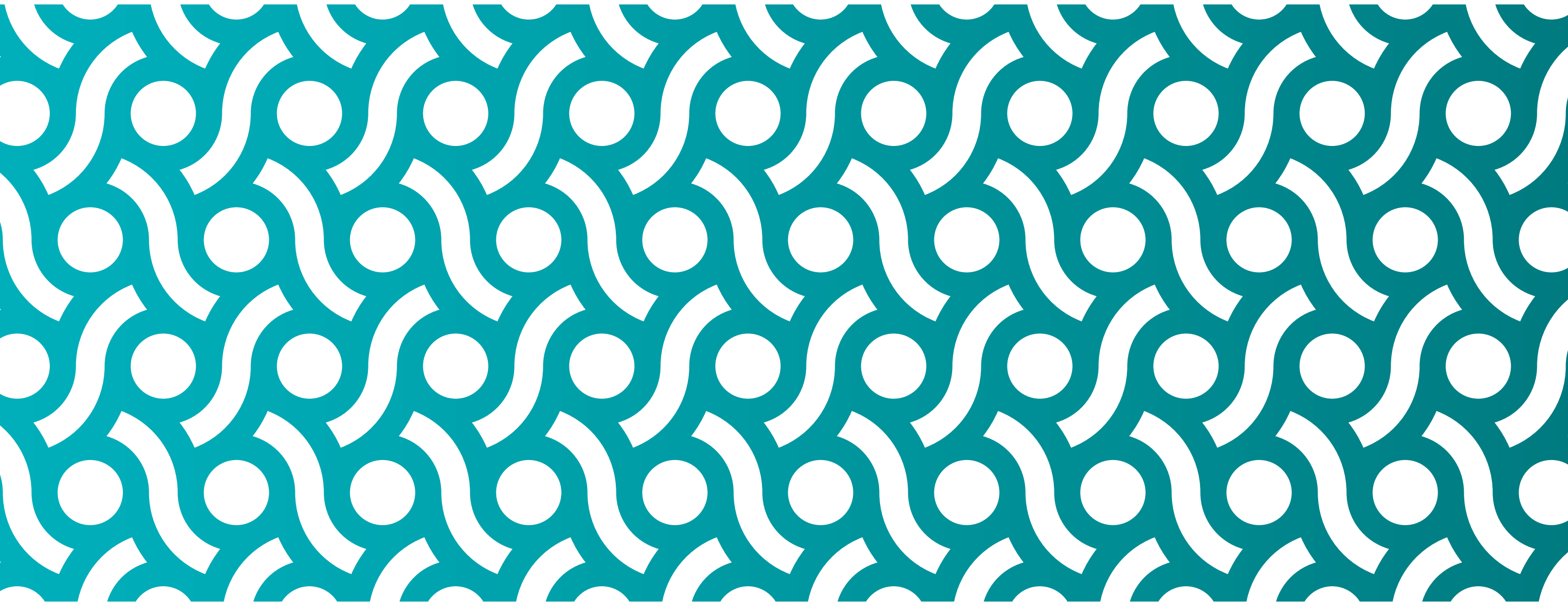
National Study of Family Experiences of Organ and Tissue Donation

Wave 4

Experiences in 2016 and 2017 – Research Report



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Executive Summary

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

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

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

Impact of prior knowledge

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

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

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

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

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

Personal views of donation

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

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

Motivations and barriers to donation

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

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

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

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

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

Interaction with ICU/ED staff

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

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

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

Brain death testing

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

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

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

Improving the hospital experience

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

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

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

The donation conversation

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

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

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

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

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

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

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

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

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

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

The donation process

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

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

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

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

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

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

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

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

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

> **The research found that the following can reduce the distress of family members between the time of consenting to donation and donation surgery:**
>
> **— Being kept informed about timeframes**
>
> **— Allowing private time with their loved one**
>
> **— Health professionals continuing to care for their loved one with respect**
>
> **— Being shielded from witnessing procedures that directly relate to surgery**

When the theatre doors close

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

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

Follow-up services and DonateLife resources

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

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

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

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

Correspondence with recipients

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

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

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

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

On reflection

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

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

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

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

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

Part A – Research overview

1 Research background

The Organ and Tissue Authority (OTA) funds Proof Research to independently conduct 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 donation.

The insights gained from surveys and conversations with donor 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 to determine how the needs of families can best be met.

This report details findings of Wave 4 of the Donor Family Study. Wave 4 represents families who made a decision about donation in 2016 and 2017, and compares findings with the previous waves of the Donor Family Study.

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.
- 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 decision and 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.

3 Research methodology

A mixed methodology comprising both quantitative and qualitative research was used to address the overall aim and objectives of the national study.

The program involved four key stages:

Stage 1 Review of research instruments and documents

Stage 2 Human Research Ethics Committee (HREC) and Research Governance (RG) submission and approval process

Stage 3 Fieldwork – quantitative and qualitative research

Stage 4 Analysis and reporting

3.1 Stage 1: Review of research instruments and documents

Wave 4 of the Donor Family Study was treated as an extension of earlier waves, with minor amendments made to the survey instruments, as required.

A list of the HREC approved study documents is shown 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 OTA
- Participant Information Statement (PIS)
- 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

3.2 Stage 2: HREC and Research Governance submission process

Approval to conduct Wave 4 of the Donor Family Study was granted by the Human Research Ethics Committees (HRECs) shown in Table 1. Whilst approval to conduct Waves 2, 3 and 4 of the study was in place, amendment requests were submitted for minor changes to the study documents. These changes were administrative only and did not effect the content or intent of the documents.

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

State/territory	Human Research Ethics Committee	Approval date
ACT	ACT Health HREC	4 September 2018
NSW	South Eastern Sydney Local Health District HREC	9 October 2018
VIC	Austin Health HREC	3 September 2018
	Australian Red Cross Blood Service Ethics Committee	23 August 2018
TAS	University of Tasmania HREC (Tasmania) Network	22 August 2018
SA	SA Department for Health and Wellbeing HREC	2 November 2018
NT	Menzies School of Health Research	24 August 2018
	Central Australian HREC	7 November 2018
WA	Sir Charles Gairdner Group HREC	28 August 2018
	St John of God Health Care HREC	17 October 2018
QLD	Townsville Hospital and Health Service HREC	8 October 2018

Site specific applications were required to conduct the research with families who declined donation, as family contact details are held by the Hospital and Health Service/hospital and not by DonateLife. Approval to conduct Wave 4 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

State/territory	Research Governance Office	Approval date
ACT	ACT Health HREC (for Canberra Hospital)	4 September 2018
NSW	Northern NSW Local Health District	28 August 2018
	The Sydney Children's Hospitals Network	18 October 2018
	Illawarra Shoalhaven Local Health District	9 October 2018
	Northern Sydney Local Health District	7 November 2018
	Hunter New England Local Health District	29 October 2018
	Western Sydney Local Health District	17 October 2018
VIC	Peninsula Health	2 October 2018
	Ballarat Health Services	10 October 2018
	Northern Health	6 September 2018
	Austin Health	19 September 2018
	Eastern Health	3 September 2018
	Western Health	2 October 2018
	The Royal Children's Hospital Melbourne	2 October 2018
	St Vincent's Health	24 October 2018
	Melbourne Health	2 October 2018
	Monash Health	3 September 2018
TAS	Covered by HREC approval (for Royal Hobart Hospital, Launceston General Hospital, North West Regional Hospital)	22 August 2018

State/territory	Research Governance Office	Approval date
SA[1]	Northern Adelaide Local Health Network	8 November 2018
	Central Adelaide Local Health Network	30 November 2018
NT	Covered by HREC approval (for Royal Darwin Hospital)	24 August 2018 (Menzies) 7 November 2018 (CAHREC)
WA	North Metropolitan Health Service	28 August 2018
	St John of God Health Care	12 September 2018
	Child and Adolescent Health Service	28 August 2018
	South Metropolitan Health Service	18 September 2018
	East Metropolitan Health Service	28 August 2018
QLD	Gold Coast Hospital and Health Service	11 February 2019
	Metro South Hospital and Health Service	8 October 2018
	Townsville Hospital and Health Service	24 October 2018
	Metro North Hospital and Health Service	14 November 2018
	Sunshine Coast Hospital and Health Service	8 October 2018

[1] On 16 August 2019, Northern Adelaide Local Health Network and Central Adelaide Local Health Network advised that they would not be participating in Wave 4 of the Donor Family Study. Families who declined donation in South Australia during 2016 and 2017 were therefore unable to provide their feedback.

3.3 Stage 3: 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.

Many family members who completed the survey or took part in a personal interview expressed their thanks to the research team and to the Organ & Tissue Authority for allowing them to share their feedback.

> **Thank you for the opportunity to be part of this survey.”**
> 2016 – Declined donation

3.3.1 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 via Australia Post direct to families.

The survey packs contained:

- Introductory letter from the hospital (for families who declined donation)
- Introductory letter from OTA
- Participant Information Statement (PIS)
- Consent Form
- Questionnaire, enclosed in a sealed envelope
- 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. In all states and territories except South Australia, survey packs were distributed to families who consented to donation between 28 August 2018 and 26 September 2018. Reminder cards were distributed between 23 October 2018 and 13 November 2018. For families in South Australia, survey invitations were sent in line with receipt of the donor family database, on 11 February 2019 with reminders mailed on 1 April 2019.

For families who **declined donation**, the majority of survey packs were distributed between 20 August 2018 and 30 October 2018. However, due to the late receipt of databases, some declining family members received their survey packs between 4 June 2019 and 16 September 2019.

