

Running Head: NEXT-OF-KIN APPROVAL DONATION OPT-OUT CONSENT

Assessing the Factors that Influence the Donation of a Deceased Family  
Member's Organs in an Opt-Out System for Organ Donation

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## Abstract

*Rationale:* Family, and sometimes longstanding friends, have considerable influence over organ donation, through agreeing or disagreeing to the donation of a deceased individual's organs. To date, most research has been undertaken within opt-in systems.

*Objective:* This study advances on previous research by assessing next-of-kin approval under opt-out legislation. We tested whether next-of-kin approval varies when the deceased is a registered donor (opted-in), registered non-donor (opted-out) or has not registered a decision under an opt-out policy (deemed consent). We also tested if the deceased's wishes influenced next-of-kin approval through relatives anticipating regret for not donating and feelings of uncertainty. Finally, we assessed whether next-of-kin's own beliefs about organ donation influenced whether they followed the deceased's wishes.

*Method:* Participants (N = 848) living in a country with opt-out legislation (Wales, UK) were asked to imagine a relative had died under an opt-out system and decided if their relatives' organs should be donated. Participants were randomly allocated to imagine the deceased had either (i) opted-in, (ii) opted-out or (iii) not registered a decision (deemed consent). The outcome variable was next-of-kin approval, with uncertainty and anticipated regret as potential mediators and next-of-kin's beliefs about organ donation as moderators.

*Results:* Next-of-kin approval was lower when the deceased had opted-out than under deemed consent. This was due to next-of-kin anticipating more regret for not donating under deemed consent than opt-out. Further analyses revealed the deceased's wishes influence next-of-kin approval, via anticipated regret, when next-of-kin did not hold negative beliefs about organ donation

*Conclusions:* The deceased's wishes were less likely to be followed when next-of-kin had negative beliefs towards donation. Developing large-scale campaigns to improve these beliefs

in the general public should make people more likely to follow the deceased's wishes. As a result, these campaigns should improve the availability of donor organs.

*Keywords:* Next-of-kin; organ donation; transplantation; affective attitudes; perceived benefits; anticipated regret; uncertainty; Wales (UK)

## Introduction

In the US 17 people die each day waiting for an organ transplant (Health Resources & Services Administration, 2022). Similarly, between 2020 and 2021, 474 people died in the UK while waiting for an organ (NHS Blood and Transplant, 2021). Therefore, it is essential to improve the number of organs available for transplantation. One strategy that can be applied to achieve this is to change a country's organ consent legislation from opt-in to opt-out policies. Opt-in requires people to take action to demonstrate they consent to their organs being used for transplantation after they die (e.g., registering as an organ donor). Under opt-out, adults are assumed to be donors unless they have taken action to show they do not want their organs to be used.

There is mixed evidence regarding the influence of consent legislation on donation rates. Although some research has found deceased donor rates are, on average, higher in opt-out than opt-in countries (Abadie & Gay, 2006; Ahmad et al., 2019; Johnson & Goldstein, 2003), other studies have found no differences in deceased donation rates (Arshad et al., 2019). Moreover, living donor rates are lower in opt-out than in opt-in countries (Horvat et al., 2010; Shepherd et al., 2014). Therefore, introducing an opt-out policy does not necessarily mean that the availability of organs will increase.

Approval of organ donation from family members or, in some cases, longstanding friends is a vital step in the organ procurement process (Rosenblum et al., 2012). As such, it is important to consider the decision-making processes undertaken by family members and longstanding friends. One concern is that, in contrast to an opt-in policy, opt-out policy increases the uncertainty of a person's wishes in cases of deemed consent, when the potential donor has not actively registered a decision (Miller et al., 2019). Therefore, although consent may be assumed in opt-out systems, this does not mean peoples' organs will be transplanted if family members and friends refuse. This is exemplified in the opt-out system used in

Wales. In this system people may a) register their wishes to donate either under the previous opt-in or current opt-out system (i.e., opt-in), b) register their wishes for their organs not to be used (i.e., actively opt-out) or c) make no active decision and deemed consent is assumed (i.e., deemed consent). In this system, family members and longstanding friends are more likely to agree to organ donation when the deceased has opted-in than under deemed consent (Noyes et al., 2019). Even following this approval, there may still be reasons why the deceased's organs cannot be transplanted (e.g., organs deemed unsuitable). Currently very little is known about the decision-making process undertaken by family members. Therefore, the current study advances the literature by developing and empirically testing a model of decision-making by next-of-kin under an opt-out system (Figure 1).

<INSERT FIGURE 1 ABOUT HERE>

This model explores how two process – uncertainty and anticipated regret – mediate the next-of-kin approval decision based on knowledge of the deceased's actions to register a decision (opt-in or opt-out) or not (deemed consent). It was hypothesized that next-of-kin will be more uncertain with deemed consent (i.e., the deceased has not registered a decision) compared to when a decision has been registered (either opt-in or opt-out). It was also hypothesized that the next-of-kin will be less likely to anticipate feelings of regret for not donating a relative's organs when the deceased has opted-out compared to deemed consent. Finally, the model predicts that next-of-kin's attitudes towards organ donation will moderate the mediating effects of anticipated regret and uncertainty. Justification of the model is described below.

### **The Deceased's Organ Donor Status**

The deceased's wishes have been found to predict next-of-kin approval of donation across many studies (Chandler et al., 2017; Kentish-Barnes et al., 2019; Ralph et al., 2014; Walker et al., 2013). Importantly, the deceased's wishes have been found to predict next-of-

kin approval in countries that use an opt-in policy (Rodrigue et al., 2006; Shepherd & O'Carroll, 2014b; Siminoff et al., 2001) and fewer studies in countries that use opt-out legislation (López et al., 2018a). For example, next-of-kin approval was lower under deemed consent than when the deceased had opted-in (Noyes et al., 2019). This difference may reflect uncertainty about the deceased's wishes under deemed consent compared to having actively registered (Miller et al., 2019; Shaw, 2017). Uncertainty reduces the likelihood of next-of-kin agreeing to donation (Walker et al., 2013). Therefore, the greater uncertainty under deemed consent may make next-of-kin less likely to agree to donation (Figure 2a, also see Figure 1 paths a1 and b1). Moreover, such uncertainty may make the next-of-kin's own attitudes towards organ donation influence their decision regarding donation (López et al., 2018a; López et al., 2018b). Thus, next-of-kin's attitudes towards organ donation may moderate the effect of uncertainty, with the effect of uncertainty enhanced with more negative attitudes.

