Australian Perspectives on Opt-In and Opt-Out Consent Systems for Deceased Organ Donation

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**Abstract**

**Introduction:** As many countries change to opt-out systems to address organ shortages, calls for similar reform in Australia persist. Community perspectives on consent systems for donation remain under-researched, therefore Australian perspectives on consent systems and their effectiveness in increasing donation rates were explored.

**Design:** In this descriptive cross-sectional study, participants completed a survey presenting opt-in, soft opt-out, and hard opt-out systems, with corresponding descriptions. Participants chose the system they perceived as most effective and described their reasoning.

**Results:** Participants (N = 509) designated soft opt-out as the most effective system (52.3%; hard opt-out 33.7%; opt-in 13.7%). Those who identified with an ethnic/cultural group or were not registered had greater odds of choosing opt-out. Six themes identified in thematic analysis reflected their reasoning: 1) who decides (individual, shared decision with family); 2) right to choose; 3) acceptability (ethics, fairness); and utility in overcoming barriers for 4) individuals (apathy, awareness, ease of donating, fear/avoidance of death); 5) family (easier family experience, family veto); 6) society (normalising donation, donation as default, expanding donor pool). Choice and overcoming individual barriers were more frequently endorsed themes for opt-in and opt-out, respectively.

**Discussion:** Results suggested the following insights regarding system effectiveness: uphold/prioritise individual's recorded donation decision above family wishes; involve family in decision-making if no donation preference is recorded; retain a register enabling opt-in and opt-out for unequivocal decisions and promoting individual control; and maximise ease of registering. Future research should establish whether systems considered effective are also acceptable to the community to address organ shortages.

**Introduction**

In response to global organ shortages several countries have adopted alternative policy that may increase rates of consent for deceased organ donation.[1] These legislative changes alter the default for donation from a system whereby a person is not considered a donor unless they opt-in (register to donate) to a system where everyone is considered a donor unless they opt-out (register to not donate).[2] Opt-out (presumed) consent systems are further distinguished as soft or hard depending on family involvement in decision-making, with the latter excluding family involvement.[3] However, family authorisation is still sought in most countries regardless of the system.[3-4]

In countries with opt-in systems such as Australia, family authorisation for donation exceeds 90% when an explicit decision for donation is registered, and decreases to approximately 60% without a recorded preference.[5] Proponents of default systems argue that without clear guidance people choose the default option.[6-7] Therefore, family consent rates may increase as families follow the default for donation in opt-out systems and authorise donation.[8] Low rates of registration are also a barrier to consent in opt-in. Accepting a default for donation is a potential solution given it is effortless and requires no action by someone wishing to donate.[6,9] However, opt-out systems are not infallible. If individuals fail to signal their donation preference (e.g., register) this may result in uncertainty and increase family veto in default (opt-out) systems.[10] Thus, while opt-out systems may lessen the gap between individuals' favourable donation attitudes or intentions and their (lack of) action to register their decision, and increase donor registrations,[11] numbers of donors and transplants may not increase.

Soft opt-out legislation increased family consent rates in Wales,[12] and England,[13] yet deceased donor numbers remained unchanged and numbers of living donors declined.[13-14] This pattern was also observed when comparing donation rates across 35 countries with opt-

in or opt-out systems– deceased donor rates did not differ significantly between systems, and living donor rates were lower under opt-out.[2] Thus, changing the system is only one step in what needs to be a broader co-ordinated effort to increase donations.[15]

Given changes to opt-out systems in other countries, calls for similar reform in Australia persist.[16] Although possibilities for reform have been explored,[16-18] there has been little examination of Australian perspectives on implementing an opt-out system.[19] Understanding these perspectives is essential to align policy with community values.[20]

In the few Australian studies identified, support for alternative consent systems appears mixed. Only 59% of residents surveyed favoured presumed consent (opt-out).[8] Favouring this system predicted donation willingness. Residents with higher agreement were older, more highly educated, and with higher income.[8] In contrast, a discrete choice study suggested Australians were receptive to alternative systems.[19] Participants considered 30 scenarios presenting two policy choices for donation, the current system and a hypothetical alternative that varied system attributes (e.g., consent system, family involvement, ease of registering). Participants identified the option the government should introduce. Changes to attributes including type of consent system, level of family involvement, and simplifying registration were favoured. Responses varied by demographic characteristics (e.g., sex, registration status).[19]

A focus group study showed 55% of Australians rated a system that prevents family veto as the second most important factor in deciding to become an organ donor.[21] Approximately 20% ranked opt-out systems as important, although this varied by age.

Collectively, these studies suggest that Australian perspectives on consent systems for donation are under-researched,[19] and perspectives may differ by individual characteristics.[8,19,21] However, studies have not explored participant perspectives on which system would be most useful in increasing donation rates and why, or what underpins

participants' evaluation of effectiveness. None included a simultaneous consideration of three existing systems. Exploring community perspectives in this way offers insights into their understanding about donation systems, how they conceptualise effectiveness, and inform alignment of policy with their values. Thus, our aim was to expand knowledge about Australian perspectives on consent systems by asking residents to choose the system they believed most effective to increase donation and to explain their choice. To ensure that choices were made on the basis of accurate information, a definition of each system was provided to participants before they chose.

## Methods

### *Design*

This descriptive cross-sectional study includes data from free-text responses to an online survey. After University ethics approval (#2019002366), participants provided informed consent through agreement with questions confirming their understanding of study information, topic, and data usage. Data from participants who consented and completed the survey were included.

### *Setting*

Participants were invited to take part via the Prolific online panel or University's School of Psychology Student Participation scheme. Prolific is a crowdsourcing platform used for participant recruitment for online surveys and market research (https://www.prolific.co/). Researchers post studies and participants who have signed up and meet study criteria are notified. Participants are paid for their time. Students in the participation scheme volunteer for research and receive course credit.