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

3.3.2 Qualitative fieldwork

In-depth interviews with families who agreed to participate in a personal interview were conducted by Proof Research. Interviews were conducted in person 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.

Interviews were conducted between 5 November 2018 and 4 October 2019. All family members interviewed gave permission for their interview to be audio recorded for transcription and analysis purposes.

Prior to each interview commencing, the offer of further support through a DonateLife Agency and Lifeline was made. There were no instances where the participant required intervention or requested further support.

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

3.4 Stage 4: Analysis and reporting

Quantitative fieldwork for families who **consented** to donation was completed in April 2019 while the fieldwork period for families who **declined** donation was completed in October 2019. Data from the questionnaires and online survey were then merged into one central file 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.

3.4.1 Analytical notes

In terms of 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 whole family unit rather than family members within that unit, this has been done and noted.
- Where possible, findings from Wave 4 are compared and contrasted against findings from Waves 1, 2 and 3.
- Throughout this report, statistically significant differences are noted for sub-groups of the sample with either 🟪 or 🟦 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 components 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 2016 and 2017 were invited to participate in Wave 4 of the Donor Family Study. 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=1,905 family members who consented to organ and tissue donation. Of these, 110 were returned to sender due to a change of address or the family member had died. This brought the total survey population to N=1,795. Of these, n=405 family members who consented to donation in 2016 or 2017 took part in Wave 4 of the Donor Family Study. This equates to an overall response rate of 22.6%, an improvement on Wave 3 (19.5%).

In terms of the qualitative research strand, 155 consenting donor family members agreed to participate in a personal interview. Of these, 24 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 distribution of the research sample with the distribution of the population of donor families, we see that the sample is in line with the population to within ± 5%.

As shown in the table, 405 individual family members took part in Wave 4 of the Donor Family Study. These individuals represent 348 unique donor families. Including members of the same donor family in the study is important as an individual family member's experience is unique and inclusion ensures that the full range of experiences is captured.

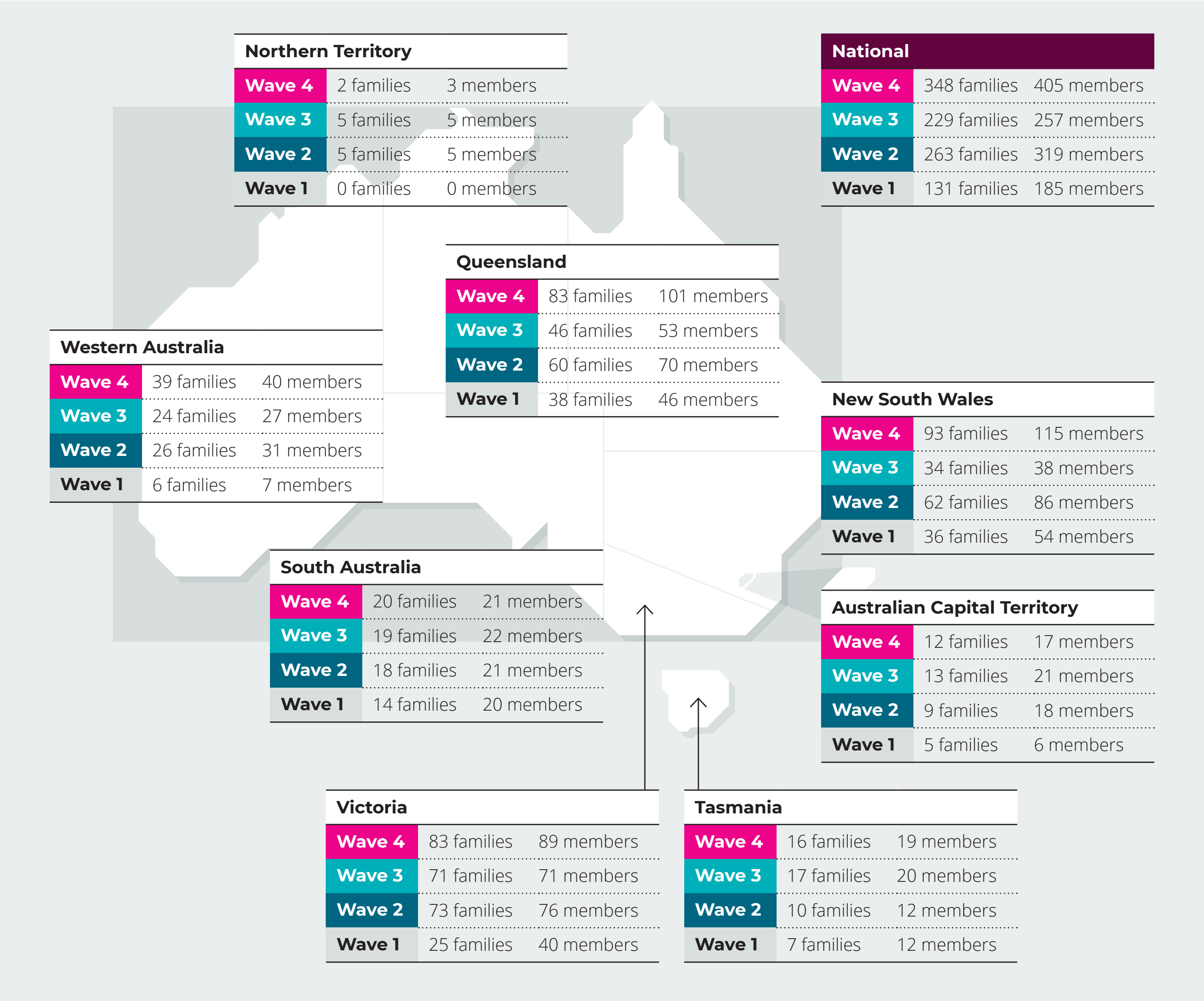
Table 3 Wave 4 – Quantitative sample distribution by state/territory (consenting strand)

	Target population		Participating sample		
State/ territory	**Consenting donor family members***	**% of national total**	**No. questionnaires completed**	**% of national sample**	**Response rate**
QLD	532	29.6%	101	24.9%	19.0%
NSW	443	24.7%	115	28.4%	26.0%
VIC	359	20.0%	89	22.0%	24.8%
WA	216	12.0%	40	9.9%	18.5%
ACT	104	5.8%	17	4.2%	16.3%
TAS	65	3.6%	19	4.7%	29.2%
SA	63	3.5%	21	5.2%	33.3%
NT	13	0.7%	3	0.7%	23.1%
Total	**1,795**	**100.0%**	**405**	**100.0%**	**22.6%**

* Excludes survey packs that were returned to sender

A comparison of the Wave 4 sample of individual family members and unique families is shown in Figure 1, together with the trend data from earlier waves.

Figure 1 Quantitative sample national breakdown



Northern Territory		
Wave 4	2 families	3 members
Wave 3	5 families	5 members
Wave 2	5 families	5 members
Wave 1	0 families	0 members

National		
Wave 4	348 families	405 members
Wave 3	229 families	257 members
Wave 2	263 families	319 members
Wave 1	131 families	185 members

Queensland		
Wave 4	83 families	101 members
Wave 3	46 families	53 members
Wave 2	60 families	70 members
Wave 1	38 families	46 members

Western Australia		
Wave 4	39 families	40 members
Wave 3	24 families	27 members
Wave 2	26 families	31 members
Wave 1	6 families	7 members

New South Wales		
Wave 4	93 families	115 members
Wave 3	34 families	38 members
Wave 2	62 families	86 members
Wave 1	36 families	54 members

South Australia		
Wave 4	20 families	21 members
Wave 3	19 families	22 members
Wave 2	18 families	21 members
Wave 1	14 families	20 members

Australian Capital Territory		
Wave 4	12 families	17 members
Wave 3	13 families	21 members
Wave 2	9 families	18 members
Wave 1	5 families	6 members

Victoria		
Wave 4	83 families	89 members
Wave 3	71 families	71 members
Wave 2	73 families	76 members
Wave 1	25 families	40 members

Tasmania		
Wave 4	16 families	19 members
Wave 3	17 families	20 members
Wave 2	10 families	12 members
Wave 1	7 families	12 members

4.3.2 Year of donation

In terms of the year-of-donation breakdown, 44% of donor families included in the Wave 4 research sample consented to donation in 2016; the remaining 56% in 2017 (Table 4).

Table 4 Total number of unique donor families by state/territory and year of donation across all waves of the study

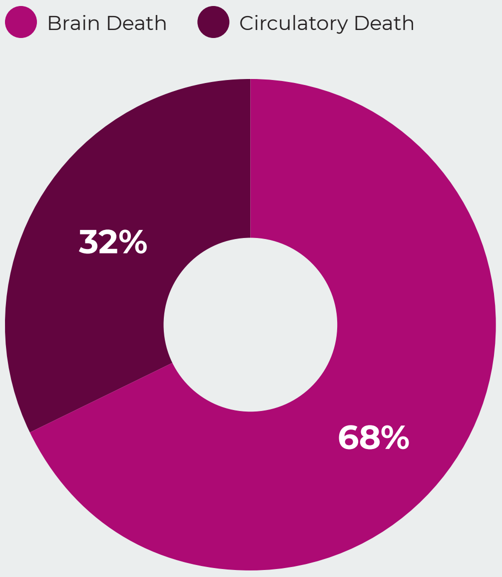
	Wave 1		Wave 2		Wave 3		Wave 4	
State/ territory	**2010** (n=54)	**2011** (n=77)	**2012** (n=123)	**2013** (n=140)	**2014** (n=102)	**2015** (n=127)	**2016** (n=153)	**2017** (n=195)
NSW	13	23	33	29	14	20	32	61
QLD	14	24	23	37	21	25	41	42
VIC	9	16	34	39	30	41	36	47
WA	4	2	13	13	8	16	19	20
ACT	2	3	6	3	7	6	7	5
TAS	4	3	5	5	10	7	6	10
SA	8	6	7	11	8	11	10	10
NT	0	0	2	3	4	1	2	–
Total	**54 (41%)**	**77 (59%)**	**123 (47%)**	**140 (53%)**	**102 (45%)**	**127 (55%)**	**153 (44%)**	**195 (56%)**

4.3.3 Donation pathway

There are two pathways to deceased donation: donation after brain death[1] (DBD) and donation after circulatory death[1] (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 2A, DBD comprises 68% of the Wave 4 sample, while DCD comprises 32%. However, the research indicates that many family members are unclear as to the donation pathway of their loved one and tend to assume DBD. For instance, 67 families reported a DBD pathway in the research when in fact it was DCD. Self-reported figures are shown in Figure 2B, tracked across previous waves.

