state registry or having a heart or an organ donor signature on his or her driver's license reflects his current intent to be a donor. This is an important fact for the Anatomical Gift Act, which says that these intention measures can be used to reflect the last wishes of a deceased donor (Glazier et al. 2009).

Furthermore, Glazier (2006) has suggested that an online registry from which one can at any time make changes to one's donation decision would make it easier to donate clearer. One might

Table 2: Demographics of Subject Population

	Number	Percent of Subjects	% Donor Before	% Donor After	PR test p-value
All Subjects	368	100%	42	58	0.000***
Breakdown by age					
18 to 21	108	29%	38	60	0.001***
22 to 30	140	38%	51	62	0.070*
31 and older	120	33%	36	53	0.009***
Breakdown by race					
Asian	54	15%	26	41	0.103
Black Hispanic	2	1%	0	0	.
Black Non-Hispanic	39	11%	31	51	0.065*
Native American	3	1%	100	100	.
Other	14	4%	21	21	.
White Hispanic	20	5%	50	55	0.752
White Non-Hispanic	236	64%	48	66	0.000***
Breakdown by Educational Background					
Grade School	4	1%	25	25	.
High School	30	8%	13	36	0.037**
Some College					

Finally, the results on Table 2 show that this effect of giving subjects the opportunity to change their organ registration status leading to more registered donors is not being driven by any particular subgroup. Table 2 breaks the experimental subjects down by demographic characteristics identified in our survey. We find directionally positive effects for every subgroup with more than 14 subjects and positive and statistically significant effects for every subgroup of more than 75 subjects.

III.2 How to ask for organ donation

The experimental variation in how BT 1 0 0 1 213.29 566.2 II.2 within subject to change Tm [BT 1

Result 4: Including a list of organs that might be donated by a deceased donor makes subjects more likely to register

Results from Table 4 show that framing the decision to register as a mandated
F K R L F H L Q Z K L F K V X E M H F W V K D Y H W R H L W ´ H U F O L F N ³, Z
G R Q R U ´ R U ³, G R Q R W Z D Q W W R U H J L V W H U D V D Q R U J D Q
directionally less likely to join the registry (between 5 and 10 percentage points
depending on the specification). The opt-in frame where a subject simply checks the box

IV.1 Design

The survey ([SHULPHQW ZDV UXQ ZLWK VXEMHFWV UHFUXLWHG IURP Amazon's Mechanical Turk platform on January 8, 2013. Subjects were told the survey would take 5 to 10 minutes (on average it was completed in just over 5 minutes). Subjects were paid $0.50 for completing the survey, a relatively large compensation for a 10 minute survey on Mechanical Turk.

In the survey, subjects were asked about what a hypothetical next of kin should do with regards to donating the organs of a recently deceased relative. The subjects were asked to make decisions about four scenarios, presented one-at-a-time in one of four random orders. All scenarios began in the same way. Subjects read:

"An individual has died. The individual's next of kin has been asked whether or not they would like to donate the organs of the deceased. The only information that the next of kin has about the wishes of the deceased is that the deceased saw this screen..."

Subjects were then

with the same decision frame but the opposite decision by the deceased (e.g. if they first answered T X H V W L R Q V D E R X W D G H F H D V H G Z K R ³ V H O H F W H G µ , W L V V X H G R Q R U ¶ ¹ U D Q H W K H \ Z H U H W K H Q D V N H G D E R X W D V H O H F W µ , Z D Q W W R U H J L V W H U D V D Q R U J D Q D Q G W L V V X opt-in frame).

After answering both questions for one frame, they answered the questions for two more scenarios with decisions being made by next of kin under the other frame. For V L P S O L F L W \ W K H R U G H U R I W K H G H F H D V H G ¶ V G H F L V L R Q kept the same for each frame (e.g. if subjects had been asked about a deceased who joined the registry in the first scenario, they were asked about a deceased who joined the registry in the third scenario). This generated four orders of scenarios. Subjects were randomly assigned to one of these four orders.

