






ORIGINAL ARTICLE

How doctors can lead the way in their communities: Co-creation, the Indian community and organ donation registration

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Key words

organ donation, Indian community, co-creation, beliefs, registration, Australian Organ Donor Register.

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Abstract

Background and Aims: Transplant success rates can increase when organs and tissues are matched within ethnic communities, but how well are the processes around organ donation understood by discrete ethnic communities in Australia? We investigated this in relation to one ethnic group, the Australian-Indian community in Sydney.

Methods: A culturally appropriate survey and dissemination strategy was co-created with Indian community members through an Advisory Panel. Items were informed by a thematic analysis of cultural beliefs shared through the advisory panel discussions and measured awareness and practices associated with organ donation and transplantation and beliefs about organ donation and registration. Donation information was provided at the end.

Results: Two hundred and thirty-eight participants completed the survey. Hinduism along with Tamil and Gujarati were the most frequently identified religious and cultural backgrounds. The processes around organ donation were not well known, and Australian Organ Donor Register registration rates were below the national average. Principal component analysis revealed positive, social, medical trust, concerns, and cardiac and brain death belief factors. Doctors played a key role in generating trust in the donation system, decisions about organ donation were embedded in family and community, and family discussion was related to increased registration. Registered participants reported higher scores on medical trust beliefs, which also predicted family discussion.

Conclusion: The information needed to understand the process of organ donation and registration in Australia is not embedded in this community, highlighting the need for programmes to be tailored to each culturally diverse community rather than culturally diverse communities in general. Doctors and the advisory panels are pivotal in this process.

Introduction

Organ donation saves and transforms lives. Organs and tissues can be transplanted between people of different ethnicities, but transplant success rates can increase when organs are matched between members of similar ethnic backgrounds.^{1,2} In Australia's opt-in donation

system, registration on the Australian Organ Donor Register (AODR) is key to increasing consent; families are more likely (82%) to give final consent to donation if their loved one has registered a consent decision compared to when the decision is not registered or unknown (39%).³ Increasing registration is, therefore, a powerful way for members of ethnic communities to help ensure suitable organ and tissue matches are available. However, registration is reported to be much lower than the

Conflict of interest: None.

national average (36%) across these communities,^{4–8} and ethnicity is not collected on the AODR, so these data are not available for discrete communities.⁹ The little research that does exist has typically focused on beliefs about organ donation through a culturally and linguistically diverse (CALD) lens, which inadvertently assumes that these beliefs are common to *all* CALD communities.^{4,6,7,10}

In this study, we investigated how organ donation and registration were understood in one migrant ethnic group, the Australian-Indian community. The Indian community is now one of the three largest migrant communities in Australia and one of the fastest-growing ethnic communities.^{11,12} At 2.6% of the total population, there are currently 673 352 Indian-born residents.¹³ Yet, no research exists on the beliefs, values and practices this community associates with organ donation and registration. This study was conducted in Southwestern and Western Sydney, NSW, which has the highest concentration of Australia's Indian diaspora.¹⁴

Methods

The study was conceptualised within a social representation framework¹⁵ and a co-creation methodology.^{16,17} Social representations theory focuses on the socially constructed and shared nature of the beliefs and knowledge held about medical and scientific issues.^{15,18} A central premise is that socially constructed knowledge needs to be understood in its own right rather than assessed against its medical or scientific counterparts.¹⁵ Co-creation, which has a natural synergy with social representations theory, is an intensive and relational research process characterised by a genuine collaborative partnership between stakeholders (e.g. academic researchers, organisations and healthcare providers) and the community.^{16,19} It is premised on trust, inclusion and community ownership^{16,20} and foregrounds the community as 'experts of their own experiences'.²⁰

Procedure

A 10-member Indian advisory panel was convened. Five were community members: three identified with the Jain religion and the Gujarati community and two identified as Hindu, one of whom identified with the Tamil community. All identified as male. Two of the community members were medical doctors, and one was a volunteer for the stakeholder organ and tissue donation organisation. Community members were invited through one of the medical doctors from the Indian community, with an additional community member nominated by the stakeholder. Four advisory panel

members were from the research team: two were associated with a university, and two were associated with the stakeholder organisation, one of whom was a specialist organ donation doctor. Three members of the research team identified as female, and one as male.