Figure 2A Donation pathway of sample – provided by DonateLife Agencies



State/territory	Brain death	Circulatory death
NSW	63	30
ACT	7	5
VIC	50	33
TAS	13	3
QLD	56	27
SA	16	4
NT	1	1
WA	31	8
Total no. unique families	**237 (68%)**	**111 (32%)**

Base: Total sample of unique families: Wave 4 (n=348)

Figure 2B Self-reported donation pathway of sample – over time

Base: Total sample of unique families: Wave 1 (n=131); Wave 2 (n=263); Wave 3 (n=229); Wave 4 (n=348)

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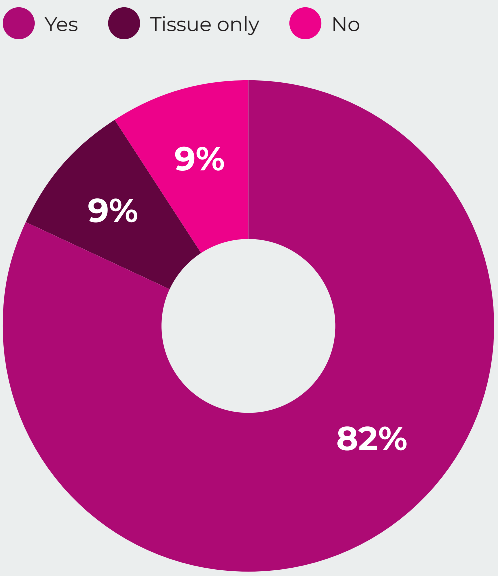
[1] The ANZICS Statement on Death and Organ Donation Edition 4 defines the standards for determining death after circulatory determination of death and neurological determination of death (formerly referred to as brain death determination). For the purpose of this report, death after neurological determination will be referred to as brain death and donation after circulatory determination of death will be referred to as circulatory death.

4.3.4 What was donated

As shown in Figure 3, donation proceeded for 91% of donor families included in the Wave 4 sample; families of intended organ donors represent 9% of the sample. There are no significant differences between 2016 and 2017 donors.

Figure 3 Donation by year of donation (unique donor families)

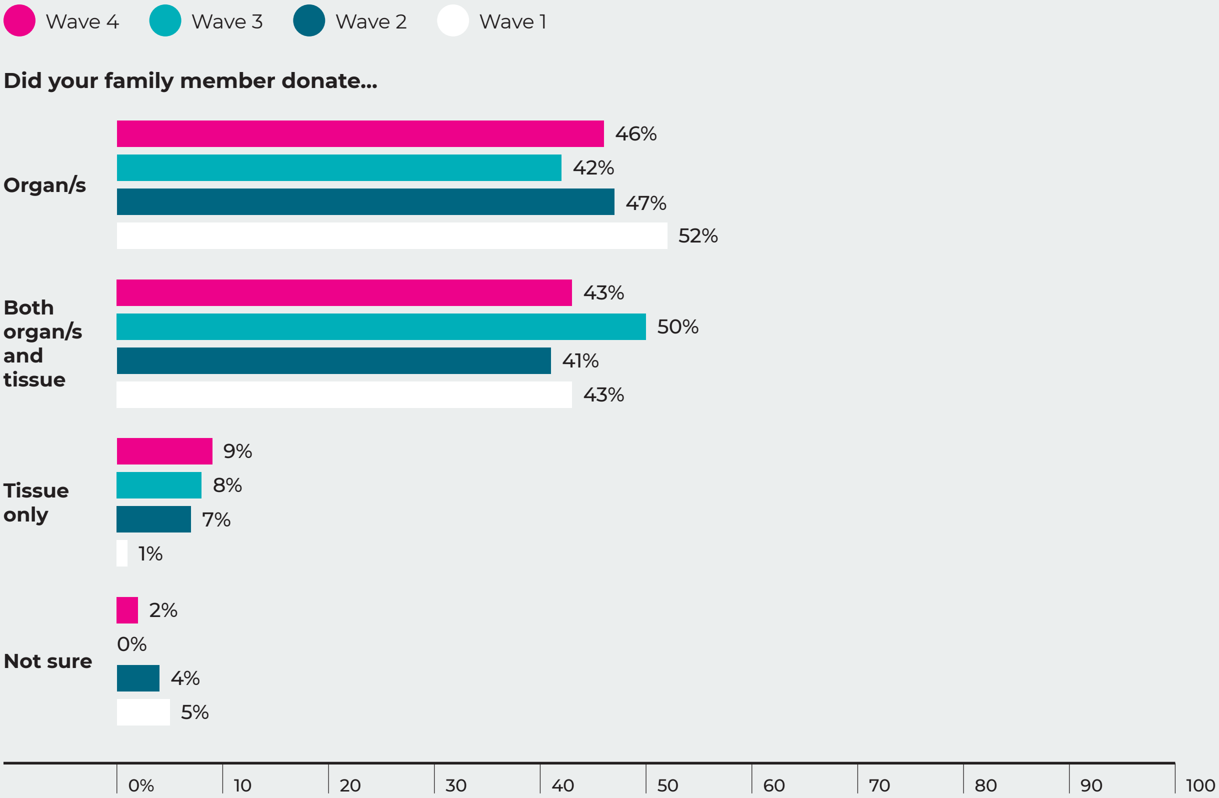


	Wave 4	Wave 4 by year of donation	
What was donated	**Total (n=348)**	**2016 (n=153)**	**2017 (n=195)**
Organs only	42%	41%	42%
Organs and tissue	39%	39%	39%
Tissue only	9%	7%	10%
Donation did not proceed	9%	12%	7%
Not sure	2%	2%	2%

Base: Total sample of unique families: Wave 4 (n=348)

Re-percentaging the data to exclude families of intended donors, 43% of the Wave 4 sample includes families who donated both organs and tissue (Figure 4).

Figure 4 Sample profile – what was donated – over all waves



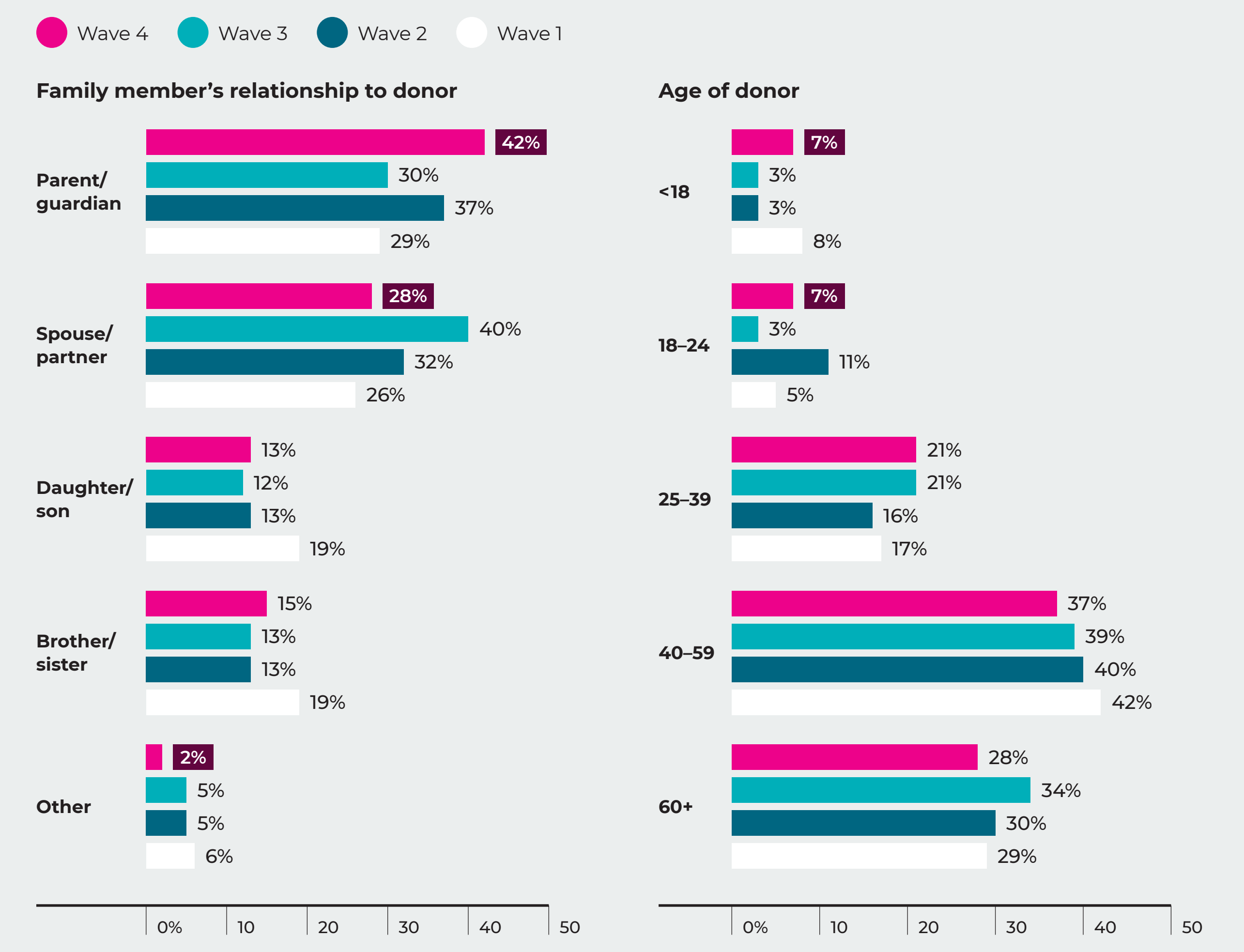
Base: Total sample of unique donor families*: Wave 4 (n=317); Wave 3 (n=213); Wave 2 (n=250); Wave 1 (n=131)

