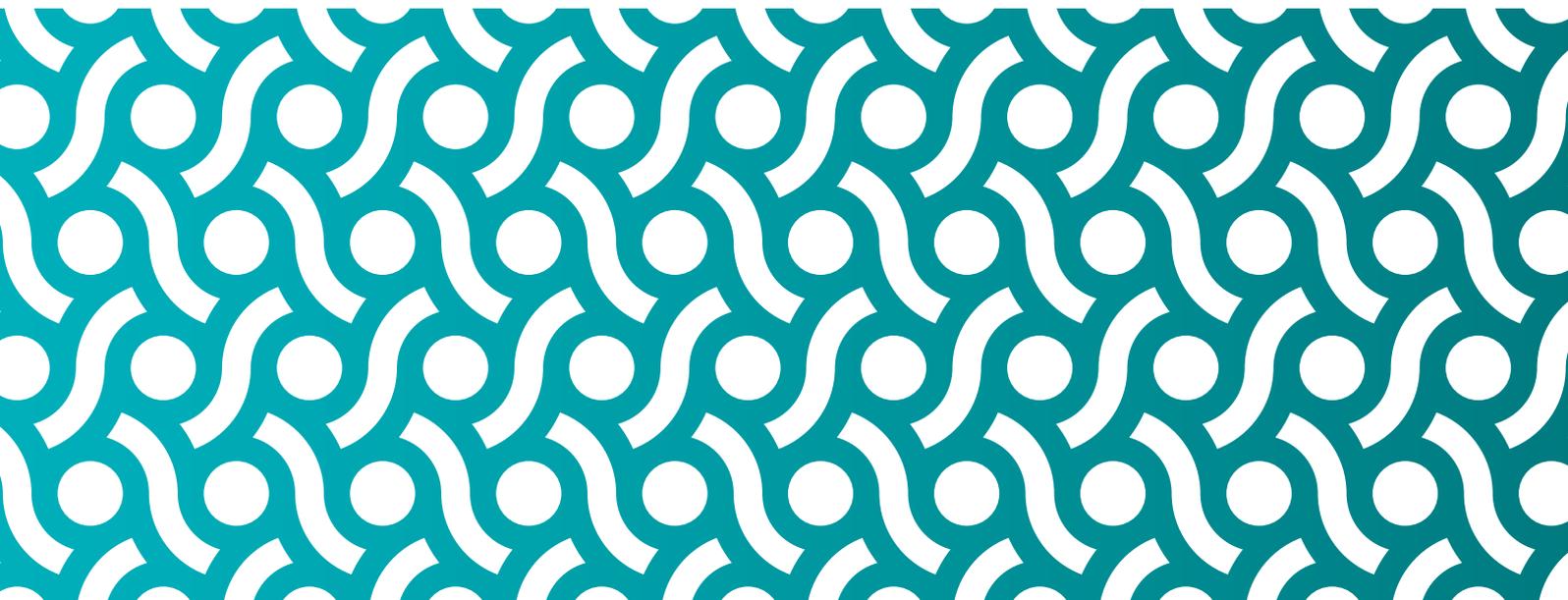


National Study of Family Experiences of Organ and Tissue Donation

Wave 4

Experiences in 2016 and 2017 – Research Report



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

PROOF



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Executive Summary

This report details the findings of Wave 4 of the National Donor Family Study and represents the views and experiences of families who made a decision about donation in 2016 and 2017. The research includes families who consented to donation and families who declined donation. The research seeks to understand families' experiences before, during and after the donation decision has been made and to ascertain and monitor how the needs of families can best be met.

All states and territories were included in the study, as were both pathways to donation – donation after brain death and donation after circulatory death. Amongst families who consented to donation, 22.6% opted to participate in the Wave 4 survey (19.5% in Wave 3; 24% in Wave 2; 18% in Wave 1) resulting in a sample size of n=405; 155 family members consented to a personal interview.

The survey response rate amongst families who declined donation in Wave 4 was 5% (8% in Wave 3; 4% in Wave 2). This resulted in 24 family members who declined donation taking part in the quantitative component of the research and 6 families consenting to a personal interview. All 6 families were interviewed.

