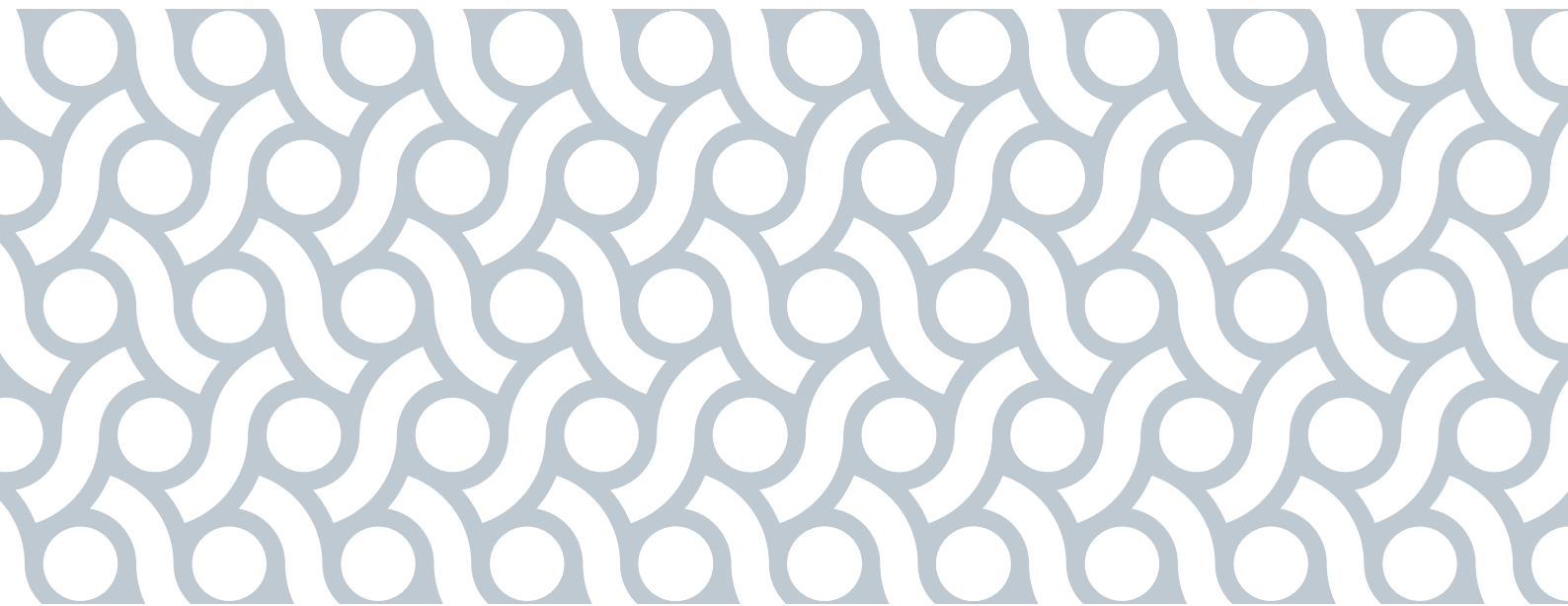


National Study of **Family Experiences of Organ and Tissue Donation**

Wave 1 – 2010 and 2011



Prepared by Proof Research Pty Ltd for the Organ and Tissue Authority

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Australian Government
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Summary Report

Background

The Organ and Tissue Authority (OTA) commissioned Proof Research Pty Ltd to conduct a national study of family experiences of organ and tissue donation for transplantation.

The purpose of this study was to provide evidence-based insight into families' experiences of the donation process from initial donation conversations through to the follow up support provided to families after a donation decision has been made.

The study aimed to inform improvements in the care and support provided to donor families by:

- › Determining factors influencing the donation decision to consent or decline;
- › Identifying the nature and quality of services provided to families at all stages of the donor families' experiences, including the timing of support and communication;
- › Identifying the way in which information is provided to families to help them with their donation decision;
- › Determining perceptions of care and support provided before, during and after the donation process;
- › Identifying family preferences in relation to support services;
- › Identifying aspects of service provision requiring improvements;
- › Investigating family attitudes in relation to contact with recipients and support provided; and
- › Investigating family attitudes on the impact of their donation decision.

This research builds on similar research undertaken with donor families since 1995, by the Australasian Transplant Coordinators Association (ACTA). The OTA now funds and

manages this research at the request of ATCA, and will undertake ongoing waves of the research to occur every two years.

This Wave 1 of the study by the OTA provides feedback from families who had a donation experience in 2010 and 2011, including families that consented to or declined donation.