### *Population*

Prolific's panel from which community participants were recruited comprises >150,000 participants aged ≥18 years, including approximately 1700 residing throughout

Australia with Australian nationality/citizenship (50% male).[22] The Participation Scheme

from which first-year psychology students were recruited was accessed at one university.

Most first-year students in Australian universities are aged ≤21 years (71%),[23] representing a

target demographic since young Australians are least likely to register their donation

preference.[24]

### Sampling

Eligible community and student participants were aged ≥18 years with Australian

nationality/citizenship. In January 2020, community participants were purposively sampled

via Prolific for approximately equal representation of males and females. From November

2019 to January 2020, first-year psychology students were recruited via convenience

sampling from the Participation Scheme. All participants self-selected into the study by

registering interest and accessing the survey link.

### Data collection

**Participant characteristics.** Participants self-reported their age (years), gender,

ethnic/cultural group identified with, and registration on the Australian Organ Donor

Register.

**Effectiveness of system.** Participants received information about 3 systems, opt-in,

soft opt-out, hard opt-out (**Table 1**) and answered "which of the following systems do you

think would be most effective in increasing organ donation rates in Australia?" by selecting

one system.

**Reasons for effectiveness.** Participants described why their chosen system would be

most effective to increase donation rates using a free-text response.

### Procedure

Participants completed an online survey that presented 3 donation consent systems

with a description of each system. Participants chose the system they believed would be most

effective and then described their reasoning. To conclude, participants reported personal characteristics.

### *Data analysis*

We summarised characteristics for the total sample and by participant type (community, student) using descriptive statistics. Differences in characteristics by participant type were tested with independent groups t-tests or chi-square tests. Participant's system choice for the total sample and by participant characteristics was summarised using descriptive statistics. We used multinomial logistic regression, with opt-in as the reference category, to examine whether characteristics (participant type, age, gender, identification with an ethnic/cultural group) and registration differentiated those who choose soft or hard opt-out from those choosing the current opt-in policy. For all tests, $P<0.05$ indicated statistically significant differences.

We used thematic analysis of free-text responses indicating participant's reasons for choosing a system.[25] Responses were grouped by system choice. One author identified similar responses within each system choice, grouped these, and proposed a preliminary theme structure. A second author reviewed the proposed theme structure and refined this until authors reached agreement. The second author coded data using the revised theme structure. Responses were labelled with system choice, participant type, gender, identification with an ethnic/cultural group, and registration status to compare groups and identify differences in themes. Prevalence of themes and differences across groups were summarised using descriptive statistics. We used z-tests to compare differences in proportions across groups describing each theme. $P<0.05$ indicated statistically significant differences.

## Results

### *Participant characteristics*

In total, 509 participants completed the survey (78.2% community, 20.8% students; mean age 30.11 years, SD=11.23; 49.7% male; 25.4% identified with an ethnic/cultural group). Thirty-four percent had joined the donor register and this matches the national average for registration.[5] Compared to community participants, students were significantly younger in age, more students identified with an ethnic/cultural group, and fewer had registered **(Table 2)**.

### *Effectiveness of system*

Of 509 participants, 52.3% chose soft opt-out as most effective, 33.7% hard opt-out, 13.7% opt-in. Multinomial logistic regression indicated that participants younger in age, who identified with an ethnic/cultural group, and who were not registered had significantly greater odds of choosing soft opt-out than opt-in. Student participants, those identifying with an ethnic/cultural group, and those not registered had significantly greater odds of choosing hard opt-out than opt-in (**Table 3**).

### *Reasons for effectiveness*

We identified 6 themes and 15 sub-themes in responses (*N*=471; 92.5%) outlining reasons for system effectiveness (**Figure 1**). Proportion of themes and sub-themes are displayed in **Figure 2** and **Supplementary Table 1**. Differences in themes by participant characteristics are reported in **Supplementary Table 2**. Exemplar quotes are in **Table 4**.

*1. Who decides?* This theme reflects participants' belief regarding who should be involved in decision-making about donation and includes sub-themes: individual decision only (1.1) and shared decision with family (1.2). 1.1 was identified across all systems, most frequently for hard opt-out, while 1.2 related only to opt-in and soft opt-out.

**1.1.** Participants choosing hard opt-out believed the decision to donate is an individual one and family should not be able to override this decision. Participants choosing opt-in or soft opt-out, suggested an alternative system, hard opt-in, which they believed was ideal because individuals could opt-in and have their choice upheld.

**1.2.** Those choosing opt-in or soft opt-out believed these systems achieved informed consent through shared decision-making between the individual and next-of-kin. In the absence of a recorded decision, family were viewed as a reliable source of information about their loved one's wishes and a back-up or safety net when individuals opposed donation. Further, family had to live with the decision and therefore should contribute to decision-making.

***2. The right to choose.*** Participants considered not only who should make the decision, they also believed people should have a choice. Approximately two-thirds choosing opt-in and one-third choosing soft opt-out emphasised this view. Sub-themes were: having a choice (2.1), and feeling forced (2.2) to donate.

**2.1.** Those choosing opt-in or soft opt-out argued that people have the right to choose donation. These systems supported individual and family free will and control in decision-making, retained individual bodily autonomy, and respected people's beliefs. In contrast, participants choosing hard opt-out argued people still can choose to not donate. Participants choosing hard opt-out believed most were willing to donate yet it protected the rights of individuals strongly against donation.

**2.2.** Participants choosing opt-in or soft opt-out described that, in contrast to hard opt-out, people did not feel forced to donate or that donation would occur against their wishes. Moreover, these systems avoided community backlash, which participants believed hard opt-out would incite.

