The Applicability of the Inclusion/Exclusion Phenomenon to Organ Donor Registration

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Statement of Sources

I declare that this report is my own original work and that contributions of others have been duly acknowledged.

Signed: ______________________________ (Paul Schokman)

On this day _____ of ______________________, 2018.
Acknowledgments

It has been my honour to have the mentoring and support of my supervisor on this project, Dr Jim Sauer. He was instrumental in refining the scope of the project, in keeping me on track with it and bringing his immense resourcefulness to the project. I would also like to acknowledge the assistance, support and encouragement of Laura Brumby who set me up with the survey software, giving me enough information and support to proceed and discover. The support of other University of Tasmania Psychology staff, and my student cohort has been immensely important, particularly those who helped with piloting the survey for timings and accuracy. I am immensely appreciative of the participants without whom there would be no data, and of those who helped to spread the survey to others through email and social media.

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The Applicability of the Inclusion/Exclusion Phenomenon to Organ Donor Registration

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Abstract

Organ donor rates in Australia consistently fail to meet demand. Organ donor registration can be made either by a blanket, cover-all question or by having the citizen select organs from a list. The inclusion/exclusion phenomenon has shown in other domains that when a person is in a situation where they are excluding items from a list, their resulting list is longer than if they are including items to a list (Kogut, 2011). We investigated whether this classic phenomenon could be exploited to increase organ donation rates. Using a 2 (opt-in, opt-out) x 3 (blanket, inclusion, exclusion) between-subjects design, we tested whether different registration conditions influenced (a) absolute donation (i.e., willingness to donate something), and (b) the number of organs donated. 141 participants (age $M = 27.7$ years, range: 18 - 73, female = 108, nonbinary = 1) were randomly allocated to one of the six registration conditions. The exclusion approach, involving having the list pre-ticked, elicited more organs donated than the inclusion approach currently used in Australia. Individual difference measures indicated that participants’ feelings of attachment to organs and fear of having the body damaged after death also influenced the number of organs donated. The inclusion/exclusion phenomenon relies on items with a low evidentiary threshold being left in under exclusion and left out under inclusion. We suggest that feelings of attachment form this evidentiary threshold.
Improving posthumous organ donation rates is a challenge for many jurisdictions. Often there is high public acceptance for the concept (i.e., people support the idea of organ donation) but a low participation rate (Johnson & Goldstein, 2003). Across jurisdictions, systems allowing citizens to register for organ donation typically fall into one of two categories, reflecting the default setting. In one system, citizens register to be considered as a posthumous donor (opt-in). In the other, citizens register to exclude themselves from the donor pool (opt-out). Registration for posthumous organ donation under either system may be presented in different ways. One approach uses a blanket-type registration, including all transplantable organs under a single yes/no question (e.g., “Do you consent to be an organ donor?”). Alternatively, potential donors may be presented with a list-selection type of registration, where potential donors choose which options they are willing or unwilling to donate from a list of transplantable organs and tissue. A robust psychological phenomenon has been observed in relation to list selection. Subtractive selection (exclusion) models elicit longer final lists than additive (inclusion) models (Kogut, 2011). We examined whether this decision-making phenomenon applies to the field of organ donor registration, and whether a small change to the presentation of the lists can improve consent rates for organ donation. Although eventual donation rates are influenced by factors other than the potential donor’s consent/registration (e.g., family members’ preferences can override the individual’s registration choice as a donor), improving consent rates is a critical first step in increasing donation rates.

Organ Donation

The importance of increasing organ donation consent rates lies in the low conversion rate of registered donors to organ transplants. Of a total 158,504 deaths in
Australia in 2017, there were just 1,192 classified potential donors, and only 510 actual donors (Organ and Tissue Authority [DonateLife], 2018). The criteria to be considered as a potential donor include (a) the death being in a hospital, (b) consent for the organ/s to be donated (from the donor and the donor’s next of kin), and (c) an identified opportunity to donate (e.g., an available compatible recipient; Organ and Tissue Authority [DonateLife], 2016). Common reasons that fewer than 50 per cent of potential donors became actual donors included (a) that the donor was not compatible with the proximate need, (b) family not consenting, and (c) medical exclusion (e.g., a positive virology or cancer test of the donated organ (Australia and New Zealand Organ Donor Registry [ANZOD], 2017; DonateLife, 2018). In Australia, and many other countries, the demand for organ donation is not being met (ANZOD, 2017; Shepherd, O’Carroll & Ferguson, 2014). Eligibility for the organ waiting list is dependent on the hopeful recipient’s condition and urgency (ANZOD, 2017). The eligibility criteria are strict, and in part, driven by the scarcity of donors. The criteria for inclusion on the waiting list are that the recipient must have (a) exhausted all other treatment options, (b) no or minimal function in their organ(s), and (c) been assessed as likely to benefit from the transplant (DonateLife, 2016).

Even with these strict criteria reducing the number of potential recipients, many individuals die on waiting lists. Further, many people are removed from the waiting list because of a change in their health condition while waiting for an organ – their health may deteriorate to a point where it is dangerous to perform the transplant surgery (ANZOD, 2017). With people dying or becoming too sick for a transplant operation, maximising the donor rate for transplantable organs is important for reducing the number of people on waiting lists, and the length of time for which they
must wait. Increasing the base of registered donors provides a larger pool of potential, and hopefully eventual, donors.

As the ability to transplant organs was introduced with advances in medical technology, jurisdictions typically adopted the intuitive opt-in model of donor registration. Under opt-in systems, individuals wishing to donate must take some action to register as a potential donor. Under opt-out systems, individuals must take action to if they want to be excluded from the donor pool. Changing to an opt-out system has successfully increased donor registrations in some countries, but not all (Shepherd, O’Carroll, & Ferguson, 2014). For example, Austria achieved a greater than five-fold increase in organ donations in the five years after changing to an opt-out system (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009). Neighbouring Germany retained an opt-in system and saw relatively static donor registration rates, with the same advances in transplant technology (Johnson & Goldstein, 2003; see figure 1). Other countries (e.g., Brazil, Chile and France), did not see immediate success from the change to the opt-out model; reportedly due to issues around medical mistrust (Dominguez & Rojas, 2013; Shepherd et al., 2014). The Australian government is resistant to changing from the opt-in system, and the Organ and Tissue Authority has an official position to remain with the opt-in system for the foreseeable future (http://www.abc.net.au/news/2017-01-04/australia-unlikely-to-follow-opt-out-organ-donation-policy/8160718).

While the status quo of the broader system remains in place, the registration system may still be finessed to help reduce the gap between available donors and potential recipients. Some jurisdictions, including Australia, present potential donors with a list of organs from which they choose which organs they are willing to donate. Opt-out jurisdictions may present potential donors with list from which they
may choose organs they are unwilling to donate. An alternative to this is the blanket registration option, equally applicable under opt-in and opt-out jurisdictions, where individuals make a single registration decision covering all transplantable organs and tissue without individual selection. For example, under the list registration approach, an individual may choose to donate their kidney, liver and pancreas but not their eye tissue or heart. Under the blanket registration they register as a donor for all organs or no organs. When an individual has a specific aversion to donating one organ, under the blanket registration they may choose not to become a donor.

![Figure 1. Effective organ donor consent rates in comparable opt-in and opt-out European countries (adapted from Johnson & Goldstein, 2003).](image)

List selection systems may give citizens more choice over their registration options under opt-in or opt-out jurisdictions. A list registration could be presented in one of two ways. First, as an inclusion method (e.g., ticking boxes to select organs for donation). Second, as an exclusion method (e.g., unticking boxes to deselect organs from donation consent). We aimed to determine whether, consistent with inclusion/exclusion phenomena in other domains (discussed in the next section), these two approaches to donor registration elicit different (a) donation consent rates,
and (b) final lists, and to compare how these approaches differ from blanket approaches.

**The Inclusion/Exclusion Phenomenon**

Presenting respondents with a list from which they may exclude unwanted items results in a larger *consideration list* than if the same list is presented in a form in which respondents select items they will include (Kogut, 2011; McDonald, Newell, & Denson, 2014; Yaniv & Schul, 1997). For example, Yaniv and Schul (1997) asked participants a series of general knowledge questions such as “Who was the director of the film Midnight Express?” and, for each question, provided a list of 20 possible answers. Participants in the inclusion condition selected plausible answers from the list, while those in the exclusion condition eliminated implausible answers. In the first study, the exclusion condition elicited larger consideration lists with, on average, 50% of the items retained as plausible correct answers compared to 18% of the list being retained in the inclusion condition. Yaniv and Schul (1997) attributed the difference between conditions to a difference in the evidentiary threshold required to act by including or excluding each item. For the inclusion condition, each item had to satisfy some evidentiary basis to be included as a plausible correct answer. That is, the evidence must be sufficient for the participant to alter an item from its default status. Similarly, for the exclusion condition, each item had to pass an evidentiary threshold (i.e., some level of confidence that the item was *incorrect*) to be removed from the list. Thus, the difference in consideration lists between the two conditions can be conceived of as an average of the number of items for which the respondents had insufficient evidence to alter the default status of the item.
McDonald et al. (2014) asked participants to nominate, from a list of 30 environmentally beneficial behaviours, which behaviours they were willing to adopt. This is not unlike a list of organs a person is willing to donate, in that the responses reflect attitudes rather than semantic knowledge (cf. Yaniv & Schul, 1997). Because it reflects attitudes (cf. semantic knowledge), one may expect a rational decision-maker to select the same items regardless of whether the list is presented in an inclusion or exclusion style. Participants in the inclusion condition circled the behaviours they would be willing to adopt, and those in the exclusion condition crossed out the behaviours they would be unwilling to adopt. Despite the different task context, and consistent with Yaniv & Schul (1997), the exclusion condition elicited a larger consideration list than the inclusion condition by about 30%.