<INSERT FIGURE 2 ABOUT HERE>

Another way in which the deceased's wishes may influence next-of-kin approval of donation is through regret. People feel regret when they think they should have acted differently (Zeelenberg & Pieters, 2007). Notably, research conducted in an opt-in consent system found that feeling regret for not donating a loved one's organs positively predicted next-of-kin approval of donation (Shepherd and O'Carroll, 2014b). This anticipated regret is also likely to influence next-of-kin approval in opt-out systems. When the deceased has actively registered as a non-donor (i.e., opted-out), next-of-kin are not likely to experience anticipated regret for not agreeing to donate their relatives' organs as the deceased's wishes are clear. In contrast, next-of-kin may be likely to anticipate high levels of regret for not following their relative's wishes to donate when the deceased has either opted-in or under deemed consent. This higher anticipated regret should subsequently increase next-of-kin approval of donation. Moreover, this anticipated regret is likely to be higher when the

potential donor has taken the extra step of actively opting-in compared to deemed consent. The deceased's organ donor status (opted-in, opted-out or deemed consent) should influence the extent to which next-of-kin anticipate regret for not donating, which, in turn, may subsequently influence their approval of donation (Figure 2b, also see Figure 1 paths a2 and b2).

### **Next-of-kin's Attitudes towards Organ Donation**

Research conducted in both opt-in and opt-out systems has found next-of-kin are more likely to agree to organ donation when they themselves have a positive attitude towards organ donation (López et al., 2018a; Rodrigue et al., 2006; Shepherd & O'Carroll, 2014b), especially when the deceased's wishes are unknown (López et al., 2018b).

People hold various affective attitudes towards organ donation (Morgan et al., 2008). These can be negative in terms of (i) bodily integrity (concern that the body should be kept whole), (ii) medical mistrust (believing that medical professionals may undertake unethical practices to gain organs), (iii) ick factor (feeling disgust towards organ transplantation), and (iv) jinx (worrying that becoming a donor may bring bad luck) or positive in terms of perceived benefits, which relates to the belief that organ donation is beneficial to the donor (O'Carroll et al., 2011). These affective attitudes are likely to influence next-of-kin approval. Indeed, next-of-kin are unlikely to give approval when they have concerns about the deceased's body being mutilated (i.e., bodily integrity concerns) (Chandler et al., 2017) or medical mistrust (Ralph et al., 2014). In contrast, next-of-kin are likely to approve donation when they believe it benefits the deceased by giving meaning to their death or allowing them to live on after they die (Walker et al., 2013).

As mentioned above, the deceased's wishes and next-of-kin's attitudes are likely to interact to predict the next-of-kin approval (López et al., 2018a; López et al., 2018b).

Therefore, the effects of the deceased's donor status on anticipated regret, uncertainty, and

next-of-kin approval will be contingent on the next-of-kin's attitudes. Under deemed consent the deceased's wishes are likely to be uncertain. In such instances, the extent to which people anticipate regret and feel uncertain should be dependent on next-of-kin's own affective attitudes (see Figure 1 paths w1 and w2). When next-of-kin hold negative attitudes (i.e., the negative affective attitudes are high), they should be less likely to anticipate regret for approving a donation under deemed consent. Therefore, next-of-kin will be unlikely to approve of donation in such instances (Figure 3a). In contrast, when next-of-kin believe that donation is beneficial (i.e., they are high in perceived benefits), they should be likely to experience anticipated regret for not approving donation, resulting in next-of-kin being willing to provide approval (Figure 3b). Moreover, when next-of-kin hold negative attitudes (i.e., the negative affective attitudes are high), they should be more reluctant to donate their relatives' organs. In such instances, next-of-kin may state the deceased's wishes are more uncertain under deemed consent compared to opt-in or opt-out. This perceived uncertainty should make next-of-kin unlikely to approve of donation (Figure 3c). In contrast, when next-of-kin believe donation is beneficial (i.e., are high in perceived benefits), they should be more supportive of donation and state they feel more certain about the deceased's wishes. Therefore, in these instances next-of-kin may be more likely to approve of donation (Figure 3d).

<INSERT FIGURE 3 ABOUT HERE>

### **The Present Study**

Approval of organ donation by family members and longstanding friends is a vital part of the organ procurement process. Based on the rationale above, there is strong support for the hypothesized model outlining these approval processes (Figures 1-3). However, most of the research used to support this model has been conducted in opt-in countries (e.g., Rodrigue et al., 2006; Shepherd & O'Carroll, 2014b; Siminoff et al., 2001; but see López et



al., 2018a; Martínez et al., 2008) and no study has tested the whole model simultaneously. Therefore, this paper aims to assess the factors that influence next-of-kin approval under an opt-out policy (i.e., Wales). It was hypothesized that the willingness to donate should be a) lower under deemed consent than when the deceased has opted-in and b) higher under deemed consent than when they have opted-out (Hypothesis 1). Moreover, it was hypothesized that these effects are likely to be due to uncertainty about the deceased's wishes (Hypothesis 2, Figure 1 paths a1 and b1) and anticipated regret for not donating a loved one's organs (Hypothesis 3, Figure 1 paths a2 and b2). It was also hypothesized that these effects will be moderated by next-of-kin's negative affective attitudes (Hypothesis 4) and perceived benefits (Hypothesis 5, Figure 1 paths w1 and w2).

## Method

### Participants

To be included in the study, participants had to be 18 years or older and currently living in Wales. Participants were recruited through an online survey provider (Qualtrics, <https://www.qualtrics.com>). There was complete data from 848 eligible participants ( $M_{age} = 37.90$ ,  $SD = 14.70$ ; range 18-85). There were 549 females (64.74%) and 286 males (33.73%); 4 participants selected 'other' and 9 participants selected 'prefer not to say'; for more details about the sample, see Supplementary Files).

### Design

This experiment was a one-way between-participants design at three levels of the deceased's organ donor status (opted-in, opted-out or deemed consent). Participants were randomly allocated to a condition by the online survey. This randomization was set up to ensure that there was equal number of participants in each condition. The dependent variable was the intention of next-of-kin to approve of donating the deceased's organs (next-of-kin approval). The mediating variables were uncertainty towards the deceased's wishes and

anticipated regret if they did not donate the deceased's organs. The potential moderating variables were the negative affective attitudes and perceived benefits.

## **Materials**

**Previous health-based philanthropy.** Participants indicated whether or not they had previously donated blood (no versus yes) and their organ donor status under the opt-out system in Wales (opted-in, opted-out or deemed consent).

**Uncertainty.** This was assessed with three items (e.g., 'I am unsure whether or not the deceased family member would support a decision to donate their organs'). Each item was rated on a five-point Likert scale (1 = *Strongly disagree*, 5 = *Strongly agree*). The mean of the items was used to calculate the scale ( $\alpha = .69$ ).

**Anticipated regret.** Two anticipated regret items were adapted from previous research (O'Carroll et al., 2016): 'If I did not allow my family member's organs to be used for transplantation purposes I would regret it later' and 'If I did not allow my family member's organs to be used for transplantation purposes I would later wish that I had' ( $r = .76, p < .001$ ). Both items were rated on a five-point Likert-type scale (1 = *Not at all*, 5 = *Very much so*). The scale was based on the mean of these two items.

