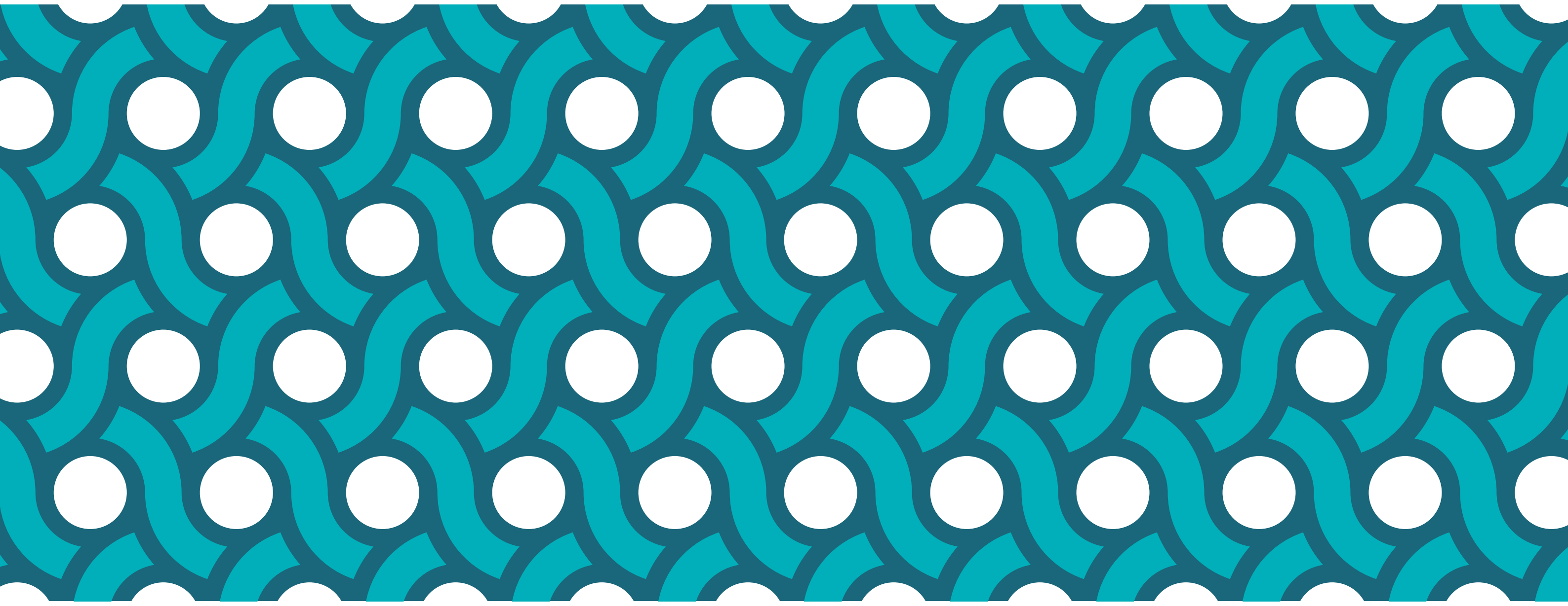
National Study of Family Experiences of Organ and Tissue Donation

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.

Part A – Research overview

1 Research background

The Organ and Tissue Authority (OTA) commissioned the National Donor Family Study to obtain information on family experiences of organ and tissue donation for transplantation. The study seeks to learn from and understand the family's experience, from early interactions with hospital and DonateLife staff and initial donation conversations, through to the follow-up contact and support provided to families after a donation decision was made.

The conversations with families and insights from families provides valuable evidence for the ongoing review and enhancement of the care and support provided to families before, during and after donation. The Donor Family Study ensures that families are heard. The findings are used in determining how the needs of families can best be met.

In 2013, OTA appointed Proof Research to conduct Wave 1 of the Donor Family Study, representing families who made a donation decision in 2010 and 2011. Wave 2, representing families who made a donation decision in 2012 and 2013, is available on the DonateLife website[1].

This report details findings of Wave 3 of the Donor Family Study, representing families who made a donation decision in 2014 and 2015, and compares findings with the earlier waves.

2 Research objectives

The overall aim of the Donor Family Study is to:

Provide evidence-based insight into the experiences of families who have been asked to consider organ and tissue donation in a hospital setting.

This aim is supported by a number of key objectives:

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

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[1] http://www.donatelife.gov.au/resources/donor-families/national-donor-family-study

3 Research methodology

A mixed methodology research program, with quantitative and qualitative components, was designed to address the aim and objectives of the national study.

The program involved five key stages:

Stage 1: Inception meeting and project set up.

Stage 2: Design research instruments and documents.

Stage 3: Human Research Ethics Committee (HREC) and Research Governance (RG) submission and approval process.

Stage 4: Fieldwork – quantitative and qualitative research.

Stage 5: Analysis and reporting.

3.1 Stage 1: Inception meeting and project set up

At the outset of the project, meetings were held between OTA, Proof Research, Donor Family Support Coordinators (DFSCs) and donor family members including representation from Donor Families Australia. Proof Research presented the proposed research methodology and through a consultative process with OTA and the DFSCs, the research program was confirmed to proceed.

3.2 Stage 2: Design research instruments and documents

Study documents approved by a number of HRECs are outlined below. These documents are included in the Appendices (A4):

- covering letter from Hospital Health Services (HHS)/hospitals (for families who declined donation)
- covering letter from the CEO of the Organ and Tissue Authority.
- Participant Information Statement
- consent form (for participation in a personal interview)
- questionnaire:
  - — families who consented to donation
  - — families who declined donation
- discussion guide for use in the in-depth personal interviews:
  - — with families who consented to donation
  - — with families who declined donation.

3.3 Stage 3: HREC and Research Governance submission process

Approval to conduct Wave 3 of the Donor Family Study was granted by the HRECs shown in Table 1. Whilst approval was granted in applications covering Waves 2, 3 and 4, amendment requests were submitted for minor changes to the study documents and research method (the latter for Western Australia only).

Table 1 List of Human Research Ethics Committees for consenting strand of research

State/territory	Families who consented to donation HREC	Approval date
ACT	ACT Health HREC	22 February 2018
NSW	Australian Red Cross Blood Service Ethics Committee	24 July 2017
	South Eastern Sydney Local Health District HREC	10 August 2017
VIC	Austin Health HREC	6 September 2017
TAS	University of Tasmania HREC (Tasmania) Network	26 July 2017
SA	SA Health HREC	3 February 2015
NT	Menzies School of Health Research	26 July 2017
	Central Australian HREC	9 August 2017
WA	Sir Charles Gairdner Group HREC	16 November 2017
	St John of God Health Care HREC	10 August 2017
QLD	Townsville Hospital and Health Service HREC	20 July 2017

Site specific applications were required to conduct the research with families who declined donation, as family contact details were held at the Hospital and Health Service/hospital and not with DonateLife. Approval to conduct Wave 3 of the Donor Family Study with families who declined donation was granted by the Research Governance Offices (RGOs) outlined in Table 2.

Table 2 List of Research Governance Offices for declined strand of research

Location	Families who declined donation RGO	Approval date
ACT	ACT Health HREC (for Canberra Hospital)	22 February 2018
NSW	Northern NSW Local Health District	22 December 2016
	The Sydney Children's Hospitals Network	31 January 2017
	Illawarra Shoalhaven Local Health District	17 March 2017
	Northern Sydney Local Health District	31 March 2017
	Hunter New England Local Health District	4 April 2017
	Western Sydney Local Health District	26 June 2017
	Sydney Local Health District	See Note 1
VIC	Peninsula Health	6 December 2016
	Ballarat Health Services and St John of God Hospital Ballarat	14 December 2016
	Northern Health	18 January 2017
	Austin Health	29 March 2017
	Eastern Health	29 March 2017
	Western Health	30 March 2017
	The Royal Children's Hospital Melbourne	4 May 2017
	St Vincent's Health	16 May 2017
	Alfred Health	See Note 1
	Melbourne Health	12 December 2017
	Monash Health	6 June 2017
TAS	Covered by HREC approval (for Royal Hobart Hospital, Launceston General Hospital, North West Regional Hospital)	26 July 2017

Location	Families who declined donation RGO	Approval date
SA	Northern Adelaide Local Health Network	10 March 2016
	Central Adelaide Local Health Network	16 March 2016
NT	Covered by HREC approval (for Royal Darwin Hospital)	26 July 2017 (Menzies) 9 August 2017 (CAHREC)
WA	Sir Charles Gairdner and Osborne Park Health Care Group	16 November 2017
	St John of God Health Care	10 August 2017
	Child and Adolescent Health Service	20 December 2017
	South Metropolitan Health Service	12 April 2018
	East Metropolitan Health Service	2 March 2018
QLD	Gold Coast Hospital and Health Service	20 July 2017
	Metro South Hospital and Health Service	25 July 2017
	Townsville Hospital and Health Service	21 August 2017
	Metro North Hospital and Health Service	20 July 2017
	Sunshine Coast Hospital and Health Service	26 July 2017

Note 1: The RGO at the locations listed requested a change to methodology that was not in line with the HREC approved methodology. The application for Site Specific Approval was therefore withdrawn and families in these locations were unable to participate in the study.

3.4 Stage 4: Fieldwork

A mixed methodology was used involving quantitative and qualitative data collection. Both stages were conducted concurrently. Integrating the data in this way provides a deeper understanding of families and their experiences.

3.4.1 Quantitative fieldwork

In all states and territories, once databases containing the name and address details of family members were received from authorised DonateLife and hospital staff, survey packs were prepared by Proof Research and distributed direct to families.

The survey packs contained:

- introductory letter from the hospital (for families who declined donation)
- introductory letter from OTA
- Participant Information Statement
- consent form
- questionnaire, enclosed in a sealed envelope, and
- a reply paid envelope for families to return their consent form and/or completed questionnaire to Proof Research.

Each pack was coded with a unique identifier which maximised anonymity and data confidentiality throughout the study. The unique identifier allowed Proof Research to isolate non-responding family members and send a respectful reminder card. The reminder cards were only sent to family members who had consented to donation; those who declined donation were not sent a reminder card.

Fieldwork was staggered according to HREC and RGO approval dates and receipt of the relevant databases. Survey packs were distributed to families who consented to donation between 20 July 2017 and 22 March 2018. Reminder cards were distributed between 30 August 2017 and 12 April 2018. For families who declined donation, survey packs were distributed between 25 July 2017 and 25 May 2018.

The survey was made available to family members in both hard copy (distributed with survey pack) and online form (link to online survey sent to families on request).

3.4.2 Qualitative fieldwork

Face-to-face in-depth interviews with families who agreed to participate in a personal interview were conducted by Proof Research. Interviews were conducted with families across Australia at a time and place that suited the participant; in the majority of cases, interviews were held in the participant's home. Rhonda McLaren, Director of Proof Research, conducted all interviews, with the interview length averaging 60 minutes.

Face-to-face interviews were conducted between 30 August 2017 and 12 July 2018. With the permission of families, the interviews were audio recorded for transcription and analysis purposes.

Those who participated in an in-depth interview were grateful for the opportunity to speak about their loved one. Whilst the topic was extremely emotive, participants spoke openly and honestly about their experience.

> **“I was really thrilled to get the letter about the feedback (research). Yeah, that made me feel really good. I wanted that… I wanted to have someone to tell.”**
> 2014 – Consented to donation

> **“Thank you for inviting my response. I see this as one more affirmation of your valuable, caring service.”**
> 2015 – Consented to donation

There were no instances where the participant was overly distressed or required intervention or further support. In all instances however, the offer of further support through the DonateLife Agency and Lifeline was made.

3.5 Stage 5: Analysis and reporting

Quantitative fieldwork for families who **consented** to donation closed in August 2018, leaving it open to accommodate families from the ACT due to late ethics approval for this jurisdiction. Hard copy questionnaires and online responses were then merged into one central database for statistical analysis. A phase of data cleansing and validation was carried out to address anomalies, missing responses and to confirm the final response rate. Recordings of all personal in-depth interviews were transcribed and full content analysis on each was carried out.

The fieldwork period for families who **declined** donation closed in August 2018, leaving it open to accommodate families from Canberra Hospital and Royal Melbourne Hospital due to late ethics approvals for these two sites.

3.5.1 Analytical notes

Below are a number of notes in reference to the analysis and reporting of findings:

- The analysis throughout this report is primarily based on individual responses, consistent with past reporting. Where it makes more sense to report on the views of a unique family unit rather than family members within that unit, this has been done and noted.
- Where possible, findings from Wave 3 are compared and contrasted against findings from Waves 1 and 2.
- Throughout this report, statistically significant differences are noted for sub-groups of the sample with this [xx] symbol.

A 'significant' difference refers to a statistically significant difference or result that is not due to chance (i.e. not just a difference that could be due to taking a sample, rather than conducting a census where we have a 100% response).

The findings of both the quantitative and qualitative analysis are reported together throughout this document.

4 Sampling – families who consented to donation

4.1 Sample frame

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, based on the contact details provided to Proof Research by the authorised DonateLife and hospital staff. This invitation included intended donors (i.e. families who consented to donation but the donation did not proceed).

4.2 Response rates

Survey packs were sent to n=1,444 family members (representing 979 unique families) who consented to organ and tissue donation. Of these, 125 were returned to sender due to a change of address or the person being deceased. This brought the total survey population to n=1,319. Of these, n=257 family members who consented to donation in 2014 or 2015 took part in Wave 3 of the Donor Family Study. This equates to an overall response rate of 19.5%, an improvement on Wave 1 (18%) but lower than Wave 2 (24%).

In terms of the qualitative research strand, 92 consenting donor family members agreed to participate in a personal interview. Of these, a random selection of 32 personal interviews were conducted face-to-face, with each interview averaging 60 minutes in duration.

4.3 Sample composition – quantitative

4.3.1 Geographic coverage

The distribution of the sample across states and territories is shown in Table 3. Comparing the research sample with the actual population of donor families shows that the sample for most states/territories is in line with population (within ± 3%). The exceptions to this are Tasmania, which is over-represented by 4.6%, Queensland, which is under-represented by 5.1%, and Western Australia, which is under-represented by 4.3%.

In total, approximately one in five donor family members (19.5%) who were invited to participate in the study did so.

Table 3 Wave 3 – Quantitative sample overview by state/territory (consenting strand)

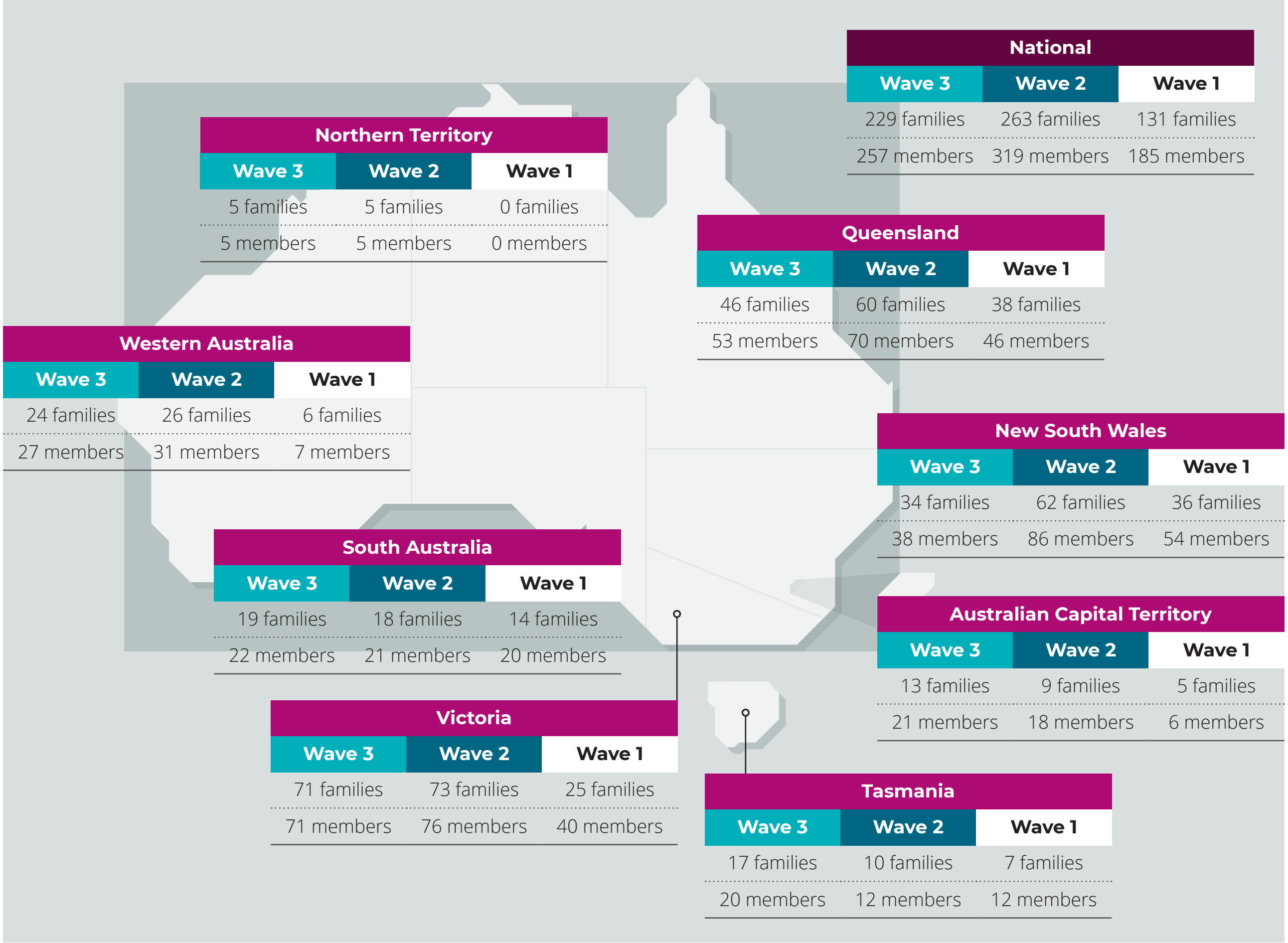
	Target population		Participating sample		
State/ territory	**Consenting donor family members***	**% of national total**	**No. questionnaires completed**	**% of national total**	**Response rate**
NSW	195	14.8%	38	14.8%	19.5%
ACT	100	7.6%	21	8.2%	21.0%
VIC	325	24.6%	71	27.6%	21.8%
TAS	42	3.2%	20	7.8%	47.6%
QLD	339	25.7%	53	20.6%	15.6%
SA	105	8.0%	22	8.6%	21.0%
NT	17	1.3%	5	1.9%	29.4%
WA	196	14.8%	27	10.5%	13.8%
Total	**1,319**	**100.0%**	**257**	**100.0%**	**19.5%**

* Excluding surveys packs that were returned to sender

As stated, a total of 257 individual family members took part in Wave 3 of the Donor Family Study. These individuals represent 229 unique donor families. Including members of the same donor family in the study is important as each individual family member's experience is unique and it ensures that the range of experiences is included.

A comparison of the Wave 3 sample of unique families and family members is shown in Figure 1, together with the trend data from Waves 1 and 2.

Figure 1 Quantitative sample national breakdown



National

Wave 3	Wave 2	Wave 1
229 families	263 families	131 families
257 members	319 members	185 members

Northern Territory

Wave 3	Wave 2	Wave 1
5 families	5 families	0 families
5 members	5 members	0 members

Queensland

Wave 3	Wave 2	Wave 1
46 families	60 families	38 families
53 members	70 members	46 members

Western Australia

Wave 3	Wave 2	Wave 1
24 families	26 families	6 families
27 members	31 members	7 members

New South Wales

Wave 3	Wave 2	Wave 1
34 families	62 families	36 families
38 members	86 members	54 members

South Australia

Wave 3	Wave 2	Wave 1
19 families	18 families	14 families
22 members	21 members	20 members

Australian Capital Territory

Wave 3	Wave 2	Wave 1
13 families	9 families	5 families
21 members	18 members	6 members

Victoria

Wave 3	Wave 2	Wave 1
71 families	73 families	25 families
71 members	76 members	40 members

Tasmania

Wave 3	Wave 2	Wave 1
17 families	10 families	7 families
20 members	12 members	12 members

4.3.2 Year of donation

In terms of the year-of-donation breakdown, 45% of families included in the Wave 3 sample consented to donation in 2014; the remaining 55% in 2015 (Table 4).

Table 4 Total number of unique donor families by state/territory and year of donation

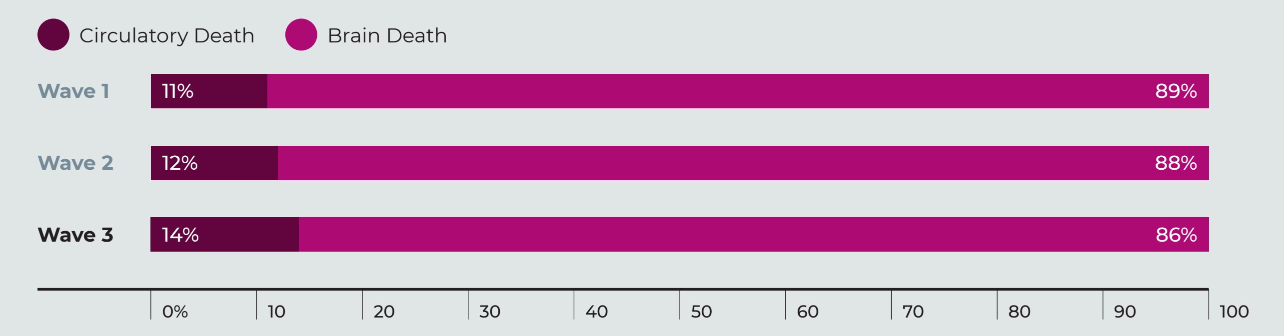
	Wave 1		Wave 2		Wave 3	
State/ territory	**2010** (n=54)	**2011** (n=77)	**2012** (n=123)	**2013** (n=140)	**2014** (n=102)	**2015** (n=127)
NSW	13	23	33	29	14	20
ACT	2	3	6	3	7	6
VIC	9	16	34	39	30	41
TAS	4	3	5	5	10	7
QLD	14	24	23	37	21	25
SA	8	6	7	11	8	11
NT	0	0	2	3	4	1
WA	4	2	13	13	8	16
Total	**54 (41%)**	**77 (59%)**	**123 (47%)**	**140 (53%)**	**102 (45%)**	**127 (55%)**

4.3.3 Donation pathway

There are two pathways to deceased donation: donation after brain death (DBD) and donation after circulatory death (DCD). Families who consented to donation after their family member was declared brain dead and those where donation followed circulatory death, were included in the Donor Family Study.

As shown in Figure 2, DBD comprises 86% of the Wave 3 sample, while DCD comprises 14%. The sample distribution for donation pathway has been consistent over time.

Figure 2 Donation pathway of sample, over time



Base: Total sample of unique families: Wave 1 (n=131); Wave 2 (n=263); Wave 3 (n=229)

Table 5 shows the donation pathway for the three waves of research, by state/territory.

Table 5 Number of donor families, with breakdown of DCD and DBD pathways, by state/territory

	Wave 1 2010/2011		**Wave 2** 2012/2013		**Wave 3** 2014/2015	
State/territory	**DCD**	**DBD**	**DCD**	**DBD**	**DCD**	**DBD**
NSW	4	32	3	59	3	31
ACT	–	5	1	8	4	9
VIC	2	23	16	57	15	56
TAS	–	7	1	9	2	15
QLD	7	31	7	53	6	40
SA	1	13	1	17	1	18
NT	–	–	1	4	–	5
WA	–	6	2	24	1	23
Total no. unique families	**14 (11%)**	**117 (89%)**	**32 (12%)**	**231 (88%)**	**32 (14%)**	**197 (86%)**

4.3.4 What was donated

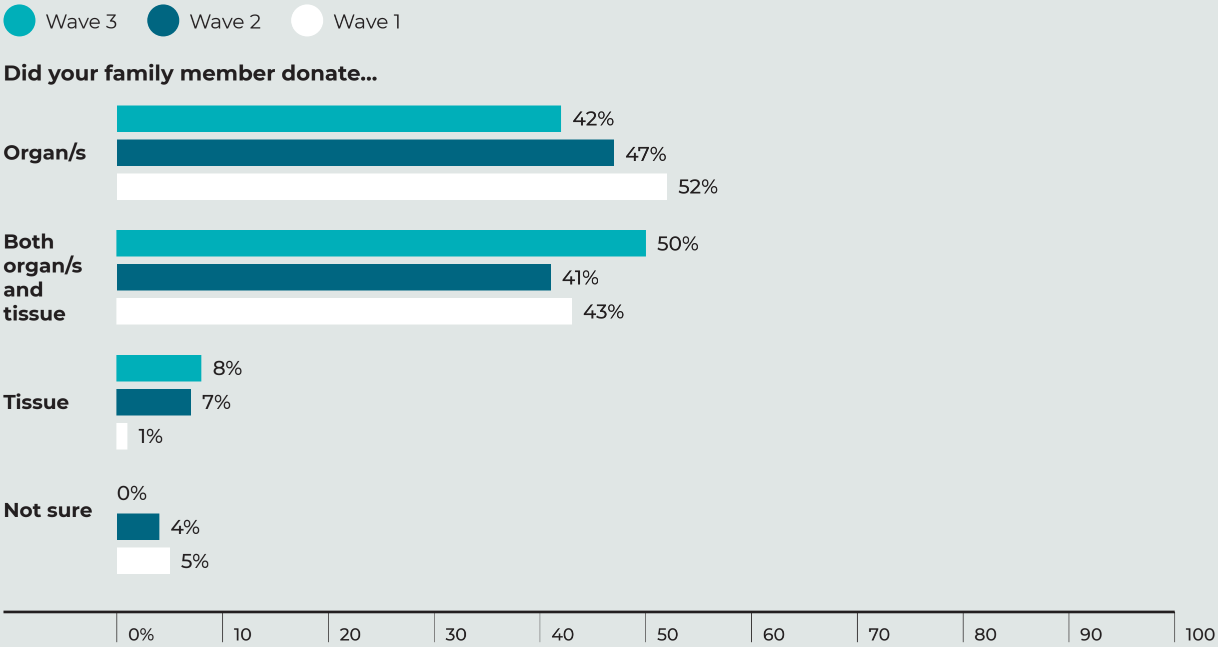
As shown in Table 6, intended donors represent 7% of the Wave 3 sample; families of those who donated only organs represent 39% and families of those who donated both tissue and organs 47% (up from 39% in Wave 2). There are no significant differences between 2014 and 2015 donors.

Table 6 Donation by year of donation

	Year of donation (unique donor families)		
	Wave 3	**Wave 3** By year of donation	
What was donated	**Total** (n=229)	**2014** (n=102)	**2015** (n=127)
Organs only	39%	42%	36%
Organs & tissue	47%	47%	46%
Tissue only	7%	4%	10%
Donation did not proceed	7%	7%	7%

Re-percentaging the data to exclude intended donors, approximately half (50%) of the Wave 3 sample includes families who donated both organs and tissue (Figure 3).

Figure 3 Sample profile – what was donated, Waves 1, 2 and 3



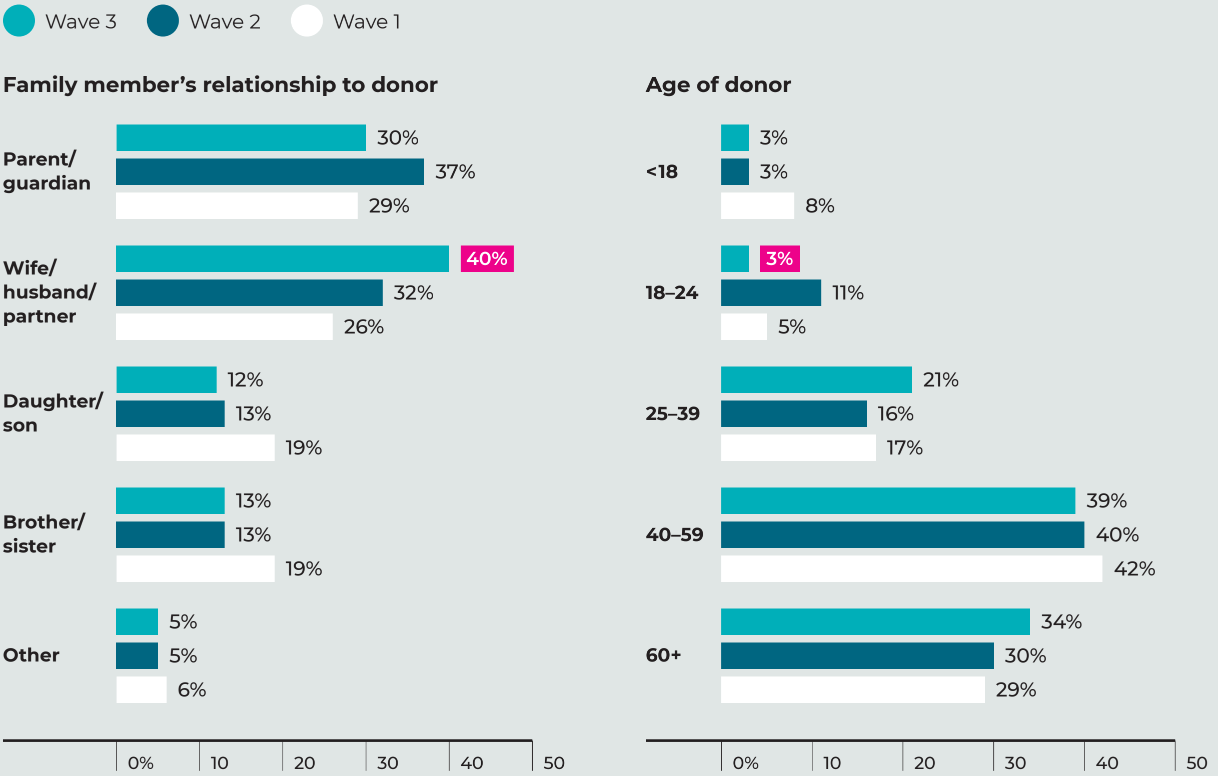
Base: Total sample of unique donor families: Wave 3 (n=213)*; Wave 2 (n=250)*; Wave 1 (n=131)

*Excludes intended donor families

4.3.5 Relationship and age

Figure 4 shows the relationship of family members to donors and the age range of donors. A wide range of family members are included in the study, with donors ranging in age from 4 to 83 years.

Figure 4 Relationship to donor and age of donor



Base: Total sample of donor family members
Wave 3 (n=257); Wave 2 (n=319); Wave 1 (n=185)

🟥 Denotes statistically significant difference

Base: Total sample of unique donor families, less non-response
Wave 3 (n=228); Wave 2 (n=261); Wave 1 (n=131)

🟥 Denotes statistically significant difference

Table 7 shows the relationship of the family member to the donor, together with the average donor age and age range. As shown, parents of donors represent 30% of the Wave 3 sample and the average age of their donor children is 35 years.

Table 7 Relationship of respondent to donor and age of donor

Relationship of respondent to donor, "I am his/her..."	Average age of donor	Age range of donor
Parent/guardian	35 years	4 to 57
Spouse/partner	57 years	26 to 83
Daughter/son	64 years	52 to 82
Brother/sister	52 years	26 to 69
Other (e.g. uncle, aunt, grandparent)	45 years	6 to 69

4.3.6 Ethnicity

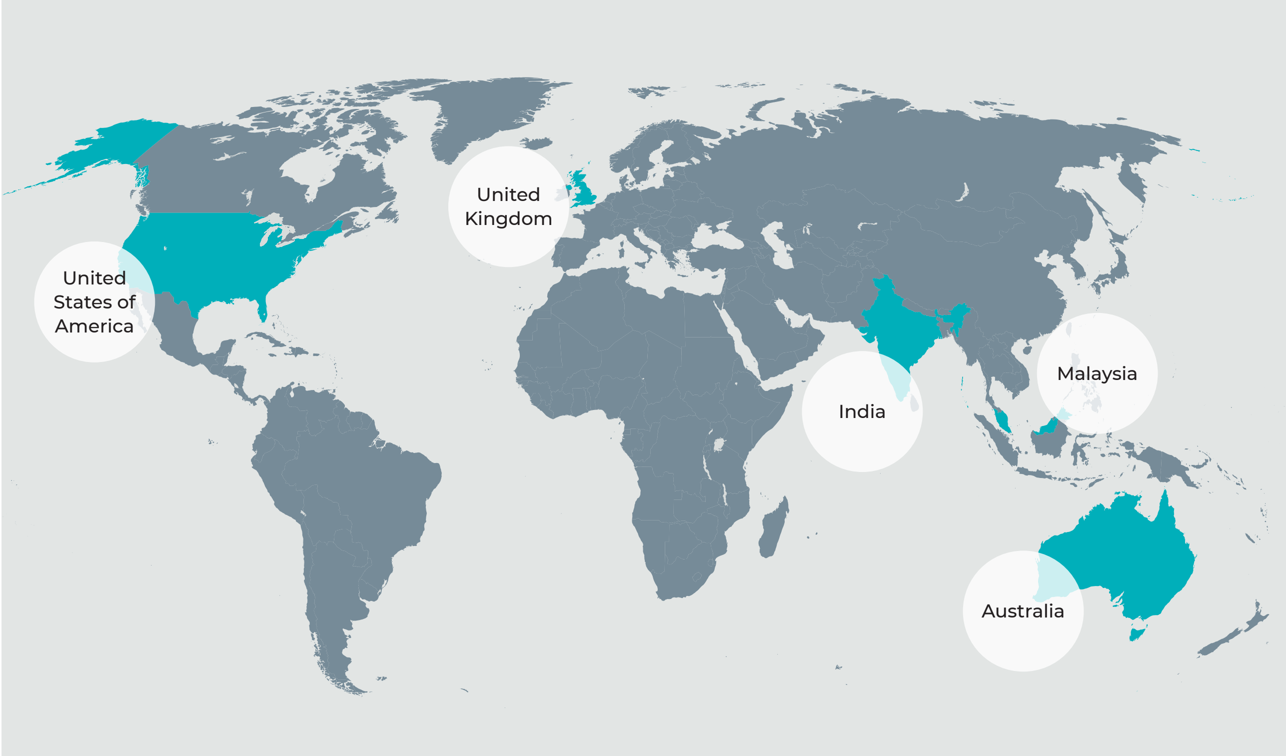
Consistent with the Wave 2 study, 2.3% of the Wave 3 donor sample are of Aboriginal or Torres Strait Islander descent. According to the latest available Census data (Australian Bureau of Statistics, 2016), Aboriginal and Torres Strait Islander peoples represent 2.8% of Australia's population.

Five per cent of the Wave 3 sample of donor families speak a language other than English at home, up from 4% in Wave 2. The languages spoken include:

- Dutch
- French
- German
- Greek
- Italian
- Mandarin
- Nepalese

The Donor Family Study also reached families living outside of Australia. In addition to the online survey being available worldwide, the hard copy survey was translated into German to allow a family living in Germany to take part. Figure 5 below shows that families in the USA, UK, India and Malaysia took part in the online survey.

Figure 5 Response distribution – online survey



4.4 Sample composition – qualitative

A summary of the qualitative sample structure is shown in Table 8.

Table 8 Qualitative sample structure of consenting donor families, by state/territory, year of donation and donation pathway

State/ territory	No. of donor family members agreed to in-depth interview	No. of face-to-face interviews conducted		Year of donation		Total personal interviews for each state/territory – consented to donation
		DBD	DCD	2014	2015	
NSW	13	3	2	–	5	5
ACT	7	1	1	1	1	2
VIC	26	7	1	6	2	8
TAS	6	2	–	1	1	2
QLD	20	5	2	3	4	7
SA	10	3	–	1	2	3
NT	2	2	–	1	1	2
WA	8	3	–	–	3	3
National	**92**	**26**	**6**	**13**	**19**	**32**

5 Sampling – families who declined donation

5.1 Sample frame

All families who declined organ and/or tissue donation in a hospital setting during 2014 and 2015, at a participating hospital, were invited to take part in Wave 3 of the Donor Family Study, with the exception of NSW families who participated in the COMFORT study[2].

The participating Wave 3 hospitals are detailed in Table 9. As shown, all states and territories took part in Wave 3, an increase on Waves 1 and 2.

5.2 Response rates

Survey packs were sent to n=488 family members who declined organ and tissue donation. Of these, n=67 were returned to sender (due to a change of address or the person being deceased), bringing the total survey population to n=421. Of these, n=33 family members from 32 families took part in Wave 3 of the Donor Family Study. This equates to an overall response rate of 7.8% (Table 9). This is up from 4.3% in Wave 2; an increase of 21 families.

Table 9 Quantitative sample overview by state/territory (declined strand)

		Target population	Participating sample	
State/ territory		**Family members who declined donation***	**No. questionnaires completed**	**Response rate**
NSW	Wave 3	50	8	16.0%
	Wave 2	58	1	1.7%
	Wave 1	Did not participate		
ACT	Wave 3	4	0	0.0%
	Wave 2	Did not participate		
	Wave 1	9	0	0.0%
VIC	Wave 3	190	13	6.8%
	Wave 2	83	2	2.4%
	Wave 1	Did not participate		
TAS	Wave 3	18	4	22.2%
	Wave 2	12	2	16.7%
	Wave 1	6	1	16.7%
QLD	Wave 3	79	5	6.3%
	Wave 2	53	5	9.4%
	Wave 1	Did not participate		
SA	Wave 3	16	1	6.3%
	Wave 2	11	0	0.0%
	Wave 1	5	0	0.0%

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[2] The COMFORT Study was research undertaken in NSW only and involved designated requesters discussing donation with families and a follow-up telephone interview being offered to families 90 days after bereavement.

		Target population	Participating sample	
State/ territory		**Family members who declined donation***	**No. questionnaires completed**	**Response rate**
NT	Wave 3	12	0	0.0%
	Wave 2	1	0	0.0%
	Wave 1	6	0	0.0%
WA	Wave 3	52	2	3.8%
	Wave 2	61	2	3.3%
	Wave 1	Did not participate		
Total	**Wave 3** (families in 2014/2015)	**421**	**33**	**7.8%**
	Wave 2 (families in 2012/2013)	**279**	**12**	**4.3%**
	Wave 1 (families in 2010/2011)	**26**	**1**	**3.8%**

* Excluding surveys packs that were returned to sender

In terms of the qualitative research strand, four families who declined donation agreed to participate in a personal interview. These families were from Tasmania, New South Wales, Queensland and Western Australia. Face-to-face interviews, each lasting for approximately 60 minutes, were conducted with each of the four family members.

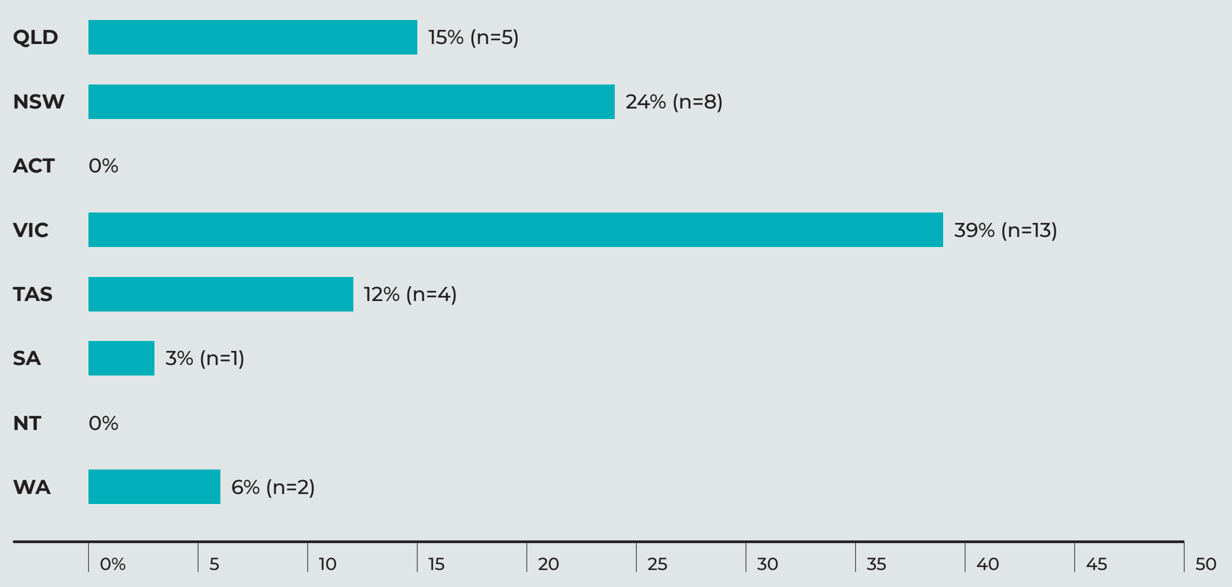
The challenge remains to improve response rates of families who declined donation, so that a greater understanding of their experiences and support required can be gained.

5.3 Sample composition – quantitative

5.3.1 Geographic coverage

As stated, 33 families who declined donation took part in the research. Their geographic distribution is shown in Figure 6.

Figure 6 Response distribution – families who declined donation (Wave 3)



Base: Total sample of family members who declined donation (n=33)

5.3.2 Year of donation decision

Table 10 shows the sample distribution by year of donation decision, across Waves 2 and 3.

Table 10 Total number of unique declined donor families by state and year of donation

	Wave 2		Wave 3	
State/ territory	**2012** (No. of families)	**2013** (No. of families)	**2014** (No. of families)	**2015** (No. of families)
NSW	0	1	3	5
VIC	0	2	5	7
TAS	0	2	2	2
QLD	3	2	3	2
WA	0	2	2	0
SA	0	0	1	0
Total	**3**	**9**	**16**	**16**

5.3.3 Relationship and age

Table 11 shows the relationship of the respondent to the potential donor, together with the average age and age range.

Table 11 Relationship of respondent to potential donor and age of potential donor

Relationship of respondent to potential donor, "I am his/her..."	Average age of potential donor	Age range of potential donor
Spouse/partner (n=21)	64 years	45 to 78
Parent/guardian (n=4)	24 years	16 to 33
Daughter/son (n=6)	69 years	63 to 77
Brother/sister (n=2)	57 years	55 to 58

5.3.4 Ethnicity

Among families who declined donation who took part in the research, 84% spoke only English at home; 16% spoke another language (Greek, Hindustani or Arabic). No families in the research sample who declined donation were of Aboriginal or Torres Strait Islander descent.

Part B – Research findings

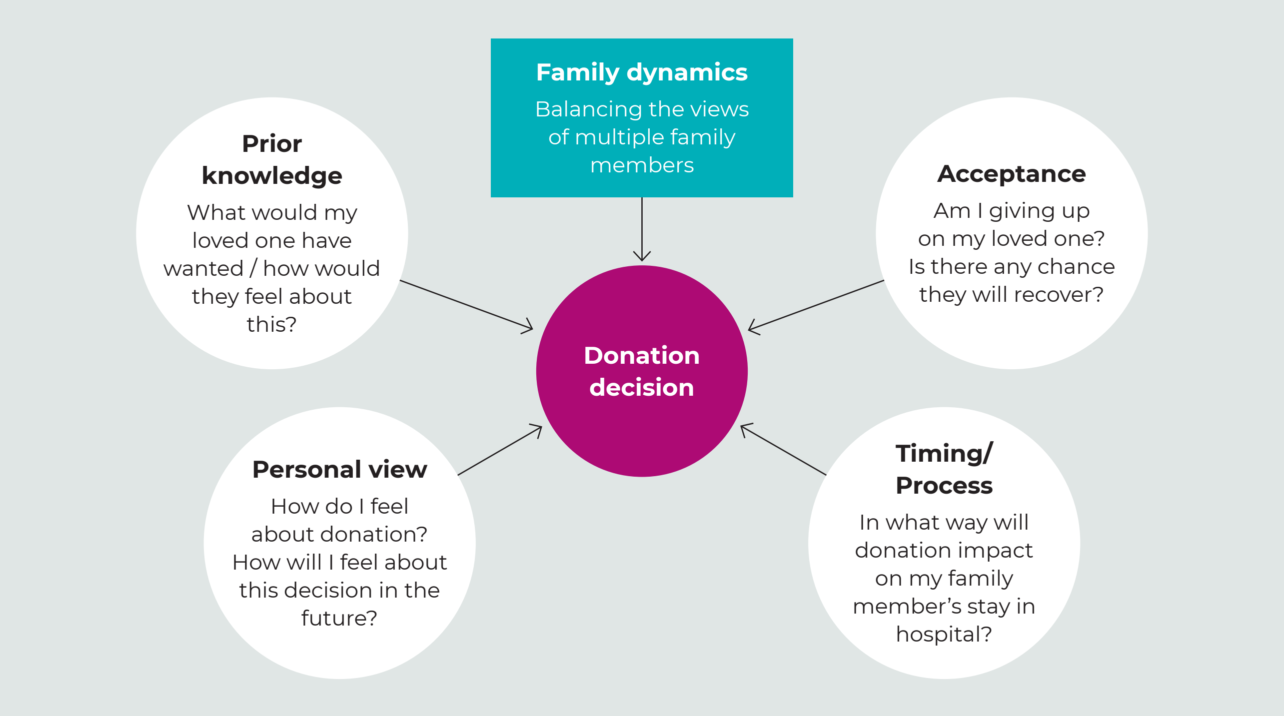
6 The decision to donate

Unlike most other important and enduring decisions, the donation decision is made at a time of enormous emotional stress and under significant time pressures. Figure 7 shows the key factors that come into play for families when asked to make a donation decision.

By far, the factor afforded the most weight is **prior knowledge**. When families know that they are carrying out their loved one's wishes – whether that be to donate or not to donate – it relieves much of the pressure that the donation decision creates. In essence, families with prior knowledge of their loved one's donation wishes feel that the decision is not actually theirs to make; they are simply enforcing a decision made earlier by their loved one.

> **We'd had that conversation… I knew what she wanted and it was crystal clear. So come the time, it was just going through the motions. It wasn't my decision to make."**
> 2015 – Consented to donation (personal interview)

Figure 7 Factors at play in donation decision



Family dynamics
Balancing the views of multiple family members

Prior knowledge
What would my loved one have wanted / how would they feel about this?

Acceptance
Am I giving up on my loved one? Is there any chance they will recover?

Donation decision

Personal view
How do I feel about donation? How will I feel about this decision in the future?

Timing/ Process
In what way will donation impact on my family member's stay in hospital?

Prior knowledge can be definitive (the patient registered on the Australian Organ Donor Register (AODR) or they had discussed donation with their family in the past) or intuitive (the patient was generous or would have wanted to help others).

In the absence of prior knowledge, family members look to their own **personal view** of donation. Inevitably if they hold a positive view of donation, the decision is likely to be a 'yes'; if family members are unsure of their own feelings about donation or if they hold a negative view, the decision is more likely to be a 'no'. More on this in Section 6.2.

Of course there are often other factors at play too, such as **acceptance**; family members need to have accepted that their loved one will not recover in order to 'make room' for the donation decision. They need to understand and be comfortable with the donation process, including any impact on **timing**.

In addition to these factors, there are **family dynamics** where, in some cases, not all members of the immediate family will share the same views. This brings us back to prior knowledge – knowing the wishes of the patient simply makes the donation decision easier and in many instances, blocks out the family dynamic 'noise'.

> **There was family conflict in relation to organ donation. It made it a lot easier knowing he wanted to be a donor."**
> 2014 – Consented to donation

6.1 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.