However, closer examination of those results shows that the difference existed for some types of behaviour but not others, with effort and opportunity moderating the effect (McDonald et al., 2014). Activities perceived to have fewer opportunities for engagement were more likely to be selected in the inclusion approach, while activities which were more effortful were more likely to be selected (and thus excluded) in the exclusion condition. McDonald et al. (2014) proposed that this result could be interpreted in terms of the status quo effect, where an existing situation (requiring no effort to change) is more readily adopted than an alternative situation (requiring effortful engagement). Where the participant perceived there to be a lower likelihood of encountering an opportunity to engage in the pro-environmental behaviour, the threshold for selecting it in the inclusion condition was more stringent than the threshold for deseleting it in the exclusion condition. When an activity was perceived to be more effortful, there was a greater likelihood that participants would cross it out in the exclusion condition, in favour of leaving some
behaviours on the list which were closer to their existing lifestyle (e.g., *not littering*, cf. *becoming vegetarian*) and thereby maintaining their own personal status quo (McDonald et al., 2014). In the inclusion condition, participants typically selected behaviours which would minimise effortful change, particularly if they perceived a higher probability of the situation arising.

Kogut (2011), and Johnson and Goldstein (2003), state a simpler view that the decision is not made (and the status quo is preserved) either because the decision requires sufficient information to make the change on the page (Kogut, 2011) or it requires unusual effort to register or de-register as an organ donor (Johnson & Goldstein, 2003). Despite the differing proposed mechanisms for the inclusion/exclusion effect, the outcome remains the same: Those presented with the exclusion (cf. inclusion) option created greater consideration lists.

**The Status Quo Effect**

The inclusion/exclusion phenomenon and opt-in/opt-out systems have a theoretical relationship in that both are subject to the status quo effect wherein the default option is most often the outcome option (Johnson & Goldstein, 2003; Kogut, 2011). The status quo effect has thus far been referred to in terms of individuals’ decisions around registering as an organ donor. It could be argued however, that it can also apply at a jurisdictional policy level. It is easier for elected representatives to avoid the potential backlash of change by keeping things the way they are. The push to change from an opt-in to an opt-out system for organ donor registration in Australia has not grabbed media and public attention in the way that other social issues (e.g., marriage equality) have. Thus, there has been little pressure on political leaders to propose the change. Despite evidence for the benefits of opt-out approaches, and a growing understanding of the boundary conditions that might limit
these benefits and how these conditions might be addressed (e.g., public education campaigns to counter myths and medical mistrust; Shepherd et al., 2014), there remains no impetus for adopting an opt-out system. Thus, we focussed on achieving the best outcome within the current, opt-in system. Specifically, we investigated whether applying known psychological phenomena – relating to decision making in list selection – influences (a) individuals’ willingness to register as organ donors, and (b) the number of organs individuals are willing to donate.

The Present Study

We focused on whether the inclusion/exclusion phenomenon influences the rate of absolute donation and/or organs registered for donation, using both opt-in and opt-out policies, and compared to blanket registration options. For the purposes of this thesis, the term organ relates not only to the strict definition of an organ, but to all transplantable body tissue for which transplantation will benefit the recipient (e.g., corneas). We sought to establish whether the inclusion/exclusion phenomenon extends to selections in organ donation and, thus, can inform an approach to the registration process and improve organ donation rates.

Proximal to our interest, Jasper and Ansted (2008) applied the inclusion/exclusion phenomenon when liberal or conservative students matched hypothetical organ transplant recipients to available organs, using either (a) an inclusive method of selecting which recipients should be considered, or (b) an exclusive method of selecting which recipients should not be considered. The outcome indicated that the inclusion/exclusion phenomenon applied within the general field of organ donation and transplantation decisions. This, together with previous work demonstrating the phenomenon extends beyond semantic memory tasks (e.g., McDonald et al., 2014), underlies our main hypotheses. A broad
hypothesis is that the inclusion/exclusion phenomenon would apply in the organ donor registration domain. Figure 2 provides examples of our inclusion/exclusion-type lists to follow the hypotheses. For the opt-in conditions, we expected that the exclusion condition would elicit a greater number of organs registered for donation than the inclusion condition in keeping with the inclusion/exclusion phenomenon.

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyes</td>
<td>Eyes</td>
</tr>
<tr>
<td>Heart</td>
<td>Heart</td>
</tr>
<tr>
<td>Lung</td>
<td>Lung</td>
</tr>
<tr>
<td>Liver</td>
<td>Liver</td>
</tr>
<tr>
<td>Kidney</td>
<td>Kidney</td>
</tr>
<tr>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Pancreas</td>
<td>Pancreas</td>
</tr>
</tbody>
</table>

Figure 2. Examples of inclusion-type list and exclusion-type list. Participants interact with the list by adding ticks to the inclusion list and removing ticks from the exclusion list. In opt-in jurisdictions, items with ticks after the respondent has completed the task would be registered for donation. In opt-out jurisdictions, the items remaining ticked after the respondent has completed the task would be removed from the donor register.

Although we expected the blanket opt-in condition to preclude participants with an objection to donating one or more specific organs from registering as donors, it is not clear what proportion of respondents would fall in this category and, therefore, whether this effect would emerge in our data. For the opt-out conditions, we expected that the exclusion list would result in fewer organs registered for donation compared with the opt-out inclusion condition, as a selected item on the consideration list is a subtraction from the starting point of 15 organs. By acting on
fewer list items in the pre-ticked exclusion condition, a greater number of organs remain selected to opt-out from the donor register. The blanket opt-out condition was expected to result in a similar magnitude as the inclusion condition, given the high acceptance of organ donation in the community (Sharpe, Moloney, Sutherland, & Judd, 2016) but also conditional upon the proportion of those with a specific objection to donating one or more organs. Finally, we expected the overall rate of organ donation to be high given that (a) some self-selection sampling bias was expected in response to the survey advertisement (i.e., favouring people predisposed toward organ donation), and (b) the high rates of reported acceptance of organ donation in the community (Newton, 2011; Sharpe et al., 2016).

Attachment to Organs and other Individual Difference Factors

The importance of considering individuals’ potential objections to donating specific organs became quickly apparent from informal conversations in preliminary discussions around this research. Some people strongly objected to donating their eyes claiming a religious belief of needing them to ‘see God’. Others strongly objected to donating their skin, heart, or other organs because they were perceived as more representative of their personage. Although anecdotal, these conversations align with reports of personal relevance (e.g., the perceived need to preserve bodily integrity to ensure progression into the afterlife) affecting individuals’ views of organ donation (Davison & Jhangri, 2014; Newton, 2011). To determine the extent to which such beliefs moderated results in our primary study, we ran a separate survey (independent of the main study) assessing how widespread such feelings of personal attachment to organs were, and to what extent they influenced individuals’ decisions to donate. We expected a negative correlation between participants’ ratings
of emotional or personal attachment to an organ and their willingness to donate that organ.

Previous research has identified other factors that influence individuals’ decisions to register as organ donors. Thus, within the primary study, measures of these factors were taken to test whether (a) the factors applied in our sample, and (b) whether they helped to explain the results. Religious beliefs show a consistent negative association with participation in organ donor programs (Cantarovich et al., 2007; Davison & Jhangri, 2014; Newton, 2011) even when the cited religion supports organ donation (Cantarovich et al., 2007). Issues around death have mixed responses. Some respondents report that organ donations give more meaning to their life beyond their death, while others avoid engaging with organ donor registration because they find death to be an uncomfortable topic (Newton, 2011). Personal relevance (e.g., knowing a transplant recipient), and family supportiveness of the issue are positively correlated registering as an organ donor, and mistrust of the medical profession, feeling like the body will be treated as a piece of meat, and fears about being unable to save the recipient correlate negatively with donor registration (Newton, 2011). We expected these relationships to emerge in our data.

Method

Participants and Design

**Primary study.** The primary experiment used a 2 (jurisdiction: opt-in, opt-out) x 3 (list condition: blanket, inclusion, exclusion) between-subjects design, with data collected in an anonymous, online survey. Participation was open to people aged 18 years or over. Course credit was offered to University of Tasmania first-year psychology students. Recruitment of these students was undertaken via a web-based registration. The study was also open to the public online, and was advertised via
social media (e.g., Facebook and Twitter), via email to friends and family, as well as
advertisements posted around the University of Tasmania Sandy Bay campus. No
remuneration was offered to participants recruited from the public.

The survey was completed by 141 participants (age $M = 27.7$ years, range: 18
- 73, median = 22; male = 32, female = 108, nonbinary = 1), of whom 95 were first-
year psychology students. Australia was the country of residence for 128
participants; of the remaining 13, the United Kingdom was the most common
country of residence, with five participants. Four participants gave a country of
residence other than Australia but provided a Tasmanian postcode. Table 1 illustrates
the participant breakdown by condition. 15 participants commenced the survey and
dropped out.

Table 1.
Number of Participants Assigned to each
Experimental Condition.

<table>
<thead>
<tr>
<th></th>
<th>Blanket</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opt-in</td>
<td>25</td>
<td>24</td>
<td>27</td>
</tr>
<tr>
<td>Opt-out</td>
<td>20</td>
<td>25</td>
<td>20</td>
</tr>
</tbody>
</table>

Supplementary study. The supplementary survey was completed by 151
participants (age $M = 31.3$ years, range: 19 - 71, median = 28; male = 63, female =
85, no response = 3) recruited through Prolific (www.prolific.ac). The hosting site
was paid GBP£0.95 (approximately AUD$2.30) per participant, of which 70% was
passed on to the participants. Three participants dropped out during the survey, and
five participants timed out (exceeding the maximum allotted time of 12 minutes;
average completion time was under 4 minutes).
Materials

**Primary survey.** Data were collected using LimeSurvey software. The inclusion and exclusion list conditions consisted of 15 organs which are currently transplantable or feasibly transplantable with advances in medical technology (see Appendix A). The list was intentionally made longer than the Australian list of nine items to ensure that if an effect was present, it was detectable. The same list was used in the supplementary survey on feelings of emotional attachment to organs. Thus, any information from the supplementary survey was directly relatable to the primary study. After confirming consent and eligibility to participate, respondents completed the organ donor registration question, with the format of this question (i.e., corresponding to one of the six cells of the experiment’s design) randomly selected by the software. Where participants were assigned to a condition with a list of organs, the order in which the organs were listed was also randomised by the software. Where the participant was assigned to a blanket condition, they did not see a list of organs, only a binary option.