**Intention of next-of-kin to approve donation of organs.** Participants rated how likely they would be to donate their deceased loved one's heart, lungs, kidneys, liver, corneas, pancreas, tissue and small bowel. These eight items were selected because they are the bodily parts that people can specify they wish to donate on the organ donor registration form in the UK. Participants rated how likely they would be to donate each body part on a five-point scale (0 = *No, not at all*, 4 = *Yes, definitely*). The mean of these items was used to calculate the scale ( $\alpha = .98$ ).

**Negative affective attitudes and perceived benefits.** The negative affective attitudes and perceived benefits were measured using an established measure (O'Carroll et al., 2011).

This UK version of the scale was adapted from a US version (Morgan et al., 2008). This 16-item measure assesses bodily integrity (e.g., ‘Removing organs from the body just isn’t right’), medical mistrust (e.g., ‘If I sign an organ donor card, doctors might take my organs before I’m actually dead’), the ick factor (e.g., ‘The idea of organ donation is somewhat disgusting’), jinx (e.g., ‘The surest way to bring about my own death is to make plans for it like signing an organ donor card’) and perceived benefits (e.g., ‘Organ donors are heroic because they save lives’; for full scale, see O’Carroll et al., 2011). Each item was rated on a seven-point Likert scale (1 = *Strongly disagree*, 7 = *Strongly agree*). In line with previous research (Morgan et al., 2008), two subscales were created from this measure: a perceived benefits subscale formed from the mean of these items and a negative affective attitudes subscale that was based on the mean of the bodily integrity, medical mistrust, ick factor and jinx items. Both scales were reliable ( $\alpha = .83$  for perceived benefits and  $.93$  for negative affective attitudes).

### **Procedure**

An institutional review board approved the study (submission reference: 17708, approved 13/09/2019). Participants imagined that one of their close family members had died from a severe brain injury, resulting in brain stem death. Participants imagined that this person had lived and died in Wales, and that they had not discussed their wishes about organ donation before they died. The deceased’s organ donor status was then manipulated. Participants imagined that the deceased a) had registered as a donor meaning they wanted their organs to be transplanted (i.e., opted-in), b) had registered as a non-donor meaning they did not want their organs to be transplanted (i.e., opted-out), or c) not registered a decision meaning that in the Welsh system they are assumed to be willing to donate their organs under deemed consent (i.e., deemed consent). Participants then completed the uncertainty,

anticipated regret, next-of-kin approval of donation, negative affective attitude, and perceived benefits measures. Finally, participants were thanked and debriefed.

### **Power Analysis**

Based on previous research (Shepherd & O'Carroll, 2014b), there was expected to be a small effect size of the deceased's donor status on next-of-kin approval (Cohen's  $d = .25$ ; see preregistration XXXXX). Given this effect size, 253 participants per group were needed to find a significant difference, based on a power of .80 and an alpha level of .05. Therefore, with the three experimental groups, the minimum sample size was 759 participants. Based on this, the aim was to recruit 800 participants to ensure there was a sufficient sample size in case participants needed to be removed. For example, the preregistration stated that the data would be analyzed with and without the outliers included and that the outliers would be removed if the results varied between these analyses. This was because differences between these results would suggest that outliers were biasing the data.

### **Statistical Analysis**

ANOVAs assessed the effect of the deceased's registration status (i.e., opted-in, opted-out or deemed consent) on next-of-kin approval of donation, uncertainty and anticipated regret. Mediation models were assessed using the Process Macro (Version 3.5.2, Hayes, 2020, Model 4). In line with the opt-out system used in Wales, the deceased donor status manipulation had three categories (opted-in, opted-out and deemed consent). In the Process Macro, the deceased's organ donor status manipulation was entered as a multi-categorical independent variable, with indicator coding used to test comparisons between conditions. The reference category was the deemed consent condition. This created two comparisons: (i) Deemed Consent vs. Opted-out and (ii) Deemed Consent vs. Opted-in. The Deemed Consent vs. Opted-out comparison assessed whether there were any differences when the deceased opted-out compared with when deemed consent was used. The Deemed

Consent vs. Opted-in comparison assessed whether there were any differences when the deceased had opted-in compared to when deemed consent was used. Indirect effects were assessed from these comparisons to next-of-kin approval of donation via uncertainty and anticipated regret.

Following this, the index of moderated mediation (Hayes, 2015) was used to determine whether the strength of the indirect effects, from deceased donor status to next-of-kin approval via anticipated regret and uncertainty, varied based on the negative affective attitudes and perceived benefits. The index of moderated mediation is calculated as part of the Process Macro (Model 8, Hayes, 2020) and compares whether an indirect effect varies as a function of a moderator. A moderated indirect effect is present when the bootstrap confidence intervals for the index of moderated mediation do not contain zero. Based on Hayes (2018), the indirect effects were tested at low (16<sup>th</sup> percentile), moderate (50<sup>th</sup> percentile) and high levels of the moderating variables (84<sup>th</sup> percentile). All variables that defined products were mean-centered. A separate analysis was conducted for each potential moderating variable.

## **Results**

### **Preliminary analyses**

Thirteen participant's perceived benefits score was outside of  $\pm 3$  standard deviations from the mean, indicating some outliers were present. The results remained the same when the analyses were undertaken with and without these outliers included. Therefore, the outliers were retained. Next-of-kin approval and perceived benefits were negatively skewed, whilst the negative affective attitudes were positively skewed. Importantly, the use of bootstrap resampling in the moderated mediation analyses made it unlikely that the findings would be bias by skew. Although the homogeneity of variance assumption was violated for the uncertainty ( $F(2, 845) = 3.74, p = .024$ ) and next-of-kin approval variables ( $F(2, 845) =$

10.43,  $p < .001$ ), the ANOVA results were likely to be robust given the equal sample sizes (Ramachandran & Tsokos, 2014).

### **Descriptive Statistics**

There were 519 participants (61.20%) who had not and 329 participants (38.80%) who had previously donated blood. Participants were more likely to be a registered organ donor ( $n = 438$ , 51.65%) or have not registered a decision (i.e., deemed consent;  $n = 347$ , 40.92%) than be a registered non-donor ( $n = 63$ , 7.43%). These statistics are similar to the registration rates in Wales at the time of the study (41% opted-in and 6% opted-out, NHS Blood and Transplant, 2020).

It was tested whether the demographic and previous health-based philanthropy variables varied based on the experimental conditions (i.e., opted-in, opted-out or deemed consent). This was because any significant effects of the experimental condition on these variables would suggest a problem with the randomization. Importantly, there were no significant effects of the experimental condition on the demographic or previous health-based philanthropy variables (Table 1).