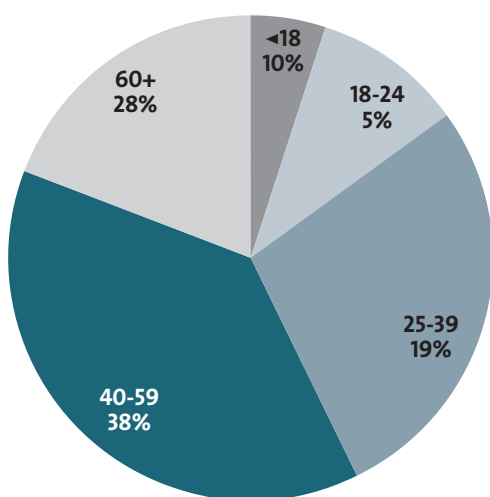
The study commenced in September 2013 and invited 700 Australian families to participate in the study by completing a survey questionnaire and/or participate in a face-to-face interview (including 674 families that consented to donation and 26 families that declined donation).

Of this group, 131 families that consented to donation (185 family members) completed the survey questionnaire. Additionally, a total of 126 family members that had consented to donation agreed to participate in a face-to-face interview. Of these, 28 family members (from different families who had consented to donation) were selected randomly and participated in face-to-face interviews in all states and territories except the Northern Territory.

This study was the first time that families who had declined donation were invited to participate in a national survey of this nature in Australia. A limited number of four states and territories were able to participate in the approach to families that declined donation with 26 of these families contacted. Of this group, one family member agreed to participate in the study and completed a survey questionnaire and agreed to participate in a family interview. An interview was conducted with this person.

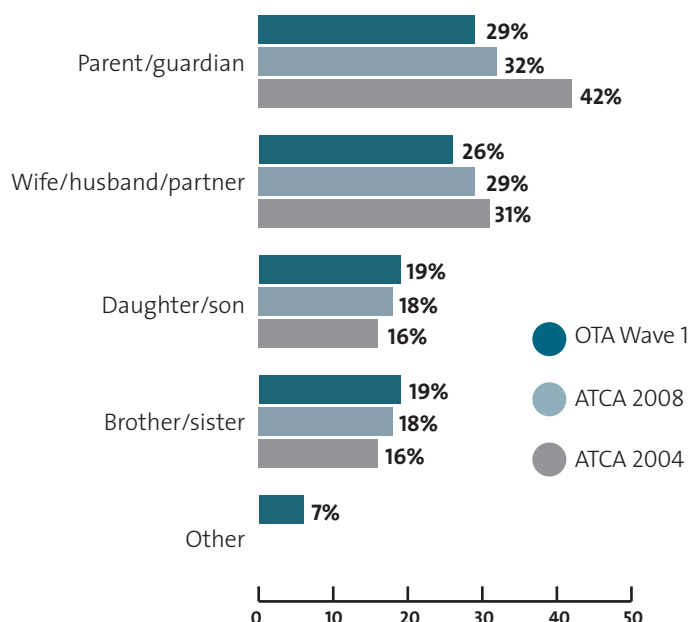
Future waves of the study will aim to invite all families that decline donation to participate in the study so that they have an opportunity to provide feedback and share their experiences.

Age of Donor



Base: Total sample Wave 1 (n=185); 2008 (n=159 BD); 2004 (n=131 BD)

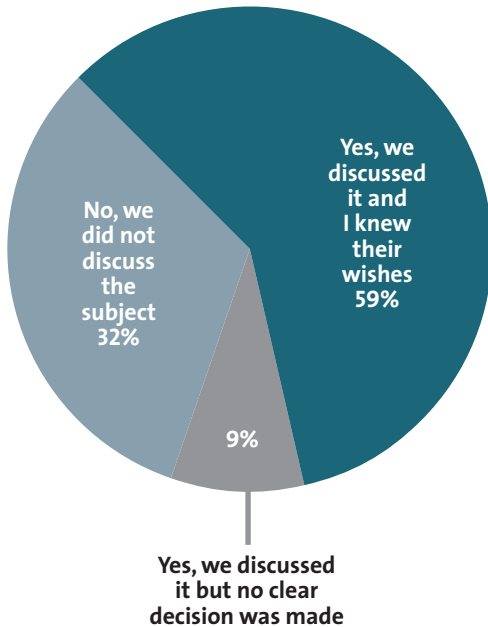
Relationship to Donor



Key Findings

Role of Prior Family Discussion

Approximately six in ten family members (59%) who participated in the study had discussed organ and tissue donation with their family member prior to being asked to consider donation. Families who had discussed organ and tissue donation with each other found the donation decision easier than families who had never had the discussion. In total, 93% of families who had a prior family discussion on donation wishes reported it made their decision easier. In contrast, 17% of those families who had not discussed donation wishes reported it made their decision more difficult.