Prior to viewing the organ donor question, participants were advised that it may not be relevant to their situation, but to respond as if completing this question was their opportunity to register their organ donor status. The question read “Imagine that you are in a region which...” followed by the type of registration an opt-in or opt-out jurisdiction would have. This was worded in terms such as “requires people to register if they want to be organ donors.” The full set of experiment questions, along with the remaining parts of the survey are presented in Appendix B.
Knowledge of, and proximity to organ donation. We also collected demographic information about participants’ donor registration status; whether they had previously registered or considered registering as an organ donor; their knowledge of whether their region has opt-in or opt-out registration and which they would prefer; and an estimate of the proportion of the population in their region they believe are registered organ donors. Proximity to organ donation was measured by two questions – whether family or close friends have required/donated organs, and whether family or close friends have been posthumous donors.

Spirituality. Religious beliefs predict people’s likelihood to register as organ donors or agree to a family member’s organ donation (Newton, 2011; Rodrigue, Cornell, & Howard, 2006; Tumin et al., 2014). The Intrinsic Spirituality Scale (ISS; Hodge, 2003) was developed in response to a need for a measure applicable beyond measuring religiosity, as many other religiosity scales were developed by believers, to capture their own version of belief (Hodge, 2003). The ISS has been validated in Christian, Cronbach’s $\alpha = .96$, Satorra-Bentler scaled $\chi^2 = 14.92$ ($df = 9, p = .92$), RMSEA = .062, CFI = .99 (Hodge, 2003), and United States-resident Muslim samples, Cronbach’s $\alpha = .93$, normed $\chi^2 = 35.43$, ($df = 9, p = .01$), RMSEA = .070, CFI = .98 (Hodge, Zidan, & Husain, 2015).

The ISS consists of six sentence-completion items, one answer option placed at 0 and the other answer option at 10 with a scaled continuum between, giving an 11-point Likert scale. The first item reads “Spirituality is...” with answers ranging from “Not part of my life” (0) to “The master motive of my life, directing every other aspect of my life” (10). The wording of the remaining items in the scale assumed the existence of the respondent’s spirituality (e.g., “When I am faced with an important decision, my spirituality...”), rendering these items irrelevant to
participants responding zero to the initial item. Thus, if participants’ responses to the first item indicated that spirituality was not part of their life, we skipped the remaining five items on the scale. Three of the scale items (items 1, 3, and 6) were reverse-coded. After re-coding reverse-scored items, scores were averaged across questions (higher scores indicating greater self-reported spirituality).

*Fears and negative beliefs about organ donation.* Some common elements of fear about organ donation were identified in the Newton (2011) meta-synthesis of organ donation research. These were fears about the organ not helping (or potentially harming) the recipient, fear that medical staff would be less willing to revive a registered donor (cf. a non-donor), and a dislike of the idea of having a mutilated body. Fear of death has also been found to negatively affect organ donor registration (Jain & Ellithorpe, 2016; Newton, 2011), as has a fear that a non-intact body could be rejected in the afterlife (Davison & Jhangri, 2014; Newton, 2011).

Given that no established scale exists to measure these concepts, we developed a scale in which the six concepts were presented in the format of statements with which the participant could register some level of agreement or disagreement, on a five-point Likert scale response (ranging from “Strongly Disagree” to “Strongly Agree”). We acknowledge that, because this is not a validated scale, any outcomes must be interpreted with caution. None of the items were reverse-coded. Scores were summed across items with a higher score indicating greater negative belief.

*Socio-cultural cognition.* Political conservatism-liberalism is a factor in people’s decisions around organ donation (Jasper & Ansted, 2008; Newton, 2011). The Hierarchy/Egalitarianism – Individualism/Communality scales (HE–IC) is a bi-axial scale developed from a *grid and group* model of culture typography (Douglas,
A questionnaire was developed to measure these axes by Kahan and Braman (2006). The grid axis refers to a person’s preference toward a class-based hierarchy at one extreme and an egalitarian society at the other. The group axis measures a person’s preference toward an individualistic or a communitarian society (Kahan & Braman, 2006).

An example of the group axis statements is “Society as a whole has become too soft and feminine.” An example of the grid axis statements is “The government should stop telling people how to live their lives.” No psychometric data could be found for this scale, however the Douglas-Wildavsky model has become a commonly used measure of social orientation (e.g. Drummond, Palmer & Sauer, 2016; Kahan & Brahman, 2006; Verweij, et al., 2006). We included this scale to determine whether participants’ responses in our sample were influenced by their socio-political ideology.

The second, third and fourth items on the HE scale were reverse-coded. On the IC scale, the second, fifth and sixth items were reverse-coded. After recoding, item scores on both scales were summed with higher scores indicating greater hierarchical/individualistic preferences.

**Trust in the health system.** Trust in the health system is cited as one reason that a switch to the opt-out system was less successful in France and Brazil compared with other nations (Shepherd et al., 2014). A short-form questionnaire measuring individuals’ trust in the medical profession was taken from Dugan, Trachtenberg, and Hall (2005). That study used three short questionnaires, relating to a named physician, the medical profession more generally (used here) and health insurers, respectively. The wording of the medical profession questions was altered slightly for our survey (e.g., “A doctor would never mislead you about anything,”
was altered to “A doctor would never intentionally mislead me about anything.”) to match the style used in the remainder of the survey, and the word intentionally was inserted to clarify interpretation of what was intended to be measured. The Dugan et al. (2005) five-item trust in the medical profession scale has good psychometric properties for a short scale (Cronbach’s $\alpha = .77$) with no variation across income and education levels.

The first item on the medical practitioner trust scale was reverse-coded. After re-coding the items were summed with a higher score indicating greater trust.

We used a seven-item questionnaire developed to measure trust in medical organisations and compare it with underutilization of health services (LaVeist, Isaac, & Williams, 2009) as a second measure of medical mistrust. A 4-point Likert scale measures levels of agreement with the statements provided. A minor wording change from “You’d better be cautious when dealing with healthcare organizations” to “You have to be cautious when dealing with healthcare organisations” was made to better fit a general vernacular without changing the meaning. Out of 17 items, the seven selected by the original authors loaded on a single factor with an internal validity of Cronbach’s $\alpha = .76$ and a test-retest reliability of $r = .70$, $p < .0001$.

There were no reverse-coded items on the scale, the scores were summed, with a higher score indicating greater trust.

**Social desirability response bias.** We expected that a survey on this topic would attract some social desirability bias in responding. The SDRS-5 (Hays, Hayashi, & Stewart, 1989) is a 5-item scale selected for its brevity, and because it is aimed at assessing bias in clinical settings. The five items were the highest-loading of the 11-item MC Form A, which in turn is the short form version of the 33-item Marlowe-Crowne scale (Crowne & Marlowe, 1960) of social desirability response.
The SDRS-5 and the Marlowe-Crowne scale differ in response type, with the latter being a true/false response option and the SDRS-5 uses a 5-point Likert scale (definitely true, mostly true, don’t know, mostly false, definitely false). The SDRS-5 was tested on a patient sample and had fair internal reliability Cronbach’s $\alpha = .68$ and good test-retest reliability $r = .75$ (Hays et al., 1989) making it a suitable short scale.

The first and fifth items on the scale score one point each for the lowest response, other responses score zero. For the remaining three items, the highest response attracts a one-point score for each item, other responses score zero. The scores were summed, with higher scores indicating greater social desirability bias.

**Social capital.** The logic behind measuring participants’ social capital level was related to the reasoning behind the use of the cultural cognition questions. Davison and Jhangri (2014) reported a discrepancy in which the Canadian native respondents were aware of the need for organ donation, knew many organ recipients, and were willing to accept organs; yet they were reluctant to become donors. While the grid-group measure tests where people’s beliefs and wishes are, a measure of social capital measures reported activity which may bridge the gap of knowledge between thoughts and actions, further informing the results of the main experiment.

An Australian study developed a 36-item questionnaire to measure social capital, covering eight orthogonal measures (Onyx & Bullen, 2000). The factors are (i) participation in the local community; (ii) social agency/social proactivity; (iii) feelings of trust and safety; (iv) neighbourhood connections; (v) family/friend connections; (vi) tolerance of diversity; (vii) value of life; and (viii) work connections. The eighth category was selectively delivered only to respondents in
paid employment and thus appeared to lose relevance in the context of the present
survey. Those questions were omitted from the survey, leaving 31 items.

A few minor wording changes were made from the original study. “Have you
ever picked up other people’s rubbish in a public place?” was adjusted to “Have you
recently picked up...” because it was felt that the use of the word “ever” may elicit
higher response scoring than the participants’ current social capital mood. The
question “If someone’s car breaks down outside your house, do you invite them into
your home to use the phone?” seems to have become outdated with a rapid spread of
portable landline phones and mobile phones. “If someone's car breaks down outside
your house, do you invite them into your home to shelter from the weather?” was
chosen as a replacement, and as offering a more compelling reason a person may or
may not invite a stranger into the house in present times.

The Onyx and Bullen (2000) social capital questionnaire uses a four-point
Likert scale with tailored responses. These were grouped as closely as possible by
response type, for a more palatable delivery of this scale, which was the longest
section of the survey.

No items were reverse-coded. After re-grouping, the items were summed,
with higher scores indicating greater social capital in each of the domains.

**Supplementary study.** This survey questionnaire contained four main
components. The first was an information sheet for the participants (see Appendix
C2). The second was a string-input box for the participants to put their Prolific
identification code for the purposes of matching responses with the provided
demographic data. The third component was the first question, which asked
participants to rate, on a six-point Likert scale, their rating of their emotional or
personal attachment to each of the listed organs (as per Appendix A). The labels
were *none at all, just a little, somewhat, moderately, quite strongly and extremely.*
The fourth component was the second question, which asked participants to rate, on a four-point Likert scale, how likely they were to donate the organ on the list. The labels were *very unlikely, unlikely, likely* and *very likely.* The order of organ items on each list was randomised, but the order of the questions was fixed.

**Procedure**

**Primary study.**

Upon entering the survey, participants read an information sheet (see Appendix C1) which included a consent box to tick which also had the participants affirm that they were over 18 years of age. Participants were then presented with their condition of the experiment. They were advised beforehand that the question was hypothetical and may not be relevant to their jurisdiction, and to answer as if it were their registration opportunity.