7 R V X P P D U L] H W K H V X E M H F W ¶ V first scenario was randomly chosen to be either: (1) a deceased who joined the registry in an opt-in frame, (2) a deceased who had not joined the registry in an opt-in frame, (3) a deceased who joined the registry in a mandated choice frame, or (4) a deceased who had not joined the registry in a mandated choice frame. Subjects then saw the opposite decision by the deceased in the same frame, the saw the first decision by the deceased in the other frame, and finally saw the opposite decision of the deceased in the other frame.

IV.2 Results

The design of the experiment allows for both a between-subject analysis of the next-of- 1 0*lestions (comparing answers from the first scenario subjects saw) and a within-subject analysis (comparing how the same subject responded to the deceased making the decision to join ² or not join ² the registry under different frames). We discuss the between-subject results first.

Result 5: Subjects think the next of kin should donate organs of an unregistered deceased more often when the deceased did not opt-in than when the deceased declined to register under mandated choice.

Table 5 reports the percent of subjects who said the next of kin should donate the organs of the deceased as well as their confidence on a 7-point scale with mean 0 constructed from the confidence answers.[25] When the deceased was not on the registry because the deceased had not opted in, 38.1% of subjects stated that the next of kin should donate the organs. When the deceased was not on the registry because they

[25] 7 K H V F D O H U D Q J H V I U R P ³ Y H U \ F R Q I L G H Q W ´ W K H D Q G ³ Y H U \ F R Q I L G H Q W ´ W K H Q H [W - 3.5, with confidence O H Y H O V V S D F H G X Q L W H D F K D Q G Z L W K D X Q L W M X P S V K R X O G G R Q D W H W R ³ Q R W F R Q I L G H Q W ´ W K H Q next of kin should donate equal to 3.5, 0.5 R I N L O V K R X O G Q R W G R Q D W H W R ³ Q R W F R Q I L G H Q W ´ W K H Q next of kin should not donate from 0.5-0.5. Q

indicated they did not want to register under a mandated choice frame, only 26.7% of subjects thought next of kin should donate. This 11.4 percentage point difference is statistically significant (t-test, 803 observations, p<0.05) and represents a 43% increase (on the base of 26.7 percent) in the number of subjects who say the next of kin should donate the organs of the deceased. Subjects are much more hesitant about donating the organs of a deceased who indicated that they did not want to be a donor in a mandated choice frame than a deceased who simply did not chose to opt to become a donor.

Table 5:

deceased was asked to register as a donor without a major experimental manipulation of state policy (followed by a long wait for people to die and next of kin to make organ donation decisions). Consequently we think it is reasonable to start the process with experimental survey data that can provide guidance about how individuals might respond to state policies and what policy might be best.[27]

V.

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Appendix A: Study Recruitment Text on CLER Website

IN ORDER TO PARTICIPATE IN THIS STUDY YOU MUST HAVE A MASSACHUSETTS DRIVER'S LICENSE, MA PERMIT, OR MA STATE ID AND WILL NEED TO PRESENT IT FOR ENTRY INTO THE STUDY. THOSE WITHOUT A MASSACHUSETTS DRIVER'S LICENSE, MA PERMIT, OR MA STATE ID WILL BE TURNED AWAY. YOU MUST ALSO KNOW THE LAST FOUR DIGITS OF YOUR SOCIAL SECURITY NUMBER.

Study Description: You will log into a state database, make a decision and complete a survey.

Compensation: Participants who arrive on time and are eligible to participate will receive $15 for completing the study. There is the possibility that some subjects will be turned away from the

Appendix B: Consent Form

Please consider this information carefully before deciding whether to participate in this research.

Purpose of the research: To understand the decision to register as an organ donor

What you will do in this research: You will (1) enter information that will be used to log you into a