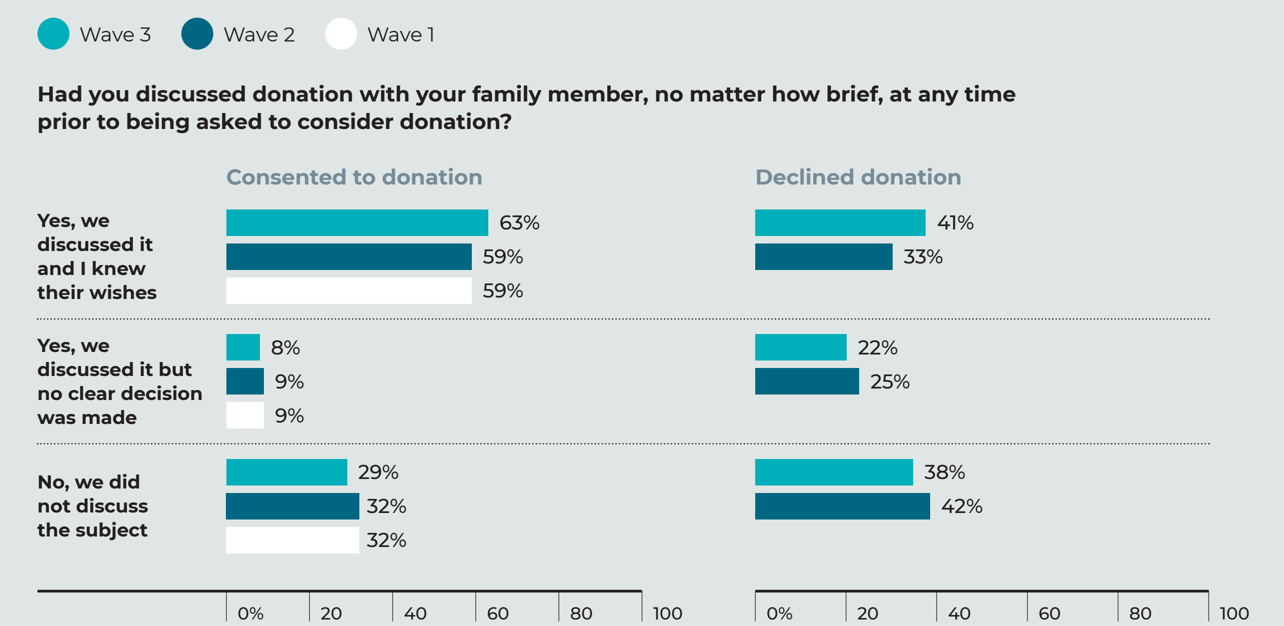
> **Oh, we'd discussed it. I didn't know a great deal about it but we discussed it and that's just what she wanted to do."**
> 2015 – Consented to donation (personal interview)

Consistent with Wave 1 and 2 findings, approximately three in five (63%) donor family members in 2014 and 2015 had discussed organ and tissue donation with their loved and knew their wishes (Figure 8). This is significantly higher than families who declined donation, where 41% of families knew their loved ones wishes after discussing the subject with them.

Conversely, 37% of families who consented to donation did not know their loved one's wishes, compared to 59% of families who declined donation. This is a significant difference and reinforces the importance of encouraging people to have the donation conversation with family members; when conversations are had and families know that their loved one supported donation, their wishes are more likely to be upheld.

> **It removed the responsibility of us deciding for him as general consensus was to respect and honour his wish to help others. The decision was already made."**
> 2015 – Consented to donation

Figure 8 Prior discussion of organ donation



Base: Total consented sample, less non-response
Wave 3 (n=257); Wave 2 (n=317); Wave 1 (n=185)

Base: Total declined sample, less non-response
Wave 3 (n=32); Wave 2 (n=12)

> **“Organ donation is an end of care, end of life decision, which is why it needs to be made before that.”**
> 2015 – Consented to donation (personal interview)

There is evidence in favour of keeping donation top of mind, for continuing to spark conversations 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.

As stated, families who discussed organ and tissue donation with each other, no matter how brief the conversation, found the donation decision considerably easier than families who had not talked about donation. Consistent with Wave 2 findings, 80% of families who had discussed donation and knew their loved one's wishes said that this made the donation decision a lot easier.

The same is found among families who declined donation, with 80% of those who discussed donation with their loved one finding the decision to decline a lot easier knowing that they did not wish to donate.

> **“I was happy that the decision not to donate was made prior to death.”**
> 2015 – Declined donation

Supporting this finding, Table 12 shows that families who did not discuss donation are more likely to find the donation decision a difficult one (14% compared with just 1% of those who discussed donation and knew their loved one's wishes). This is consistent with findings from Wave 1 and Wave 2 (16% and 11% respectively of families who had not discussed donation found the decision a difficult one).

Table 12 Impact of donation discussion on decision – families who consented to donation

Impact of degree of discussion	Discussed and knew wishes (n=163)	Discussed but no clear decision made (n=20)	Total discussed donation (n=183)	Did not discuss donation (n=74)
Made our decision a lot easier	80%	25%	74%	19%
Made our decision a bit easier	14%	30%	15%	6%
Made decision easier – net	**94%**	**55%**	**90%**	**25%**
Did not impact on our decision	5%	20%	7%	61%
Made our decision a bit more difficult	1%	25%	4%	11%
Made our decision a lot more difficult	–	–	–	3%
Made decision more difficult – net	**1%**	**25%**	**4%**	**14%**

🟦 Significantly higher than total sample 🟥 Significantly lower than total sample

> **“We wish we had discussed it as a family prior to be prepared in the scenario we had.”**
> 2015 – Declined donation

> **“It made our decision more difficult as my stepfather and I did not know my mother's wishes. However, I am an organ donor and felt that if we could save a few lives, then it was important to do so.”**
> 2015 – Consented to donation

> **“Having discussed it with him made our decision easy. If I had not, it would have been difficult to process information.”**
> 2015 – Consented to donation

Among families who declined donation, 25% of families who did not discuss donation found the decision to decline a difficult one (Table 13).

Table 13 Impact of donation discussion on decision – families who declined donation

Impact of degree of discussion	Discussed and knew wishes (n=10)	Discussed but no clear decision made (n=7)	Total discussed donation (n=17)	Did not discuss donation (n=12)
Made our decision a lot easier	**80%**	14%	53%	17%
Made our decision a bit easier	–	43%	18%	8%
Made decision easier – net	**80%**	**57%**	**71%**	**25%**
Did not impact on our decision	10%	14%	12%	50%
Made our decision a bit more difficult	10%	29%	18%	17%
Made our decision a lot more difficult	–	–	–	8%
Made decision more difficult – net	**10%**	**29%**	**18%**	**25%**

🟦 Significantly higher than total sample 🟪 Significantly lower than total sample

> **“ If my husband's licence had been ticked regarding donation, it would have been a lot easier.”**
>
> 2015 – Declined donation

Prior knowledge of a loved one’s donation wishes is unquestionably important for families when making a donation decision.

Family members were asked how knowing or not knowing the wishes of their family member impacted their decision to donate. Table 14 shows responses from families who had discussed donation with their loved one and from families who had not had the conversation. As shown, families who had not talked about donation struggled more with their donation decision and in some cases, these families continue to second guess that decision years later.

> **“ You are always left wondering have you made the right decision for your loved one.”**
>
> 2015 – Consented to donation

Table 14 also shows that the biggest impact on the donation decision amongst those who had discussed donation with their loved one was the thought of being able to honour their loved one’s wishes. Even when the conversation wasn’t explicitly had, if a family member was made aware that their loved one had recorded their wishes on the Australian Organ Donor Register or on their driver licence, this made the donation decision much easier.

> **“ We had not spoken about it, but the doctors confirmed he was signed up as a donor – so then there was no question.”**
>
> 2014 – Consented to donation

Table 14 The way in which donation discussion impacts the donation decision

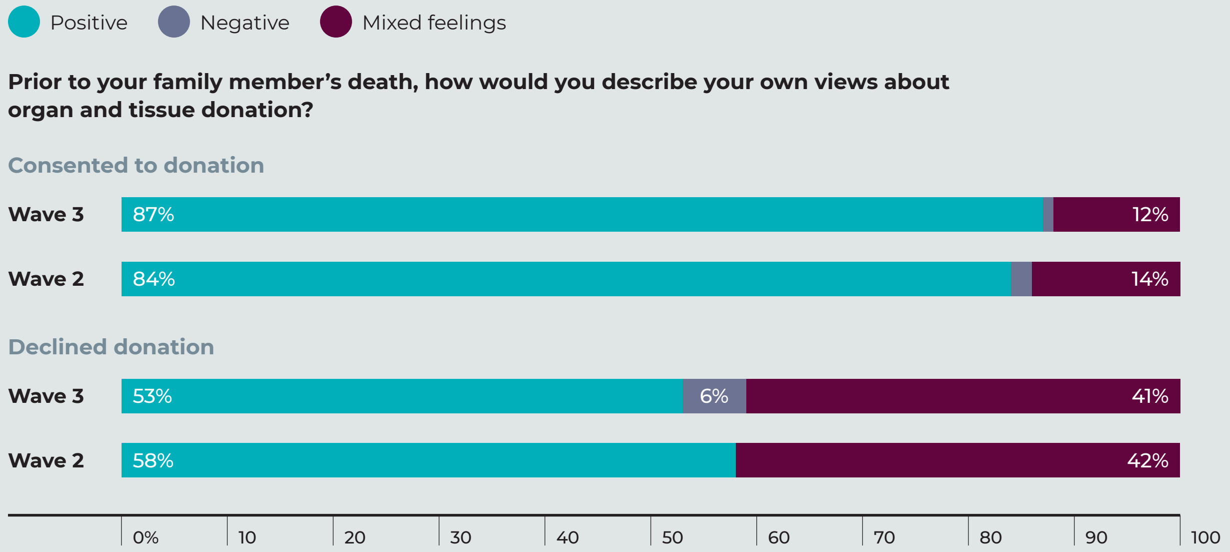
In what way did knowing or not knowing the wishes of your family member impact on your decision to donate?	Those who had discussed donation (n=139)	Those who had not discussed donation (n=40)
Wanted to honour his/her wishes/knew wishes of the donor/ donor indicated wishes on AODR or driver licence so decision was easier	61%	38%
There was no question about what to do/no doubts/we were certain	15%	–
Knowing made the decision easier at a difficult time	12%	–
Loved one was generous/would would have wanted to help others	6%	10%
Provided a chance for someone else to live/a positive outcome	6%	15%
Felt comfortable with decision/reassured about decision	6%	–
We would have donated anyway/believe in donation	6%	–
Seemed like the right thing to do/no reason to refuse	4%	–
All family members were in agreement due to wishes being known	3%	–
No impact on decision to donate, the donor was child, or the decision was made with other family members (for those who had not discussed donation)	1%	15%
Made decision more difficult because wishes were unknown	–	10%
Not knowing wishes means we're always wondering if we made the right decision	–	8%
Not knowing wishes made it difficult for the whole family to agree	–	3%
Other reason (one response each)	9%	3%

6.2 Personal views of donation

As shown in Figure 9, 87% of donor family members were supportive of organ donation prior to their family member’s death, compared with 53% of family members who declined donation. This is a statistically significant difference. Thirteen per cent of donor family members had mixed feelings (12%) or did not support donation (1%), but still consented to donation, compared with 47% of family members who declined donation. Again, this difference is significant. This means that when a favourable view of donation is held, families are more likely to consent to donation; when a negative or mixed view is held, the decision is more likely to be a ‘decline’.

> **“We made use of the chapel and then imagined all the people our son was helping that day. I could see them getting their phone calls and rushing into hospital. That is the only thing that made sense about our son's tragic accident.”**
> 2014 – Consented to donation

Figure 9 Personal views of donation



Prior to your family member’s death, how would you describe your own views about organ and tissue donation?

Base: Total consented sample, less non-response: Wave 2 (n=317); Wave 3 (n=257)
Total declined sample, less non-response: Wave 2 (n=12); Wave 3 (n=32)

> **“It was probably a conversation that we weren't... we weren't in favour of donating her organs so your mind just isn't there really. That's what I think. ‘I don't want to talk about this. We're not going there and that's the end of the story.’”**
> 2014 – Declined donation (personal interview)

For those who are unsure about donation, hesitation mostly stems from wanting to protect their loved one. There appears to be a lack of knowledge and understanding of the process of donation, as well as some misperceptions of how the donor will be treated during surgery.

> **“I suppose you think ‘I just don't want her body disturbed anymore. Leave her body alone’, you know, it's like that.”**
> 2014 – Declined donation (personal interview)

Improving the general community’s views of organ donation will improve consent rates. Continue to raise awareness of the positive aspects of organ and tissue donation (and the benefits to both the recipient and donor family) while addressing misperceptions.

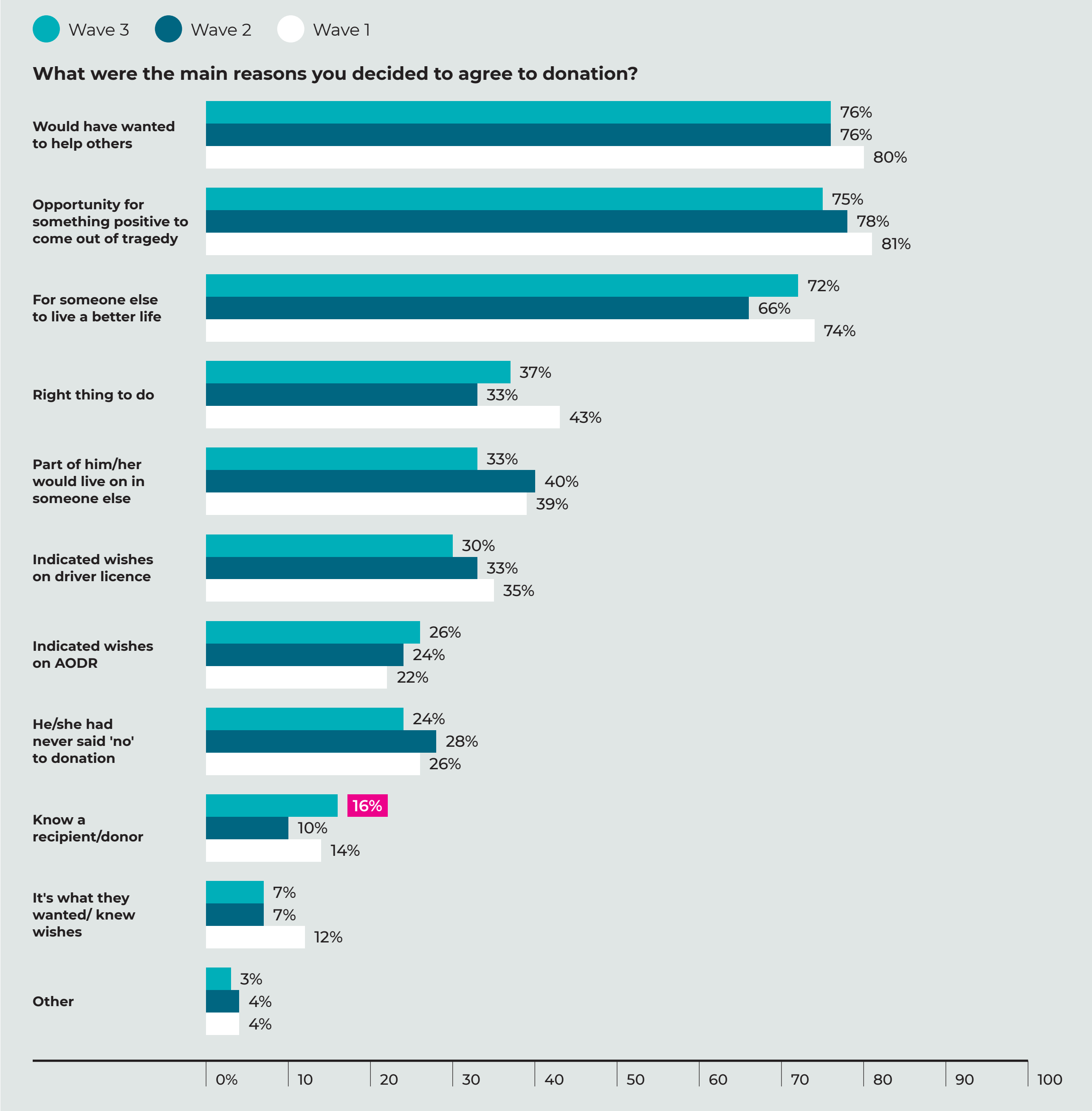
6.3 Motivations for donation

Consistent with Waves 1 and 2, the majority of donor families (75%) in 2014 and 2015 saw organ and tissue donation as a chance for something positive to come out of a personal tragedy (Figure 10).

> **I knew that we had lost him and I thought, 'this just can't be the end. Something's got to be more of this. There's got to be some sort of positivity out of our tragedy'."**
> 2015 – Consented to donation (personal interview)

> **Nothing can help lessen the grief of losing your loved one, but if something positive can come out of a tragedy, then it makes it worthwhile."**
> 2015 – Consented to donation

Figure 10 Motivations for donation



Base: Total sample, less non-response: Wave 3 (n=257); Wave 2 (n=318); Wave 1 (n=185)

🟥 Denotes statistically significant difference

In addition, three quarters (76%) of donor family members were motivated to donate because they felt that their loved one would have wanted to help others. In this way, their loved one's final act of donation feels apt as it fits with the generous and helpful nature of the donor.

> **What would he want? He would want to help."**
> 2014 – Consented to donation (personal interview)

Altruism is also evident, with 72% of donor family members agreeing to donation so that someone else can live/live a healthier life.

> **To me, it's common sense and I don't see why anyone would ever say no when you can help another human being."**
> 2015 – Consented to donation (personal interview)

6.4 Barriers to donation

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. This is consistent with Wave 2 (50% net figure).

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 (consistent with Wave 2). Two families (7%) did not consent because they weren't happy with the care provided at the hospital, while another two families (7%) felt that they did not have sufficient information to allow them to make an informed donation decision.

> **If licence (drivers) would have been ticked by hubby, it would have made our decision to donate a lot easier. I felt like the doctor pressured us. Not a good practice from health profession. We were under enough pressure having this happen to us."**
> 2015 – Declined donation

Other family members felt overwhelmed by the amount of information that was provided at the hospital and indeed, the amount of information that was requested of them during the family donation interview. For them, declining was the 'easier' option.

> **We wanted to go ahead with it but the information was too overwhelming at the time. We feel the questions should have started with major organ donations, not the smaller ones (i.e. eyes/cornia). It was too much to take in at a sudden death situation."**
> 2014 – Declined donation

> **I wasn't prepared enough for the indepth information."**
> 2014 – Declined donation

A full list of reasons for declining donation is shown in Table 15.

Table 15 Reasons for declining donation

What were the main reasons you decided to decline donation?	Wave 2 (n=12)	Wave 3 (n=30)
He/she had been through enough	33% (n=4)	33% (n=10)
I didn't know what he/she would have wanted	25% (n=3)	23% (n=7)
He/she didn't want to donate	17% (n=2)	20% (n=6)
Donation was going to take too long and I couldn't wait	8% (n=1)	17% (n=5)
I didn't want their loved one to have surgery for donation	25% (n=3)	17% (n=5)
I didn't accept his/her death and couldn't agree to donation	17% (n=2)	17% (n=5)
Donation is against my religious beliefs	–	13% (n=4)
I didn't have enough information about what was involved with donation	17% (n=2)	7% (n=2)
Other family members declined (but I would have consented)	17% (n=2)	–
I don't like the idea of donation	8% (n=1)	7% (n=2)
I wasn't happy with the care	–	7% (n=2)
Other	17% (n=2)	23% (n=7)

In time of great distress, some family members look to the health professionals caring for their loved one for guidance on the decision. The timing, tone and inferences used by clinical staff when discussing donation cannot be underestimated.

> **The doctor at the hospital where they transferred my husband pressured us to donate his organs. The second hospital spoke about letting hubby die with dignity."**
> 2015 – Declined donation

Seventeen per cent of families who declined donation felt that the process was going to take too long and they were not prepared to wait due to the emotional stress.

> **… it meant that she would have to be kept on a machine for another 24 hours at least, after her death, until the drugs were neutralised and [donation] could occur. Had it been possible immediately, I believe we would have agreed to have it done. Death was bad enough, but prolonging it didn't seem okay."**
> 2015 – Declined donation

Outlined below are brief synopses of the decision-making process of four families who declined donation. Each of these families took part in a personal in-depth interview.

1 Communication

The family member knew his wife's wishes, that she was in favour of donation. He initiated the donation conversation and communicated to the medical team on more than one occasion that his wife was a donor.

Not knowing what to expect of the process, he assumed that donation would take place; that with his verbal consent, the process would be automatic. There was no follow up by the hospital or DonateLife until several days after she had died and the family member was organising her funeral.

This was disappointing and upsetting as the family had wanted to donate and had mentally prepared themselves for this. The family member is somewhat angry and frustrated about this experience.

"It must have been a communication error. That's all I can think. And I would just hope that it's not something that happens all the time because it was a bit upsetting for the kids, you know, because they had prepared themselves because we had always said if anything happens to either of us or both of us at the same time, we're organ donors." — 2014

2 Timing

Family member was personally in favour of donation and assumed that her father would also have been. When faced with the donation decision, unfortunately the next of kin was in the midst of a complex family situation. She was worried about her Mum (her father was her mother's carer; she had dementia and urgently needed to go into aged care).

Her father was in a very busy hospital and had been brought in (and died) on a weekend. Family member felt that because of this, there was less support available at the hospital that would normally be available. She feels that had there been more support, she could have had the headspace to make a different donation decision. At it was, it was too much to deal with on her own with everything else going on. Keeping her father 'alive' for organ donation was too much to handle under the circumstances.

"I think that was the hardest... I don't think we could have stayed there any longer. It was too much. I think the fact that he would still be kept alive until everything could be done and he wasn't really dead, it was just too much at that time." — 2014

3 Opposed to donation

Family member's wife died unexpectedly during surgery. The family was not open to donation from the outset. The daughter knew that her mother was not in favour of donation and it was not something that the family member had ever spoken to his wife about.

The family were not aware of the risks of surgery and expected to see their wife and mother alive and well soon after the procedure. Under these circumstances, the hospital staff raising the option of donation seemed inappropriate. The adult daughter has particularly strong negative feelings about the experience and may reconsider her own position regarding organ donation.

For the family member, the feeling was more one of not wanting his wife to go through donation surgery or to be put through any further medical procedures.

— 2014

4 Follow up

Family member was approached by a doctor at the hospital about organ donation and responded that they were open to it. He knew his wife was in favour of organ donation. Following this conversation, he never met anyone from DonateLife or was spoken to about it again.

Meanwhile, family member started to feel pressure from extended family staying in his home to bring the situation to a close and allow his wife to be buried. He was also learning from a friend with a medical background the additional steps and time required with donation. Additionally, he is the father of two children, one of whom has special needs, and he didn't know how he could explain donation to his sons and this son particularly. So, following days without contact from DonateLife or further mention of donation by the medical team, family member's mindset moved from a 'yes' to a 'no'.

He feels that the outcome may have been different had the hospital or DonateLife followed up on the initial donation conversation but also appreciates that the possible need for an autopsy may have prevented further discussion on donation.

"Maybe there were some legalities around the fact that the death certificate wasn't going to be signed there and then." — 2014

Donation opportunities can be lost if communication with family members about the process and timing is not consistent and clear.

7 At the hospital

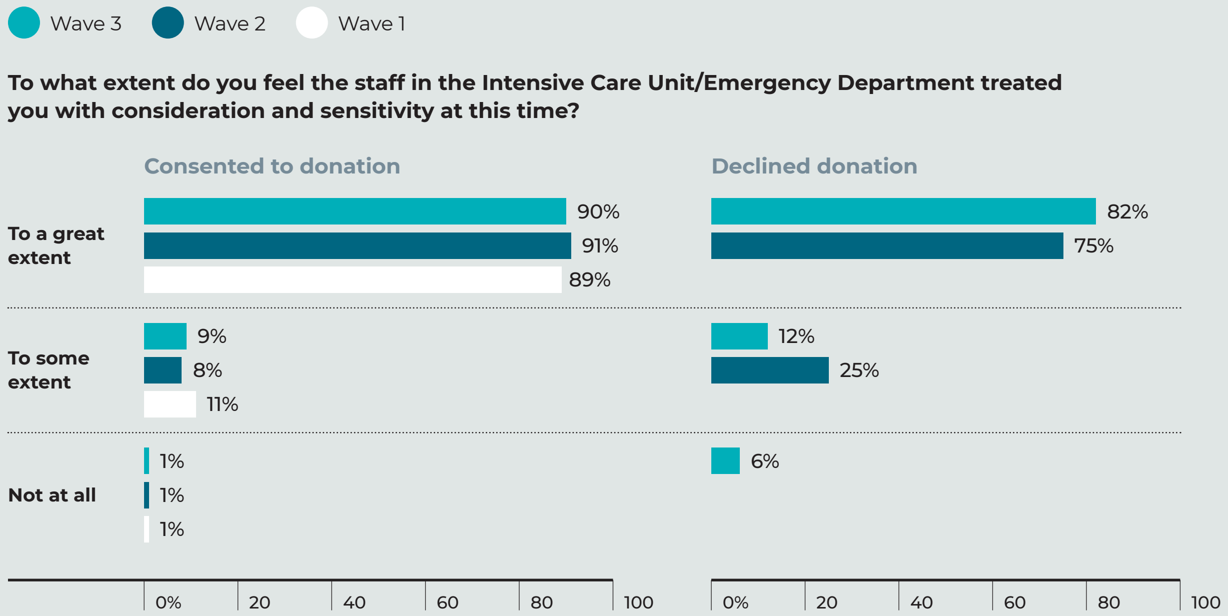
7.1 interaction with ICU/ED staff

As shown in Figure 11, almost all donor families (99%) feel that staff in the Intensive Care Unit or Emergency Department treated them with consideration and sensitivity prior to any discussions about donation (90% feel this occurred to a great extent; 9% to some extent). These findings are consistent with Waves 1 and 2.

The vast majority of families who declined donation also feel they were treated with consideration and sensitivity prior to making their donation decision (82% feel this occurred to a great extent; 12% to some extent). There are, however, some inconsistencies in the level of support provided to families during this time.

> **All staff acted with empathy and dignity. I could not have wished for better service and medical support.”**
> 2014 – Declined donation

Figure 11 Interaction with ICU/ED staff prior to donation decision



Base: Total sample of families who consented to donation, less non-response Wave 3 (n=257); Wave 2 (n=316); Wave 1 (n=183)

Base: Total sample of families who declined donation Wave 3 (n=33); Wave 2 (n=12)

Families generally experience the medical staff, particularly the ICU staff, as kind and gentle, yet efficient. They are particularly appreciative of kindness and respect shown to their loved one, such as addressing them by name and talking to them.

> **He was just so kind and gentle and he would go up to [name] to checking stuff and he would go, ‘hey [name], I'm here and I'm just going to check on this and I'm just going to hold your hand for a moment’ and he spoke to him all the time.”**
> 2015 – Consented to donation (personal interview)

As shown in Figure 11 above, 1% of donor family members and 6% of families who declined donation feel that ICU/ED staff did not demonstrate sufficient sensitivity towards them. Whilst these figures represent a small proportion of family members, it is important to understand that the slightest insensitive comment or gesture may influence a donation decision or negatively impact family members.

> **“One staff was very rude and not sensitive at all. One nurse in particular was very insensitive, rude and blunt about my father's condition.”**
>
> 2015 – Declined donation

> **“The staff were very caring to the patient taking any statistic they needed but not very concerned about the family unit.”**
>
> 2015 – Declined donation

> **“The only negative aspect to the care in ICU was that we took some photos and were told (very unkindly) by a nursing staff member that they had to be deleted as my husband had not given permission for them to be taken. This is such a point of sadness for me now as I would love to have those photos. I am so angry that due to my shock and distress the photos were deleted.”**
>
> 2014 – Consented to donation

> **“One (male) doctor told me that maybe it was a good thing that I did not have any children with my partner because that could have made my future with a new partner more complicated. I was shocked at his insensitive statement. I understand that the doctors are under huge amounts of pressure but I wonder if they receive enough training in how to deal with grief and loss.”**
>
> 2015 – Consented to donation

7.2 Delivering news of death/impending death

7.2.1 Clarity of communication

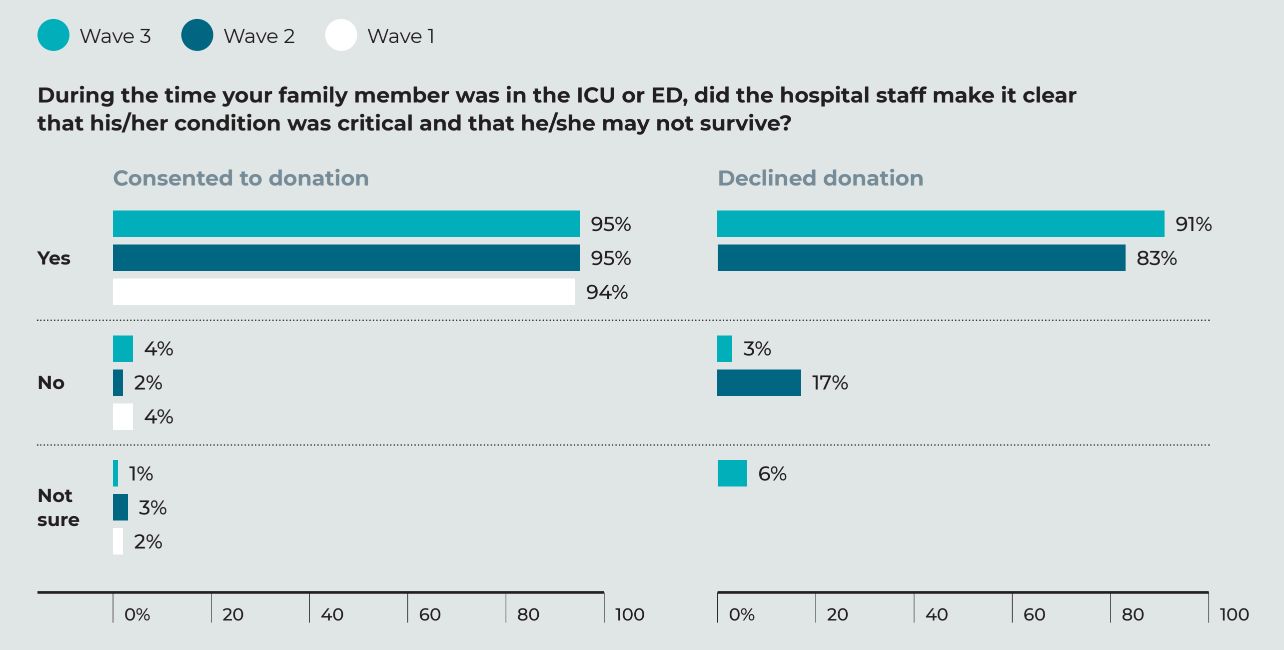
In the vast majority of cases (95%) in 2014 and 2015, ICU and ED staff have been skilled at ensuring family members fully realise the gravity of the situation and that their loved one is not likely to survive. Findings have been consistent over the past few waves of research.

Among families who declined donation in 2014 and 2015, 91% felt that the prognosis was clearly communicated to them, a slight, although not significant, improvement since Wave 2 (Figure 12).

> **“I know sometimes people don't like it straight forward but I would personally rather know the truth, especially when you're making decisions for somebody else.”**
>
> 2014 – Declined donation (personal interview)

> **“There was no confusion whatsoever.”**
>
> 2015 – Consented to donation (personal interview)

Figure 12 Clarity of communication – prognosis



Base: Total sample of families who consented to donation, less non-response Wave 3 (n=257); Wave 2 (n=313); Wave 1 (n=184)

Base: Total sample of families who declined donation, less non-response: Wave 3 (n=32); Wave 2 (n=12)

That said, some families (5% of families who consented to donation and 9% of families who declined donation) feel that they were not fully informed of the likely outcome for their loved one.

> **“They never actually said over that Monday, Tuesday, Wednesday that my sister won't recover.”**
>
> 2015 – Consented to donation (personal interview)

> **“Euphamisms like 'will never fully recover' are not useful. They leave room for doubt. Did they mean 'he can't survive' or 'his tennis serve will be rubbish from now on'?”**
>
> 2014 – Consented to donation

If families have false hope that their loved one will recover, the subsequent donation conversation is likely to feel ill-timed and inappropriate.

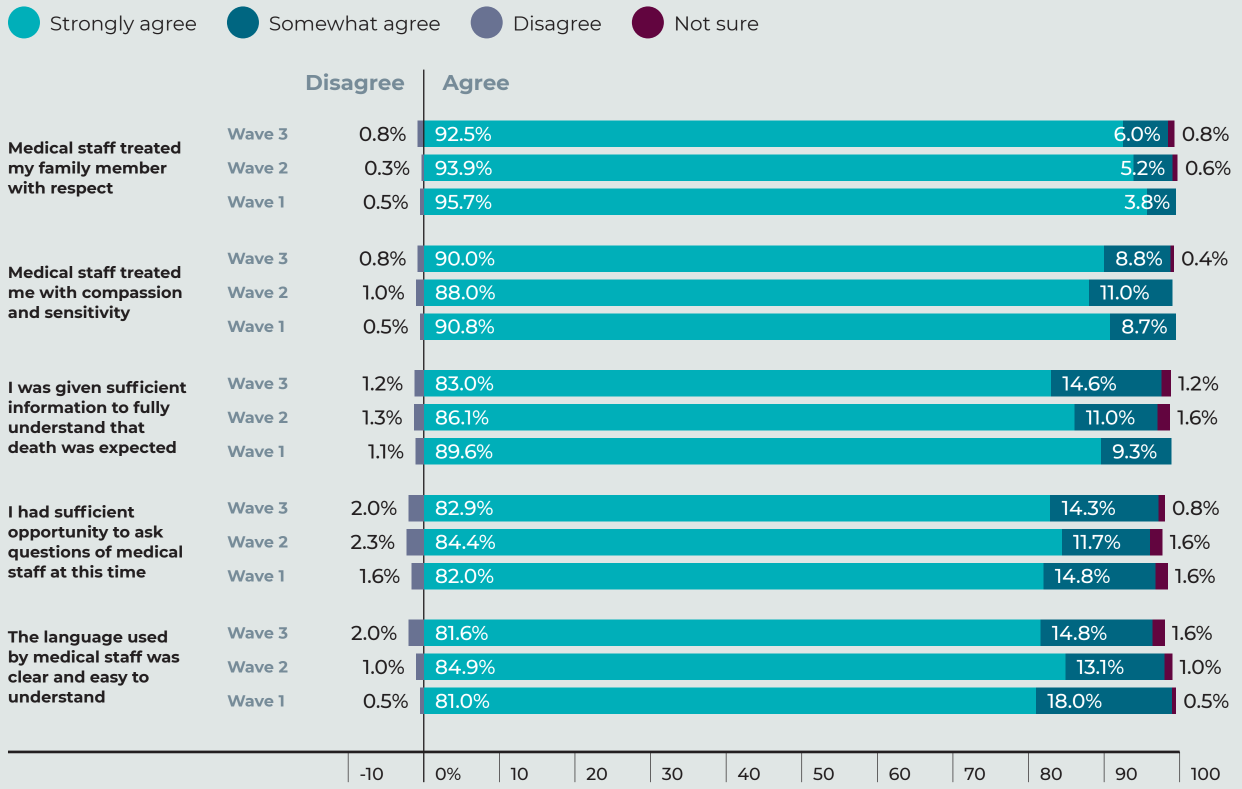
Providing information to help families to understand that their loved one will not recover requires clear, concise and consistent communication from medical staff, delivered with compassion and genuine care.

7.2.2 Treatment of families

Depending on the individual circumstances of each donor, medical staff may have discussed with family members either testing for brain death or withdrawal of cardio respiratory support. When family members think back to that time, the vast majority of families who consented to donation (99%) recall medical staff treating their family member with respect and they themselves being treated with compassion and sensitivity. These figures have been consistent over time (Figure 13).

Consistent with previous years and as shown in Figure 13, there is room for improvement around the language used by medical staff (82% strongly agree that the language was clear and easy to understand) and ensuring families have sufficient opportunities to ask questions of medical staff at this time (83% strongly agree that this was the case).

Figure 13 Treatment of consenting families by medical staff



Base: Total sample of families who consented to donation, less non-response | **NB:** Base sizes vary by statement

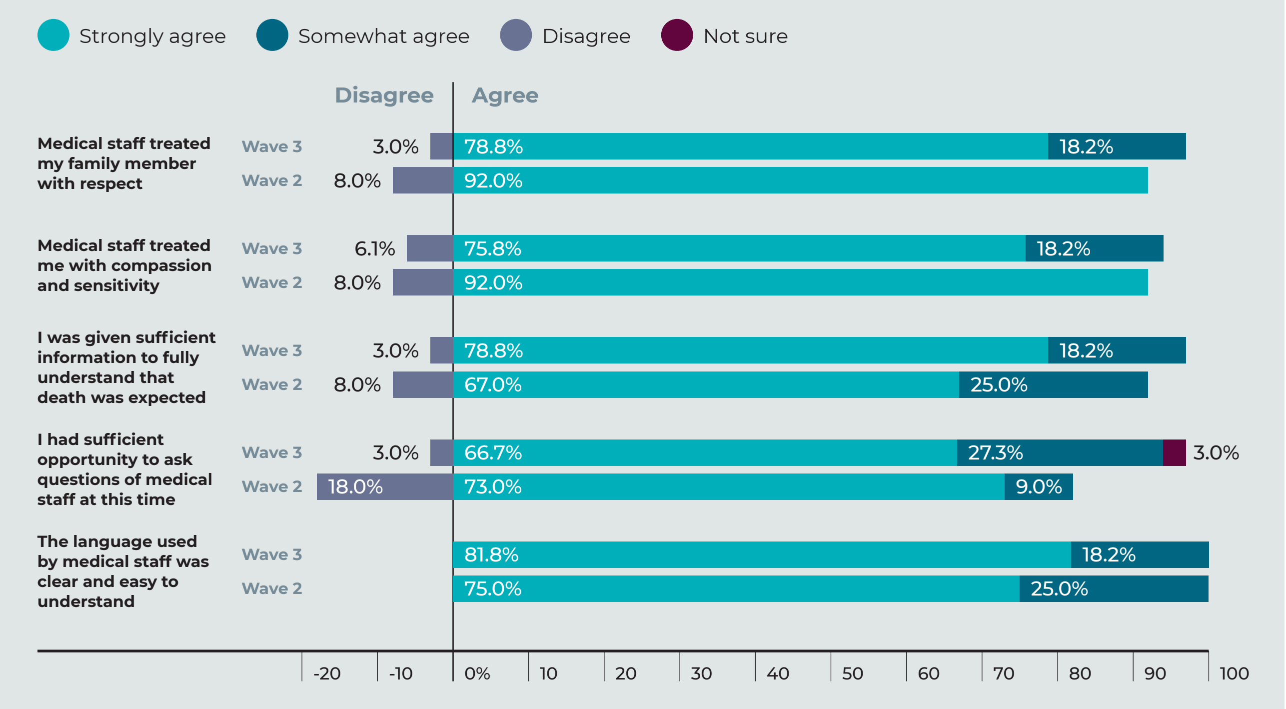
> **The word that we kept hearing was ‘catastrophic’. So many times we heard that word. I realise now that that’s obviously the word …… that the medical staff use to get the message across to people how serious it is.”**
>
> 2014 – Consented to donation (personal interview)

> **They basically said my wife had had a…. what are the words they used? A ‘non-life-sustaining event; not compatible with life.’ It sort of struck me as a very odd term. It's almost a medical term, a soft way of saying she died. It was an odd way of putting things.”**
>
> 2015 – Consented to donation (personal interview)

> **Communication between different specialists be more open, language be simplified and clarified. Not once did anyone ask my sister-in-law or my husband if they clearly understood. I have a medical background and did the clarifying.”**
>
> 2015 – Consented to donation

Whilst still a good result, agreement with the five statements measured is significantly lower amongst families who declined donation, as shown in Figure 14.

Figure 14 **Treatment of families who declined donation by medical staff**



Base: Total sample of families who declined donation, less non-response | **NB:** Base sizes vary by statement

> **Some doctors were terrific and the nursing staff were marvellous. Some doctors were cold, dismissive and judgemental.”**
>
> 2015 – Declined donation

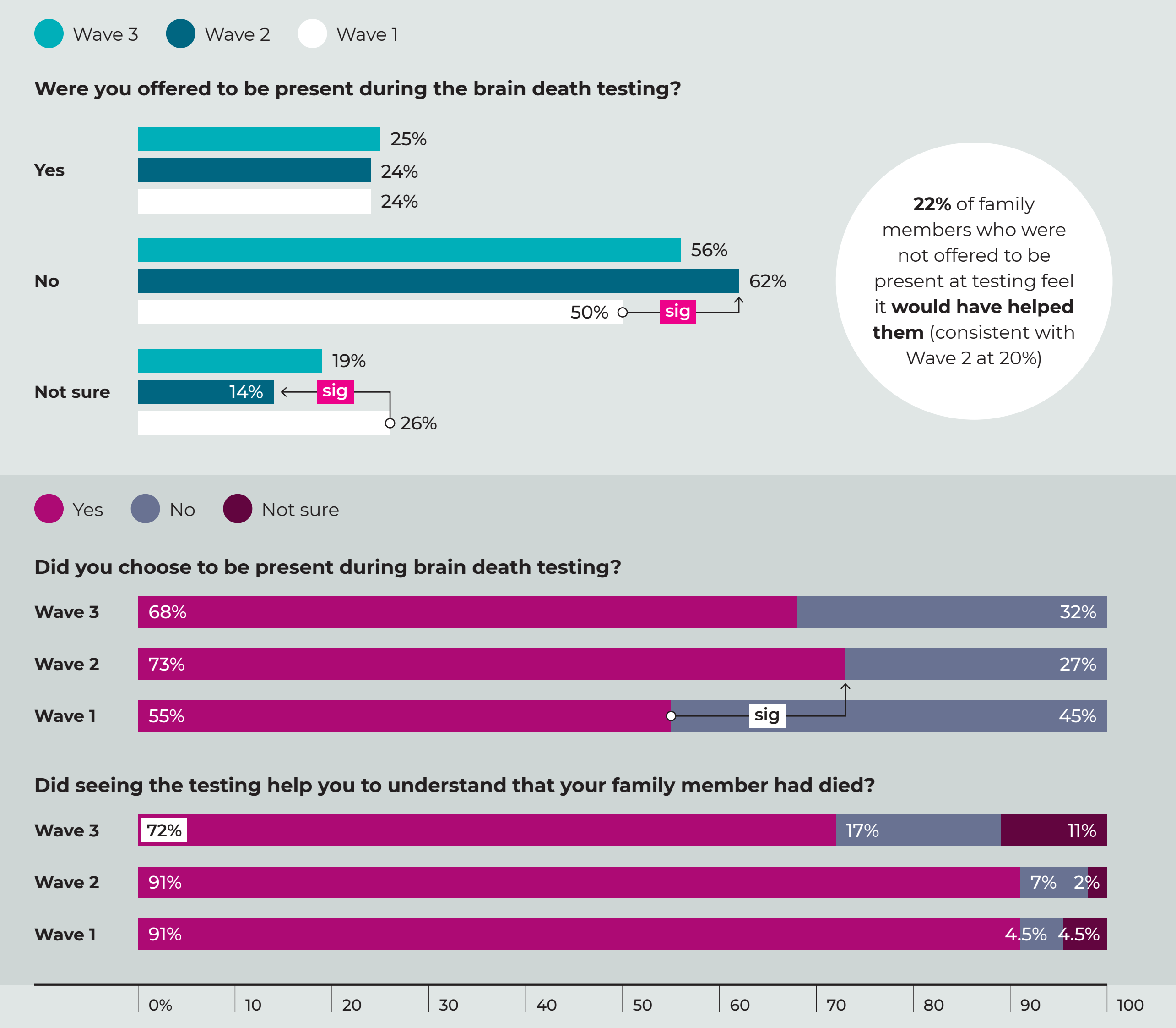
> **The hospital were beautiful, I mean the nursing staff were just amazing.”**
>
> 2014 – Declined donation (personal interview)

7.3 Brain death testing

Of the unique family units who participated in the study, 86% had family members who donated after brain death (DBD). As shown in Figure 15, 25% of DBD donor family members were offered the option to be present during brain death testing during 2014 and 2015. This is consistent with donor families in Waves 1 and 2 and is also consistent with families who declined donation (28%, Figure 16). In Wave 3, a greater number of families who went on to decline donation were not asked if they wished to be present (up from 27% in Wave 2 to 60%).

Of those families who were invited to attend the testing, 68% of consenting donor families and 86% of families who declined donation, opted to be present (this difference is not significant).

Figure 15 Brain death testing – consenting families

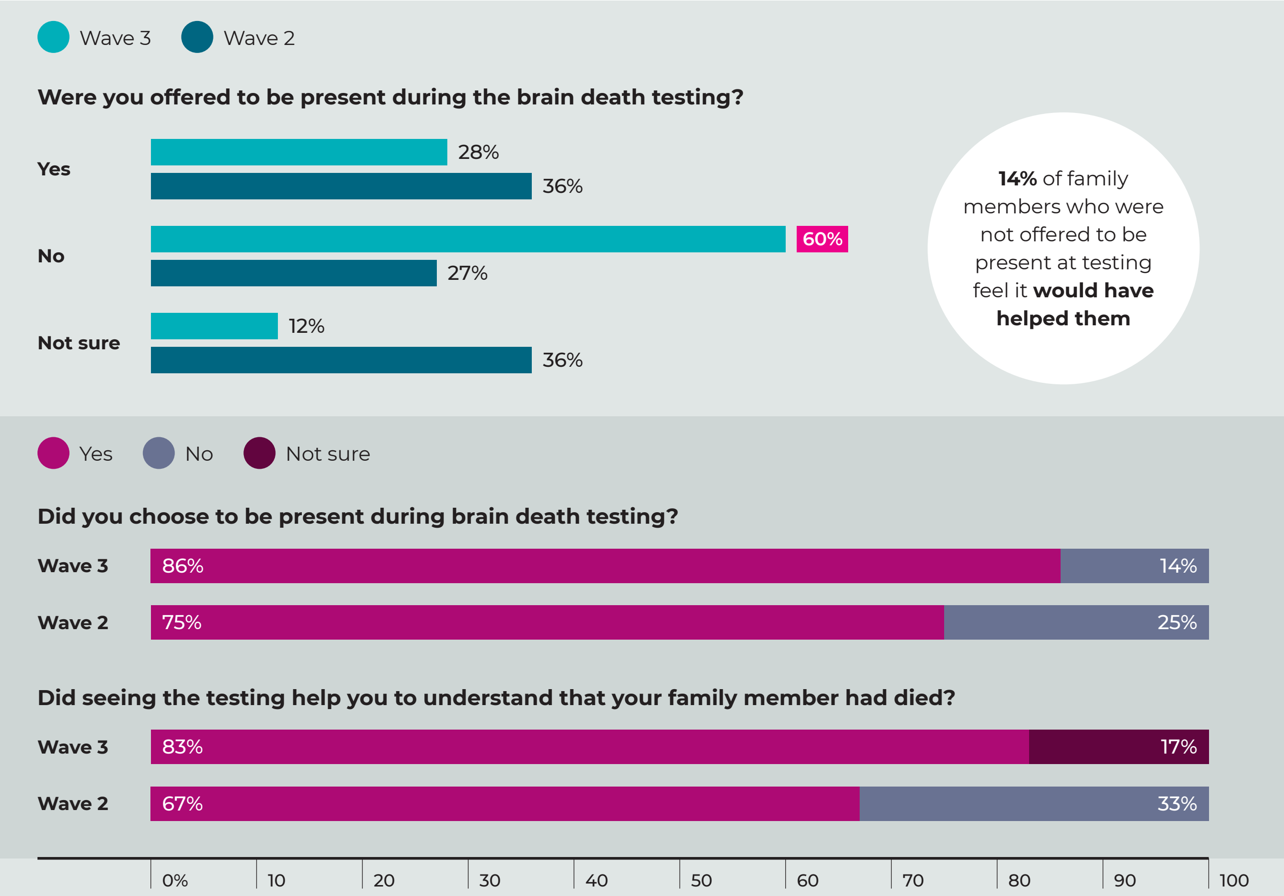


22% of family members who were not offered to be present at testing feel it **would have helped them** (consistent with Wave 2 at 20%)

Base: Total DBD sample, less non-response: Wave 3 (n=209); Wave 2 (n=262); Wave 1 (n=163)
DBD sample who were offered to be present at testing: Wave 3 (n=53); Wave 2 (n=64); Wave 1 (n=40)
Family members who witnessed brain death testing: Wave 3 (n=36); Wave 2 (n=46); Wave 1 (n=22)

🟥 ⬜ Denotes statistically significant difference

Figure 16 Brain death testing – declining families



14% of family members who were not offered to be present at testing feel it **would have helped them**

Base: Families who declined donation, less non-response: Wave 3 (n=25); Wave 2 (n=11)
Families who declined donation, who were offered to be present at testing: Wave 3 (n=7); Wave 2 (n=4)
Families who declined donation, who witnessed brain death testing: Wave 3 (n=6); Wave 2 (n=3)

🟥 Denotes statistically significant difference

Family members describe witnessing brain death testing as confronting and upsetting, however in most cases, seeing the tests provided an understanding that their family member had indeed died. This understanding and acceptance of the situation is a necessary precursor to making a donation decision.