* Excludes intended donor families

4.3.5 Relationship and age

Figure 5 shows the relationship of surveyed family members to donors and the age range of donors. As per previous waves, a wide range of family members are included in the study, with donors ranging in age from 1 month to 82 years.

Figure 5 Relationship to donor and age of donor



Base: Total sample of donor family members: Wave 4 (n=405); Wave 3 (n=257); Wave 2 (n=319); Wave 1 (n=185)

■ Denotes statistically significant difference from previous Wave

Base: Total sample of unique donor families, less non-response: Wave 4 (n=344); Wave 3 (n=228); Wave 2 (n=261); Wave 1 (n=131)

■ Denotes statistically significant difference from previous Wave

Table 5 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 42% of the Wave 4 sample and the average age of their donor children is 31 years.

Table 5 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	31 years	1 month to 57 years
Spouse/partner	59 years	24 to 77 years
Daughter/son	65 years	36 to 82 years
Brother/sister	48 years	4 to 69 years
Other (brother-in-law, aunt, niece, grandparent)	42 years	14 to 55 years

4.3.6 Ethnicity

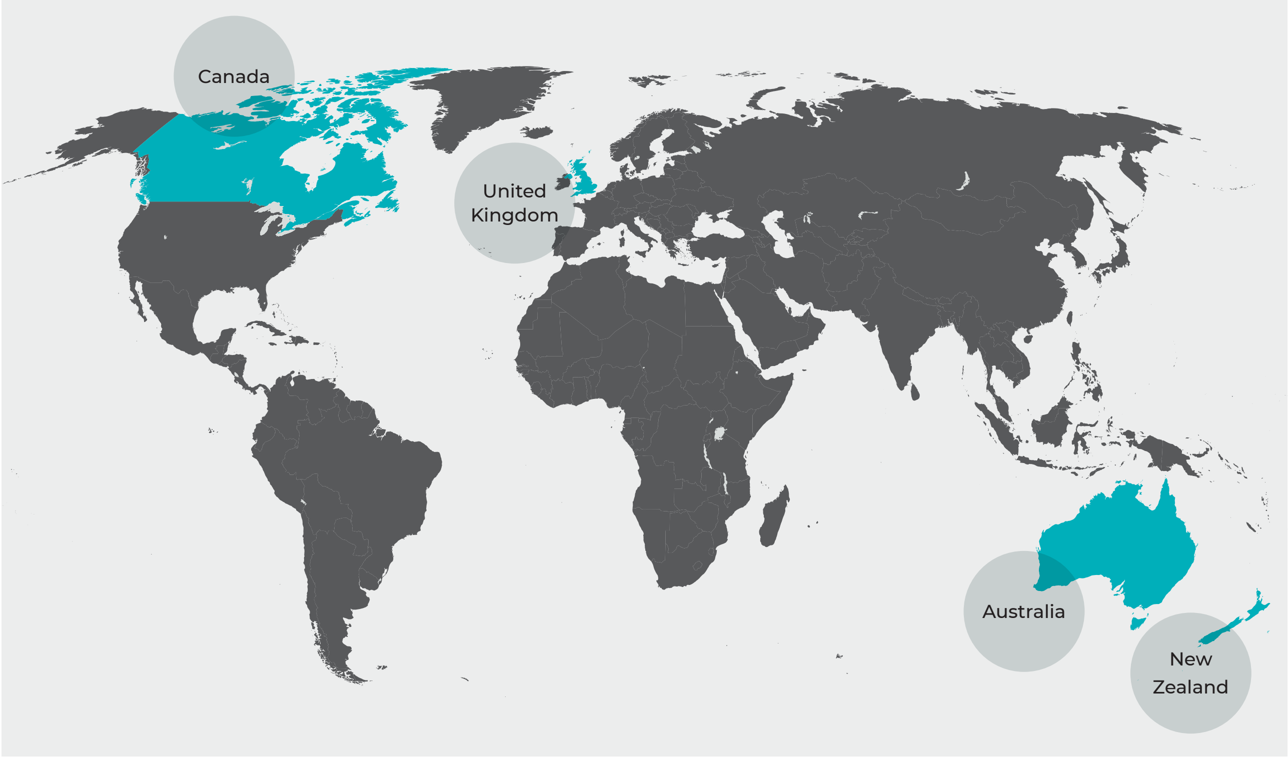
Consistent with the Wave 2 and 3 studies, 2.3% of the Wave 4 donor sample are of Aboriginal or Torres Strait Islander (ATSI) descent. According to the latest available Census data (Australian Bureau of Statistics, 2016), Aboriginal and Torres Strait Islander peoples represent 2.8% of Australia's population.

Six percent (6%) of the Wave 4 sample of donor families state that their loved one spoke a language other than English at home (5% in Wave 3). The languages spoken include:

- Arabic
- Burmese
- Chinese
- Dutch
- Greek
- Italian
- Japanese
- Lithuanian
- Maltese
- Mandarin
- Polish
- Punjabi
- Sinhalese
- Spanish
- Swahili
- Vietnamese

The Donor Family Study also reached families living outside of Australia. Figure 6 shows that families in Canada, United Kingdom and New Zealand took part in the online survey.

Figure 6 Response distribution – online survey



4.4 Sample composition – qualitative

A summary of the qualitative sample structure of family members who consented to donation is shown in Table 6.

Table 6 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	Intended	2016	2017	
NSW	50	3	–	1	1	3	4
QLD	38	2	3	–	3	2	5
VIC	33	3	2	1	1	5	6
WA	15	3	–	–	–	3	3
ACT	7	–	1	1	–	2	2
TAS	5	2	–	–	2	–	2
SA	7	1	1	–	1	1	2
NT	–	–	–	–	–	–	–
National	**155**	**14**	**7**	**3**	**8**	**16**	**24**

As shown, 155 donor family members agreed to take part in a face-to-face interview. Of these, interviews were conducted with 24 families, including three families who consented but the donation did not proceed (intended families).

Interviews were conducted across all states and territories, with the exception of Northern Territory where no families agreed to take part in the interviews.

5 Sampling – families who declined donation

5.1 Sample frame

All families who declined organ and/or tissue donation in a hospital setting during 2016 and 2017, at a participating hospital, were invited to take part in Wave 4 of the Donor Family Study. Identification of families who declined donation, for the purpose of inviting participation in the study, is complex given their limited contact with DonateLife. It is pleasing that more hospitals are now participating in the study, giving more families who declined donation an opportunity to share their experience. The increase in the target population across waves relates to this increased participation and does not necessarily reflect an increase in the number of families declining donation.

The participating Wave 4 hospitals are detailed in Table 7. All states and territories, with the exception of South Australia, chose to take part in the declined strand of the national Donor Family Study, Wave 4.

5.2 Response rates

Survey packs were sent to N=525 family members who declined organ and tissue donation. Of these, n=48 were returned to sender due to a change of address or the person being deceased, bringing the total survey population to N=477. Of these, n=24 family members took part in Wave 4 of the Donor Family Study. This equates to an overall response rate of 5%, lower than the Wave 3 response rate of 7.8% (Table 7).