<INSERT TABLE 1 ABOUT HERE>

### **Effect of Deceased Donation Status on Next-of-Kin Approval of Donation (Hypothesis 1)**

It was hypothesized that next-of-kin approval would be lower when the deceased had opted-out (i.e., under opt-out) than when they had not registered a decision (i.e., under deemed consent). It was also predicted that next-of-kin approval would be lower under deemed consent than when the deceased had opted-in (i.e., under opt-in). The deceased's organ donor status (i.e., opted-in, opted-out or deemed consent) had a significant effect on next-of-kin donation decisions ( $F(2, 845) = 35.00$ ,  $p < .001$ ,  $\eta_p^2 = .08$ ). Planned comparisons showed that next-of-kin approval was significantly lower under opt-out ( $M = 2.13$ ,  $SD = 1.36$ ) than deemed consent ( $M = 2.88$ ,  $SD = 1.13$ ,  $t(845) = 7.40$ ,  $p < .001$ ,  $d = 0.60$ ). In

contrast, there was no significant difference in next-of-kin approval under opt-in ( $M = 2.84$ ,  $SD = 1.08$ ) compared to under deemed consent ( $t(845) = 0.32$ ,  $p = .751$ ,  $d = 0.03$ ). Therefore, these results supported the hypothesis that next-of-kin approval would be higher under deemed consent compared to opt-out. However, the hypothesis that next-of-kin approval of organ donation would be lower under deemed consent than under opt-in was not supported.

### **Indirect Effects of Deceased's Organ Donor Status on Next-of-Kin Approval via Uncertainty (Hypothesis 2) and Anticipated Regret (Hypothesis 3)**

It was hypothesized that the deceased's organ donor status (i.e., opted-in, opted-out or deemed consent) would indirectly affect next-of-kin approval through a) uncertainty and b) anticipated regret. It was hypothesized that next-of-kin would have greater uncertainty when the deceased had not registered a decision (i.e., under deemed consent) compared to having opted-in (i.e., under opt-in) or out (i.e., under opt-out) and this uncertainty may reduce next-of-kin approval (Figure 2a). It was also hypothesized that next-of-kin will be more likely to anticipate regret for not donating under deemed consent than under opt-out and that this regret should increase next-of-kin approval (Figure 2b). Additionally, it was expected that next-of-kin should be more likely to anticipate regret under opt-in than under deemed consent and that this regret should increase next-of-kin approval of donation.

**Hypothesis 2 - Indirect effect via uncertainty.** ANOVA showed that the deceased's organ donor status (i.e., opted-in, opted-out or deemed consent) had a significant effect on levels of uncertainty ( $F(2, 845) = 15.56$ ,  $p < .001$ ,  $\eta_p^2 = .04$ ). Planned comparisons showed that people felt more uncertain under deemed consent ( $M = 2.89$ ,  $SD = 0.94$ ) than under opt-out ( $M = 2.62$ ,  $SD = 0.89$ ,  $t(845) = 3.39$ ,  $p < .001$ ,  $d = 0.29$ , also see pathway from 'Deemed consent vs. Opted-out' to 'Uncertainty' in Figure 4) or under opt-in ( $M = 2.45$ ,  $SD = 0.99$ ,  $t(845) = 5.53$ ,  $p < .001$ ,  $d = 0.45$ , also see pathway from 'Deemed consent vs. Opted-in' to 'Uncertainty' in Figure 4). However, uncertainty did not predict next-of-kin approval (Figure

4). Therefore, contrary to the hypotheses, the effect of the deceased's organ donor status on next-of-kin approval was not due to uncertainty about the deceased's wishes.

<INSERT FIGURE 4 ABOUT HERE>

**Hypothesis 3 - Indirect effect via anticipated regret.** There was a significant effect of the deceased's organ donor status (i.e., opted-in, opted-out or deemed consent) on anticipated regret ( $F(2, 845) = 18.78, p < .001, \eta_p^2 = .04$ ). Planned comparisons showed that next-of-kin were less likely to feel anticipated regret under opt-out ( $M = 2.96, SD = 1.36$ ) than under deemed consent ( $M = 3.50, SD = 1.18; t(845) = 5.16, p < .001, d = 0.43$ , see also pathway from 'Deemed consent vs. Opted-out' to 'Anticipated Regret' in Figure 4), but that there was no difference in anticipated regret under opt-in ( $M = 3.53, SD = 1.24$ ) compared to deemed consent ( $t(845) = 0.29, p = .776, d = 0.03$ , see also pathway from 'Deemed consent vs. Opted-in' to 'Anticipated Regret' in Figure 4). Therefore, this demonstrates an effect of the deceased's organ donor status on anticipated regret. Additionally, anticipated regret predicted next-of-kin approval of donation (Figure 4) and indirectly links the deceased's decision to the next-of-kin approval; specifically, whilst comparing deemed consent to opted-out (95% CI [-0.44, -0.19]). Thus, next-of-kin were more likely to feel anticipated regret for not donating under deemed consent than under opt-out. This higher level of anticipated regret made next-of-kin more likely to approve of donation.

In contrast, there was no significant indirect effect via anticipated regret comparing deemed consent to opt-in decisions (95% CI [-0.10, 0.13]). Therefore, there was some support for the hypothesized indirect effect of the deceased's organ donor status on next-of-kin approval via anticipated regret; specifically, this only occurred when deemed consent was compared with when the deceased had opted-out.



### **Moderating Role of the Negative Affective Attitudes (Hypothesis 4) and Perceived Benefits (Hypothesis 5)**

As mentioned above when testing the simple mediation (Hypothesis 3), it was found that a) next-of-kin anticipated more regret under deemed consent than under opt-out and b) this higher regret subsequently led to higher next-of-kin approval of donation. Therefore, there was an indirect effect from the deceased's organ donor status (deemed consent vs. opted-out) on next-of-kin approval via anticipated regret. Next, the analyses tested whether this indirect effect from the deceased's organ donor status on next-of-kin approval via anticipated regret varied based on next-of-kin's negative affective attitudes (Hypothesis 4) and perceived benefits (Hypothesis 5).

**Moderating role of negative affective attitudes (Hypothesis 4).** It was hypothesized that the indirect effect from the deceased's organ donor status (i.e., opted-out vs. deemed consent) on next-of-kin approval via anticipated regret would be most likely when next-of-kin do not hold negative affective attitudes. Indeed, when next-of-kin do not hold negative affective attitudes, they should be more likely to anticipate regret for not donating under deemed consent than opt-out. This higher regret should subsequently increase next-of-kin approval of donation. In contrast, when next-of-kin hold negative affective attitudes, they should be unlikely to anticipate regret under both deemed consent and opt-out. This lower anticipated regret may reduce the likelihood of next-of-kin approval varying under deemed consent and opt-out.

For the negative affective attitudes, the confidence intervals for the index of moderated mediation did not contain zero (Table 2). This showed that the indirect effect from the deceased's organ donor status (i.e., deemed consent vs. opted-out) to next-of-kin approval via anticipated regret varied based on next-of-kin's negative affective attitudes. As hypothesized, when next-of-kin do not hold negative affective attitudes, the indirect effect

from the deceased's organ donor status to next-of-kin approval via anticipated regret was significant, as demonstrated by the confidence intervals not including zero at low and moderate levels of the negative affective attitudes (Table 2). These results show that when next-of-kin did not hold negative affective attitudes (i.e., these attitudes were low or moderate), anticipated regret was higher under deemed consent compared to under opt-out. This higher anticipated regret subsequently increased next-of-kin approval.

