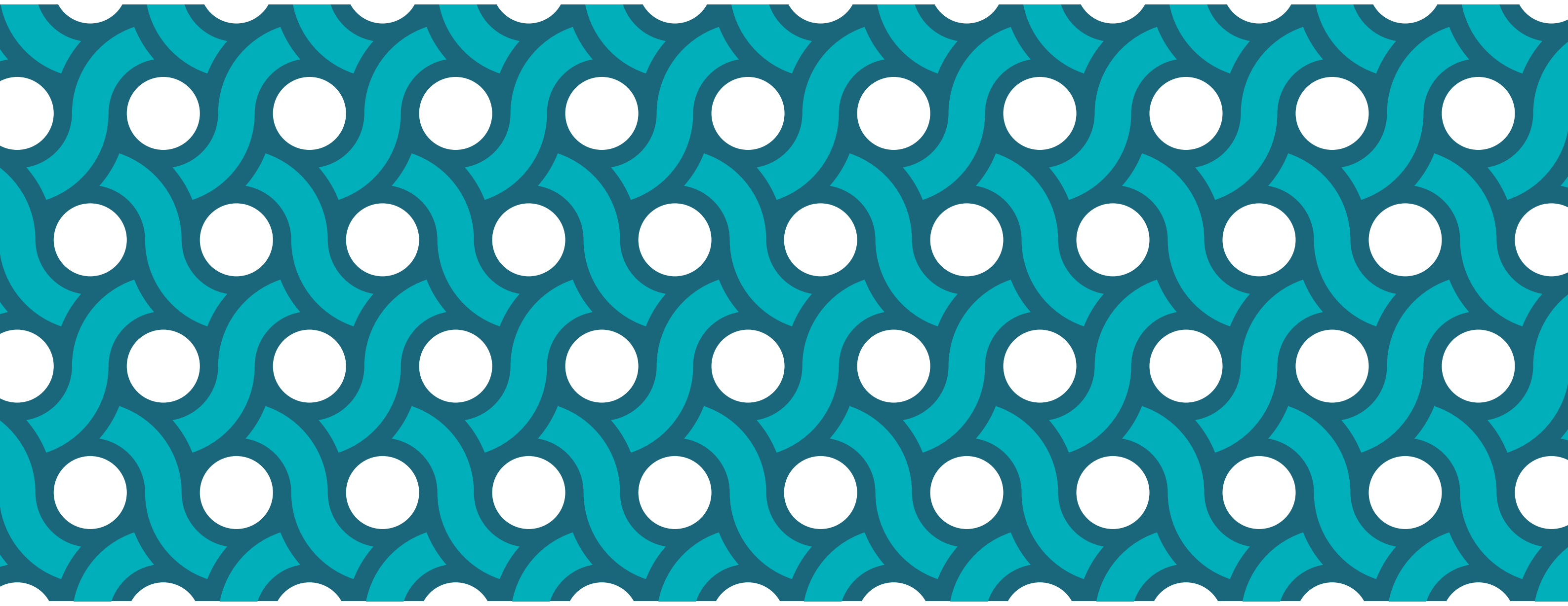
National Study of Family Experiences of Organ and Tissue Donation

Wave 3
2014 and 2015 – Research Report



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

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Executive summary

This report details the findings of Wave 3 of the National Donor Family Study and represents the views and experiences of families who made a donation decision in 2014 and 2015. 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 families who consented to organ and/or tissue donation in a hospital setting during 2014 and 2015 were invited to participate in Wave 3 of the Donor Family Study. This invitation included families who consented to donation but the donation did not proceed (intended donors). Amongst families who consented to donation, 19.5% opted to participate in the Wave 3 survey (24% in Wave 2; 18% in Wave 1) resulting in a sample size of n=257; 92 family members consented to a personal interview.

The survey response rate amongst families who declined donation in Wave 3 was 8% (4% in Wave 2). This resulted in 33 family members who declined donation taking part in the quantitative component of the research and four families consenting to a personal interview. All four families were interviewed. All states and territories were included in the study.

Impact of prior knowledge

Findings from the Donor Family Study continue to bring to light the importance of prior knowledge of a loved one's wishes regarding donation in making a donation decision. Those who had discussed donation and knew the wishes of their loved one found the decision much easier than those who hadn't.

Consistent with Wave 1 and 2 findings, 63% of donor family members in 2014 and 2015 had discussed organ and tissue donation with their loved one and knew their wishes. This is significantly higher than families who declined donation, where 41% of families knew their loved ones wishes after discussing the subject with them.

> **There is evidence in favour of keeping donation top of mind and for encouraging people to register their wishes and make those wishes known to family members. Continued efforts are needed to encourage more families in Australia to discuss donation.**

Personal views of donation

Eighty-seven per cent of families that consented to donation (donor families), were supportive of organ donation prior to their family member's death, compared with 53% of family members who declined donation.

For those who are unsure about donation, hesitation mostly stems from wanting to protect their loved one. The survey found that families who made a decision about donation in 2014 and 2015 appear to have a lack of knowledge and understanding about the process of donation, as well as some misperceptions of how their loved one will be treated during surgery.

> **Improving the general community's views of organ donation will improve consent rates. There is a need for the Organ and Tissue Authority to continue to raise awareness of the positive aspects of organ and tissue donation.**

Motivations and barriers to donation

Consistent with Waves 1 and 2, 75% of donor family members in 2014 and 2015 saw organ and tissue donation as a chance for something positive to come out of a personal tragedy. In addition, 76% of donor family members were motivated to donate because they felt that their loved one would have wanted to help others.