Table 7 Wave 4 – 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 4	100	4	4.0%
	Wave 3	50	8	16.0%
	Wave 2	58	1	1.7%
	Wave 1	Did not participate		
QLD	Wave 4	84	6	7.1%
	Wave 3	79	5	6.3%
	Wave 2	53	5	9.4%
	Wave 1	Did not participate		
VIC	Wave 4	188	9	4.8%
	Wave 3	190	13	6.8%
	Wave 2	83	2	2.4%
	Wave 1	Did not participate		
WA	Wave 4	80	2	2.5%
	Wave 3	52	2	3.8%
	Wave 2	61	2	3.3%
	Wave 1	Did not participate		
ACT	Wave 4	9	2	22.2%
	Wave 3	4	0	0.0%
	Wave 2	Did not participate		
	Wave 1	9	0	0.0%

		Target population	Participating sample	
State/ territory		**Family members who declined donation***	**No. questionnaires completed**	**Response rate**
TAS	Wave 4	12	1	8.3%
	Wave 3	18	4	22.2%
	Wave 2	12	2	16.7%
	Wave 1	6	1	16.7%
SA	Wave 4	Did not participate		
	Wave 3	16	1	6.3%
	Wave 2	11	0	0.0%
	Wave 1	5	0	0.0%
NT	Wave 4	4	0	0.0%
	Wave 3	12	0	0.0%
	Wave 2	1	0	0.0%
	Wave 1	6	0	0.0%
Total	**Wave 4** (families in 2016/2017)	**477**	**24**	**5.0%**
	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%**

* Excludes survey packs that were returned to sender

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

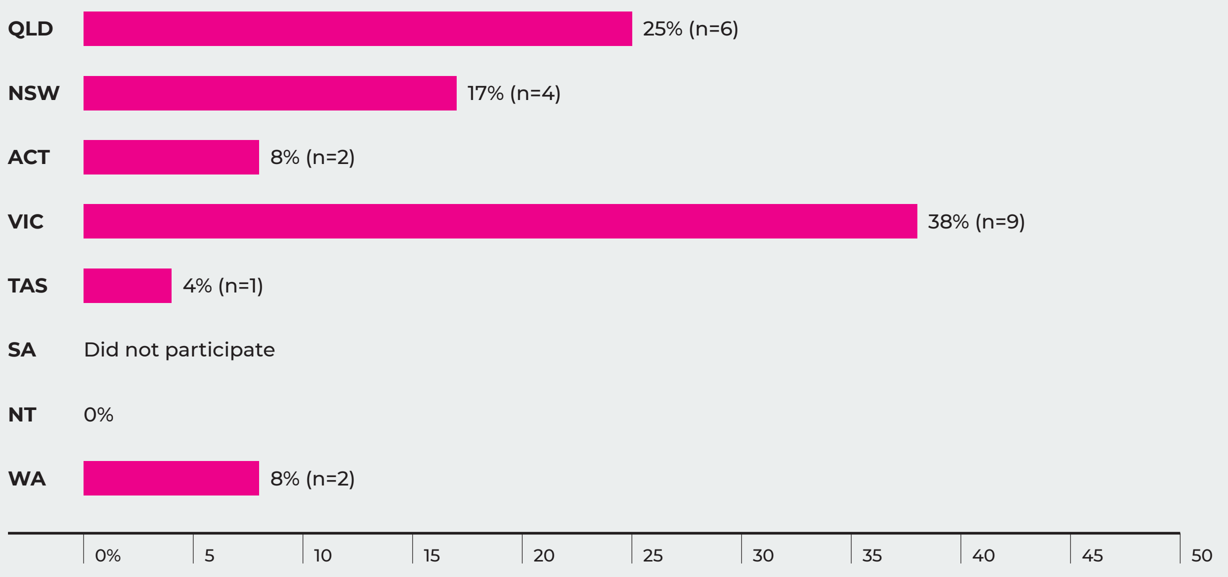
Further effort is required to improve response rates of families who declined donation, so that a greater understanding of their experiences can be gained.

5.3 Sample composition – quantitative

5.3.1 Geographic coverage

As stated, 24 families who declined donation took part in the research. Their geographic distribution is shown in Figure 7.

Figure 7 Response distribution – families who declined donation (Wave 4)



Base: Total sample of family members who declined donation (n=24)

5.3.2 Year of donation decision

Table 8 shows the sample distribution by year of donation decision, across previous waves.

Table 8 Total number of participating unique families who declined donation by state and year of donation

	Wave 2		Wave 3		Wave 4	
State/ territory	**2012** (No. of families)	**2013** (No. of families)	**2014** (No. of families)	**2015** (No. of families)	**2016** (No. of families)	**2017** (No. of families)
QLD	3	2	3	2	2	4
NSW	0	1	3	5	3	1
ACT	N/A	N/A	0	0	0	2
VIC	0	2	5	7	6	3
TAS	0	2	2	2	1	0
WA	0	2	2	0	1	1
SA	0	0	1	0	N/A	N/A
Total	**3**	**9**	**16**	**16**	**13**	**11**

5.3.3 Relationship and age

Table 9 shows the relationship of the respondent to the potential donor, together with the average age and age range.

Table 9 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=12)	64 years	49 to 74
Parent/guardian (n=8)	27 years	19 to 44
Daughter/son (n=3)	69 years	63 to 76
Brother/sister (n=1)	67 years	68

5.3.4 Ethnicity

Among families who declined donation that took part in the research, 87% spoke only English at home; 13% spoke another language (Greek, German, Italian). No families in the research sample who declined donation were of Aboriginal or Torres Strait Islander descent.

5.4 Sample composition – qualitative

A summary of the qualitative sample structure of family members who declined donation is shown in Table 10. Six family members (from six individual families) agreed to a personal interview and all six family members were interviewed.

Table 10 Qualitative sample structure of families who declined donation, by state/territory and year of donation decision

State/ territory	No. of family members agreed to in-depth interview	Year of death		Total personal interviews for each state/territory – declined donation
		2016	2017	
NSW	1	1	–	1
ACT	–	–	–	–
VIC	1	–	1	1
TAS	–	–	–	–
QLD	4	–	4	4
SA	–	–	–	–
NT	–	–	–	–
WA	–	–	–	–
National	**6**	**1**	**5**	**6**

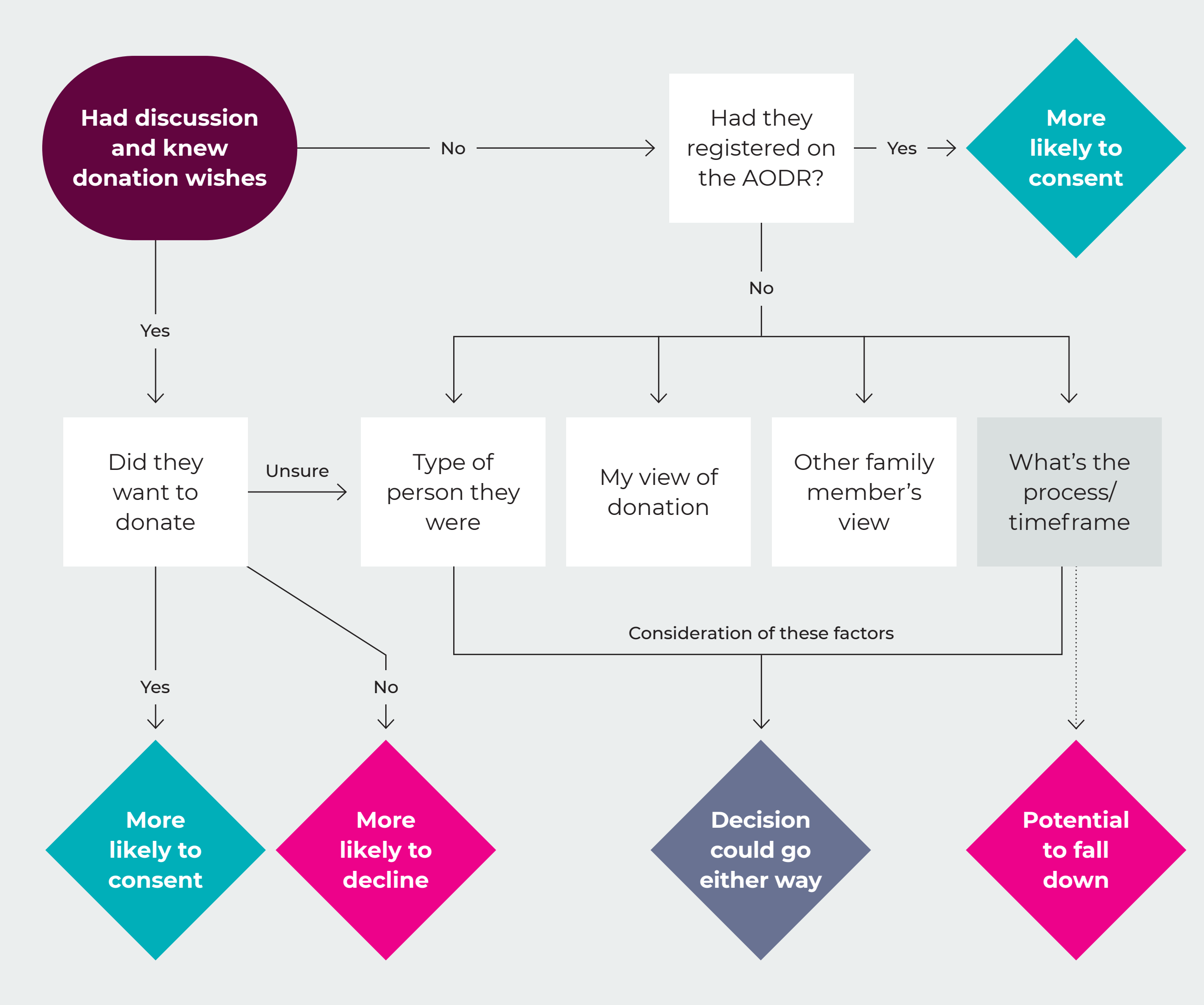
6 The decision to donate or not to donate

In the midst of a serious accident or illness, some family members think about donation fairly quickly and raise the subject with health professionals themselves. As we'll see in Section 8, these families represent 22% of consenting donor family members and typically they will have discussed donation with their loved one or will be searching for something positive to come out of the very negative situation they find themselves in. Donation gives them this.

However, for other family members, donation is the last thing on their mind and the subject is inevitably raised by health professionals, including medical and nursing professionals. These family members will be sensitive to the timing and approach of staff. More on this in Section 8.

Unlike most other important and enduring decisions, a decision about whether to agree to donation or not is made at a time of enormous emotional stress and under significant time pressures. Whilst every family is different, the Donor Family Study has identified similarities in the paths leading to a consent or a decline. These paths are shown in Figure 8.

