

RUNNING HEAD: Young people, family discussion and organ donation

Young people's views on how to encourage family discussion about organ donation

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Conflicts of interest

The authors have no conflicts of interest to declare.

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Abstract

Context: Discussing organ donation wishes with family prior to receiving a request for donation is essential to increase family consent. For young people who have already decided to be a donor ('young donors'), notifying family is particularly critical. However, many young donors are unaware of the need for this discussion, have low motivation to discuss, and have not notified family of their wishes.

Objectives: To explore young donors' views on, experience with, and suggestions to encourage family discussion, and opinions about advertising/social marketing campaign materials.

Participants: Young donors, who were Australian residents ($N = 13$; 10 females) aged 18-28 years ($M = 23.00$; $SD = 2.74$), participated in one of four focus groups.

Results: Motivations for family discussion were having their wishes respected by family and reducing family distress. Barriers to discussing were not thinking about it and forgetting unless an immediate opportunity for discussion was provided. Young donors had different approaches to initiating family discussion depending on anticipated family reactions and confidence in discussing; straightforward ('just say it') and casual ('no big deal') or involving preparation and in-depth discussion. Campaign materials including information and personal stories about transplant recipients were perceived as effective in capturing attention and encouraging family discussion.

Conclusions: Gaining the perspective of young donors to encourage family discussion is crucial. Key findings highlighted the need to consider young donors' approaches to initiating family discussion and incorporating prompts and opportunities to facilitate family discussion in the development of future message appeals.

Keywords: organ donation, consent, communication, campaigns

Introduction

Increasing family consent for organ donation in countries with opt-in and soft opt-out consent systems is vital to ensure willing donors become actual donors.¹ A behaviour critical to increasing family consent is having a conversation about organ donation wishes with family prior to receiving a request for organ donation.²⁻⁴ However, many individuals are unaware of the need for this discussion or have not discussed their wishes with family. For instance, in Europe approximately 40% surveyed had discussed organ donation with family⁵ and in the US less than 50% of Americans had family members who shared donation wishes with them.⁶ In Australia, 43% surveyed were not certain of their loved ones' donation wishes and 60% had not talked about donation in the past year.⁷ A national survey showed that Australians aged 18 to 29 years, particularly, were the least likely to have discussed donation wishes with family compared to older age groups.⁸ Furthermore, approximately half surveyed did not know that family consent is required for organ donation to occur.

International research also supports this trend. Young people are unlikely to have talked to family about their donation wishes⁹ and cite a lack of motivation to do so.¹⁰ Reasons for this lack of motivation to discuss may be associated with deficits in knowledge about the donation process or issues related to communicating donation wishes (e.g. lack of general knowledge about organ donation, being unsure how or when to raise the topic),¹⁰⁻¹⁴ as well as decision salience or confidence (e.g. uncertainty about the donation decision, not thinking about it, not ready to talk about it).^{10,13-15} Fear related to organ donation or family discussion (e.g., fear life-saving measures will not be taken if wishes are known, uncomfortable talking about the death of self or others),^{11,12,16,17} and concerns about family (e.g. feeling pressured by family to change their decision, having to defend or justify their decision to family, creating distress or conflict if family disagree) may also play a role.⁹⁻¹¹

These beliefs, however, relate to the motivations of samples which include young people who do (i.e. young donors), are unsure about, or do not, wish to donate without identifying whether particular beliefs are more important in decision making for people with different organ donation preferences. It is conceivable that young donors have different

beliefs about and barriers to family discussion, compared to young people who are unsure about their decision. Accordingly, in addition to eliciting young donors views on family discussion, strategies are needed to increase young donors awareness of the need for discussion, overcome barriers associated with family discussion, and increase motivation to share donation wishes with family.

