



The Right Stuff: Information on Organ Donation



The sensitive issue of providing information about organ donation to families of potential donors whilst not seeming to pressure them into giving consent has been addressed by a randomised controlled trial in Australia.

The trial compared two videos of a simulated conversation about organ donation, the only difference being the amount of information conveyed on the benefits of donation. Steve John Philpot, Intensive Care Consultant at Alfred Health, Melbourne, Australia, and colleagues, have published their results in [PLOS One](#).

Background

Research published in 2015 by [Lewis et al.](#) showed that family donation conversations with trained requesters led to a higher rate of consent to organ donation. Dr. Philpot, in an email to *ICU Management & Practice*, noted that since the two-day Family Donation Conversation (FDC) workshops began in 2012 there have been more than 1000 attendees nationally. Trained requesters may be [DonateLife](#) specialist staff or other senior hospital staff such as intensive care specialists who have undergone the core FDC workshop. Ideally the person undertaking the trained requester role is not a member of the treating clinical team, said Philpot. The trained requester and the treating clinical team work collaboratively to plan and conduct family donation conversations. A team-based approach with flexibility in how roles are undertaken is encouraged with the active participation of the Trained Requester.

The study reported in *PLOS One* set out to find out how much of the improved consent rate resulted from conveying information about the benefits of donation, and what the attitudes of members of the public is to the delivery of such information.

Family Decisions on Donation in Australia

Data from the January-December 2015 DonateLife Audit of 76 hospitals that represent more than 90% of all organ donation activity in Australia shows that of the proportion of families approached for organ donation there was a refusal rate of 37.7%. The key reasons given for non-consent include (note: families can give multiple reasons):

- Family believed the patient would not want to donate - 37%

- Family didn't like the idea of organ donation - 18%
- Cultural religious reasons - 13%
- Family did not know patient's wishes - 8%
- Family was concerned about disfigurement - 8%

Amount of Information

The researchers set out to compare attitudes of participants who watched one of two recorded family donation conversations where different information was provided.

The "Supportive" video contained information about the potential benefits of donation and transplantation, the rarity of the opportunity for donation, and the need for organs, in addition to information about the organ donation process.

The trial participants (recruited from a large company) watched one of the two videos, then completed a questionnaire about their understanding of the rarity of organ donation, the adequacy of the information provided, their level of discomfort and general attitudes, and the degree to which they felt the doctor was trying to convince the family member to say yes to donation.

See Also: [Specialist Nurses Help Boost Transplant Figures](#)

Results

There was wide variation in what trial participants considered to be the 'right' amount of information on organ donation. However, the group who watched the conversation that included information on the benefits of donation were:

More likely to:

- say that the information provided was sufficient;
- report that the doctor was trying to convince the family member to say yes to donation.

No more likely to:

- feel uncomfortable or;
- feel that the doctor was uncaring or cared more about transplant recipients than he did for the patient and their family.

Rarity of Donation is Unknown

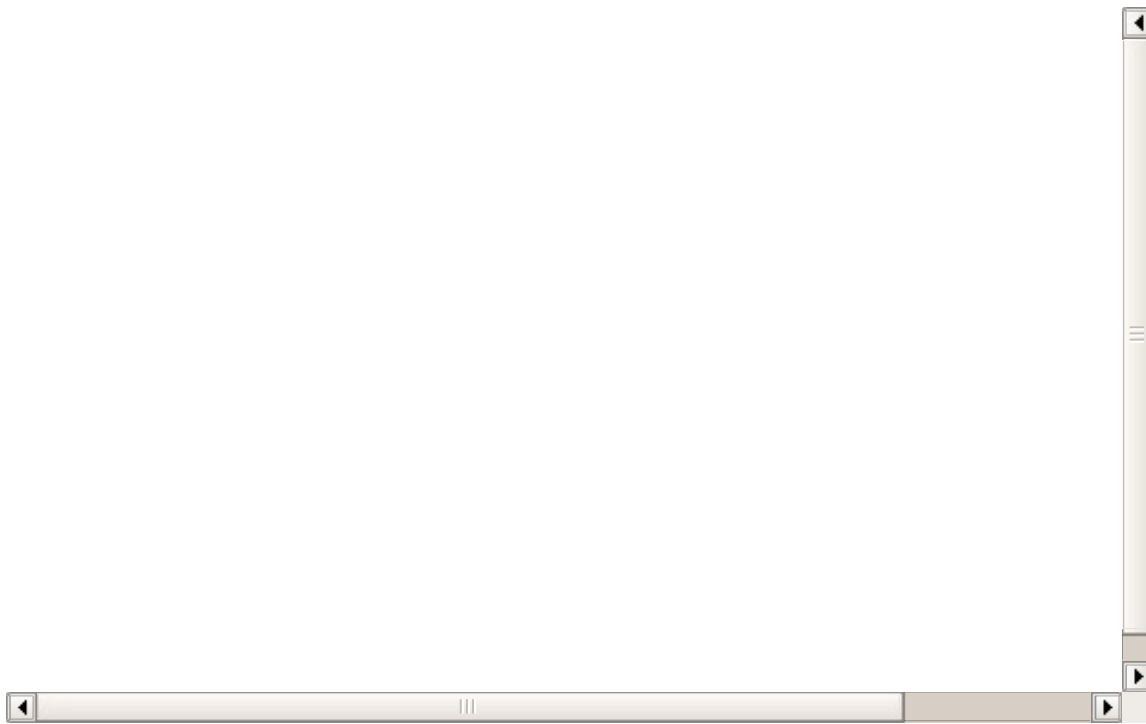
Only half of the participants were able to correctly identify that organ donation is a rare opportunity before watching one of the videos. In the control group, the proportion of correct identification fell, whereas in the supportive group it increased.