<INSERT TABLE 2 ABOUT HERE>

In contrast, the indirect effect from the deceased's organ donor status to next-of-kin approval via anticipated regret was not significant when people held negative affective attitudes. This was shown by the fact that at high levels of the negative affective attitudes the confidence intervals for this indirect effect contained zero (Table 2). This was due to anticipated regret not varying under deemed consent or opt-out when next-of-kin held negative affective attitudes. As such, the indirect effect found when testing Hypothesis 3 was non-significant when next-of-kin held the negative affective attitudes.

Overall, these results reflect the fact that the indirect effect from the deceased's organ donor status to next-of-kin approval via anticipated regret that was found when testing Hypothesis 3 varied based on whether or not next-of-kin held negative affective attitudes. When next-of-kin did not hold negative affective attitudes, they anticipated higher regret for not donating under deemed consent compared to under opt-out. Importantly, this higher regret increased next-of-kin approval of donation. However, when next-of-kin held negative affective attitudes, anticipated regret did not vary under deemed consent or under opt-out, resulting in the indirect effect from the deceased's organ donor status on next-of-kin approval via anticipated regret being non-significant. Therefore, these results provide support for Hypothesis 4; specifically, that the indirect effect from the deceased's organ donor status to

next-of-kin approval via anticipated regret would vary based on next-of-kin's beliefs in the negative affective attitudes.

**Moderating role of perceived benefits (Hypothesis 5).** The analyses also tested whether the indirect effect from the deceased's organ donor status on next-of-kin approval via anticipated regret varied based on perceived benefits. It was hypothesized that this indirect effect would be likely to occur when next-of-kin perceived that organ donation had benefits. In contrast, it was hypothesized that this indirect effect would be less likely when next-of-kin did not perceive organ donation to be beneficial.

When perceived benefits was the moderator, the confidence intervals for the index of moderation mediation contained zero (Table 2). This showed that perceived benefits did not moderate the indirect effects of deceased donor status on next-of-kin approval via anticipated regret. The reason why the index of moderated mediation was non-significant was that the indirect effect from the deceased's organ donor status to next-of-kin approval via anticipated regret was significant in both people who did and did not view organ donation as beneficial. Therefore, support was not found for Hypothesis 5.

### **General Discussion**

This study supports literature demonstrating next-of-kin approval is predicted by anticipated regret (Shepherd & O'Carroll, 2014b), the deceased's wishes (Chandler et al., 2017; Kentish-Barnes et al., 2019; Noyes et al., 2019), and next-of-kin's attitudes (Martínez et al., 2008; López et al., 2018a; López et al., 2018b). However, this study further develops this research by empirically testing a model of next-of-kin decision making about organ donation under an opt-out system. When the deceased had registered as a non-donor (opted-out), next-of-kin were unlikely to feel anticipated regret for not donating and thus unlikely to approve of donating their deceased relative's organs. In contrast, when the deceased had not registered a decision (deemed consent), next-of-kin were more likely to feel anticipated regret

and more likely to approve of donating their relative's organs. However, this process only happened when next-of-kin did not hold negative affective attitudes towards organ donation. When next-of-kin held negative affective attitudes, the deceased's decision was less likely to influence anticipated regret or next-of-kin approval of donation. Importantly, given the limited research into approval of donation by next-of-kin in opt-out systems, these novel findings make an important contribution to the understanding of the processes that influence next-of-kin approval of donation.

Although the findings generally supported the hypotheses, there were some exceptions. For example, under deemed consent, it was hypothesized that next-of-kin should be more uncertain about their loved one's wishes. This uncertainty should, in turn, reduce next-of-kin approval. In line with the hypotheses, uncertainty was greater under deemed consent than opt-in. However, uncertainty did not predict next-of-kin approval. Moreover, in contrast to the negative affective attitudes, the processes that influence next-of-kin approval did not vary based on next-of-kin's beliefs about the perceived benefits of organ donation. This suggests that negative affective attitudes may be more influential on these processes than this positive affective attitude.

### **Theoretical Contributions**

Decisions about whether or not to donate a loved one's organs can be based on rationale deliberation, heuristics or emotions (Bellali & Papadatou, 2007; López et al., 2018a). A heuristic that can be used is for relatives to base the decision on their own attitudes towards donation (López et al., 2018b). Importantly, in line with previous research (Martínez et al., 2008), this study found that the deceased's wishes and next-of-kin's attitudes are not independent processes, but instead may interact to determine next-of-kin approval. When people do not hold the negative affective attitudes, they are likely to make a decision based on the deceased's wishes. However, when people have a negative attitude towards donation,

they are less likely to decide based on the deceased's wishes and instead use the heuristic of relying on their own attitudes.

Although stress is likely to determine whether or not heuristic-based processing is used (Starck & Brand, 2012), it is important to note that people may also make a decision based on their emotions (Greene et al., 2001; Haidt, 2001; Loewenstein et al., 2011). Indeed, people are unlikely to support actions that are linked to negative emotional responses, such as disgust (Schnall et al., 2008) and regret (Zeelenberg & Pieters, 2007). The current study demonstrates how emotion-based processes may guide decisions about whether or not to agree to someone's organs being donated. This suggests that in addition to the heuristic based on family and longstanding friend's own beliefs, it is important to also consider how decisions about donating someone's organs may depend on emotions, such as anticipated regret. As such, stress-based emotional processes may influence whether or not rational decision making is used (Starck & Brand, 2012), whilst emotional processes that rely on anticipated regret influence whether or not people agree to the donation of someone's organs.

### **Strengths and Limitations**

A number of previous studies have assessed the factors that influence decision making about organ donation by family members and longstanding friends (e.g., Martínez et al., 2008; Noyes et al., 2019; Shepherd & O'Carroll, 2014b). However, this study builds on this research in a number of important and novel ways. First, an experimental approach was used to assess the effect of the deceased's organ donor status (i.e., opt-in, opt-out or deemed consent) and next-of-kin's affective attitudes on next-of-kin approval in an opt-out system with an opt-in and opt-out register. Second, the analyses tested the role of anticipated regret in mediating the effect of the deceased's organ donor status on next-of-kin approval in opt-out systems. Third, it was demonstrated that negative affective attitudes are more likely to influence next-of-kin approval of donation than perceived benefits.