Impact of prior knowledge

Whilst every family is different, the Donor Family Study has identified similarities in the experiences leading to a donation consent or a decline. Most importantly, families with prior knowledge of their loved one's donation wishes feel that the decision is not actually theirs to make; they are simply enacting a decision made earlier by their loved one. This means that those who have discussed donation and know what their loved one wanted, find it much easier to decide, than those who haven't discussed donation previously.

Just over half (54%) of donor family members in 2016 and 2017 who participated in the study had discussed organ and tissue donation with their loved one and knew their wishes. This is a significant decrease since Wave 3 findings, where 63% of families had discussed donation and wishes were known.

Just under half (46%) of participating family members who declined donation knew their loved ones wishes after discussing the subject of donation with them.

Overall around one third of participating family members throughout Australia had not discussed organ and tissue donation with their loved one prior to being asked to make a decision about donation in the hospital, making the decision a difficult one.

Prior knowledge of a loved one's donation wishes is important for families when making a decision about donation. Continued efforts are needed to promote family conversations about donation and to encourage people to register on the Australian Organ Donor Register.

Personal views of donation

Eighty-six percent of donor family members who participated in the research were supportive of organ donation prior to their family member's death, compared with 46% of family members who declined donation. This is a statistically significant difference and shows that an individual's own disposition towards donation has some influence over the donation decision.

Further efforts are needed to improve public perception of organ and tissue donation, which in turn will improve consent rates.

Motivations and barriers to donation

Consistent with previous research waves, most donor families (77%) in 2016 and 2017 saw organ and tissue donation as a chance for something positive to come out of a personal tragedy, and to give some meaning to their loss.

In addition, 77% of donor family members were motivated to donate because they felt that their loved one would have wanted to help others. Again, this key motivation has remained consistent over the years.

In terms of barriers, 39% of participating families who declined donation during 2016 and 2017, did so because they felt that their loved one had been through enough and/or they didn't want them to have the donation surgery. This is consistent with Wave 3 (43%).

The next strongest barrier to donation, at 35%, is believing that their loved one would not want to donate. Interestingly, this response was often coupled with responses such as 'they've been through enough' or 'I don't like the idea of donation' further reinforcing the complexity of the decision for many.

Not knowing the wishes of their loved one was reason to decline donation for 22% of families who participated in the study.

Interaction with ICU/ED staff

The experiences of those who are asked to consider donation begins in the Intensive Care Unit (ICU) or Emergency Department (ED) of hospitals across Australia. All families, irrespective of whether they consented to or declined donation feel that staff in these departments treated them with consideration and sensitivity prior to any discussions about donation.

Ninety-four percent (94%) of families who consented to donation and 91% of those who declined donation felt that medical staff clearly communicated the prognosis for their family member. Clarity of the prognosis is necessary as families need to move to a place of acceptance to 1) be open to the donation conversation, and 2) feel comfortable with their decision about donation in years to come.

Helping families to understand that their loved one will not recover requires clear, concise and consistent communication and information from hospital staff, delivered with compassion and genuine care. In most instances, this is delivered.

Brain death testing

During 2016 and 2017, 36% of family members whose loved one experienced the brain death pathway, were asked if they would like to be present during the brain death testing of their loved one. This is significantly higher than the 25% of families who were asked during 2014 and 2015.

Of those families who were invited to attend the testing, 66% opted to be present. Of those families who chose to be present, 85% said that it helped them to understand that their loved one had died.

Not all family members feel the need to witness brain death testing. However, an informed decision cannot be made unless the purpose of the test is explained and family members are given an opportunity to be present during testing. Family members who choose to attend should be emotionally supported by hospital staff during the testing. The purpose of each individual procedure and the reaction being observed should be explained as the testing progresses.

Improving the hospital experience

When asked how their experience at the hospital (prior to the donation conversation) could have been made easier for them and their family, many family members talk positively about hospital staff and say that nothing more could have been done.