*3. What is acceptable?* This theme encompasses views on ethical or fair systems, and comprises sub-themes: ethical system (3.1), ethically controversial but effective (3.2), and fairest system (3.3). Registered participants choosing opt-in (vs. not), mentioned theme 3 significantly more frequently. Significantly more participants identifying with an ethnic/cultural group (vs. not) and choosing soft opt-out subscribed to theme 3.

**3.1.** Participants debated the ethical or moral nature of systems. Those choosing opt-in or soft opt-out viewed these systems as most ethical because the chance of improper use of organs, crime and corruption were reduced, and family needs considered.

**3.2.** Participants choosing hard opt-out believed this system was most effective to increase the number of organ donors, however they also acknowledged hard opt-out as unethical and clarified that choosing hard opt-out did not mean they personally supported its implementation in Australia.

**3.3.** Participants choosing opt-in or soft opt-out also considered the fairness of the system. These systems were described as offering more checks and balances and being fairer or reasonable. Soft opt-out particularly was viewed as the middle ground because it struck a balance between increasing donation rates while respecting individual choice and beliefs.

*4. Overcomes individual barriers.* A prominent theme amongst participants choosing opt-out is that these systems overcome individual barriers to donation/registering. However, those choosing soft opt-out who identified with an ethnic/cultural group (vs. not) endorsed theme 4 significantly less. Individual barriers include sub-themes: apathy and lack of awareness (4.1), ease of donating (4.2), and fear/avoidance of death (4.3).

**4.1.** A few participants choosing opt-in believed its effectiveness would increase with greater awareness and promotion of donation. In contrast, approximately half choosing opt-out believed that most people want to donate, yet are lazy, lack awareness, or haven't thought about registering, and opt-out overcomes these barriers. Moreover, participants believed opt-

out would motivate people to make a choice about donation, particularly those against donation.

**4.2.** Participants believed opt-out, but not opt-in, made donation easier by increasing convenience, removing the need for action, and having fewer hoops to go through for donation to occur.

**4.3.** Additionally, some participants viewed opt-out as removing obstacles regarding fear or avoidance of death. Since everyone is automatically considered a donor, opt-out removes the need to think or talk about donation or death.

*5. Overcomes family barriers.* Participants considered the utility of a system in overcoming barriers regarding family consent and this theme is reflected in sub-themes: family experience is easier (5.1) and family cannot veto (5.2). Significantly more registered (vs. not) participants choosing opt-in subscribed to theme 5.

**5.1.** Regardless of system choice, participants believed each would make the experience easier for family. Opt-in provided family with greater clarity about their loved one's wishes since they had made their donation decision explicit by registering. Soft opt-out gave family comfort as they have a say in what happens to loved ones and it is easier to donate since donation is the default choice. Conversely, participants choosing hard opt-out believed family's experience would be easier as they did not have to decide.

**5.2.** This sub-theme was evident only for participants choosing hard opt-out. Participants viewed hard opt-out as effective because it removed family involvement, specifically their option to go against the individual's decision, and subsequently increased donation rates. However, many also acknowledged this approach was not ideal nor widely accepted.

*6. Overcomes societal barriers.* Participants choosing opt-out viewed these systems as overcoming societal-level barriers to donation. However, students (vs. community) choosing

hard opt-out endorsed theme 6 significantly less. Sub-themes included: normalises donation (6.1), donation is the default (6.2), and expanded donor pool (6.3).

**6.1.** Participants believed opt-out systems, particularly soft opt-out, normalised donation and removed stigma by making donation/consent socially acceptable. Although, several participants noted, for opt-out to be successful, a transition period is needed to allow people to adjust. Others believed generational shifts would occur as attitudes towards opt-out became more positive over time. Some participants also viewed soft opt-out as a gateway to future implementation of hard opt-out.

**6.2.** Opt-out systems were viewed as effective because their default is donation and people would be more likely to agree with the default.

**6.3.** Participants believed opt-out systems expanded the donor pool. Most conceptualised this expansion as increased numbers of donors, not increased registration or consent.

## Discussion

Australians reported a preference for soft opt-out as the effective system to increase donation rates. Students, those who were younger in age, identified with an ethnic/cultural group, and were not registered organ donors had greater odds of choosing opt-out (soft and/or hard) than opt-in. These findings align with Australian research reporting similar levels of agreement with presumed consent, that differed by personal characteristics and registration status.[8,19] Participants' reasons for system effectiveness comprised inter-linked themes and sub-themes centering on perceived choice, the role of family, ethics, and utility in overcoming barriers to donation.

Choice was essential to participant's perception of system effectiveness, particularly opt-in and soft opt-out. Participants designated these systems as effective because they included individual and family perspectives and enabled people to make informed decisions

and donate of their own free will instead of feeling forced. Tension between equating free will with opt-in and feeling forced with opt-out, connects with UK research showing that residents planning to opt-out associated opt-in with freedom of choice and opt-out as threatening autonomy.[26]

Other participants considered hard opt-out effective because they believed the decision to donate was personal, and not a family choice. Hard opt-out preserved individual's recorded choice while removing family veto and enabled the choice not to donate if opposed. A systematic review of European countries also noted opt-out was favoured because it preserved individual choice.[27] Family right to veto was a top concern in changing the Australian system[19] or deciding to donate.[21]

However, ethics and acceptability of systems was also a core indicator of system effectiveness. Hard opt-out was generally viewed as unacceptable, controversial and ethically questionable despite its potential to increase donation rates. Participants described likely public backlash against perceived violations of individual and family rights, cultural or religious values, and exploitation of citizens if hard opt-out was implemented. Similar concerns about opt-out were reported in European and UK research including infringement on personal freedoms, government control, compromised body integrity and medical treatment.[26-27] Ethics and fairness of systems were valued by those choosing opt-in, particularly those registered, or soft opt-out, especially those identifying with an ethnic/cultural group.