Despite this, it is also important to consider the limitations of this research. In line with previous research (Shepherd & O'Carroll, 2014b), this study used vignettes to assess next-of-kin approval of donation. The use of these vignettes allowed for a) the deceased's wishes to be experimentally manipulated and b) the assessment of these processes without the potential emotional distress the research could cause if it were to interview families who had recently lost a loved one. However, how people believed they would act when reading the vignette may not always match their behavior in real-life. People underestimate the influence of their emotions on future decisions (Loewenstein, 2005). Moreover, a group of people usually decide whether or not to approve the donation of the deceased's organs. In such situations, although an individual may support donation, there may be disagreement with other family members. This disagreement may prevent family members from agreeing to organ donation (Martínez et al., 2008; Walker et al., 2013), especially when there is anger and aggression in the decision-making process (López et al., 2018a). Given that the vignettes were completed by a single individual, group processes were unlikely to be captured in the current study. The use of vignettes may also partly explain why in this study next-of-kin approval was similar under deemed consent and opt-in, whereas research has suggested family members and longstanding friends are less likely to approve of donation under deemed consent compared to under opt-in (Noyes et al., 2019). Similarly, this may explain why some participants were willing to donate their deceased loved one's organs when they had opted-out. However, it is important to note that the general findings of this research supported previous work undertaken in families who had previously been required to determine whether their loved one's organs could be transplanted (Martínez et al., 2008; Rodrigue et al., 2006). Therefore, although this was a limitation, it is unlikely to influence the overall findings of the research.

Another limitation is that participants were asked to imagine that the deceased had not discussed organ donation with them previously. This ensured different assumptions about this were not being undertaken by participants. As a result, the findings are most applicable to situations in which the deceased has not discussed organ donation. However, this is currently the case with most families in the UK - only 40% of people have let their family know about their organ donation wishes (NHS Blood and Transplant, 2019). Further research is needed to determine the role of these factors when the deceased has discussed their decision to donate. In addition, participants imagined a close loved one had died. As such, this research focuses on the decision-making processes in next-of-kin. Although donation decisions are often undertaken by people close to the deceased (e.g., spouse, parents, siblings, children; López et al., 2018a; Rodrigue et al., 2008), approval of organ donation can also be provided by more distant family and longstanding friends. Given that distant family and longstanding friends can make donation decisions, it is important to consider the factors that influence these decisions. This is especially important given that distant family and longstanding friends may not know the deceased, and their wishes, as well as close family. Therefore, future research needs to test whether the factors assessed in this study (i.e., deceased donor status, affective attitudes, regret and uncertainty) influence decision-making by distant family and longstanding friends.

It is also important to consider the influence of demographic factors. In line with other survey-based research (O'Carroll et al., 2016), there were more females than males in our sample. Importantly, controlling for the participant's gender did not influence the results, suggesting that the unequal number of males and females did not bias our findings. In addition, in this study we did not measure religiosity or ethnicity, which have been found to influence relative's decisions about organ donation (Chandler et al., 2017; López et al., 2018a). The use of randomization ensured religiosity and ethnicity were unlikely to bias the

manipulation. However, further research is needed to determine how religiosity and ethnicity influences the other factors included in this study (i.e., affective attitudes, uncertainty and anticipated regret).

### **Implications**

The findings significantly enhance the understanding of the crucial issue of next-of-kin approval of donation; therefore, it is important to discuss the implications of this research. In most other areas, an advance directive made by an individual could/would not be overruled by family members and longstanding friends after death. However, this can and does happen in organ donation and the findings of this study suggest that although people generally follow the wishes of the deceased, their approval varies depending on their own attitudes towards organ donation. There are clear benefits to having family members and longstanding friends providing input into the donation process. For example, there may be some situations where there are genuine grounds to overrule the registered decision of the deceased, such as when the deceased has changed their mind about donation after they have registered a decision (Shaw et al., 2017). The input of family members and longstanding friends is especially important when consent is presumed (for a discussion, see Shaw, 2017). However, it is important to try and ensure that the deceased's final wishes about organ donation is the main factor driving the next-of-kin's decision.

This study suggests the deceased's wishes influences next-of-kin approval via anticipated regret. However, this indirect effect was unlikely to occur when people believed the negative affective attitudes. Therefore, undertaking large-scale campaigns in the general population to tackle the negative affective attitudes is likely to be effective. Importantly, such campaigns are likely to have several benefits. First, these campaigns may reduce the emotional burden to families and friends by tackling the barriers to approval outside of the organ procurement process (Martínez et al., 2008). Second, given that people's perceptions of



healthcare staff are linked to their emotional reactions (López et al., 2018a), tackling the negative affective attitudes may improve people's perceptions of these staff. Improving the perceptions of staff is likely to increase the likelihood that people will agree to donate the organs of a deceased family member (Kentish-Barnes et al., 2019; Ralph et al., 2014). Finally, affective attitudes influence organ donor registration in both opt-in (Morgan et al., 2008; O'Carroll et al., 2011) and opt-out systems (Miller et al., 2019), and the effectiveness of organ donor registration interventions (Doherty et al., 2017; O'Carroll et al., 2016; for a discussion, see Ferguson et al., 2019). Therefore, effectively targeting these may also improve organ donor registration. Although there may be other factors that prevent the deceased's organs from being transplanted (e.g., organs being deemed as unsuitable), refusal by family members and longstanding friends is a major barrier to donation. Therefore, finding strategies to tackle the negative affective attitudes should increase people's willingness to donate the organs of a deceased family member or longstanding friend, thereby improving organ donation rates.

In addition, it may be important to encourage people to discuss their donation wishes with next-of-kin. Although the current study assessed next-of-kin approval when the deceased had not discussed their wishes, next-of-kin approval is more likely when the deceased has discussed donation as next-of-kin are more confident of the deceased's wishes (Rodrigue et al., 2006, 2008). This confidence should result in people being more likely to anticipate regret for not following the deceased's wishes, thereby increasing the likelihood of the deceased's wishes being the main factor driving next-of-kin decisions.

### **Conclusions**

This study assessed the role of the deceased's wishes, anticipated regret, negative affective attitudes and perceived benefits on next-of-kin approval of donation in an opt-out consent system. Anticipated regret had a significant effect on next-of-kin approval of

donation. Importantly, this process varied based on next-of-kin's negative affective attitudes. This process occurred at low and moderate (but not high) levels of the negative affective attitudes. Based on this, it is important to target the negative affective attitudes that family members and longstanding friends may hold to support the advance directive of the deceased, improve approval of donation and thus increase organ donation rates.

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### Figure Captions

Figure 1. The predicted moderated mediation model demonstrating the role of the deceased's organ donor status on next-of-kin approval via uncertainty and anticipated regret. For simplicity, this model only contains an overall affective attitudes variable. However, in the analyses the negative affective attitudes and perceived benefits were tested as separate moderating variables.

Figure 2. The predicted mediation from deceased donor status to next-of-kin approval via a) uncertainty about the deceased's wishes and b) anticipated regret.

Figure 3. The predicted moderated mediation model demonstrating the moderating effects of a) the negative affective attitudes on the indirect effect via anticipated regret, b) perceived benefits on the indirect effect via anticipated regret, c) the negative affective attitudes on the indirect effect via uncertainty and d) perceived benefits on the indirect effect via uncertainty.

Figure 4. The role of uncertainty and anticipated regret in mediating the effect of deceased donor status on next-of-kin approval of donation.

**Table 1.** Association of condition with demographic and health-based philanthropy. For the association between sex and condition, the chi-squared only contained the male and female categories to avoid the analysis containing frequencies less than 5.