Next, basic demographic data was collected (i.e., age, gender, country of residence). Information on occupation, education, relationship status and number of children was also collected, after some jurisdictional knowledge questions. The survey then moved through the individual difference scales, randomising the order of questions within scales unless the scale information unless this was discouraged by the scale’s author/s. The order of questions was set out in a way that mostly alternated questions identifiably proximal to organ donation with those less obviously so (e.g., trust in the health system, cf. social desirability response).

At the end of the survey, participants were debriefed about the study and thanked for their time. Links were provided to (a) a separate survey to collect the details of participants seeking course credit, and (b) the website of the Organ and Tissue Authority in Australia (www.donatelife.gov.au).
**Supplementary study.** Following ethics approval, the survey was made available to a pool of approximately 29,000 participants who had previously registered with Prolific (www.Prolific.ac) to participate in academic research in return for payment.

On entering the survey, participants read an information sheet (see Appendix C2) and indicated their consent to participate. Next, participants were presented with the list of organs (see Appendix A), with the items presented in a random order. Participants rated the level to which they felt personally or emotionally attached to each organ (on a six-point Likert scale ranging from *none at all* to *extremely*, see Appendix D) and, on the next page, the likelihood they would consent to posthumously donating each organ on a four-point Likert scale (from *very likely* to *very unlikely*, see Appendix D). Participants were then debriefed and thanked before exiting the survey.

**Results**

**Data Screening**

**Primary survey.** There were 156 respondents to the main survey. 138 completed the survey in full. Three more of the responses were considered to have completed as they reached page 47 of 48 after we were advised of a survey software failure on some iPad branded devices and Safari browser software which rendered the ‘submit’ button inoperable).

**Supplementary survey.** Responses were screened for validity, primarily by each participant’s site rating\(^1\) out of 100 (*M* = 99.54, range: 87 - 100, median = 100).

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\(^1\) Prolific.ac includes information about each participant (e.g., demographics). Included in the data is a quality rating based upon the number of surveys they have participated in, and how many of their survey responses have been rejected. Higher rating indicates a lower proportion of rejected responses, thus indicates greater reliability.
Data were analysed to identify participants with invariant responses (i.e., an individual’s response was the same for all items). Of the 151 participants, 13 were invariant on the feelings of attachment scale, 65 were invariant on the willingness to donate scale, and 11 were invariant on both scales. Excluding those cases from analysis did not affect the mean ratings in a meaningful way (e.g., attachment $M_{\text{full}} = 3.59$; $M_{\text{variant}} = 3.50$). The invariant data were retained for calculating mean differences but were excluded from analyses correlating individuals’ attachment and willingness to donate.

**Primary Study Results**

Participants in the blanket conditions selected simply to become a donor or not, while participants in the list conditions could select in a way that gave a continuous registration score from zero to 15. With this in mind, we first considered whether conditions differed in terms of absolute donation rates (i.e., a binary variable representing willingness to donate *something*). There was a strong bias toward donating in all conditions (see Table 2).

Table 2.

*Absolute Donor Registrations for All Participants.*

<table>
<thead>
<tr>
<th></th>
<th>Opt-In</th>
<th></th>
<th>Opt-out</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Donors</td>
<td>Non-Donors</td>
<td>Donors</td>
<td>Non-Donors</td>
<td></td>
</tr>
<tr>
<td>Blanket</td>
<td>22</td>
<td>3</td>
<td>18</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Inclusion</td>
<td>21</td>
<td>3</td>
<td>21</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Exclusion</td>
<td>26</td>
<td>1</td>
<td>18</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

We conducted a 2 (jurisdiction: opt-in, opt-out) x 3 (list condition: blanket, inclusion, exclusion) x 2 (decision: donor, non-donor) hierarchical loglinear analysis.
We used the loglinear model selection option in SPSS to generate a saturated model with backwards elimination. No valid model was generated (3-way effect: \( p = .721 \)), indicating no significant effect of condition on willingness to donate. Partial likelihood ratio \( \chi^2 \) is shown in Table 3.

**Table 3. Partial Associations from the Loglinear Regression of Donation on Jurisdiction Type and Registration Condition.**

<table>
<thead>
<tr>
<th>Effect</th>
<th>df.</th>
<th>Partial Association</th>
<th>( \chi^2 )</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opt-In/Out*Blanket/Inclusion/Exclusion</td>
<td>2</td>
<td>0.68</td>
<td>.714</td>
<td></td>
</tr>
<tr>
<td>Opt-In/Out*Donate</td>
<td>1</td>
<td>0.26</td>
<td>.608</td>
<td></td>
</tr>
<tr>
<td>Blanket/Inclusion/Exclusion*Donate</td>
<td>2</td>
<td>1.58</td>
<td>.455</td>
<td></td>
</tr>
<tr>
<td>Opt-In/Out</td>
<td>1</td>
<td>0.86</td>
<td>.354</td>
<td></td>
</tr>
<tr>
<td>Blanket/Inclusion/Exclusion</td>
<td>2</td>
<td>0.17</td>
<td>.918</td>
<td></td>
</tr>
<tr>
<td>Donate</td>
<td>1</td>
<td>99.90</td>
<td>&lt;.001</td>
<td></td>
</tr>
</tbody>
</table>

Next, we considered the list condition data alone in a 2 (jurisdiction: opt-in, opt-out) x 2 (list condition: inclusion, exclusion) ANOVA to test whether there was an effect of the inclusion/exclusion phenomenon on the number of organs registered for donation. The list condition data violated the assumption of homogeneity of variance, Levene’s \( W(3,92) = 4.95, p = .003 \) (see Figure 3). No significant difference between the mean registrations was found in the nonparametric measure Welch’s \( F(3,48) = 2.37, p = .082 \), but given that it was approaching significance, we investigated further. Figure 4 shows the mean registrations for each condition. A contrast analysis of the four list-type conditions was conducted, coded in the high and low hypothesized results (high [1]: opt-in, exclusion with opt-out inclusion; low [-1]: opt-in, inclusion with opt-out exclusion). The contrast analysis showed no
significant difference in group means at the 0.05 alpha level in the non-parametric measure, \( t(71) = 1.91, p = .060 \). However, again this suggested that the hypothesized pattern may attain significance with greater power.

![Graph](image)

**Figure 3.** Distribution of list-condition registrations with density estimates.

Condition 3 (opt-in, inclusion) has a more even distribution than the other conditions. Condition 4 is opt-in exclusion, condition 5 is opt-out inclusion and condition 6 is opt-out, exclusion. We acknowledge that the density estimates show values below zero and that this is not feasible. The software used to create the chart doesn’t facilitate creating a zero cut-off.

We calculated effect sizes between the conditions’ registration responses (see Table 4). Following Cohen’s (1988) guidelines, there was one medium effect size and there were three small effect sizes between conditions: (i) opt-out, inclusion was greater than opt-in, inclusion; (ii) opt-out, inclusion was greater than opt-out, exclusion; (iii) opt-in, exclusion was greater than opt-in, inclusion; and (iv) opt-out, inclusion was greater than opt-in, exclusion. These differences are consistent with the hypothesised effects of the inclusion/exclusion phenomenon on participants’ registration choices.
Table 4.

Hedges’ g Effect Sizes of List Conditions on Registrations.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Opt-in Inclusion</td>
<td>-</td>
<td>0.36^</td>
<td>0.73*</td>
<td>0.19</td>
</tr>
<tr>
<td>Opt-in Exclusion</td>
<td>-</td>
<td>-</td>
<td>0.31^</td>
<td>0.15</td>
</tr>
<tr>
<td>Opt-out Inclusion</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.46^</td>
</tr>
<tr>
<td>Opt-out Exclusion</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: * denotes medium effect size, ^ denotes small effect size

Donor Registration Status. Participants were asked about their prior consideration of organ donation. We separated participants into those who had registered as organ donors (or opted-out) and those who had not registered either way. Having registered as an organ donor indicates that there has been some motivation to register, and a choice made prior to entering the experimental condition. With a commitment to action the difference in an experimental condition
may have less influence on their responses compared with those who have not taken action to register. We shall refer to the participants who had previously registered as committed, and the non-registered as uncommitted. Fifty-five participants reported that they were committed, leaving 86 who were uncommitted. All committed participants registered as donors (or didn’t opt-out). Table 5 shows the absolute registration decision in the study for the 86 uncommitted participants.

Table 5.

<table>
<thead>
<tr>
<th>Absolute Donor Status for the Uncommitted Participants.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opt-In</td>
</tr>
<tr>
<td>Donors</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>Blanket</td>
</tr>
<tr>
<td>Inclusion</td>
</tr>
<tr>
<td>Exclusion</td>
</tr>
</tbody>
</table>

As with the full dataset, no valid model was generated from a 2 (jurisdiction: opt-in, opt-out) x 3 (list condition: blanket, inclusion, exclusion) x 2 (decision: donated, not donated) hierarchical loglinear analysis (3-way effect: $p = .830$), indicating that there was no significant effect of the conditions on the absolute decision to donate.

For the uncommitted participants in the list conditions, we ran a 2 (jurisdiction: opt-in, opt-out) x 2 (list condition: inclusion, exclusion) ANOVA. Again, the data did not meet the assumption of normal distribution, Levene’s test $p = .011$. We found no main effect of the list condition, Welch’s $F(3,29) = 2.68, p = .066$, however there was a significant interaction between jurisdiction type and list condition, $F(1,56) = 4.71, p = .034$. There was no significant difference in number of organs registered between the opt-out, $M = 8.08, SD = 7.25$ and the opt-in exclusion
conditions, $M = 9.75$, $SD = 6.33$. However, for the inclusion conditions, the opt-in condition, $M = 7.00$, $SD = 5.55$ elicited fewer organs donated than did the opt-out inclusion condition, $M = 12.00$, $SD = 4.58$. Among the participants in the list conditions who had previously registered their donor registration choice, no such difference was found (see Figure 5). Thus, for uncommitted participants, the strength of their feelings about each item on the list in the inclusion condition influenced their response.