See Also: [Ethical Change Recommended to Increase Donor Organs in USA](#)

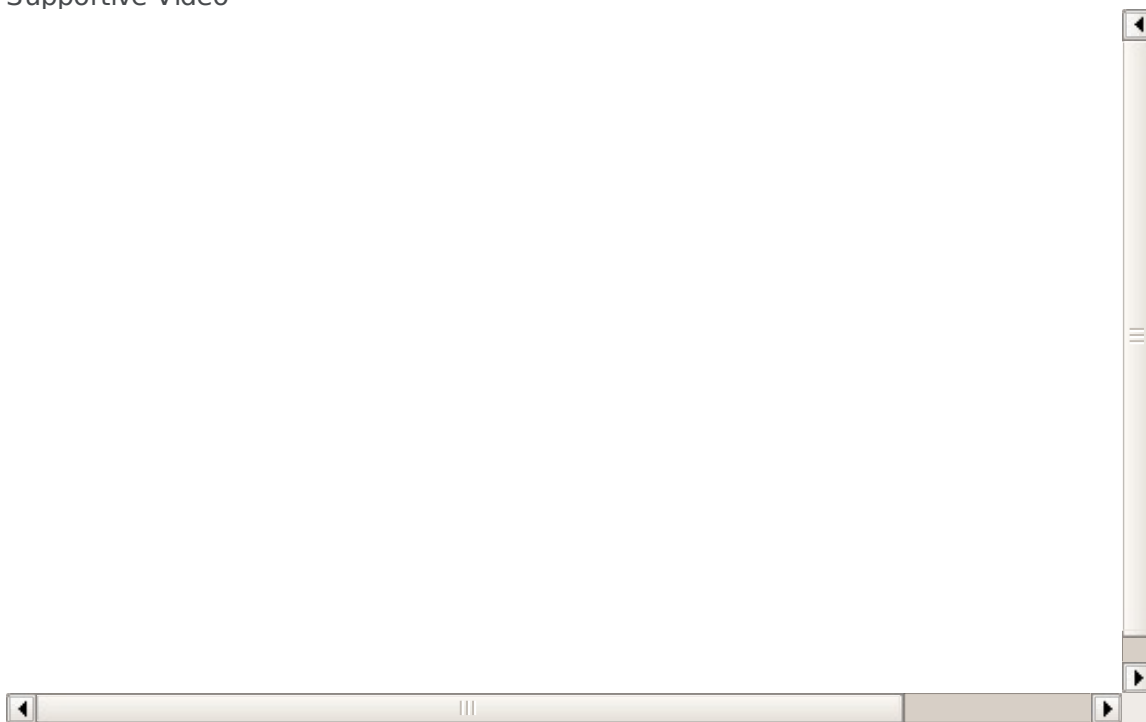
The researchers note that the study's limitations include not collecting information on level of education. Dr. Philpot stated: "Ideally, donation conversations are conducted in a manner which is tailored to the needs of the family members. This will include modifying the information provided on account of the educational level, health literacy and communication styles of the family. The nature of our study was such that the donation conversation shown could not be tailored as such."

The researchers conclude that discussions about donation can include information about the process and the benefits without the risk of putting pressure on families to give consent against the wishes of their family member.

Control Video



Supportive Video



Sources: With thanks to Dr. Steve Philpot (additional background information from the [Organ and Tissue Authority](#))
Videos included with permission.

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