A prominent concern against opt-out systems, particularly hard opt-out, was family distress if they had no say. Moreover, decision-making was considered burdensome for grieving families, and participants debated system merits in alleviating this burden. Those choosing hard opt-out argued that family did not decide and so the burden was removed. Community perspectives in Wales, Ireland, and Scotland similarly favoured opt-out systems

because they eliminate the burden of decision-making for family.[27] Participants selecting soft opt-out believed family should be involved in decision-making and the default for donation underpinning opt-out provided guidance thus lessening distress. Those considering opt-in effective also preferred family involvement and thought an individual's recorded decision made their wishes clear thus decreasing burden. These findings concur with Australian research whereby participants, although concerned about family veto, prioritised family involvement in decision-making.[19]

An alternative system, hard opt-in, was suggested by some to address concerns about choice, family involvement, and ethics. Participants proposed upholding an individual's recorded choice under opt-in, and consulting family if no decision was recorded. Hard opt-in better captured the balance between supporting individual autonomy and family involvement in decision-making. Isdale and Savulescu[17(p.95)] similarly proposed an individual's explicit "consent-into" donation should be legally upheld, without family veto. This approach concurs with practice in legally upholding end-of-life decisions (advanced directives, wills) despite family objection, and promotes a norm for families to support donation.[17]

A final indicator of effectiveness commonly reported for opt-out systems is their usefulness in overcoming individual barriers to donation. Participants reasoned that most people support donation and would donate yet are lazy or uncertain how to register. Thus, deeming everyone a donor under opt-out removes these barriers. Further, placing the onus on people to opt-out if they object, increased ease and accessibility for willing donors since no action was required. A UK study similarly found that residents supporting deemed consent perceived it as an "effortless choice".[28(p.7)]

**Strengths and limitations**

This study is one of few to examine Australian's perspectives on donation systems, and is unique in focusing on perceived system effectiveness. However, participants chose

between (existing) systems rather than spontaneously generating their own description of an effective system.  Further, they also considered system effectiveness generally, rather than specific aspects of each system,[19] or personal acceptance of a system,[8] thus limiting direct comparisons with prior Australian studies. Further, participant's choice of a system to increase donation rates, was not one they would necessarily support or accept (particularly hard opt-out), suggesting a simultaneous exploration of these aspects is needed. The hard opt-out definition stated that family were not consulted. While it is possible participants interpreted this as family not being informed that donation occurred, comments indicated they understood that hard opt-out removed family veto. None mentioned family not being informed as an issue of concern. Participants received detailed information about systems, however most failed to appreciate that the number of people who die in a way that makes them eligible to donate remains the same. Instead, they believed opt-out systems expanded the donor pool and saved more lives. This knowledge gap should be addressed in public education campaigns occurring alongside policy change.

**Conclusions**

Results provide insights for policy makers, governing authorities, and donation advocates in identifying potential facilitators or barriers to different registry systems. Four main insights are apparent: 1) uphold or prioritise individual's recorded donation decision above family wishes; 2) involve family in decision-making if no donation preference is recorded; 3) retain a register enabling opt-in *and* opt-out so that individual's decisions are unequivocal and feelings of personal control increase;[28] and 4) maximise ease of registering a donation decision. Retaining the option to register when applying for a driver's license in all states/territories (South Australia is the only state with this option) or partnering with organisations to offer additional avenues to register (vehicle registration, phone/internet providers) may be effective. While Australians may consider alternative consent systems for

donation,[8,19] it is unclear whether a system chosen for effectiveness is also acceptable to the community in addressing organ shortages.

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**Table 1**. Information presented to participants about opt-in, soft opt-out, and hard opt-out consent systems for deceased organ donation

| Consent system | Description |
| --- | --- |
| Opt-in | In Australia's current system, organ donation is termed OPT-IN. That is, all adults are considered to be non-donors by default unless they record their decision on the Australian Organ Donor Register as to whether they would like to donate their organs, or not donate their organs, in the event of their death. Where this registration does not occur, then all adults ARE NOT considered an organ donor when they die. In this system, adults are also encouraged to tell their family their decision to donate or not. The families of those who have died are consulted to give consent for donation before an organ donation goes ahead, with the expectation that they will support the deceased person's decision about organ donation. |
| Soft opt-out | You are living in a country with an OPT-OUT SYSTEM of organ donation. In this system, all adults are considered to be an organ donor by default when they die. People are encouraged to record their decision on the Australian Organ Donor Register as to whether they would like to donate their organs in the event of their death, or if they want to opt-out and not be considered an organ donor. However, if people do not opt-out or do not record their decision on the register, then all adults ARE still considered an organ donor when they die anyway. In this system, adults are also encouraged to tell their family their decision to donate or not. For all potential donors, the families of those who have died are consulted to give consent for donation before an organ donation goes ahead, with the expectation that they will support the deceased person's decision about organ donation. |
| Hard opt-out | You are living in a country with an OPT-OUT SYSTEM. In this system, all adults are considered an organ donor when they die by default. People are encouraged to record their decision on the Australian Organ Donor Register as to whether they would like to donate their organs in the event of their death, or if they want to opt-out and not be considered an organ donor. However, if people do not opt-out or do not record their decision on the register, then all adults ARE considered an organ donor when they die anyway. For all potential donors, the families of those who have died are NOT consulted before an organ donation goes ahead. |