Amongst those who provided suggestions to improve, the focus is on:

- Greater empathy and kindness from hospital staff
- More privacy (for family discussions, with loved one and to receive updates)
- Improved environment for the family's comfort
- Regular updates and clearer information

The donation conversation

In 2016 and 2017, one third (32%) of donation conversations were initiated by the next of kin or family members, consistent with previous waves (33% amongst families who went on to consent to donation and 8% of families who went on to decline donation). Health professionals continue to be the primary initiator of donation conversations (57% amongst families who consented to donation and 75% amongst families who declined donation, a significant difference).

In 2016 and 2017, 43% of consenting family members were asked about donation by a health professional before (14.2%) or at the same time (28.9%) as being told of their family member's brain death or expected death. The timing of the donation conversation with families who declined donation is consistent with that of families who consented.

Whilst the research tells us that families are more receptive to the donation conversation after they have had time to accept that their loved one is not going to recover, timing is only one part of the equation. The approach is also a factor.

The donation conversation should only be raised by health professionals after brain death or expected death has been confirmed with and understood by the family, and the family provided with some time to digest the news.

In the vast majority of cases, family members who consented to donation feel that initial discussions about donation were handled sensitively and with compassion (89% of family members strongly agree). The majority of families who declined donation (74%) also strongly agree that the conversation was handled sensitively.

With regards to making an informed decision about donation, 96% of donor family members agree (87% strongly) that they were given sufficient information. Families who declined donation are significantly less likely to feel this way (65% strongly agree and 22% somewhat agree that they were given sufficient information).

In 2016 and 2017, 97% of donor families agree (89% strongly) that their family was provided with enough opportunities to ask questions of hospital staff about donation. Families who declined donation are significantly less likely to feel they were given enough opportunities to ask questions (70% strongly agree; 22% somewhat agree), although this is a marked improvement over previous waves.

The majority (96%) of donor families feel that they were given enough time to discuss donation and to make their decision (86% strongly agree). Families who declined donation were much less likely to feel that they were given enough decision-making time (57% strongly agree; a significant difference).

When asked how the way in which donation was discussed with them at the hospital could have been improved after they consented to donation, 52% of family members feel that no improvements were necessary as the discussions were handled well and staff were compassionate and supportive. There is still scope, however, to improve communication with family members, to ensure that they understand the broad steps in the process leading to donation.

Family members need a private room or space in which they can gather, discuss donation and make a decision that is right for them. They should be provided with sufficient information to enable them to make an informed decision and hospital staff should ensure that families know that they can ask questions at any time. Key pieces of information required at this stage are around the process and timelines.

The donation process

Ninety-six percent of donor families recall meeting with the DonateLife coordinator, nurse or doctor. After this meeting, 84% of donor family members felt well informed; 14% still had unanswered questions and 2% left the meeting with no clear understanding of the donation process.

Significantly fewer families who went on to decline donation met with a DonateLife coordinator, nurse or doctor (63%). Of the 15 families who did meet with a DonateLife coordinator, nurse or doctor and subsequently declined donation, 60% felt they were well informed after this meeting. The remaining families left the meeting with unanswered questions (20%) or with no clear understanding of the donation process (20%).

To summarise, families who consented to donation are more likely to have met with a DonateLife coordinator, nurse or doctor and from there, are more likely to have understood the donation process.

In 2016 and 2017, 57% of consenting donor family members recall being provided with written information explaining organ and tissue donation whilst in hospital. Of families who declined donation, just 8% say they received written information.

Information delivered verbally should be tailored to the needs of individual family members – succinct and delivered in layman's terms for ease of processing, or more detail when requested. Written information is also important for donor families to receive whilst in hospital. The written information is the supplementary detail that families need to consolidate their understanding of donation.

In most instances (84% of donor families and 75% of families who declined donation), families were offered support from a social worker, counsellor or chaplain during their stay in hospital.

In terms of the information provided to families about donation surgery, 88% of donor family members feel they were given the information they wanted and 85% feel that the *amount of information* they received was just right.

Almost all families (93%) feel that they were given enough time with their family member prior to donation surgery.