> **“As dreadful as it was to watch my loved one not react to any of the testing, I needed to see it for myself. It takes much bravery but it did give me closure. I personally needed to see that, that everything that could be done, was done. When you are emotional you keep a glimmer of hope, even though I was told differently. I knew he was gone, I just needed closure.”**
>
> 2015 – Consented to donation

> **“I am very pleased I sat in… not mistrusting anyone at the hospital but I think it showed to me that he's not responding.”**
>
> 2015 – Consented to donation (personal interview)

> **“Although it was traumatic to watch, there was no doubt ever to linger about the possibility of recovery. Sensitively done and explained by the doctor who referred to my daughter by name every time he touched her.”**
>
> 2015 – Consented to donation

Many family members who attended brain death testing recall the sensitivity and compassion with which the testing was conducted and also state that a clear explanation of the tests was provided by doctors.

> **“The doctor was great and explained what he was doing and why. As much as it hurt, I had to be there to prove he was brain dead.”**
> 2014 – Consented to donation

However, there is room for improvement on this aspect, with some family members calling for a better explanation of the process (before and during the testing) and what the tests mean.

> **“Better explanation of what they were doing to test brain function. I was left unsure if there was hope or not and whether we were making the right decision.”**
> 2015 – Consented to donation

> **“In retrospect, I don't feel that this was fully explained i.e. what was involved and what it meant. I was likely not very accepting that this was the reality and seeing the test and having more information would have helped. It would also have made the later process of reviewing/doubting that I had made the right decision less painful.”**
> 2014– Consented to donation

In addition, clear communication of the purpose of clinical testing to determine brain death is always necessary, as in some cases, family members feel that the tests are less scientific than expected.

> **“I know the machines were breathing for her but they say she's brain dead, but how do you know? She could just be unconscious and you might be pricking her with a needle or putting ice on her or whatever, how do you know she's not just asleep and you're saying she's brain dead, it's like, do some more tests!”**
> 2015 – Consented to donation (personal interview)

More than half (56%) of donor family members and 60% of family members who declined donation were not given an opportunity to attend the brain death testing. On reflection, many of these families are okay with this, but some families (22% of those who consented to donation and 14% of families who declined donation) would like to have witnessed the tests.

> **“I was not present in the process of brain testing. The doctors just gave us the test results. I wished I could have attended. Maybe that would have helped me to understand that my partner's brain is dead. Hooked up to machines, the chest is still moving, the skin was still warm. It was as if my partner was just in a very deep sleep. Seeing the testing might have helped to understand that his brain is no longer working.”**
> 2015 – Consented to donation

> **“Being present would have helped me to understand the dire situation.”**
> 2015 – Consented to donation

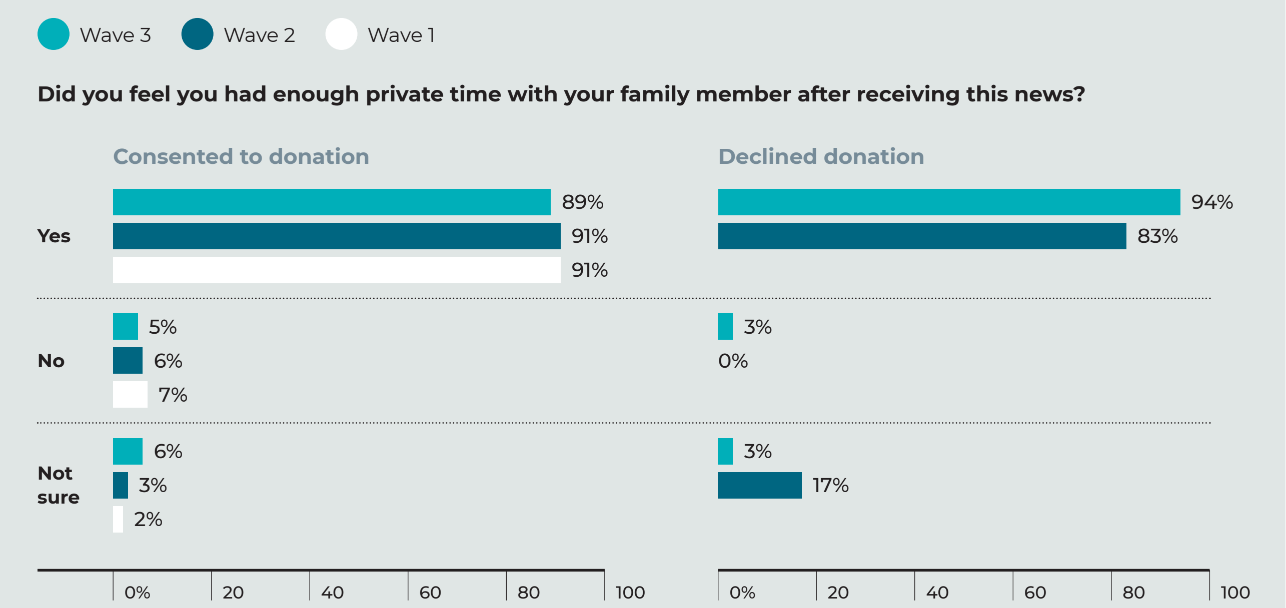
The opportunity to be present at brain death testing should be given to all families. To enable families to make an informed decision, the purpose and nature of the testing should be clearly explained.

It is important that family members who choose to attend are emotionally supported by medical staff during the testing procedure.

7.4 Time with family member post-prognosis

In 89% of cases, family members who consented to donation felt they were given enough private time with their family member after receiving the news that their loved one was brain dead or was unlikely to survive. As shown in Figure 17, this has remained consistent across Waves 1 and 2. During 2014 and 2015, 94% of families who declined donation also felt that they were given sufficient time with their loved one post-prognosis.

Figure 17 Amount of private time with family member



Base: Total sample who consented to donation, less non-response Wave 3 (n=256); Wave 2 (n=313); Wave 1 (n=183)

Base: Total sample of families who declined donation, less non-response: Wave 3 (n=32); Wave 2 (n=12)

Five per cent of family members who consented to donation and 3% of family members who declined donation felt that they did not have enough private time with their family member after receiving news that their loved one would not survive. This feeling of a lack of time can sometimes be more about the quality of time and the environment, rather than the amount of time.

> **“A private room was only made available immediately before turning off the ventilator. We would have liked more private time, particularly for the short time my children had with him.”**
> 2015 – Declined donation

The four key things families need from hospital health professionals are:

- **clarity of information and of the likely outcome**
- **compassion and understanding**
- **time to absorb the information, and**
- **private time to have with their loved one and family.**

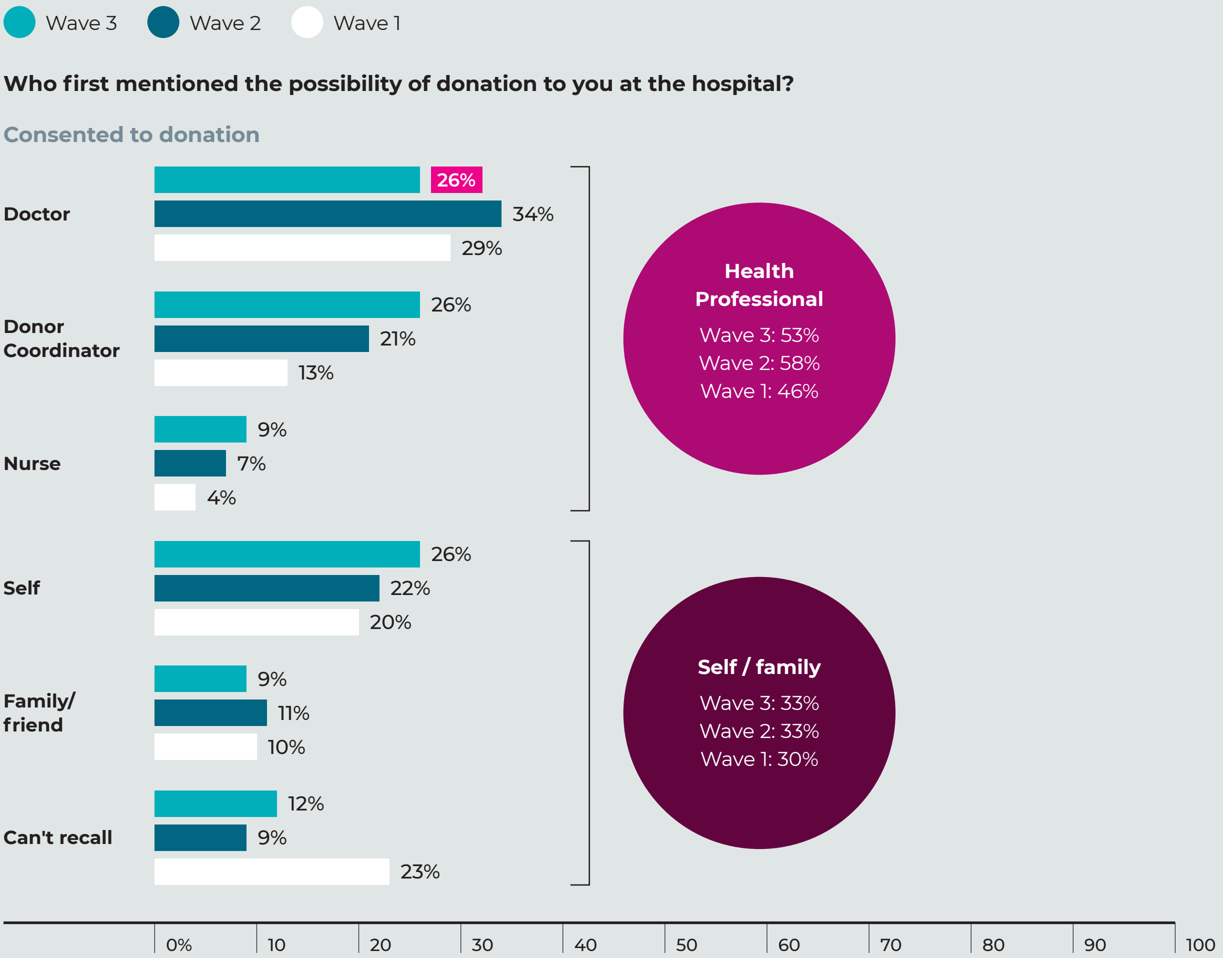
8 The donation conversation

8.1 Approaching the family

The possibility of donation continues to be primarily raised by health professionals (53% amongst consenting families; consistent with Wave 2). As shown in Figure 18a, during 2014 and 2015, the donation conversation was instigated by doctors in 26% of cases (a significant decrease on the previous two year period), Donor (Donation Specialist) Coordinators in 26% of cases and nurses in 9% of cases. There is potential that responses indicating that a nurse instigated the donation conversation are actually referring to donation specialist nurse coordinators.

> **“She said, ‘yes, he can be [a donor], and we'll get in touch with the DonateLife team here at the hospital.’ They did that and the next day they came and sat down with us, it was [name] and [name] who were beautiful.”**
> 2015 – Consented to donation (personal interview)

Figure 18a Who instigated the donation conversation – consented to donation



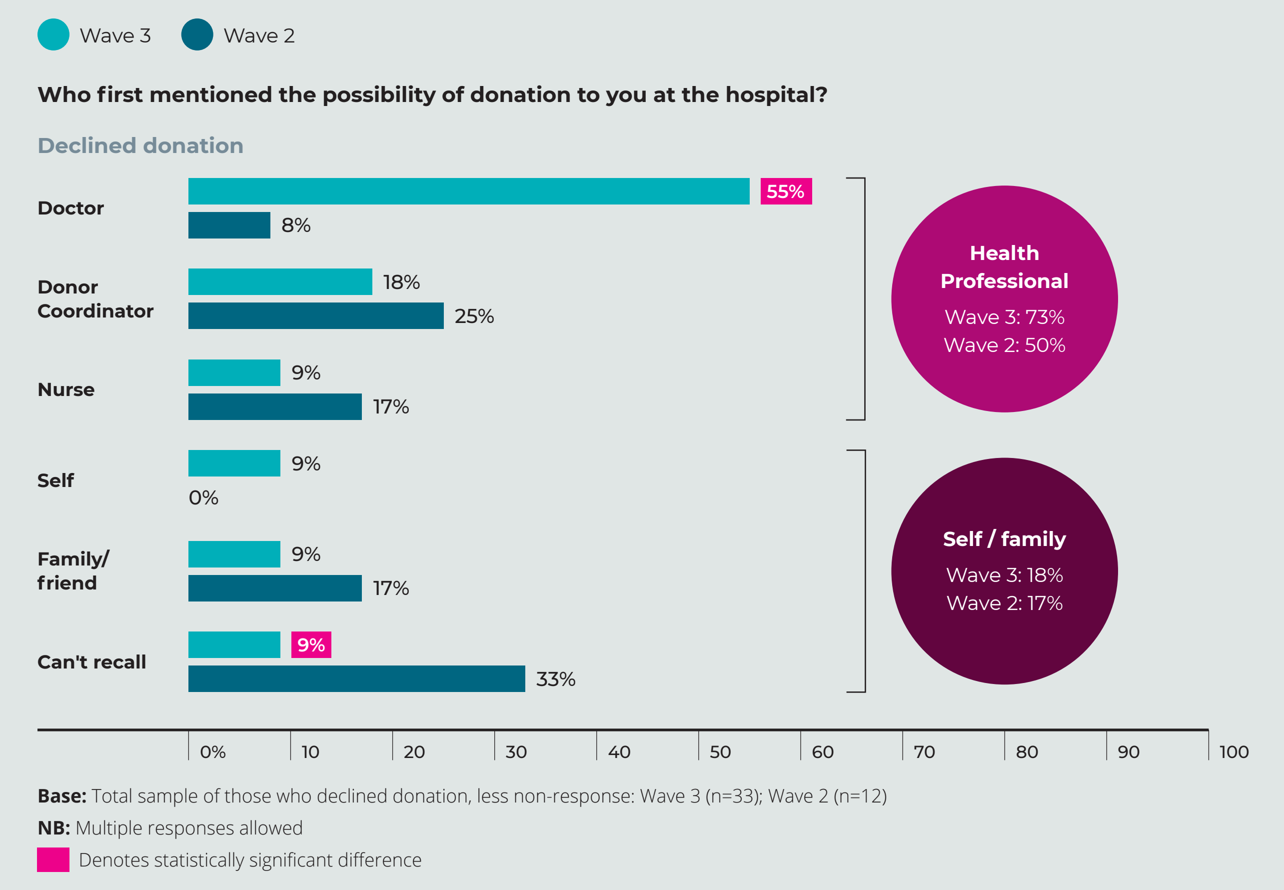
Base: Total sample of those who consented to donation, less non-response: Wave 3 (n=257); Wave 2 (n=314); Wave 1 (n=184)

NB: Multiple responses allowed

🟥 Denotes statistically significant difference

Looking specifically at families who declined donation, just over half of the donation conversations were initiated by a doctor (55%), significantly higher than conversations in 2012 and 2013 (Figure 18b).

Figure 18b Who instigated the donation conversation – declined donation



During 2014 and 2015, one third (33%) of donation conversations were instigated by the next of kin or family members; consistent with Waves 1 and 2. Sometimes, families actually felt that donation should have been raised by a health professional rather than left to them to instigate the conversation.

> **“Donation was not discussed until I asked. I felt uncomfortable asking if donation was possible.”**
>
> 2015 – Consented to donation

> **“If organ donation raised as a topic by medical staff rather than by us. We felt the responsibility was left with us. We felt we were leading the discussion which was and still is an added burden.”**
>
> 2015 – Consented to donation

Amongst families who declined donation, the conversation was raised by family members in 18% of cases. In many of these cases, donation was raised by the family to simply say that they knew their loved one did not wish to donate. In other cases, the family actually thought they consented to donation.

> **“Permission was not declined. I was of the understanding our permission to donate organs was accepted at the time of discussion.”**
>
> 2014 – Declined donation

Amongst families where donation was initially raised by hospital staff, 27% say that they expected to be asked about donation; 40% feel it was preferable that the topic was raised by a hospital staff member.

Just 5% of donor family members feel that being asked about donation by a hospital staff member added to their family's distress (Figure 19a). This appears to be more about the timing than about the subject being raised by a health professional, as for more than half of these family members, the donation request came either before (29%) or at the same time as (29%) the news of their family member's expected death.

> **“A doctor told our son about organ donation and that we should consider it – before we had even arrived at the hospital!!”**
> 2014 – Consented to donation

Allowing family members some time between delivery of the news that their loved one will not survive and being asked to consider donation is preferred.

Table 16 shows who instigated the donation conversation across waves and by donation pathway. There are no statistically significant differences between pathways in the proportion of conversations raised by a health professional (52% in DBD cases; 61% in DCD cases).

Table 16 Donation conversation instigator by donation pathway (over time)

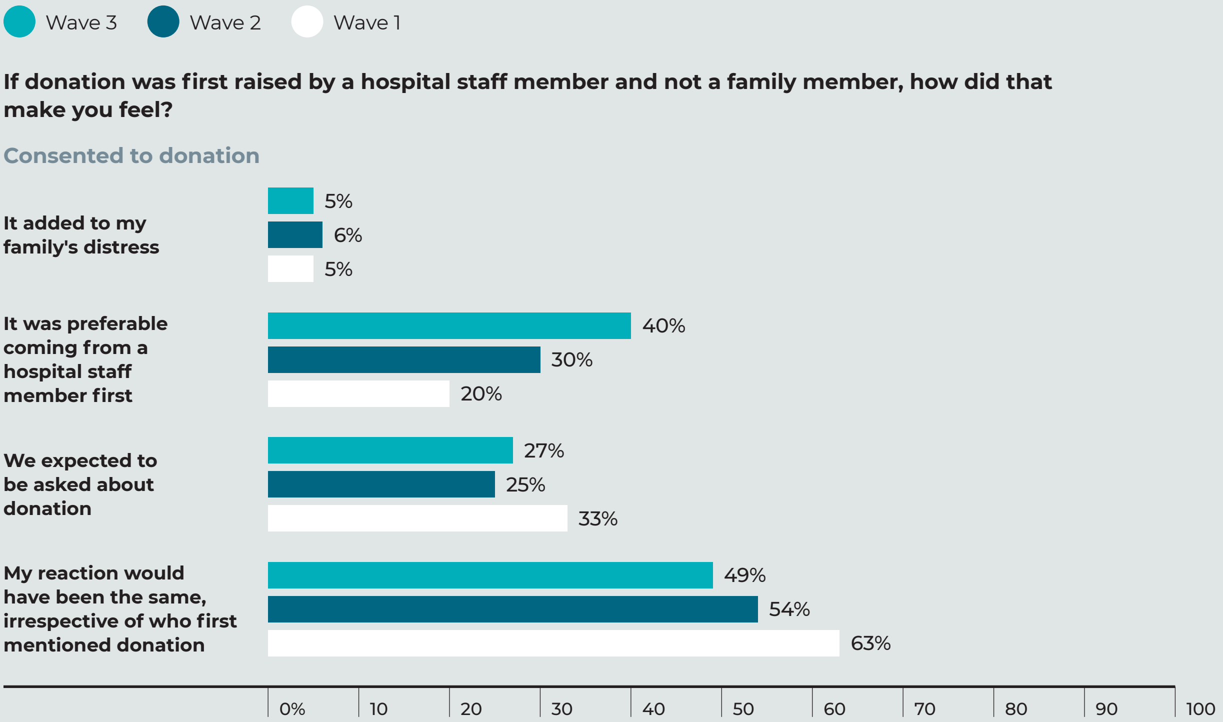
	Year of study					
Who first mentioned the possibility of donation to you at the hospital?	**Wave 1 – DBD** (n=164)	**Wave 1 – DCD** (n=20)	**Wave 2 – DBD** (n=276)	**Wave 2 – DCD** (n=38)	**Wave 3 – DBD** (n=219)	**Wave 3 – DCD** (n=38)
Doctor	31%	10%	34%	37% ▲	25% ▼	29%
Nurse	4%	5%	6%	13%	8%	16%
Donor coordinator	12%	20%	21% ▲	18%	26%	24%
Total health professional	**47%**	**35%**	**57% ▲**	**61%**	**52%**	**61%**
Family member/friend	10%	10%	12%	8%	10%	3%
Self	19%	30%	22%	24%	26%	29%
Other*	1%	–	1%	–	1%	5%
Total family/self	**30%**	**40%**	**33%**	**32%**	**35%**	**26%**
Can't recall	23%	25%	9% ▼	8%	12%	8%

* Includes hospital counsellor, the patient (before death), hospital staff member

■ Denotes statistically significant difference

NB: Data in table represents the views of all family members who consented to donation, rather than individual families (to be consistent with the way the question was measured in 2004 and 2008).

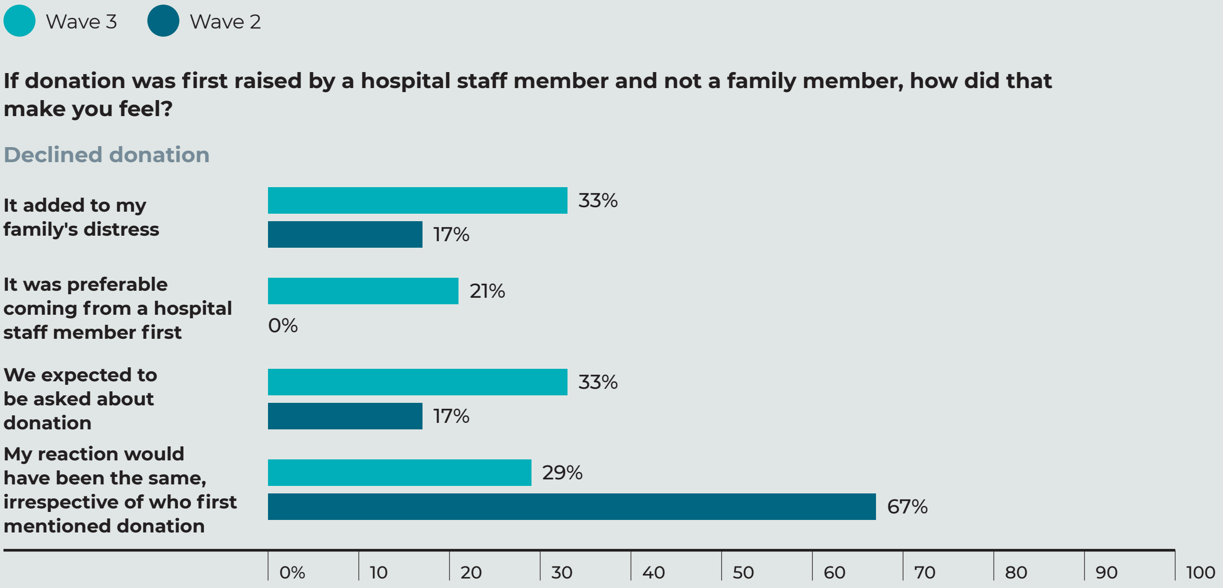
Figure 19a Reaction to donation being raised by hospital staff member – consented to donation



Base: Consenting family members who had topic of donation raised by medical staff, less non-response
Wave 3 (n=130); Wave 2 (n=174); Wave 1 (n=82)

NB: Multiple responses allowed

Figure 19b Reaction to donation being raised by hospital staff member – declined donation



Base: Declining family members who had topic of donation raised by medical staff, less non-response
Wave 3 (n=24); Wave 2 (n=6)

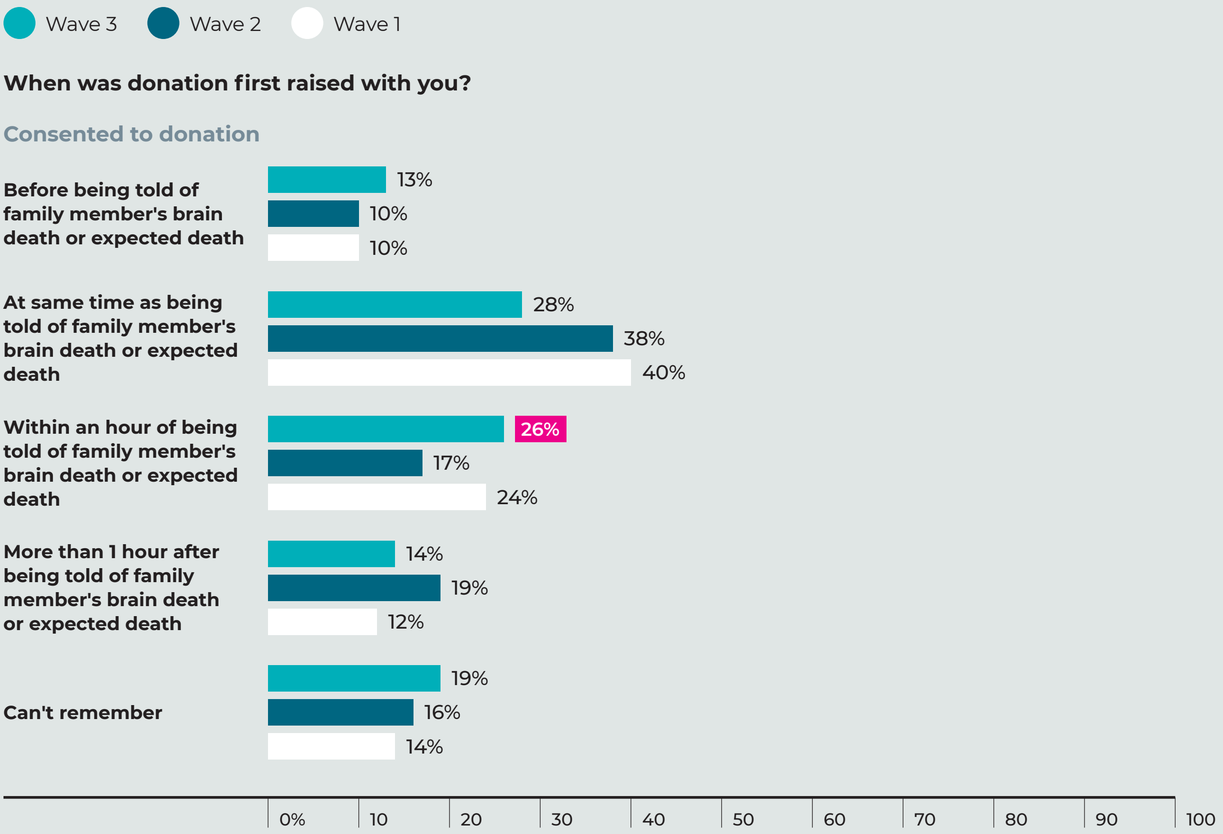
NB: Multiple responses allowed

8.2 Timing of the donation conversation

In 2014 and 2015, 40% of consenting family members were asked about donation by a health professional *before* (13%) or *at the same time* as (28%) being told of their family member's brain death or expected death; a further 40% were asked *after* the grave news was delivered (Figure 20a). Wave 3 sees a significant increase in the number of families being asked to consider donation by a health professional *within an hour* of being told of their family member's death/expected death (from 17% in Wave 2 to 26% in Wave 3).

The timing of the donation conversation with families who later went on to decline donation is consistent with that of families who subsequently consented to donation (Figure 20b).

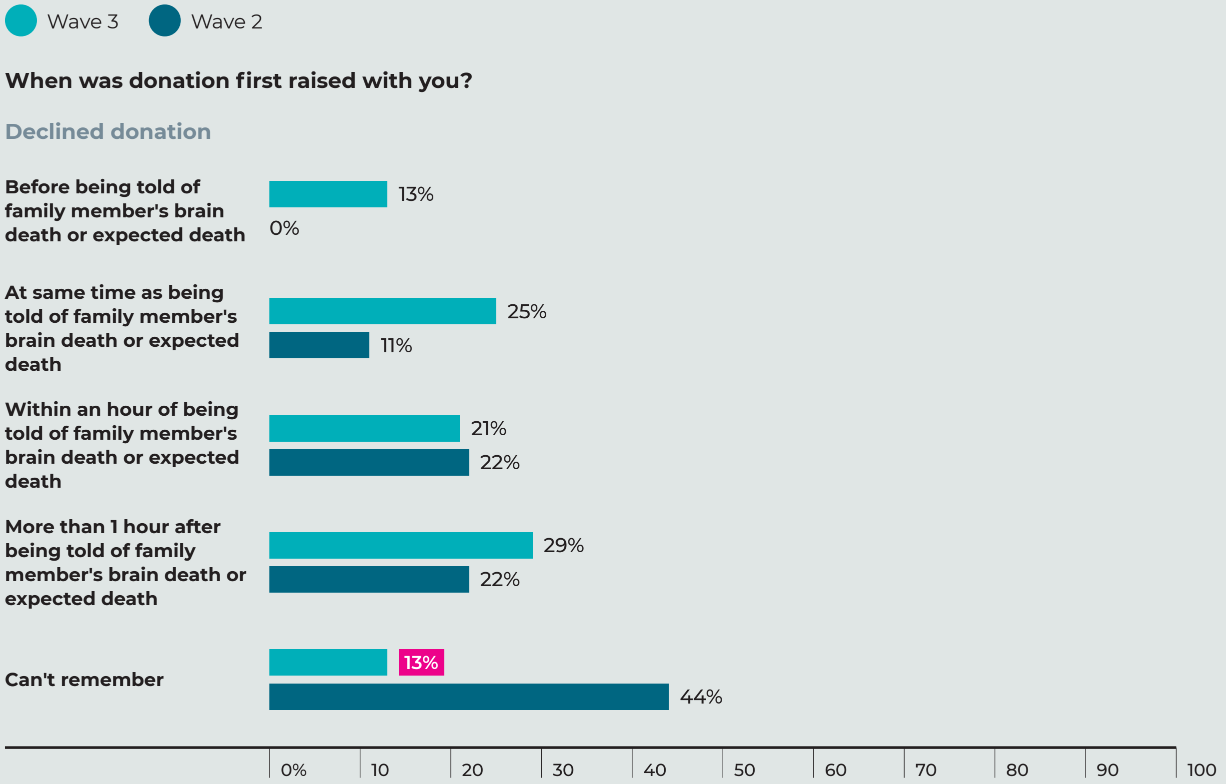
Figure 20a Timing of the donation conversation – consented to donation



Base: Consenting family members where donation was raised by health professionals, less non-response
Wave 3 (n=134); Wave 2 (n=178); Wave 1 (n=84)

■ Denotes statistically significant difference

Figure 20b Timing of the donation conversation – declined donation



Base: Declining family members where donation was raised by health professionals, less non-response
Wave 3 (n=24); Wave 2 (n=9)

🟥 Denotes statistically significant difference

Table 17 details the timing of the donation conversation, when instigated by a health professional, across states/territories. There are only two significant differences – in the Northern Territory in 2014 and 2015, all conversations were instigated before or at the same time as delivery of the grave news, and in the ACT, 60% of conversations were instigated within an hour of the news being delivered.

Table 17 Timing of the donation conversation (consented to donation) – by state/territory

When raised by health professional	**QLD** (n=30)	**ACT** (n=10)*	**NSW** (n=24)*	**VIC** (n=35)	**TAS** (n=8)*	**SA** (n=13)*	**WA** (n=11)	**NT** (n=3)*
Before	17%	30%	8%	14%	13%	–	–	33%
At same time	30%	10%	38%	23%	25%	38%	9%	67%
Before/same time as bad news delivered	**47%**	**40%**	**46%**	**37%**	**38%**	**38%**	**9%**	**100%**
Within an hour	20%	60%	21%	37%	13%	15%	18%	–
More than an hour	13%	–	17%	6%	25%	23%	36%	–
After bad news delivered	**33%**	**60%**	**38%**	**43%**	**38%**	**38%**	**55%**	**–**
Can't recall	20%	–	17%	20%	25%	23%	36%	–

* Caution: small base

🟥 Denotes statistically significant difference

Table 18 shows that there are no significant differences between donation pathways in the timing of the donation conversation when raised by health professionals.

Table 18 Timing of donation (consented to donation) – by donation pathway

	Wave 1 – 2010/2011		Wave 2 – 2012/2013		Wave 3 – 2014/2015	
Time of instigating donation conversation	**DBD** (n=77)	**DCD** (n=7)*	**DBD** (n=155)	**DCD** (n=23)*	**DBD** (n=112)	**DCD** (n=22)*
Before	10%	–	11%	4%	12%	18%
At same time	38%	71%	39%	30%	27%	32%
Within an hour	26%	–	17%	17%	26%	27%
More than an hour	12%	14%	17%	30%	15%	9%
Can't recall	14%	14%	15%	17%	21%	14%

* Caution: small base

NB: Data has been filtered to only include families where donation was first raised by health professionals.

In total, three quarters (74%) of donor family members feel that the timing of the approach by health professionals was appropriate; 19% are not sure and 7% feel the timing was inappropriate (Figure 21). These finding are consistent with Waves 1 and 2.

> **Professionally done. No time is a good time, but they are able to gauge people on how and when to do it."**
> 2014 – Consented to donation

Even though the timing of the donation conversation, when raised by a health professional, is consistent across families who consented to donation and those who declined donation, significantly more families who declined donation felt that the timing was inappropriate (35%). This means that stated dissatisfaction with the timing is actually only partly related to timing and partly related to the approach taken.

> **The doctor was more concerned about the donation than about our feelings."**
> 2015 – Declined donation

> **I don't think the people who were present were sympathetic to my son's situation and they need not have been there."**
> 2015 – Declined donation

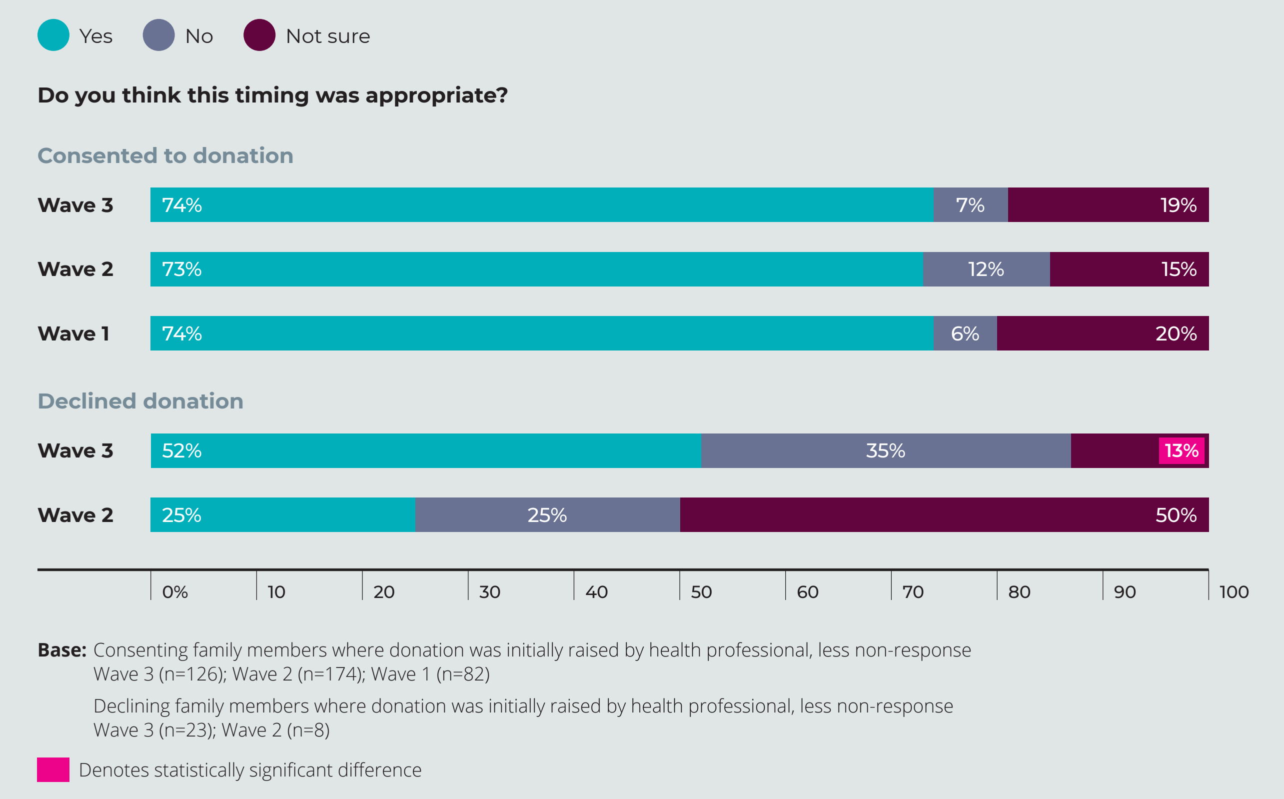
> **The question about donation occurred in front of a room of specialists. This should have been asked in private as it is a very PERSONAL decision. No-one needs that pressure at the time of passing!"**
> 2015 – Consented to donation

> **The timing could have been better and it shouldn't have been done with a crowd of medical people in the room."**
> 2015 – Declined donation

In the majority of cases, these families wanted more time to process what had happened to their loved one before being asked to consider donation. In the view of one family, however, the donation conversation was actually raised too late. They had accepted that life support would be removed but declined donation so as to not prolong the time in hospital.

> **We knew he was dying for two days before it was mentioned… It should have been raised sooner … We had accepted life support would be turned off and then we were expected to make a decision that would prolong the process."**
> 2015 – Declined donation

Figure 21 Appropriateness of donation conversation timing



Base: Consenting family members where donation was initially raised by health professional, less non-response Wave 3 (n=126); Wave 2 (n=174); Wave 1 (n=82)

Declining family members where donation was initially raised by health professional, less non-response Wave 3 (n=23); Wave 2 (n=8)

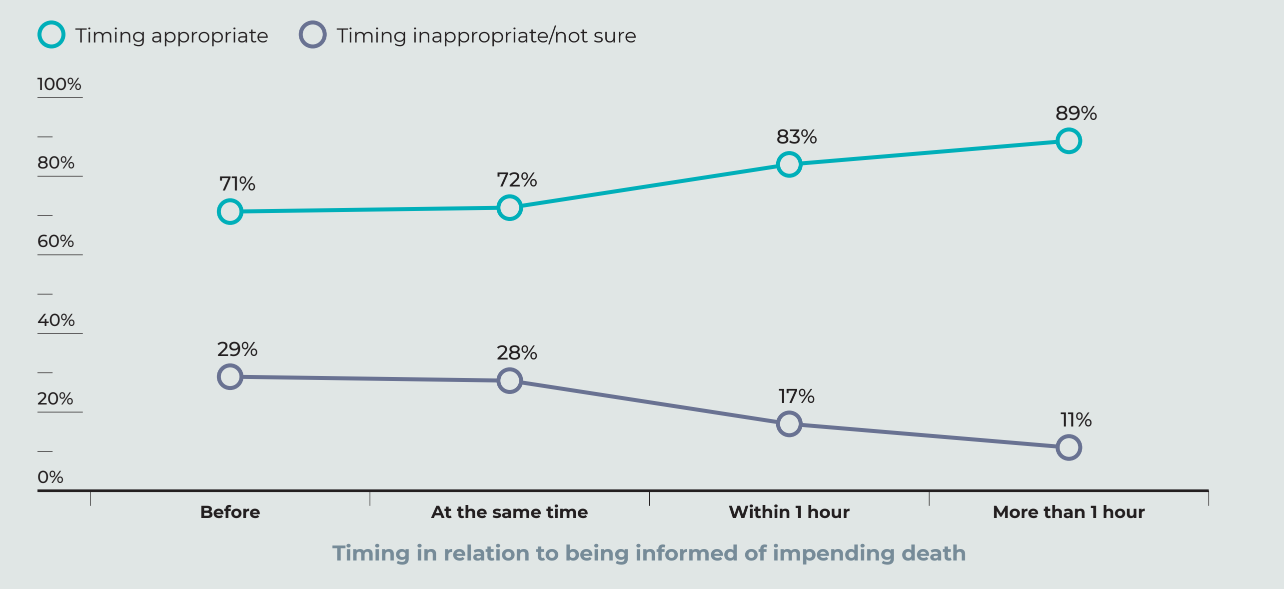
🟥 Denotes statistically significant difference

Figure 22 shows that when donation is raised by a health professional, 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.

> **“I recall the shock and disbelief when I was told of the expected death and organ donation was raised too close to the diagnosis.”**
>
> 2014 – Declined donation

> **“I had had a bit of time to grapple with my brother's passing before thinking of donation.”**
>
> 2015 – Consented to donation

Figure 22 Appropriateness of timing when donation raised by health professional



Base: Families who consented to donation, where donation request was raised by a health professional, less non-response: Wave 3 (n=126)

> **“We flew from [state], arriving at hospital at 10:30pm. Told by hospital staff that she was down for donation. This was a shock to me as I didn't know she was so ill. I hadn't even seen her when I was told this.”**
>
> 2014 – Consented to donation

Consistent with findings from previous waves of the Donor Family Study, raising donation before or at the same time as delivering news of death or impending death can, at a minimum, take families by surprise and at most, offend and upset families.

> **“Saturday morning they said, ‘she's brain dead, there's nothing we can do.’ And then straight away it was....bang, ‘do you want to donate her organs?’”**
>
> 2015 – Consented to donation (personal interview)

> **“When you are told that your family member is brain dead and in the same breath told you can donate their organs, that hospital member obviously has no compassion with what is happening.”**
>
> 2015 – Declined donation

> **“Having to make a decision without having fully understood or accepted the likely outcome.”**
>
> 2014 – Consented to donation

Families have to know that their loved one has or will soon die, before they can receive new information about donation as an end of life possibility. There is no golden rule for the best time to raise the topic, rather medical staff are advised to use their judgement and be guided by how the family are responding to information.

> **“I would not donate due to how the family is made to wait and hold onto a false hope for days.”**
>
> 2014 – Consented to donation

In addition, care should be taken to ensure that private conversations between staff members are had out of ear-shot of family members.

> **“This is one other little thing that I didn't think was really so great and I understand these things happen in hospitals sometimes, but my eldest brother was there by himself. He didn't have any other family there at that point because we were all a bit scattered. He actually overheard one of the doctors in the hallway saying, ‘we've got a possible organ donor.’”**
>
> 2015 – Consented to donation (personal interview)

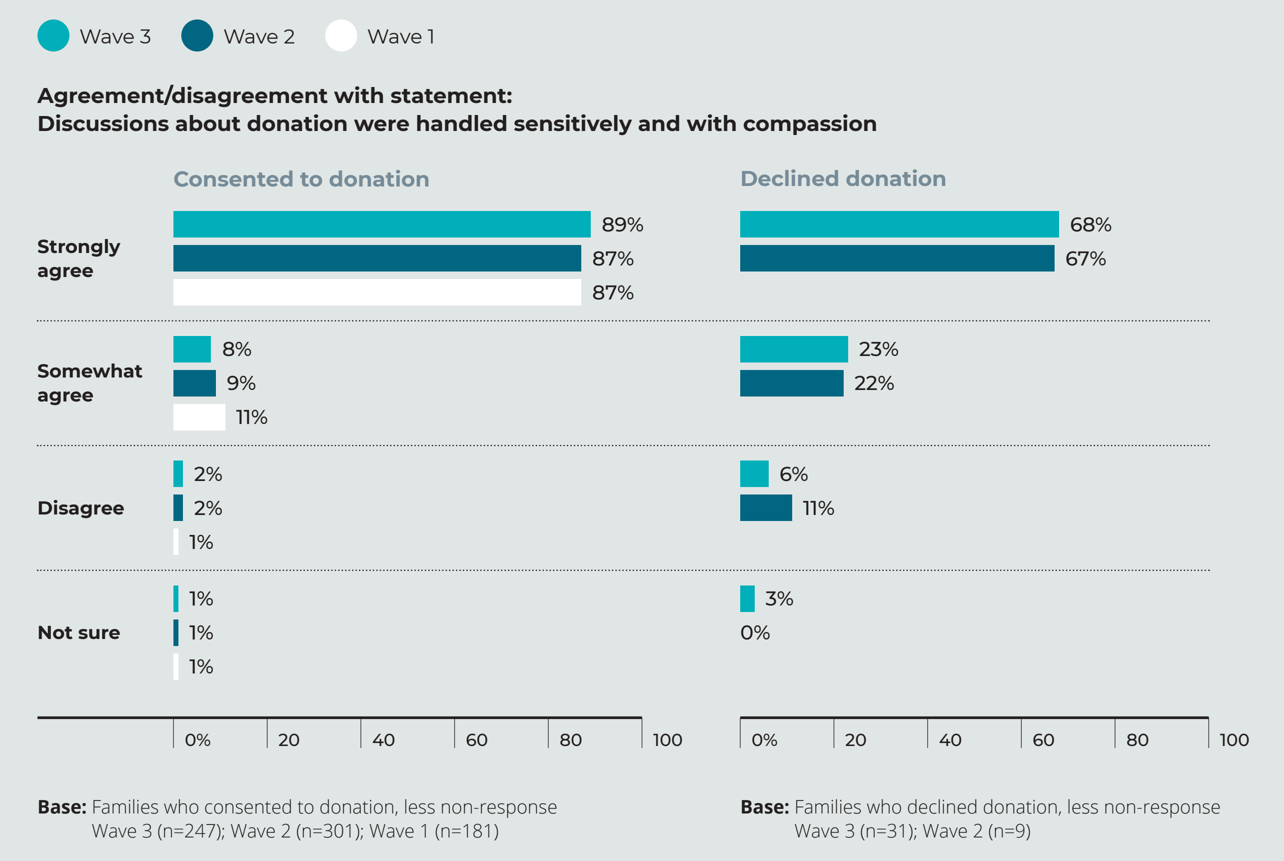
The research findings indicate that the donation conversation should not be initiated before or at the same time as delivering bad news to families; rather the timing is considered to be more appropriate when the conversations are separated and paced in line with the family’s needs.

The donation conversation should only be raised 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. The time needed will vary by family.

8.3 Tone of conversation

In the vast majority of cases, family members who later consented to donation feel that initial discussions about donation were handled sensitively and with compassion (89% of family members strongly agree). This is significantly less so amongst families who later declined donation (68% strongly agree). Findings are consistent with Waves 1 and 2 (Figure 23).