The advisory panel met five times during the year in addition to virtual contact and regular emails. Each meeting was audio recorded. The co-creation process for the survey is detailed in Table 1.

Thematic analysis of the first advisory panel meeting.

The recorded discussion was transcribed and subjected to a reflexive thematic analysis.²¹ Community members' comments in the transcript were shared understandings that reflected how the community panel members thought organ and tissue donation was understood in their community, even though this was not necessarily their own understanding or view. The transcript was read by three members of the research team. The comments were assigned codes and cross-validated between the three researchers.

Three key themes were inductively derived: 'Information about organ donation and registration is not in the community', 'Trusted people and a trusted organ donation system' and 'The scriptures and processes around death and organ donation'. These are described below with an explanation of how the theme was explored in the survey. Although presented separately, the themes are inter-linked.

Table 1 Co-creation process for survey development

1. In the first meeting, the community panel members were asked to draw from their roles and experiences and discuss how they thought people in their community understood organ donation and registration. A thematic analysis of this discussion informed the first draft of the survey, in conjunction with previous research that has investigated organ donation in Australia.²⁴
2. The draft survey was refined through the next two advisory panel meetings, with particular attention to the appropriateness of the language, placement of the items and grouping of items into survey sections. The community panel members advised that although there was diversity in the languages spoken within the Indian community, English was the language understood by most Indian migrants and therefore the most appropriate to use.
3. The draft survey was piloted in the community ($N = 30$) through contacts of the community panel members. Feedback was sought on the face and content validity, suitability of the language and whether other issues needed to be addressed.
4. The final survey (ABROAD: Attitudes Beliefs, Reactions to Organ Donation among Indian- Australians) comprised 21 items in addition to demographic and registration questions. At the end of the survey, an information section provided details about the process of organ donation and transplantation in Australia (participants were unable to go back in the survey at this point).

Information about organ donation and registration is not in the community

This theme highlighted that many people do not have the necessary information to understand the process of organ donation and registration in Australia. Numerous reasons for this were given, including the inadequacy of available information and the fact that organ donation was not discussed openly in the community. It was also noted that there was no media coverage in Australia when someone (in their community) was an organ donor. This was compared to the huge media coverage that occurs when someone donates in India. This theme also highlighted that individuals need to be understood within the context of their family and community and that this is important when talking or providing information about organ donation and registration.

This theme was explored in the survey in the section *Organ donation and transplantation in Australia*. Survey items asked the extent to which people believed organ donation and transplantation happened in Australia, whether it was possible to transplant organs from someone deceased to save the life of another person, whether there were enough donated organs to meet transplantation needs, and the extent of agreement that the opportunity to be an organ donor does not happen very often. Items also asked whether anyone was known who had donated an organ or received a transplant. Items that asked about the individual's registration/donation decision were coupled with items that asked how the family would respond.

Trusted people and a trusted organ donation system

Trust as a theme emerged in the discussion in two forms. First, you need a 'key person' who is trusted and known to the community to engage successfully with people about organ donation. This person may be a spiritual or community leader, and they should also be registered; otherwise, they do not have 'the strength', that is, the authority to talk about it.

Second, a lack of trust in the integrity of Australia's organ donation system may underpin fears about organ donation, such as not being dead when organs are removed. This fear may be driven by beliefs about attempts to buy kidneys in India or organ trafficking in other countries.

This theme was explored in the survey through the section *Beliefs about medical trust and donation*. Items asked whether being registered as an organ donor would affect the quality of medical care received, if a person agreed to be an organ donor, whether they would be declared dead too soon and whether the doctors involved in

organ donation could be trusted. These questions were positively worded to prevent distress in the community (advised by community panel members).

The scriptures and processes around death and organ donation

This theme highlighted that some community members want to understand how organ donation aligns with the religious literature. In particular, what the timeframe is between death and organ donation; if the soul has departed, then the body is 'just a dress'; with no meaning, so donation could occur. The emphasis given to the body at death may also differ depending on the holy books used in that community. Some people may fear that organ donation impedes purification by fire. Death and the word death may also be feared. When death is talked about by non-medical people in the community or the word death is used, it can stop further engagement about organ donation.