Figure 8 Pathways to donation decision



As shown in Figure 8, when a loved one’s donation wishes are known, either in the form of **prior knowledge** or via the **Australian Organ Donor Register** (AODR), it relieves much of the pressure that making a decision about donation in the hospital 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 enacting a decision made earlier by their loved one. Prior knowledge is discussed in greater detail in Section 6.1.

In the absence of knowledge of what their loved one would have wanted, families typically consider several things and ask themselves questions such as:

1 What type of person was my loved one? What would they want?

> “ **My mum was so caring and giving, we just knew she would want to donate if she could.”**
>
> 2016 – Consented to donation

2 How do I feel about donation?

> “ **I was surprised at the depth of ‘no’ that I felt. There was no ‘hmm, maybe’. It was just a definite ‘NO’!”**
>
> 2016 – Declined donation

3 How does the rest of our family feel about donation? What do they want to do?

> “ **Not knowing his wishes meant we didn't have the comfort of knowing we were fulfilling them, but myself and my family were all very pro-donation and felt it was the right thing to do. We hoped he would agree.”**
>
> 2016 – Consented to donation

4 What is the process and timeframe associated with donation?

> “ **It's too long a process. I said no.”**
>
> 2017 – Declined donation

Of course the first three questions above are personal and out of the control of hospital staff, although having said this, more work could be done to improve public understanding of donation. This emphasises the importance of continuing to educate and raise awareness of donation in the community. More on this in Section 6.2.

However, the last point above, no. 4, can be influenced by hospital staff and DonateLife. Family members are looking for clear, easy-to-understand information about the process and likely timeframe. What are the broad steps in the process and how long will it take? How will donation impact on their loved one’s stay in hospital? Providing timely information and keeping families up-to-date is essential.

6.1 Impact of prior knowledge

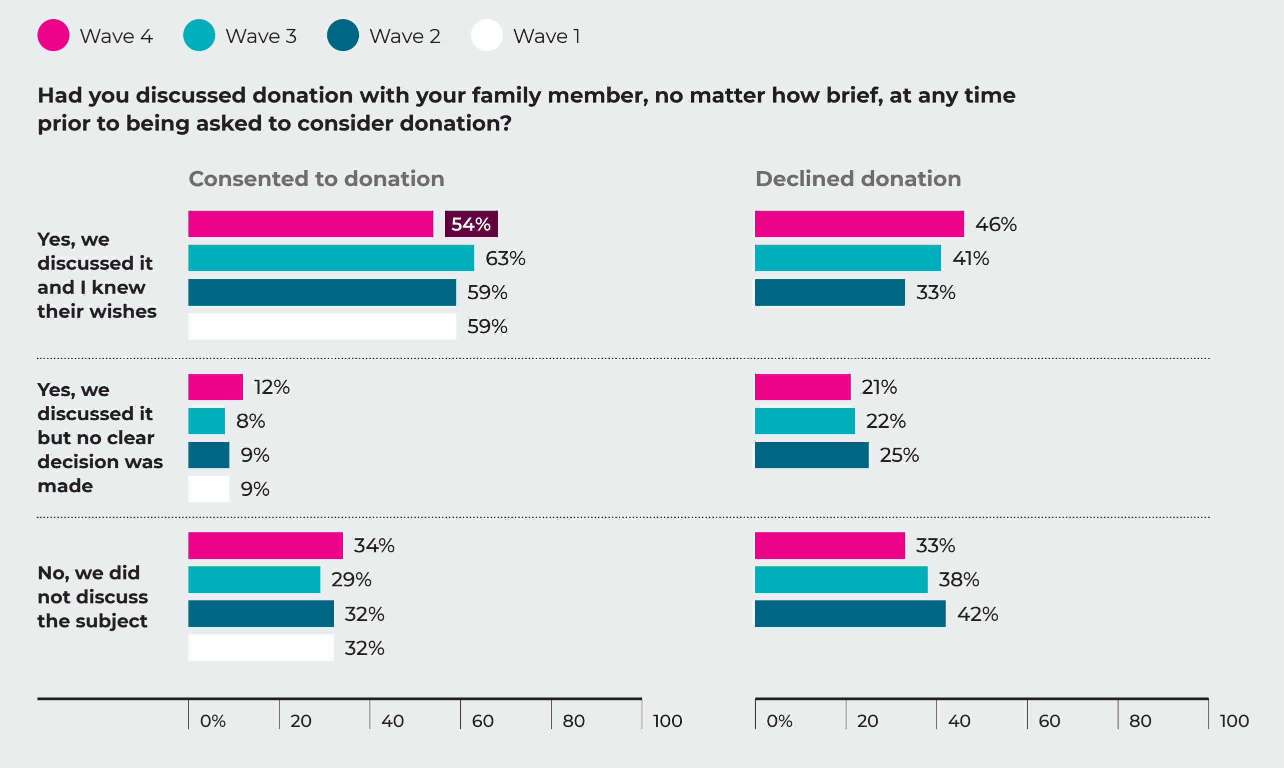
Findings from the Donor Family Study continue to highlight the importance of prior knowledge of a loved one's donation wishes when it comes time to making the decision about whether to agree to donation or not. Those who have discussed donation and know the wishes of their loved one find it much easier than those who haven't had the discussion, to make a decision about donation.

> **Apart from coming to terms with our loss, the decision to approve the donation was relatively easy knowing his wishes."**
> 2016 – Consented to donation

Just over half (54%) of family members in 2016 and 2017 had discussed organ and tissue donation with their loved one and knew their wishes (Figure 9). This is a significant decrease since Wave 3 findings, where 63% of families had discussed donation and wishes were known.

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

Figure 9 Prior discussion of organ donation



Base: Total consented sample, less non-response:
Wave 4 (n=405); Wave 3 (n=257); Wave 2 (n=317); Wave 1 (n=185)

Base: Total declined sample, less non-response:
Wave 4 (n=24); Wave 3 (n=32); Wave 2 (n=12)

■ Denotes statistically significant difference from previous Wave

As shown in Figure 9, overall around one third of family members throughout Australia had not discussed organ and tissue donation with their loved one prior to being asked to make a decision about donation in the hospital. As we'll see shortly, this makes the decision a very difficult one.

> **“Not knowing his wishes for sure made it harder to decide.”**
> 2017 – Consented to donation

> **“We were conscious that it may not have been his wishes, so it made the decision more difficult.”**
> 2017 – Consented to donation

> **“I felt it was difficult to make this decision as I didn't feel it was my right to say what to do with my daughter's organs as it was her body, not mine.”**
> 2016 – Consented to donation

Given the positive impact of knowing a loved one's donation wishes on the decision making process, family discussions about donation should be further encouraged throughout the community.

Consistent with findings from Waves 2 and 3, 79% of families who had discussed donation and knew their loved one's wishes said that this made the donation decision *a lot easier*.

Table 11 Impact of donation discussion on donation decision – families who consented to donation

Impact of degree of discussion	Discussed and knew wishes (n=219)	Discussed but no clear decision made (n=48)	Total discussed donation (n=267)	Did not discuss donation (n=138)
Made our decision a lot easier	79%	27%	70%	14%
Made our decision a bit easier	14%	31%	17%	13%
Made decision easier – net	**93%**	**58%**	**87%**	**27%**
Did not impact on our decision	7%	33%	12%	55%
Made our decision a bit more difficult	–	8%	2%	13%
Made our decision a lot more difficult	–	–	–	5%
Made decision more difficult – net	**0%**	**8%**	**2%**	**18%**

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

The same is found among families who declined donation (Table 12), with 55% 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.

> **“It was her decision. I respectfully followed that.”**
> 2016 – Declined donation

> **“You have to do as you are asked. It made it easy.”**
> 2016 – Declined donation

Further, among families who declined donation, 25% of those who *did not* have the conversation with their loved one found the decision to decline a difficult one (Table 12). This is consistent with findings from Wave 3.

Table 12 Impact of prior discussion on the donation decision – families who declined donation

Impact of degree of discussion	Discussed and knew wishes (n=11)	Discussed but no clear decision made (n=5)	Total discussed donation (n=16)	Did not discuss donation (n=8)
Made our decision a lot easier	55%	–	38%	12%
Made our decision a bit easier	18%	–	12%	–
Made decision easier – net	**73%**	**–**	**50%**	**12%**
Did not impact on our decision	18%	–	12%	63%
Made our decision a bit more difficult	–	20%	6%	–
Made our decision a lot more difficult	9%	80%	31%	25%
Made decision more difficult – net	**9%**	**100%**	**37%**	**25%**

> **I think you should do what each person says and wants, and then you have to do it that way. But because there was no discussion and it was just at that moment, I could not make such a decision, to be honest. I was not able to."**
> 2017 – Declined donation

Family members were asked in what way knowing or not knowing the wishes of their family member impacted on their decision to donate. Table 13A shows responses from families who had discussed donation with their loved one and compares Wave 4 findings to Wave 3.

Table 13A Impact of prior discussion on the donation decision – consented to donation

	Those who had discussed donation	
In what way did this impact on your decision to donate?	**Wave 3** (n=139)	**Wave 4** (n=224)
Wanted to honour his/her wishes/knew wishes of the donor/ donor indicated wishes on AODR or DL so decision was easier	61%	56%
Knowing made the decision easier at a difficult time	12%	12%
There was no question about what to do/no doubts/we were certain	15%	11%
Loved one was generous/would have wanted to help others	6%	10%
We would have donated anyway/believe in donation	6%	9%
Provided a chance for someone else to live/a positive outcome	6%	7%
Felt comfortable with decision/reassured about decision	6%	7%
Made it easier for family members to agree as wishes were known	3%	5%
Seemed like the right thing to do/no reason to refuse	4%	2%
No impact on decision to donate/donor was child/decision was made with other family members	1%	1%
Made decision more difficult because wishes were unknown	–	1%
Other reason (one response each)	9%	0.4%

As shown in the table above, 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 (56%).