Figure 23 Tone of donation conversation



Base: Families who consented to donation, less non-response
Wave 3 (n=247); Wave 2 (n=301); Wave 1 (n=181)

Base: Families who declined donation, less non-response
Wave 3 (n=31); Wave 2 (n=9)

> **I called him the professor, but I don't know what he was. He talked about the attributes of someone that would donate their organs and it was him to a T. You know, just helping others, I don't know I just remember always thinking the way he put it together was just so comforting."**
>
> 2014 – Consented to donation (personal interview)

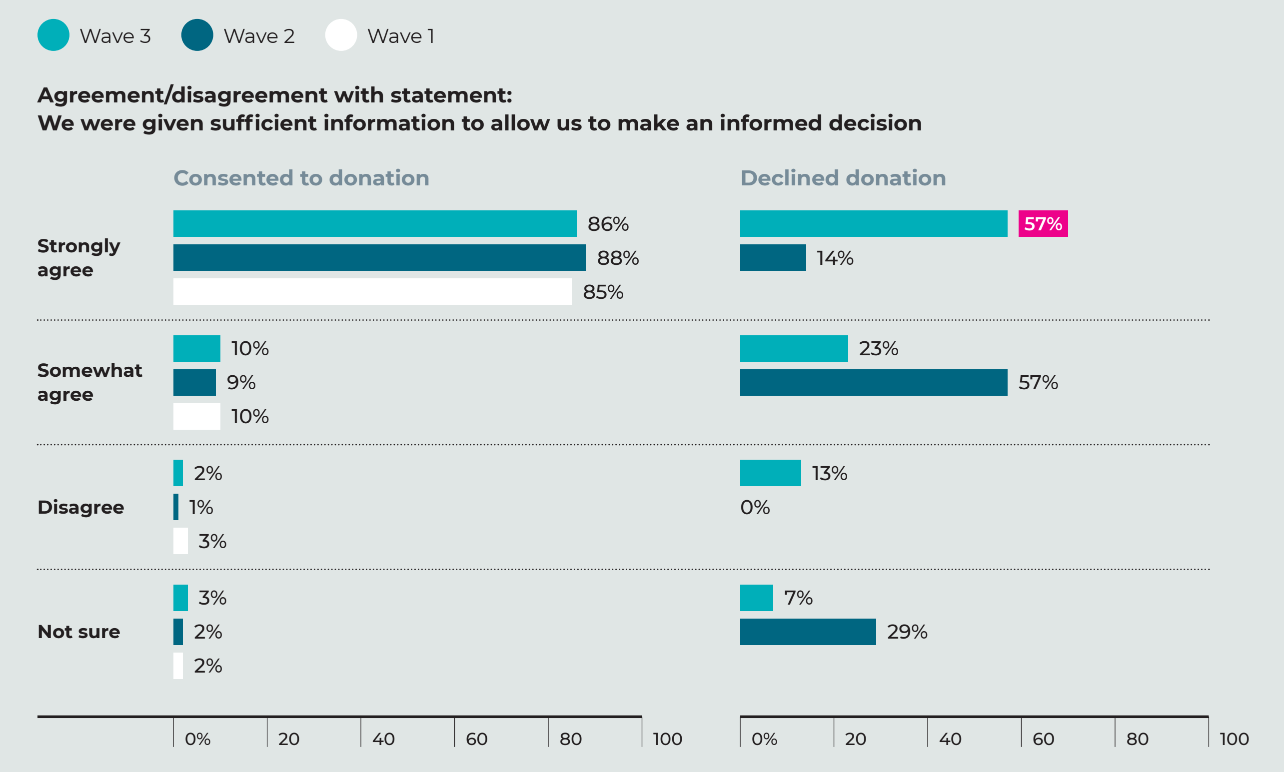
8.4 Information

With regards to making a decision about donation, 96% of donor family members agree (86% strongly agree) that they were given sufficient information to allow them to make an informed decision (Figure 24); consistent with previous waves.

> **Enough information was provided by caring professionals to help our decision and our family through this time. Any more detailed/complex information would not have been absorbed by us at that time."**
>
> 2015 – Consented to donation

> **I had all the information I needed. I'm not a person that needs to know the details, so all I need to know is 'are they going to be going to other people' and 'it needed to be done soon', and 'there was no chance of my wife going to survive.' Give me those three things, that's all I needed to know. The details weren't really relevant."**
>
> 2015 – Consented to donation (personal interview)

Figure 24 **Sufficient information to make an informed decision**



Base: Total sample of families who consented to donation, less non-response: Wave 3 (n=238); Wave 2 (n=290); Wave 1 (n=179)

Base: Total sample of families who declined donation, less non-response: Wave 3 (n=30); Wave 2 (n=7)

🟥 Denotes statistically significant difference

> **More information about what is involved would have been helpful.”**
> 2014 – Declined donation

Although an improvement on Wave 2, families who declined donation are significantly less likely to feel that they were given sufficient information to allow them to make an informed decision (57% strongly agree that they were).

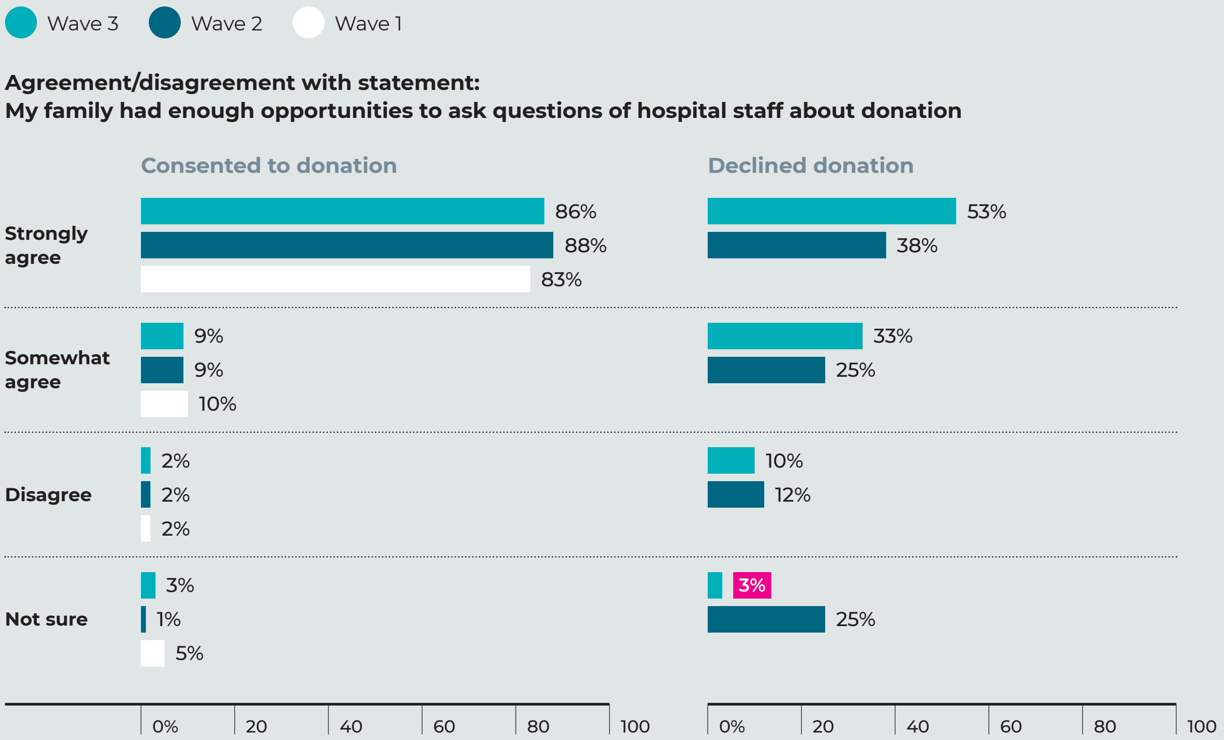
Hospital staff should be guided by each family as to the amount of information offered at this stage. As shown in the above comment, some family members need more information about the donation process while others (as shown in the comment below) are perhaps more pragmatic and wish to proceed without knowing the details.

> **They wanted to explain more about what they do and that sort of stuff and I said that we didn’t want to know. We agreed to donation on the spot.”**
> 2015 – Consented to donation (personal interview)

As families are emotionally drained whilst in hospital, they are unlikely to fully absorb the information provided. Knowing that they are able to ask questions of the medical team at any time is therefore important. Figure 25 shows that 95% of donor families in 2014 and 2015 agree (86% strongly) that their family was provided with enough opportunities to ask questions of hospital staff about donation. Families who declined donation were significantly less likely to feel they were given sufficient opportunities to ask questions (53% strongly agree).

Further, 95% of donor family members agree that hospital staff answered their questions (85% strongly agree). This is consistent with earlier waves, as shown in Figure 26. Again, families who declined donation are significantly less likely to agree that this occurred (57% strongly agree).

Figure 25 Opportunities to ask questions



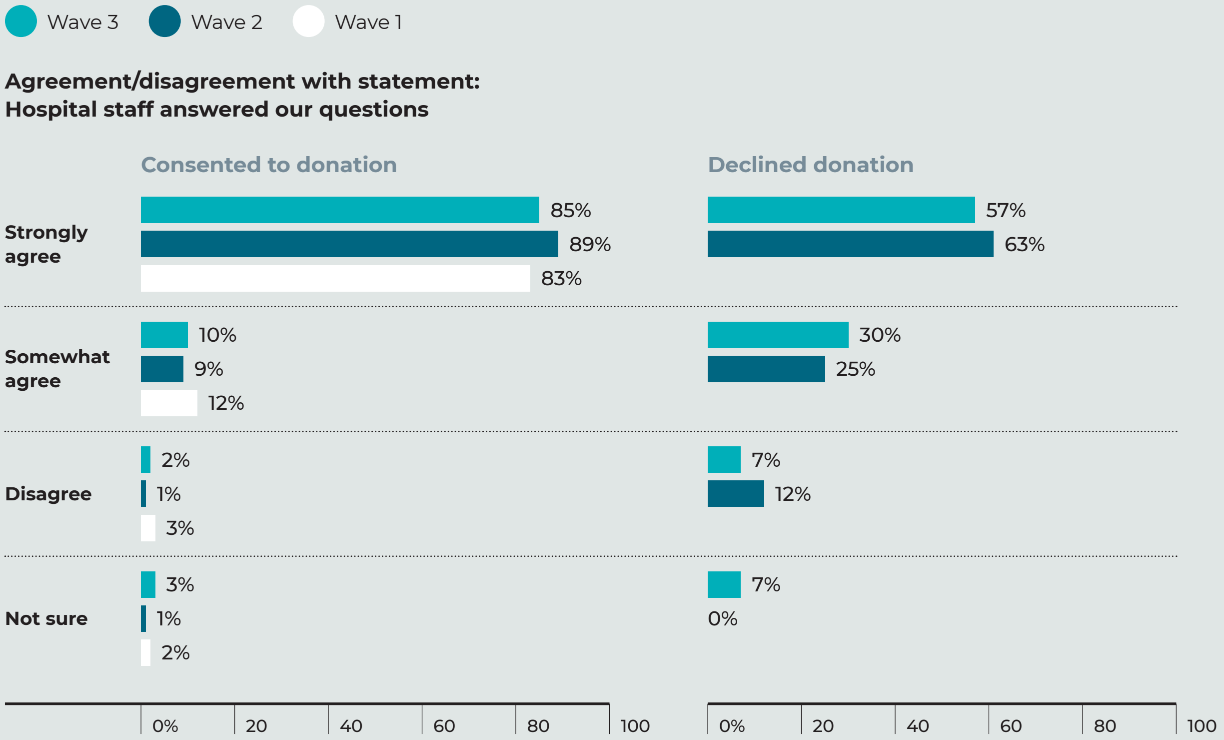
Agreement/disagreement with statement:
My family had enough opportunities to ask questions of hospital staff about donation

Base: Family members who consented to donation, less non-response Wave 3 (n=244); Wave 2 (n=290); Wave 1 (n=179)

Base: Family members who declined donation, less non-response: Wave 3 (n=30); Wave 2 (n=8)

🟥 Denotes statistically significant difference

Figure 26 Hospital staff answered questions



Agreement/disagreement with statement:
Hospital staff answered our questions

Base: Family members who consented to donation, less non-response Wave 3 (n=239); Wave 2 (n=290); Wave 1 (n=179)

Base: Family members who declined donation, less non-response: Wave 3 (n=30); Wave 2 (n=8)

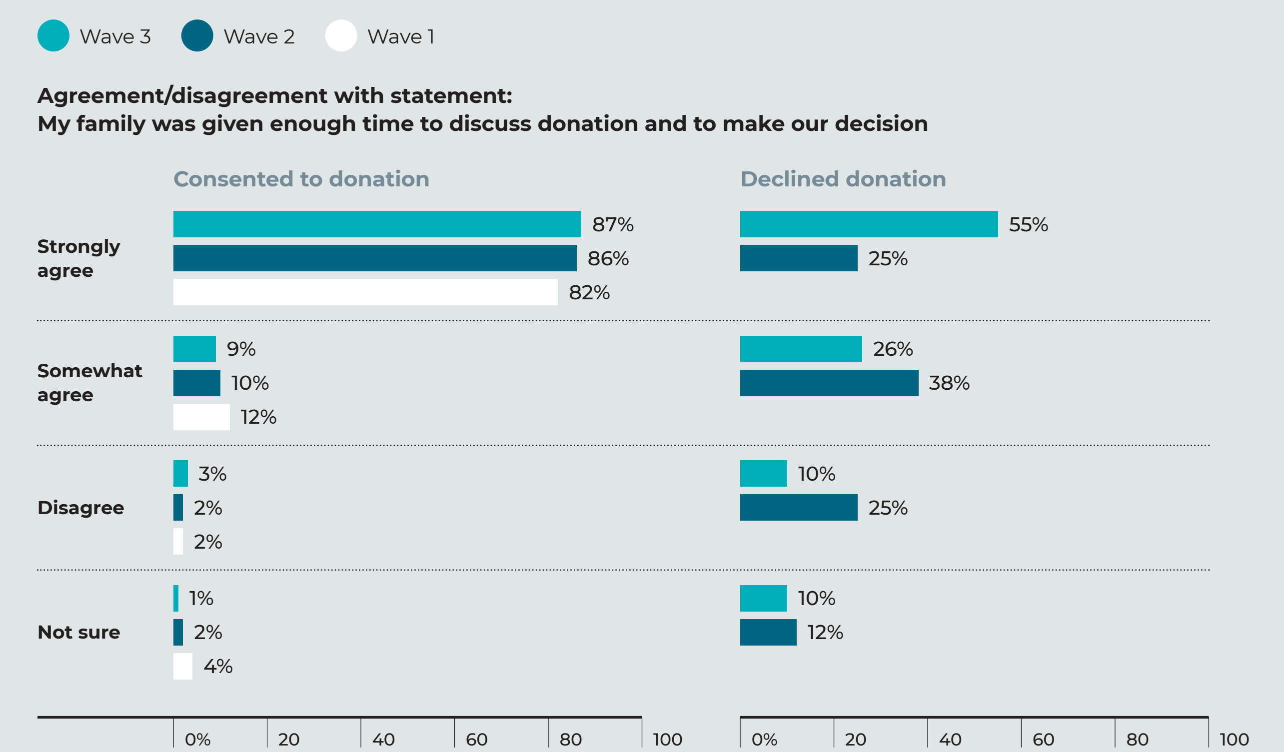
8.5 Time to consider donation

The majority of donor families felt that they were given enough time to discuss donation and to make their decision (96% agree in total; 87% strongly agree), as shown in Figure 27.

> **When I think back, we were treated with compassion, empathy and respect; given time to understand things, ask questions and a private lounge area to speak with DonateLife.”**
> 2015 – Consented to donation

Families who declined donation were much less likely to feel that they were given enough decision-making time (81% agree; 55% strongly agree). Further, significantly more families who declined donation felt rushed or pressured to make a donation decision (24% compared with 7% of families who consented to donation).

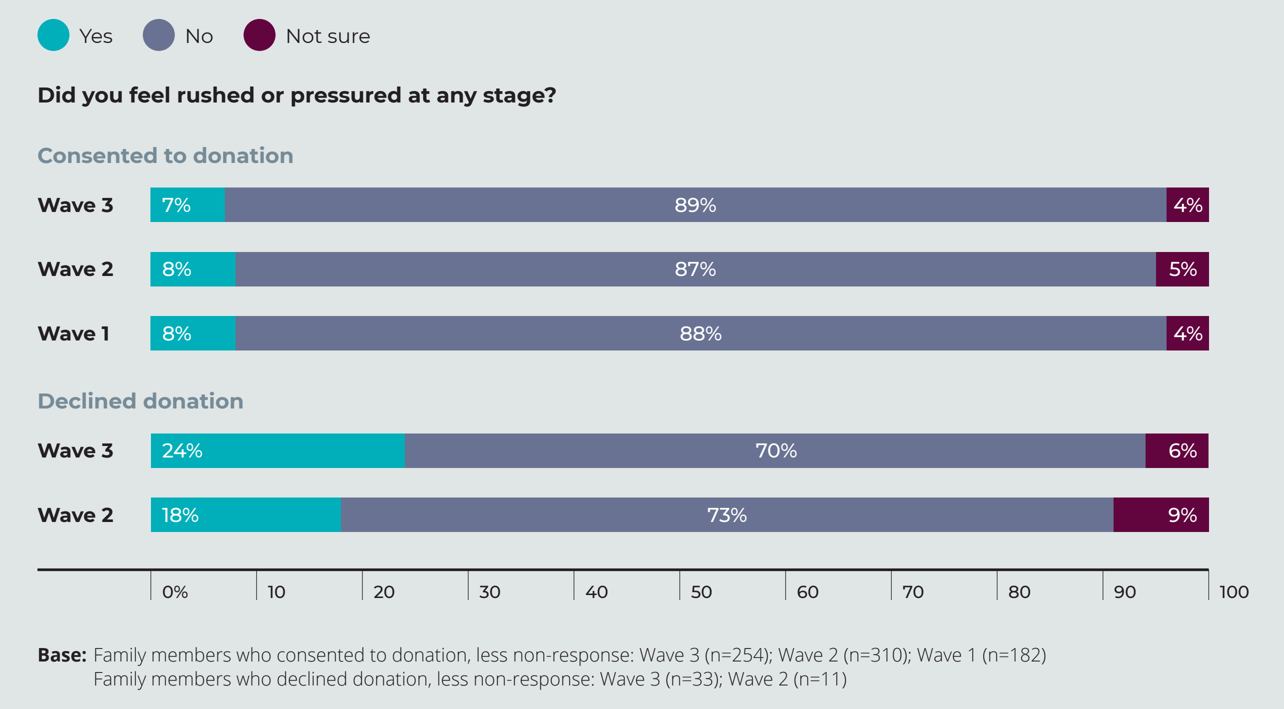
Figure 27 Time to make a decision



Base: Family members who consented to donation, less non-response Wave 3 (n=238); Wave 2 (n=288); Wave 1 (n=180)

Base: Family members who declined donation, less non-response: Wave 3 (n=31); Wave 2 (n=8)

Figure 28 Rushed or pressured



Base: Family members who consented to donation, less non-response: Wave 3 (n=254); Wave 2 (n=310); Wave 1 (n=182)
Family members who declined donation, less non-response: Wave 3 (n=33); Wave 2 (n=11)

> **I felt that we had to make a decision while the doctor was still in the room. We had no private time to discuss it.”**
>
> 2014 – Declined donation

> **Our family was asked to consider organ donation before we had even arrived at the hospital to find out about our son. I felt pushed to make a decision.”**
>
> 2014 – Declined donation

If possible, family members should be provided with a private room or space in which they can gather, discuss donation and make a decision that is right for them. This simple act will be regarded as a sign of respect and consideration.

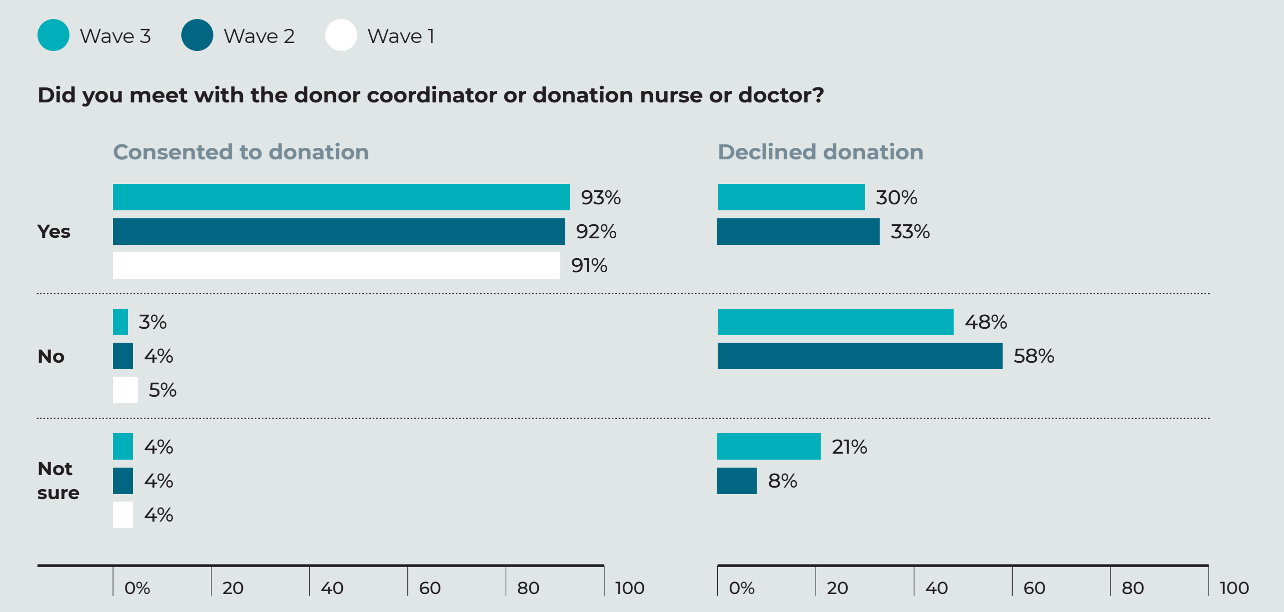
9 Moving toward donation

9.1 Understanding of the donation process

Nine in ten donor families in 2014 and 2015 (93%) recall meeting with the donor coordinator or donation nurse/doctor (Figure 29). After this meeting, 80% of donor family members felt well informed; 18% still had unanswered questions and 2% left the meeting with no clear understanding of the donation process (Table 19). These findings are consistent with Waves 1 and 2.

> **I think my issue with it was, yes, we were happy to donate organs but I didn't really know the process."**
> 2014 – Consented to donation (personal interview)

Figure 29 Meeting donation staff



Base: Families who consented to donation, less non-response
Wave 3 (n=257); Wave 2 (n=317); Wave 1 (n=183)

Base: Families who declined donation, less non-response
Wave 3 (n=33); Wave 2 (n=12)

As shown in Figure 29, significantly fewer families who went on to decline donation met with a donor coordinator, donation nurse or doctor (30%). This may indicate that families who decline donation are doing so before having an opportunity to meet with a donor coordinator, or that some families weren't offered this meeting.

Half (50%) of the families who met with a donor coordinator, donation nurse or doctor (and later declined donation) felt that they were well informed after this meeting; the remaining families left the meeting with some unanswered questions (20%) or with no clear understanding of the donation process (30%).

Families who declined donation are significantly:

- less likely to meet with a donor coordinator, nurse or doctor, and
- more likely to not understand the donation process (among those who did speak with a donor coordinator, nurse or doctor).

Table 19 Understanding of donation process after meeting with donation staff

Understanding of donation process after speaking with donor coordinator, donation nurse or doctor	Consented to donation			Declined donation	
	Wave 1 (n=164)	**Wave 2** (n=290)	**Wave 2** (n=240)	**Wave 2** (n=3)*	**Wave 3** (n=10)*
I was well informed and knew all that I needed to know about the donation process	82%	83%	80%	100%	**50%**
I was informed but still had some questions	16%	14%	18%	–	20%
I didn't have a good understanding of the donation process	2%	2%	2%	–	**30%**

* Caution: small base

🟥 Denotes statistically significant difference

Nine in ten donor family members (91%) were made aware that even if donation was agreed to, it may not happen for any number of reasons. This is consistent with Wave 1 (90%) and Wave 2 (88%). It is essential that this practice continues for all families who consent to donation, in order to manage expectations.

> **“ It was very disappointing for us that our big fit healthy young man's organs weren't able to be used. We all felt sad that he couldn't help others in his time of dying.”**
> 2014 – Consented to donation – intended

9.2 Provision of written information

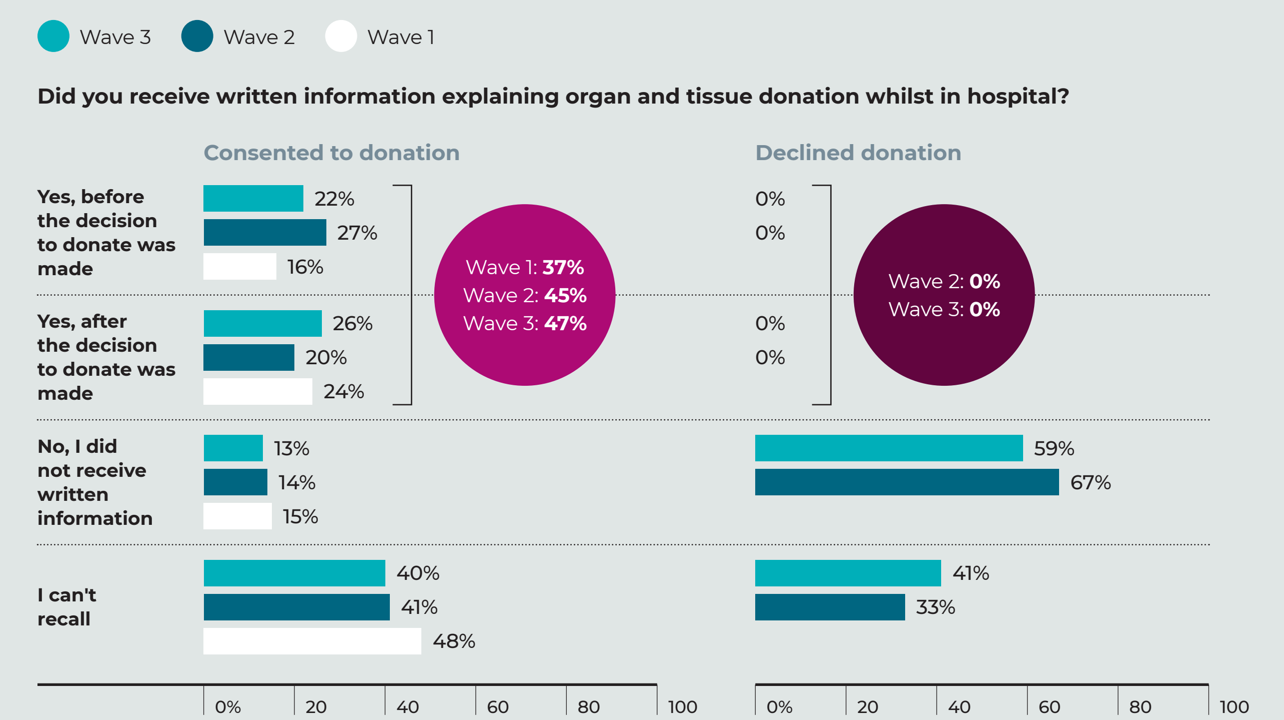
In 2014 and 2015, 47% of family members recall being provided with written information explaining organ and tissue donation whilst in hospital (Figure 30), consistent with the previous two years. One in eight donor family members (13%) were not given written information about donation and 40% can't remember if they received any information.

> **“ [I wanted] better information about the donation process and what to expect when you make your decision.”**
> 2015 – Consented to donation

> **“ No, I think we had enough information. And they gave us small pamphlets and booklets and things to read through, and a phone number, and said 'please ring us'. And they were always on hand.”**
> 2015 – Consented to donation (personal interview)

Of families who declined donation, 59% were not provided with written information explaining donation, whilst a substantial proportion (41%) do not recall if they received anything.

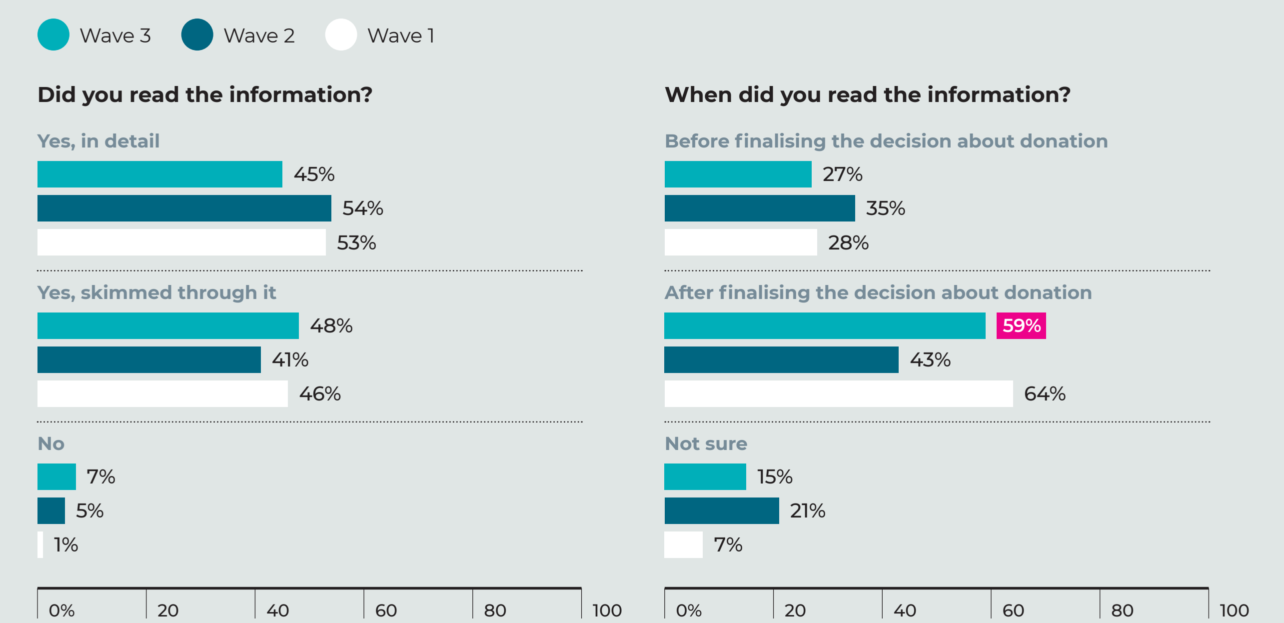
Figure 30 Receipt of written information



Base: Total sample who consented to donation, less non-response: Wave 3 (n=254); Wave 2 (n=316); Wave 1 (n=183) **NB:** Multiple response
Total sample who declined donation, less non-response: Wave 3 (n=32); Wave 2 (n=12)

For those who did receive information when in hospital, just under half (45%) read the information in detail, while half (48%) skimmed through it. Seven per cent of families who were given information decided not to read it (Figure 31). This is consistent with Waves 1 and 2.

Figure 31 Reading of written information



Base: Family members who consented to donation and received written information:Wave 3 (n=119); Wave 2 (n=143); Wave 1 (n=68)
Those who read the information, less non-response: Wave 3 (n=111); Wave 2 (n=133); Wave 1 (n=67)

🟥 Denotes statistically significant difference

For those 93% of donor family members who read the written information they were provided with in hospital, 59% read it after they had already made their donation decision; 27% read the information before finalising their donation decision.

As shown in Table 20, almost all (95%) family members who received and read the written information explaining organ and tissue donation whilst in hospital, found it to be useful (42% found it to be very useful). Those who read the information in detail found it to be more useful (compared to those who skimmed through it), which emphasises the importance of encouraging readership of the information, in their own time. This is consistent with findings from Wave 1 and Wave 2.

> **It wasn't too much. Obviously, there's a lot of information that you get at a time like that, but no, it was very respectful and they were lovely. And they gave us all information packs and cards. And you know, they said you can call us anytime if you need to know anything.”**
> 2015 – Consented to donation (personal interview)

Table 20 Usefulness of information by readership

Usefulness of written information	Wave 1 total who received and read information (n=66)	Wave 2 total who received and read information (n=136)	Wave 3 total who received and read information (n=110)	Read in detail (n=53)	Skimmed through (n=57)
Very useful	54.5%	52%	42%	**60%**	25%
Quite useful	41.0%	44%	53%	40%	**65%**
Not useful	4.5%	2%	5%	–	11%
Can't recall	–	1%	–	–	–

■ Denotes statistically significant difference

Written information is important for donor families to receive whilst in hospital, however it should not replace verbal communication from health professionals. Verbal information should be succinct and delivered in layman's terms for ease of processing.

The written information is the supplementary detail that families need to consolidate their understanding of the donation process.

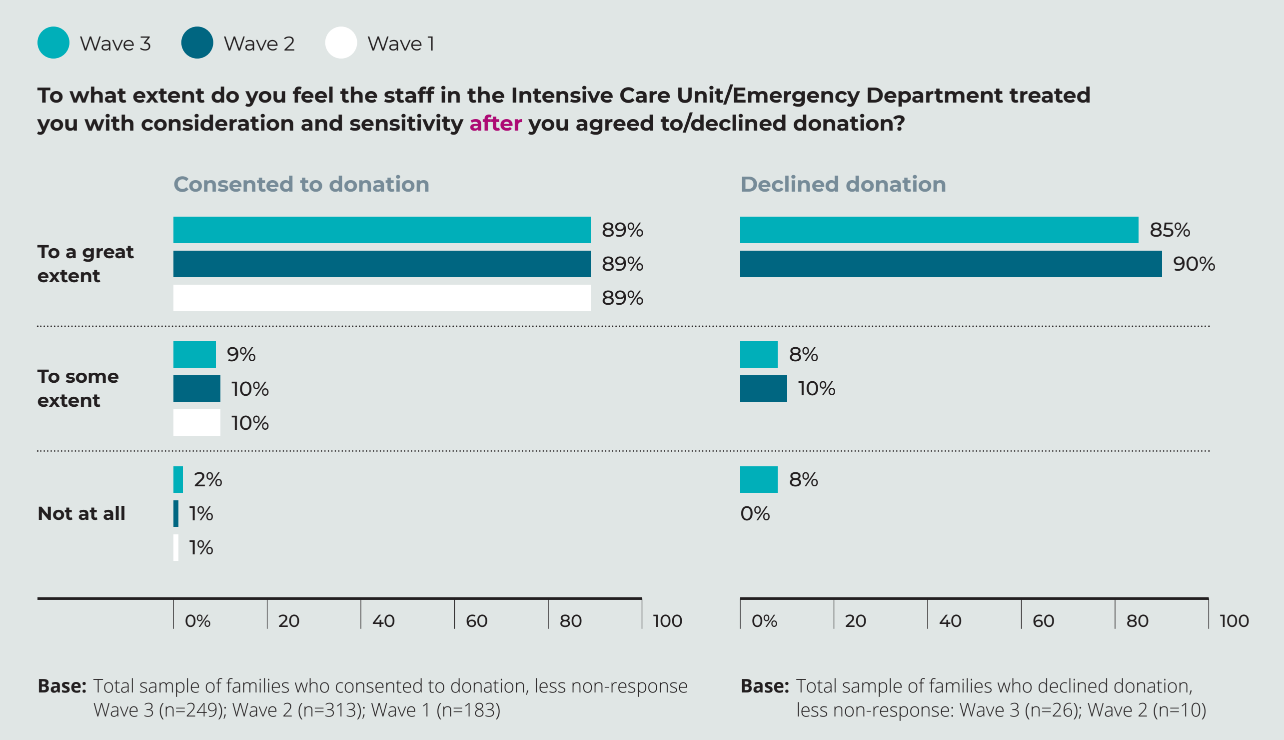
9.3 Support from health professionals – after consenting to donation

Nine in ten families feel that staff in the ICU or ED treated them with consideration and sensitivity after they made their donation decision, irrespective of whether that decision was to decline or consent (Figure 32). This is consistent with Waves 1 and 2.

> **Our decision didn't seem to make a difference. We were treated the same before and after."**
> 2014 – Consented to donatiion

> **The hospital treated us and my father with impeccable care, irrespective of our decision."**
> 2014 – Consented to donatiion

Figure 32 Treatment by staff after donation decision



Base: Total sample of families who consented to donation, less non-response Wave 3 (n=249); Wave 2 (n=313); Wave 1 (n=183)

Base: Total sample of families who declined donation, less non-response: Wave 3 (n=26); Wave 2 (n=10)

9.3.1 Small but meaningful gestures

In explaining the quality of care families received post their donation decision, it's the little things, the small gestures from hospital staff, that families remember so clearly. The offer of handprints, a lock of hair, a handmade quilt all become treasured keepsakes. The offer of playing the donor's favourite piece of music during surgery demonstrates great kindness and respect for the donor and this small act provides solace for the family and reassures them that their loved one will be treated with respect during surgery.

> **The quilt was wonderful, especially being able to choose the one that we felt suited our family member."**
> 2015 – Consented to donation

> **We were even asked if we would like special music to be played in theatre. That was special."**
> 2015 – Consented to donation

> **The staff could not have been more sensitive, caring and compassionate. They took fingerprints, handprints and gave us snippets of his hair in key rings. All treasured keepsakes."**
> 2015 – Consented to donation

These gestures, though small, are deeply meaningful for families.

Whilst care of the patient is of course paramount, being mindful of the physical and emotional needs of family members should not be overlooked. When hospital staff check in with family members to simply ask how they are, ask if they have slept or eaten, ask if they need anything, families remember these genuine and heartfelt acts of kindness. In their minds, this helps to solidify their donation decision as the right thing to do.

> **On the night before our son was due to be an organ donor, the ICU nurse got a bed chair for me so I could cuddle up to our son and sleep. It was the best sleep I had for 10 days. Also, they moved our son to a larger room to accommodate our large family."**
> 2014 – Consented to donation

> **The ICU nurse caring for my husband was amazing, made me feel so important and like a VIP in a sense. He ensured that I had time with my husband whilst he was on life support, he ensured I ate and drank something showing understanding towards me of my shock and disbelief and also inability to absorb and comprehend things fully."**
> 2014 – Consented to donation

Consistent with findings from Waves 1 and 2, when treatment of families and/or the donor post-consent is inconsistent with that received pre-consent, families can doubt their donation decision. Families need to feel that their loved one still matters, even though they have died or will soon die.

> **The staff were so kind and considerate. They told me my son was a hero. Those words have brought me great comfort."**
> 2015 – Consented to donatiion

The level of care, consideration and compassion shown to family members and the donor must continue to be consistently high at all times – before and after the donation decision has been made, irrespective of a consent or decline response.

9.3.2 Support of social worker, counsellor or chaplain

In 2014 and 2015, 78% of donor family members were offered the support of a social worker, counsellor or chaplain at some time during their family member's stay in hospital (Figure 33), which is consistent with earlier waves. Seven in 10 families (70%) who declined donation were also offered this type of support; 12% were not offered and 18% cannot recall.

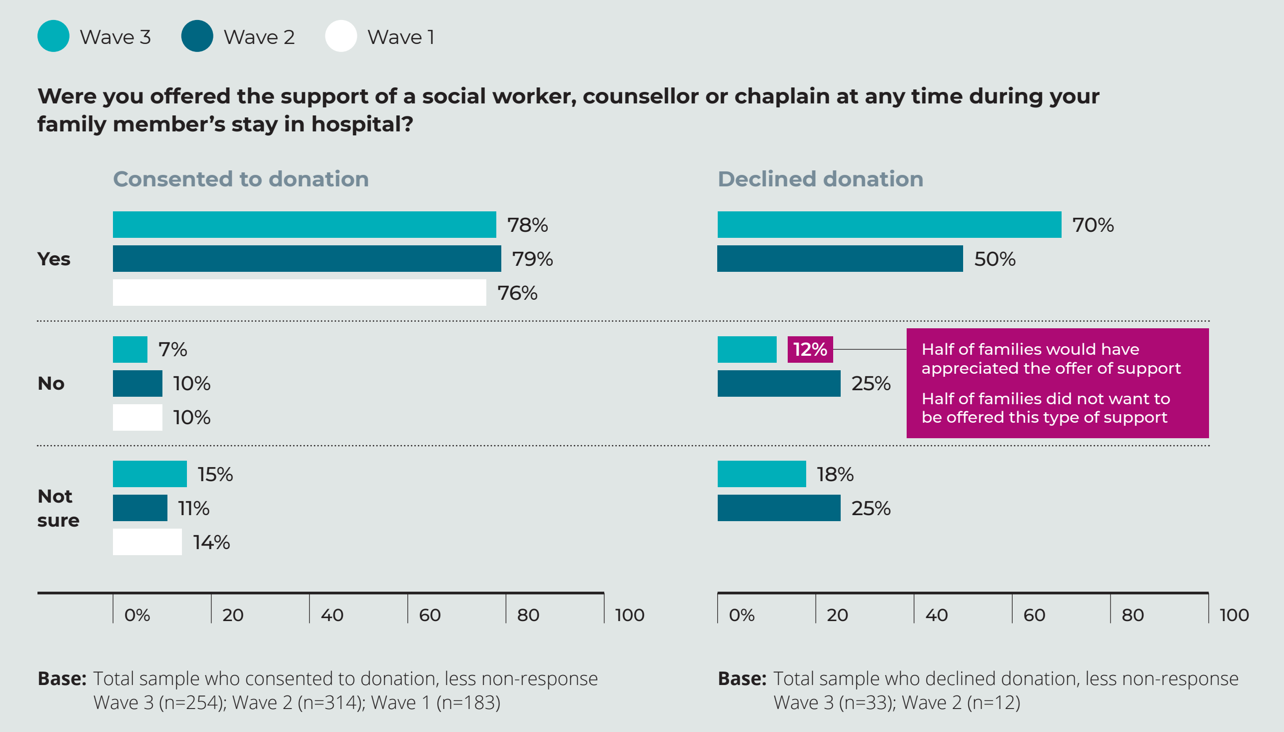
For those families who declined donation and were not offered the support of a social worker, counsellor chaplain, half said that on reflection, they would have appreciated this type of offer.

> **Hospital did not offer or provide a pastoral care worker, psychologist or counsellor to assist with our grief. I specifically requested assistance as I am in the medical/nursing field and am aware of the resources that are available."**
> 2015 – Declined donation

Feedback from families about hospital social workers is mixed, with some families having a positive experience and others finding their interaction with a social worker less than satisfactory. Regarding the latter, complaints appear to centre around a perceived lack of interpersonal skills.

> **All of a sudden, after she was pronounced dead, we gathered ourselves and in comes a counsellor and she goes, 'I'm a counsellor and I'm here to talk to you, do you want to come and talk with me?' It's like 'no, just go away, I don't want to talk to a counsellor. I want to sit here and process the fact that I've just lost my baby girl. I want to cry with my family and you want to talk to me? Go away'."**
> 2015 – Consented to donation (personal interview)

Figure 33 Support offered during stay in hospital



Base: Total sample who consented to donation, less non-response Wave 3 (n=254); Wave 2 (n=314); Wave 1 (n=183)

Base: Total sample who declined donation, less non-response Wave 3 (n=33); Wave 2 (n=12)

Table 21 shows findings across the three waves of research, split by donation pathway. There are no significant differences in support offered between donation pathways (77% of DBD family members were offered support; 79% for DCD family members).

Table 21 Support of social worker, counsellor or chaplain, by pathway to donation

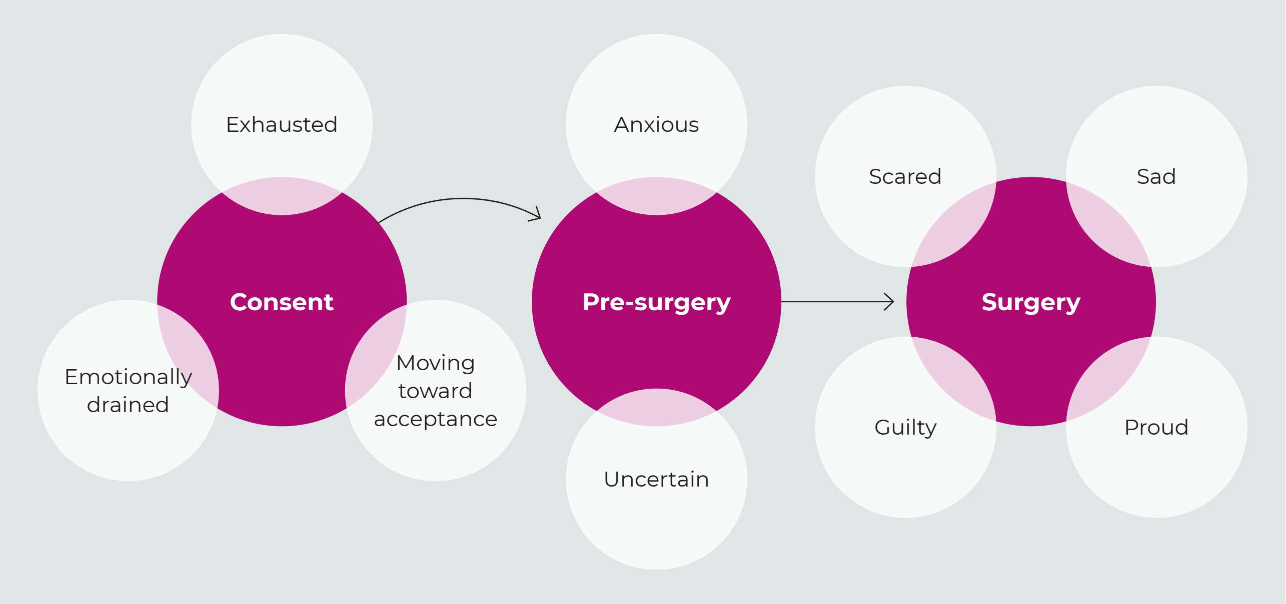
	2010/2011 Family members		2012/2013 Family members		2014/2015 Family members	
Offered support of social worker, counsellor or chaplain	**DBD** (n=163)	**DCD** (n=20)	**DBD** (n=277)	**DCD** (n=37)	**DBD** (n=216)	**DCD** (n=38)
Yes	74%	**95%**	78%	84%	77%	79%
No	11%	–	10%	8%	8%	5%
Not sure	15%	5%	11%	8%	15%	16%

🟥 Denotes statistically significant difference

9.4 The donation process

As found during earlier waves of the Donor Family Study, the time between consenting to donation and when donation surgery takes place can be very distressing for family members. Whilst they have made their donation decision, family members still need support and care and still need to know that their loved one is important.

Figure 34 Emotions at play between consent and donation surgery



Families are often emotionally spent at this point in time, knowing that what happens next is the final chapter in their loved one's life. As such, they need:

- care for themselves (have they slept, have they eaten, do they need anything?)
- care for their loved one (continue to show respect; refer to the patient by name)
- easy-to-digest information
- accurate timeframes
- to be kept informed, especially if delays are expected, and
- private time with their loved one to say goodbye.