One strategy that may prove effective is the use of persuasive message appeals designed specifically for young donors to encourage family discussion. To date, previous research has been limited in its use of persuasive message appeals to encourage people to provide consent for organ donation, despite the success of this approach in other health domains in influencing individuals' attitudes, intentions, and in some instances behaviour.¹⁸⁻²⁰ With few exceptions,^{21,22} existing studies focus solely on using persuasive messages to encourage people to sign a donor card or register their consent on a donor register.²³⁻²⁹ Increasingly, research shows that family discussion, rather than registering, is the behaviour most likely to raise family awareness of loved one's wishes and subsequent consent for donation.³⁰

This study represents the first of three phases of a larger project on developing and testing persuasive message appeals to encourage young donors to share their donation wishes with family. Specifically, we targeted young people who wished to be organ donors to qualitatively explore, and derive in-depth understanding of, their views, experience, and advice regarding family discussion, and their personal opinions about existing organ donation campaign materials and how these could be modified for young people. Key findings will then inform recommendations for the development of future message appeals targeting young donors and family discussion.

Methods

Participants and Procedure

After receiving ethical approval from the institutional review board, a convenience sample of 13 young people attending a university in Queensland, Australia were recruited via class websites, email, and snowballing to participate in one of four 1-hour focus groups

during October, 2010 and February, 2011. Participants gave their written and verbal consent to audio recording of focus group discussions and were provided with an information sheet explaining the anonymous, confidential, and voluntary nature of their participation.

Participants received a movie ticket as recognition of their time commitment and contribution.

Participants were Caucasian, mostly female (10 females, 3 males), ranged in age from 18 to 28 years ($M_{\text{age}} = 23.00$; $SD_{\text{age}} = 2.74$), and did not consider themselves to be overly religious

or spiritual ($M = 2.85$; $SD = 2.70$; Range = 0 not at all to 7 a large extent). Self-rated

knowledge of organ donation was below average on a 7-point scale ($M = 3.00$; $SD = 1.00$;

Range 1 very poor to 4 average). All participants wanted to be organ donors upon death.

One participant had joined the donor registry, four had notified family of their wishes, and two had performed both behaviours. Over half (7 participants; 53.8%) had seen a government campaign promoting discussion of organ donation wishes with family prior to the study.

Measures

Table 1 lists the focus group questions. During the course of the focus group participants shared their views on family discussion about organ donation (e.g. positives and negatives), people in their social network who may support (or not) such a discussion, and what factors would motivate or be a barrier to discussion with family. Participants were then asked to consider how they would start a conversation with family to notify them of their donation wishes and the resources they may need to do so. Also, participants were asked to consider other young people who may have difficulty starting a conversation with their family and to make suggestions for these people as to how they could start a conversation and the resources they may need. To engage participants in thinking about the factors that would motivate them to have a discussion, we presented them with four different sets of campaign materials originating from either the USA or Australia: 1) the “Can we talk?” brochure; 2) the “You have the power to donate life” brochure; 3) the “DonateLife - Ok” campaign brochure and advertisement; and 4) the “Sign on to save lives” brochure (see Table 2 for a description of campaign materials). These campaign materials were chosen because they each incorporated a unique aspect to encourage discussion and varied in their focus on either

discussion, joining a registry, or organ donation generally (Table 2). The sequence in which materials were presented to participants was varied to control for bias due to ordering effects. Participants shared their initial reaction to each of the materials and commented on what they thought was the main message, message effectiveness, what they would change (if anything), and whether the materials would help them to make a decision about and actually discuss their donation wishes with family.

Statistical Analysis

Focus group discussions were transcribed verbatim and de-identified for data analysis. After each focus group, transcripts were analysed to identify recurring themes in response to each question.³¹ As new responses were obtained from focus groups, transcripts were re-coded to incorporate these. Recruitment for focus groups ceased when it was clear that no new information was emerging and young donor's views were largely consistent across groups.

Results

Views on family discussion

Participants identified advantages of having a conversation about organ donation prior to death as reducing family distress, confusion and arguments; making the decision to consent to donation easier for family in a difficult time; and making family aware of your decision thus increasing the chances your wishes will be respected.