> **“It felt like approval had been given.”**
> 2017 – Consented to donation

> **“Although we were upset, we kept going back to what he wanted to do, so that reminded us that it was the only 'right' option for us.”**
> 2017 – Consented to donation

> **“Our family knew that this is what my daughter wanted, so we wanted to honour her wishes.”**
> 2017 – Consented to donation

As shown in Table 13B, families who had not talked about donation struggled more with their decision and often fell back on their loved one’s character and values to inform their decision (30%). Referring back to Figure 8, this is one of the four areas of consideration for families in the absence of prior knowledge.

> **“Just not knowing for sure if he wanted to donate. It played on my mind, but in the end I knew my brother was a caring person and would have done anything to help another. So in the final decision, I knew it was the right thing to do.”**
> 2016 – Consented to donation

Even when the conversation wasn’t explicitly had, if their loved one had registered on the AODR or had mentioned their views towards donation to a friend or another family member, this information then guided the family to proceed with donation, buoyed by the thought of carrying out their loved one’s final wishes (Table 13B, 21%).

Table 13B Impact of no prior discussion – consented to donation

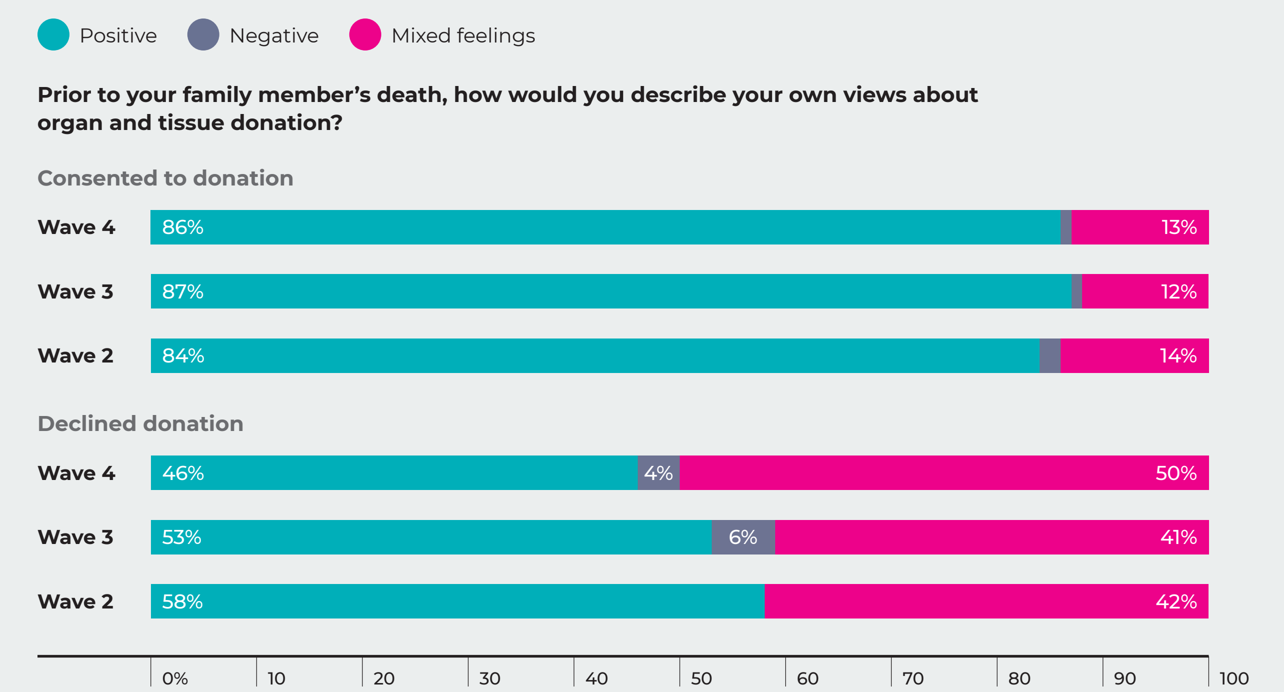
	Those who had not discussed donation	
In what way did this impact on your decision to donate?	**Wave 3** (n=40)	**Wave 4** (n=87)
Loved one was generous/would have wanted to help others	10%	**30%**
Wanted to honour their wishes as indicated on AODR or DL/other family knew of donor’s wishes, so decision was easier	38%	21%
Provided a chance for someone else to live/a positive outcome	15%	15%
No impact on decision to donate/donor was child/decision was made with other family members	15%	14%
Not knowing wishes made it difficult for the family to agree	3%	8%
We would have donated anyway/believe in donation	–	8%
Seemed like the right thing to do/no reason to refuse	–	6%
Made decision more difficult because wishes were unknown	10%	5%
Not knowing wishes means we’re always wondering if we made the right decision	8%	5%
It made the decision easier	–	3%
Other reason (one response each)	3%	5%

Prior knowledge of a loved one’s donation wishes is incredibly important for families when making the decision on whether to donate or not. Continued efforts are needed to promote family conversations about donation and to encourage people to register to be a donor on the AODR.

6.2 Personal views of donation

As shown in Figure 10, 86% of donor family members were supportive of organ donation prior to their family member's death, compared with 46% of family members who declined donation. This is a statistically significant difference. It shows that a person's own disposition towards donation has some influence over the donation decision. When a negative or mixed view of donation is personally held, families are more likely to decline donation; when a favourable view is held, families are more likely to consent.

Figure 10 Personal views of donation prior to loved one's death



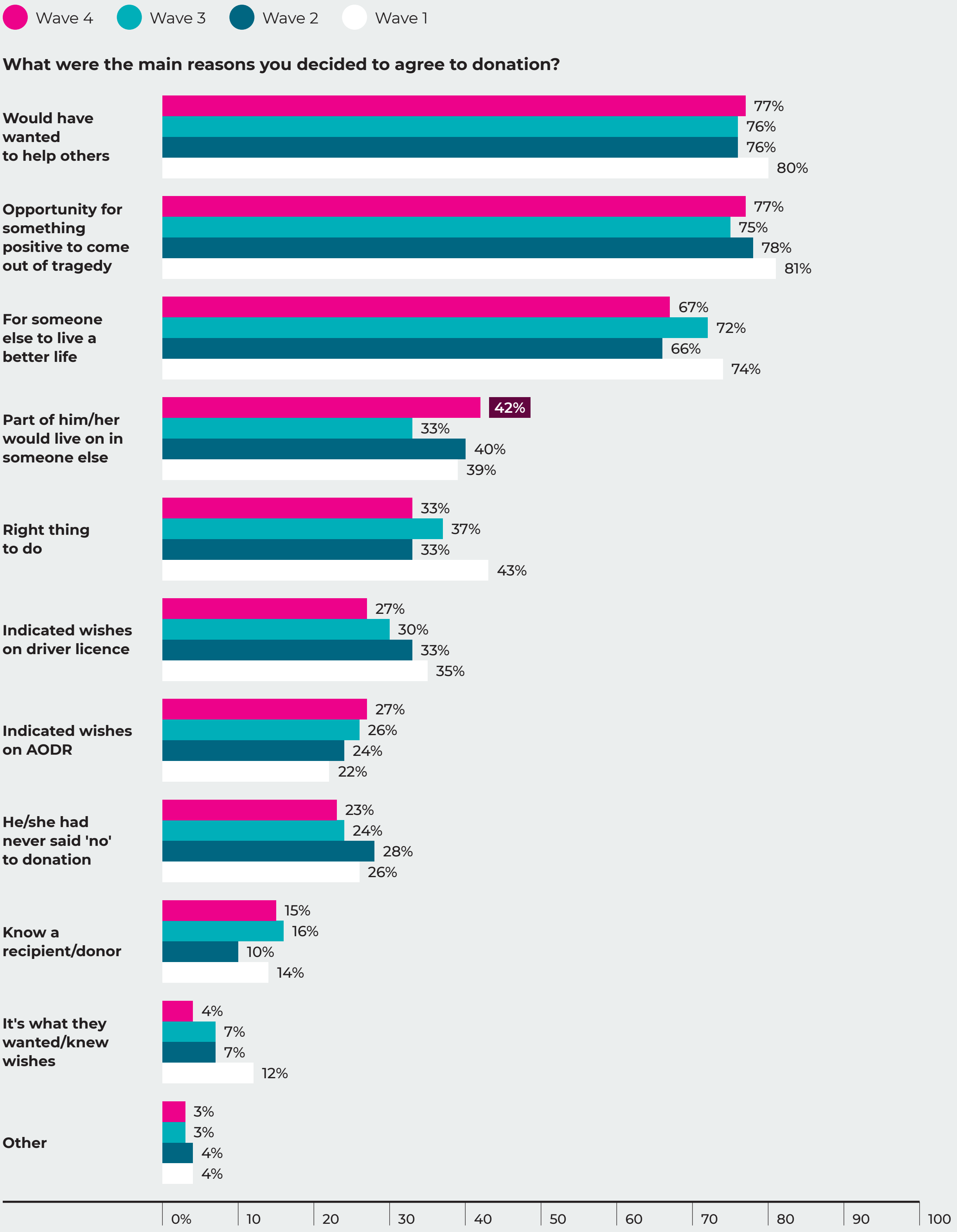
Base:
Total consented sample, less non-response: Wave 2 (n=317); Wave 3 (n=257); Wave 4 (n=404)
Total declined sample, less non-response: Wave 2 (n=12); Wave 3 (n=32); Wave 4 (n=24)

Further efforts are needed to improve public understanding of organ and tissue donation, to encourage discussion and if supportive, registration.