	Total (n=181)	Discussed and knew wishes (n=109)	Discussed but did not fully know wishes (n=16)*	Did not discuss donation (n=56)
Made our decision a lot easier	57%	84%	19%	14%
Made our decision a bit easier	11%	9%	37.5%	7%
Did not impact on our decision	26%	6%	37.5%	62.5%
Made our decision a bit more difficult	5%	1%	6%	12.5%
Made our decision a lot more difficult	1%	–	–	4%

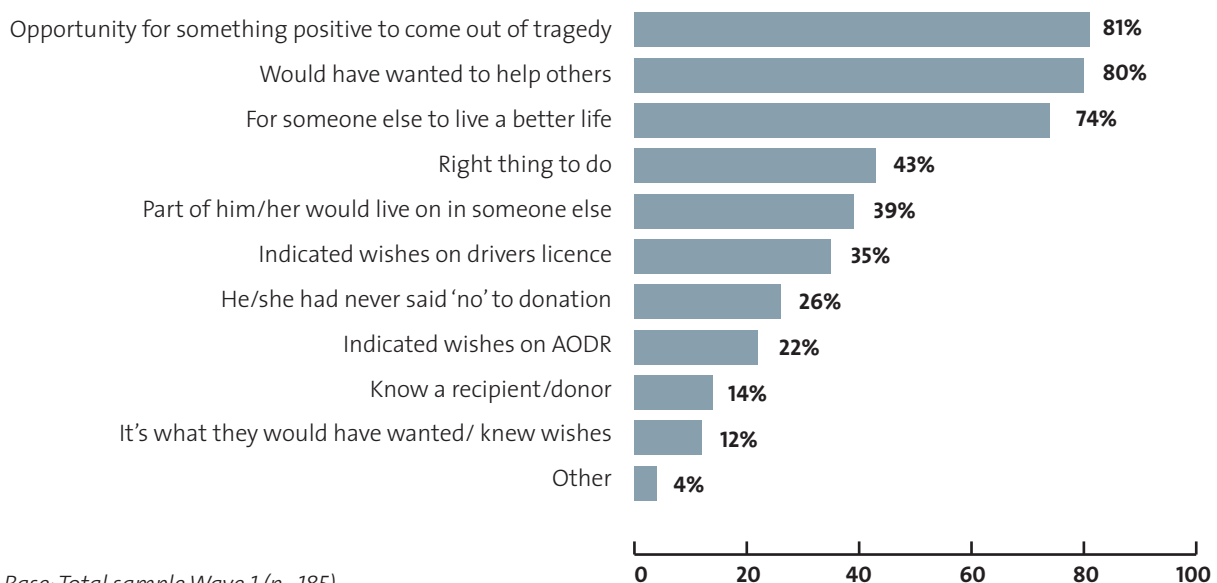
* Caution: Small base

Note: Highlighted figures are statistically significant results.

Family Reasons for Donating

The majority of donor families (81%) see organ and tissue donation as a chance for something positive to come out of a tragedy. Other strong motivating factors for donation were that their family member would have wanted to help others (80%) and so that someone else could live a better life (74%).

Motivations for Donation



Base: Total sample Wave 1 (n=185)

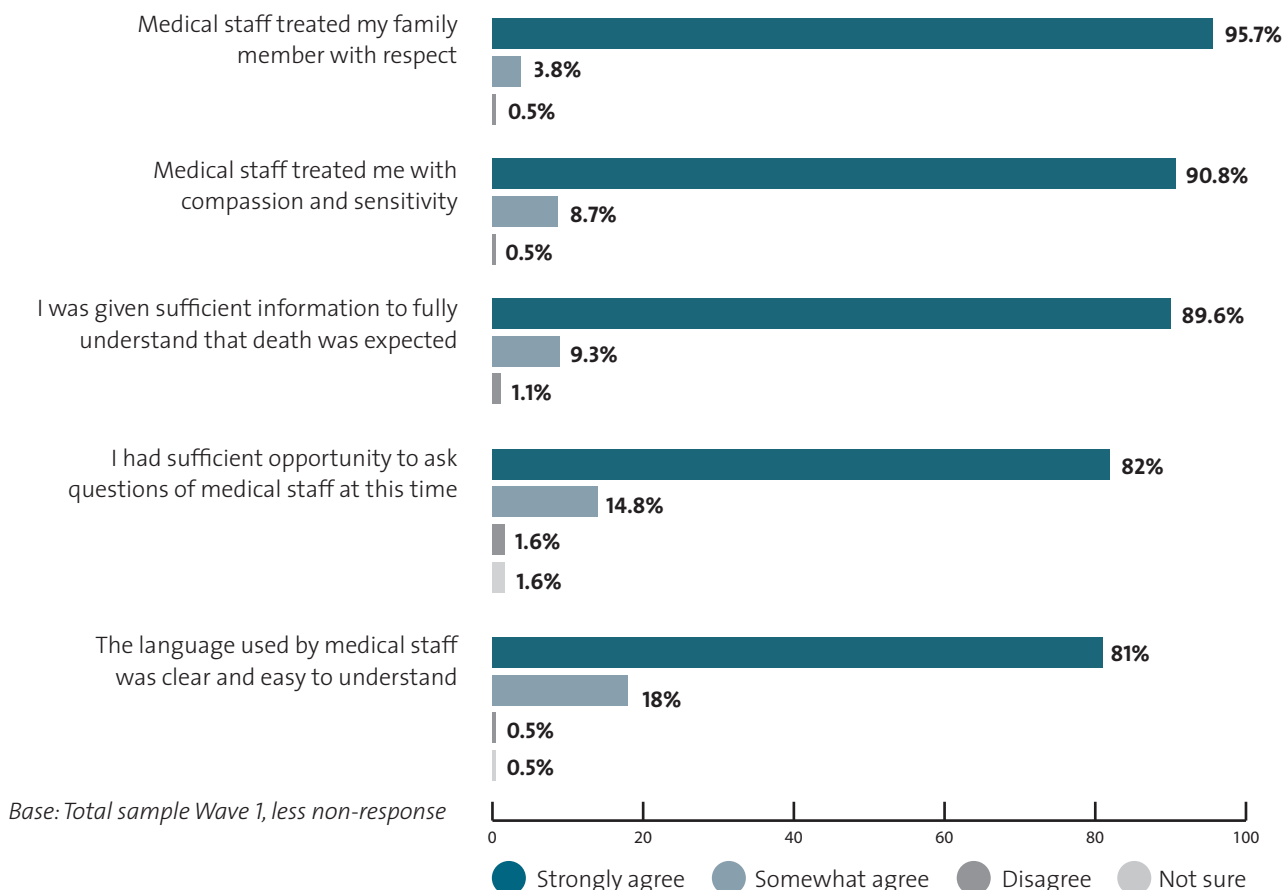
Support Provided Before, During and After Donation