"I hate to use this example but you know when you watch those TV shows like House and things like that, and how all those families get into massive arguments about whether that person wanted to donate their organs and stuff like that?...So I guess it gives more closure on that and makes it much more clearer". (Male, 18 years)

Disadvantages of discussion were creating conflict with family members or disagreement; feeling uncomfortable or awkward talking about donation or death; and being persuaded to change your decision.

"Talking about death is uncomfortable and when I spoke about it with my mum I said, 'Mum when I die...', [and] she started freaking out before I'd even said the rest of the

sentence! So yeah particularly with your parents, they don't want to think about you being dead". (Female, 25 years)

Young donors believed that people in their social network would support family discussion in most cases (except where strong religious beliefs may exist), especially parents and family members. Barriers that young donors believed would prevent discussion with family included: myths about donation (e.g., mistreatment of the body, jinxing death by talking about it); believing that talking about donation or death would be uncomfortable or awkward; perceived family disapproval for the discussion and having to justify the decision; laziness or lack of motivation to discuss; having plenty of time to talk about it later, and not thinking about organ donation or remembering to have a discussion.

"I don't know...I don't know why I haven't done it. It seems like I'd be jinxing it or something (death)...I suppose just laziness as well. Like it seems important to me but I think I'd only really think it was 100% important when I'm dead. So it's like I have plenty of time and the fact that it's not pushed on me to do it, I suppose that's why I haven't". (Female, 22 years)

Knowing how important it is to discuss donation wishes because of the role family play in giving consent, having personal experience (e.g., a relative/friend needing a transplant or dying), and having a prompt that provides an immediate reminder to discuss (e.g., ad on Facebook, television program) were all considered to be factors that would motivate young donors to talk with family.

"Maybe TV, maybe they need to do it online like if there was an ad on Facebook, with a link about registering your decision you might think, 'oh yeah I'll just go do that'. Like you're not going to sit on the couch [while watching TV] and go, 'oh I'll just go to my computer and do it". (Female, 25 years)

Starting the donation conversation

When asked to consider how they would start a discussion with family for the purposes of sharing their donation wishes, participants thought they would be direct in their

approach by making a statement that they want to donate/register their wishes or taking action first by registering and then telling family.

“My family is rather blunt so I think I’d just have to say it, like ‘I’ve registered my consent to donate organs’ and just see how it goes. Yeah...I’d have to register first and then tell them I think and once it’s done it’s done and I guess they’ll have to accept it” (Male, 19 years)

Starting the conversation by asking family whether they would like to donate their own organs or whether they would want to donate the young person’s organs was another strategy suggested. This strategy was thought to allow participants to gauge family reaction or attitudes to donation prior to introducing their own donation preference. Participants also felt that making the conversation casual or informal was important.

“I think that I would just say that it was something I need to discuss and to clear up. It’s only something that you would have to talk about once. You’d just go over for a visit and sit around having tea or coffee or something, nothing big...Yeah I don’t imagine it to be a difficult situation at all”. (Female, 22 years)

Participants who anticipated disagreement or family objection to their decision thought that ensuring a captive audience (e.g., “I’d trap my mum in the car”) or having a conversation with both parents at the same time would minimise potential adverse reactions and increase the chances of discussion.

Resources for self and others

Participants believed that resources such as information about the donation process or facts and statistics about donation would be useful as preparation for the discussion or to give to their parents or family member/s after the discussion had occurred. The only resource that participants thought may help to facilitate a discussion was their organ donor registry card or registry brochure. In terms of resources for others, participants believed that other young people may find general information about organ donation to be useful, or facts and statistics to refer to during a conversation, especially for those anticipating or experiencing difficulty.

Suggestions to motivate others

Participants offered a number of suggestions for young people who may have difficulty starting the donation conversation. These suggestions were directed by their own preferences and how comfortable they felt with discussing their organ donation wishes. These suggestions included being straightforward (i.e. 'just say it'), being clear that the conversation is important to you, and choosing carefully who you talk to (i.e. a family member who you believe is likely to support you).