**Table 2.** Participant characterics for the total sample and comparisons by participant type

| Characteristic | | Total (N = 509) | Student (N = 106) | Community (N = 398) | Difference statistic ($t$ or $\chi^2$) | $P$ value |
|---|---|---|---|---|---|---|
| | | **Mean (SD)** | **Mean (SD)** | **Mean (SD)** | | |
| Age in years | $M$, SD | 30.11 (11.23) | 21.40 (6.06) | 32.40 (11.15) | $t\,(311.01) = -13.60$ | $P < 0.001$ |
| | Range | 18-82 | 18-55 | 18-82 | | |
| | | **N (%)** | **N (%)** | **N (%)** | | |
| Gender | Male | 253 (49.7%) | 50 (47.2%) | 203 (50.4%) | $\chi^2 = 0.49$ | $P = 0.513$ |
| | Female | 251 (49.3%) | 56 (52.8%) | 195 (48.4%) | | |
| | Other | 5 (1.0%) | - | - | | |
| Identifies with ethnic or cultural group | Yes | 128 (25.4%) | 47 (44.3%) | 81 (20.1%) | $\chi^2 = 26.20$ | $P < 0.001$ |
| System preference | Opt-in | 70 (13.9%) | 19 (17.9%) | 51 (12.7%) | $\chi^2 = 11.89$ | $P = 0.003$ |
| | Soft opt-out | 264 (52.4%) | 66 (62.3%) | 201 (49.9%) | | |
| | Hard opt-out | 170 (33.7%) | 21 (19.8% | 151 (37.5%) | | |
| | No | 376 (74.6%) | 59 (55.7%) | 322 (79.9%) | | |
| Registered on the Australian Organ Donor Register | Yes | 174 (34.2%) | 22 (20.8%) | 152 (37.7%) | $\chi^2 = 10.73$ | $P = 0.001$ |
| | No | 253 (49.7%) | 84 (79.2%) | 251 (62.3%) | | |
| | Unsure | 82 (16.1%) | - | - | | |

**Table 3**. Multinomial logistic regression predicting consent system preference

| | b(SE) | Odds Ratio | 95% CI for Odds Ratio | |
| --- | --- | --- | --- | --- |
| | | | Lower | Upper |
| **Soft opt-out vs. Opt-in** | | | | |
| Intercept | 3.08 (0.64)*** | | | |
| Age in years | -0.35 (.013)** | 0.97 | 0.94 | 0.99 |
| Type (0 student, 1 community) | -0.17 (0.36) | 0.84 | 0.42 | 1.71 |
| Gender (0 male, 1 female) | -0.01 (0.28) | 0.99 | 0.57 | 1.71 |
| Identifies with ethnic or cultural group (0 no, 1 yes) | 0.74 (0.30)* | 2.10 | 1.17 | 3.76 |
| Registered on the Australian Organ Donor Register (0 no, 1 yes) | -1.47 (0.41)*** | 0.23 | 0.10 | 0.51 |
| | | | | |
| **Hard opt-out vs. Opt-in** | | | | |
| Intercept | 2.08 (0.67)** | | | |
| Age in years | -0.02 (0.01) | 0.98 | 0.96 | 1.01 |
| Type (0 student, 1 community) | -0.84 (0.41)* | 0.43 | 0.19 | 0.96 |
| Gender (0 male, 1 female) | 0.45 (0.30) | 1.57 | 0.87 | 2.81 |
| Identifies with ethnic or cultural group (0 no, 1 yes) | 0.80 (0.33)* | 2.23 | 1.18 | 4.21 |
| Registered on the Australian Organ Donor Register (0 no, 1 yes) | -1.53 (0.42)*** | 0.22 | 0.10 | 0.49 |

Note. $R^2 = 0.10$ (Cox & Snell), 0.12 (Nagelkerke). Model $\chi^2$ (10) = 53.13, $p < 0.001$. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

**Table 4.** Themes, sub-themes and exemplar quotes organised by system choice

| Theme | Sub-theme | Exemplar quote |
| --- | --- | --- |
| 1. Who decides? | 1.1 Individual decision only | "Personally, I feel family should not be asked for consent. It is not their choice. And many might try and prevent it from happening because of their personal motives/reasons, regardless what the deceased person wanted. People in grief don't think clearly. When you became an organ donor, I am certain you were of more sound mind." (Hard opt-out)<br><br>"I actually think the better option is not provided. I think it would be better for adults to opt-in and then the families DO NOT get consulted and therefore do NOT have the opportunity to change the decision and whatever the deceased person wanted is what will happen. For example, if a deceased person has indicated on the donor register he/she wants to be an organ donor then the family is NOT consulted, but informed of the deceased person's decision." (Opt-in) |
| | 1.2 Shared decision with family | "I believe your family should also be a reliable source when it comes to consent at the time of your death. Even if you haven't opted in, your family would know you well enough to decide if it's something you would've wanted to do." (Opt-in)<br><br>"I think it is always important to consult family as the decision needs to not impact on their grieving process. However soft opt-out provides more opportunity for donations." (Soft opt-out) |
| 2. The right to choose | 2.1 Having a choice to donate | "I understand how important organ donation is but in the end it is your body and you should be the one who states if you wish to donate organs or not. Just because someone hasn't recorded their option shouldn't give the right to donate their organs without their consent in my view." (Opt-in)<br><br>"I think this will raise the rates of organ donation because everyone will default to being a donor but if they do not feel comfortable registering on the system |