The majority of donor family members (96%) feel that medical staff treated their family member with respect. Nine in ten donor family members (91%) feel they were treated with compassion and sensitivity during their time at the hospital, prior to consenting to donation.

Whilst ratings are very high, there is some room for improvement around the language used by medical staff (81% strongly agree that the language was clear and easy to understand) and ensuring families have sufficient opportunities to ask questions (82% strongly agree that they had enough opportunities to ask questions of medical staff).

**Note – Some responses from families indicate that the term ‘medical staff’ may include doctors, nurses and donation staff.*

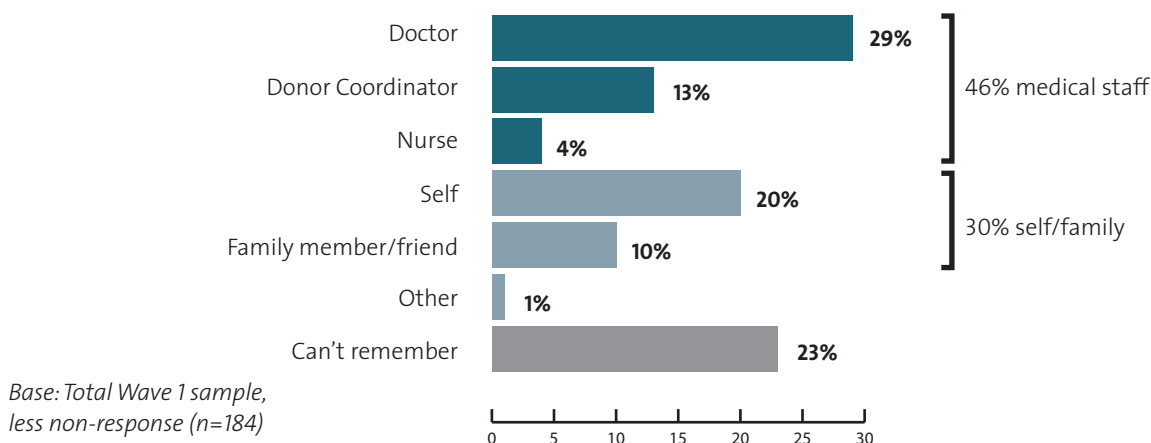
Treatment by staff



Raising donation

The possibility of donation is primarily mentioned to families by medical staff (46%). This comprises: doctors 29%; donor coordinators 13%; and nurses 4%.

One in five family members (20%) raise the subject of organ donation with medical staff themselves. In total, the donation topic is raised by the family in 30% of cases.

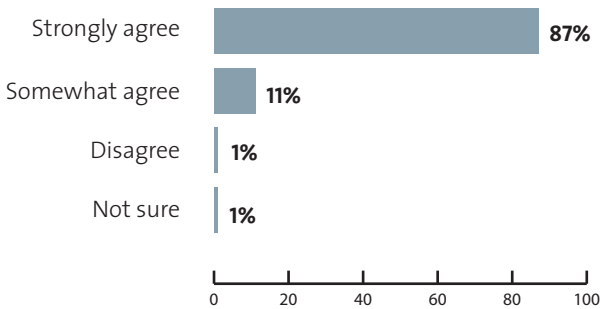


Family Donation Conversation

Almost all donor family members (98%) agreed that discussions about donation were handled sensitively and with compassion, and 95% of donor family members agreed that they were given sufficient information to make an informed decision about organ and tissue donation.