Amongst the research sample of families who declined donation during 2014 and 2015, 43% declined because they felt that their loved one had been through enough and/or they didn't want their loved one to have the donation surgery. Not knowing the wishes of their loved one was reason to decline donation for 23% of families, while 20% of families were honouring the wishes of their loved one by not donating.

At the hospital – ICU and ED

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. Ninety-nine per cent of families who went on to consent to donation and 94% of families who declined donation feel that staff in these departments treated them and their family member with sensitivity and consideration.

Ninety-five per cent of families who consented to donation and 91% of families who declined donation felt that medical staff clearly communicated the prognosis for their family member.

> **Clear and consistent communication from health practitioners is required and in most cases, delivered.**

For the Donation after Brain Death (DBD) pathway donors, brain death testing is required. Among 25% of families who consented to donation and 28% of families who declined donation, the offer to be present during brain death testing was made by medical staff. For families who chose to be present during testing, 72% of those who consented to donation and 83% of those who declined donation stated that witnessing the testing helped them to understand that their family member had died.

> **The research indicates that all families should be given an opportunity to be present during brain death testing due to the important role it plays in helping families to accept that their loved one has died. Acceptance of the situation is a necessary precursor to making a decision about donation.**

The donation conversation

In 2014 and 2015, the donation conversation was initiated primarily by health professionals (53% amongst families who consented to donation and 73% amongst families who declined donation).

In terms of the timing of this conversation when initiated by health professionals, 74% of donor family members and 52% of families who declined donation felt that the timing of the approach was appropriate. The perceived appropriateness of the timing increases when families are given a sufficient amount of time to process the news of impending death or brain death of their family member before being asked to consider donation.

> **The donation conversation should not be initiated before or at the same time as delivering news of death or impending death to families; rather the timing is more appropriate when the conversations are separated and paced in line with the family's needs.**

The majority (97%) of families who consented to donation agree that discussions about donation were handled with sensitivity and compassion. Families who declined donation are slightly less likely to feel this way (91% agree).

Donor families are given enough information (96% agree), opportunities to ask questions (95% agree), answers to their questions (95% agree) and time to discuss donation and make their decision (96% strongly agree). Families who declined donation also feel that these things occurred, although to a lesser extent (80%, 86%, 87% and 81% agree respectively).

Eighty-nine per cent of donor families (including intended donor families) and 85% of families who declined donation feel that they were treated with consideration and sensitivity after making their donation decision.

The donation process

Ninety-three per cent of donor families recall meeting with the DonateLife coordinator, nurse or doctor. Significantly fewer families who went on to decline donation recall meeting with a donor coordinator, donation nurse or doctor (30%). This may indicate that families who decline donation have not had the opportunity to talk with donation specialist staff before making their decision. For those families who recall meeting with a donor coordinator, 80% of donor family members and 50% of families who declined donation felt well informed.

In most instances (78% of donor families and 70% of families who declined donation), families were offered support from a social worker, counsellor or chaplain. The majority of donor family members (81%) feel they were provided with the right type and amount of information about donation surgery. Almost all families (94%) feel that they were given enough time with their family member prior to surgery. This is consistent with Wave 1 and Wave 2 research findings.

Most donor family members (94%) felt that their loved one was treated with respect by ICU staff in the lead up to donation surgery.

> **The time between consent and donation surgery is often difficult for families. At this time, families require private time with their loved one and to be kept informed of timeframes.**

Follow-up services and DonateLife resources

During 2014 and 2015, 97% of donor family members were offered ongoing contact from a DonateLife coordinator, nurse or doctor, a Donor Family Support Coordinator, hospital social worker or hospital chaplain. Further, ongoing support was offered to 93% of intended donor families and 16% of families who declined donation. All families who declined donation stated that they would have found information about bereavement support services helpful.

In terms of DonateLife resources, donor families find the initial phone call informing families of the outcome of the donation to be incredibly helpful (99% of those who received it say it was helpful). Receiving basic information about transplant recipients is also considered helpful by 99% of donor family members who received this.

Eighty-one per cent of donor family members feel the contact they have had with DonateLife has been at the right level; one in eight (13%) family members feel that contact with donation agency staff has been lacking. These findings are consistent with Waves 1 and 2.

> **Contact from DonateLife links families with support services to assist them after donation. 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.**

Contact with recipients

The survey found that 44% of donor families members in 2014 and 2015 are aware that they are able to write to recipients. This is consistent with Wave 2.

Sixty-three per cent 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. Receiving information about recipients (either through autonomous correspondence or through DonateLife) helps families to heal and reassures them that their donation decision was the right one.

Despite choosing to receive correspondence, 22% of donor families have not received any (consistent with Waves 1 and 2). These families generally feel a sense of disappointment with the lack of contact.

On reflection

The vast majority of donor families (92%) find comfort in the donation of their loved one's organs; 50% finding a great deal of comfort and 42% finding some comfort. For these family members, donation has helped them in their grief (64%) and provided meaning to them (63%).

The survey found that just 3% of donor families and 7% of families who declined donation in 2014 and 2015 are not comfortable with their donation decision in hindsight. A lack of contact from recipients or information about recipients (19%) continues to be a key trigger leading to some level of regret, as is the actual process of donation (19%). Further, fitting with the importance of encouraging families to discuss donation, 23% of donor family members who are not entirely comfortable with their decision are questioning whether their loved one would have wanted to donate.

Consistent with Waves 1 and 2, 89% of donor family members and 88% of intended donor family members would donate their own organs/tissues after death. Among families who declined donation in 2014 and 2015, 70% would make the same decision again, suggesting that 30% of families who declined donation may feel some level of regret in their decision.