| Theme | Sub-theme | Exemplar quote |
|---|---|---|
| | | they can still talk about it with their family and still have control." (Soft opt-out) |
| | | "If people are truly against organ donation, they will make their wishes known and they will be respected. Their rights aren't being taken away. This option gives us the best chance of more organ donation in Australia." (Hard opt-out) |
| | 2.2 Avoids feeling forced to donate | "The most important concern I have about organ donation is that the donor's bodily autonomy is respected. Under a hard opt-out system, this autonomy is lessened due to the lack of awareness about the Australian Organ Donor Register. In case of an untimely death the donor will have virtually no choice." (Soft opt-out) |
| | | "For some people, organ donation might be a distressing subject. So, when there is an opt-out system, soft or hard, either way, it doesn't give that person the opportunity to not think about it." (Opt-in) |
| | | "I think for most people soft-opt out systems would work best as a hard-opt out system could potentially get negative press and this could create a backlash which leads some to rush out and ensure they have 'opted out'. The fact that it removes the element of choice for families of deceased persons could also lead to conflict with groups whose cultural or religious beliefs discourage organ donation and further create a negative sentiment within society that could create a stigma around the use of donated organs." (Soft opt-out) |
| 3. What is acceptable | 3.1 Ethical decision | "It is the most ethical way to do it. I feel the other systems can leave themselves open to abuse and corruption." (Opt-in) |
| | | "Everyone is considered a donor by default at the time of death, but at the same time, families have the final say whether or not the organs should be donated, |

| Theme | Sub-theme | Exemplar quote |
|---|---|---|
| | | which I think is morally correct compared to the hard opt-out system." (Soft opt-out) |
| | 3.2 Ethically controversial but effective | "As a compulsory system, the hard opt-out system takes away a person's right to own their own person/self upon death. This would be an atrocious system if adopted and I will not support it and will lobby strongly for it to be dropped. However, it is the most effective option that will increase organ donation rates." (Hard opt-out) |
| | | "It would increase the rates of organ donation since people would simply forget and not think about death or what happens to them, and then when they die their organs would be unethically harvested from them without their consent. It is unethical but the most efficient." (Hard opt-out) |
| | 3.3 Fairest system | "This system offers a balance between the two extremes and ultimately would create the chance for many more organ donors with accepting families understanding that the organs are better suited with someone who can still be saved, and gives the option to the people who want to maintain the body for funerals or religious beliefs." (Soft opt-out) |
| 4. Overcomes individual barriers | 4.1 Apathy and lack of awareness | "I believe this system will increase organ donation rates, as in the current system, people have to go out of their way to register, which probably doesn't happen that often. There are probably people who want to donate out there who just don't sign up because they don't know the option is there, or they can't be bothered." (Soft opt-out) |
| | | "In an opt-in system people are typically slow at taking action to formally record their desire to donate organs even though that is their desire. If the situation was reversed, those who opposed it would have no hesitation in recording that they will not donate." (Soft opt-out) |

| Theme | Sub-theme | Exemplar quote |
|---|---|---|
| | | "People who do not wish to undergo something are much more likely to go out of their way to NOT do it, therefore only those who do not want to donate will do so and those who are indifferent will be more likely to be helpful." (Hard opt-out) |
| | 4.2 Fear/avoidance of death | "A lot of people don't even want to think about the possibility of their own death. It scares them too much. However, when dead they would prefer that their organs are used to save someone else's life. But they just don't register or talk to their family members because the topic is too 'morbid'." (Hard opt-out) |
| | | "Not a lot of young healthy people tend to think about it as they don't think about their mortality. And their organs would be the most healthy and in good condition. It's also not on a lot of forms. I'm 23 and only once have I been asked on a legal form." (Soft opt-out) |
| | 4.3 Easier to donate | "For the people that would like to be organ donors but do not understand that they would need to opt in, having a hard opt out organ donation system would mean that they do not have to go to the trouble of opting in. This just makes it more convenient for people to be organ donors while it makes it less convenient for non-donators." (Hard opt-out) |
| 5. Overcomes family barriers | 5.1 Family experience is easier | "The system of opting-in is the most respectful to donors, and gives their families clarity about their wishes. This in turn allows families to have a clear sense of what donors would have wanted, rather than be left with uncertainty, guilt, regret etc. It puts less burden on grieving families this way." (Opt-in) |
| | | "It provides a norm that can be useful to the families of the deceased in deciding whether to approve organ donation, and makes it more likely that the family will have some knowledge of the deceased person's wishes." (Soft opt-out) |

| Theme | Sub-theme | Exemplar quote |
|---|---|---|
| | | "If people feel strongly about it, they can register [to not donate] and it doesn't require grieving families to make complex decisions." (Hard opt-out) |
| | 5.2 Family cannot veto | "This would be most effective as it doesn't allow the grieving family to interfere and greatly increases the number of people registered" (Hard opt-out) |
| | | "I'm not convinced that a 'hard' system is the way to go, but I believe it would improve rates as families would not have to be consulted in time-critical situations, and it also resolves situations where a disagreement amongst family members may lead to organs not being donated." (Hard opt-out) |
| 6. Overcomes societal barriers | 6.1 Normalises donation | "Opt-out will give the impression that it is 'normal' to donate organs, and it may become public view that it is unfavourable to opt-out of organ donation, leading to less people indicating that they do not want to donate." (Soft opt-out) |
| | | "I think Hard opt-out will be best. However, initial implementation e.g. a decade, to start off with Soft opt-out, then transition into Hard opt-out, so people have had the chance to adjust to the new system." (Hard opt-out) |
| | 6.2 Donation is the default | "People tend to agree with the default option presented and I suspect many people would simply agree that the organs be donated unless they had specific religious/cultural objections." (Soft opt-out) |
| | 6.3 Expanded donor pool | "By automatically considering all people as donors unless expressly opted out I would assume that the average number of donors would increase." (Soft opt-out) |
| | | "A hard opt-out system would mean that the vast majority of people who have donatable organs upon their death will be considered donors, so far more donations would be possible." (Hard opt-out) |