Agreement/ disagreement with statement:

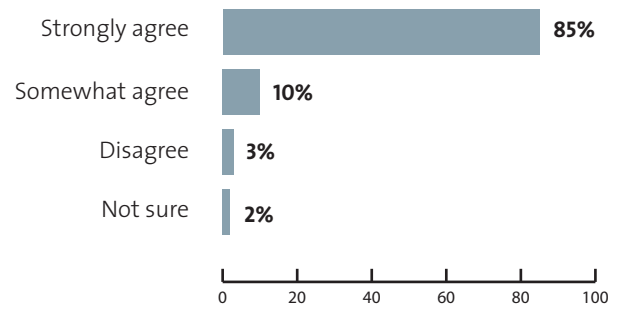
Discussions about donation were handled sensitively and with compassion



Base: Total Wave 1 sample, less non-response (n=181)

Agreement/ disagreement with statement:

We were given sufficient information to allow us to make an informed decision



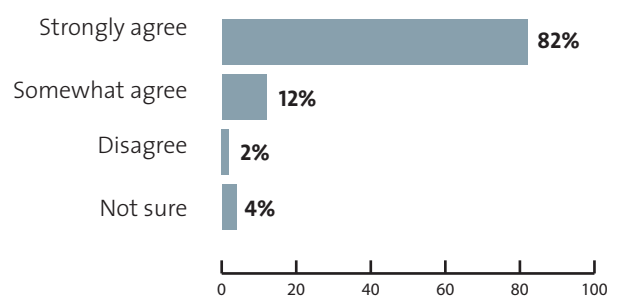
Base: Total Wave 1 sample, less non-response (n=179)

The majority of donor families strongly agree that their family was provided with enough opportunities to ask questions of hospital staff about donation (83%), and that hospital staff answered their questions (83%).

Agreement/ disagreement with statement:

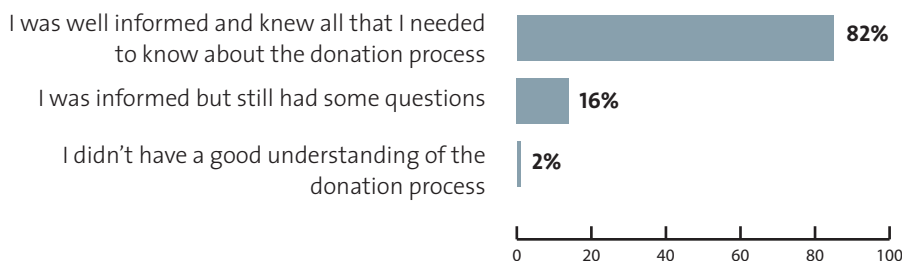
My family was given enough time to discuss donation and to make our decision

While 94% of families in total felt they were given enough time to discuss donation and to make a decision (82% strongly agree), some families felt rushed or pressured to make a decision. It is important to allow families a broad timeframe to make their decision.



Base: Total Wave 1, less non-response (n=180)

"Which statement best describes your understanding of the donation process after speaking with the donor coordinator / donation nurse or doctor?"



Base: Those who met with a donor coordinator / donation nurse or doctor (n=164)

After meeting with the donor coordinator or donation nurse/ doctor, 82% of donor families felt well informed and felt that they knew all they needed to know about the donation process.

Some families (16%) still had unanswered questions, while a further 2% of families left the meeting with no clear understanding of the donation process.

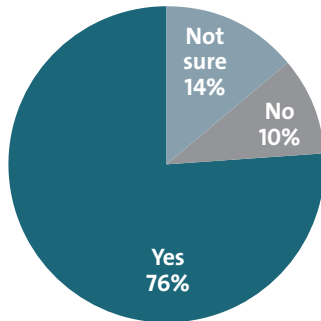
Family Support Services

Support Offered to Families

Just over 3 in every 4 donor family members (76%) were offered the support of a social worker, counsellor or chaplain at some time during their family member's stay in hospital. In 85% of cases, families were offered ongoing contact with staff from the hospital or organ and tissue donation agency, following donation.

During Family Member's Stay in Hospital

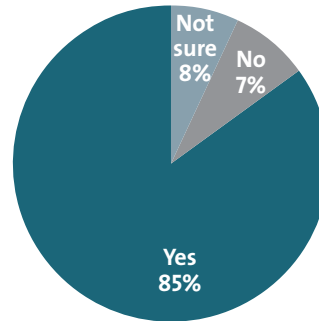
"Were you offered the support of a social worker, counsellor or chaplain at any time during your family member's stay in hospital?"



Base: Total sample Wave 1, less non response (n=183)

Following Donation

"Were you offered any ongoing contact with staff from the hospital or organ and tissue donation agency, for example, a social worker, chaplain or donor coordinator / donation nurse or doctor?"