Following Cohen’s (1988) guidelines, there was one large effect size, one medium effect size and two small effect sizes between conditions: (i) opt-out, inclusion was much greater than opt-in, inclusion; (ii) opt-out, inclusion was greater than opt-out, exclusion; (iii) opt-in, exclusion was greater than opt-in, inclusion; and (iv) opt-in, exclusion was slightly greater than opt-out, exclusion (see Table 6). These

*Figure 5.* Mean (95% CI) organs registered by uncommitted participants. There was an interaction effect in list-condition participants who have not acted to register their organ donor choice. The inclusion conditions differ from each other, but the exclusion conditions do not, suggesting different interactions with the lists.
effect sizes further support the interaction effect – that the inclusion-type lists had a greater influence between opt-in and opt-out conditions.

Table 6.

*Hedges’ g Effect Sizes of List Conditions on Registration for Uncommitted Participants.*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Opt-in Inclusion</td>
<td>-.</td>
<td>.46^</td>
<td>.99**</td>
<td>.17</td>
</tr>
<tr>
<td>Opt-in Exclusion</td>
<td>-</td>
<td>.41^</td>
<td>.25^</td>
<td></td>
</tr>
<tr>
<td>Opt-out Inclusion</td>
<td>-</td>
<td>-</td>
<td>.67*</td>
<td></td>
</tr>
<tr>
<td>Opt-out Exclusion</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: ** denotes large; * denotes medium; ^ denotes small effect sizes.

**Individual Difference Factors.** Individuals’ negative beliefs about donating organs were associated with their registration choices. The questions used in the survey were not from a previously developed and validated scale. The sample sizes in this study are not likely to be large enough to constitute a stable factor analysis (MacCallum, Widaman, Zhang, & Hong, 1999), nor are the questions oblique. However, the relationships between the questions and their results were analysed to determine the validity of tests using a total score. Sampling adequacy was in the middling range of the Kaiser-Meyer-Olkin test (KMO = .702; Kaiser, 1974), and Bartlett’s test of sphericity ($\chi^2 = 156.7, p < .001$). Appendix D has the full correlation matrix for these six questions. There were only two non-significant intercorrelations: (i) *fear that the donated organ would not help the recipient and don’t like the idea of my body being damaged after death* (Pearson’s $r = .114, p = .090$); and (ii) *fear that the donated organ may harm the recipient and don’t like the idea of my body being*...
damaged after death, $r = .112, p = .092$. No intercorrelations were excessively high, the largest being fear that the donated organ would not help the recipient and fear that the donated organ may harm the recipient, $r = .563, p < .001$. These two factors with the highest intercorrelations explained 61 per cent of the total variance, with the lowest component explaining 7 per cent of the variance. Overall, it appeared that the data was, in general, all measuring the types of fears which Newton (2011) identified and were sufficient also to measure as a total score.

A binary logistic regression was performed to determine the effects of participants’ negative beliefs on their choice to register as a donor or not. The model predicted decision to register, $\chi^2(6) = 33.14, p < .001$, explaining 42.6% (Nagelkerke $R^2$) of the variation in choice to donate, and correctly classifying 90.1% of cases. Sensitivity was high (97.6%) but specificity was low (26.7%) indicating that there was a bias in the test scores against identifying those who do not hold these fears. The positive predictive value of donor status given negative belief ratings was 91.8%, and the predictive value of a non-donor status was 57.1%. Of the six fear questions, two were statistically significant: A 1.05-point increase in the negative belief that donor status would the likelihood that their life would be saved had a 2.23 times greater likelihood to result in a non-donor status ($B = -.80, SE = 0.289, p = .003$); and a 1.3-point increase in concern about having their body damaged after death increased the chance of a non-donor status by 2.6 times ($B = -.958, SE = .325, p = .013$).

We ran a hierarchical linear regression of the list conditions’ registration scores on the six types of negative belief. This indicated that, for all four of the list conditions, the model with three factors: (i) aversion to having their body damaged after death, $M = 2.18, SD = 1.37$, (ii) fear that they are less likely to have their life
saved, $M = 1.77$, $SD = 1.04$, and (iii) fear that the organ would not help the recipient, $M = 2.64$, $SD = 1.18$, explained between 26.5% and 53.6% of the variation in response, dependent on the condition (see Table 7).

The other individual difference measures offered little-or-no systematic predictive value of donor registration, and the few statistically significant findings were treated as potential Type I errors. For example, the social agency subgroup of the social capital measure explained 20% of the variance in the opt-in, inclusion condition ($p = .016$) but had no predictive value in the other conditions. Thus, for brevity and to avoid unwarranted speculation, we do not report the analyses of other individual difference variables here.

There was no evidence of systematic social desirability biased responding, $M = 0.85$, $SD = 1.05$. Two respondents scored the maximum score of 5 points, seven more scored 3 or 4 points. 68 respondents scored zero.

Table 7.

*Optimal Models from the Hierarchical Regression of Donor Response on Negative Beliefs. The Model Selected the Same Three Negative Belief Items in each Condition.*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Adj $R^2$</th>
<th>$F$</th>
<th>df</th>
<th>$p$ (F)</th>
<th>$\Delta R^2$</th>
<th>$\Delta F$</th>
<th>$p$ (model)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opt-in, inclusion</td>
<td>.465</td>
<td>7.65</td>
<td>3, 20</td>
<td>.001</td>
<td>.358</td>
<td>15.38</td>
<td>.001</td>
</tr>
<tr>
<td>Opt-in, exclusion</td>
<td>.265</td>
<td>3.88</td>
<td>3, 21</td>
<td>.024</td>
<td>.272</td>
<td>8.88</td>
<td>.007</td>
</tr>
<tr>
<td>Opt-out, inclusion</td>
<td>.500</td>
<td>9.68</td>
<td>3, 23</td>
<td>&lt;.001</td>
<td>.386</td>
<td>20.09</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Opt-out, exclusion</td>
<td>.536</td>
<td>8.32</td>
<td>3, 16</td>
<td>.001</td>
<td>.504</td>
<td>20.63</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

We asked participants’ opinions on whether their jurisdiction should be opt-in or opt-out. 53 per cent of respondents selected a preference for an opt-in system,
44 per cent preferred an opt-out system, and the remaining four respondents were unsure.

**Supplementary Study Results**

Participants’ feelings of attachment and likelihood of donating organs are presented in Figure 6. There was a strong negative correlation between the rating of attachment to each item and the likelihood of donating it, Pearson’s $r = -.906$, $p < .001$, $R^2 = .801$. There was a strong positive correlation between the likelihood of donating in the supplementary study and registration to donate organs in the primary study’s list conditions, Pearson’s $r = .916$, $p < .001$, $R^2 = .838$. Figure 7 shows the relationship between ratings of attachment and willingness to donate in the supplementary study and likelihood of registering to donate organs in the primary study.

*Figure 6.* Participants’ ratings (95% CI) of feeling of attachment (scale of 6) and likelihood to donate (scale of 4) for each of the organs.
Discussion

We investigated whether the inclusion/exclusion phenomenon would appear in the field of organ donor registration, and whether the presentation method would affect potential donors’ absolute choice to be a donor, or the number of organs they registered for donation. If presentation method affects donor registration behaviour, the findings could inform us of ways to improve organ donation rates within the existing system and inform future policy. We hypothesised that, consistent with prior research across a variety of domains (e.g. Kogut, 2011; McDonald et al., 2014; Yaniv & Schul, 1997), exclusion conditions would elicit longer final lists than inclusion conditions. For an opt-in jurisdiction, a longer list would mean a greater number of organs donated; and for an opt-out jurisdiction this would mean fewer organs donated.

Figure 7. Feeling of attachment and likelihood to donate each organ in the supplementary survey, with registration response from the main survey list condition.
Although the results failed to achieve statistical significance at the $p < .05$ level, the effect sizes did show that, among the opt-in conditions, the exclusion condition returned a greater number of organs registered for donation than the inclusion condition. Among the opt-out conditions, the inclusion condition retained a greater number of registered organs through having fewer opt-outs than the exclusion condition. In the opt-in, inclusion condition, participants appear to have interacted more with the items on the list compared with the other list conditions (see figure 3). The opt-in, inclusion condition had the fewest 15-item donors – to do so would have involved ticking every box. In the opt-out, inclusion condition, participants mostly selected to remain being a donor, and this condition had the fewest non-donors – to do so would have involved ticking every box.

When we looked at only the uncommitted participants (i.e., not having prior organ donor registration), the effect of the conditions was magnified, and an interaction effect appeared. By looking only at the uncommitted participants, we were looking at the target market for new organ donors and excluding those who are less likely to be influenced by their previous decision. For the uncommitted participants, the number of organs donated under the inclusion conditions differed between the opt-in and opt-out conditions, as we had hypothesised. However, under the exclusion conditions, there was no such difference. This indicates that, in the decision-making process, the effect of having the boxes all pre-ticked encouraged more people to leave them ticked. Where the boxes were un-ticked, participants were less likely to tick all the boxes.

This interaction finding follows the theory behind the inclusion/exclusion phenomenon, that there is an evidentiary threshold eliciting differences between inclusion and exclusion conditions. Typically, the evidentiary threshold provides
what Yaniv and Schul (1997) termed a *burden of proof*, the strength of which causes different interactions with the list items. Yaniv, Schul, Raphaelli-Hirsch and Maoz (2002) suggested that the evidentiary threshold in their inclusion/exclusion study was a level of knowledgeability about the parliamentary elections. McDonald et al, (2014) suggested that the evidentiary threshold was the likelihood that adopting the pro-environmental behaviour would disrupt the respondent’s routines. In our study, fewer participants passed the evidentiary threshold to tick every item, compared with the conditions where an evidentiary threshold had to be passed to untick the items, causing an interaction effect. This left us to consider what the basis of the evidentiary threshold may be, so we considered two of the other main findings: (a) attachment to organs, and (b) negative beliefs about organ donation.