**Supplementary Information Table 1.** Proportion of sub-themes endorsed by participants organised by system choice

| No. | Subtheme | Opt-in (N = 58) | Soft opt-out (N = 254) | Hard opt-out (N = 159) |
|-----|----------|-----------------|------------------------|------------------------|
| 1.1 | Individual decision only | 3.40% | 0.08% | 11.90% |
| 1.2 | Shared decision with family | 17.20% | 28.00% | - |
| 2.1 | Having a choice to donate | 58.60% | 20.50% | 9.40% |
| 2.2 | Avoids feeling forced to donate | 25.90% | 12.60% | - |
| 3.1 | Ethical decision | 15.50% | 4.30% | - |
| 3.2 | Ethically controversial but effective | - | - | 19.50% |
| 3.3 | Fairest system | 5.20% | 5.50% | - |
| 4.1 | Apathy and lack of awareness | 6.90% | 40.60% | 48.40% |
| 4.2 | Fear/avoidance of death | 3.40% | 5.50% | 3.80% |
| 4.3 | Easier to donate | 1.70% | 5.10% | 3.80% |
| 5.1 | Family experience is easier | - | 2.80% | 3.80% |
| 5.2 | Family cannot veto | 3.40% | - | 28.80% |
| 6.1 | Normalises donation | - | 7.10% | 4.40% |
| 6.2 | Donation is the default | - | 3.10% | 9.40% |
| 6.3 | Expanded donor pool | - | 17.70% | 10.70% |

**Supplementary Information Table 2.** Themes organised by system choice with comparisons across participant type, gender, identification with an ethnic group, and registration status

| Themes | Opt-in system | | | | | | Soft opt-out system | | | | | | Hard opt-out system | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 1 | 2 | 3 | 4 | 5 | 6 | 1 | 2 | 3 | 4 | 5 | 6 |
| | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) |
| Students [a] | 9.1 | 63.6 | 9.1 | 9.1 | 0.0 | 0.0 | 25.9 | 25.9 | 10.3 | 51.7 | 5.2 | 34.5 | 21.1 | 21.1 | 21.1 | 63.2 | 21.1 | **5.3** |
| Community [b] | 21.3 | 61.7 | 23.4 | 12.8 | 4.3 | 0.0 | 29.1 | 33.2 | 9.7 | 48.5 | 2.0 | 25.0 | 10.7 | 7.9 | 19.3 | 54.3 | 30.0 | **27.1** |
| *p* value | 0.353 | 0.907 | 0.292 | 0.735 | 0.484 | - | 0.635 | 0.293 | 0.893 | 0.669 | 0.189 | 0.153 | 0.190 | 0.065 | 0.853 | 0.464 | 0.422 | **0.038** |
| Males [c] | 13.3 | 56.7 | 23.3 | 10.0 | 0.0 | 0.0 | 27.2 | 30.7 | 12.3 | 45.6 | 2.6 | 28.9 | 9.1 | 5.7 | 21.6 | 54.5 | 23.9 | 26.1 |
| Females [d] | 25.0 | 67.9 | 17.9 | 14.3 | 7.1 | 0.0 | 29.9 | 31.4 | 8.0 | 51.8 | 2.9 | 26.3 | 15.7 | 12.9 | 17.1 | 57.1 | 34.3 | 22.9 |
| *p* value | 0.256 | 0.380 | 0.612 | 0.616 | 0.138 | - | 0.638 | 0.905 | 0.257 | 0.328 | 0.885 | 0.646 | 0.205 | 0.114 | 0.479 | 0.744 | 0.150 | 0.643 |
| Identify with ethnic or cultural group [e] | 20.0 | 63.6 | 10.0 | 9.1 | 0.0 | 0.0 | 23.4 | 27.9 | **15.6** | **37.7** | 3.1 | 29.7 | 14.7 | 15.2 | 23.5 | 60.6 | 32.4 | 20.6 |
| Do not identify with ethnic or cultural group [f] | 12.5 | 61.1 | 22.5 | 13.9 | 5.0 | 0.0 | 28.1 | 32.6 | **7.4** | **52.8** | 2.5 | 24.6 | 10.1 | 7.9 | 16.7 | 54.0 | 25.4 | 23.2 |
| *p* value | 0.394 | 0.831 | 0.170 | 0.539 | 0.214 | - | 0.460 | 0.480 | **0.049** | **0.035** | 0.794 | 0.416 | 0.443 | 0.190 | 0.356 | 0.488 | 0.409 | 0.746 |
| Registered [g] | 20.0 | 40.0 | **60.0** | 20.0 | **20.0** | 0.0 | 30.9 | 34.0 | 8.5 | 51.1 | 3.2 | 21.3 | 14.5 | 11.3 | 12.9 | 50.0 | 25.8 | 32.3 |
| Not registered [h] | 18.9 | 64.2 | **17.0** | 11.3 | **1.9** | 0.0 | 26.9 | 30.0 | 10.6 | 48.1 | 2.5 | 30.6 | 10.3 | 8.2 | 23.7 | 58.8 | 30.9 | 19.6 |

| Themes | Opt-in system | | | | | | Soft opt-out system | | | | | | Hard opt-out system | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 1 | 2 | 3 | 4 | 5 | 6 | 1 | 2 | 3 | 4 | 5 | 6 |
| | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) | (%) |
| *p* value | 0.952 | 0.286 | **0.023** | 0.568 | **0.034** | - | 0.495 | 0.508 | 0.587 | 0.644 | 0.742 | 0.108 | 0.426 | 0.514 | 0.094 | 0.276 | 0.489 | 0.070 |