This theme was explored in the survey section *Social beliefs about organ donation*. Items asked whether organ donation would affect purification by cremation, the extent to which a person's religion had clear guidance that organ donation was permitted, whether organ donation had a positive impact on the soul, the benefit of donation to others long after death, and whether the respondent's religion was open to organ donation. The majority of these questions were worded positively on the advice of community panel members. Care was taken with how the word 'death' was used in the survey.

The survey. The survey items were presented in five sections: (i) awareness of organ donation and transplantation in Australia; (ii) beliefs associated with organ donation: cardiac and brain death, donation and the individual, medical care and organ donation, and social beliefs about organ donation (measured on a 7-point Likert scale, 1 = strongly disagree, 7 = strongly agree); (iii) donation decisions and the AODR; (iv) demographics; and (v) an information section on the processes of organ donation, transplantation and registration in Australia.

Survey dissemination. Advisory panel members disseminated the final survey in online and hard-copy format to members of the Indian community through community networks, at local events, and through local community and social media.

Ethics approval. The research was approved by the Southern Cross University Human Research Ethics Committee. Informed consent was given by all members

participating in the advisory panel meetings. Completion of the survey was taken as informed consent.

Survey participants. Two hundred and thirty-eight participants completed the survey ($M_{age} = 42.7$ years, $SD = 11.2$; 46.2% identified as male, 36.8% as female, and 2.1% as non-binary, 14.9% did not answer). Most participants resided in Sydney (90%), and 63.4% identified with a religious or spiritual group, with Hinduism (and denominations) being the most frequently reported (38.9%). The majority of participants (68%) were born in India. Tamil and Gujarati were the most frequently reported cultural backgrounds (26% and 17.1% respectively). Engineer (10.1%), information technology professional (9.7%) and doctor (5.9%) were the most common occupations.

Results

Awareness of organ donation and transplantation in Australia

Approximately half of the survey participants strongly agreed that organ donation happened in Australia (58%), that organ transplantation was possible (50%), and that there were not enough donated organs (49%). Only 30% strongly agreed that the opportunity to be an organ donor does not happen very often (Fig. 1). Fifty-seven per cent (57.1%) had heard of the AODR, 41.6% had discussed organ donation with their family, but only 24.4% had registered an AODR organ donation decision.

Figure 1 Frequency distribution for organ donation awareness questions ($N = 238$). (■) Organ donation and transplantation happens in Australia; (■) it is possible organs from a person who is deceased in order to save the life of a person who needs an organ transplant; (■) the opportunity to be an organ donor does not happen very often; (■) there are not enough donated organs to meet transplantation needs.

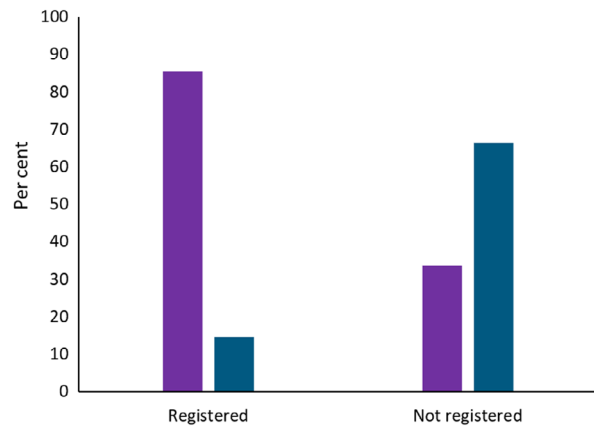
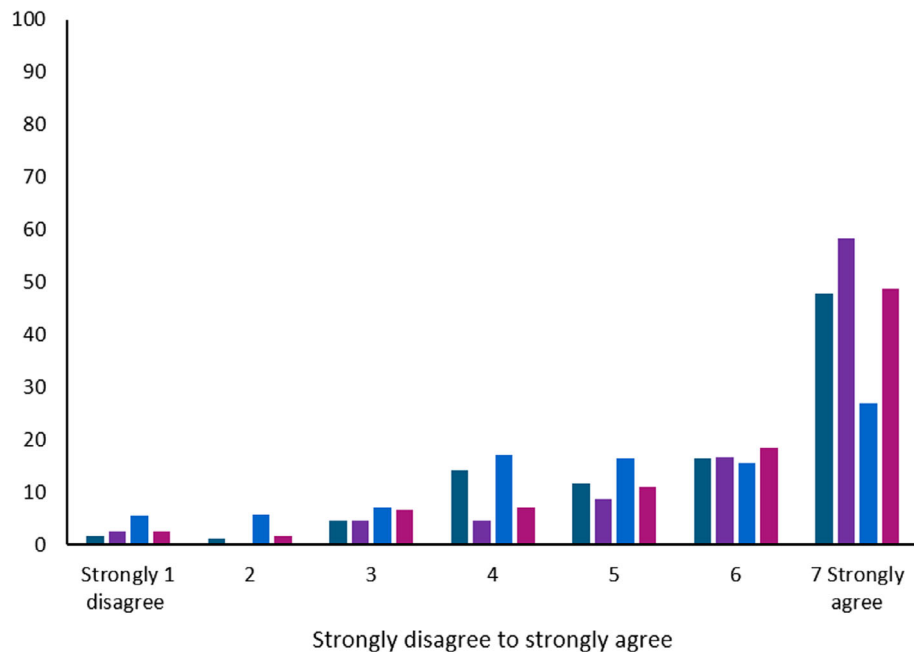


