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Published in:
Transplant International

DOI:
[10.1111/tri.12307](https://doi.org/10.1111/tri.12307)

Published: 01/06/2014

Document Version
Peer reviewed version

[Link to publication](#)

Citation for published version (APA):

Irving, M., Jan, S., Tong, A., Wong, G., Craig, J., Chadban, S., Rose, J., Cass, A., Allen, R., & Howard, K. (2014). What factors influence people's decisions to register for organ donation? the results of a nominal group study. *Transplant International*, 27(6), 617-624. <https://doi.org/10.1111/tri.12307>

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"This is the peer reviewed version of the following article: Irving, M. J., Jan, S., Tong, A., Wong, G., Craig, J. C., Chadban, S., Rose, J., Cass, A., Allen, R. D. and Howard, K. (2014), What factors influence people's decisions to register for organ donation? The results of a nominal group study. *Transpl Int*, 27: 617–624., which has been published in final form at <http://dx.doi.org/10.1111/tri.12307>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving."

Received Date : 16-Dec-2013
Revised Date : 08-Jan-2014
Accepted Date : 05-Mar-2014
Article type : Original Article

What factors influence people's decisions to register for organ donation? The results of a nominal group study

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This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/tri.12307

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Support and financial disclosure declaration: This project is supported by the Australian Research Council (ARC) Discovery Project Grant DP 0985187. The study funder had no role in study design; collection, analysis, and interpretation of data; writing the report; and the decision to submit the report for publication. AT is supported by a NHMRC Research Fellowship (ID1037162) AC is supported by a National Health and Medical Research Council Principal Research Fellowship. SJ is supported by an NHMRC Senior Research Fellowship.

Financial conflict of interest

None

Abstract

Introduction: Rates of transplantation from deceased donors remain low, despite high rates of expressed support. We aimed to better understand this mismatch through determining community attitudes regarding willingness to register as organ donors.

Methods: Participants were recruited from the general public in four Australian states. Using nominal group techniques, participants ranked factors they believed were important when deciding to register as a deceased donor. **Results:** Thirteen nominal groups with 114 participants were conducted. 24 factors were ranked by three or more groups. The top ten factors were: saving lives, own decision to donate, family opinions, benefit to recipients, process of organ donation, positive media, positive closure, clarity of consent and body dignity. Other factors included: the

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consent system, religious and cultural beliefs and incentives for donation. Participant age was a potential modifier of responses.

Conclusion: Willingness to register as an organ donor is highly influenced by the altruistic motive of saving lives and improving lives for others, this should be harnessed in communication campaigns. Further research on ethical incentives for organ donation and continued efforts to promote support from religious groups, may be useful. Many believe the sole right to consent to donation is theirs and not their families, consent policies reflecting this should be explored.

Introduction

Continued efforts are being made to increase the availability of deceased donor organs for transplantation, to meet the high demand for those on the waiting lists, through publically funded campaigns, such as 'Donate life' and 'United network for organ sharing'.^[1-3] But there still remains a mismatch between supply and demand for donated organs, with nearly 120 000 currently waiting for a transplant in the United States, over 7 000 in the UK and over 1000 waiting for a kidney transplant in Australia.^[4-6] Recently studies have found that altruism, the ability to save lives, body wholeness and dignity, fear of medical neglect, family attitudes and religion of the potential donor, grief and fear from the donor family, all influence attitudes to organ donation.^[7, 8] However, the relative importance of these factors in the decision making process, to be willing to be a donor after death, have not been assessed. This is important in assigning relative priority to the range of programs that can be implemented in this area. Currently in Australia, nearly 6 million individuals have signed an online legal consent registration for organ and tissue donation; this constitutes approximately 30% of the population.^[9] Increasing this willingness to donate both in Australia and internationally is of paramount importance.

The nominal group technique has been used previously to evaluate priorities for health services, policies and research in relation to choices for cancer treatments and setting priorities in other health settings.^[10, 11] The technique is based on consensus development methods in which participants spend time discussing required topic as a group and then rank discussed factors in order of importance to the individual. It uses a quantitative approach to data analysis within a qualitative research framework.^[12] It is a technique that uses group deliberation and discussion and therefore potentially minimises responses based on misunderstanding of the subject matter and allows more considered responses to questions, making it highly suited to the subject matter of organ donation.