We found a strong negative relationship between feelings of attachment to organs and the likelihood to donate. We will discuss how such feelings may provide the evidentiary threshold for the inclusion/exclusion phenomenon in the context of organ donor registration. McDonald et al. (2014), when measuring the effect of the inclusion/exclusion phenomenon in the context of adopting environmentally friendly behaviours, proposed that the thresholds for deciding which behaviours to adopt was oriented around the behaviours which maintained the greatest status quo in the respondent’s pattern of behaviour. For example, where there was a smaller probability that the behaviour would be required (i.e., it is less likely to disrupt their routine), it was more likely to be chosen. When the prospective organ donor has a strong attachment to an organ, this may motivate their desire to keep the status quo and not donate the organ. Thus, feelings of attachment may be the basis upon which a person may decide to select an organ for donation in an inclusion situation, or to deselect it from the list, dependent on whether they are presented with an inclusion
or exclusion condition. Where the strength is moderate to low, the item may be skipped over in the inclusion condition, but also not deselected in the exclusion condition. This explanation fits within the primary concept that the difference between the inclusion and exclusion consideration lists is due to some individual difference factor within which a threshold must be met for selection or deselection (Samuelson & Zeckhauser, 1988). A very strong feeling of attachment may influence an individual’s decision not to register as an organ donor under any condition.

We included blanket opt-in and opt-out conditions (consistent with current practice in many jurisdictions) in which no list is presented. We believed that an individual who had an objection to donation may choose not to be registered as a donor in either blanket condition. In the absence of a list they were unable to exclude the organ/s with the objection from registration, hence they would exclude all organs. We were uncertain of the proportion of respondents who would have an objection to donating an organ, and who would decline to donate (in a blanket condition) based on that objection.

The proportion of participants having an objection to donating one or more organs was high. In fact, in the supplementary survey 80 of the 151 participants (53%) rated some item on the list as unlikely or very unlikely to donate. When we considered only the nine organs on the Australian registration form, this proportion decreased to 72 of the 151 participants (48%). While the conditions of the supplementary study may have influenced this statistic by priming the respondents with the feelings of attachment question, it does indicate that the prevalence of an objection to donating some organs may be high. The results of the main study, in which the conditions did not have that possible prime effect, support this notion. For example, in the opt-in, inclusion condition, of the 22 participants who registered to
donate at least one organ in that condition, just 11 agreed to donate all nine of the organs on the Australian registration form (Appendix A indicates these nine organs). These numbers indicate a similar prevalence of an objection to donating one or more organs, however the objections did not show up in the blanket conditions, with both conditions having a high donor registration rate. The objections did show up in the primary study’s four list-type conditions.

One explanation for the high blanket-condition donation rate in the presence of such objections is that the use of a list primes the respondent to recall their objection, where the blanket question does not. Thus, when presented with the simple option to become a donor, it may be that, without the list present, the decision does not involve a consideration of the individual organs included in the decision. When an inclusion-style list condition is offered, the respondent is primed to decide on each item individually, increasing the salience of objections related to individual organs. It follows that the exclusion-style of presenting the opt-in list elicits a response in between that of the opt-in blanket condition and the opt-in inclusion list. While there may be some element of a priming effect as they cast their eyes briefly over the pre-ticked list, the interaction with each item may be reduced for the motivated donor. This would less often raise the salience of any objection. We must also consider the possibility that the high registration rate in the blanket conditions was simply due to a response bias in our sampling. If we were to assume that we had attracted a sample biased toward becoming organ donors, this could reduce the effect of objections. This weakening of the effect of objections could be exacerbated by the lack of salience in the no-list blanket conditions.

Prior research (e.g., Newton, 2011, Sharpe et al., 2016) found that fears and negative beliefs have a reducing effect on organ donor registrations. We measured
six negative beliefs and found three to be statistically associated with the differences in registration responses in all four list conditions, although each received low average scores from participants. The concern of having the body damaged after death is one which conceivably could associate with an evidentiary threshold of attachment to organs, and the concept of maintaining the status quo. The fear that medical personnel would be more willing to let a donor die is conceptually more closely associated with avoidance of donor registration. The fear that the donated organ would not help the recipient feels somewhat irrational in the absence of an effect of spirituality. The latter two negative beliefs do not conceptually link well with variability of response in the list conditions, and it may be that the questions primed the salience of the fears among the same participants for whom seeing organs listed in the registration conditions influenced their response.

We could not look at a chart of these results and expect these to be reflective of the ecological organ donor rates measurable between jurisdictions, nor is that what we intended to demonstrate. Unlike ecological registrations, our participants were placed in the registration conditions (albeit having sought out the survey) rather than seeking to register to donate/opt-out. Our outcomes are intended to represent citizens’ behaviour at registration rather than population-level registrations. To illustrate, we could return to the example of opt-in jurisdiction Germany and opt-out jurisdiction Austria. If, hypothetically, Germany used an inclusion registration, and Austria used an exclusion registration, we could not expect that those countries’ citizens have an average of 9.54 organs and 10.65 organs registered respectively. In Austria, the opt-out registrations are subtracted from the approximate 99% of the population who are automatically registered as full donors. This would mean that the approximate 1% of the population who registered to opt-out may still have 10.65
organs registered, were this condition and these findings to apply. Conversely in Germany, it would be the registered 12% of the population who have 9.54 organs registered on average, leaving the remainder of the population as non-donors. This does not diminish any findings of this study, but this example highlights the difference between studying registration decisions and jurisdictional outcomes. We also are not accounting for jurisdictional rules around seeking family consent regardless of registration choices, with such rules commonplace in both opt-in and opt-out jurisdictions.

**Limitations**

A design limitation it that our study placed respondents in the situation of registering under conditions they may not have ordinarily sought. For 95 of our participants, there was possibly little motivation beyond course participation credit. Ordinarily, the person registering will have a higher level of motivation. In opt-out jurisdictions, the motivation is based on an objection to donating, either of a specific organ, or more generally. The motivation in an opt-in jurisdiction is more likely to have an element of altruism, or perhaps, social desirability. When it comes to the registration decision, these factors will play into the choices people make when they do register. This may have exaggerated the effect of our manipulation, if registering citizens have a strong motivation to donate. However, if a public campaign was run in a way which captured less motivated citizens (e.g., seeking registrations at doctors’ surgery visits), offering an exclusion-type list may prove to elicit more organs donated than an inclusion-type list.

Another limitation of this study to ecological validity is that our *opt-in, inclusion* condition did not include the *donate all* option found on the Australian registration form. The presence of this option may allow the respondent to
effectively bypass the list in a similar way that a donation-motivated responder to
our exclusion condition would. However, it could be argued that the presence of an
un-ticked list may still increase the salience of feelings of attachment and objections
to donating.

The method of exclusion we used was different from some other studies. For
example, McDonald et al. (2014) provided their lists of environmentally beneficial
behaviours on paper. The inclusion condition had participants tick items to include,
the exclusion condition had participants put a line through items to exclude them. In
contrast, providing a pre-ticked list (allowing participants to deselect items if they
wished), changed the way the participants interacted with the list. In hindsight, our
method did not force participants to interact with each item on the list in the same
way as prior inclusion/exclusion research. Perhaps more of our opt-in, exclusion
participants left the boxes ticked without considering the organs, more closely
operating as a blanket condition. This would exaggerate the response found in that
condition, especially for our uncommitted participants. What our conditions did do,
however, was model an approach which could be easily adopted into the Australian
online registration system with a simple change to offering pre-ticked boxes.

**Opportunities for Further Research**

Future research in this area could introduce an exclusion method which
forces participants to more actively engage with each item on the list, to determine
whether this elicits a different result, and whether it shows any effect of the
individual difference factors. More generally, it offers the opportunity to measure the
ways in which people interact with a list if it is pre-selected, compared with lists
which are not, and compared to the previously-used opt-out approaches. This may be
informative for decision theory with increasing online services and decision-making
undertaken using electronic devices. More advanced presentations of electronic registration could also be investigated, such as having a list appear on demand for those who wish to selectively register, but having the list hidden for those who wish to blanket donate. This could further measure whether such approaches reduce the salience of objections and feelings of attachment.

A further research opportunity also exists in investigating attachment to organs and whether there is some association with negative beliefs, such as posthumous mutilation. Our method collected the data on these from separate samples, so were unable to make such analysis. It could be suggested that fear of having posthumous mutilation and attachment both relate to having an objection to donating an organ. Research in this area could inform future education campaigns and inform donor registration drives.

**Conclusion**

We investigated the differences in list presentation formats, and opt-in versus opt-out systems, on organ donor consent rates. Based on our findings, the condition which most closely replicates the current Australian registration form elicits the fewest number of organs donated. This was, however, without that form’s option to donate all organs, which is likely to improve consent rates.

In practical terms, this finding has implications for electronic registration forms, such as those in use in Australia, in the absence of a desire to move toward an opt-out model. We suggest that inclusion lists increase the salience of objections to donation, where a simple change to offering pre-ticked boxes may make the process more comfortable for those with lower-level feelings of attachment to organs and thereby may meet shortfalls in the availability of organs for which feelings of attachment are more prevalent.
References


doi:https://doi.org/10.1007/BF00055564


Appendix A

The list of fifteen organs and tissue used in this study.

An asterisk (*) denotes the nine organs/tissue which appear on the Australian donor registration form.

- Lungs *
- Eyes (Eye tissue *)
- Heart *
- Bone Marrow
- Limbs/Fingers/Toes
- Kidney *
- Nose/Ear/Mouth Tissue
- Brain (or part)
- Liver *
- Reproductive Organs
- Heart Valves *
- Stem Cells
- Pancreas *
- Skin Tissue *
- Bone Tissue *
Appendix B

The survey questions in the primary survey.

Imagine that you are in a region which requires people to register if they want to be organ donors. You are presented with the following question:

I wish to register my consent to donate my organs and/or tissues for transplantation, in the event of my death.

☐ I want to be an organ donor.
☐ I do not want to be an organ donor.

Imagine that you are in a region where everyone is considered by default to be an organ donor. You are presented with the following question:

I wish to register my decision NOT to donate my organs or tissue, in the event of my death.

☐ I do not want to be an organ donor.
☐ I want to remain being an organ donor.

Imagine that you are in a region which requires people to register if they want to be organ donors. You are presented with the following question.

I wish to register my consent to donate the following organs and/or tissues for transplantation, in the event of my death:

(You may select as many or as few as you like. The 'Donate None' option will exclude all other selections.)