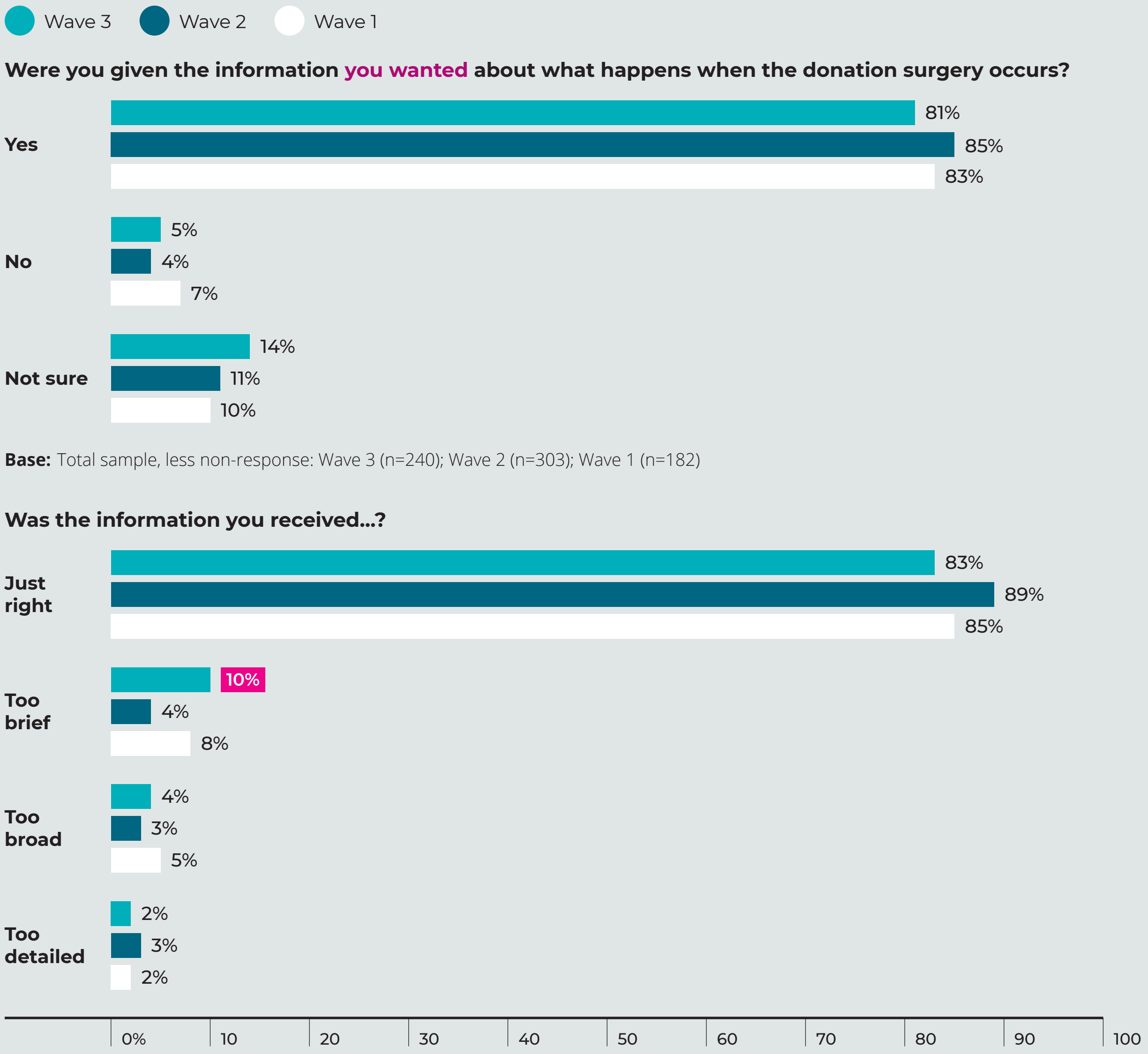
> **I loved how respectfully my husband was treated throughout the whole process. He remained a person – not just a set of organs."**
> 2015 – Consented to donation

> **We were informed of all that was happening day or night, when the process was delayed and then rescheduled. Totally informed before and after."**
> 2015 – Consented to donation

9.4.1 Information provided to families

In terms of the information provided, 81% of donor family members feel they were given the information they wanted about the donation surgery and 83% felt that the amount of information they received was just right (Figure 35). This is consistent with Waves 1 and 2. Ten per cent of families in 2014 and 2015 felt that the information they received about donation surgery was too brief, a significant increase since Wave 2.

Figure 35 Information about donation surgery



Base: Total sample, less non-response: Wave 3 (n=240); Wave 2 (n=303); Wave 1 (n=182)

Base: Total sample, less non-response: Wave 3 (n=226); Wave 2 (n=282); Wave 1 (n=181)

🟥 Denotes statistically significant difference

> **She tried to explain it so I could understand it.”**
>
> 2015 – Consented to donation (personal interview)

9.4.2 Information sought from families – informed consent

As part of the consent process, family members are asked to nominate which organs and tissues they consent to being donated. One of the findings to emerge strongly from the research in Wave 1 was the difficulty faced by families when asked to make these decisions. This finding was again prevalent in Wave 2 and Wave 3, although to a slightly lesser extent.

Positives

The DonateLife coordinators conducting the informed consent meeting are praised by families for their openness, patience and non-judgemental attitude. Families recall being treated with respect during this meeting and not feeling pressured into agreeing to anything that they were not comfortable with. DonateLife staff freely answer all questions and do their best to make families feel comfortable.

> **“It [the consent process] wasn't daunting at all. I think probably what made it easier was because it was something we always spoke about. They were both beautiful and I think that made it a lot easier to deal with.”**
> 2015 – Consented to donation (personal interview)

> **“They were kind and sensitive and knew they were asking very awkward questions. I suppose they were trying to make sure that we knew what we were doing.”**
> 2015 – Consented to donation (personal interview)

Consistent with Wave 2 research findings, many donor families can more easily understand the impact of organ donation over tissue donation. The donation of skin, bone and eye tissue is, for some, difficult to grasp. How will this type of donation benefit others and how will it impact the appearance of my loved one?

Negatives

Some families feel that they should not have to go through the process of informed consent for every organ and tissue, particularly if their loved one has already made their wishes in this regard clear via the Australian Organ Donor Register. They find the process to be overly lengthy and detailed and become overwhelmed.

Requesting consent for every organ and tissue is felt to:

- be a lengthy process that further drains families emotionally
- be a lengthy process that takes away from time they could be spending with their loved one, and
- create an unwelcome image of body parts.

> **“There's this big bloody list. It's not just your heart and your lungs, it's tissues and bones and bits and pieces. And all these other bits and pieces added confusion to the exercise of organ donation. I know when they explain it, and you're not necessarily in a position of clear thought at the time because in Mum's mind they're chopping up her daughter.”**
> 2015 – Consented to donation (personal interview)

> **“I was pressured into answering a long list of questions that I was not prepared to answer. I had not been informed that I would face this. I thought all I would have to do is sign a consent.”**
> 2015 – Consented to donation

More common in this wave, was a preference for this process to be more transparent; family members want to be told upfront of the types of things that may preclude their loved one from being a donor of certain organs or tissues, so that they don't go through the process of coming to a 'yes' only to be told later that their loved one was unable to donate certain organs due to medical reasons.

> **I felt that was extremely stressful and I feel that that could have been avoided, because they couldn't use his organs as it all turned out. So I felt like I went through all of this trauma for nothing."**
> 2015 – Consented to donation – intended (personal interview)

> **Instead of having to go through the entire process, it should have been avoided by doing a medical check with his GP at the beginning of the process and not at the end."**
> 2015 – Consented to donation

> **All my family are donors but when faced with making the decision and facilitating the process, much more was involved than we ever thought. It would be good if there was more information available to families at the time people opt for organ donation. Whilst you can never really be prepared, I think early and detailed information is very important."**
> 2015 – Consented to donation

Families should be informed prior to the meeting of the expected duration of the meeting and what it involves. The meeting should be held in a private room and families offered breaks when needed.

9.4.3 Timing – prior to donation surgery

As in previous research waves, 'time' is a recurring theme amongst families in Wave 3. As is the nature of donation, death is sudden and unexpected. All of a sudden, 'time's up' for their loved one and this is understandably hard for families to accept. In this environment comes the option of donation which can simultaneously create more time pressures and prolong the process of dying and saying goodbye for families.

Most commonly, family members found the extra time involved with donation to be difficult. Many families feel the time for testing to be done for matches is like an additional sacrifice. In some cases families appreciate the precious additional time to sit with their loved one and say goodbye.

> **I was happy to agree to donation but felt the time involved (however necessary) made it very hard for the family."**
> 2014 – Consented to donation

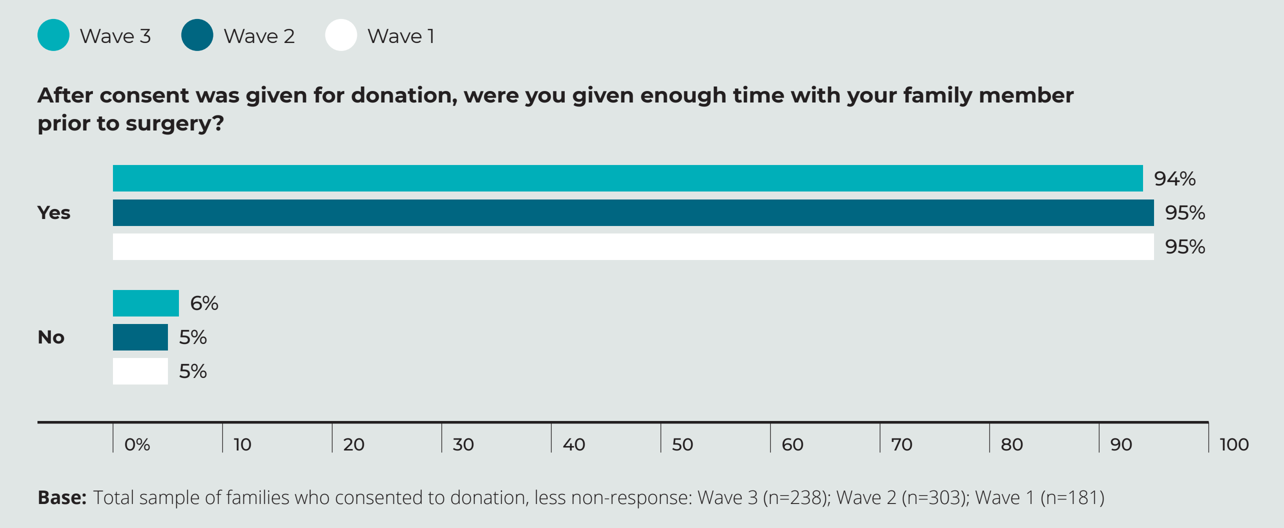
> **The extended time between waiting for the coordinator to get to the hospital and surgery wait time = more than 2 days. Prolonged the painful goodbye."**
> 2015 – Consented to donation

> **There are blessings in having that time and space too. As such a large family, it allowed time for everybody to be able to come in and say their goodbyes and for us to all hug each other and grieve together."**
> 2015 – Consented to donation (personal interview)

In any case, family members typically find it difficult to function with uncertain timeframes including time when the informed consent meeting will take place and the expected time for donation surgery. As much as possible, health professionals should provide firm timings to manage family members' expectations.

Just over nine in ten donor family members (94%) feel they were given enough time with their family member prior to donation surgery; 6% feel they were not (Figure 36). This is consistent with Waves 1 and 2.

Figure 36 Time with family member prior to surgery



Base: Total sample of families who consented to donation, less non-response: Wave 3 (n=238); Wave 2 (n=303); Wave 1 (n=181)

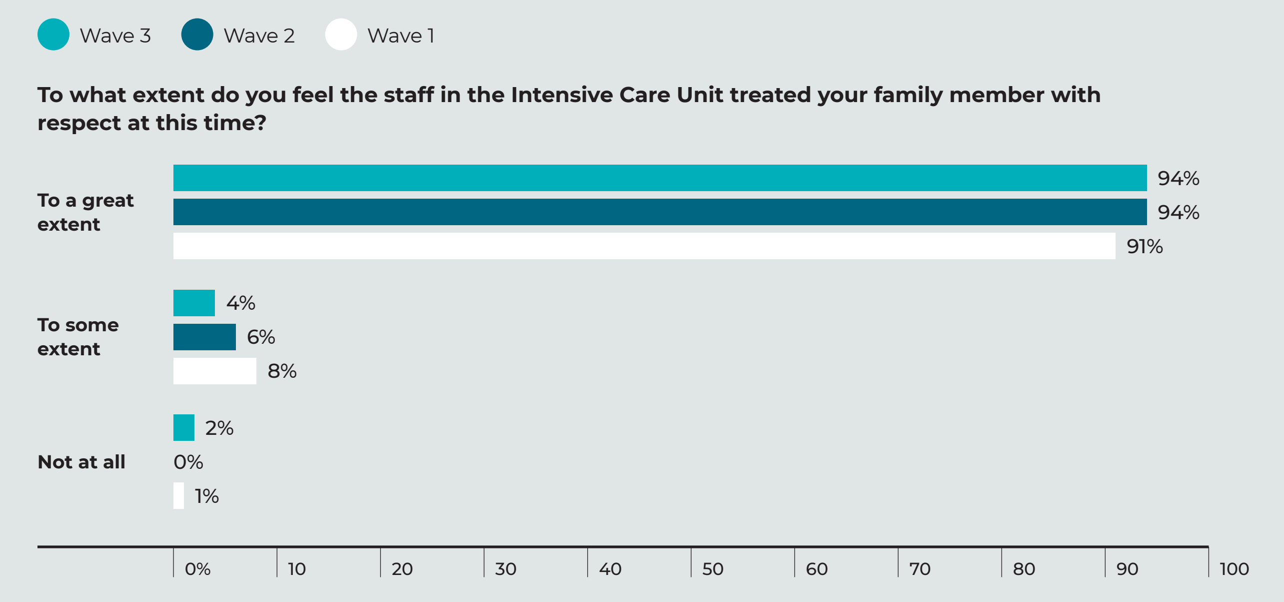
The difficult time between consent and donation surgery must be efficient and informed. Families must be kept up-to-date with accurate information regarding the likely time of donation surgery. If there are delays, family members must be informed and provided with an explanation for the delays.

At all times, families must continue to be treated with sensitivity and compassion.

9.4.4 ICU staff

Generally speaking, the majority of donor families have positive experiences with ICU staff. As shown in Figure 37, 94% of donor family members felt their loved one was treated with respect by ICU staff in the lead up to donation surgery. As in previous waves there are many stories of the beautiful and caring ways in which their loved ones were treated.

Figure 37 Treatment by staff prior to surgery



Base: Total sample, less non-response: Wave 3 (n=238); Wave 2 (n=300); Wave 1 (n=182)

> **I cannot praise the staff enough for their kindness, honesty and care through the process."**
>
> 2014 – Consented to donation

> **A gorgeous nurse cried with me. They were so wonderful, I'll never forget that. It was the beginning of the sad end though, going through the organ donation processes and saying goodbye. I was treated with respect all the way."**
>
> 2015 – Consented to donation

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 the donor with respect**

9.5 Improving the donation discussion – the view of families

As part of the Donor Family Study, family members were asked how the way in which donation was discussed with them at the hospital could have been improved after they consented to donation. Findings were collected verbatim and have been grouped together and shown in Table 22. Findings from Wave 3 are shown, together with results from earlier waves of research. There are no statistically significant differences across waves.

Table 22 Improving the donation conversation

How could the way in which donation was discussed with you at the hospital have been improved after you agreed to donation?	Wave 1 (n=97)	Wave 2 (n=128)	Wave 3 (n=121)
No improvements necessary/discussions handled very well	49%	49%	48%
Staff were compassionate and supportive/kept family members informed	–	16%	9%
Provide more information regarding timing and delays/process took too long/ lengthy process waiting for donation surgery	4%	5%	7%
Difficult to say due to highly emotional state at the time	–	4%	5%
A debriefing process would be appreciated/make sure the family understands what's happening at all times/keep family better informed about the process	2%	3%	5%
Provide a private room for discussions and meeting with staff/provide a larger room for families to gather (include tissues, tea and coffee)	–	2%	3%
Personal details about the donor should not be discussed in front of the whole family/questions not tailored to young person, therefore inappropriate line of questioning/medical history questioning too taxing	1%	4%	3%
The timing – we felt rushed	3%	1%	2%
Ensure all family members are able to say goodbye to donor/not all family members had opportunity to say goodbye due to timing and poor communication	–	2%	2%
More compassion/understanding/empathy	1%	2%	2%
Improve timing of discussion with DonateLife staff/had to wait a long time to talk with DonateLife staff member	2%	1%	2%
Nothing could make it easier/difficult and confronting decision to make	3%	2%	1%

How could the way in which donation was discussed with you at the hospital have been improved after you agreed to donation?	Wave 1 (n=97)	Wave 2 (n=128)	Wave 3 (n=121)
More discussion/don't feel it was discussed with hospital staff (on what happens after you say goodbye, the process)	–	2%	1%
Provide a better explanation of why some organs cannot be used	2%	1%	1%
Do not provide details of how donation surgery will be conducted	–	1%	–
Provide more feedback after donation/more prompt follow-up with families post-donation	–	2%	–
Don't know/can't think of anything specific	6%	11%	16%

NB: Table excludes 'other' one-off responses

As shown in the table, half of family members feel that the discussions were handled well and that no improvements are necessary.

> **We felt very comfortable, appreciated and respected for our decision to donate."**
> 2014 – Consented to donation

> **I can't really think of a way it could be handled better. The staff involved were highly sensitive, caring and professional."**
> 2014 – Consented to donation

There is, however, room to improve communication with family members after consent is provided, to ensure that family members understand the process and are as comfortable as possible with what's happening. The most common suggestion from families is around the timing of the donation process and, as stated in the previous section, the need to be kept informed and provided with accurate timeframes.

Letting family members know that they are free to change their mind about donation at any time is appreciated and alleviates some of the pressure that families may feel at this time.

> **It's difficult but I think telling me that I can change my mind at any time instead of 'if you would like to discuss it further' would have been better."**
> 2015 – Consented to donation

> **We should have been told what was involved and how the timing of my Dad's passing would be dictated by the medical staff not our family."**
> 2015 – Consented to donation

9.5.1 Next of kin

When family dynamics are at play, skill is required of health professionals to 'read the room' when dealing with distraught families. For example, there may be a family disagreement over who the next-of-kin is, who should sign the consent forms etc. or even who the key decision-makers are. Health professionals must try to understand these family dynamics and work with individual family members to facilitate the process and smooth the way through this difficult time.

> **They insisted on contacting my husband's estranged siblings in the UK to gain their consent despite the fact that I was his next of kin. It delayed the process and put me through hell. They should not have made contact with them.”**
>
> 2015 – Consented to donation

> **My uncle (who was not my mum's next of kin) seemed to run the show. Doctors seemed to report to him, which was infuriating, but the DonateLife Coordinator was wonderful.”**
>
> 2014 – Consented to donation

> **Advise staff that parents hurt as much as 'next of kin' and try sympathising with the parents too. I LOST MY SON AND YOU DIDN'T ACKNOWLEDGE ME.”**
>
> 2015 – Consented to donation

9.6 Withdrawal of life support

A key time for families is their final moments of saying goodbye, whether in ICU or just before their loved ones goes into theatre for donation surgery. The withdrawal of life support is a painful experience for families and as such, they need understanding, respect and privacy.

The research found that there were a number of instances where this emotional and important time for families was impinged on by the presence of others. In one instance, while a husband was saying goodbye to his wife, someone came in and started cleaning in the room. In another instance, medical staff could be heard chatting and even laughing nearby while a mother was having her last moments with her daughter.

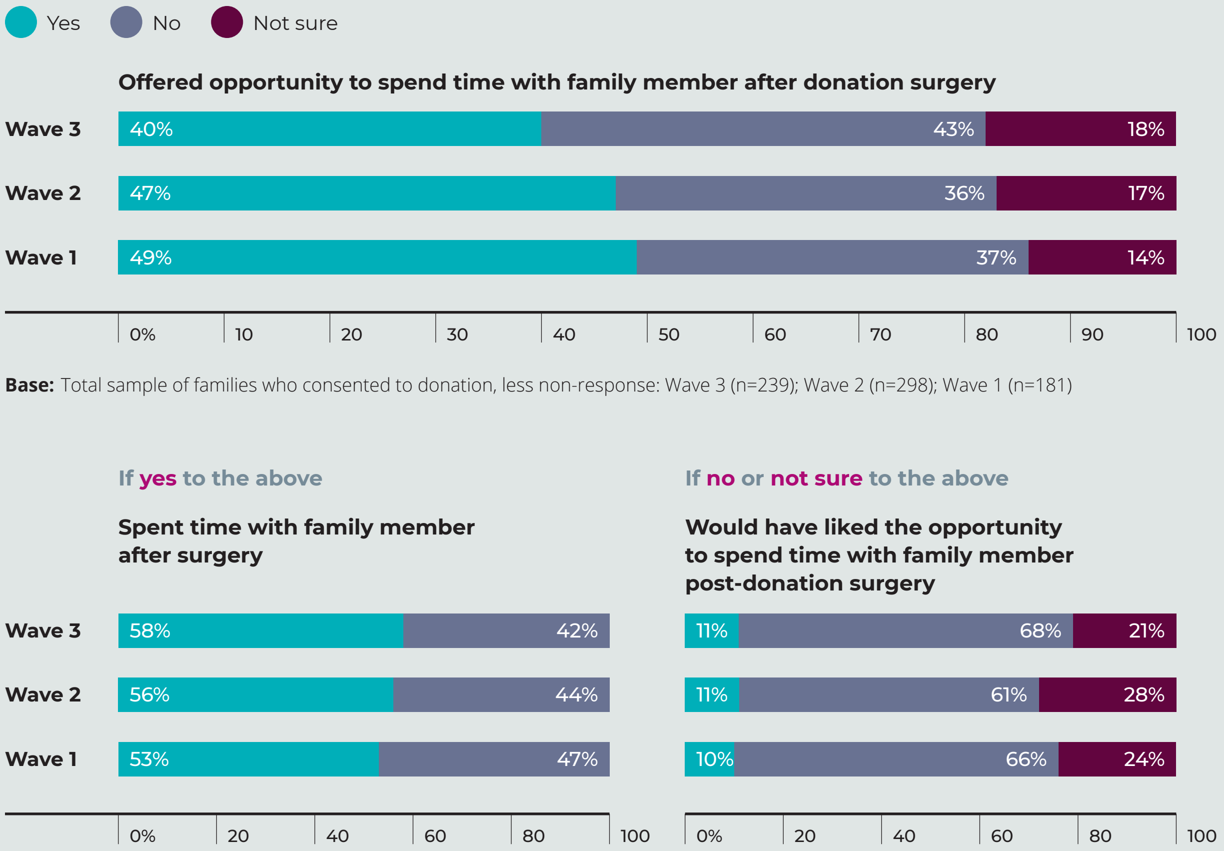
> **When they took [name] from the ICU and we went downstairs to where we had to say our final goodbyes to her, the nurses and the doctors were standing there watching us say goodbye and I thought 'no, this is like a show' and I didn't like that. I can understand they only have a certain amount of time but I thought why couldn't they just go outside, or say 'look, you've only got a little while to say goodbye but we'll knock on the door in 10 minutes or 5 minutes'.”**
>
> 2015 – Consented to donation (personal interview)

10 After donation surgery

As shown in Figure 38, two in five (40%) donor family members in 2014 and 2015 were offered an opportunity to spend time with their family member after donation surgery. This is consistent with earlier years.

Of those who were offered, more than half (58%) opted to see their family member after surgery. The majority of these family members (83%), describe the experience as a positive one; 4% describe the experience negatively, while 13% are still unsure how they feel about it.

Figure 38 After donation surgery



Base: Total sample of families who consented to donation, less non-response: Wave 3 (n=239); Wave 2 (n=298); Wave 1 (n=181)

Base: Those who were offered opportunity to spend time with family member post-surgery, less non-response
Wave 3 (n=92); Wave 2 (n=136); Wave 1 (n=88)

Base: Those who were **not** offered an opportunity to spend time with family member post-surgery, or who do not recall, less non-response
Wave 3 (n=137); Wave 2 (n=155); Wave 1 (n=91)

Positive experience

Those who saw their loved one post-surgery and felt it was a positive experience spoke of them looking at peace and comfortable. Having the opportunity to be with them, without the machines, tubes and noise was appreciated, as was being in a room that felt respectful of their loved one.

> **After the donation, he looked so peaceful. It again made me feel that we had made the right decision to donate organs and also to see him for a last time.”**
> 2014 – Consented to donation

Negative experience

The experience of seeing a loved one post-donation surgery is negative when the donor does not look ‘like themselves’ or when the donor is left in a cold, sterile and uninviting room.

> **When my son was returned to us after surgery, his abdominal area was completely flat and sunken. Effort could have been made to fill or pad this area to make him look more normal.”**
> 2014 – Consented to donation

> **Having to go into the bowels of the hospital morgue area probably wasn't the most comforting process, as it made her body seem like rubbish to be dealt with, but the overall experience was helpful. A less underground cement environment would have been more appropriate to say goodbye after the high tech shiny experience to keep her organs functioning. A simple area up in the main hospital would have been more appropriate and respectful to her gift.”**
> 2014 – Consented to donation

> **The contrast of before donation (warm room/activity) to after donation (a cold, heartless room that resembled a storeroom) was upsetting. A small bunch of flowers would have said a thousand words! It was like ‘Well, we've sales-pitched what we needed; he's of no use to us now’."**
> 2015 – Consented to donation

Seeing their loved one after donation surgery is a personal decision to be made by individual family members, and the opportunity should be offered to all.

It is important to let family members know about any physical changes that may take place in their loved one post-surgery, so that a fully informed decision can be made.

To demonstrate respect for the family, consideration should be given to the environment in which the donor is placed post-surgery. Ideally this should be in a private room with a peaceful setting.

As part of the Donor Family Study, family members were asked if they wished to share anything additional about their experience at the hospital after donation surgery took place. Responses have been coded into like themes and these are detailed in Table 23.

Table 23 Experience at the hospital after donation

Is there anything else you would like to add about your experience at the hospital after the donation took place?	Wave 1 (n=61)	Wave 2 (n=98)	Wave 3 (n=73)
Good experience/moving experience/tastefully handled	2%	4%	**21%**
Already said goodbye before surgery/didn't want to see family member after surgery/wanted to remember them as they were	15%	12%	19%
Didn't stay/was not present/didn't return to hospital	21%	33%	**15%**
Hospital staff compassionate/respectful/supportive/kind	11%	11%	14%
Agonising/felt lost/too stressful/too upset	5%	9%	8%
Received results of surgery by phone/received phone call when surgery had taken place	2%	4%	7%
Had minimal time as surgery needed to commence/no time to spend with them	3%	2%	7%
Post-donation environment – cold and sterile	–	–	7%
Regret not seeing family member after donation	2%	6%	5%
Gave us more time to spend with them/opportunity to say final goodbye/provided comfort	8%	6%	5%
No support after surgery/didn't know where to go/nobody to support us after surgery	–	6%	5%
Was given enough time before surgery/understood timeframe	–	–	5%
Was not given opportunity to see family member after surgery/had to say goodbye before/felt rushed	–	7%	4%
Regret seeing family member after surgery	–	2%	3%
We knew our loved one would be cared for and respected	5%	2%	3%
Hospital staff were not compassionate/were insensitive	3%	4%	1%
Experience was surreal/confronting/strange	10%	4%	1%
DonateLife team wonderful/kind/compassionate/respectful/professional	5%	6%	–
Took a long time/wish it was faster/process dragged on	2%	5%	–
Body was sent straight to coroner after surgery	–	5%	–
Need to provide a quieter room in ICU for family to gather and grieve, without being told to leave because room is needed	3%	3%	–
Other comments (each totalling < 1% of responses)	23%	**5%**	11%

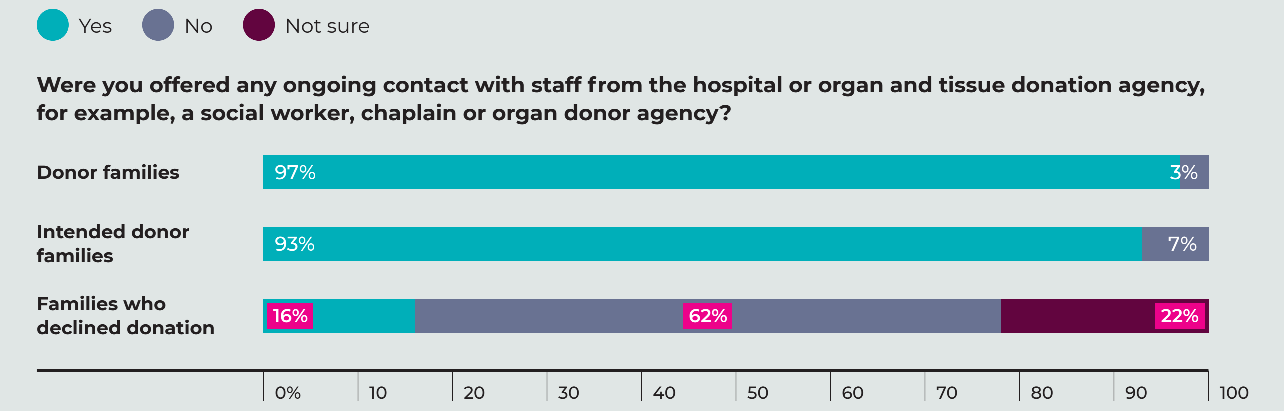
■ Denotes statistically significant difference

11 Follow-up services

In Australia, donor families are offered support through the National Donor Family Support Service, providing resources and counselling to support the donor's nominated next-of-kin. As the Donor Family Study is open to all family members, those who were not the nominated next-of-kin have taken part in the research and may not initially have been offered this service. This participation is important but may distort the responses regarding family follow-up services.

During 2014 and 2015, 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. This is consistent with 95% in Wave 2 and up from 85% in Wave 1. Further, ongoing support was offered to 93% of intended donor families and 16% of families who declined donation (Figure 39).

Figure 39 Follow-up services and resources offered



Base: Total Wave 3 sample, less non-response: Donor families (n=234); Intended donor families (n=15); Declined families (n=32)

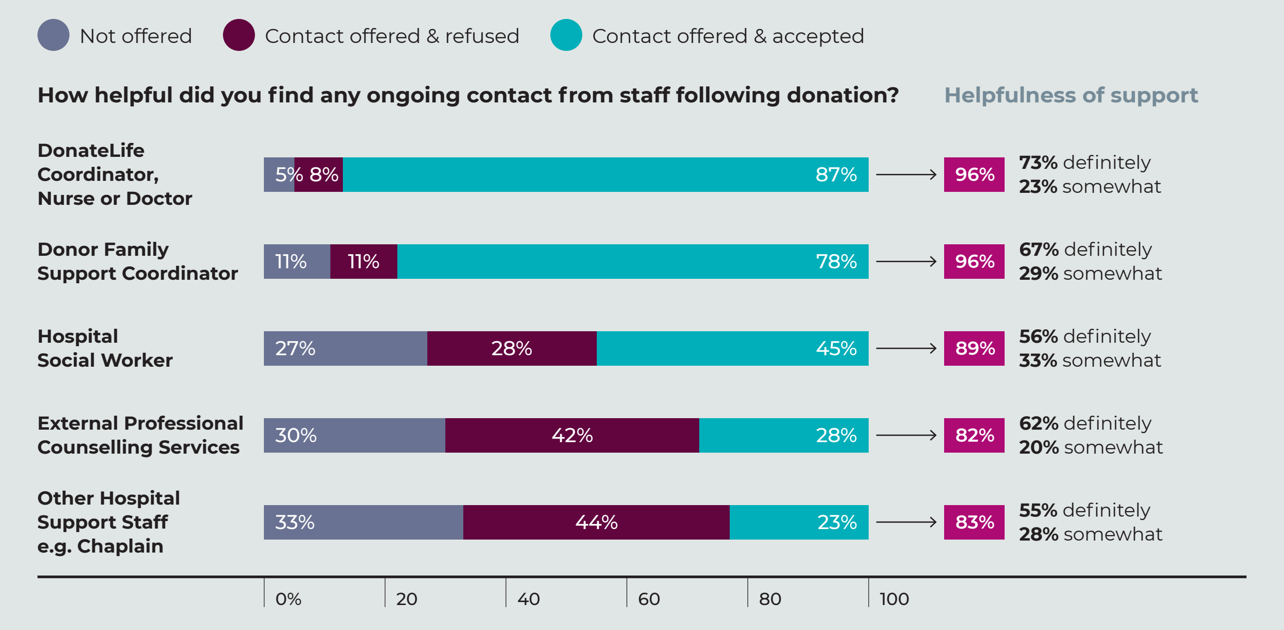
■ Denotes statistically significant difference

The following section details the support offered by staff position and the perceived helpfulness of same.

11.1 Support offered

Donor family members were asked if they were offered any ongoing contact from DonateLife, hospital staff or external services. Findings are shown in Figure 40 below and discussed in more detail in this section.

Figure 40 **Follow-up services and resources offered to donor families – staff**



Base: Total Wave 3 sample (families in 2014 and 2015 who consented to donation), less non-response

DonateLife Coordinator, nurse or doctor

During 2014 and 2015, 95% of donor family members were offered ongoing contact from the DonateLife Coordinator, nurse or doctor (92% in 2012/2013); 87% accepted and received support (up from 52% in Wave 1 and consistent with 88% in Wave 2). This support was found to be helpful by 96% of donor families; consistent with Wave 2 findings (98%).

Donor Family Support Coordinator

Ongoing contact with a Donor Family Support Coordinator (DFSC) was offered to 89% of family members during 2014 and 2015; consistent with the previous two years (87%). Approximately 8 in 10 family members (78%) accepted and received support (up from 59% in Wave 1 and consistent with 78% in Wave 2). Of those families who chose to be in touch with a DFSC, 96% found the contact helpful, 67% very much so.

In some cases, families didn't feel ready to accept the offer of a counsellor or someone to talk to immediately after the death of their loved one, although would have been open to it some time after.

> **“They did offer but it was right at the beginning. Further down the track, if they offered it again, I would have taken it.”**
> 2015 – Consented to donation

> **“I spoke to DonateLife social worker a couple of times and she was helpful – I chose to stop after 2 or 3 calls.”**
> 2014 – Consented to donation

Family members appreciate the support offered to them and even appreciate just knowing that they can contact DonateLife whenever they need to. Mostly, family members appreciate receiving updates on the progress of recipients.

> **“I think probably some follow-up, a few more follow-up letters without having to ask for them would be great.”**
> 2014 – Consented to donation (personal interview)

Hospital social workers/hospital support staff

Looking at hospital social workers and other hospital support staff such as chaplains, the findings indicate that this type of support is offered to donor families less often and is found to be somewhat less helpful than ongoing contact with donation support staff.

> “ **The option of social worker input for siblings may have been beneficial.”**
> 2014 – Consented to donation

> “ **I found the social worker very unprofessional and she actually caused me distress and tension.”**
> 2014 – Consented to donation

Contact from a hospital social worker was offered to three quarters (73%) of donor family members (up from 66% during Wave 2). Just over two in five (45%) donor family members did have contact with a hospital social worker (consistent with Wave 2) and of these, 89% found it helpful.

As stated earlier, 16% of families who declined donation (5 families) were offered support from hospital staff. In all cases, support for these families came from a hospital social worker; 4 of the 5 families found the contact helpful to some extent; 1 family did not.

Support from other hospital staff such as chaplains, was offered to 67% of donor family members in Wave 3 (consistent with 60% in Wave 2). However, a significantly lower proportion of donor family members (23%) accepted this offer (consistent with Wave 2). Many of these family members found this type of support to be helpful (83%).

External provider

Ongoing contact with an external provider, such as counsellor or psychologist, was offered to 70% of donor family members during 2014 and 2015 (consistent with the previous two years at 67%). Just 28% of donor family members accepted this offer of support and of those, 82% found it helpful.

Table 24 details the support distribution by state.

Table 24 Support offered to donor families by state/territory (noting that responses include additional family members who may have not been offered support as this contact is made with nominated senior next of kin)

Type of support offered	QLD (n=45–51)	ACT (n=19–21)*	NSW (n=29–36)	VIC (n=51–66)	TAS (n=15–19)*	SA (n=17–21)*	WA (n=23–27)	NT (n=2–5)*
DonateLife Coordinator, nurse or doctor	94%	90%	92%	95%	100%	100%	96%	100%
Donor Family Support Coordinator	85%	86%	94%	95%	100%	74%	85%	100%
Hospital Social worker	78%	68%	69%	70%	93%	59%	74%	100%
Other hospital staff (e.g. chaplain)	71%	55%	52%	67%	87%	67%	74%	100%
Total support offered – Wave 3	**94%**	**95%** ▲	**97%**	**99%**	**100%** ▲	**100%**	**96%**	**100%**
Total support offered – Wave 2	**99%** ▲	**71%**	**99%**	**92%** ▲	**80%**	**95%** ▲	**100%**	**100%**
Total support offered – Wave 1	**88%**	**100%**	**93%**	**77%**	**83%**	**70%**	**100%**	**–**

* Caution: small base

🟥 Denotes statistically significant difference

11.1.1 Helpfulness of support

Families who consented to donation

Table 25 outlines ways in which donor family members find ongoing contact helpful. One third (35%) of those who received ongoing contact found solace in knowing that their donation decision continued to help others.

> **“Follow-up information about the outcome of the donation made us feel that we had made the right decision.”**
> 2015 – Consented to donation

Table 25 Helpfulness of ongoing contact

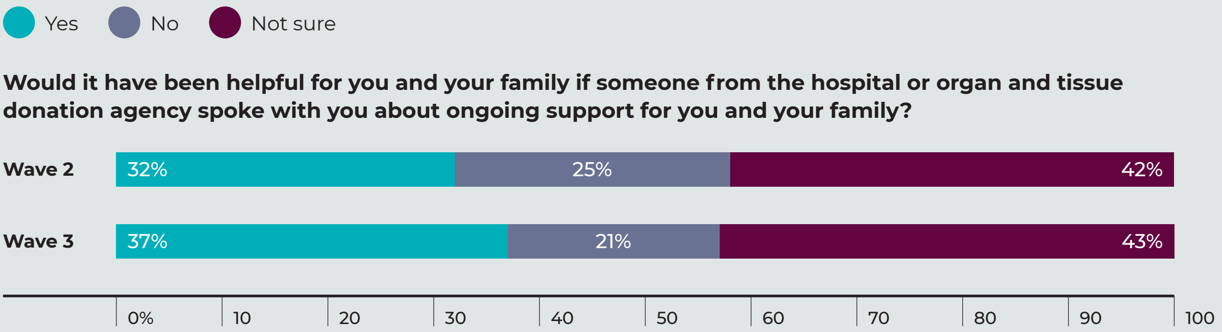
In what way was the ongoing contact helpful to you?	Wave 1 (n=122)	Wave 2 (n=161)	Wave 3 (n=128)
Found out the outcome of the donation/gave us progress updates on recipients/ to know our decision was helping others	30%	**19%**	**35%**
Provided comfort and support/very compassionate	17%	11%	18%
DonateLife Coordinator was helpful, supportive and understood my situation	–	**20%**	13%
Ongoing correspondence with recipients is very helpful	1%	**7%**	10%
Follow-up calls were helpful	1%	3%	**10%**
Felt like we weren’t forgotten/felt like we were cared for/nice to be checked up on	20%	13%	9%
Helped the grieving process/gave us closure	13%	**5%**	9%
It provided useful information/answered our questions	9%	**2%**	**7%**
Nice to know the support is there if we need it	3%	**11%**	7%
Counselling/memorial services/DonateLife events helpful	4%	9%	5%
Private counselling/grief support group was helpful	–	**6%**	5%
The support helped validate/reinforce our decision	2%	4%	4%
Helped being able to talk about my family member/someone to talk to/someone external from the family to talk to	7%	8%	3%
Ongoing contact helped us a lot (no further information)	1%	**6%**	2%
Our family member is recognised and appreciated for their contribution	16%	**5%**	2%
Keepsakes – hair and handprint was lovely/lapel pin helpful	–	2%	2%
Other	6%	2%	2%
Don’t know/not sure	1%	1%	–

🟥 Significantly higher than the previous wave 🟦 Significantly lower than the previous wave

Donor family members who were not offered ongoing contact from DonateLife support staff or hospital support staff were asked if it would have been helpful if someone from the hospital or donation agency spoke with them about support. As shown in Figure 41, 37% of donor family members would have found this helpful, while 21% would not; two in five (43%) are undecided. These findings are consistent with Wave 2.

> **“The follow-up through DonateLife has consisted of two phone calls in just over 2½ years. I am extremely disappointed by the lack of service that I have had.”**
> 2014 – Consented to donation

Figure 41 Perceived helpfulness of ongoing support, if it had been offered



Base: Those who were not offered ongoing contact from one or more of hospital or DonateLife staff following donation, less non-response Wave 3 (n=68); Wave 2 (n=59)

Families who declined donation

For the families who declined donation who were not offered ongoing support, 20% feel now that this type of support would have been useful; 64% do not and 16% are unsure. All families who declined donation (100%) said that they would have found information about bereavement support services helpful, while just 14% said that a follow up phone call from the DonateLife agency would have been helpful.

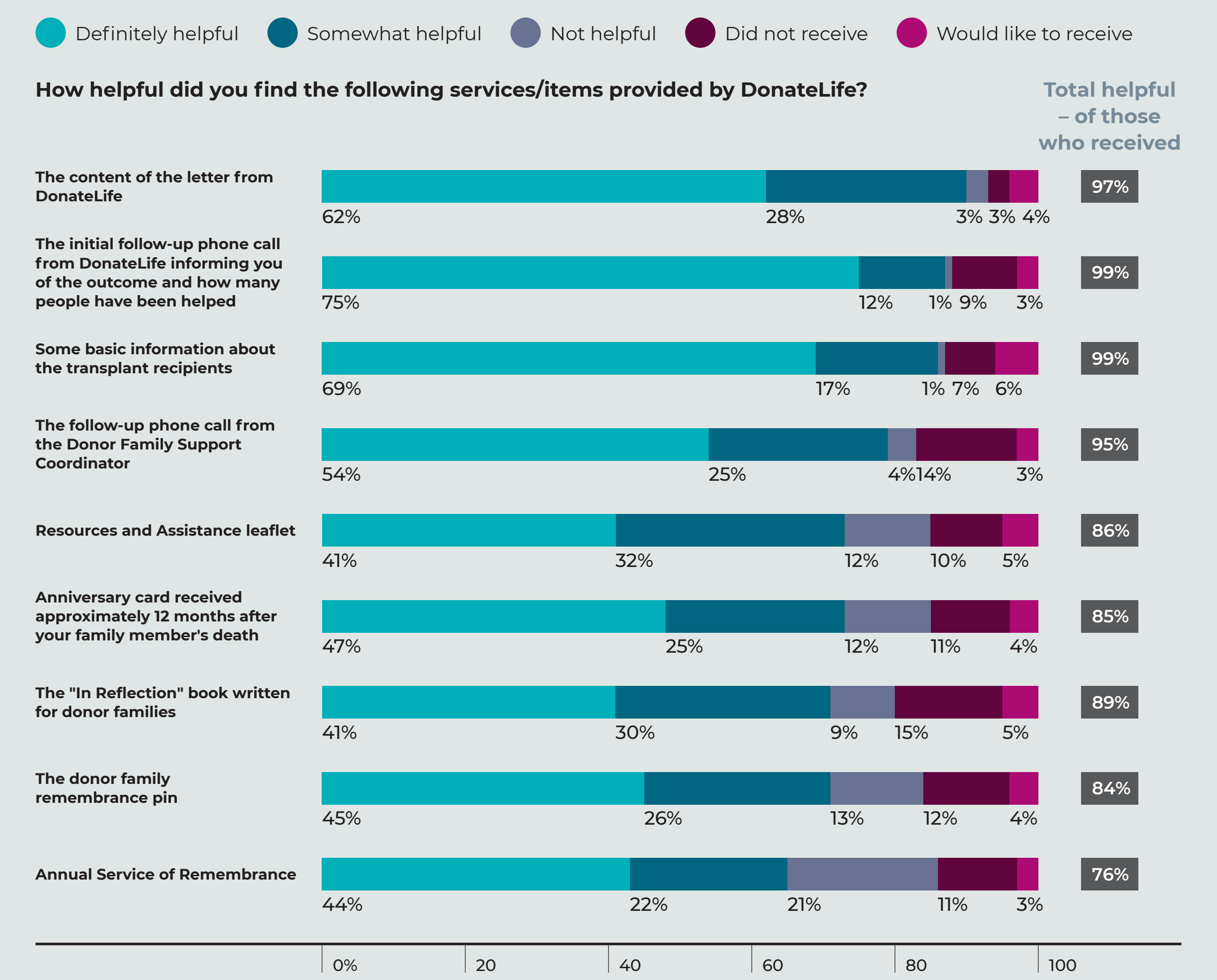
Apart from family counselling to help process and cope with grief, families who decline donation struggle to articulate any other services that may be useful.

The level and type of support needed will vary for each donor family member and this may even change for them over time. Unless they opt out from contact, some donor family members may benefit from the offer of ongoing support from DonateLife, where they feel welcome and know that they can reach out to someone when needed.

11.2 DonateLife resources

Donor family members were asked to rate the level of helpfulness of nine support services/items provided by DonateLife, that they may or may not have received. Findings are shown in Figure 42 and compared with findings of Wave 1 and Wave 2 in Table 26.

Figure 42 Helpfulness of support provided to donor families



Base: Wave 3 families who consented to donation, less non-response. 'Don't know' responses not shown on chart. Base sizes vary (n=217 to n=241)

Table 26 Helpfulness of services/resources

How helpful did you find the following services/items provided by DonateLife? Amongst those who received the service/item	**Total helpful** (definitely + somewhat)		
	Wave 1	**Wave 2**	**Wave 3**
Initial phone call from DonateLife informing you of the outcome	99%	99%	99%
The content of the letter from DonateLife	99%	98%	97%
Basic information about the transplant recipients	100%	99%	99%
Follow-up phone call from the Donor Family Support Coordinator	92%	**97%**	95%
Resources and Assistance leaflet	Not measured	91%	86%
Anniversary card	90%	91%	85%
‘In Reflection’ book	93%	92%	89%
Donor family remembrance pin	Not measured	88%	84%
Annual Service of Remembrance	82%	83%	**76%**

🟥 Significantly lower than the previous wave 🟦 Significantly higher than the previous wave

As shown above, the vast majority of families who receive these services find them to be helpful, suggesting that all families should be offered them.

> “ **All the family was surprised in a positive way by all the attention we received.”**
> 2014 – Consented to donation

> “ **Follow up calls were caring and offered further support. Printed information was sensitively presented and contained contact information we were not aware of.”**
> 2015 – Consented to donation

11.2.1 Initial follow-up phone call

Of great importance to donor family members is the initial follow-up phone call from DonateLife informing them of the outcome of donation (88% recall receiving this call and of those, 99% found it to be helpful). A conversation with a DonateLife staff member as soon as possible after donation surgery can provide some reassurance for families (that surgery went well) and solace for families (that others have been helped).

> “ **I liked how we were informed which organs were donated and how they helped the people who received them.”**
> 2015 – Consented to donation

11.2.2 Letter from DonateLife

Similarly, the letter from DonateLife is received by 93% of donor family members. Most (97%) who received this letter found the content helpful. This letter is usually sent to the nominated senior next-of-kin (whose details are held by the DonateLife agency. As stated earlier, the Donor Family Study is open to all family members, not just the senior next of kin, so findings regarding the receipt of correspondence from DonateLife may be under-reported.

> “ **The decision isn't easy but I'm glad it wasn't dragged out. The letter to say who it helped and what was donated made the hard time a little bit easier.”**
> 2015 – Consented to donation

11.2.3 Information about transplant recipients

Eight in ten donor family members (86%) report receiving information about transplant recipients from DonateLife and of those, almost all (99%) found the information to be helpful, consistent with Waves 1 and 2. In most cases, this is what donor families need – to hear that their loved one’s gift has been received and that it has made a positive difference to the recipient’s life.