Figure 2 Registration status by discussion with family ($N = 192$). (■) Discussed donation with family; (■) had not discussed donation with family (or unsure).

Thirty-two per cent (31.5%) knew someone who had received an organ transplant (see Table S1 for Tamil and Gujarati statistics).

Discussing organ donation with family and registration on the AODR

Participants who reported they had registered were more likely to also report they had discussed donation with their family than participants who had not registered ($\chi^2(1, N = 192) = 42.3, P < 0.001$ (Fig. 2). The presence of

Table 2 Factor loadings for the five belief scales

| Item | Factor loadings | | | | |
|---|-----------------|--------------|--------------|---------------|--------------|
| | 1 | 2 | 3 | 4 | 5 |
| Factor 1 – Social beliefs | | | | | |
| My religion is open to the idea of organ donation | 0.763 | −0.071 | 0.118 | 0.207 | 0.090 |
| Donating an organ would enable that part of myself to live on | 0.750 | 0.078 | −0.065 | −0.061 | 0.092 |
| Organ donation would have a positive impact on my soul | 0.713 | 0.084 | −0.026 | −0.100 | −0.121 |
| Deciding to donate my organs at the end of life adds extra meaning to my life | 0.641 | 0.060 | 0.005 | −0.255 | 0.178 |
| When I donate an organ, the benefit to others will continue on long after my death | 0.605 | −0.084 | −0.016 | −0.169 | 0.177 |
| Factor 2 – Beliefs about concerns | | | | | |
| A person who donates their organs may not be purified by cremation | 0.029 | 0.829 | −0.014 | 0.003 | −0.046 |
| The thought of my body being cut up after I am gone makes me feel uneasy | −0.153 | 0.814 | −0.122 | −0.153 | 0.075 |
| Organ donation leaves the body disfigured | 0.151 | 0.798 | 0.050 | −0.002 | −0.069 |
| By agreeing to be an organ donor, doctors might declare me dead too soon | 0.058 | 0.722 | 0.133 | 0.259 | −0.024 |
| Factor 3 – Cardiac and brain death beliefs | | | | | |
| Brain death is permanent and cannot be reversed | 0.053 | −0.033 | 0.804 | 0.084 | −0.001 |
| If someone has been diagnosed as brain dead by two doctors, they are clinically and legally dead | −0.226 | 0.110 | 0.721 | −0.027 | 0.283 |
| Brain death occurs when a person has absolutely nil brain function | 0.154 | −0.001 | 0.634 | −0.310 | −0.145 |
| Cardiac death occurs when a person's heart stops | 0.142 | −0.112 | 0.573 | −0.355 | −0.092 |
| Factor 4 – Positive beliefs | | | | | |
| Organ donation is about helping other people | 0.047 | 0.001 | 0.043 | −0.814 | 0.087 |
| Giving organs after my life has finished is a way of putting some parts of the body to beneficial use | 0.095 | −0.134 | 0.139 | −0.679 | 0.024 |
| The act of donating organs is about giving life to someone else | 0.043 | 0.024 | 0.050 | −0.821 | 0.117 |
| Factor 5 – Medical trust beliefs | | | | | |
| I can trust the doctors involved in organ donation | 0.121 | 0.037 | −0.001 | −0.047 | 0.792 |
| Being registered as an organ donor won't affect the quality of medical care I receive | 0.107 | −0.145 | 0.074 | −0.082 | 0.668 |