	Condition			Significance
	Deemed consent	Opted-out	Opted-in	
<i>Continuous variable</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	
Age	37.56 (14.31)	37.09 (15.08)	39.06 (14.68)	$F(2, 843) = 1.38, p = .253, \eta_p^2 < .01$
<i>Categorical variables</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	
Sex				
Male	89 (10.50%)	103 (12.15%)	94 (11.08%)	
Female	190 (22.41%)	175 (20.64%)	184 (21.70%)	
Other	2 (0.24%)	2 (0.24%)	0	$\chi^2(2) = 1.68, p = .433, V = .05$
Preferred not to say	2 (0.24%)	4 (0.47%)	3 (0.35%)	
Participant's organ donor registration status				
Opted-in	158 (18.63%)	138 (16.27%)	142 (16.75%)	$\chi^2(4) = 5.07, p = .280, V = .06$

Opted-out	18 (2.12%)	27 (3.18%)	18 (2.12%)	
Deemed consent	107 (12.62%)	119 (14.03%)	121 (14.27%)	
Participant's previous blood donor status				
Not donated	171 (20.17%)	181 (21.34%)	167 (19.69%)	$\chi^2(2) = 1.21, p = .546, V = .04$
Donated	112 (13.21%)	103 (12.15%)	114 (13.44%)	

**Table 2.** Indexes of moderated mediation testing significance of the indirect effect from deceased's donor registration status (deemed consent vs. opted-out) to next-of-kin approval of donation at different levels of a) the negative affective attitudes and b) perceived benefits.

	Index of moderated mediation	Indirect effects at different levels of moderator		
	95% CI	Low	Moderate	High
		95% CI	95% CI	95%CI
Moderating role of negative affective attitudes on indirect effects via anticipated regret	<b>0.02, 0.21</b>	<b>-0.63, -0.25</b>	<b>-0.42, -0.17</b>	-0.28, 0.04
Moderating role of perceived benefits on indirect effects via anticipated regret	-0.12, 0.02	<b>-0.26, -0.01</b>	<b>-0.31, -0.11</b>	<b>-0.45, -0.12</b>

*Note.* Significant results are in bold.