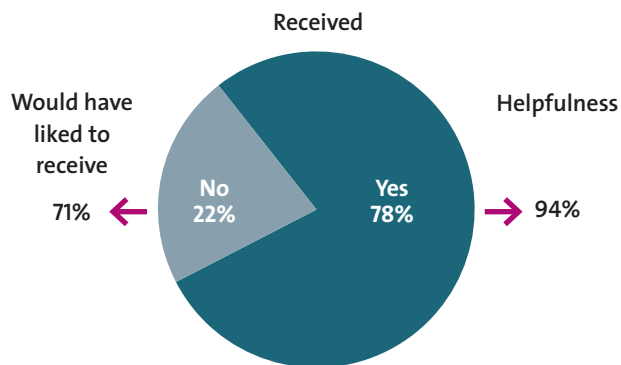


Base: Total sample Wave 1, less non response (n=182)

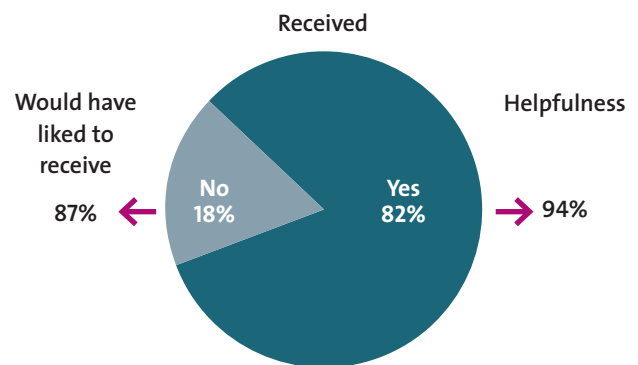
Services Received / Would Like to Have Received

The study reported the services that were received by donor family members and whether they found those services helpful. It also reported whether the family members who did not receive each service would have liked to.

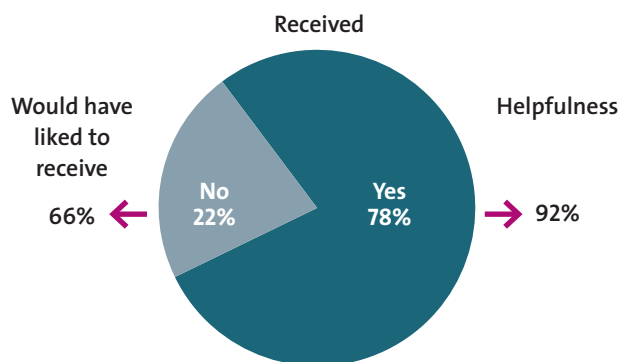
A follow up phone call from the donor coordinator / donation nurse or doctor



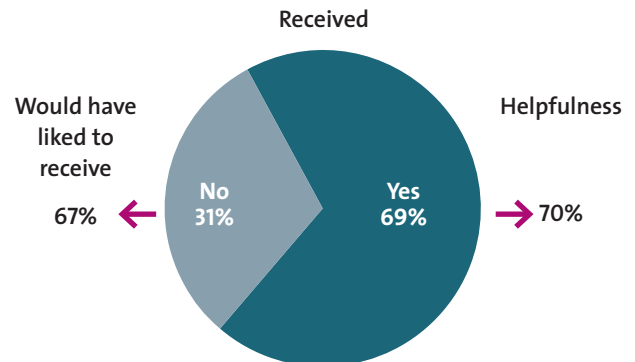
Basic information about the transplant recipients



Follow up from the donor family support coordinator



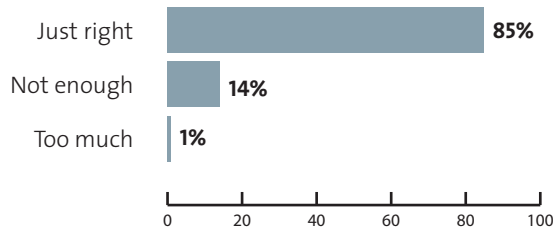
Information about bereavement support services in your area



Base: Total sample Wave 1, less non response (n=176)