Component loadings >0.50 are in boldface. Extraction method: principal component analysis.

family in the individual's registration decision was also reflected in comments such as 'I am waiting for all in my family to approve before I register', 'I haven't discussed with my family yet', 'Not sure how my family would feel – haven't discussed that yet!'

Beliefs about organ donation and transplantation

Responses to the 21 belief items were subjected to a principal component analysis (PCA) with an Oblimin

Table 3 Descriptive statistics for summated scale scores (N = 194)

| Belief scale | α | M (95% CI) | | | Pearson's r | | | | |
|---|------|---------------|-----------------|-----------------|-------------|--------|--------|--------|--|
| | | Overall | Reg | Not Reg | 1 | 2 | 3 | 4 | |
| Social | 0.77 | 5.8 (5.6–6.0) | 6.0 (5.7–6.3) | 5.8 (5.6–6.0) | | | | | |
| Concerns | 0.81 | 2.7 (2.4–2.9) | 2.2 (1.8–2.6) | 2.7 (2.4–3.0)* | −0.02 | | | | |
| Cardiac | 0.76 | 5.6 (5.5–5.8) | 5.8 (5.5–6.2) | 5.7 (5.5–5.9) | 0.35** | −0.09 | | | |
| Positive | - | 6.4 (6.3–6.5) | 6.7 (6.5–6.8)* | 6.3 (6.1–6.5)* | 0.72** | −0.14 | 0.56** | | |
| Medical trust | 0.77 | 5.9 (5.7–6.1) | 6.5 (6.2–6.7)** | 5.7 (5.4–5.9)** | 0.49** | −0.16* | 0.38** | 0.55** | |
| Descriptive data on items removed | | | | | | | | | |
| A person is not really dead until their heart stops beating, even if brain death has been declared. | | 5.1 (4.9–5.4) | 5.3 (4.8–5.8) | 5.0 (4.7–5.3) | | | | | |
| My religion has guidance that organ donation is permitted. | | 4.9 (4.6–5.2) | 5.0 (4.4–5.6) | 4.8 (4.4–5.1) | | | | | |
| A person who has donated an organ will have a piece missing when they are donated or buried. | | 3.9 (3.2–4.5) | 3.8 (3.2–4.4) | 4.0 (3.6–4.4) | | | | | |

*P < 0.05.

**P < 0.001.

95% CI, 95% confidence interval; Reg, registered.

rotation. Three items with loadings under 0.5 were removed (Table 3), resulting in a parsimonious five-factor solution that accounted for 66.12% of the variance (31.89%, 14.45%, 9.04%, 5.59% and 5.13% respectively, see Table 2). Scales were constructed for each factor by averaging scores across the items in each factor. All were reliable.

Correlations among the scales are in Table 3. *Concerns* were negatively associated with *medical trust*; all others were positively associated, especially *positive beliefs*.

Beliefs about organ donation seldom occur in isolation,¹⁸ and this was evidenced by the strong correlations between several of the beliefs (Table 3). The relationship of these beliefs with *discussion with family* was explored through a backward stepwise binary logistical regression. The five belief scales were first entered as independent variables to investigate whether they predicted *discussion with family*, the binary dependent variable (0 = discussed with family, 1 = did not discuss).

In the first step, all five beliefs were entered. In the second step, *social*, *positive*, *cardiac* and *concerns* were eliminated from the model. The model was statistically significant χ^2 (1, $N = 184$) = 6.86, $P = 0.03$, with *medical trust* significantly predicting the likelihood of *discussion with family* ($z = 2.50$, $P = 0.012$). Holding all other independent variables constant, the odds of *discussion with family* increased by 1.36 (1.07–1.74) (39%) for every one-unit increase in *medical trust*. That is, for every incremental increase on the *medical trust* belief scale, the odds of *discussion with family* increased by 39%.