"I think identifying the significance of it and the importance of it. I mean this is only based on the limited information I have but I perceive it as a very important thing. So if people can highlight that to their families then it might make talking about it seem a little more worthwhile". (Female, 22 years)

For those young people who felt very apprehensive, suggestions included dropping hints as a way to introduce the idea until they felt prepared to have an actual conversation, making it a conversation that encourages discussion rather than just making a statement, giving an explanation for their reasons for wanting to donate, bringing along a neutral support person, and encouraging family members to take the perspective of a person needing a transplant (e.g. 'imagine if you needed an organ'). To remind young people to have a discussion with family it was suggested that young people use everyday occurrences such as a Television program to encourage them.

"Bring it up in discussion. So giving them [parents] time to talk about it rather than saying 'this is my decision that's it', because I mean they're not really going to carry it out if they don't understand your wishes...yeah explain why you want to become an organ donor and then you know, ask their opinion and make them feel like they have a say". (Female, 22 years)

Views on campaign materials

'Can we talk?'. Compared to the other campaign materials, this resource was the least talked about during the focus group discussions and participant reactions were mixed. Some participants commented that it was not 'eye-catching' enough or was too simplified

while others thought the multicultural perspective was important and commented that this aspect was missing in the Australian campaign materials. Some participants thought the suggestion contained in the brochure to focus the discussion on the gift of life rather than the end of life would be a good conversation starter and would engage a young person whereas others did not believe the suggestion was helpful. The conversation below between two participants exemplifies these mixed reactions.

"I guess that's one strategy you could use. But in a way I find it hard to relate to that because like I've said before, I'm pretty blatant about it so it's hard for me to imagine someone who finds it difficult. But yeah I think it would help". (Female, 24 years)

"Yeah that's a good one; I do think that saying 'when I die' is probably not a good way to start the conversation...[pause]...I think the concentrate on the gift of life is a bit corny though". (Female, 25 years)

"Yeah I mean that's great but then what do I do or actually say? So maybe little points about mentioning this or bringing that up". (Female, 24 years)

'You have the power to donate life'. All but one participant favoured the personal stories and pictures of recipients included in this resource. Participants commented that the stories and pictures caught their attention and helped to confirm the decision they had made to be a donor.

"I would say that I really enjoy the little stories because everything else is facts but this is what happens after everything is done and what your organ can do for someone. It's always interesting to see what the outcome is rather than the little details of how it happened or what organs you can donate". (Male, 19 years)

"You need to start off with the personal stories first because it doesn't make any sense otherwise. Because you can't really imagine yourself being one of those statistics but you can imagine yourself in one of those stories". (Female, 22 years)

In contrast, one participant found the inclusion of pictures and stories to be manipulative.

"I didn't like it, it just feels like its making you feel guilty by putting in these pictures of happy healthy children and father-child relationships, a bit clichéd. It's like a guilt and I don't like what it's doing. I don't feel touched by it I just feel like it's manipulating me." (Female, 24 years).

The inclusion of a 'family notification card' was thought to be helpful for young people who were apprehensive about having a discussion with family; however, one participant felt that the card was impersonal.

"I think it's a good idea, you could just give it to the person who is your next of kin. Yeah, it's more like here read this!...If I was in a situation that was a bit difficult I could just hand this to them to start the discussion". (Male, 18 years)

'DonateLife - Ok' campaign. The majority of participants preferred the 'DonateLife - Ok' campaign brochure because it was informative without giving too much information, straightforward, objective, had a question and answer format and included links to resources where participants could find out more information. Participants believed the brochure would facilitate family discussion because it included suggestions as to when a discussion could be started and the topics that could be discussed. Also, some participants suggested the brochure would be a good resource to prepare them for the discussion as well as to give to family after a discussion had occurred.

"This one was probably one of the better ones because they had the whole discuss with your family thing, and they went on trying to help you bring it up. Whereas the other ones just told you the importance of it, this one was trying to get you into situations where you could bring it up. Like general everyday situations where it might be useful for you to bring it up". (Male, 19 years)

Although these suggestions were helpful, some participants commented that in addition to examples about when to have a conversation, suggestions about what to say were needed. One participant felt that the brochure was not personal enough in comparison to the 'you have the power to save a life' brochure.