☐ Lungs
☐ Eyes
☐ Heart
☐ Bone Marrow
☐ Limbs/Fingers/Toes
☐ Kidney
☐ Nose/Ear/Mouth tissue
☐ Brain (or part)

☐ Liver
☐ Reproductive Organs
☐ Heart Valves
☐ Stem Cells
☐ Pancreas
☐ Skin Tissue
☐ Bone Tissue
☐ Donate None

Imagine that you are in a region which requires people to register if they want to be organ donors.

You are presented with the following question.

I wish to register my consent to donate the following organs and/or tissues for transplantation, in the event of my death:

(You may select as many or as few as you like. The 'Donate None' option will exclude all other selections.)

☒ Heart
☒ Eyes
☒ Liver
☒ Stem Cells
☒ Nose/Ear/Mouth tissue
☒ Lungs
☒ Heart Valves
☒ Bone Tissue

☒ Brain (or part)
☒ Pancreas
☒ Reproductive Organs
☒ Limbs/Fingers/Toes
☒ Kidney
☒ Skin Tissue
☒ Bone Marrow
☒ Donate None
Imagine that you are in a region where everyone is considered by default to be an organ donor.

You are presented with the following question:

I wish to register my decision **NOT** to donate the following organs or tissue, in the event of my death:

(You may select as many or as few as you like. The 'Donate all' option will exclude all other selections.)

<table>
<thead>
<tr>
<th>Selected items will be removed from the donor list.</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Heart</td>
</tr>
<tr>
<td>☐ Eyes</td>
</tr>
<tr>
<td>☐ Liver</td>
</tr>
<tr>
<td>☐ Stem Cells</td>
</tr>
<tr>
<td>☐ Nose/Ear/Mouth tissue</td>
</tr>
<tr>
<td>☐ Lungs</td>
</tr>
<tr>
<td>☐ Heart Valves</td>
</tr>
<tr>
<td>☐ Bone Tissue</td>
</tr>
</tbody>
</table>

Imagine that you are in a region where everyone is considered by default to be an organ donor.

You are presented with the following question:

I wish to register my decision **NOT** to donate the following organs or tissue, in the event of my death:

(You may select as many or as few as you like. The "Donate All" option will override all other selections.)

<table>
<thead>
<tr>
<th>Selected items will be removed from the donor list.</th>
</tr>
</thead>
<tbody>
<tr>
<td>☑ Heart</td>
</tr>
<tr>
<td>☑ Eyes</td>
</tr>
<tr>
<td>☑ Liver</td>
</tr>
<tr>
<td>☑ Stem Cells</td>
</tr>
<tr>
<td>☑ Nose/Ear/Mouth tissue</td>
</tr>
<tr>
<td>☑ Lungs</td>
</tr>
<tr>
<td>☑ Heart Valves</td>
</tr>
<tr>
<td>☑ Bone Tissue</td>
</tr>
<tr>
<td>☑ Brain (or part)</td>
</tr>
<tr>
<td>☑ Pancreas</td>
</tr>
<tr>
<td>☑ Reproductive Organs</td>
</tr>
<tr>
<td>☑ Limbs/Fingers/Toes</td>
</tr>
<tr>
<td>☑ Kidney</td>
</tr>
<tr>
<td>☑ Skin Tissue</td>
</tr>
<tr>
<td>☑ Bone Marrow</td>
</tr>
<tr>
<td>☑ Donate All</td>
</tr>
</tbody>
</table>

Please enter your age (in years)


What is your gender?

☐ Male
☐ Female
☐ Other (Specify) ______________________

What is your country of residence?

☐ Australia
☐ New Zealand
☐ Other (Specify) ______________________

(Optional) What is the postal / zip code of your usual residence?


The next few questions relate to your general knowledge of organ donation in your region.

Are you an organ donor, either by registration or by default?
- Yes
- No
- Unsure

Does the region you live in have automatic posthumous organ donor consent?
- Yes. Everyone is a donor, and they can register not to donate.
- No. Only people who have registered can be organ donors.
- I don’t know.

What system do you think your region should have?
- Optional consent, people register to be organ donors
- Automatic consent, people are naturally considered to be organ donors
- I don’t know

What percentage of the population in your state/territory/county do you think are registered organ donors?
- 0-10%
- 10-20%
- 20-30%
- 30-40%
- 40-50%
- 50-60%
- 60-70%
- 70-80%
- 80-90%
- 90-100%

What best describes your main occupation?
- Working full time
- Working part-time/casual
- Student
- Volunteer
- Retired
- Unemployed
- Unable to work

What best describes your highest level of formal education achieved?
- Year 10 / High school or lower
- Year 12 or equivalent
- Technical Certificate (e.g., TAFE)
- Bachelor Degree
- Post-Graduate Degree
- PhD

What best describes your current relationship status?
- Married
- Partnered
- Dating
- Single

How many children do you have?
- 0
- 1
- 2
- 3
- 4
- 5
- 6+

Have any of your family and/or close friends required an organ transplant?
- Immediate family (e.g., parent / sibling)
- Extended family (e.g., grandparent, aunt, cousin)
- Close friend
- Family of close friend
- Friend
- I’m not sure
- No
Have any of your family and/or close friends posthumously donated organs?

☐ Immediate family (eg, parent / sibling)
☐ Extended family (eg, grandparent, aunt, cousin)
☐ Close friend
☐ Family of close friend
☐ Friend
☐ I’m not sure
☐ No

For the following question(s), spirituality is defined as one’s relationship to God, or whatever you perceive to be the ultimate transcendence. The question(s) use a sentence completion format to measure various attributes associated with spirituality. An incomplete sentence fragment is provided, followed directly below by two phrases that are linked to a scale ranging from 0 to 10. The phrases, which complete the sentence fragment, anchor each end of the scale. The 0 to 10 range provides you with a continuum on which to reply, with 0 corresponding to absence or zero amount of the attribute, while 10 corresponds to the maximum amount of the attribute. In other words, the end points represent extreme values, while the five corresponds to a medium, or moderate, amount of the attribute.

Please select the number along the continuum that best reflects your initial feeling.

Spirituality is

The master motive of my life, directing every other aspect of my life. 10 .......................................................... Not part of my life. 0

In terms of the questions I have about life, my spirituality answers

No questions. 0 .................................................................................................................. Absolutely all my questions. 10

Growing spirituality is

More important than anything else in my life. 10 .......................................................... Of no importance to me. 0

When I am faced with an important decision, my spirituality

Plays absolutely no role. 0 .......................................................... Is always the overriding consideration. 10

When I think of the things that help me to grow and mature as a person, my spirituality

Has no effect on my personal growth. 0 .......................................................... Is absolutely the most important factor in my personal growth. 10

My spiritual beliefs affect

Absolutely every aspect of my life. 10 .......................................................... No aspect of my life. 0

The next set of questions asks about some common perceptions of organ donation.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I worry that my donated organ won't help the recipient.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I don't like the thought that my donated organ may harm the recipient.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel that medical personnel wouldn't try so hard to save me if they know I'm an organ donor.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I don't like the idea of my body being damaged to take my organs.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am afraid of dying.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I fear being rejected in the afterlife if my body isn't complete.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
The next two question sets are about how you think the world should be.

Please rate how much you agree or disagree with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have gone too far in pushing equal rights in this country</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our society would be better off if the distribution of wealth was more equal</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We need to dramatically reduce inequalities between the rich and poor, whites and people of colour, and men and women</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discrimination against minorities is still a very serious problem in our society</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It seems like people of colour, women, homosexuals and other groups don’t want equal rights, they want special rights just for them</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Society as a whole has become too soft and feminine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please rate how much you agree or disagree with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The government interferes far too much in our everyday lives</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes government needs to make laws that keep people from hurting themselves</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s not the government’s business to try to protect people from themselves</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The government should stop telling people how to live their lives</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The government should do more to advance society’s goal, even if that means limiting the freedom and choices of individuals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government should put limits on the choices individuals can make so they don’t get in the way of what’s good for society</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The following are a few questions about your trust in doctors:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes doctors care more about what is convenient for them than about their patients’ medical needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctors are extremely thorough and careful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I completely trust doctors’ decisions about which medical treatments are best</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A doctor would never intentionally mislead me about anything</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All in all, I trust doctors completely</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following questions are about your trust in healthcare organisations (eg. Hospitals):

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have to be cautious when dealing with healthcare organisations.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patients have sometimes been deceived or misled by healthcare organisations</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>When healthcare organisations make mistakes they usually cover them up</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Healthcare organisations have sometimes done harmful experiments on patients without their knowledge</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Healthcare organisations don’t always keep your information totally private</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Sometimes I wonder if healthcare organisations really know what they’re doing</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Mistakes are common in healthcare organisations</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Listed below are a few statements about your relationships with others. How much is each statement TRUE or FALSE for you? *

<table>
<thead>
<tr>
<th>Definitely True</th>
<th>Mostly True</th>
<th>Don’t Know</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am always courteous even to people who are disagreeable</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>There have been occasions when I took advantage of someone</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I sometimes try to get even, rather than forgive and forget</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I sometimes feel resentful when I don’t get my way</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>No matter who I’m talking to, I’m always a good listener</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
**Social Capital**