Nine per cent (8.8%) of participants identified as either a nurse or doctor. Logistical regression was performed to investigate whether occupation as a doctor/nurse mediated the probability of *medical trust* predicting *discussion with family*. No significant effects were found (Fig. S1).

Discussion

The aim of our research was to understand what beliefs, values and practices members of the Indian community in Sydney associated with organ donation and registration. Currently, this information does not exist. To address this, the ABROAD survey was co-created with members of the Indian community and disseminated through community networks, events and local community and social media.

Several insights can be taken from this research. Firstly, approximately 50% of those surveyed were not certain about the practices associated with organ donation in Australia, and AODR registration rates were well below the national average of 36%.³ Only 57% of participants in this sample had heard of the AODR, and only 24% had

registered an AODR donation decision. These statistics mirror the findings from the thematic analysis that many people in Sydney's Indian community do not know about the processes of organ donation and transplantation in Australia (see Vincent *et al.*²² for registration data for people of Indian origin in other countries).²³

Secondly, trust is paramount in increasing awareness about organ donation and registration. Engagement with the community about organ donation must be through people whom the community trusts, and people need to believe there is integrity in Australia's organ donation system. This highlights the unique and leading role that medical doctors/professionals from these communities can play in bridging the gap between community members and the organ donation system. The importance of trust also emerged in the relationship between *medical trust* beliefs (trust in medical doctors and quality of care) and *discussion with family* about organ donation. As *medical trust* beliefs increased, so did the probability of *discussion with family*.

Thirdly, understanding how an individual's donation decision is embedded in the family and the community may be the key to increasing registration. This was highlighted in the advisory panel discussions and the survey responses and needs to be explored further. For example, what constitutes 'family'? Are discussions about organ donation occurring before or after registration? Would family registration be an effective strategy?

Finally, many participants reported that organ donation was a noble act and aligned with their community values, but these positive beliefs were coupled with uncertainty. Table 3 shows the negative correlation between positive beliefs and concerns is weak, but the items removed from the PCA suggest the responses to the belief items become more uncertain as the items become more specific. When asked about brain death, the responses indicate more certainty when this referred to being legally dead (Table 3), compared to when brain death was coupled with a person's heart still beating (see removed items, Table 3). Similarly, responses to 'my religion being open to the idea of organ donation' were more certain compared to responses to the removed item 'My religion has guidance that organ donation is permitted'.

Beliefs about organ donation are interdependent and do not exist in isolation. Our earlier research demonstrated the context in which the beliefs are elicited may increase or decrease the strength of the belief.^{14,24} For example, in the current research, as agreement with *medical trust* beliefs (trust in doctors and the quality of medical care) increased, so did *social beliefs* and *cardiac beliefs*, and vice versa. Taken into the intensive care unit, when a loved one has died, it is unlikely that only one of

these beliefs will be driving the family's final donation decision – if donation is considered for the first time. When the donation decision is unknown, the stressful nature of this context may lead the family to make the decision of least discomfort, a donation decline.¹⁴

There are limitations to this research. The sample of 238 participants was relatively small, although not in comparison to previous research with culturally diverse communities in Australia (e.g. references 4,10), and it was a convenience sample. Although a great deal of time was spent on working with the advisory panel to develop the items, the results do indicate the need to refine the specificity of some of these items (Table 3).

Conclusion

This research demonstrates that AODR registration rates in the Australian-Indian community are much lower than the national average and highlights the unique and leading role that medical doctors/professionals can have in their own communities engendering trust in the organ donation system. The important link between discussing organ donation with family and registration was also highlighted.

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We need to understand what culturally diverse communities associate with the processes of organ donation in Australia if registration rates are to be increased. We need to do this in ways that are both culturally appropriate and tailored specifically to each community. The advisory panel is pivotal in this process. Organ transplantation saves and transforms lives, but transplant success rates *can increase* when organs are matched between members of similar ethnic backgrounds. We need to increase registration in Australia's diverse communities for this to be realised.

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site:

Data S1. Supporting Information.