The aim of this study was to determine the relative importance of individual factors considered by members of the general public that influence their willingness to register as an organ donor after death.

Materials and methods

Participant selection

All participants were recruited by market research companies in four states in Australia including New South Wales, Victoria, South Australia and Queensland. Participants were eligible if they were English speaking, 18–80 years of age and able to give informed consent. Participants were purposively sampled to achieve gender balance, a range of cultural backgrounds, and a varied representation of initial views on organ donation (based on a simple question of “on a scale of 1 to 10, how would you rate your attitude to organ donation with 1 being completely disagree and 10 being completely agree”). Participants were reimbursed for their time and transport expenses. Ethics approval was obtained from the University of Sydney Human

Research Ethics committee. All participants gave their informed consent prior to their inclusion in the study.

Data collection

Each two hour nominal group was conducted in three stages: 1) preliminary questions and prompts about the participants' general thoughts and attitudes to organ donation; 2) a group discussion around the factors that would influence each participant's decision to be an organ donor, with each respondent being asked to nominate their top 5 factors. The facilitator (AT or MI) generated a comprehensive list of all factors identified by the group, supplemented with additional factors identified from the literature^[8]; and 3) The list of factors were displayed on a whiteboard and a printed copy was provided for the participants who were then asked to individually rank all the factors in order of how important that factor was for them in their decision to register as an organ donor, starting from 1 as the most important, 2 as the second most important and so on. All sessions were digitally audio-recorded and transcribed verbatim, with qualitative data being reported separately.^[7]

Nominal Group Ranking

The rankings of individual respondents' were used to calculate a summary mean importance score for each factor, using methods applied in previous nominal group studies.^[13-17] Firstly, a ranking for each factor was calculated for each participant: the highest ranked factor for each respondent was given a value of 10, the next most important given 9, and so on. If a factor was not ranked in the 10 most important it was assigned a value of 0. Secondly, a mean importance score for each factor across all groups was calculated by summing the individual ranking scores and dividing this by the maximum possible summed ranking score for that item. The

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maximum possible summed ranking score for a given factor was calculated by multiplying the number of participants who considered the outcome by 10 (the maximum rank score). For example, if all participants ranked a factor as the most important, the mean importance score would be 100%; a score of 0% meant that all participants who ranked that outcome did not score it in the top 10 most important factors. Mean importance scores and the number of times a factor was reported in the top 10 were calculated for all participants' responses. Differences in mean importance scores across age groups and state of residence were assessed using analysis of variance (ANOVA).

Results

Thirteen nominal groups were conducted from May to August 2010 around Australia. Groups consisted of between seven to ten participants in the following cities: Sydney (4 groups), Melbourne (3 groups), Brisbane (3 groups) and Adelaide (3 groups). Participants were placed in age groups, to encourage open discussion: 18-25 years (4 groups conducted), 26-49 years (5 groups conducted) and 50 years and over (4 groups conducted). Each nominal group lasted 2 hours and was facilitated by one of the authors (AT or MI). Participant characteristics are provided in Table 1.

Forty three (38%) participants reported they were from various non-English speaking backgrounds. Of the 114 participants, 110 (96%) provided attitudinal scores at recruitment. Twenty (18%) participants rated their attitude to organ donation as 'negative' (between one and four), 27(25%) rated themselves as 'neutral' (between five and six) and 63 (57%) rated themselves as generally positive (between seven and ten), as per purposive sampling methods.

Nominal Group Rankings

A total of 24 factors were nominated for ranking by at least 3 of the 13 focus groups.

The factors were given an overall ranking based on the mean importance score.

Factors are presented and analysed if they were ranked by at least three groups.

(Figure 1) Mean importance scores were analysed for differences in responses

between age groups and factors were placed into categories relating to: 1)

Outcomes -Perceived outcomes of kidney transplant recipients, 2) *Policy* -policies

that underpin the legislation and guidelines for organ and tissue donation, 3)

Education-knowledge and information and 4) *Attitudes*-beliefs regarding organ

donation, in an effort to facilitate policy and practice implications. (Table 2)

The ten highest ranked factors as important in influencing the decision to register as

an organ donor include: 1) Saving lives - The ability to save lives through the act of

donation, 2) Own decision – having sovereignty over their decision to donate without

the possibility of it being overruled in particular by other family members, 3)