Level of Contact With Donation Agency Staff

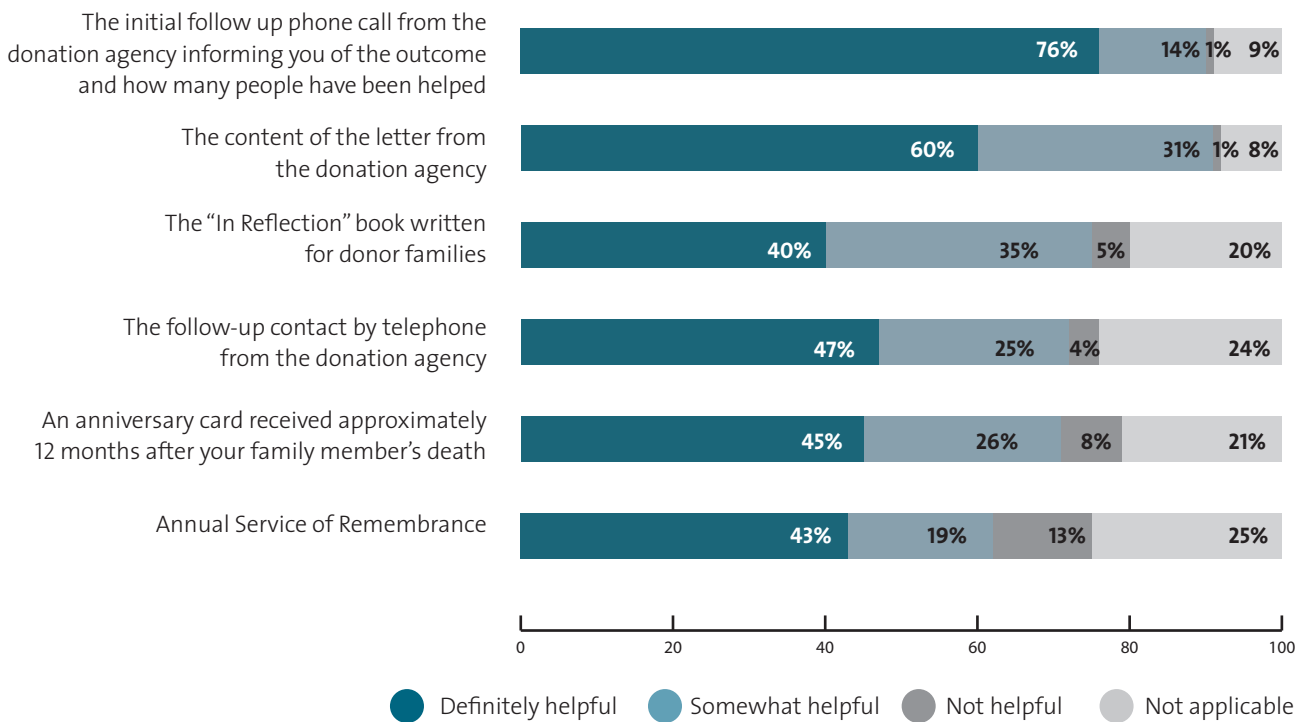
Most donor family members (85%) feel the contact they have had with donation agency staff has been at the right level. A small group of family members (14%) would have liked more follow-up contact after donation.



Base: Total sample Wave 1, less non response (n=177)

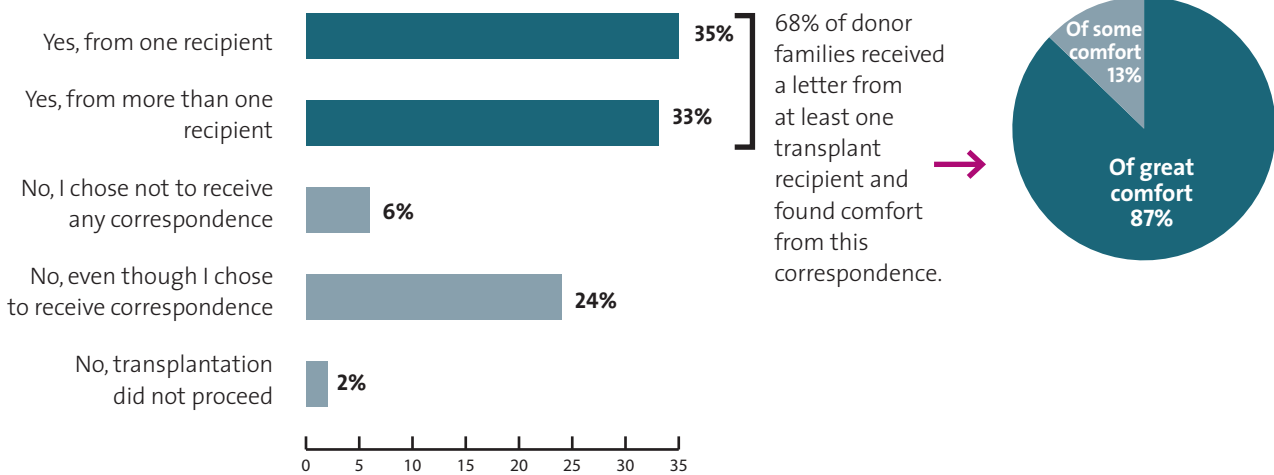
Helpfulness of Support Provided

Donor family members appreciated the range of support services provided, with the majority of family members (90%) finding the initial follow-up phone call from the donation agency to be the most helpful. When asked about other support services that could be offered, donor family members expressed a desire to have more information about recipients post transplant.