The vast majority of donor families have positive experiences with ICU staff; 93% of donor family members feel that their loved one was treated with respect by ICU staff in the lead up to donation surgery.

The research found that the following can reduce the distress of family members between the time of consenting to donation and donation surgery:

- Being kept informed about timeframes
- Allowing private time with their loved one
- Health professionals continuing to care for their loved one with respect
- Being shielded from witnessing procedures that directly relate to surgery

When the theatre doors close

A recurring theme with donor families in 2016 and 2017 is the lack of support many feel when their loved one is taken to surgery. Often family members feel lost and alone at this stage. They don't know what to do or where to go. Do they wait? Do they go home? How should they respond to this situation?

It may be helpful to prepare families and talk through options on how they might like to spend this time. Families may also benefit from having a social worker or suitable person available to support family members when their loved one is taken to surgery.

Follow-up services and DonateLife resources

During 2016 and 2017, 97% of donor family members were offered ongoing contact following donation from a DonateLife coordinator, nurse or doctor, a Donor Family Support Coordinator, hospital social worker or hospital chaplain. Further, ongoing support was offered to 94% of intended donor families (families who agreed to donation however donation was not able to occur due to medical or other reasons) and 21% of families who declined donation.

In terms of DonateLife resources, donor families find the initial phone call informing them of the outcome of the donation to be incredibly helpful (97% of those who received it say it was helpful). Receiving basic information about transplant recipients is also considered helpful by 97% of donor family members who received this. The 'Resources and Assistance' leaflet and 'In Reflection' book provided by DonateLife is considered to be helpful by 92% and 91% of families who received them.

Most donor family members (77%) feel the contact they have had with DonateLife has been at the right level. One in five (20%) donor family members feel they've not had enough contact with DonateLife since their loved one died, a significant increase since Wave 3 (13%).

Contact from DonateLife provides families with support and reassurance of their donation decision. Family members need to feel that their loved one is not forgotten and that their donation is appreciated. One of the greatest comforts for family members is to know the progress of recipients.

Correspondence with recipients

More than half (53%) of donor family members in 2016 and 2017 who participated in the study know that they may write to recipients at any time. This is a statistically significant increase since Wave 3 where 44% of families knew this.

Sixty-two percent (62%) of unique donor families have received a letter, via DonateLife, from at least one transplant recipient. In almost all cases (99%), this letter provided comfort to the donor family. Overwhelmingly, families who receive correspondence from recipients are grateful. It makes them feel thankful that their loved one's gift was meaningful and that it changed a life.

Despite opting in to receive correspondence from recipients, 29% of donor families in 2016 and 2017 have not received any. These families generally feel a sense of disappointment, and sometimes hurt, by the lack of contact.

DonateLife and the Organ and Tissue Authority should continue working with transplant teams to convey the importance of recipients and recipient families writing to donor families.

On reflection

For 96% of donor families (including families of intended donors), the donation decision made in 2016 and 2017 still sits well with them today; 85% very much so. When reflecting, only 4% of family members who consented to donation are no longer comfortable with their decision to donate. A lack of contact from recipients or information about recipients (18%) continues to be a key trigger leading to some level of regret, as is the actual process of donation (16%) and the process of making the decision (12%).

Thirty-five percent (35%) of families who declined donation are not entirely comfortable with their decision about donation today. Some of these family members wanted to donate but there were other members of the family who didn't, and in the absence of knowledge of what their loved one would have wanted, the family opted to decline. Others just couldn't face donation at the time, even though they support organ and tissue donation themselves. On reflection, some feel that they may have made a different decision if they had more time.

The majority of donor families (89%) find comfort in the donation of their loved one's organs and tissues; 46% finding a great deal of comfort and 43% finding some comfort. For these family members, donation has helped them in their grief (65%) and provided meaning to them (61%).

Consistent with Waves 1 to 3, 88% of donor family members and 91% of intended donor family members would donate their own organs and/or tissues after death. Among families who declined donation in 2016 and 2017, 83% would make the same decision again, while 17% are unsure.

We thank all the families who contributed to this report to help inform the direction and planning of the Organ and Tissue Authority, donation and transplantation in this country.