“This is too clean and sterile [‘DonateLife - Ok’ campaign brochure]. It looks like it was done by a graphic designer whereas this one [‘you have the power to save a life’ brochure] kind of looks like it’s done by a three year old and it says ‘help me save my life’”.

‘Sign on to save lives’. Participant responses to this resource were mixed. Some participants believed that the brochure was effective and informative, described the whole process, provided an action that participants could take (joining the registry), and concisely noted the importance of discussing with family. Other participants thought that the importance of discussion was not made clear and that the imagery included in the brochure did not support family discussion. The following two quotes exemplify participant concerns:

“Yeah it’s not really [importance of discussion included in brochure], but what’s more important? It sounds like it’s more important to discuss it than to go online and register, but this isn’t telling me that...I guess it also seems easier for me to have a discussion with my mum or sister than to go online and register. I mean since your decision may get overridden by your family’s decision anyway, why not just focus on the actual conversation rather than all this stuff about ‘how do I register?’” (Female, 25 years)

“That one was really bad. There’s no pictures of people, just a line of people standing in a white room not really doing anything. They’re obviously not living life and they’re obviously not discussing organ donation”. (Female, 22 years)

Preferred campaign materials. Overall, participants preferred the ‘DonateLife - Ok’ campaign brochure/materials and the ‘You have the power to donate life’ brochure or a combination of the two as compared to the other resources. In particular, participants who had yet to discuss their donation wishes with family preferred the ‘DonateLife - Ok’ campaign materials to any other resource (see Table 3). Participants felt that the combination of the personal stories and pictures in the ‘you have the power to donate life resource’ and the information in the ‘DonateLife - Ok’ campaign brochure would be most optimal to raise interest and awareness of the need to discuss donation wishes with family and to facilitate family discussion. The following quote explains why participants believed the combination of personal stories and information would be effective.

“If you really wanted to push the idea of discussion then I suppose you could help them visualise the discussion in a picture. So I think a mixture of saying ‘these are the people you can help [‘you have the power to donate life resource’] by discussing it with your family’ [the ‘DonateLife - Ok’ campaign], so it’s like a 2-point thing. You need to discuss it with your family so you can help these people”. (Female, 22 years)

When asked if any of the resources would motivate them to have a discussion, several participants commented that although the campaign materials would raise awareness they would need additional reminders to have the discussion, and especially opportunities that allowed them to take immediate action.

“I would think about it for a minute and then go back to whatever I was doing and unless I was prompted again online, I don’t think I would necessarily do anything”. (Female, 24 years)

“I think it’s really about getting the message from there [brochure] to your conversation. Like if I was in a waiting room with my mum and I opened up this [‘DonateLife - Ok’ campaign brochure], I’d probably talk about it then. It’s just like taking the next step really.” (Female, 25 years)

Discussion

Prior research with young people has focussed predominantly on developing and testing interventions or persuasive message appeals for signing a donor card or joining a registry²⁵⁻²⁹ rather than encouraging family discussion. We extended this prior work by asking young donors their views on family discussion and the optimal way to encourage discussion, and the aspects of existing resources they thought were effective, with the aim of using study findings to develop persuasive message appeals to encourage family discussion.

Summary of key findings

Overall, key findings showed young people’s beliefs in this study were similar to those reported in prior research.^{9,10,12-14} The belief that family discussion would ensure young donors’ wishes were respected was especially important and was raised by all participants. Making the experience less stressful for family was another key concern. Similar to prior

research,^{10,15} participants also noted that sharing donation wishes with family was not something they thought about doing. Further, if they were prompted to think about family discussion they would need additional future prompts or an immediate opportunity for action before they would discuss their wishes. The need for an immediate opportunity for action is consistent with Siegel and colleagues' work which demonstrated that individuals who are given an immediate and complete registration opportunity and who were also aware of this opportunity registered at significantly higher rates.^{32,33}

A novel finding was that young donors described two different approaches they would take when initiating family discussion about organ donation depending upon how confident they felt in their own ability to have a conversation and also the reactions they expected from loved ones when they raised the topic. Young people who appeared confident about positive family reactions and how they would initiate discussion described an approach that was straightforward ('just say it') and casual or informal and referred to 'not making a big deal out of it'. In comparison, participants who anticipated potentially unfavourable family reactions and were worried about having to justify or explain their decision felt they needed information to prepare for an in-depth discussion and to give to family afterwards as well as specific examples of what to say to start the discussion.