> **Advice on the impact of donation for recipients was treasured."**
> 2014 – Consented to donation

Many families have ongoing needs when it comes to information about recipients. While early information is important and appreciated, many donor family members wish to be kept updated as to the health progress of recipients.

> **I cannot complain about the resources we received like phone calls from DonateLife checking on how the family were coping. We were given updates on the recipients' conditions and given information on how to go about answering a letter sent by one of our recipients."**
> 2014 – Consented to donation

> **Well I loved the fact that DonateLife was very quick to send me the correspondence to say what had gone where."**
> 2014 – Consented to donation (personal interview)

11.2.4 Annual Service of Remembrance

An invitation to attend an Annual Service of Remembrance was sent to 86% of donor family members in 2014 and 2015, consistent with previous waves of research. For those who received an invitation, 76% (83% in wave 2) found it helpful, even if they choose not to attend.

> **I find the annual service of remembrance particularly helpful. It is great to hear others' experiences both from other donor families and recipients and know our loved ones are not being forgotten."**
> 2014 – Consented to donation

Almost all participants in the qualitative phase of the research mentioned the Annual Service of Remembrance. Some choose not to go, or don't feel ready to attend in the first year; some would like to go but other commitments and distance are barriers, but almost all are glad that it takes place and that they continue to be invited. Families appreciate that their loved one has not been forgotten.

11.2.5 Other services offered

Not all donor family members will respond positively to all services and/or items offered by DonateLife. The important thing is to offer these to families; to let them know that they are in your thoughts and that their loved one will not be forgotten. Family members can then choose to opt in or out of communication from DonateLife as they please, and their preferences may even change over time.

> **The phone calls were so welcomed in the early days. The letters were exactly what I needed along with the opportunity to respond. The Remembrance Service is such a good way to reflect on our son's life in those early years. I wear my pin proudly."**
> 2014 – Consented to donation

> **I like the different envelopes so open them as I can cope."**
> 2015 – Consented to donation

> **I find that each reminder is very hurtful."**
> 2015 – Consented to donation

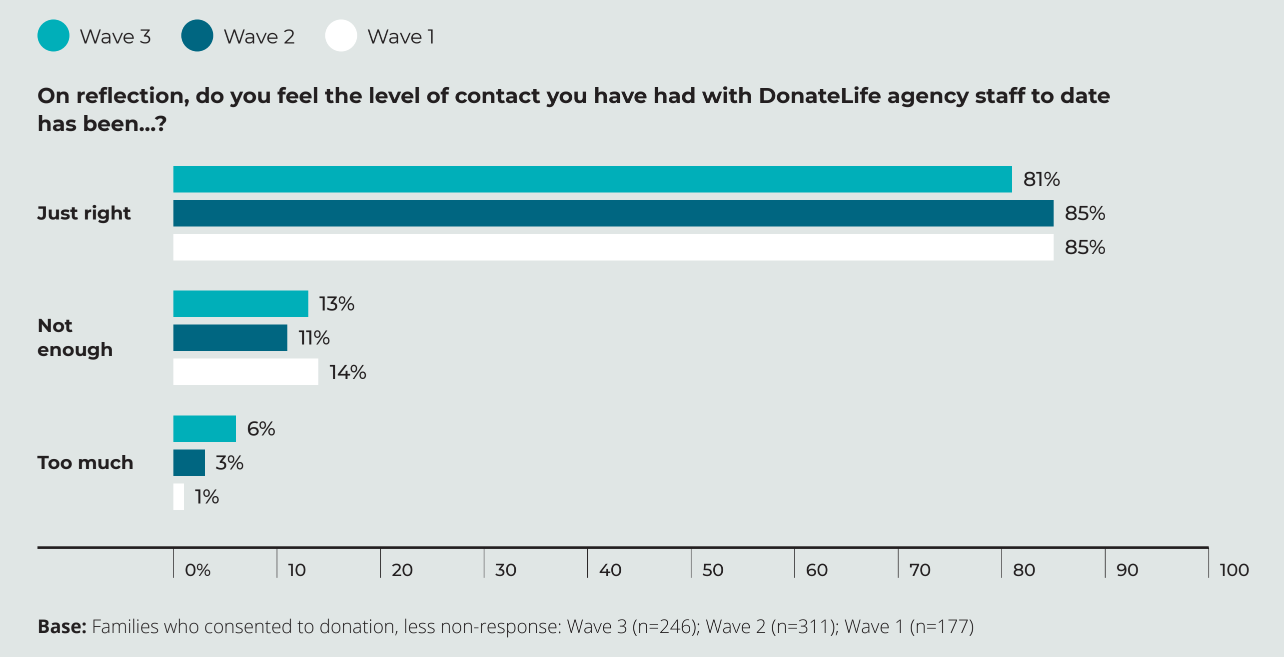
> **I remember all resources were very helpful. I have read through the 'In Reflection' book many times – very comforting."**
> 2015 – Consented to donation

> **I valued all the initial resources and contact but later material and invitations do not help where I currently find myself."**
> 2015 – Consented to donation

11.3 Amount of contact with DonateLife

As shown in Figure 43, most donor family members (81%) 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.

Figure 43 Contact with DonateLife agency staff



Base: Families who consented to donation, less non-response: Wave 3 (n=246); Wave 2 (n=311); Wave 1 (n=177)

There are no significant differences by state, as shown in Table 27 below.

Table 27 Level of contact with donation agency staff, by state/territory

Amount of information	QLD (n=50)	ACT (n=21)*	NSW (n=37)	VIC (n=67)	TAS (n=20)*	SA (n=20)*	WA (n=26)*	NT (n=5)*
Just right	78%	62%	76%	87%	90%	85%	81%	100%
Not enough	16%	29%	16%	6%	10%	10%	12%	–
Too much	6%	10%	8%	6%	–	5%	8%	–

* Caution: small base

11.4 Other services

Donor family members were asked what other services could be offered to better support family members. As shown in Table 28, 1 in 6 donor family members (17%) would like more updates on recipients (consistent with Waves 1 and 2), while a further 7% feel that more contact with recipients would be beneficial.

Table 28 Other services to support donor family members

What other services could be offered to better support family members?	Wave 1 (n=114)	Wave 2 (n=99)	Wave 3 (n=82)
None/can't think of any	34%	25%	23%
I got all the support/information I needed	20%	**8%**	15%
How the recipients are going/more updates on recipients	15%	19%	17%
More contact in general/check to see how we're going	4%	8%	10%
More access to social workers/counsellors/ongoing counselling	2%	6%	10%
Would like to meet recipients or have more contact with them	4%	6%	7%
Set up a donate family group in our area/online support group	3%	5%	5%
Better support in regional areas	2%	5%	9%
Disappointed didn't receive letter from recipient	–	4%	1%
Specific support (for children/young people/men)	2%	3%	1%
Support in writing letters for both donors and recipients	–	3%	–
How to cope with grief	4%	3%	–
Allow more than one relative to be a contact person/provide support for all family members	3%	3%	7%
None/prefer to source own support/rely on support from friends	–	3%	–
More information about the donation process/raise awareness of donation	–	2%	4%
Would like to be more involved in DonateLife campaigns/events to raise awareness	2%	1%	1%
No longer want ongoing updates/don't want to be reminded	–	–	9%
Other one-off mentions	11%	**4%**	7%

■ Denotes statistically significant difference

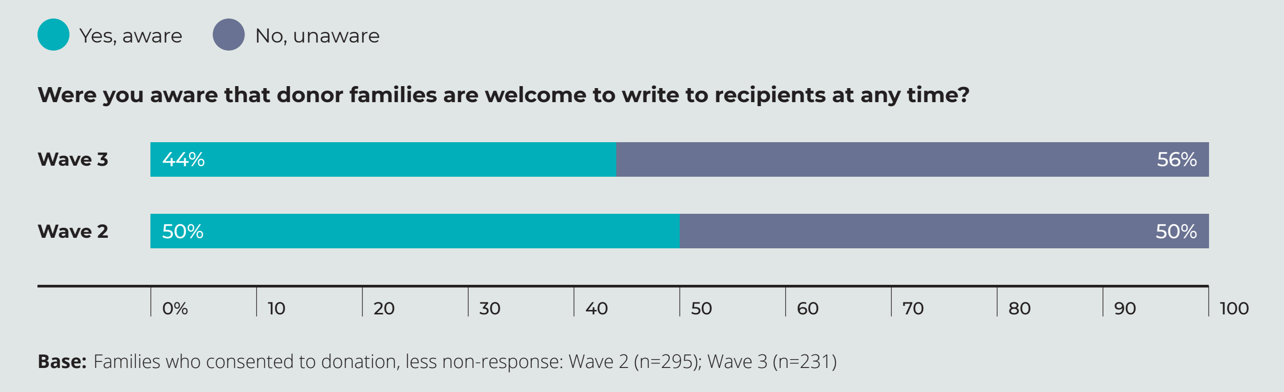
Contact from DonateLife links family members with support services to assist them after donation. Family members need to feel that their loved one is not forgotten and that their gift is appreciated. One of the greatest gifts for family members is to know how recipients are doing.

12 Contact with recipients

12.1 Writing to recipients

As shown in Figure 44, less than half of donor family members are aware that they are welcome to write to recipients. This is consistent with Wave 2.

Figure 44 Writing to recipients



Base: Families who consented to donation, less non-response: Wave 2 (n=295); Wave 3 (n=231)

> **I feel disappointed that the option of writing to the recipient or receiving correspondence was not mentioned at all. We would have definitely chosen this.”**
>
> 2014 – Consented to donation

> **My understanding was that the recipients could write to the donor family via the Donor Registry (the letter would be passed on to me). I was not aware I could write to the recipient.”**
>
> 2015 – Consented to donation

Donor families have mixed views about writing to recipients, although the general consensus is that it is a positive thing that this option is available. Some are of the view that recipients should write to donor families first, while others simply state that they wouldn’t know what to say or would not like recipients to feel obliged to respond. In any case, donor families are grateful that the option is there.

> **I have written at least 100 letters to the recipients but never on paper. I feel guilty about this but at some stage it will happen.”**
>
> 2014 – Consented to donation

Of course, there is a risk that a donor family member may be disappointed should a recipient not choose to respond. Expectations must therefore be managed carefully.

> **I have written to four of my son's recipients but have not received one reply. This really disappoints us.”**
>
> 2015 – Consented to donation

Consistent with research findings from Wave 2, some donor families are concerned about the restrictions placed on them regarding what they can and can’t write to recipients so as not to identify the donor. Whilst they are aware of the laws around anonymity, not being able to refer to their loved one by name is hurtful. Talking about a loved one who has died is one way of keeping that person’s memory alive.

Some donor families also express a desire to meet recipients, should the other party agree. Many take matters into their own hands and through social media, attempt to find recipients themselves.

> **What’s the point? I was told you can’t say the donor’s name or your own name and can’t find out the recipient’s name, so it’s just two ghosts sharing letters.”**
>
> 2014 – Consented to donation

> **“I wish that if both parties agreed that we could name donor and dates; also meet recipients if they wanted.”**
> 2014 – Consented to donation

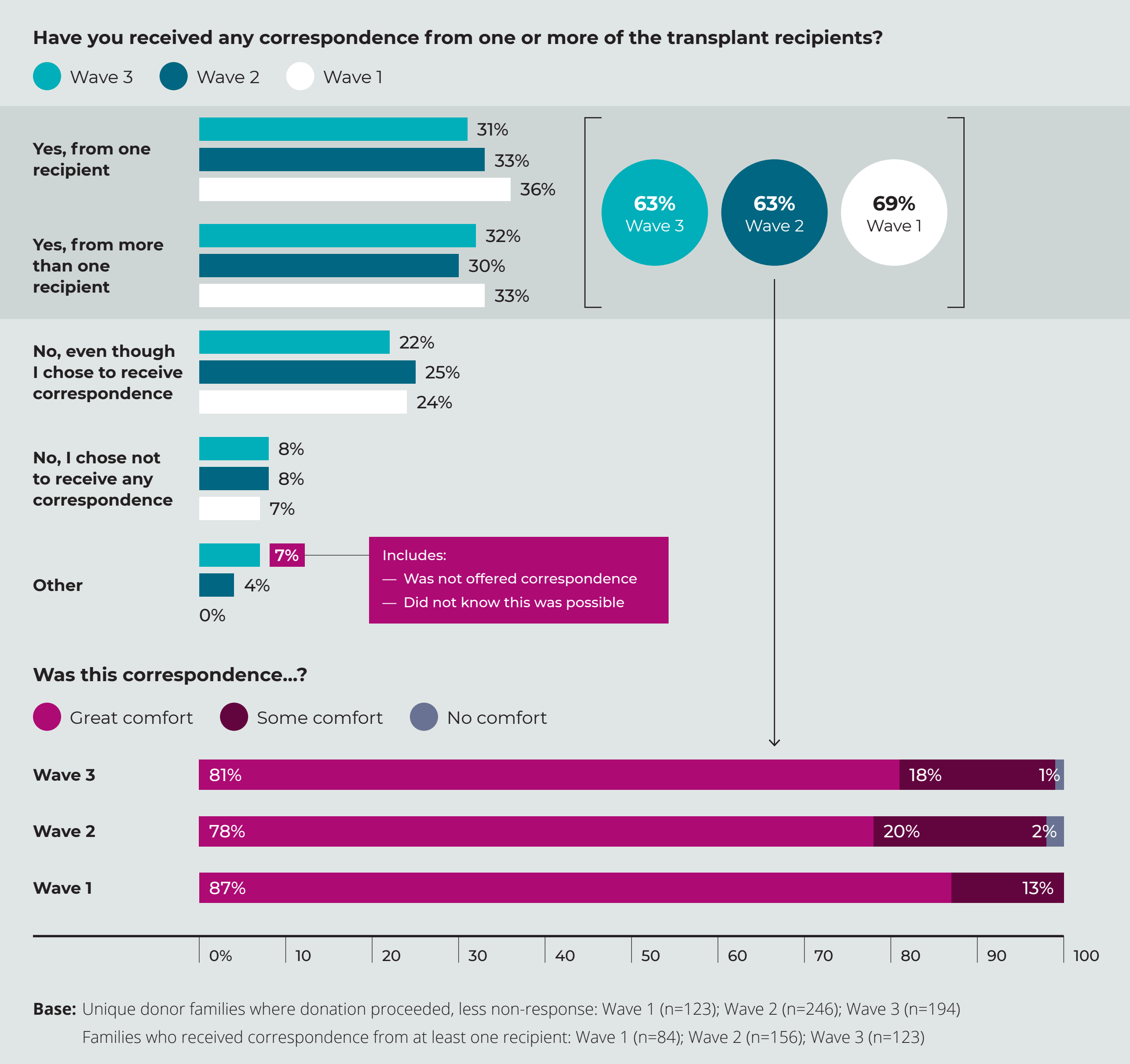
Ensure that family members are made aware that they are welcome to write to recipients at any time, should they wish to. It is important, however, to not guarantee a response from the recipient.

12.2 Deidentified contact with recipients

In 2014 and 2015, two thirds (64%) of donor families received a letter from at least one transplant recipient (Figure 45). This is consistent with Waves 1 and 2. The correspondence provided comfort to 99% of these families; again, consistent with previous waves.

At the time of the research, 21% of donor families in 2014 and 2015 had not received any correspondence from recipients, even though they chose to.

Figure 45 Deidentified contact with recipients



Base: Unique donor families where donation proceeded, less non-response: Wave 1 (n=123); Wave 2 (n=246); Wave 3 (n=194)
Families who received correspondence from at least one recipient: Wave 1 (n=84); Wave 2 (n=156); Wave 3 (n=123)

Overwhelmingly, families that receive correspondence from recipients are thankful. They are thankful that the recipient cared enough to say 'thank you'; they are thankful that their loved one's gift was meaningful, that it changed a life. Most of all, they are thankful that something positive has come out of their tragedy – that their loved one's death has resulted in some good.

> **She said 'I'll never know you but I'll be eternally grateful.' And it's just to see that in words is really, yeah it's awesome."**
> 2015 – Consented to donation (personal interview)

> **I received a lovely letter Christmas 2015. I so wanted to reply but I didn't know where to start. After completing this survey maybe I should – I'd hate to think the recipient thought I didn't appreciate it, I truly did. I cried and cried when I got it. I'm so glad that person got a second chance at life, my partner would've loved that."**
> 2015 – Consented to donation

> **Mum got a letter that Christmas from one of the recipients. She was ecstatic. A letter about a person who had got their life back and could enjoy their grandchildren and activities because of this donation. And they were very grateful. Mum keeps that letter with her all the time."**
> 2015 – Consented to donation (personal interview)

12.3 Impact of no contact from transplant recipients

Donor family members who chose not to receive any correspondence from transplant recipients (8% of donor families) are generally comfortable with the decision they made (Table 29), although a small proportion (17%) would now like to receive correspondence.

Families who wanted to receive correspondence from recipients but have yet to, generally feel a sense of disappointment with the lack of contact. Consistent with findings from Waves 1 and 2, whilst there is some level of understanding that it may be difficult for recipients to write to donor families, a heartfelt 'thank you' would help donor families heal.

Table 29 Impact of not receiving letter/card from recipient

	Wave 1		Wave 2		Wave 3	
How do you feel about not receiving any correspondence from the transplant recipients to date?	**Wanted to receive** (n=30)	**Chose not to receive** (n=8)	**Wanted to receive** (n=74)	**Chose not to receive** (n=20)	**Wanted to receive** (n=43)	**Chose not to receive** (n=12)
Disappointed/let down/bitter/sad	33%	–	19%	–	23%	–
Would like to receive correspondence from recipient	10%	–	14%	5%	30%	17%
Would like to know the progress of recipients/how donation helped/who received organs	13%	–	11%	–	26%	–
A thank-you would be nice/would show recipients' appreciation	10%	–	7%	–	21%	–
Fine/ok about no correspondence	10%	63%	12%	47%	19%	33%
Feel disappointed, but accept that it may not be easy to write & respect privacy of recipient	–	–	7%	–	14%	–
Would help in the grieving process/would help provide closure and meaning	7%	–	18%	–	7%	–

	Wave 1		Wave 2		Wave 3	
How do you feel about not receiving any correspondence from the transplant recipients to date?	**Wanted to receive** (n=30)	**Chose not to receive** (n=8)	**Wanted to receive** (n=74)	**Chose not to receive** (n=20)	**Wanted to receive** (n=43)	**Chose not to receive** (n=12)
Ambivalent/not sure I would want it	–	–	–	–	7%	17%
Would have liked correspondence but didn't know it was allowed/wasn't offered this option	3%	–	2%	–	2%	–
Not entirely comfortable with receiving correspondence/would rather not know	–	–	–	11%	2%	17%
Understand if recipients aren't up to it/ might not be easy/it's their decision/they will write when ready	10%	–	12%	–	–	–
Donation was enough/not necessary to receive correspondence/enough to know others were helped	7%	38%	2%	37%	–	–
Another member of the family received correspondence/another family member decided about correspondence	3%	–	2%	5%	–	8%
Other	–	–	7%	–	5%	17%

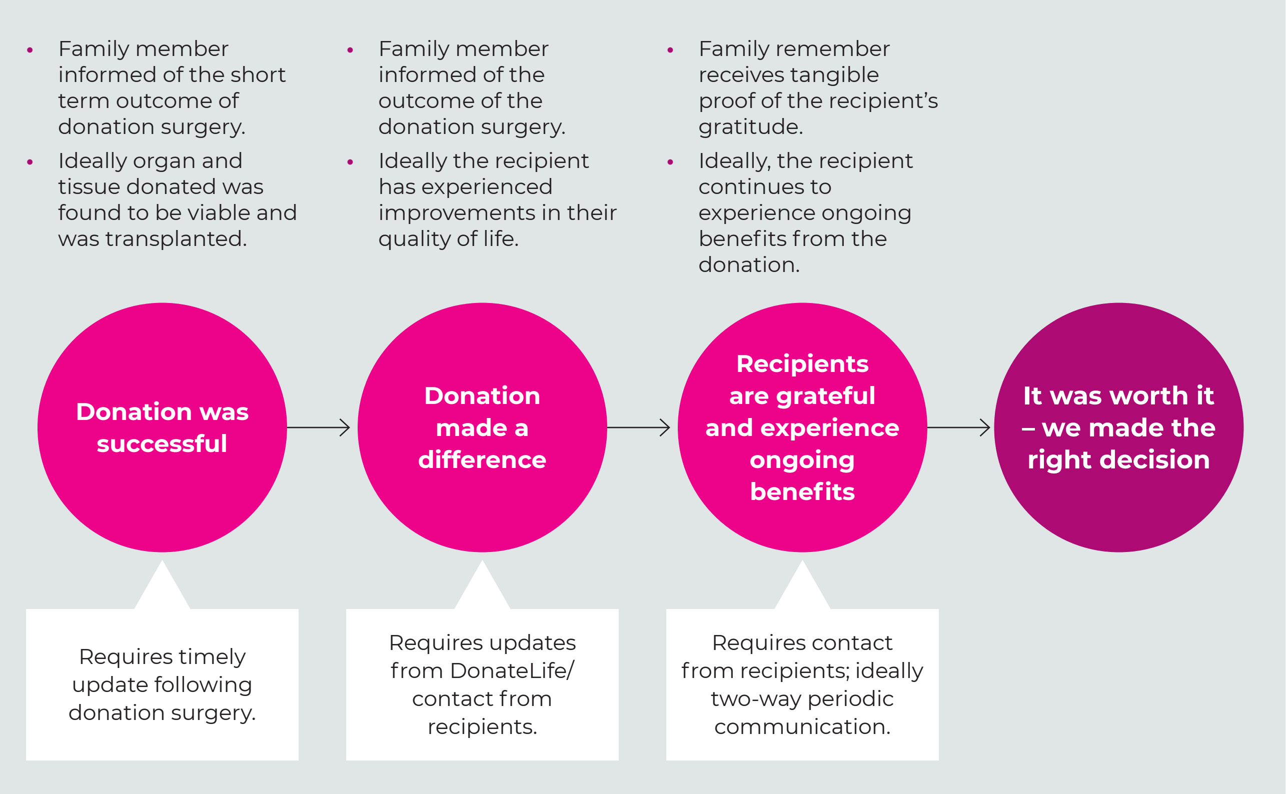
> **Very disappointed that my family and myself have had no correspondence [from recipients]. Each year of no contact I have growing feelings of anger. I have now decided not to attend the annual service of remembrance."**
>
> 2015 – Consented to donation

> **I would have loved a letter. Just to know someone has a better quality of life would have helped enormously as it makes it personal rather than abstract (even though anonymous)."**
>
> 2014 – Consented to donation

> **A letter from one of the recipients to let us know how they are going. That would help make it just a little bit better."**
>
> 2015 – Consented to donation

As shown above, for many donor families, receiving correspondence from recipients is incredibly moving and provides great comfort. Whilst this is out of the control of DonateLife, at the very least, information about recipients should be provided to donor families regularly, or when requested. As shown in Figure 46, receiving information about recipients helps families to heal and reassures them that their donation decision was the right one.

Figure 46 Affirming the choice to donate – the role of information about recipients



- Family member informed of the short term outcome of donation surgery.
- Ideally organ and tissue donated was found to be viable and was transplanted.

Donation was successful

Requires timely update following donation surgery.

- Family member informed of the outcome of the donation surgery.
- Ideally the recipient has experienced improvements in their quality of life.

Donation made a difference

Requires updates from DonateLife/ contact from recipients.

- Family remember receives tangible proof of the recipient's gratitude.
- Ideally, the recipient continues to experience ongoing benefits from the donation.

Recipients are grateful and experience ongoing benefits

Requires contact from recipients; ideally two-way periodic communication.

It was worth it – we made the right decision

> “ **That would be lovely. I'd really like to hear how they're going. And what that does is give you some justification that you made the right decision.”**
>
> 2014 – Consented to donation

Unfortunately not receiving information about recipients can have a negative affect on donor families, causing some to regret their donation decision.

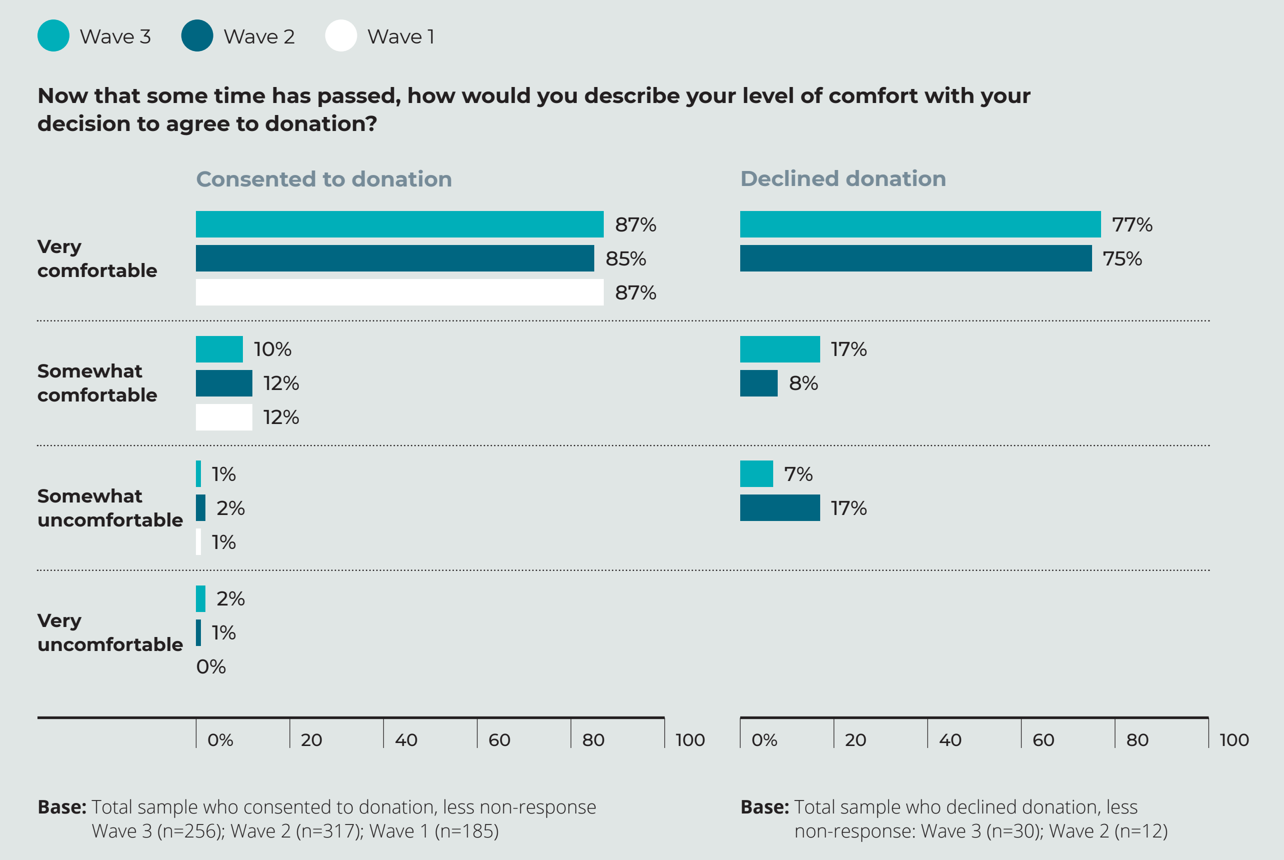
> “ **I feel like I may have made the wrong decision in co-signing the papers to donate my father's organs and I feel like I don't have closure after his death. My father's heart is beating in someone else and we don't know who it is and how they are going.”**
>
> 2014 – Consented to donation

13 On reflection

13.1 Level of comfort in decision

For 97% of donor families (including intended donor families), the donation decision made in 2014 and 2015 still sits well with them today; 87% very much so. These findings are consistent with Waves 1 and 2.

Figure 47 Level of comfort with donation decision



Base: Total sample who consented to donation, less non-response Wave 3 (n=256); Wave 2 (n=317); Wave 1 (n=185)

Base: Total sample who declined donation, less non-response: Wave 3 (n=30); Wave 2 (n=12)

As shown in Figure 47, 23% of families who declined donation are not entirely comfortable with their donation decision today. Mostly these families feel regret in not helping others through donation.

> **While I would like to have known that her organs were keeping someone alive, I also wanted her to be buried intact.”**
> 2015 – Declined donation

> **I know my wife had a lot of healthy organs that could have been used to help others.”**
> 2014 – Declined donation

> **That maybe we could have helped someone.”**
> 2014 – Declined donation

There are families who, in essence, support organ and tissue donation, however their ultimate decision for their family was to decline. In one particular case, this was due to the time delay that would have been needed for donation to progress. Whilst this family would have liked to donate, they feel today that the decision they made in that moment was the right one for their family.

> **It was the idea of prolonging the whole process because of the [donation] process, then trying to explain to young children what's going on and they're devastated. You opened the discussion; did I make the right decision? Yes, I think I did. Not because I didn't want to do it but because long-term, and what was going on in that environment, that was the right decision. Am I for organ donation? Yes, I am but I suppose it's a little bit of circumstance. And I think even if you're open to it, it doesn't mean you should do it. It just depends on the circumstances."**
>
> 2014 – Declined donation (personal interview)

Family members who consented to donation but who now are not entirely comfortable with their decision cite a number of reasons as listed in Table 28. 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%).

> **The way the process was run made the grieving much harder for our family. I feel a bit haunted by the experience and don't feel sure my father was fully deceased when he was taken away. They didn't explain it properly and they also kept changing the timing through the night by texting and calling to change the time. It felt like it was no longer about saying goodbye to my Dad and more about what suited the medical team. I really really really wish we hadn't done it."**
>
> **I have doubt that it was the right and respectful thing to happen to my father. It also made saying goodbye and grieving much harder."**
>
> 2015 – Consented to donation

> **He doesn't like me talking about it. He has huge regret. And I've had the conversation with my Mum since and she's like 'I meant to register as an organ donor but watching what you went through, I don't want to do it.'"**
>
> 2014 – Consented to donation (personal interview)

Further, fitting with the importance of encouraging discussions around donation, 23% of family members who are not entirely comfortable with their donation decision are questioning whether their loved one would have wanted to donate.

Table 30 Reasons for not being entirely comfortable with donation decision

Please explain why you are not entirely comfortable with your decision to donate	Wave 1 (n=22)	Wave 2 (n=40)	Wave 3 (n=26)
Not sure if decision was right/not sure if decision was the wish of family member who donated	18%	13%	23%
Not enough information about recipients/not enough communication from recipients/no thank you from recipients	14%	15%	19%
Process of deciding is too difficult – felt rushed/emotional and exhausting time/traumatic/very long process	9%	10%	19%
Donation didn't proceed (medically unsuitable/outside of timeframe)/donation process was unsatisfactory	5%	10%	15%
Difficult to come to terms with family member's body not being 'whole'/hard to 'give away' part of loved one	9%	10%	12%

Please explain why you are not entirely comfortable with your decision to donate	**Wave 1** (n=22)	**Wave 2** (n=40)	**Wave 3** (n=26)
Lack of compassion and support afterwards/once decision was made/felt like donor and donor family no longer mattered	5%	5%	8%
Was life support removed too soon?	5%	5%	8%
Was treated insensitively by hospital staff	5%	5%	8%
Difficult coming to terms with the death	9%	10%	4%
Unsure whether family member was dead at time of retrieval/wonder if family member felt pain during donation surgery	5%	10%	4%
Other response	32%	13%	12%

Table 30 highlights some information and support gaps in the hospital setting. Twelve per cent of donor families (shaded) who are not entirely comfortable with their decision to donate in 2014 or 2015 have unanswered questions regarding the timing of their family member's death and donation. A further 8% have been left with a feeling that their loved one no longer mattered after donation.

> **The lack of care given by staff once they knew they weren't trying to save her life."**
> 2014 – Consented to donation

> **It felt like the right thing to do at the time but not every day since."**
> 2015 – Consented to donation

> **It's difficult to explain, but it felt like I was giving a part of my wife away."**
> 2015 – Consented to donation

13.2 The impact of donation

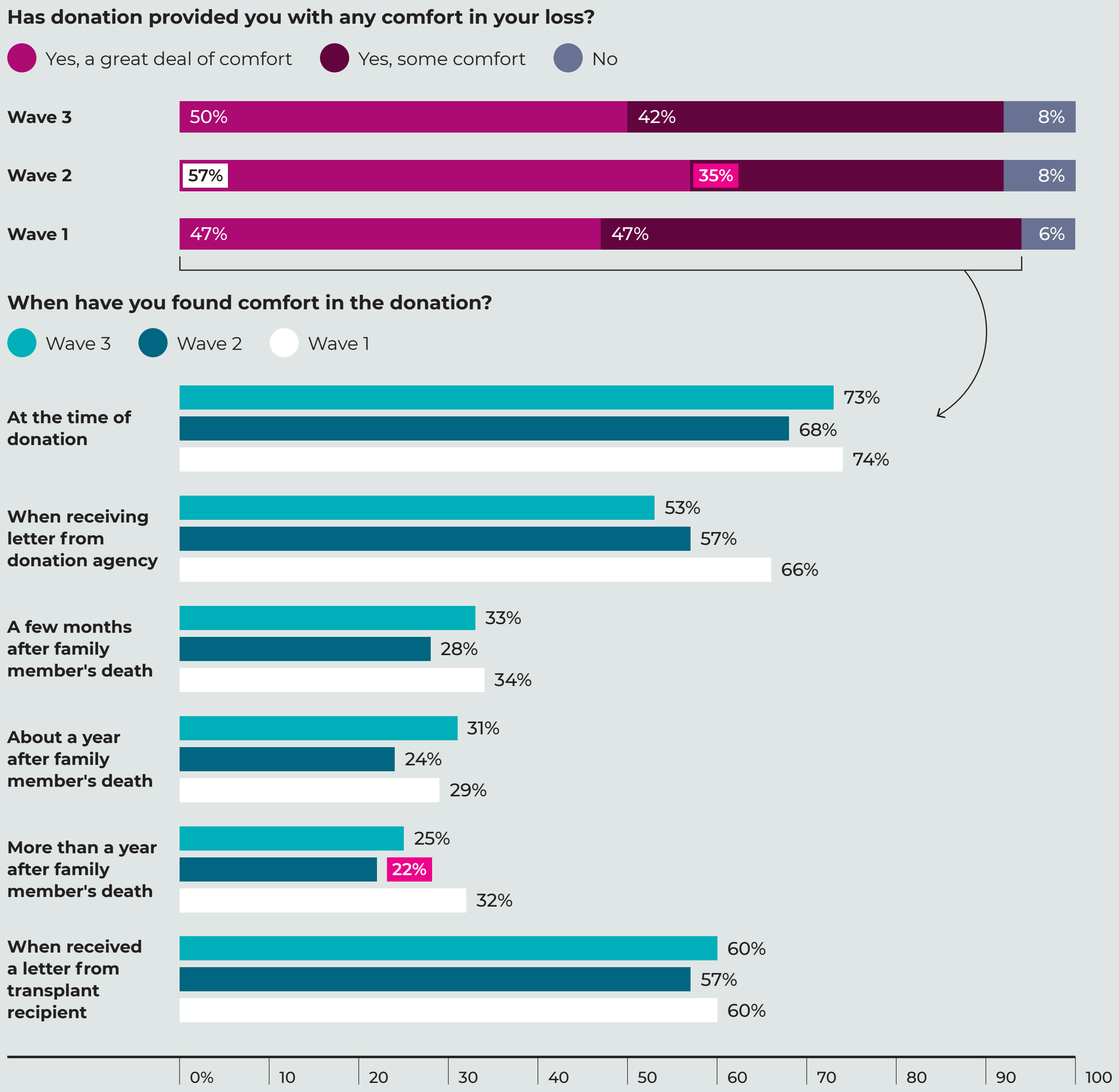
The vast majority of donor families (92%) found comfort in the donation of their loved one's organs; 50% finding a great deal of comfort and 42% finding some comfort.

For many, donation provides comfort in the days, weeks, months and years following a loved one's death. Importantly though, and consistent with Wave 2, organ donation also provides immediate solace (whilst at the hospital) to the majority of consenting family members (73%).

> **Donation was the only thing that made her death bearable and less senseless."**
> 2014 – Consented to donation

> **To me that was the only bonus, that was the only way of really getting through it. Just something coming out of something that was just awful."**
> 2014 Consented to donation (personal interview)

Figure 48 The impact of donation



Base: Total sample, less non-response: Wave 1 (n=180); Wave 2 (n=314); Wave 3 (n=248)
Those who found comfort in donation, less non-response: Wave 1 (n=170); Wave 2 (n=281); Wave 3 (n=215)

NB: Multiple responses allowed

🟥 ⬜ Denotes statistically significant difference

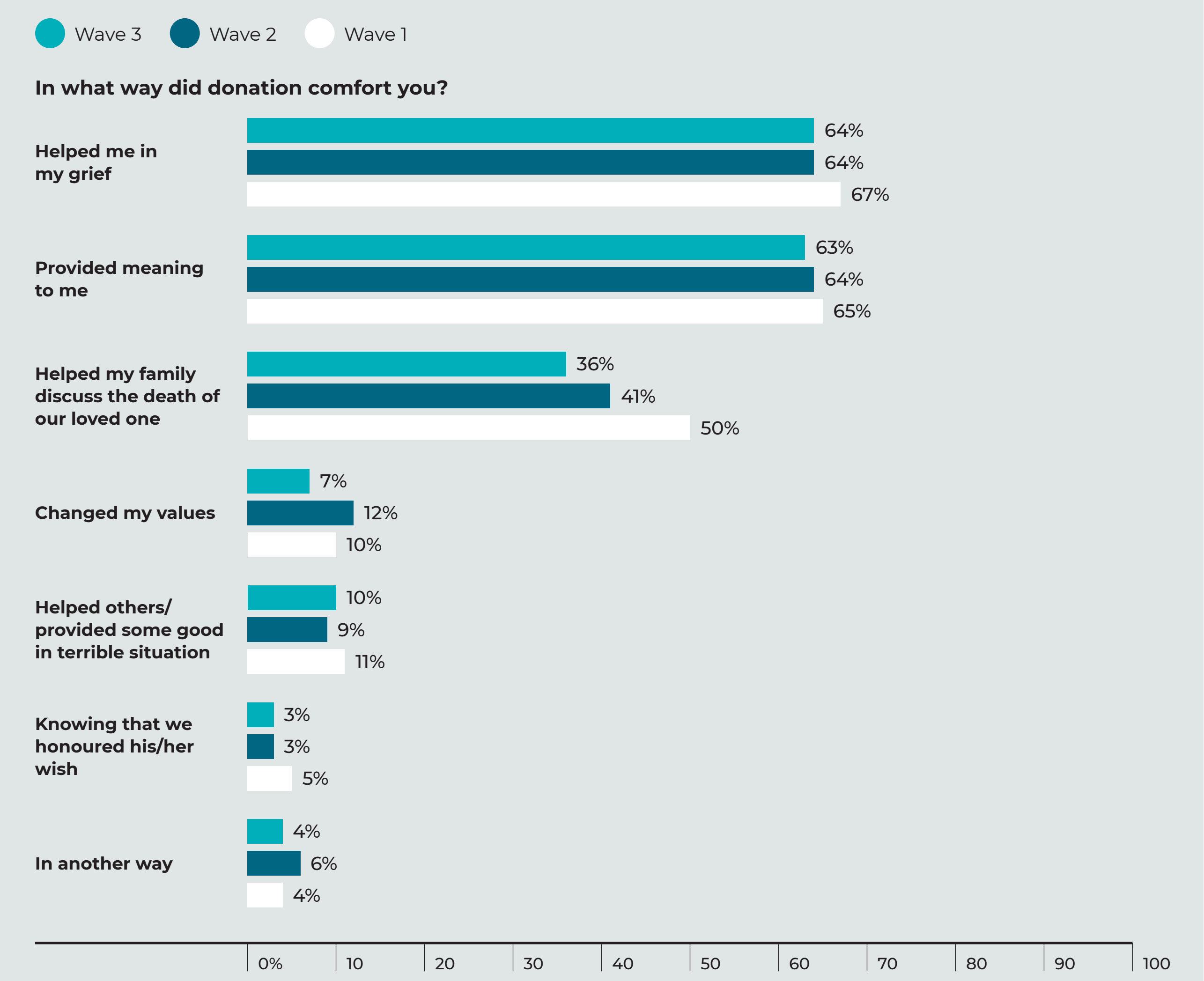
The data in Figure 48 also demonstrates the importance of contact from transplant recipients. Three in five (60%) donor family members who are comforted in their loss by donation feel that sense of comfort when they receive a letter from a recipient.

> **“We received a thank you card from a recipient. It is one of the most treasured items of mine. When I feel stricken with grief, I look at the card and find comfort, or I will read a message from DonateLife and find comfort.”**
>
> 2014 – Consented to donation

> **“I think that's blown our minds because when you talk about it as a family you're only thinking of your main organs, you're not thinking the extent and how far it can actually go. A couple of months ago I asked for another update and [name] is up to helping 42 people, so that to us is just mind blowing.”**
>
> 2015 – Consented to donation (personal interview)

In terms of how donation helps, approximately two thirds of donor family members who found comfort in donation feel that donation provides meaning to them (63%) and helps them in their grief (64%). Knowing that their loved one helped others gives some peace to families.

Figure 49 How donation has provided comfort



Base: Those who found comfort in donation, less non-response: Wave 1 (n=168); Wave 2 (n=282); Wave 3 (n=210)

NB: Multiple responses allowed

> **“The fact that other people can live on, like that’s a good thing. It makes it feel like his death wasn’t in vain.”**
>
> 2015 – Consented to donation (personal interview)

Donor family members also find comfort in the kind actions of hospital staff. Gestures such as handprints, a lock of hair or a specially made quilt, are beautiful reminders of their loved one and of the gift they gave to others through donation.

> **The donate quilt was wonderful – especially being able to choose the one that we felt suited our family member.”**
>
> 2015 – Consented to donation

> **Once we made the decision, a staff member took my family and myself to choose a beautiful handmade quilt which we wrapped around our daughter which made us feel lovely.”**
>
> 2015 – Intended donor family member

> **The staff could not have been more sensitive, caring and compassionate. They took fingerprints, hand prints and gave us snippets of his fair in key rings. All treasured keepsakes.”**
>
> 2015 – Consented to donation

13.3 The impact of donation on future intentions

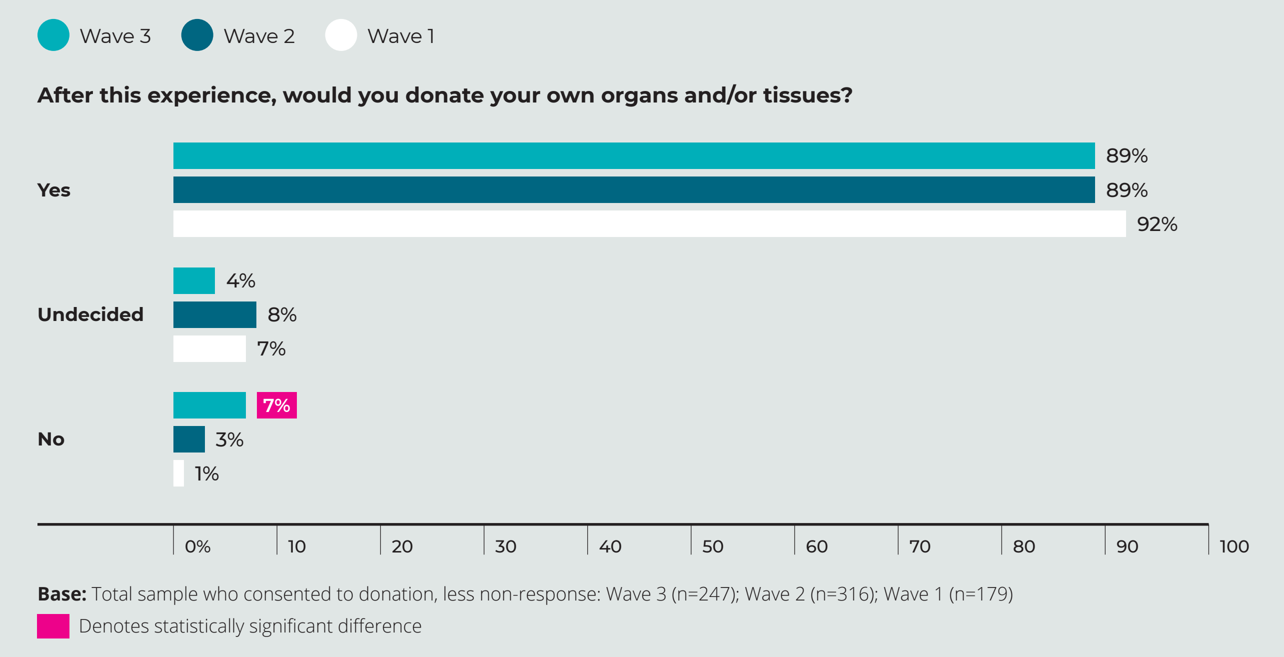
After the donation experience, 89% of donor family members would donate their own organs and/or tissues after death (Figure 50). There has been no significant change in this sentiment since Wave 1. Four per cent of donor family members are undecided, while 7% would not wish to donate; the latter being a significant increase from 3% in Wave 2.

> **I am really pissed off that not one recipient has bothered to contact us. My kids deserve better.”**
>
> 2015 – Consented to donation

> **I would not want to put my family through the process involved with organ donation. It is cruel and antiquated.”**
>
> 2015 – Consented to donation

> **While I am glad that someone benefited from receiving my Dad's kidneys, I feel I've let my Dad down. I don't feel 100% sure he was completely gone when they took him. There is a haunting and horrible feeling about what happened. I also felt we didn't get the time to sit with him and grieve naturally.”**
>
> **Also, the way the timing was based around what suited the medical team and not us made it feel like Dad was a product for harvesting, not a person.”**
>
> **I feel the donation process made the grieving process harder and I feel I let my Dad down letting that happen to him.”**
>
> 2015 – Consented to donation

Figure 50 Impact of experience on decision to donate own organs and/or tissues



Base: Total sample who consented to donation, less non-response: Wave 3 (n=247); Wave 2 (n=316); Wave 1 (n=179)

🟥 Denotes statistically significant difference

The majority (88%) of intended donor family members would donate their own organs and/or tissues, while 12% are undecided. This is consistent with Wave 2 findings (80% of intended donor family members would donate).

Among families who declined donation in 2014 and 2015:

- 70% would make the same decision again
- 15% would make a different donation decision, and
- 15% are unsure.

> **I guess it may have helped us if we had known in advance that 'life' would have to be prolonged by 24 hours for [donation] to occur. We simply could not take the thought of doing this – we wanted her to go quietly and rest peacefully.”**
> 2015 – Declined donation

Table 31 shows that prior to their donation experience, 87% of family members held positive views about donation, 12% had mixed feelings and 1% held negative views.

The donation experience can influence a person’s own views and wishes when it comes to donation; a positive experience can lead a person to change their previously held negative views, while a negative experience can turn a person away from registering on the AODR.

It is pleasing to see that of those family members who had mixed feelings about donation, 61% would now donate their own organs, mostly because they’ve seen the positive outcome of donation.