<table>
<thead>
<tr>
<th>Question</th>
<th>1 Never/No</th>
<th>2</th>
<th>3</th>
<th>4 Always/Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel valued by society?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>If you were to die tomorrow, would you be satisfied with what your life has meant?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Have you recently picked up other people's rubbish in a public place?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Some say that by helping others you help yourself in the long run.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Do you agree?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Do you help out a local group as a volunteer?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Do you feel safe walking down your street after dark?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Do you agree that most people can be trusted?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>If someone's car breaks down outside your house, do you invite them into your home to shelter from the weather?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Can you get help from friends when you need it?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Does your area have a reputation for being a safe place?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>If you were caring for a child and needed to go out for a while, would you ask a neighbour for help?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>No, not at all: 1</th>
<th>2</th>
<th>3</th>
<th>4 Yes, several (at least 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you attended a community event in the past 6 months (e.g., school fete, art/craft exhibition)?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Are you on a management committee or organising committee for any local group or organisation?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Have you ever been part of a project to organise a new service in your area (e.g., youth club, recreation facility, scout hall)?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How many people did you talk to yesterday? (Many = at least 10)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>In the past week, how many phone conversations have you had with friends? (Many = at least 6)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Questionumed</td>
<td>No. not at all</td>
<td>2</td>
<td>3</td>
<td>You, definitely, 4</td>
</tr>
<tr>
<td>-------------</td>
<td>---------------</td>
<td>---</td>
<td>---</td>
<td>------------------</td>
</tr>
<tr>
<td>Do you enjoy living among people of different lifestyles?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your local community feel like home?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If you need information to make a life decision, do you know where to find that information?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If you disagree with what everyone else agreed on, would you feel free to speak out?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think that multiculturalism makes life in your area better?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If you have a dispute with your neighbours (eg. fences, dogs) are you willing to seek mediation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If a stranger, someone different, moves into your street, would they be easily accepted by the neighbours?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questionumed</th>
<th>No. not at all</th>
<th>2</th>
<th>3</th>
<th>Yes, frequently, 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 5 years, have you ever taken part in a local community project or working bee?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you visited a neighbour in the past week?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past 5 years, have you ever joined a local community action to deal with an emergency? (Frequently = at least 5 times)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past 6 months, have you done a favour for a sick neighbour? (Frequently = at least 5 times)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you an active member of a local organisation or club (eg. sport, craft, social club)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Questionumed</th>
<th>No, hardly ever</th>
<th>2</th>
<th>3</th>
<th>Yes, nearly always, 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you go outside your local community to visit your family?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When you go shopping in your local area are you likely to run into friends and acquaintances?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over the weekend do you have meals with people from outside your household?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much have you previously considered posthumous (post-death) organ donation??

- I have registered as a donor by individually selecting which organs I wish to donate.
- I have registered to individually select which organs I do not wish to donate.
- I have registered as a donor by ticking a donate all option.
- I have registered to indicate I do not want to be an organ donor.
- I have thought I should be, but have not registered.
- I have thought I would not like to be, but have not opted-out.
- I have thought about it and don't want to register either way.
- I have thought about it a little but have not decided.
- I have not thought much about it before.
- I have never considered it.
Appendix C1

The information and consent sheet from the primary survey.

1. Invitation
You are invited to participate in the confidential online Posthumous Organ Donor Registration Survey. The study is being conducted by Dr. James Sauer (Senior Lecturer, Division of Psychology, School of Medicine, UTAS) and Mr Paul Schokman (Honours Student, Division of Psychology, School of Medicine, UTAS). This study is being conducted in partial fulfilment of an Honours degree for Mr Schokman under the supervision of Dr Sauer.

2. What is the purpose of the survey?
The survey is being conducted as a research project within the University of Tasmania Health Sciences (Psychology) as an honours project. The aim is to investigate factors which may improve the rates of posthumous organ donation - the organ donations people can make after their death.

3. Why have I been invited to participate?
Participation is open to anyone over the age of 18. Your participation is voluntary, and there are no consequences should you decide not to participate.

4. What will I be asked to do?
The survey will take an average person about 20 minutes to complete (including reading this page) and will involve answering questions in relation to your choices in registering for posthumous organ donor registration, your beliefs and attitudes in related aspects such as religiosity, social views and social outlook, prior exposure to organ donation issues and some demographic information. This information is being collected because previous research has found strong connections between these issues and organ donation. There are no ‘right’ or ‘wrong’ answers to the questions in this survey, other than the most true answer for you. Where there are multiple selections available you are free to select as many or as few as you like. References to organ donation are intended to mean the donating of organs and tissue after a person's death, to a recipient who requires that organ/tissue to improve their health. Your responses will be anonymous. Informed consent is implied by completion and submission of the survey.

5. Are there any possible benefits from participation in this study?
Participation in the survey provides you the opportunity to contribute to the knowledge about why people choose to be organ donors. First year psychology students at the University of Tasmania are offered course participation credit for completion. All participants will be rewarded with the knowledge that they have made a valuable contribution to an important field of study.

6. Are there any possible risks from participation in this study?
There are no foreseeable risks associated with the survey. However, be aware that, because it is a survey about posthumous organ donation, there
are themes relating to death and serious illness. If such questions raise issues for you, then you are free to withdraw from the survey at any time. If you experience any distress as a result of participation please feel free to contact the research supervisor, Dr Sauer. Alternatively, should you wish to access counselling or support services, in Australia you can contact Lifeline on 131 114 or, if you are a student or staff member at the University of Tasmania, the University of Tasmania counselling service on (03) 6226 2697 or (03) 6324 3787.

7. What if I change my mind during or after the study? If you complete some survey questions but choose to not submit the survey, your responses will not be recorded. As this survey does not allow for the identification of participants, once a completed survey is submitted results are unable to be withdrawn.

8. What will happen to the survey information? Data will be treated as confidential and will only be used for the study and any follow-up studies within the same research field. Information collected will be kept in a secure location at the University of Tasmania and access will be at the discretion of the researchers.

9. How will the results of the study be published? Results will be published in a bound thesis held within the faculty and as a poster presentation within the psychology faculty. Results may also be published in academic peer reviewed journals or as the subject of posters or presentations at conferences. Interested participants can contact the researchers by the email addresses below to find out more about the results of the study.

10. What if I have questions about this study? If you have any questions about the study, please contact the researcher by email: pauls12@utas.edu.au or the Research Supervisor: jim.sauer@utas.edu.au

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [insert here].

We appreciate and look forward to your participation in this survey.

☐ I have read and understood the information provided about this study, I confirm I am over 18 years old, and I consent to participating.
Appendix C2

The information and consent sheet from the supplementary survey.

1. Invitation

You are invited to participate in this confidential online Emotional Attachment to the Body survey.

The study is being conducted by Dr. James Sauer (Senior Lecturer, Division of Psychology, School of Medicine, UTAS) and Mr Paul Schokman (Honours Student, Division of Psychology, School of Medicine, UTAS). This study is being conducted in partial fulfilment of an Honours degree for Mr Schokman under the supervision of Dr Sauer.

2. What is the purpose of the survey?

The survey is being conducted as a research project within the University of Tasmania Health Sciences (Psychology) as an honours project. The aim is to investigate factors which affect people's organ donation choices. It is a supplementary survey to a larger project on organ donor registration behaviour.

3. Why have I been invited to participate?

Participation has been sought through Prolific Academic, with which you are involved.

4. What will I be asked to do?

The survey will take an average person about 10 minutes to complete (including reading this page), and will involve answering questions in relation to your feelings of personal or emotional attachment to different body parts which may be listed as organs which can be donated now or potentially in the future.

There are no ‘right’ or ‘wrong’ answers to the questions in this survey, other than the most true answer for you. References to organ donation are intended to mean the donating of organs and tissue after a person's death, to a recipient who requires that organ/tissue to improve their health.

Your responses will be anonymous. Informed consent is implied by completion and submission of the survey.

5. Are there any possible benefits from participation in this study?

Participation in the survey provides you the opportunity to contribute to the knowledge about why people choose to be organ donors.

As a Prolific Academic participant, you are being paid for your time to complete this survey at the suggested market rate.

6. Are there any possible risks from participation in this study?

There are no foreseeable risks associated with the survey. However, be aware that, because it is a survey about posthumous organ donation, it may raise thoughts about death and serious illness. If such thoughts may cause issues for you, then you are free to withdraw from the survey before completion.

If you experience any distress as a result of participation please feel free to contact the research supervisor, Dr Sauer. Alternatively, should you wish to access counselling or support services, in Australia you can contact Lifeline on 131 114 or, if you are a student or staff member at the University of Tasmania, the University of Tasmania counselling service on (03) 6226 2697 or (03) 6324 3787. Similar services exist in other countries to assist you, such as Mental Health America (1-800-273-
TALK) and in the UK Samaritans on 116 123.

7. What if I change my mind during or after the study?

If you complete some survey questions but choose to not submit the survey, your responses will not be recorded. As this survey does not allow for the identification of participants, once a completed survey is submitted results are unable to be withdrawn.

8. What will happen to the survey information?

Data will be treated as confidential and will only be used for the study and any follow-up studies within the same research field. Information collected will be kept in a secure location at the University of Tasmania and access will be at the discretion of the researchers.

9. How will the results of the study be published?

Results will be published in a bound thesis held within the faculty and as a poster presentation within the psychology faculty. Results may also be published in academic peer reviewed journals or as the subject of posters or presentations at conferences. Interested participants can contact the researchers by the email addresses below to find out more about the results of the study.

10. What if I have questions about this study?

If you have any questions about the study please contact the researcher by email: pauls12@utas.edu.au or the Research Supervisor: jim.sauer@utas.edu.au

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [insert here].

We appreciate and look forward to your participation in this survey.

☐ I have read and understood the information provided about this study, I confirm I am over 18 years old, and I consent to participating.
Appendix D

The supplementary survey questions.

Participant demographic data was provided separately by Prolific (www.prolific.ac).

For each of the following organs / tissue, how much do you feel personally or emotionally attached to that body part? *

Please choose the appropriate response for each item:

<table>
<thead>
<tr>
<th></th>
<th>None at all</th>
<th>Just a little</th>
<th>Somewhat</th>
<th>Moderately</th>
<th>Quite strongly</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lungs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone Marrow</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limbs/Fingers/Toes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nose/Ear/Mouth tissue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain (or part)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reproductive Organs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart Valves</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stem Cells</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreas</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin Tissue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone Tissue</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

For each of the following organs/tissue, how likely is it that you would consent to have it donated upon your death? *

Please choose the appropriate response for each item:

<table>
<thead>
<tr>
<th></th>
<th>Very likely</th>
<th>Likely</th>
<th>Unlikely</th>
<th>Very Unlikely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lungs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone Marrow</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limbs/Fingers/Toes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nose/Ear/Mouth tissue</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain (or part)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reproductive Organs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart Valves</td>
<td></td>
<td></td>
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<tr>
<td>Stem Cells</td>
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<tr>
<td>Pancreas</td>
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<tr>
<td>Skin Tissue</td>
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<td></td>
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</tr>
<tr>
<td>Bone Tissue</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>