Young people felt that the optimal resource was one that was informative and included personal stories. Personal stories were viewed very favourably because they caught young people's attention and were something they could relate to; a finding that is consistent with prior research suggesting the importance of details about transplant recipients to individual decision-making.^{13,34-38} Some participants felt that showing a family a notification card describing that they wished to be a donor was one potential way to start a conversation. Suggestions regarding the optimal time to start a conversation and topics to talk about during a conversation were also viewed as helpful; however, some participants felt that in addition to these suggestions, specific advice on what to say to raise the topic was needed (see also¹³).

Limitations of the study

Despite the strength of using qualitative research to uncover young people's perspective on communicating consent for organ donation with family, our use of a convenience sample of predominantly female, Caucasian, highly educated young people limits generalizability of the findings to young people in the broader community. Nevertheless, the majority of organ donation research with young people has been conducted with university students, especially those enrolled in a psychology course of whom the majority are female. Our focus on young people rather than a range of ages also limits generalizability of the findings. However, young people, particularly those who have already decided they wish to donate, are an important population to target because they represent a potential source of viable, healthy organs, and are more likely to have causes of mortality that increase their chances of eligibility for donation (e.g., road trauma). We chose campaign materials for evaluation by participants that included mention of the need for family discussion and offered a unique suggestion that may encourage discussion (e.g., family notification card, focussing the conversation on life rather than the end of life) but were not able to incorporate additional resources that may have elicited different responses from participants. In particular, one resource, 'Can we talk', was not well received by participants and this study may have benefited from piloting of these resources prior to study commencement.

Recommendations for future campaigns

Drawing on key findings from this study several suggestions can be offered for future advertising/social marketing campaigns and the development of persuasive message appeals to encourage young donors' to engage in family discussion.

1. Emphasise the importance of family discussion for enabling donation wishes to be respected and to reduce family distress.
2. Include suggestions on what to say in conversation.
3. Acknowledge that different approaches to family discussion are used (i.e. no big deal vs. being prepared) and create appeals/materials that reflect these.

4. Encourage individuals to create immediate opportunities for family discussion or notification.
5. Recognise the need for reminders and multiple prompts to encourage discussion.
6. Include stories that young people can relate to as well as facts.

Conclusion

It is critical to obtain the perspective of young people in developing interventions or persuasive appeals to encourage young organ donor's discussion of their wishes with family. In doing so we highlighted not only young donors views on the importance of having their wishes respected and reducing family distress but also two different approaches that young people may adopt in initiating family discussion depending upon their concerns about family reaction and their efficacy in doing so. Furthermore, personal stories of recipients and donors were highlighted as an important way of engaging young people to consider family discussion, and particularly the need for an immediate opportunity or multiple prompts to ensure family discussion occurs was noted.