Improving quality of life – the ability to improve the quality of life for the recipients

through their act of donation. 4) Family opinions/implications – What were their

families views on organ donation? Would donation make their death more difficult for

their family? 5) Better understanding benefit to recipient – Knowing and

understanding the benefits of organ donation for the recipient; was the potential gain

for the recipient worth it? 6) Better understanding of organ donation process – how

were organs procured, how did they get the recipient? 7) Media/awareness –

Learning through media and awareness campaigns that included positive recipient

stories and dispel myths about organ donation, 8) Positive closure – organ donation

was seen as a ‘good note to go out on’, culturally it was deemed as giving back to

the community, a parting gift. 9) Clarity of consent – if one did register as an organ

donor would their organs go to a recipient or could it be used as research? 10) Body

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dignity – How would their body be treated during the donation process, would it be treated with dignity?

Other factors ranked included factors pertaining to the consent system for organ donation and suggestions for alternate consent systems, religious and cultural beliefs associated with organ donation, including the importance of positive messages from religious groups regarding organ donation and the use of incentives to encourage organ donation, including direct and indirect incentives and acknowledgements.

There was significant heterogeneity by age groups in relation to the mean importance score for some factors (Table 2). The mean importance of having a compulsory choice consent system (where everyone is forced to choose and register a donation decision), whilst ranked low, was significantly higher for 26-49 year olds, compared to younger respondents ($p=0.049$); similarly having an opt-out consent system, where everyone is assumed to be a donor unless they explicitly register their opposition, was also more important for respondents aged 26-49 compared to both younger ($p=0.039$) and older ($p=0.003$) respondents. Younger participants rated religious and cultural beliefs (including importance of positive message from religious leaders) higher than the other age groups ($p=0.04$). In addition, participants aged over 50 years considered indirect incentives such as reimbursement of funeral expenses to be more important than respondents aged 18-25 years ($p=0.05$). State of residence did not significantly influence the importance score of the factors identified.

Discussion

When considering whether to become an organ donor the members of general community regarded altruistic influences as the most important factors in the donation decision. They were most influenced by the ability to save and improve lives through donation, but they wanted sovereignty in their decision to donate. System changes discussed included: Additional clarity about the benefits of organ donation for the recipients and the process by which donation occurred, perhaps to confirm their beliefs that they were in fact impacting recipient's lives through their donation. They indicated that they would be influenced by positive media stories, including positive recipient stories regarding donation, and education to dispel common organ donation myths. Some believed that alternative donation consent systems, such as an opt-out system, or a compulsory choice system were appropriate, and others were quite willing to consider the availability of financial compensations such as reimbursement of funeral costs.

Altruism is in fact one of the driving forces as a motivator for donation. The community overwhelmingly values these aspects as the most important factors in deciding to be a donor. Given that five of the top ten factors pertained to altruistic influences or the call for further education to assist in confirming the altruistic benefits of organ donation for the individual indicate that future effective recruitment campaigns should be geared toward appealing to individuals' sense of altruism by highlighting the implications for survival and quality of life for those who do and do not receive a transplant. Further research into how best this concept could be communicated with the general community and minority community groups could be undertaken.

Consent systems for organ donation currently differ internationally and remain controversial. It is current policy in Australia that objections to donation by the family are to be upheld even when in conflict with the known intentions of the potential donor.^[18] This study suggests that changes to the model that gives individuals sovereignty over donation choices would be closer in-step with community values. Participants ranked sovereignty over decision as the second highest factor in importance in the decision to register as an organ donor. Whilst strictly speaking this is not a factor affecting their decision, but rather it reflects their conviction that their decision, once made, should not be vetoed by family members. At first glance, this might seem to be contradicted by the high regard individuals placed on the input of family members (ranked 4th). There is, however, a distinction - the first is based on perceived infringement of individuals' rights - where individuals have lost the control over their ability to undertake the final consent of the donation of their organs; the second is simply a valuing of the opinions of other family members in making this decision and is consistent with individuals' maintaining ultimate rights to determining the fate of their organs. For example, an individual may consult with their family in weighting the decisional factors for donation, but as seen in this study, hold convictions that their decision be upheld should the opportunity arise. How this would be translated to policy is not simple either.