Base: Total sample Wave 1, less non response
Base sizes vary by type of support (n=170 to n=175)

Deidentified Contact with Recipients



Base: Total Wave 1 sample of unique donor families, less non response (n=125)

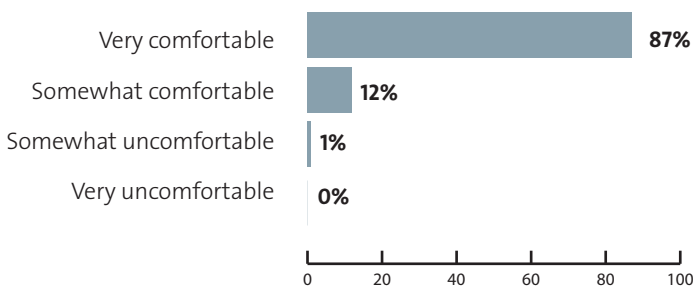
Base: Families who have received correspondence from at least one recipient, less non response (n=84)

Approximately seven in every ten donor family members (68%) received a deidentified letter from at least one transplant recipient. This letter provided great comfort to these family members.

One quarter of donor family members (24%) had not received any correspondence from recipients, even though they chose to.

Level of Comfort with Donation Decision

Almost all of the donor family members who participated in the study (99%) are comfortable with the decision to donate their family member's organs and/or tissues, with 87% being very comfortable with this decision.

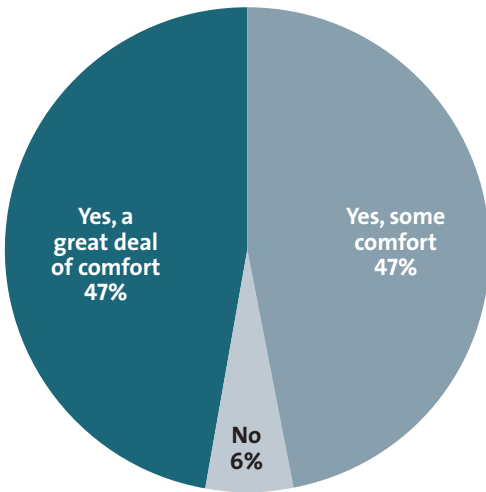


Base: Total sample Wave 1 (n=185)

The Impact of Donation

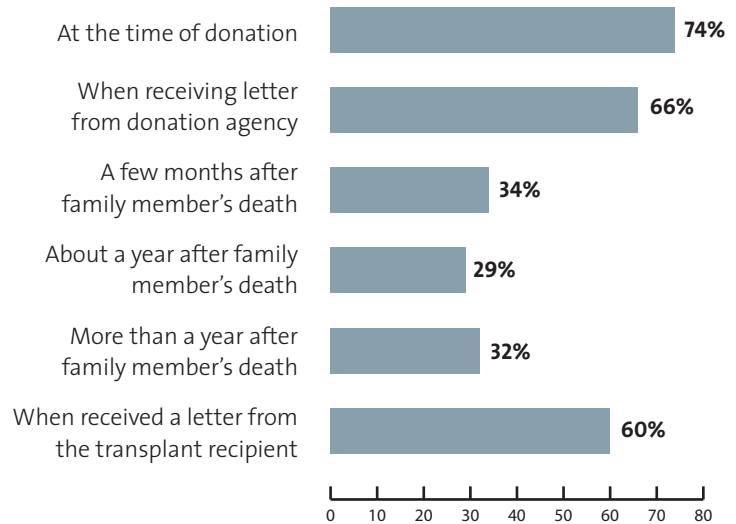
The majority of donor family members report that donation provided them with comfort in their loss (94%). Of these, 74% said they found comfort in the donation at the time of donation, and at other milestones after the donation. These responses show that organ and tissue donation can provide immediate and longer term comfort.

Has donation provided you any comfort in your loss?



Base: Total sample Wave 1, less non response (n=180)

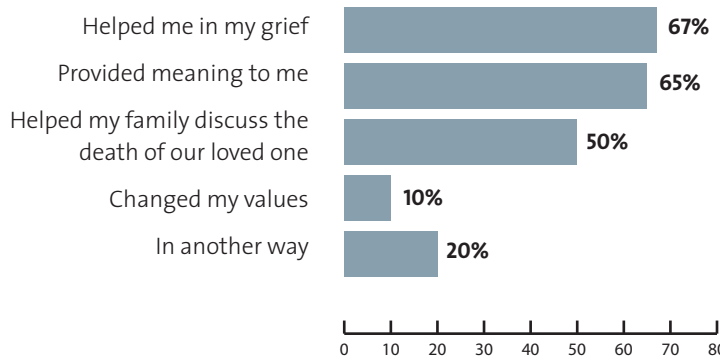
When have you found comfort in the donation



Base: Those who found comfort in the donation (n=170)
Multiple response

Comfort Provided by Donation

Donor family members say that donation has helped them in their grief (67%), provided meaning to them (65%) and helped their family to discuss the death of their loved one (50%)



Base: Those who found some comfort in donation (n=170)
Multiple response

“I feel entirely satisfied with the decision and even a little proud of it.” 2011