Figure 1

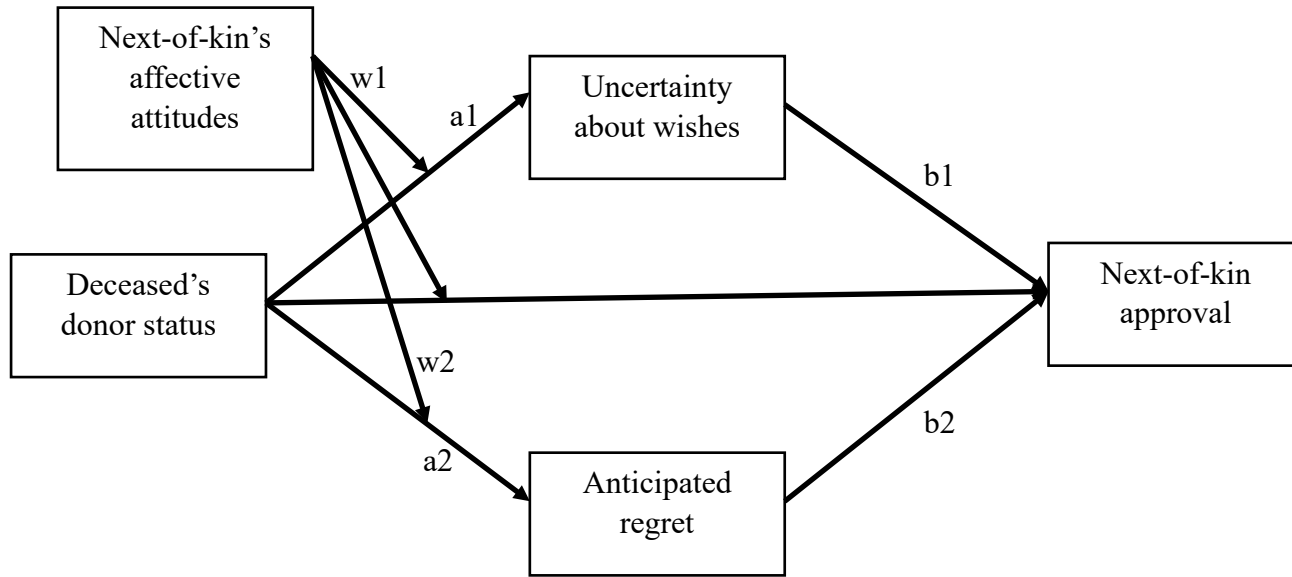


Figure 2

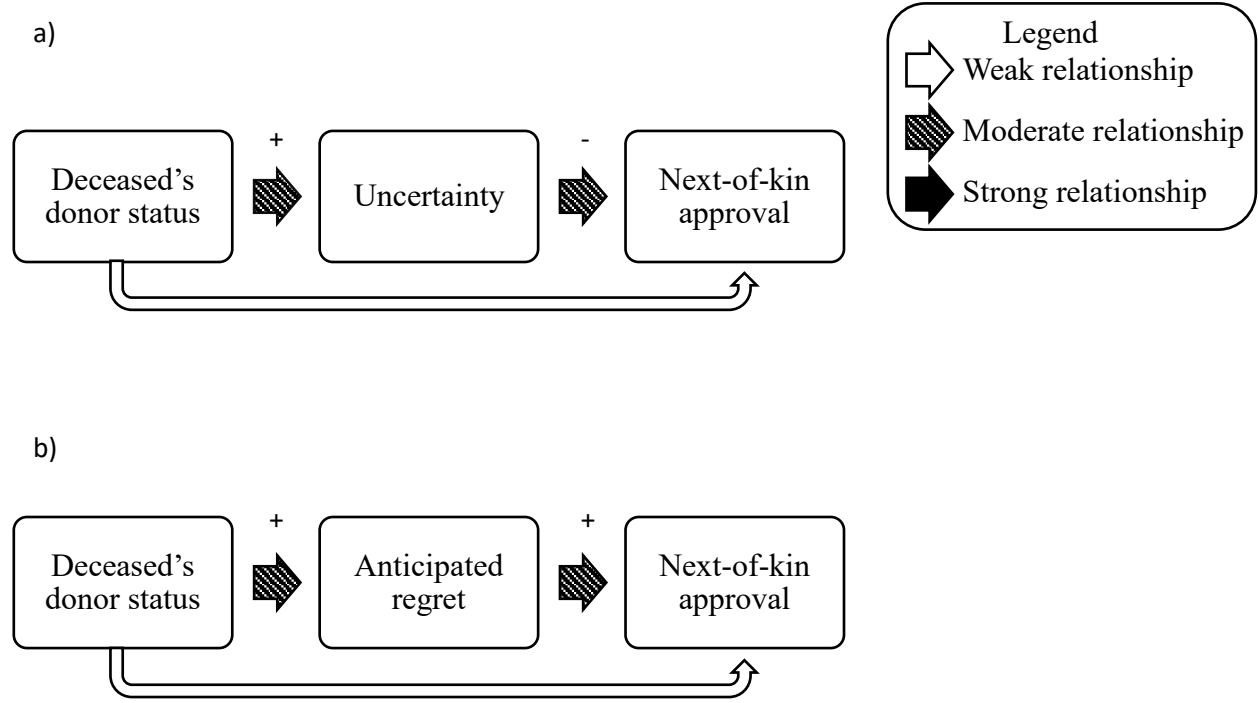


Figure 3

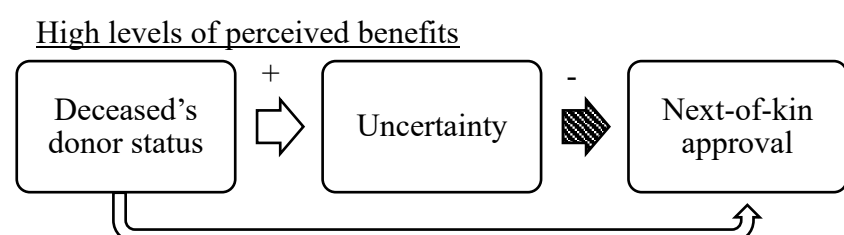
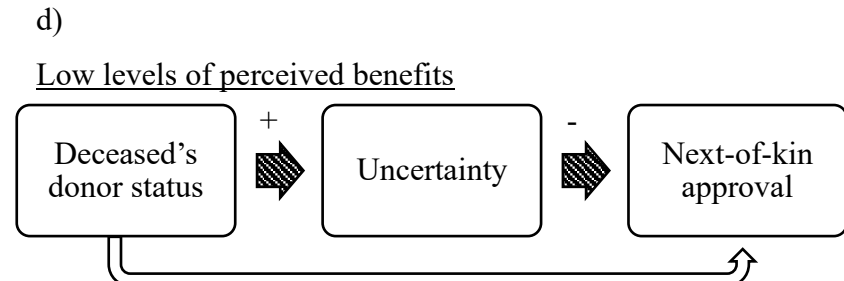
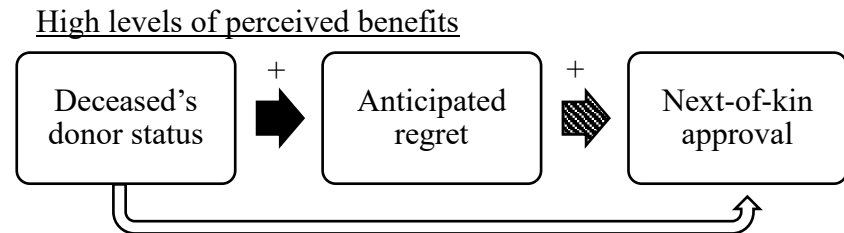
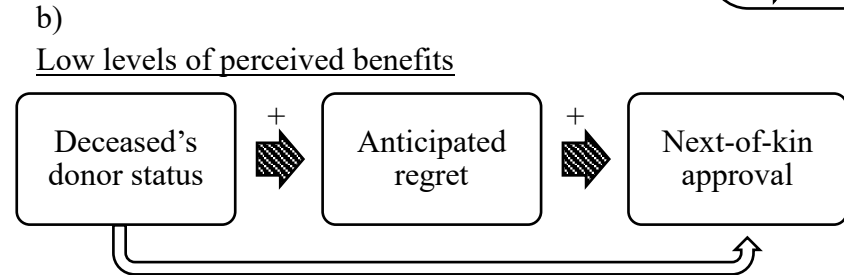
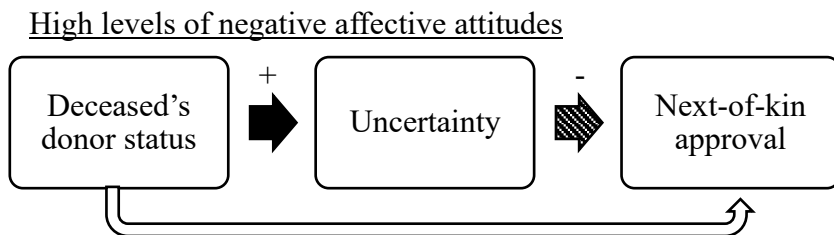
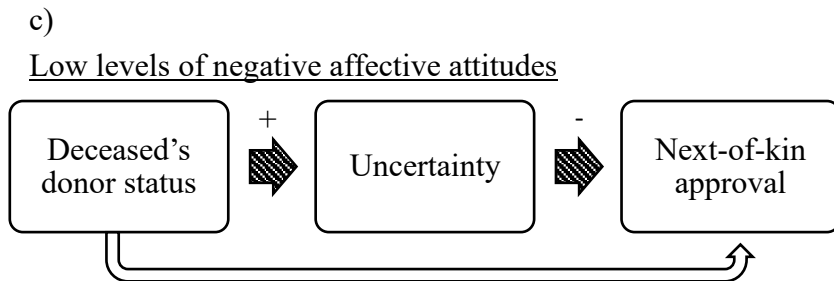
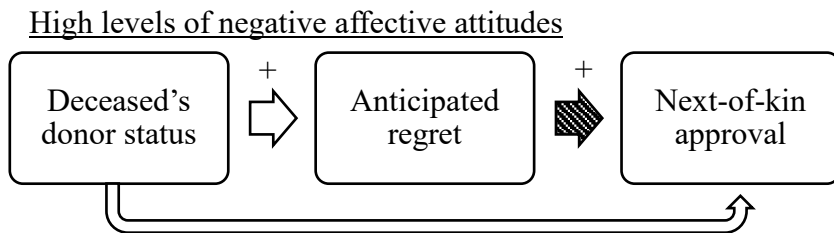
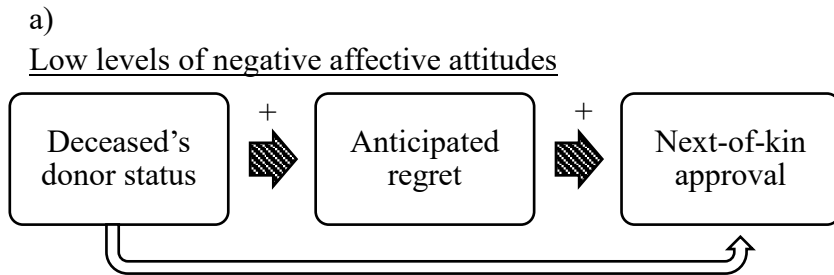
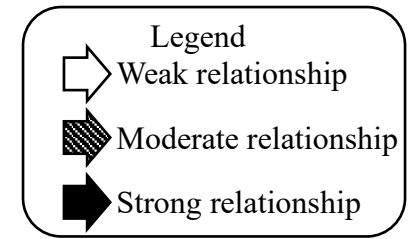


Figure 4