A 'compulsory choice' or 'opt-out' system was ranked 16th and 17th respectively by the groups, but was ranked higher by the 26-49 year age group than the other age groups. Models such as these have been used successfully, to some degree internationally, but remains unsuccessful in other contexts.^[19, 20] and recently the Welsh Government introduced a 'soft' opt-out system to come into effect in 2015.^[21] Although, current literature suggests that there are conflicting views on the impact of these models, ranging from 'sizable effect on donation rates^[22] to 'unlikely to explain variation in donation rates'.^[23] In light of this further research into the feasibility and

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acceptability of alternative consent systems such as these should continue to be undertaken. Whatever model is chosen, participants in this study strongly suggest that the consent system has an easily accessible singular entry point, is simple and clearly states the differences between consent for donation and research.

Incentives for organ donation continues to be debated and was highlighted in this study with older respondents (>50 years) were more likely to rank indirect incentives higher than the other age groups. Perhaps, this age group may have experienced the real costs of funeral expenses for a loved one and would find payment of funeral expenses for organ donors as appealing. There are varying views on incentives for organ donation in the community and the medical literature. Some, believe that altruism should be the only motivator for deceased organ donation, whilst others believe that ethical incentives have a place in the organ donation process.^[24, 25]

Studies of the impact of incentives for organ donation provide varying and conflicting recommendations, ranging from 'no impact'^[26] to a decrease in donation rates.^[27]

The offer of incentives also raises the issue of ethics and commercialisation in organ donation for some. Would incentive render the human body a commodity, leaving it open to market forces? Does monetary reward invalidate the altruistic benefits of donation?^[28, 29] In comparing the values associated with 'volunteerism' and organ donation, studies show 'volunteerism' have a high correlation with altruism, but also a high correlation with image or social reputation, of being seen to be pro-social. It is thought that extrinsic incentives may diminish this altruistic motivation for volunteers.^[29, 30] This too may hold true for organ donation, with some reporting a diminished, even tarnished social standing when accepting monetary compensation for organ donation.^[31] There is some agreement, though, that indirect incentives such as funeral expenses, donation to a charity and donor recognition are seen as

ethically acceptable 'incentives' to organ donation.^[24, 32] With some of these strategies slowly becoming policy, recently in the United Kingdom, the Nuffield Council for Bioethics recommended exploration of interventions, such as reimbursement of funeral expenses, to promote donation.^[33] The role of incentives in organ donation should continue to be evaluated and assessed in practice, especially the use of indirect incentives.

The role and impact of religion on organ donation was shown here to have an effect on decision making. Religious and cultural beliefs was ranked 15th overall, but was ranked significantly higher by the younger age group (18-25years). This younger age group may be looking for education and confirmation from their religious leaders that organ donation is supported. Previous studies have found that people opposing organ donation on religious grounds also had lower knowledge regarding organ donation.^[34] This request for knowledge from the younger participants regarding religious support could be reflected in continued organ donation education campaigns to this age group especially as all major religions support organ donation.^[35]

This study has a number of strengths; we included participants who had varying views on organ donation and were from varying cultural backgrounds. Although all the participants were English-speaking, a proportion (38%) reported also speaking another language at home. This is comparable to the 39% of Australians who nominate their ancestry as being outside of English speaking countries.^[36, 37]

Members of the general public tend to hold a complex range of personal views that influence their decision to become an organ donor. Altruism provides the greatest

motivator for organ donation. Continued efforts in communicating the altruistic benefits of donation through the discussion of potential recipient benefits, as well the implications for quality of life and survival for those who do not receive a transplant should be undertaken. Including information on the organ donation process itself may also be of benefit in education campaigns. Although overall support for organ donation was fairly consistent across age groups, the reasons for such support / opposition varied. As such differing communication strategies are needed to target the specific needs of the different age groups . Support from religious groups for organ donation is imperative. Further research is needed in the area of ethical incentives for organ donation. In terms of policy implications our study suggests that the community have a preference for a consent model whereby their personal decisions regarding organ donation are upheld and not overruled by family members.