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Table 1

Focus group questions

Construct	Questions
Demographics	<p>Sex (<i>Male, Female</i>)</p> <p>Age (<i>in years</i>)</p> <p>To what extent do you consider yourself to be a religious/spiritual person? (<i>0 not at all to 7 a large extent</i>)</p> <p>Have you registered to be an organ donor on the Australian Organ Donor Register? (<i>Yes, No</i>)</p> <p>Have you previously discussed your decision to be an organ donor with a family member (<i>Yes, No</i>)</p> <p>Overall, how would you rate your knowledge on the topic of organ donation (<i>1 very poor to 7 excellent</i>)</p> <p>Have you previously seen a campaign in Australia about organ donation and/or communicating organ donation wishes? (<i>Yes, No</i>). If yes, please give details about the campaign (free text response)</p>
Beliefs	<p>What are the advantages that come to mind about discussing your decision with your family members?</p> <p>Who are the individuals or groups that would approve of you discussing your decision with your family members?</p> <p>What are the factors that would prevent or discourage you from discussing your decision with your family members?</p>
Starting the donation conversation	<p>Imagine that your next task was to go home and actually talk to your family member/s about your wish to be a donor. Think about and describe how you would go about the actual process of raising the issue of organ donation and discussing your wish to be a donor with your family member/s.</p>
Resources needed	<p>In relation to discussing your decision with your family member/s, what information/resources would you need?</p> <p>Do you think other people would need information/resources to help them discuss their decision with their family member/s?</p>
Suggestions for others	<p>If you had the opportunity to give some advice to people who have difficulty discussing their organ donation decision with their family, what are some strategies that you might suggest that would help them to discuss their decision with their family member/s?</p>
Campaign materials	<p>In general, what do you think and/or feel about these materials?</p> <p>What was your first reaction when you saw each of them?</p> <p>What do you think is the main message that each of the brochures/materials is making?</p> <p>If we were called in to assist designing of future brochures/materials, what would you change?</p> <p>Is there a particular brochure/materials that you thought was the best? Why?</p>

Do you think it would influence your behaviour? Do you think it would influence other people's behaviour?
What about the worst or least effective brochure/materials? Why?
Would any of these brochures/materials help you to think about and plan how you were going to discuss your decision with your family member/s? Would these brochures/materials help you actually discuss your decision with your family member/s?

Table 2

Campaign materials

Campaign (Source)	Origin (Date)	Materials	Description
Can we talk? (The Links, Incorporated and Roche)	USA (2006)	Brochure	A brochure designed to assist in starting the organ donation conversation with family and targeted specifically at the African American community. It includes facts and statistics as well as some tips to start the conversation: “seek advice from someone you trust, knowledge is power, dispel the myths, and don’t focus the conversation on the end of life”. http://www.linksinc.org/Downloads/Conversation_Starter_Guide.pdf
You have the power to donate life (Donate Life America)	USA (2003)	Brochure	A brochure designed to raise awareness about organ and tissue donation. It includes facts and statistics about organ and tissue donation, including how the donation process works and who receives donated organs and tissue. Pictures of prospective and actual transplant recipients and brief quotes are included also. The brochure includes a removable family notification card that can be completed and shared with next-of-kin. http://store.donatelife.net/ProductDetail.aspx?did=12790&pid=70386
‘Donate – Life Ok’ campaign (Phase 1) (DonateLife)	Australia (2010)	Brochure and printed adverts	A brochure and printed advertisements from the first phase of the campaign which encouraged discussion of donation wishes with family in the event that they are asked to consent. The brochure includes information to assist people to ‘discover the facts about donation’ and provides facts and statistics, ‘decide to become a donor’ and includes information about joining the register, and ‘discuss your decision with family’ and includes suggestions for appropriate situations in which to discuss organ donation with family and discussion topics. The printed advertisements present an image of a person who wants to be a donor and informs people to discuss their decision with family because they have the final say.
Sign on to save lives (Australian Government and Medicare)	Australia (2008)	Brochure	A brochure for the Australian Organ Donor Register. It includes brief facts about organ donation and the donation process, information about the Australian Organ Donor Register, eligibility for joining and how to join. A brief explanation of why discussing donation wishes with family is important is also included.

Table 3

Preferred campaign materials to discuss organ donation

Campaign materials	No. (%) of respondents		
	Overall ^a (<i>n</i> = 12)	Discussed with family (<i>n</i> = 5)	Not Discussed with family (<i>n</i> = 7)
'Can we talk?'	1 (8.3%)	1 (20.0%)	-
'You have the power to donate life'	3 (25.0%)	2 (40.0%)	1 (14.3%)
'DonateLife - Ok' campaign	6 (50.0%)	1 (20.0%)	5 (71.4%)
'Sign on to save lives'	2 (16.7%)	1 (20.0%)	1 (14.3%)

^a Of 13 participants, 1 did not answer this question