> **It’s a feel good thing to help someone else at a time like this.”**
> 2014 – Consented to donation

Donor family members who responded ‘no’ or ‘undecided’ cite two main reasons:

1. Lack of contact from recipients
2. The donation process (more on this in Section 9.5)

Table 31 Impact of donation on personal views

Personal views about donation	Total (n=247)	Would donate own organs and/or tissues?	
Generally positive	87%	Yes	94%
		No	2%
		Undecided	4%
Mixed feelings	12%	Yes	61%
		No	6%
		Undecided	32%
Generally negative	1%	Yes	–
		No	100%
		Undecided	–

14 Summary of comparison between waves

This section of the report provides a quick reference and comparison between the research data collected from families who consented to donation in Wave 1 (sample size of n=185 donor family members), Wave 2 (sample size of n=319 family members) and Wave 3 (sample size of n=257 donor family members), where direct comparisons can be made.

14.1 The decision to donate

Experience		Wave 1	Wave 2	Wave 3	Location
Donation pathway (unique family units)	Brain death	89%	88%	86%	Table 5
	Circulatory death	11%	12%	14%	Table 5
Prior discussion	Yes and knew wishes	59%	59%	63%	Figure 8
	Yes, but unclear on wishes	9%	9%	8%	Figure 8
	Did not discuss	32%	32%	29%	Figure 8
Impact of knowing wishes of family member (amongst those who had previously had discussion): • Wave 1: n=125 • Wave 2: n=216 • Wave 3: n=183	Made decision a lot easier	76%	80%	74%	Table 12
	Made decision a bit easier	13%	11%	15%	Table 12
	No impact	10%	8%	7%	Table 12
	Made decision a bit more difficult	2%	1%	4%	Table 12
	Made decision a lot more difficult	–	–	–	Table 12
Main reasons for agreeing to donation (top 3 reasons – Wave 2)	Opportunity for something positive to come out of a tragedy	81%	78%	75%	Figure 10
	Family member would have wanted to help others	80%	76%	76%	Figure 10
	For someone else to live a better life	74%	66%	72%	Figure 10

14.2 At the hospital (prior to consenting)

Experience		**Wave 1**	**Wave 2**	**Wave 3**	**Location**
Hospital staff made it clear that family member would not survive	Yes	94%	95%	95%	Figure 12
	No	4%	2%	4%	Figure 12
	Not sure	2%	3%	1%	Figure 12
ICU/ED staff treated family with consideration and sensitivity	To a great extent	89%	91%	90%	Figure 11
	To some extent	11%	8%	9%	Figure 11
	Not at all	1%	1%	1%	Figure 11
Was given sufficient information to understand that death was expected	Total agree	99%	97%	98%	Figure 13
	Disagree/not sure	1%	3%	2%	Figure 13
Language used by medical staff was clear and easy to understand	Total agree	99%	98%	96%	Figure 13
	Disagree	1%	2%	4%	Figure 13
Medical staff treated family with compassion and sensitivity	Total agree	99.5%	99%	99%	Figure 13
	Disagree	0.5%	1%	1%	Figure 13
Medical staff treated donor with respect	Total agree	99%	99%	98%	Figure 13
	Disagree	1%	1%	2%	Figure 13
Had sufficient opportunity to ask questions of medical staff	Total agree	97%	96%	97%	Figure 13
	Disagree/not sure	3%	4%	3%	Figure 13
Had enough private time with family member after receiving grave news	Yes	91%	91%	89%	Figure 17
	No	7%	6%	5%	Figure 17
	Not sure	2%	3%	6%	Figure 17
Brain death testing					
Offered to be present during brain death testing	Yes	24%	24%	25%	Figure 15
	No	50%	**62%**	56%	Figure 15
	Not sure	26%	**14%**	19%	Figure 15
Chose to be present during brain death testing (among those who were offered)	Yes	55%	**73%**	68%	Figure 15
	No	45%	**27%**	32%	Figure 15
Seeing tests helped in understanding that loved one had died (among those who attended brain death testing)	Yes	91%	91%	**72%**	Figure 15
	No/not sure	9%	9%	**28%**	Figure 15
Would have helped to have option of being present (among those who were not offered)	Yes	18%	20%	22%	Figure 15
	No/not sure	82%	80%	78%	Figure 15

🟥 Denotes statistically significant difference

14.3 The donation conversation

Experience		Wave 1	Wave 2	Wave 3	Location
Who initially raised donation	Doctor	29%	34%	26%	Figure 18a
	Donor coordinator	13%	**21%**	26%	Figure 18a
	Nurse	4%	7%	9%	Figure 18a
	Health professional – Net	**46%**	**58%**	**53%**	Figure 18a
	Self	20%	22%	26%	Figure 18a
	Family member	10%	11%	9%	Figure 18a
	Self/family – Net	**30%**	**33%**	**33%**	Figure 18a
When donation was first raised (in relation to being told of family member's death or expected death)	Before	10%	10%	13%	Figure 20a
	At the same time	40%	38%	28%	Figure 20a
	Within 1 hour	24%	17%	26%	Figure 20a
	More than 1 hour	12%	19%	14%	Figure 20a
Appropriateness of timing	Yes	74%	73%	74%	Figure 21
	No/not sure	26%	27%	26%	Figure 21
Discussions with hospital staff about donation prior to donation decision being made					
Discussions were handled sensitively and with compassion	Total agree	98%	96%	97%	Figure 23
	Disagree/not sure	2%	4%	3%	Figure 23
Family had enough opportunities to ask questions about donation	Total agree	93%	**97%**	95%	Figure 25
	Disagree/not sure	7%	**3%**	5%	Figure 25
Hospital staff answered questions	Total agree	95%	98%	95%	Figure 26
	Disagree/not sure	5%	2%	5%	Figure 26
Given sufficient information to allow an informed decision to be made	Total agree	95%	97%	96%	Figure 24
	Disagree/not sure	5%	3%	4%	Figure 24
Given enough time to discuss donation and make decision	Total agree	94%	96%	96%	Figure 27
	Disagree/not sure	6%	4%	4%	Figure 27
Feel pressured or rushed	Yes	8%	8%	7%	Figure 28
	No	88%	87%	89%	Figure 28
	Not sure	4%	5%	4%	Figure 28

■ Denotes statistically significant difference

14.4 Moving toward donation

Experience		Wave 1	Wave 2	Wave 3	Location
Met with DonateLife coordinator, nurse or doctor	Yes	91%	92%	93%	Figure 29
	No	5%	4%	3%	Figure 29
	Not sure	4%	4%	4%	Figure 29
Understanding of donation process after speaking with DonateLife coordinator, nurse or doctor	Well informed	82%	83%	80%	Table 19
	Still had questions	16%	14%	18%	Table 19
	Not a good understanding of donation process	2%	2%	2%	Table 19
Made aware that donation may not happen even after consent	Yes	90%	88%	91%	Page 55
Written information					
Received written information	Before decision was made	16%	**27%**	22%	Figure 30
	After decision was made	24%	20%	26%	Figure 30
	Did not receive written information	15%	14%	13%	Figure 30
	Can't recall	48%	41%	40%	Figure 30
Read information (amongst those who received it)	Yes, in detail	53%	54%	45%	Figure 31
	Yes, skimmed through it	46%	41%	48%	Figure 31
	Did not read	1%	5%	7%	Figure 31
When information was read (amongst those who received information)	Before finalising decision	28%	35%	27%	Figure 31
	After finalising decision	64%	**43%**	59%	Figure 31
	Not sure	7%	**21%**	15%	Figure 31
Usefulness of written information (amongst those who read it)	Very useful	55%	52%	42%	Table 20
	Quite useful	41%	44%	53%	Table 20
	Not useful	5%	2%	5%	Table 20
Support from health professionals – after consenting to donation					
Staff in ICU or ED treated family with consideration and sensitivity after consenting to donation	To a great extent	89%	89%	89%	Figure 32
	To some extent	10%	10%	10%	Figure 32
	Not at all	1%	1%	1%	Figure 32
Offered support of a social worker, counsellor or chaplain	Yes	76%	79%	78%	Figure 33
	No	10%	10%	7%	Figure 33
	Not sure	14%	11%	15%	Figure 33

Experience		Wave 1	Wave 2	Wave 3	Location
Donation process					
Given enough time with family member prior to surgery	Yes	95%	95%	94%	Figure 36
	No	5%	5%	6%	Figure 36
Given the information you wanted about donation surgery	Yes	83%	85%	81%	Figure 35
	No/not sure	17%	15%	19%	Figure 35
Information about donation surgery	Too detailed	2%	3%	2%	Figure 35
	Too broad	5%	3%	4%	Figure 35
	Too brief	8%	4%	10%	Figure 35
	Just right	85%	89%	83%	Figure 35
Staff in ICU treated family member with respect	To a great extent	91%	94%	94%	Figure 37
	To some extent	8%	6%	4%	Figure 37
	Not at all	1%	–	2%	Figure 37

■ Denotes statistically significant difference

14.5 After donation surgery

Experience		Wave 1	Wave 2	Wave 3	Location
Offered opportunity to spend time with family member after donation surgery	Yes	49%	47%	40%	Figure 38
	No	37%	36%	43%	Figure 38
	Not sure	14%	17%	18%	Figure 38
Spent time with family member after surgery (amongst those who were offered)	Yes	53%	56%	58%	Figure 38
	No	47%	44%	42%	Figure 38
Would have liked the opportunity to see family member post-surgery (amongst those who were not offered)	Yes	10%	11%	11%	Figure 38
	No	66%	61%	68%	Figure 38
	Not sure	24%	28%	21%	Figure 38

14.6 Follow-up services

Experience		Wave 1	Wave 2	Wave 3	Location
Offered ongoing contact after donation from DonateLife coordinator, nurse or doctor, a DFSC, hospital social worker or hospital chaplain	Yes	85%	**95%**	97%	Figure 39
Level of contact with DonateLife agency staff to date	Too much	1%	3%	6%	Figure 43
	Not enough	14%	11%	13%	Figure 43
	Just right	85%	85%	81%	Figure 43

■ Denotes statistically significant difference

14.7 Contact with recipients

Experience		Wave 1	Wave 2	Wave 3	Location
Awareness of donor families being able to write to recipients	Aware	N/A	50%	44%	Figure 44
	Unaware	N/A	50%	56%	Figure 44
Received correspondence from any transplant recipients (amongst unique donor families): • Wave 1: n=125 • Wave 2: n=246 • Wave 3: n=205	Yes, from one or more	69%	63%	63%	Figure 45
	No, even though I wanted to	24%	25%	22%	Figure 45
	No, I chose not to receive any	7%	8%	8%	Figure 45
Correspondence from recipients (amongst unique donor families who received any correspondence from recipients): • Wave 1: n=84 • Wave 2: n=156 • Wave 3: n=124	Of great comfort	87%	78%	81%	Figure 45
	Of some comfort	13%	20%	18%	Figure 45
	Of no comfort	–	2%	1%	Figure 45

14.8 On reflection

Experience		Wave 1	Wave 2	Wave 3	Location
Level of comfort with decision to agree to donation	Very comfortable	87%	85%	87%	Figure 47
	Somewhat comfortable	12%	12%	10%	Figure 47
	Somewhat uncomfortable	1%	2%	1%	Figure 47
	Very uncomfortable	–	1%	2%	Figure 47
Donation provided any comfort in loss	Great deal of comfort	47%	**57%**	50%	Figure 48
	Yes, some comfort	47%	**35%**	42%	Figure 48
	No	6%	8%	8%	Figure 48
In what way donation has provided comfort (amongst those who found comfort in donation) – top 3 responses	Provided meaning	65%	64%	63%	Figure 49
	Help in time of grief	67%	64%	64%	Figure 49
	Helped family discuss death of our loved one	50%	41%	36%	Figure 49
After donation experience, feelings towards donation personally	Would donate after death	92%	89%	89%	Figure 50
	Would not donate after death	1%	3%	7%	Figure 50
	Undecided	7%	8%	4%	Figure 50

🟥 Denotes statistically significant difference

Staff were absolutely wonderful and amazing with us. We couldn't have been happier with the decision we made, the people it helped and the people that helped us through it – the wonderful ICU staff & the DonateLife team."

2015 – Consented to donation

Appendices

A1 Glossary of key terms

This glossary provides definitions of the terms used throughout this research report.

Experience	Location
Brain Death Testing	A series of clinical tests carried out by two medical practitioners with experience and qualifications according to state and territory laws to determine that brain death has occurred. Two separate series of tests, one by each medical practitioner, is performed, however these tests may not be conducted simultaneously. Brain death may also be tested using special x-rays of the head to demonstrate that there is no blood flow to the brain if aforementioned clinical tests are unable to be completed.
DonateLife agencies	Organ and tissue donation agencies responsible for implementing the national program for organ and tissue donation in their respective state or territory. DonateLife agencies employ specialist staff in organ and tissue donation coordination, professional education, donor family support, communications and data and audit roles.
Donation after brain death (DBD)	When organ donation occurs after brain death has been determined and before cessation of circulation.
Donation after circulatory death (DCD)	When organ donation occurs after circulatory (formerly cardiac) death has been determined to have occurred, on the basis of the absence of circulation (and of other vital signs).
Donor Family Support Coordinator (DFSC)	Support Coordinators provide and/or organise counselling, coordinate and assist in the provision of support to donor families.
Family	Those closest to the person in knowledge, care and affection, including the immediate biological family; the family of acquisition (related by marriage or contract); and the family of choice and friends (not related biologically or by marriage or contract).
Human Research Ethics Committees (HRECs)	Committees that review research proposals involving human participants to ensure that they are ethically acceptable and in accordance with relevant standards and guidelines.
'In Reflection' booklet	A DonateLife resource that provides information for donor families in dealing with the grieving process.
Interviews	A research tool in which a researcher asks questions (mostly open ended questions) of participants. Interviews are conducted face-to-face and are audio-taped (with permission of the participant) for later transcription and analysis.
Organ and Tissue Authority (OTA)	Statutory body established under the Australian Organ and Tissue Donation and Transplantation Authority Act 2008 to implement the national program. The OTA's role is to work with states and territories, clinicians, consumers and the community sector to implement a world's best practice approach to organ and tissue donation and transplantation system for Australia.
Participant Information Statement (PIS)	Document provided to research participants. It outlines in plain and simple language, information about the project, including what participating in the project involves, benefits and risks of participation and privacy statements, so individuals can make an informed decision regarding participation in the research study.

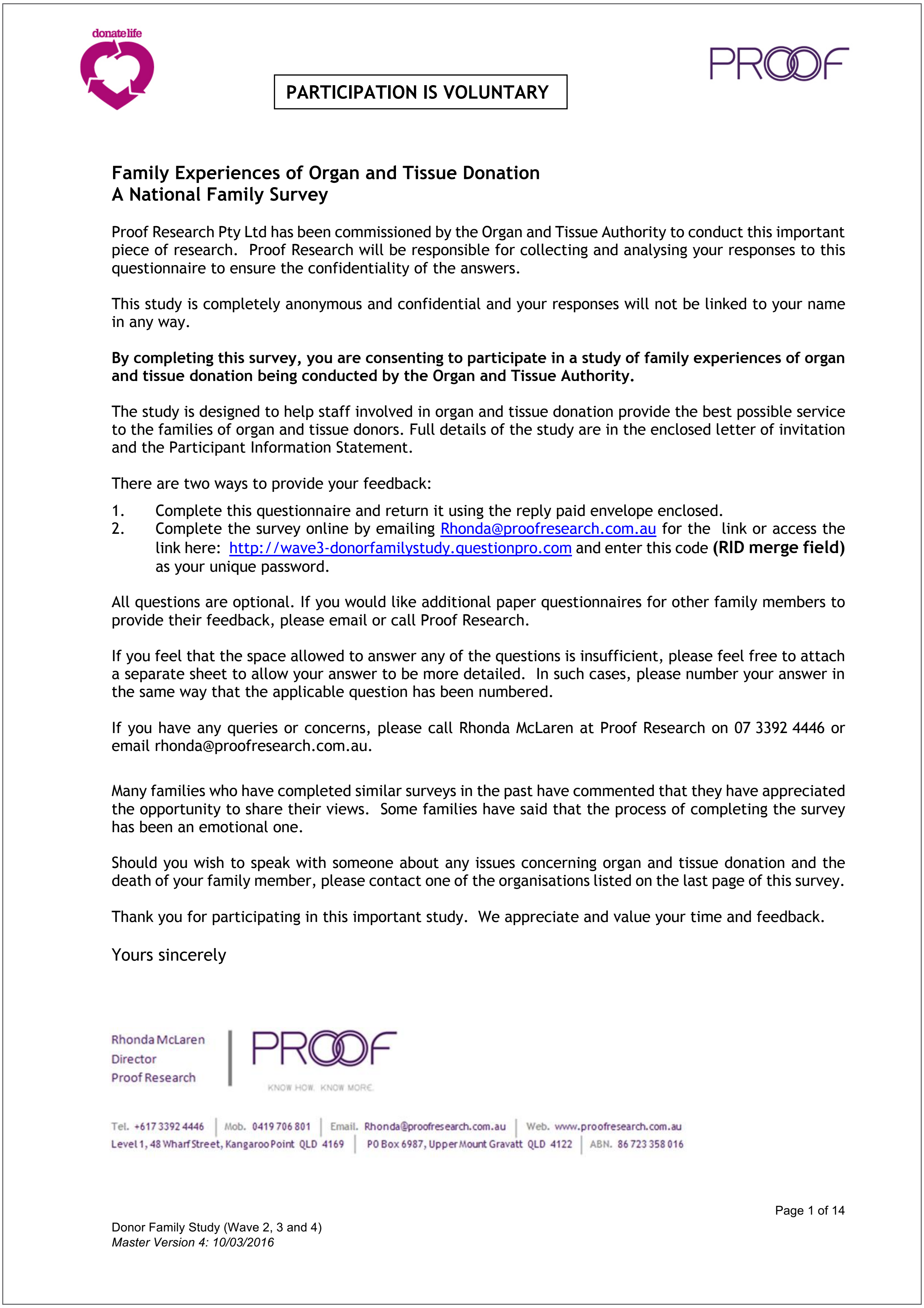
Experience	Location
Qualitative research	Empirical research in which the researcher explores relationships using textual, rather than quantitative data. In-depth interviews are a form of qualitative research.
Quantitative research	Empirical research in which the researcher explores relationships using numeric data. Survey is a form of quantitative research. Results can be generalised to the population in question within the margin of error.
Recipient	An individual who has received the tissue or organ transplant from the donor.
Service of Remembrance	Services held across Australia in recognition of those who have been affected by organ and tissue donation and transplantation.
Unique donor families	Individual family units that may comprise more than one family member. Where stated throughout the report, a unique donor family represents the views of one family unit.

A2 List of tables

A3 List of figures

A4 Research instruments

A4.1 Questionnaire – Consenting families



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PARTICIPATION IS VOLUNTARY

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Family Experiences of Organ and Tissue Donation
A National Family Survey

Proof Research Pty Ltd has been commissioned by the Organ and Tissue Authority to conduct this important piece of research. Proof Research will be responsible for collecting and analysing your responses to this questionnaire to ensure the confidentiality of the answers.

This study is completely anonymous and confidential and your responses will not be linked to your name in any way.

By completing this survey, you are consenting to participate in a study of family experiences of organ and tissue donation being conducted by the Organ and Tissue Authority.

The study is designed to help staff involved in organ and tissue donation provide the best possible service to the families of organ and tissue donors. Full details of the study are in the enclosed letter of invitation and the Participant Information Statement.

There are two ways to provide your feedback:

1. Complete this questionnaire and return it using the reply paid envelope enclosed.
2. Complete the survey online by emailing Rhonda@proofresearch.com.au for the link or access the link here: http://wave3-donorfamilystudy.questionpro.com and enter this code **(RID merge field)** as your unique password.

All questions are optional. If you would like additional paper questionnaires for other family members to provide their feedback, please email or call Proof Research.

If you feel that the space allowed to answer any of the questions is insufficient, please feel free to attach a separate sheet to allow your answer to be more detailed. In such cases, please number your answer in the same way that the applicable question has been numbered.

If you have any queries or concerns, please call Rhonda McLaren at Proof Research on 07 3392 4446 or email rhonda@proofresearch.com.au.

Many families who have completed similar surveys in the past have commented that they have appreciated the opportunity to share their views. Some families have said that the process of completing the survey has been an emotional one.

Should you wish to speak with someone about any issues concerning organ and tissue donation and the death of your family member, please contact one of the organisations listed on the last page of this survey.

Thank you for participating in this important study. We appreciate and value your time and feedback.

Yours sincerely

Rhonda McLaren
Director
Proof Research

PROOF
KNOW HOW. KNOW MORE.

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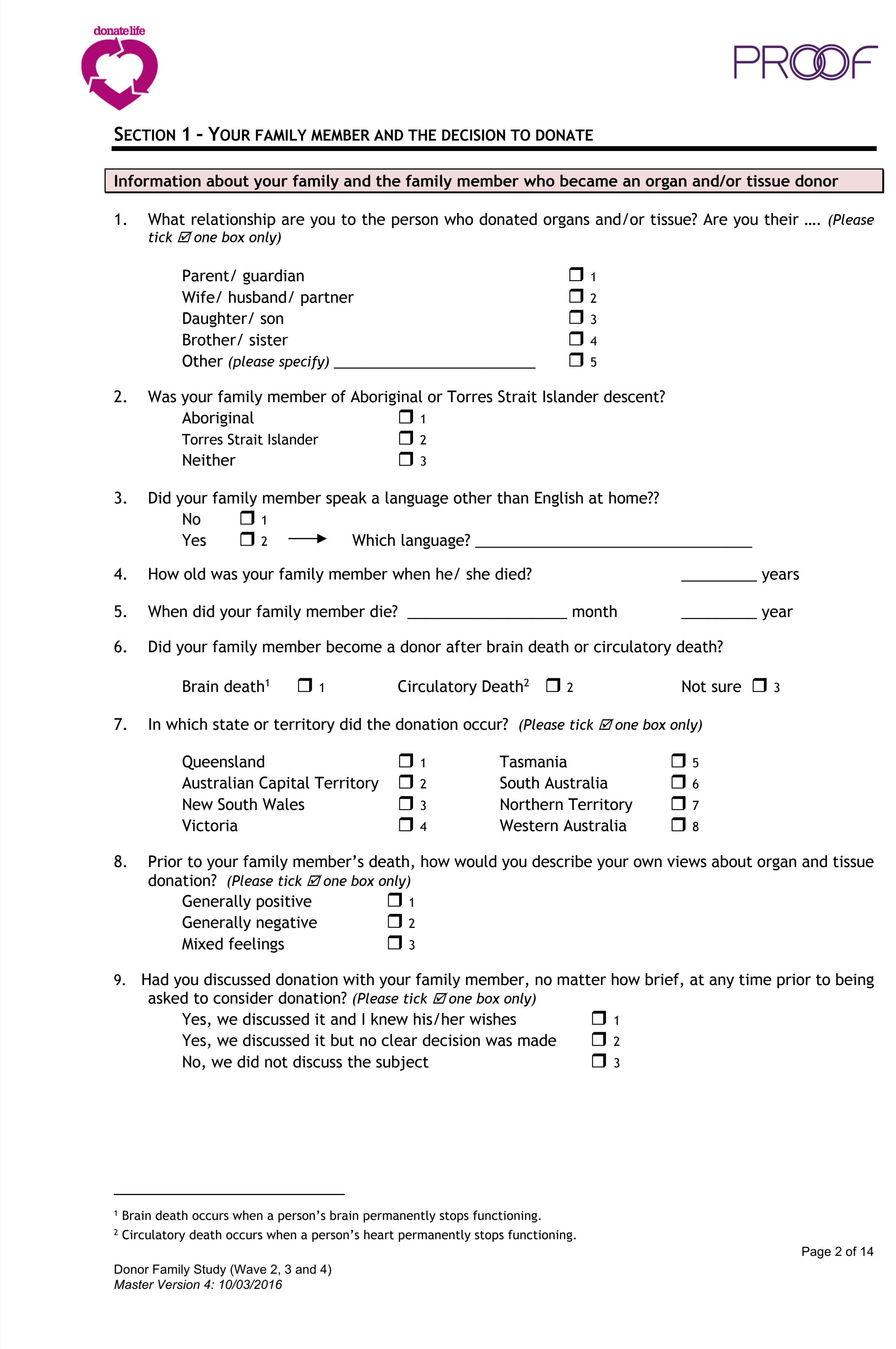


SECTION 1 - YOUR FAMILY MEMBER AND THE DECISION TO DONATE

Information about your family and the family member who became an organ and/or tissue donor

1. What relationship are you to the person who donated organs and/or tissue? Are you their …. *(Please tick ☑ one box only)*

Parent/ guardian	☐ 1
Wife/ husband/ partner	☐ 2
Daughter/ son	☐ 3
Brother/ sister	☐ 4
Other *(please specify)* ______________________	☐ 5

2. Was your family member of Aboriginal or Torres Strait Islander descent?

Aboriginal	☐ 1
Torres Strait Islander	☐ 2
Neither	☐ 3

3. Did your family member speak a language other than English at home??

No ☐ 1
Yes ☐ 2 → Which language? ______________________________

4. How old was your family member when he/ she died? ________ years

5. When did your family member die? ________________ month ________ year

6. Did your family member become a donor after brain death or circulatory death?

Brain death[1] ☐ 1 Circulatory Death[2] ☐ 2 Not sure ☐ 3

7. In which state or territory did the donation occur? *(Please tick ☑ one box only)*

Queensland	☐ 1	Tasmania	☐ 5
Australian Capital Territory	☐ 2	South Australia	☐ 6
New South Wales	☐ 3	Northern Territory	☐ 7
Victoria	☐ 4	Western Australia	☐ 8

8. Prior to your family member's death, how would you describe your own views about organ and tissue donation? *(Please tick ☑ one box only)*

Generally positive	☐ 1
Generally negative	☐ 2
Mixed feelings	☐ 3

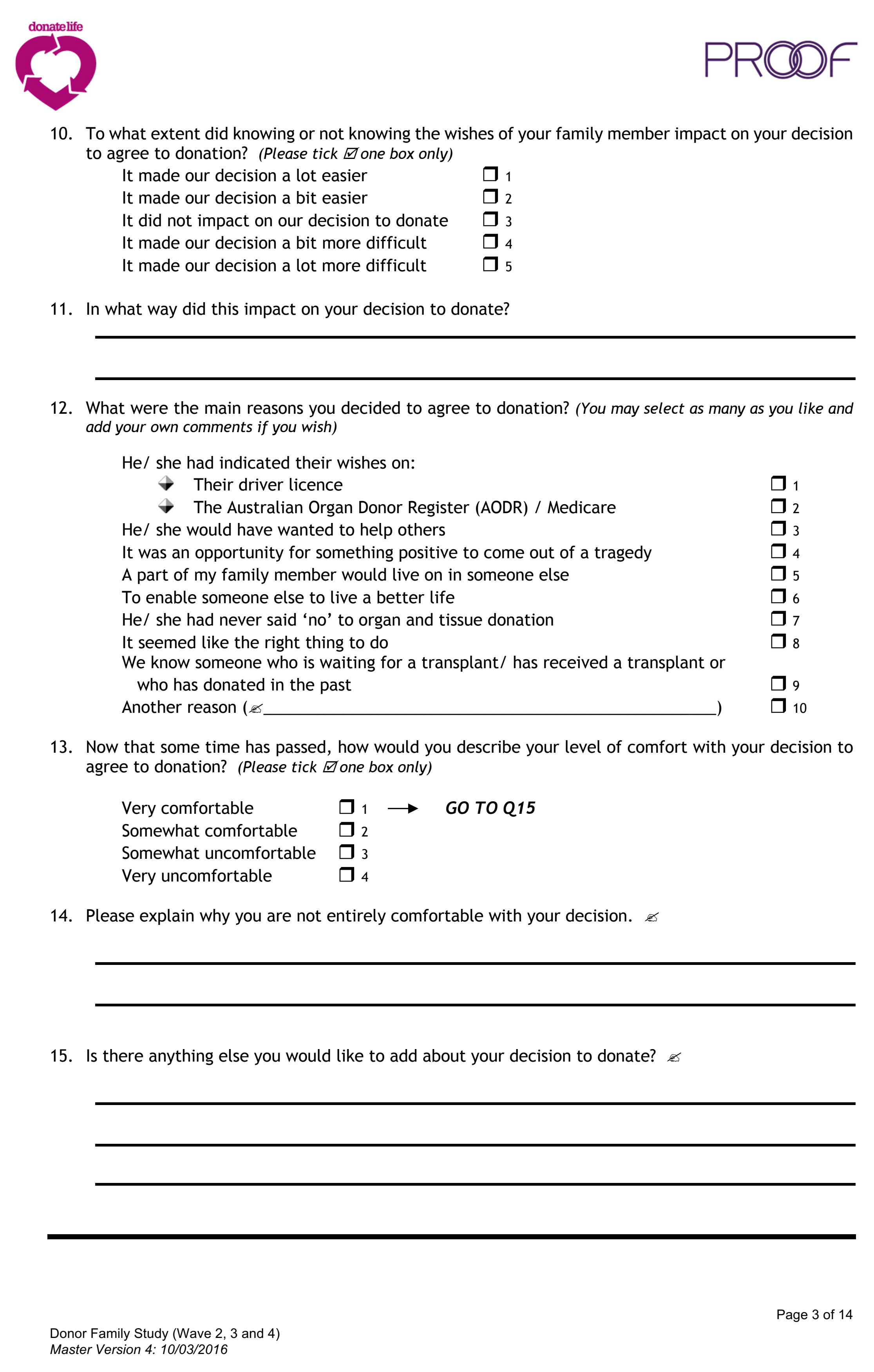
9. Had you discussed donation with your family member, no matter how brief, at any time prior to being asked to consider donation? *(Please tick ☑ one box only)*

Yes, we discussed it and I knew his/her wishes	☐ 1
Yes, we discussed it but no clear decision was made	☐ 2
No, we did not discuss the subject	☐ 3

---

[1] Brain death occurs when a person's brain permanently stops functioning.

[2] Circulatory death occurs when a person's heart permanently stops functioning.



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10. To what extent did knowing or not knowing the wishes of your family member impact on your decision to agree to donation? *(Please tick ☑ one box only)*

It made our decision a lot easier	☐ 1
It made our decision a bit easier	☐ 2
It did not impact on our decision to donate	☐ 3
It made our decision a bit more difficult	☐ 4
It made our decision a lot more difficult	☐ 5

11. In what way did this impact on your decision to donate?

____

____

12. What were the main reasons you decided to agree to donation? *(You may select as many as you like and add your own comments if you wish)*

He/ she had indicated their wishes on:	
◆ Their driver licence	☐ 1
◆ The Australian Organ Donor Register (AODR) / Medicare	☐ 2
He/ she would have wanted to help others	☐ 3
It was an opportunity for something positive to come out of a tragedy	☐ 4
A part of my family member would live on in someone else	☐ 5
To enable someone else to live a better life	☐ 6
He/ she had never said 'no' to organ and tissue donation	☐ 7
It seemed like the right thing to do	☐ 8
We know someone who is waiting for a transplant/ has received a transplant or who has donated in the past	☐ 9
Another reason (✍____________________________)	☐ 10

13. Now that some time has passed, how would you describe your level of comfort with your decision to agree to donation? *(Please tick ☑ one box only)*

Very comfortable	☐ 1	→ ***GO TO Q15***
Somewhat comfortable	☐ 2	
Somewhat uncomfortable	☐ 3	
Very uncomfortable	☐ 4	

14. Please explain why you are not entirely comfortable with your decision. ✍

____

____

15. Is there anything else you would like to add about your decision to donate? ✍

____

____

____

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Donor Family Study (Wave 2, 3 and 4)
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SECTION 2 - AT THE HOSPITAL

These questions will help us to understand your experiences at the hospital prior to consenting to donation

16. During the time your family member was in the Intensive Care Unit or the Emergency Department, did the hospital staff make it clear that his/ her condition was critical and that he/ she may not survive? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

17. To what extent do you feel the staff in the Intensive Care Unit/Emergency Department treated you with consideration and sensitivity at this time? *(Please tick ☑ one box only)*

To a great extent ☐ 1
To some extent ☐ 2
Not at all ☐ 3

18. Is there anything else you would like to add? ✍

____

____

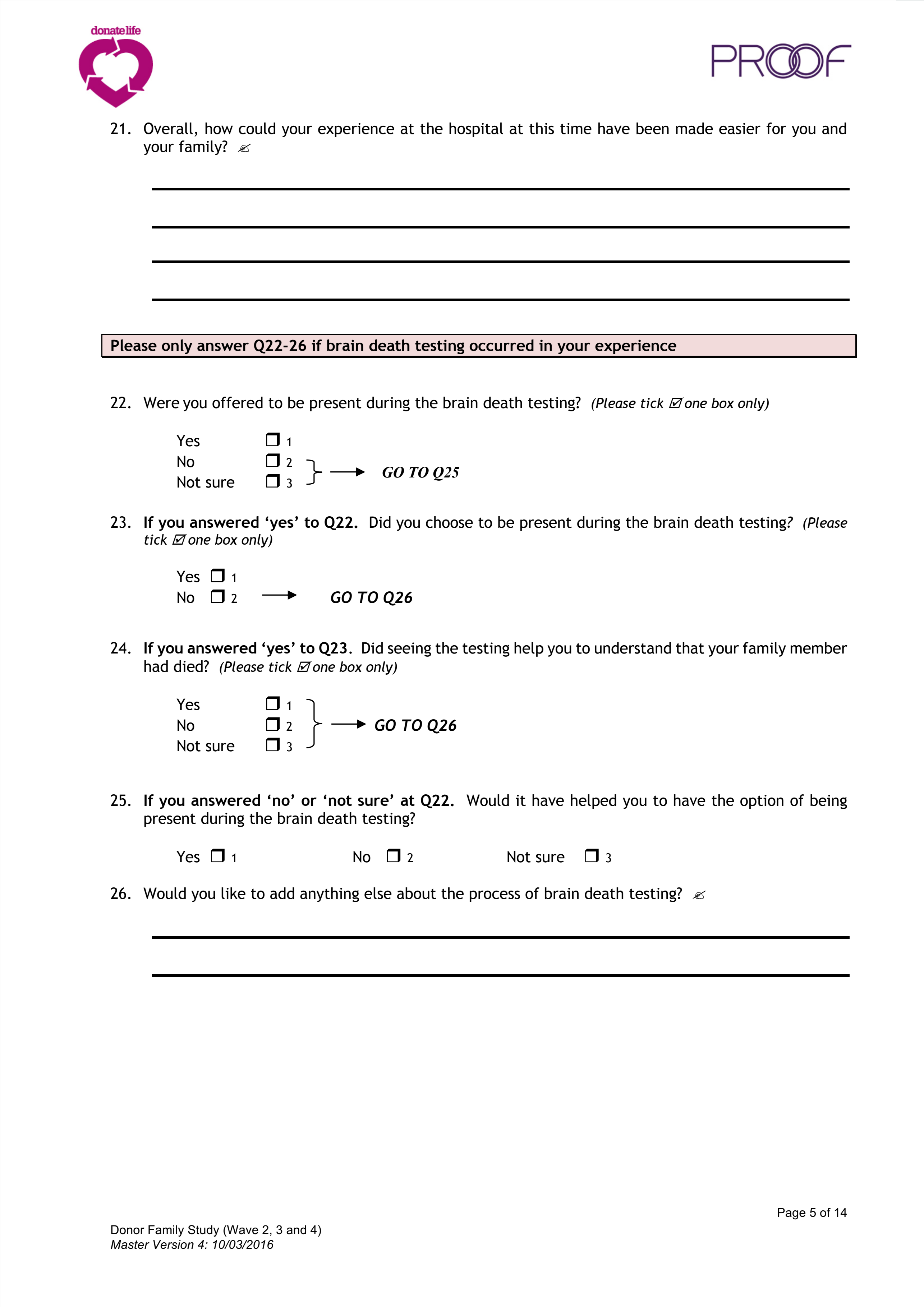
____

19. Depending on the individual circumstances of your family member, medical staff may have discussed with you either testing for brain death or turning off the ventilator. Thinking back to that time, do you agree or disagree with each of the following statements? *(Please tick ☑ one box only for each statement)*

	Strongly agree 3	**Somewhat agree** 2	**Disagree** 1	**Not sure** 9
a) I was given sufficient information to fully understand that death was expected	☐	☐	☐	☐
b) The language used by medical staff was clear and easy to understand	☐	☐	☐	☐
c) Medical staff treated me with compassion and sensitivity at this time	☐	☐	☐	☐
d) Medical staff treated my family member with respect	☐	☐	☐	☐
e) I had sufficient opportunity to ask questions of medical staff at this time	☐	☐	☐	☐

20. Did you feel you had enough private time with your family member after receiving this news? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3



PROOF

21. Overall, how could your experience at the hospital at this time have been made easier for you and your family? ✍

Please only answer Q22-26 if brain death testing occurred in your experience

22. Were you offered to be present during the brain death testing? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2 } → ***GO TO Q25***
Not sure ☐ 3 }

23. **If you answered 'yes' to Q22.** Did you choose to be present during the brain death testing? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2 → ***GO TO Q26***

24. **If you answered 'yes' to Q23.** Did seeing the testing help you to understand that your family member had died? *(Please tick ☑ one box only)*

Yes ☐ 1 }
No ☐ 2 } → ***GO TO Q26***
Not sure ☐ 3 }

25. **If you answered 'no' or 'not sure' at Q22.** Would it have helped you to have the option of being present during the brain death testing?

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

26. Would you like to add anything else about the process of brain death testing? ✍

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Donor Family Study (Wave 2, 3 and 4)
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SECTION 3 - DISCUSSING ORGAN AND TISSUE DONATION

The following questions will help us to understand the way in which donation is discussed with families

27. Who first mentioned the possibility of donation to you at the hospital?

Doctor	☐ 1	→ **CONTINUE**
Nurse	☐ 2	
DonateLife coordinator	☐ 3	
Family member/ close friend	☐ 4	→ **GO TO Q32**
Other *(relationship to you: __________________________)*	☐ 5	
I raised it myself	☐ 6	
Can't remember	☐ 9	→ **CONTINUE**

28. When was donation first raised with you? *(Please tick ☑ one box only)*

Before I was told of my family member's death or expected death	☐ 1
At the same time as I was told of my family member's death or expected death	☐ 2
Within an hour of being told of my family member's death or expected death	☐ 3
More than 1 hour after being told of my family member's death or expected death	☐ 4
Can't remember	☐ 9

29. Do you think this timing was appropriate? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

30. Is there anything else you would like to add about the timing? ✍

____

____

31. If donation was first raised by a hospital staff member and not a family member, how did that make you feel? (*You may select as many as you like*).

It added to my family's distress	☐ 1
My reaction would have been the same, irrespective of who first mentioned it	☐ 2
It was preferable coming from a hospital staff member first	☐ 3
We expected to be asked about donation	☐ 4

32. Thinking back to the discussions you had with hospital staff about donation <u>prior to your decision</u>, how strongly do you agree or disagree with each of the following statements?
(Please tick ☑ one box only for each statement)

	Strongly agree **3**	**Somewhat agree** **2**	**Disagree** **1**	**Not sure** **9**
a) The discussions about donation were handled sensitively and with compassion	☐	☐	☐	☐
b) My family had enough opportunities to ask questions of hospital staff about donation	☐	☐	☐	☐
c) Hospital staff answered our questions	☐	☐	☐	☐
d) We were given sufficient information to allow us to make an informed decision	☐	☐	☐	☐
e) My family was given enough time to discuss donation and to make our decision	☐	☐	☐	☐

33. Did you feel rushed or pressured at any stage? *(Please tick ☑ one box only)*

Yes	☐ 1	
No	☐ 2	→ ***GO TO Q35***
Not sure	☐ 3	→ ***GO TO Q35***

34. In what way did you feel rushed or pressured?

____

____

____

Consenting to organ and/or tissue donation

35. Did you meet with a DonateLife coordinator, nurse or doctor? *(Please tick ☑ one box only)*

Yes	☐ 1	
No	☐ 2	→ ***GO TO Q37***
Not sure	☐ 3	→ ***GO TO Q37***

36. Which of these statements best describes your understanding of the donation process after speaking with the DonateLife coordinator, nurse or doctor? *(Please tick ☑ one box only)*

I was well informed and knew all that I needed to know about the donation process	☐ 1
I was informed but still had some questions	☐ 2
I didn't have a good understanding of the donation process	☐ 3

37. Were you made aware that even if donation was agreed to, the donation may not happen for a number of reasons? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

38. Did you receive written information explaining organ and tissue donation whilst in hospital? *(Please tick ☑ all that apply)*

Yes, before the decision to donate was made	☐ 1	
Yes, after the decision to donate was made	☐ 2	
No, I did not receive written information	☐ 3 →	***GO TO Q42***
I can't recall	☐ 4 →	***GO TO Q42***

39. Did you read the information? *(Please tick ☑ one box only)*

Yes, in detail	☐ 1	
Yes, skimmed through it	☐ 2	
No	☐ 3 →	***GO TO Q42***

40. When did you read the information about donation?

Before finalising your decision about donation	☐ 1
After finalising your decision about donation	☐ 2
Not sure	☐ 3

41. How useful was the written information? *(Please tick ☑ one box only)*

Very useful	☐ 1
Quite useful	☐ 2
Not useful	☐ 3

42. To what extent do you feel the staff in the Intensive Care Unit or Emergency Department treated you with consideration and sensitivity after you agreed to donation? *(Please tick ☑ one box only)*

To a great extent	☐ 1
To some extent	☐ 2
Not at all	☐ 3

43. What further comments would like to make? ✍

____

____

44. Were you offered the support of a social worker, counsellor or chaplain at any time during your family member's stay in hospital? *(Please tick ☑ one box only)*

Yes	☐ 1
No	☐ 2
Not sure	☐ 3

45. How could the way in which donation was discussed with you at the hospital have been improved after you agreed to donation? ✍

____

____

46. Did your family member donate …. *(Please tick ☑ one box only)*

Organ/s ☐ 1   Tissue ☐ 2   Both organs & tissue ☐ 3   Not sure ☐ 4

OR:
Donation did not proceed ☐ 5 → ***PLEASE GO TO SECTION 4***

The donation process

47. After consent was given for donation, were you given enough time with your family member prior to surgery? *(Please tick ☑ one box only)*

Yes ☐ 1   No ☐ 2

48. Were you given the information <u>you wanted</u> about what happens when the donation surgery occurs? *(Please tick ☑ one box only)*

Yes ☐ 1   No ☐ 2   Not sure ☐ 3

49. Was the information you received ….? *(Please tick ☑ one box only)*

Too detailed ☐ 1   Too broad ☐ 2   Too brief ☐ 3   Just right ☐ 4

50. To what extent do you feel the staff in the Intensive Care Unit treated your family member with respect at this time? *(Please tick ☑ one box only)*

To a great extent ☐ 1
To some extent ☐ 2
Not at all ☐ 3

51. What else would you like to add about the donation process? ✍

After the donation surgery

52. Were you offered the opportunity to spend time with your family member <u>after</u> the donation surgery? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2 → ***GO TO Q55***
Not sure ☐ 3 → ***GO TO Q55***

53. **If you answered 'yes' at Q52.** Did you spend time with your family member after the donation surgery? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2

54. **If you answered 'yes' at Q52.** How would you describe this experience? *(Please tick ☑ one box only)*

Positive ☐ 1   Negative ☐ 2   Not sure ☐ 3

55. **If you answered 'no' or 'not sure' to Q52.** Would you have wanted the opportunity to spend time with your family member after donation surgery? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

56. Is there anything else you would like to add about your experience at the hospital after the donation took place? ✍

____

____

SECTION 4 - FOLLOWING DONATION

Follow up services and resources

57. How helpful did you find any ongoing contact from staff following donation? *(Please tick ☑ one box per row)*

	Definitely helpful 3	Somewhat helpful 2	Not helpful 1	Contact Not offered	Chose not to receive
a) DonateLife coordinator, nurse or doctor	☐	☐	☐	☐	☐
b) Donor Family Support Coordinator	☐	☐	☐	☐	☐
c) Hospital social worker	☐	☐	☐	☐	☐
d) Other hospital support staff such as a chaplain	☐	☐	☐	☐	☐
e) External professional counselling services (other than from DonateLife agencies)	☐	☐	☐	☐	☐
f) Other – please specify ____________	☐	☐	☐	☐	☐

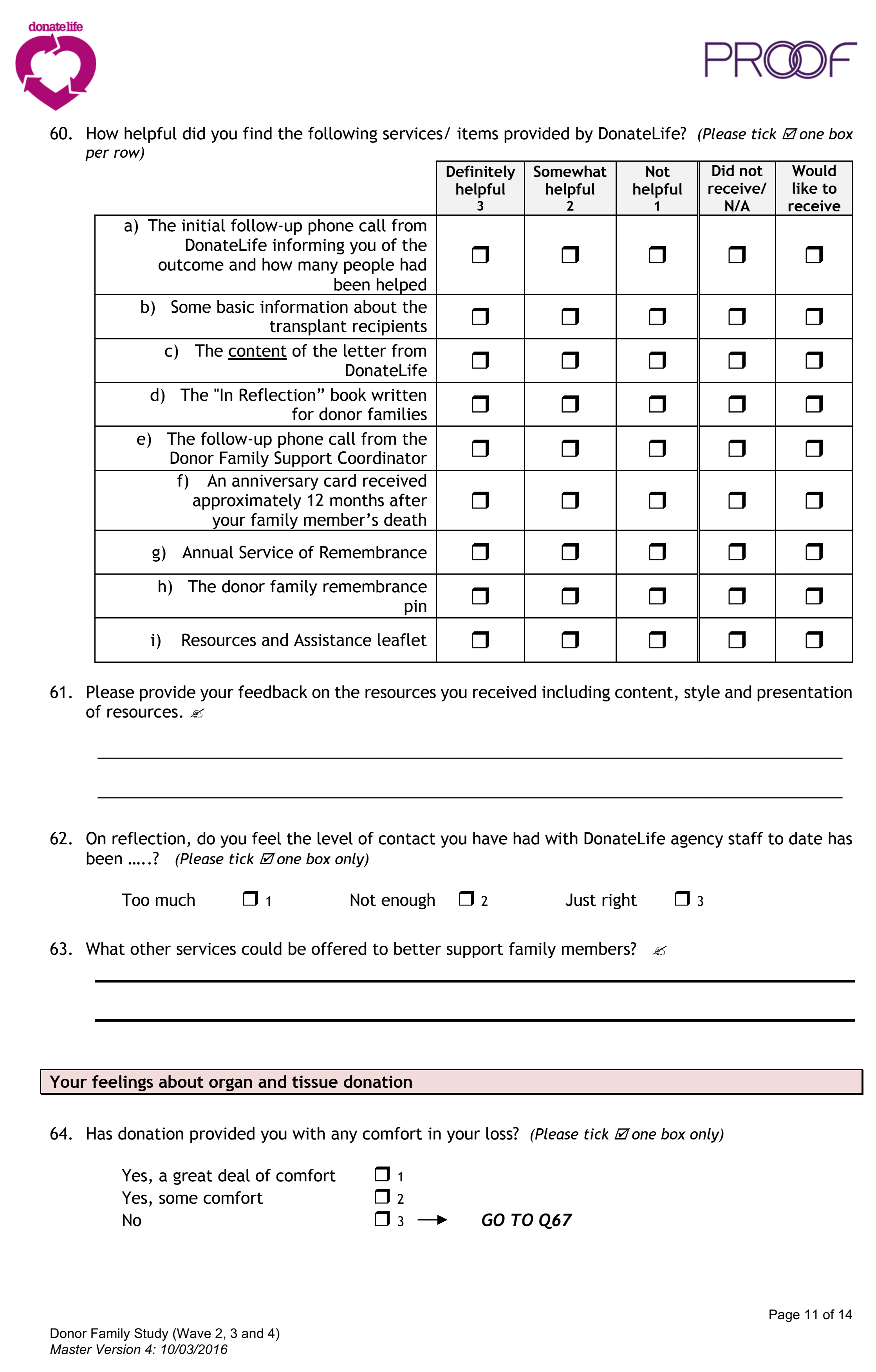
58. If you found ongoing contact helpful, please provide comments on the ways it was helpful to you? ✍