Table 1: Demographics of respondents involved in the nominal groups

Characteristic	18-25 years n =34	26-49 years n =42	50 years + n =38	Total n =114
Age, years (Mean) (SD, range)				40.13 (16.7, 18-75)
Sex (n, %)				
Male	15 (44%)	21 (50%)	20 (53%)	56 (49%)
Female	19 (56%)	21 (50%)	18 (47%)	58 (51%)
Speaks other language at home (n, %)	17 (50%)	19 (45%)	14 (37%)	50 (44%)
Attitude towards organ donation* (n)	32	41	37	110
Mean rank (SD)	7.38 (2.18)	6.68 (2.59)	6.76 (2.73)	6.91 (2.52)
Negative (1-4) n(%)	3 (9)	7 (17)	10 (27)	20 (18)
Neutral (5-6) n(%)	7 (22)	13 (32)	7 (19)	27 (25)
Positive (7-10)n(%)	22(69)	21(51)	20(54)	63(57)

*Self-reported scale of 1 being definitely disagree to 10 being definitely agree with organ donation as a concept

Table 2: Factors important to respondents in considering whether to become an organ donor

					All	18- 25	26- 49	50 +	p ¹
Transplant recipient outcomes – altruistic influences									
1	Saving lives	13	114 (100.0)	96.5	83.4	80.9	89.5	78 .9	0.11
3	Improving quality of life	9	83 (72.9)	84.33	51.3	40.4	58.5	54 .3	0.11
Organ donation policies and system									
2	Own decision - families cannot overrule decision	13	114 (100.0)	87.72	54.5	46.8	53.1	62 .9	0.14
9	Clarity of consent –research vs transplant	13	114 (100.0)	51.810	27.2	26.8	27.9	26 .8	0.98
16	Consent - compulsory choice system -	12	107 (93.9)	46.7	19.5	12.9	29.4	16 .3	0.04
17	Consent - opt out system	13	114 (100.0)	46.5	19.0	14.7	30.7	10 .0	0.00 3
18	Consent – single, simple, easily accessible	11	98 (86.0)	56.1	18.3	24.7	13.8	16 .0	0.19
20	Hospital staff approach: who and how	10	85 (74.6)	45.9	15.5	9.6	15.3	21 .1	0.20
22	Incentives - indirect financial eg reimbursement of funeral expenses, donation to charity, reduced health insurance premiums	9	79 (69.3)	32.9	13.2	7.3	11.4	25 .0	0.05
23	Acknowledgement / thank you to donor	6	53 (46.5)	35.8	10.8	7.8	14.4	7 .0	0.47
24	Incentives - direct payment to family	5	43 (37.7)	44.2	7.4	12.0	6.7	5 .6	0.48
Knowledge and information									
5	Better understanding benefit to recipient(s)	3	24 (21.1)	79.24	42.5	40.0	43.5	-	0.81
6	Better understanding of process of taking organs & how they get to recipient	10	90 (78.9)	67.88	36.9	35.4	40.9	33 .7	0.68
7	Positive media, awareness, education, dispel myths, positive recipient stories	12	107 (93.9)	69.26	34.1	24.1	39.4	38 .2	0.09
12	Having a broad understanding of the allocation process	3	28 (24.6)	50.0	23.2	27.8	24.4	18 .0	0.79
14	Concerns over quality of own organs	8	75 (65.8)	42.7	21.1	16.3	18.1	26 .7	0.36
Beliefs / issues									
4	Family opinion / implications	10	91 (79.8)	68.17	44.3	49.1	30.0	51 .7	0.05
8	Positive closure, 'good note to go out on'	5	45 (39.5)	75.65	30.0	38.9	28.6	22 .5	0.21
10	Body dignity	12	104(91.2)	59.69	26.9	26.8	32.6	18 .6	0.15
11	Choice over recipient, specifically priority for own family	12	105 (92.1)	49.5	26.5	30.0	26.0	24 .7	0.83
13	Reciprocity -if willing to accept organ then should be willing to donate	10	91 (79.8)	48.4	22.3	27.4	23.0	16 .0	0.30
15	Religious & cultural beliefs (including the importance of positive message from religions)	13	114 (100.0)	41.2	21.0	32.4	18.6	13 .4	0.04
19	Previous personal experience	12	104 (91.2)	45.2	18.2	23.2	17.8	13 .9	0.41

¹rank based on mean importance score, for factors identified by 3 or more groups; ¹ p-value for analysis of variance (ANOVA), 2df

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Acknowledgement:

The results presented in this paper have not been published previously in whole or part, except in abstract form.

Figure 1: Mean importance scores for factors associated with the decision to be willing to be an organ donor (identified by 3 or more groups)