[a] Student: Total n = 88, Opt-in n = 11, Soft opt-out n = 58, Hard opt-out n = 19.
[b] Community: Total n = 383, Opt-in n = 47, Soft opt-out n = 196, Hard opt-out n = 140.
[c] Male: Total n =232, Opt-in n = 30, Soft opt-out n = 114, Hard opt-out n = 88.
[d] Female: All n = 235, Opt-in n = 28, Soft opt-out n = 137, Hard opt-out n = 70.
[e] Identify ethnic group (yes): Total n = 128, Opt-in n = 30, Soft opt-out n = 64, Hard opt-out n = 34.
[f] Do not identify ethnic group (no): Total n = 381, Opt-in n = 40, Soft opt-out n = 203, Hard opt-out n = 138.
[g] Registered Total n = 161, Opt-in n = 5, Soft opt-out n = 94, Hard opt-out n = 62.
[h] Not registered Total n = 310, Opt-in n = 53, Soft opt-out n = 160, Hard opt-out n = 97.
*Note.* Participants mentioned multiple themes and sub-themes therefore percentages may total to more than 100%.
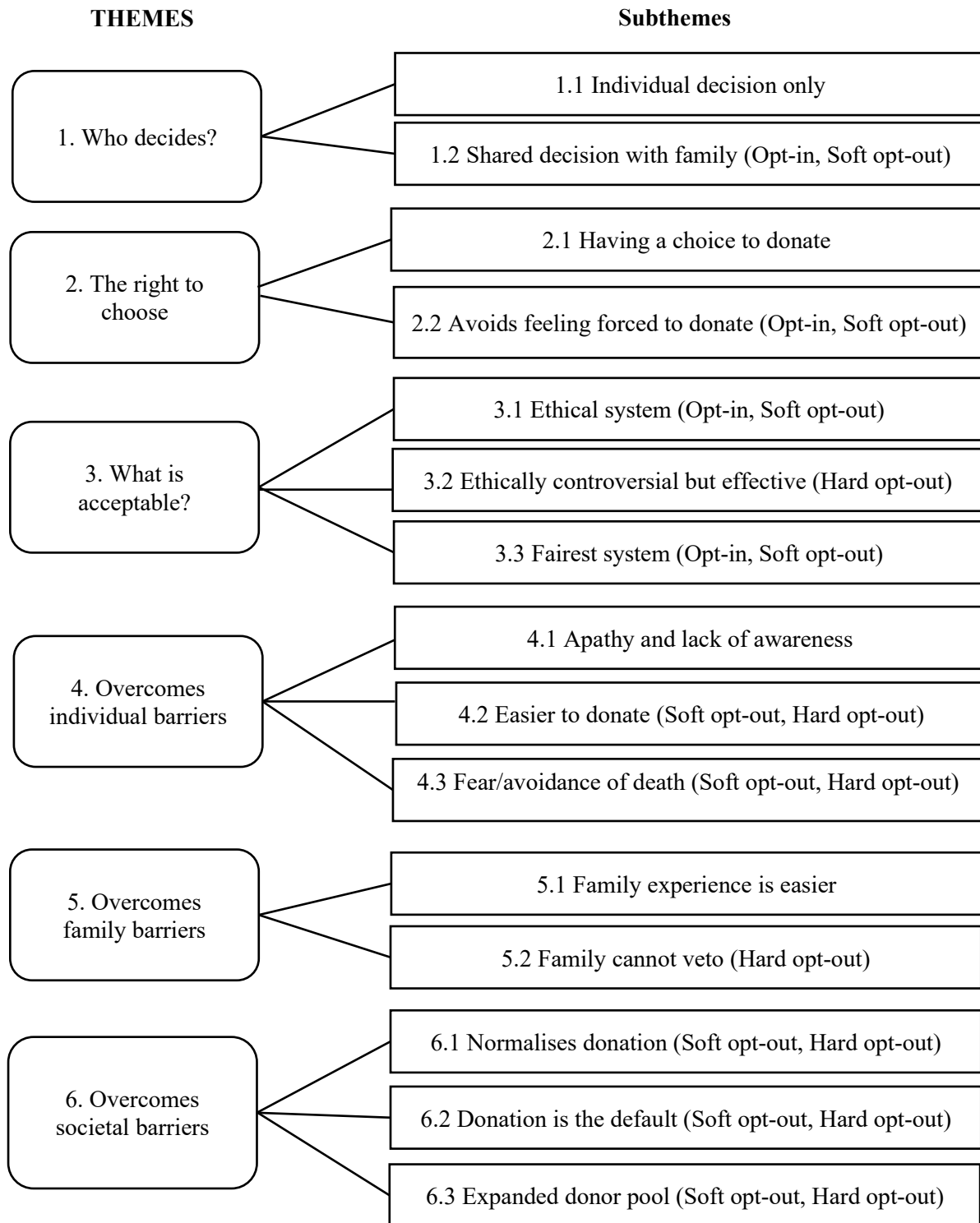
| THEMES | Subthemes |
|---|---|

**1. Who decides?**
- 1.1 Individual decision only
- 1.2 Shared decision with family (Opt-in, Soft opt-out)

**2. The right to choose**
- 2.1 Having a choice to donate
- 2.2 Avoids feeling forced to donate (Opt-in, Soft opt-out)

**3. What is acceptable?**
- 3.1 Ethical system (Opt-in, Soft opt-out)
- 3.2 Ethically controversial but effective (Hard opt-out)
- 3.3 Fairest system (Opt-in, Soft opt-out)

**4. Overcomes individual barriers**
- 4.1 Apathy and lack of awareness
- 4.2 Easier to donate (Soft opt-out, Hard opt-out)
- 4.3 Fear/avoidance of death (Soft opt-out, Hard opt-out)

**5. Overcomes family barriers**
- 5.1 Family experience is easier
- 5.2 Family cannot veto (Hard opt-out)

**6. Overcomes societal barriers**
- 6.1 Normalises donation (Soft opt-out, Hard opt-out)
- 6.2 Donation is the default (Soft opt-out, Hard opt-out)
- 6.3 Expanded donor pool (Soft opt-out, Hard opt-out)

**Figure 1.** Structure for themes and subthemes organised by opt-in, soft opt-out, and hard opt-out systems.

**Figure 2.** Proportion of themes endorsed by participants organised by their system choice