____

____

59. **If you ticked that ongoing contact was not offered to you in Q57.** Would it have been helpful for you and your family if someone from the hospital or organ and tissue donation agency spoke with you about ongoing support for you and your family? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3



donatelife

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60. How helpful did you find the following services/ items provided by DonateLife? *(Please tick ☑ one box per row)*

	Definitely helpful 3	Somewhat helpful 2	Not helpful 1	Did not receive/ N/A	Would like to receive
a) The initial follow-up phone call from DonateLife informing you of the outcome and how many people had been helped	☐	☐	☐	☐	☐
b) Some basic information about the transplant recipients	☐	☐	☐	☐	☐
c) The content of the letter from DonateLife	☐	☐	☐	☐	☐
d) The "In Reflection" book written for donor families	☐	☐	☐	☐	☐
e) The follow-up phone call from the Donor Family Support Coordinator	☐	☐	☐	☐	☐
f) An anniversary card received approximately 12 months after your family member's death	☐	☐	☐	☐	☐
g) Annual Service of Remembrance	☐	☐	☐	☐	☐
h) The donor family remembrance pin	☐	☐	☐	☐	☐
i) Resources and Assistance leaflet	☐	☐	☐	☐	☐

61. Please provide your feedback on the resources you received including content, style and presentation of resources. ✍

____

____

62. On reflection, do you feel the level of contact you have had with DonateLife agency staff to date has been …..? *(Please tick ☑ one box only)*

Too much ☐ 1   Not enough ☐ 2   Just right ☐ 3

63. What other services could be offered to better support family members? ✍

____

____

Your feelings about organ and tissue donation

64. Has donation provided you with any comfort in your loss? *(Please tick ☑ one box only)*

Yes, a great deal of comfort ☐ 1
Yes, some comfort ☐ 2
No ☐ 3 → ***GO TO Q67***

Page 11 of 14

Donor Family Study (Wave 2, 3 and 4)
Master Version 4: 10/03/2016

65. When have you found comfort in the donation? *(You may tick ☑ as many boxes as applicable)*

At the time of donation	☐ 1
When you received the letter from the donation agency	☐ 2
A few months after your family member’ s death	☐ 3
About a year after your family member’s death	☐ 4
More than a year after your family member’s death	☐ 5
When you received a letter from the transplant recipient (if applicable)	☐ 6

66. In what way did donation comfort you? *(You may tick ☑ as many boxes as applicable)*

Helped me in my grief	☐ 1
Helped my family discuss the death of our loved one	☐ 2
Provided meaning to me	☐ 3
Changed my values	☐ 4
In another way *(please specify __________________________________)*	☐ 9

67. After this experience, would you donate your own organs and/or tissues? *(Please tick ☑ one box only)*

Yes	☐ 1	→ ***GO TO Q69***
No	☐ 2	
Undecided	☐ 3	

68. Please share your reasons for feeling this way. ✍

____

____

Contact with recipients

69. Have you received any correspondence from one or more of the transplant recipients? *(Please tick ☑ one box only)*

Yes, from one recipient	☐ 1	
Yes, from more than one recipient	☐ 2	
No, I chose not to receive any correspondence	☐ 3	→ ***GO TO Q71***
No, even though I chose to receive correspondence	☐ 4	→ ***GO TO Q71***
No, transplantation did not proceed	☐ 5	→ ***GO TO Q71***

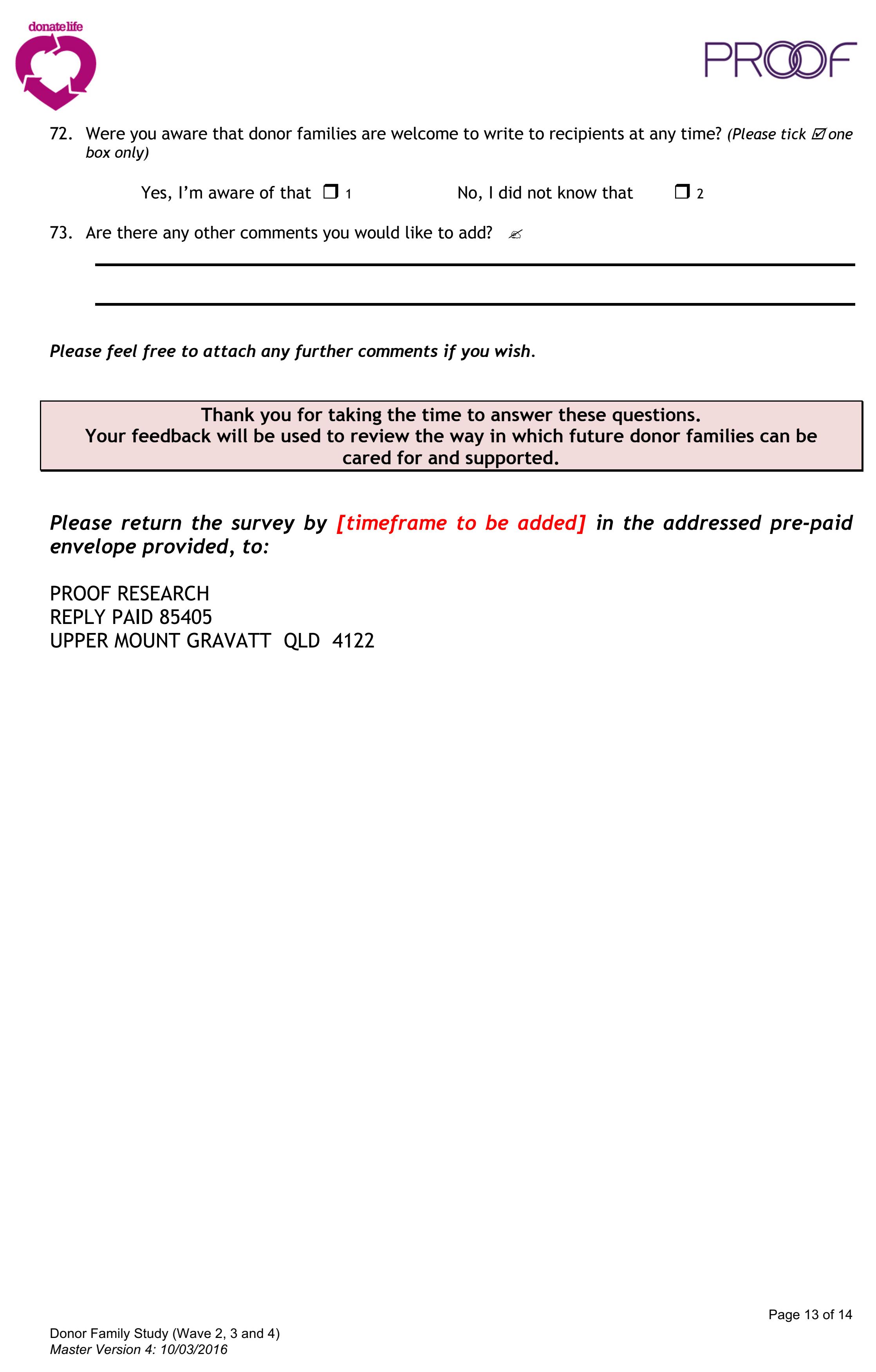
70. Was this correspondence …..? *(Please tick ☑ one box only)*

Of great comfort to you	☐ 1
Of some comfort to you	☐ 2
Of no comfort to you	☐ 3

71. **If you answered ‘no’ to Q69.** How do you feel about not receiving any correspondence from the transplant recipients to date? ✍

____

____



72. Were you aware that donor families are welcome to write to recipients at any time? *(Please tick ☑ one box only)*

Yes, I'm aware of that ☐ 1   No, I did not know that ☐ 2

73. Are there any other comments you would like to add? ✍

____

____

Please feel free to attach any further comments if you wish.

Thank you for taking the time to answer these questions.
Your feedback will be used to review the way in which future donor families can be cared for and supported.

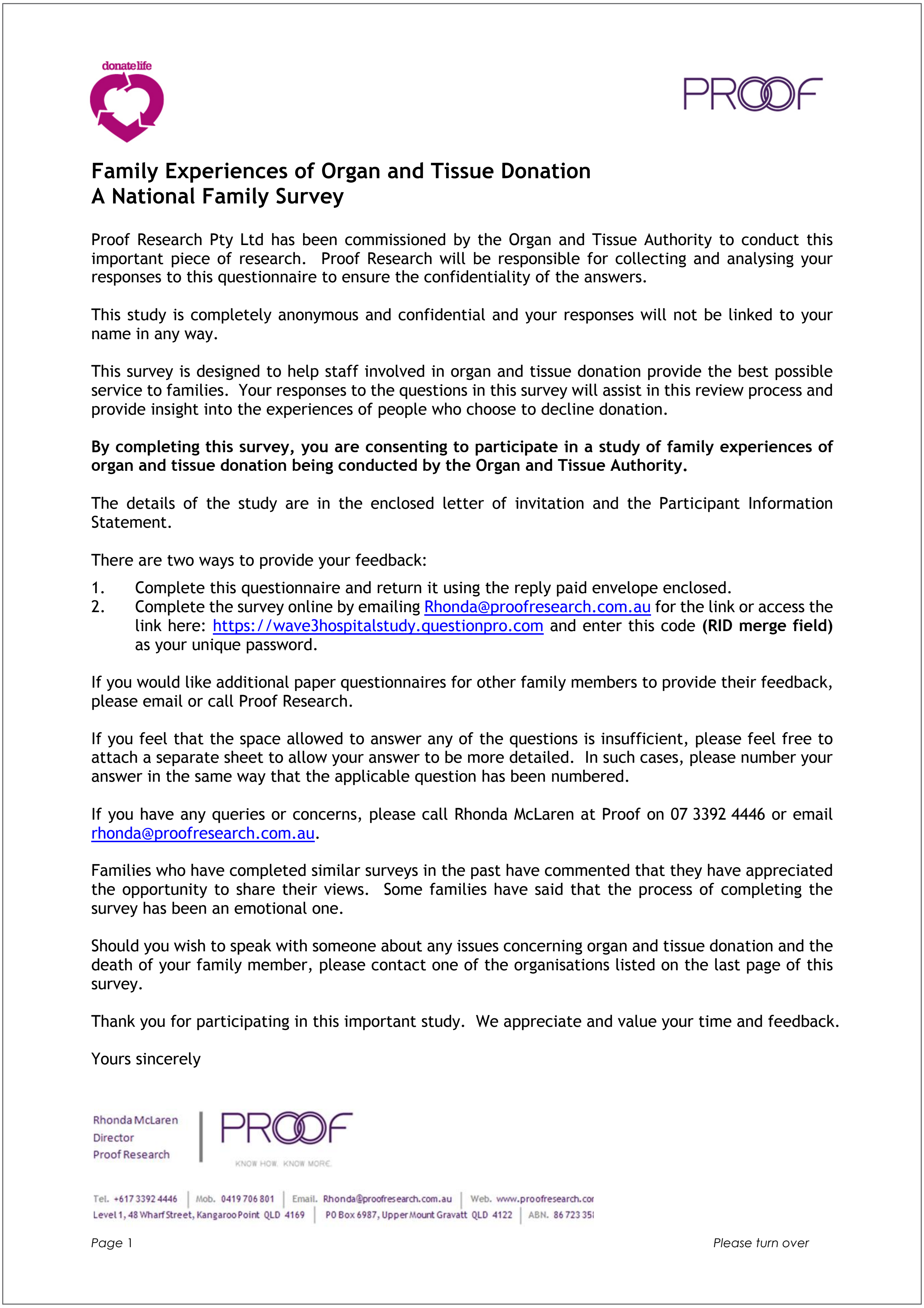
Please return the survey by [timeframe to be added] in the addressed pre-paid envelope provided, to:

PROOF RESEARCH
REPLY PAID 85405
UPPER MOUNT GRAVATT QLD 4122

If you would like to speak with someone about the survey, or any other issues concerning organ and tissue donation and the death of your relative, please contact:

NSW:	***DonateLife NSW*** Alison Barnwell 02 8566 1705
ACT:	***DonateLife ACT*** Sean Dicks 02 6174 5625
NT:	***DonateLife NT*** Andrea James 08 8944 1396
QLD:	***DonateLife Qld*** Diane Murphy 07 3176 2350
SA:	***DonateLife SA*** Lesley Sheffield 08 8207 7117
VIC:	***DonateLife Vic*** Michelle Skinner 03 8317 7411
TAS:	***DonateLife Tas*** Verity Shugg 03 6222 7806
WA:	***DonateLife WA*** David Easton 08 9222 8557
NATIONAL:	***Lifeline 24hr Crisis*** 13 11 14

A4.2 Questionnaire – Families who declined donation



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Family Experiences of Organ and Tissue Donation
A National Family Survey

Proof Research Pty Ltd has been commissioned by the Organ and Tissue Authority to conduct this important piece of research. Proof Research will be responsible for collecting and analysing your responses to this questionnaire to ensure the confidentiality of the answers.

This study is completely anonymous and confidential and your responses will not be linked to your name in any way.

This survey is designed to help staff involved in organ and tissue donation provide the best possible service to families. Your responses to the questions in this survey will assist in this review process and provide insight into the experiences of people who choose to decline donation.

By completing this survey, you are consenting to participate in a study of family experiences of organ and tissue donation being conducted by the Organ and Tissue Authority.

The details of the study are in the enclosed letter of invitation and the Participant Information Statement.

There are two ways to provide your feedback:

1. Complete this questionnaire and return it using the reply paid envelope enclosed.
2. Complete the survey online by emailing Rhonda@proofresearch.com.au for the link or access the link here: https://wave3hospitalstudy.questionpro.com and enter this code **(RID merge field)** as your unique password.

If you would like additional paper questionnaires for other family members to provide their feedback, please email or call Proof Research.

If you feel that the space allowed to answer any of the questions is insufficient, please feel free to attach a separate sheet to allow your answer to be more detailed. In such cases, please number your answer in the same way that the applicable question has been numbered.

If you have any queries or concerns, please call Rhonda McLaren at Proof on 07 3392 4446 or email rhonda@proofresearch.com.au.

Families who have completed similar surveys in the past have commented that they have appreciated the opportunity to share their views. Some families have said that the process of completing the survey has been an emotional one.

Should you wish to speak with someone about any issues concerning organ and tissue donation and the death of your family member, please contact one of the organisations listed on the last page of this survey.

Thank you for participating in this important study. We appreciate and value your time and feedback.

Yours sincerely

Rhonda McLaren
Director
Proof Research

PROOF
KNOW HOW. KNOW MORE.

Tel. +617 3392 4446 | Mob. 0419 706 801 | Email. Rhonda@proofresearch.com.au | Web. www.proofresearch.co
Level 1, 48 Wharf Street, Kangaroo Point QLD 4169 | PO Box 6987, Upper Mount Gravatt QLD 4122 | ABN. 86 723 35

Page 1 *Please turn over*

SECTION 1 – YOUR FAMILY MEMBER AND THE DECISION TO DECLINE DONATION

Information about your family and the family member who died in hospital

1. What relationship are you to the person who died in hospital? Are you their …. *(Please tick ☑ one box only)*

Parent/ guardian ☐ 1
Wife/ husband/ partner ☐ 2
Daughter/ son ☐ 3
Brother/ sister ☐ 4
Other *(please specify)* ________________________ ☐ 5

2. Was your family member of Aboriginal or Torres Strait Islander descent?

Aboriginal ☐ 1
Torres Strait Islander ☐ 2
Neither ☐ 3

3. Did your family member speak a language other than English at home??

No ☐ 1
Yes ☐ 2 ⟶ Which language? ______________________________

4. How old was your family member when he/ she died? _________ years

5. When did your family member die? __________________ month _________ year

6. In which state or territory did your family member die? *(Please tick ☑ one box only)*

Queensland ☐ 1
ACT ☐ 2
New South Wales ☐ 3
Victoria ☐ 4
Tasmania ☐ 5
South Australia ☐ 6
Northern Territory ☐ 7
Western Australia ☐ 8

7. Prior to your family member's death, how would you describe your own views about organ and tissue donation? *(Please tick ☑ one box only)*

Generally positive ☐ 1
Generally negative ☐ 2
Mixed feelings ☐ 3

8. Had you discussed donation with your family member, no matter how brief, at any time prior to being asked to consider donation? *(Please tick ☑ one box only)*

Yes, we discussed it and I knew his/her wishes ☐ 1
Yes, we discussed it but no clear decision was made ☐ 2
No, we did not discuss the subject ☐ 3

9. To what extent did knowing or not knowing the wishes of your family member impact on your decision to decline donation? *(Please tick ☑ one box only)*

It made our decision a lot easier ☐ 1
It made our decision a bit easier ☐ 2
It did not impact on our decision ☐ 3
It made our decision a bit more difficult ☐ 4
It made our decision a lot more difficult ☐ 5

10. In what way did this impact on your decision to decline donation?

____

____

11. What were the main reasons you decided to decline donation? *(You may select as many as you like and add your own comments if you wish)*

I didn't know what he/she would have wanted ☐ 1
He/she didn't want to donate ☐ 2
I don't like the idea of donation ☐ 3
He/ she had been through enough ☐ 4
I didn't accept his/her death and couldn't agree to donation ☐ 5
I wasn't happy with the care ☐ 6
Donation was going to take too long and I couldn't wait ☐ 7
I declined donation because it is against my religion ☐ 8
I declined donation because it is against my culture ☐ 9
I didn't want him/her to have surgery for donation ☐ 10
I wanted the donated organs to go to specific people ☐ 11
I didn't have enough information about what was involved with donation ☐ 12
Another reason (✍____) ☐ 13

12. Now that some time has passed, how would you describe your level of comfort with your decision? *(Please tick ☑ one box only)*

Very comfortable ☐ 1 → ***GO TO Q14***
Somewhat comfortable ☐ 2
Somewhat uncomfortable ☐ 3
Very uncomfortable ☐ 4

13. Please explain why you are not entirely comfortable with your decision. ✍

____

____

14. Is there anything else you would like to add about your decision to decline donation? ✍

____

____

____

SECTION 2 – AT THE HOSPITAL

These questions will help us to understand your experiences at the hospital prior to being asked to consider donation

15. During the time your family member was in the Intensive Care Unit or the Emergency Department, did the hospital staff make it clear that his/ her condition was critical and that he/ she may not survive? *(Please tick ☑ one box only)*

    Yes ☐ 1 No ☐ 2 Not sure ☐ 3

16. To what extent do you feel the staff in the Intensive Care Unit/Emergency Department treated you with consideration and sensitivity <u>at this time</u>? *(Please tick ☑ one box only)*

    To a great extent ☐ 1
    To some extent ☐ 2
    Not at all ☐ 3

17. Please add any other comments you wish to make about your time at the hospital. ✍

18. Depending on the individual circumstances of your family member, medical staff may have discussed with you either testing for brain death or turning off the ventilator. Thinking back to that time, do you agree or disagree with each of the following statements? *(Please tick ☑ one box only for each statement)*

	Strongly agree 3	**Somewhat agree** 2	**Disagree** 1	**Not sure** 9
a) I was given sufficient information to fully understand that death was expected	☐	☐	☐	☐
b) The language used by medical staff was clear and easy to understand	☐	☐	☐	☐
c) Medical staff treated me with compassion and sensitivity at this time	☐	☐	☐	☐
d) Medical staff treated my family member with respect	☐	☐	☐	☐
e) I had sufficient opportunity to ask questions of medical staff at this time	☐	☐	☐	☐

19. Did you feel you had enough private time with your family member after receiving this news? *(Please tick ☑ one box only)*

    Yes ☐ 1 No ☐ 2 Not sure ☐ 3

20. Overall, how could your experience at the hospital at this time have been made easier for you and your family? ✍

Please only answer Q21-25 if brain death testing occurred in your experience

21. Were you offered to be present during the brain death testing? *(Please tick ☑ one box only)*

Yes	☐ 1	
No	☐ 2	→ ***GO TO Q24***
Not sure	☐ 3	→ ***GO TO Q24***

22. **If you answered 'yes' at Q21.** Did you choose to be present during the brain death testing? *(Please tick ☑ one box only)*

Yes	☐ 1	
No	☐ 2	→ ***GO TO Q25***

23. **If you answered 'yes' at Q21.** Did seeing the testing help you to understand that your family member had died? *(Please tick ☑ one box only)*

Yes	☐ 1	→ ***GO TO Q25***
No	☐ 2	→ ***GO TO Q25***
Not sure	☐ 3	→ ***GO TO Q25***

24. **If you answered 'no' or 'not sure' to Q21.** Would it have helped you to have the option of being present during the brain death testing?

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

25. Would you like to add anything else about the process of brain death testing? ✍

____

____

SECTION 3 - DISCUSSING ORGAN AND TISSUE DONATION

The following questions will help us to understand the way in which donation is discussed with families

26. Who first mentioned the possibility of donation to you at the hospital?

Doctor	☐ 1	→ ***CONTINUE***
Nurse	☐ 2	→ ***CONTINUE***
DonateLife coordinator	☐ 3	→ ***CONTINUE***
Family member/ close friend	☐ 4	→ ***GO TO Q31***
Other person *(Relationship to you:* ____________________*)*	☐ 5	→ ***GO TO Q31***
I raised it myself	☐ 6	→ ***GO TO Q31***
Can't remember	☐ 9	→ ***CONTINUE***

Donor Family Study (Wave 2, 3 and 4)
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27. When was donation <u>first</u> raised with you? *(Please tick ☑ one box only)*

Before I was told of my family member's death or expected death	☐ 1
At the same time as I was told of my family member's death or expected death	☐ 2
Within an hour of being told of my family member's death or expected death	☐ 3
More than 1 hour after being told of my family member's brain death or expected death	☐ 4
Can't remember	☐ 9

28. Do you think this timing was appropriate? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

29. Is there anything else you would like to add about the timing? ✍

____

____

____

30. If donation was first raised by a hospital staff member and <u>not</u> a family member, how did that make you feel? (*You may select as many as you like*).

It added to my family's distress	☐ 1
My reaction would have been the same, irrespective of who first mentioned it	☐ 2
It was preferable coming from a hospital staff member first	☐ 3
We expected to be asked about donation	☐ 4

31. Thinking back to the discussions you had with hospital staff about donation <u>prior to your decision</u>, how strongly do you agree or disagree with each of the following statements? *(Please tick ☑ one box only for each statement)*

	Strongly agree 3	**Somewhat agree** 2	**Disagree** 1	**Not sure** 9
a) The discussions about donation were handled sensitively and with compassion	☐	☐	☐	☐
b) My family had enough opportunities to ask questions of hospital staff about donation	☐	☐	☐	☐
c) Hospital staff answered our questions	☐	☐	☐	☐
d) We were given sufficient information to allow us to make an informed decision	☐	☐	☐	☐
e) My family was given enough time to discuss donation and to make our decision	☐	☐	☐	☐

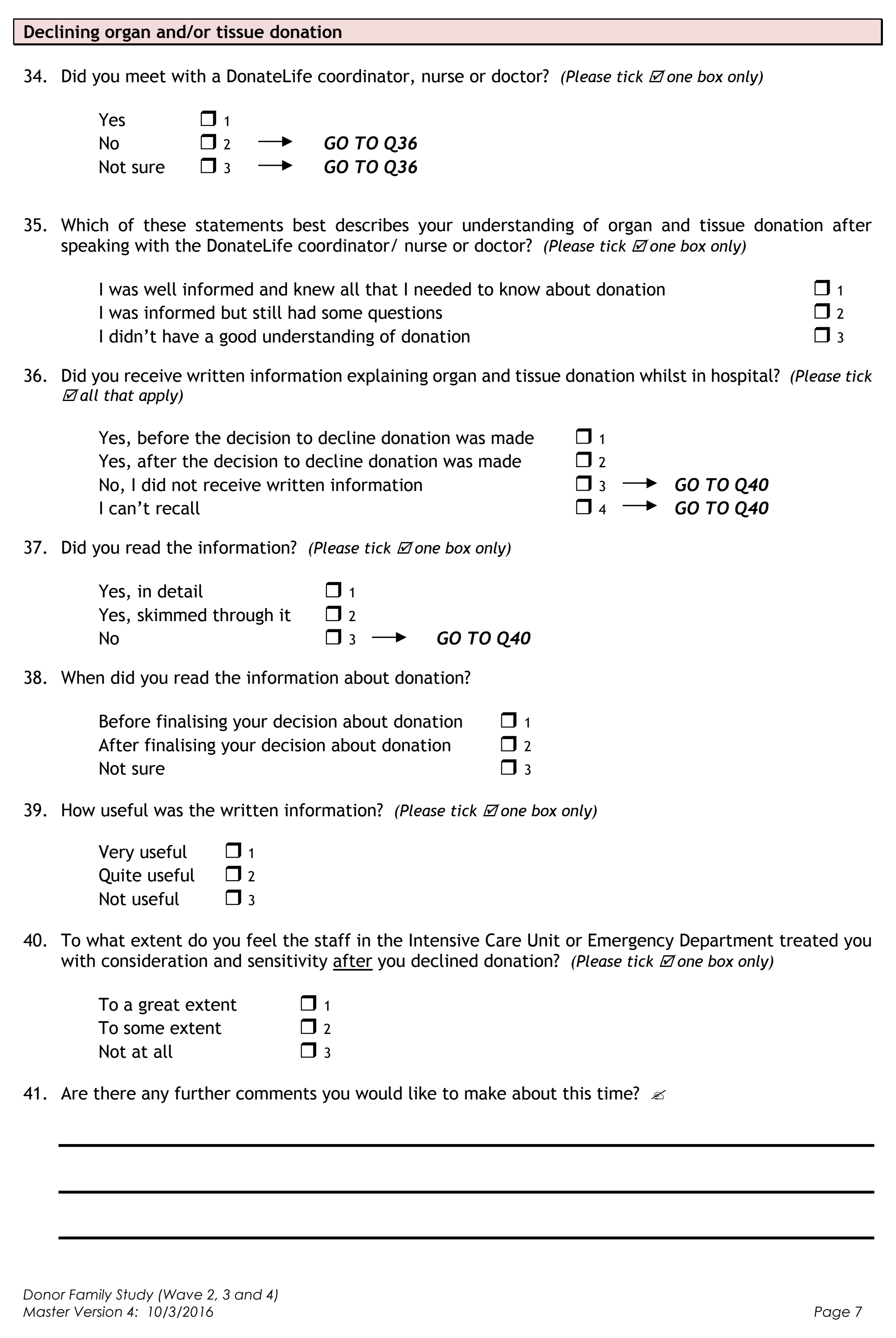
32. Did you feel rushed or pressured at any stage? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2 ⟶ ***GO TO Q34***
Not sure ☐ 3 ⟶ ***GO TO Q34***

33. In what way did you feel rushed or pressured?

____

____



Declining organ and/or tissue donation

34. Did you meet with a DonateLife coordinator, nurse or doctor? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2 → ***GO TO Q36***
Not sure ☐ 3 → ***GO TO Q36***

35. Which of these statements best describes your understanding of organ and tissue donation after speaking with the DonateLife coordinator/ nurse or doctor? *(Please tick ☑ one box only)*

I was well informed and knew all that I needed to know about donation ☐ 1
I was informed but still had some questions ☐ 2
I didn't have a good understanding of donation ☐ 3

36. Did you receive written information explaining organ and tissue donation whilst in hospital? *(Please tick ☑ all that apply)*

Yes, before the decision to decline donation was made ☐ 1
Yes, after the decision to decline donation was made ☐ 2
No, I did not receive written information ☐ 3 → ***GO TO Q40***
I can't recall ☐ 4 → ***GO TO Q40***

37. Did you read the information? *(Please tick ☑ one box only)*

Yes, in detail ☐ 1
Yes, skimmed through it ☐ 2
No ☐ 3 → ***GO TO Q40***

38. When did you read the information about donation?

Before finalising your decision about donation ☐ 1
After finalising your decision about donation ☐ 2
Not sure ☐ 3

39. How useful was the written information? *(Please tick ☑ one box only)*

Very useful ☐ 1
Quite useful ☐ 2
Not useful ☐ 3

40. To what extent do you feel the staff in the Intensive Care Unit or Emergency Department treated you with consideration and sensitivity <u>after</u> you declined donation? *(Please tick ☑ one box only)*

To a great extent ☐ 1
To some extent ☐ 2
Not at all ☐ 3

41. Are there any further comments you would like to make about this time? ✍

42. Were you offered the support of a social worker, counsellor or chaplain at any time during your family member's stay in hospital? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2 → Would you have liked to be offered this support? Yes ☐ 1 No ☐ 2
Not sure ☐ 3

43. How could the way in which donation was discussed with you at the hospital have been improved? ✍

____

____

____

SECTION 4 - FOLLOW UP SERVICES

Follow up services from the hospital and the organ and tissue donation agencies

44. Were you offered any ongoing contact with staff from the hospital or organ and tissue donation agency, for example, a social worker, chaplain or organ donor agency? *(Please tick ☑ one box only)*

Yes ☐ 1 → ***GO TO Q46***
No ☐ 2
Not sure ☐ 3

45. **If you answered 'no' or 'not sure' to Q44.** Would you have liked somebody to contact you? ✍

Yes ☐ 1 }
No ☐ 2 } ***GO TO Q49***
Not sure ☐ 3 }

46. **If you answered 'yes' to Q44.** From whom did you receive contact? *(Please tick ☑ all that apply)*

Social worker ☐ 1
DonateLife coordinator, nurse or doctor ☐ 2
Hospital Chaplain ☐ 3
DonateLife Donor Family Support Coordinator ☐ 4
Other (______________________) ☐ 5

47. To what extent did you find this contact helpful? *(Please tick ☑ one box only)*

To a great extent ☐ 1
To some extent ☐ 2
Not at all ☐ 3 → Why? ______________________________ → ***GO TO Q49***

48. In what way was the contact helpful? ✍

____

____

49. To help hospitals and organ and tissue donation agencies provide the best service, which of the following services, if any, would you have found helpful? *(Please tick ☑ all that apply)*

A follow up phone call from the DonateLife agency	☐ 1
Information about bereavement support services	☐ 2

50. What other services do you feel could be offered to better support family members? ✍

Your feelings about organ and tissue donation

51. On reflection, would you make the same decision now? *(Please tick ☑ one box only)*

Yes ☐ 1 No ☐ 2 Not sure ☐ 3

52. Is there anything else you would like to share about your decision? ✍

53. In your view as someone who has experienced the loss of a family member and been asked to consider donation, what would help other people in the same situation?

Please feel free to attach any further comments if you wish.

Thank you for taking the time to answer these questions.
Your feedback will be used to review the way in which future donor families can be cared for and supported.

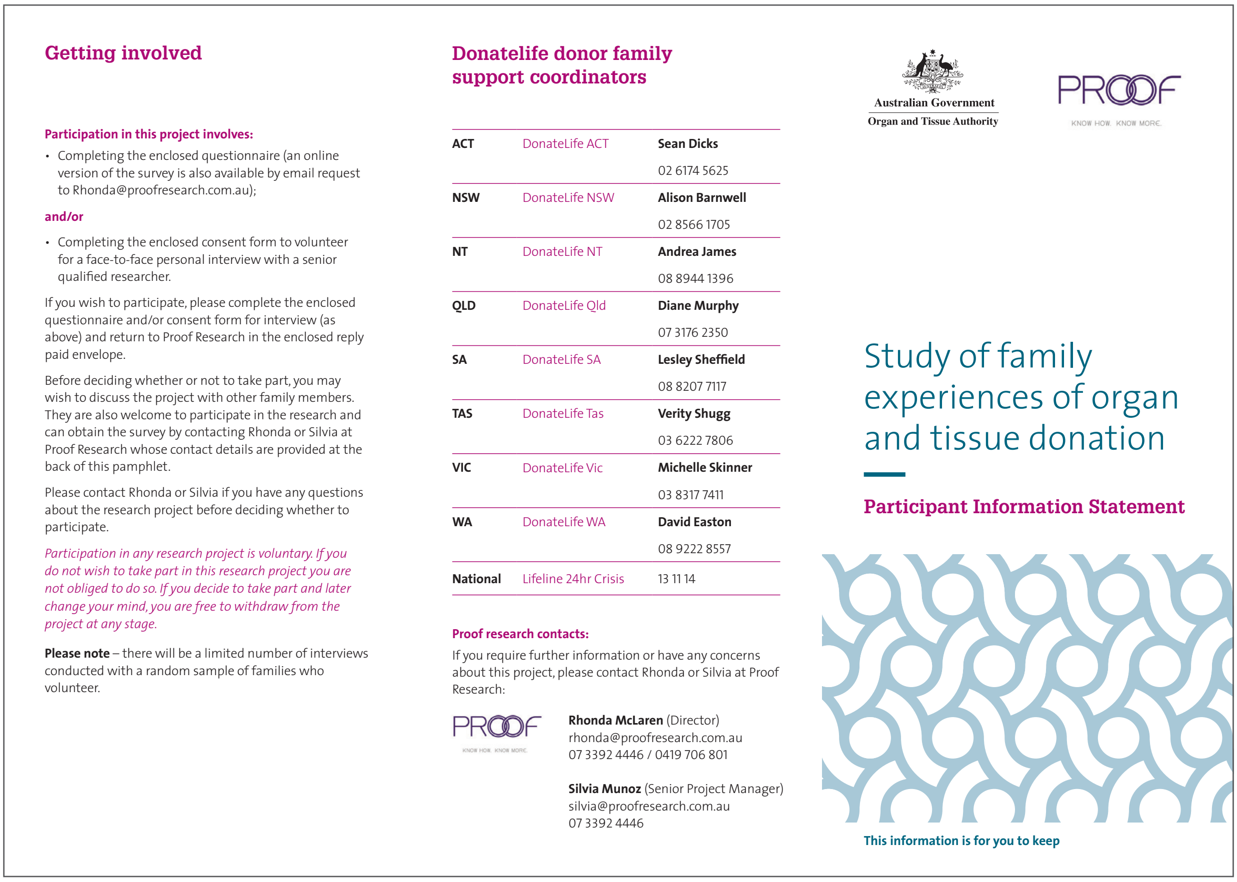
Please return the survey by [add timeframe] in the addressed pre-paid envelope provided, to:

PROOF RESEARCH
REPLY PAID 85405
UPPER MT GRAVATT QLD 4122

If you would like to speak with someone about the survey, or any other issues concerning organ and tissue donation and the death of your relative, please contact:

NSW:	***DonateLife NSW*** Alison Barnwell 02 8566 1705
ACT:	***DonateLife ACT*** Sean Dicks 02 6174 5625
NT:	***DonateLife NT*** Andrea James 08 8944 1396
QLD:	***DonateLife Qld*** Diane Murphy 07 3176 2350
SA:	***DonateLife SA*** Lesley Sheffield 08 8207 7117
VIC:	***DonateLife Vic*** Michelle Skinner 03 8317 7411
TAS:	***DonateLife Tas*** Verity Shugg 03 6222 7806
WA:	***DonateLife WA*** David Easton 08 9222 8557
NATIONAL:	***Lifeline 24hr Crisis*** 13 11 14

A4.3 Participant information statement



Getting involved

Participation in this project involves:

- Completing the enclosed questionnaire (an online version of the survey is also available by email request to Rhonda@proofresearch.com.au);

and/or

- Completing the enclosed consent form to volunteer for a face-to-face personal interview with a senior qualified researcher.

If you wish to participate, please complete the enclosed questionnaire and/or consent form for interview (as above) and return to Proof Research in the enclosed reply paid envelope.

Before deciding whether or not to take part, you may wish to discuss the project with other family members. They are also welcome to participate in the research and can obtain the survey by contacting Rhonda or Silvia at Proof Research whose contact details are provided at the back of this pamphlet.

Please contact Rhonda or Silvia if you have any questions about the research project before deciding whether to participate.

Participation in any research project is voluntary. If you do not wish to take part in this research project you are not obliged to do so. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Please note – there will be a limited number of interviews conducted with a random sample of families who volunteer.

Donatelife donor family support coordinators

ACT	DonateLife ACT	**Sean Dicks** 02 6174 5625
NSW	DonateLife NSW	**Alison Barnwell** 02 8566 1705
NT	DonateLife NT	**Andrea James** 08 8944 1396
QLD	DonateLife Qld	**Diane Murphy** 07 3176 2350
SA	DonateLife SA	**Lesley Sheffield** 08 8207 7117
TAS	DonateLife Tas	**Verity Shugg** 03 6222 7806
VIC	DonateLife Vic	**Michelle Skinner** 03 8317 7411
WA	DonateLife WA	**David Easton** 08 9222 8557
National	Lifeline 24hr Crisis	13 11 14

Proof research contacts:

If you require further information or have any concerns about this project, please contact Rhonda or Silvia at Proof Research:

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Rhonda McLaren (Director)
rhonda@proofresearch.com.au
07 3392 4446 / 0419 706 801

Silvia Munoz (Senior Project Manager)
silvia@proofresearch.com.au
07 3392 4446

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Study of family experiences of organ and tissue donation

Participant Information Statement

This information is for you to keep

Participant Information

About The Project

The project is a national survey with families across Australia who have consented to or declined organ and/or tissue donation in a hospital setting. The research aims to capture the experiences of families during conversations about the death of a family member and the potential for organ and tissue donation. The research seeks to obtain feedback on the support services provided to families throughout the donation process and following donation.

The Organ and Tissue Authority has commissioned Proof Research Pty Ltd for this important research project which is being conducted as part of the Australian Government's National Reform Programme to create a nationally consistent and coordinated approach to organ and tissue donation for transplantation.

The Organ and Tissue Authority is committed to the ongoing improvement of support services available to families. This study is therefore important to determine if current processes and mechanisms are supporting families, and to identify what aspects of services need to be improved.

Families in Australia who made a decision about organ and tissue donation during 2012 and 2013 in a hospital setting are invited to participate in this research project. This invitation is offered equally to families that agreed to donation and families that declined donation.

Participation is voluntary.

Why Participate?

This research provides families with an opportunity to share their experiences and provide feedback about services they found beneficial and those that were not beneficial and could be improved upon, or other services that could be introduced.

The findings will be used to address gaps and improve donor family support services and professional practice. Your contribution will help to improve these important and sensitive services for other families faced with decisions concerning organ and tissue donation in the future.

Factors To Consider

Many families in the past who have participated in the national survey have commented that they have appreciated the opportunity to share their views. Some have said that the process of completing the survey was an emotional one.

We understand that participation in the research may cause some individuals emotional distress when recalling experiences. Throughout any time in the research, should you wish to speak with someone about any issues concerning organ and tissue donation and the death of your family member, please contact the DonateLife Donor Family Support Coordinator in your State or Territory (details listed on the back of brochure).

Lifeline contacts are also provided if you prefer not to contact DonateLife and wish to speak with someone about feelings of loss and grief.

Confidentiality

Information collected from this survey will be non-identifiable (meaning your responses will not be linked to your name) and kept confidential. It will only be disclosed with your permission, except as required by law.

To maximise confidentiality:

- Unique ID codes will be used to code and track questionnaire completions, maximising anonymity of your responses and data confidentiality protocols.
- All data collected will be non-identifiable. Personal details including your name will not be asked or collected in the questionnaire.

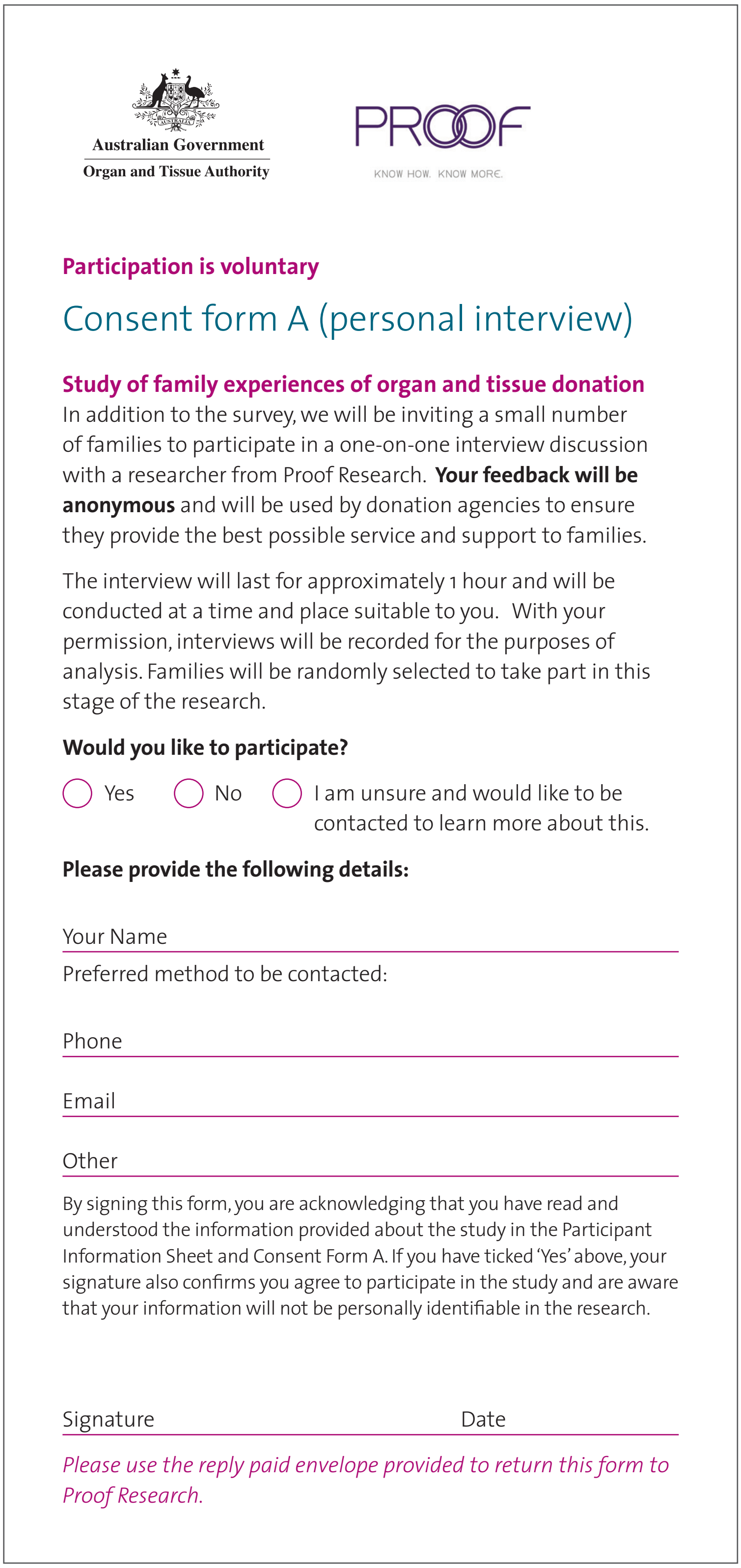
Proof Research will be responsible for collecting and analysing your responses. If any information is published as a result of this research, your feedback will be provided in such a way that you cannot be identified.

If you have any comments or complaints about any aspect of the project, such as the way it is being conducted or any questions about your rights as a research participant, you may contact Eva Mehakovic at the Organ and Tissue Authority by email to eva.mehakovic@donatelife.gov.au or by phoning (02) 6198 9881.

Ethics

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) as issued by the National Health and Medical Research Council. The National Statement provides the guidelines by which the Departmental Ethics Committee and other Human Research Ethics Committees operate. The ethical aspects of this research project have been approved by a number of Ethics Committees across Australia.

A4.4 Consent form



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Participation is voluntary

Consent form A (personal interview)

Study of family experiences of organ and tissue donation
In addition to the survey, we will be inviting a small number of families to participate in a one-on-one interview discussion with a researcher from Proof Research. **Your feedback will be anonymous** and will be used by donation agencies to ensure they provide the best possible service and support to families.

The interview will last for approximately 1 hour and will be conducted at a time and place suitable to you. With your permission, interviews will be recorded for the purposes of analysis. Families will be randomly selected to take part in this stage of the research.

Would you like to participate?

○ Yes ○ No ○ I am unsure and would like to be contacted to learn more about this.

Please provide the following details:

Your Name ______________________________

Preferred method to be contacted:

Phone ______________________________

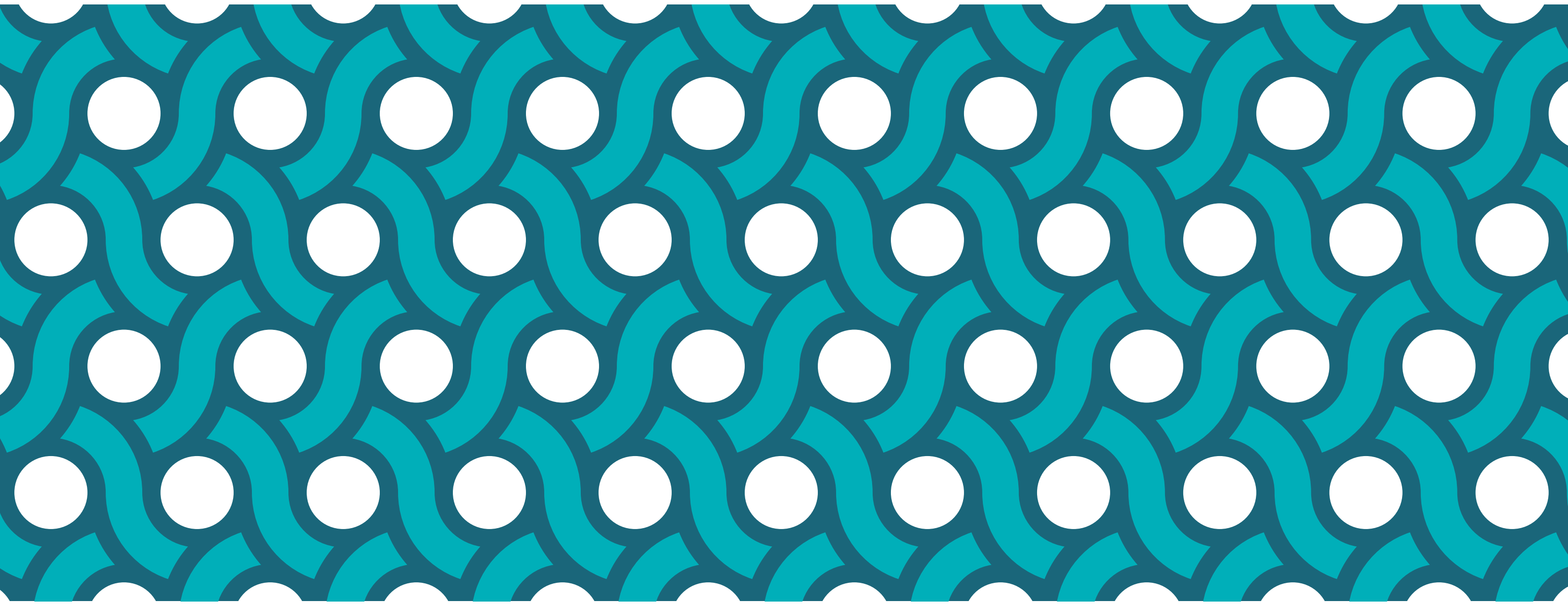
Email ______________________________

Other ______________________________

By signing this form, you are acknowledging that you have read and understood the information provided about the study in the Participant Information Sheet and Consent Form A. If you have ticked 'Yes' above, your signature also confirms you agree to participate in the study and are aware that your information will not be personally identifiable in the research.

Signature ____________________ Date ____________

Please use the reply paid envelope provided to return this form to Proof Research.



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