6.3 Motivations for donation

Consistent with previous research waves, most donor families (77%) in 2016 and 2017 saw organ and tissue donation as a chance for something positive to come out of a personal tragedy, and to give some kind of meaning to their loss (Figure 11).

Figure 11 Motivations for donation



Base: Total sample, less non-response: Wave 4 (n=404); Wave 3 (n=257); Wave 2 (n=318); Wave 1 (n=185)

■ Significantly different to Wave 3

> **“I am very proud of my daughter’s decision to donate her organs. It is of great comfort to me to know that something positive has come out of this absolute tragedy.”**
> 2017 – Consented to donation

> **“Giving her organs, that was one way of giving some meaning to it.”**
> 2017 – Consented to donation

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

> **“I just decided his death was a big enough waste. I thought he would like to help people.”**
> 2017 – Consented to donation

Altruism continues to be evident as a motivitating factor, with 67% of donor family members agreeing to donation so that someone else can live/live a healthier life.

> **“As much as it hurt to lose our son, we felt his life was worth something because he saved and helped so many people.”**
> 2017 – Consented to donation

6.4 Barriers to donation

Amongst the surveyed 24 families who declined donation during 2016 and 2017, 39% declined because they felt that their loved one had been through enough and/or they didn’t want him/her to have the donation surgery. This is consistent with Wave 3 (43%).

> **“Once I was told it would take days to do the organ donation, I said no as I did not want my wife to suffer any longer than necessary.”**
> 2017 – Declined donation

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

> **“I was too worried at the time to give any concern to organ donation.”**
> 2016 – Declined donation

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

> **“I definitely could not agree as I didn’t know what my daughter would have wanted.”**
> 2017 – Declined donation

A full list of reasons for declining donation is shown in Table 14.

Table 14 Reasons for declining donation across Waves 2, 3 and 4 of the study

What were the main reasons you decided to decline donation?	**Wave 2** (n=12)	**Wave 3** (n=30)	**Wave 4** (n=23)
He/she didn't want to donate	17% (n=2)	20% (n=6)	35% (n=8)
I didn't want him/her to have surgery for donation	25% (n=3)	17% (n=5)	30% (n=7)
He/she had been through enough	33% (n=4)	33% (n=10)	26% (n=6)
I didn't know what he/she would have wanted	25% (n=3)	23% (n=7)	22% (n=5)
Donation was going to take too long and I couldn't wait	8% (n=1)	17% (n=5)	9% (n=2)
I didn't accept death and couldn't agree to donation	17% (n=2)	17% (n=5)	4% (n=1)
Donation is against my religious beliefs	–	13% (n=4)	4% (n=1)
Other family members declined	17% (n=2)	–	4% (n=1)
I don't like the idea of donation	8% (n=1)	7% (n=2)	4% (n=1)
I wanted the donated organs to go to specific people	–	–	4% (n=1)
I didn't have enough information about what was involved with donation	17% (n=2)	7% (n=2)	–
I wasn't happy with the care	–	7% (n=2)	–
Other	17% (n=2)	23% (n=7)	22% (n=5)

Six families who declined donation volunteered to have a personal interview with the researcher. Analysis of their interviews reveals four common themes, all present in the above table of reasons for declining donation. They are:

1 Lengthy donation process

> **“I couldn't do it to my mother. I couldn't let her stay alive for 14 hours, have extra time extended… just sitting there watching and then pulling the machines off and watching her die. And then Mum's body during the surgery, so I just said, it's too long.”**

2 Not knowing the wishes of the loved one

> **“She didn't sign anything... we just didn't know. And for me, the main reason is that when someone passes away you should leave them in peace. I mean, I can of course understand if you can save a life it's a wonderful thing, but on the other hand I could never have done this. I mean, if she had said before, ‘I want to do it’, I probably would have.”**

3 Respecting the loved one's religious beliefs

> **“Because her religious beliefs were quite strong, in that we are supposed to return to the earth whole, in one piece in the same way that we were born into the earth. And, so yeah, she was against it.”**

4 One family member was opposed to donation

> **“I was pretty upset because I knew that was my wife's wish, but I couldn't go against one daughter. If it was another family member, probably yeah. But not the three children. They all had to agree with it, and two did, one didn't.”**

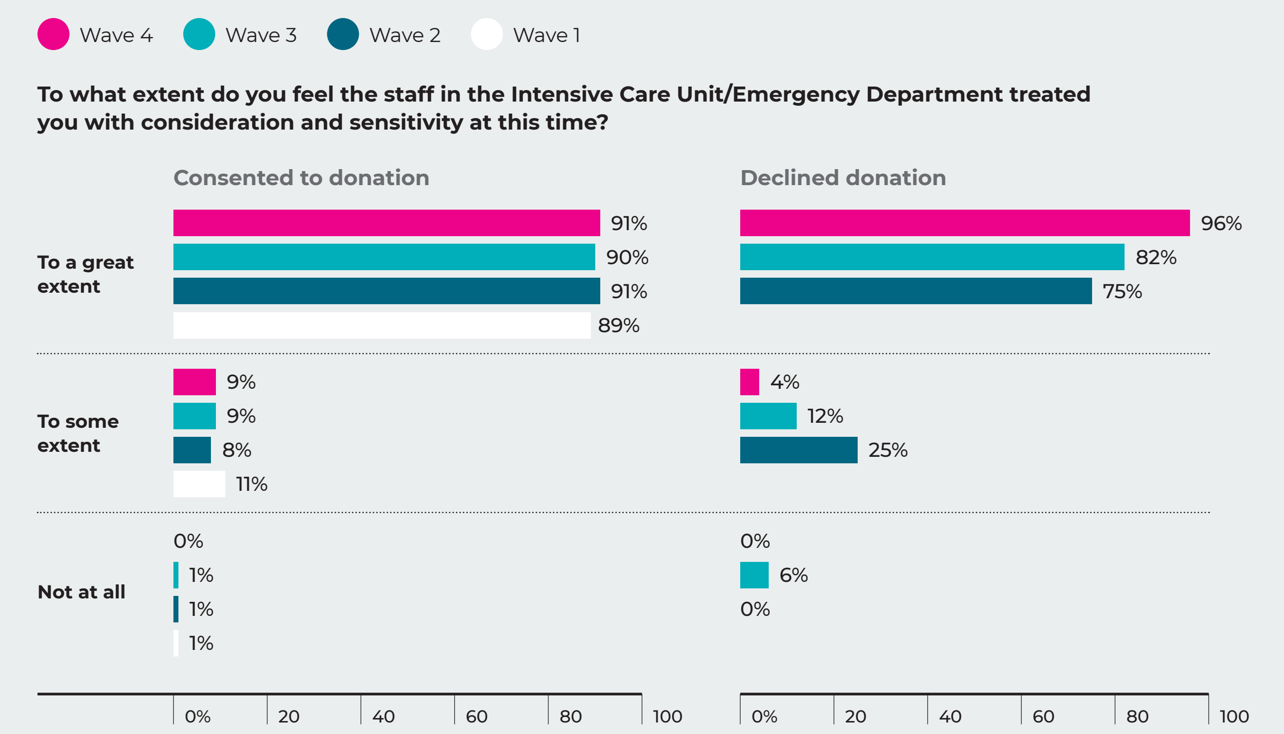
7 At the hospital

7.1 Interaction with ICU/ED staff

As shown in Figure 12, all donor families feel that staff in the Intensive Care Unit (ICU) or Emergency Department (ED) treated them with consideration and sensitivity prior to any discussions about donation (91% feel this occurred to a great extent; 9% to some extent). These findings are consistent with earlier research waves.

The vast majority of families who declined donation also feel they were treated with consideration and sensitivity prior to making their donation decision (96% feel this occurred to a great extent; 4% to some extent). Improvements in this area have been seen over time.

Figure 12 Interaction with ICU/ED staff prior to donation decision



Base: Total sample of families who consented to donation, less non-response: Wave 4 (n=402); Wave 3 (n=257); Wave 2 (n=316); Wave 1 (n=183)

Base: Total sample of families who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=33); Wave 2 (n=12)

More often than not, families experience great kindness, compassion and sensitivity in the ICU. Families are especially appreciative of kindness shown to their loved one and of thoughtfulness and empathy shown to family members.

> **“The hospital staff are the most brilliant, caring, sensitive and wonderful people on Earth. They need to know this.”**
> 2017 – Consented to donation

> **“The nursing staff caring for my daughter were amazing, respectful, compassionate and also with me. I was in awe of that.”**
> 2016 – Declined donation

> **“The staff were so kind, caring and gentle. They looked after my brother with so much care.”**
> 2017 – Consented to donation

Family members who said that staff in the ICU and ED treated them with sensitivity only *to some extent* generally experienced inconsistencies in the level of care shown to them by medical staff, as demonstrated in the following family comments.

> **There was a vast difference in staff sensitivity, and we experienced both extremes – great care and understanding and appalling bluntness and insensitivity."**
>
> 2017 – Consented to donation

> **Everyone was crying when the doctor just rudely, like, he was really rude that doctor said, 'You're too hysterical to talk to now, I'll come back when you're not so hysterical.' And so I'm saying, 'please please please, don't go, don't go.' We all felt the doctors were unsympathetic and harsh when they spoke to us. Nurses were wonderful."**
>
> 2017 – Consented to donation

In 2016 and 2017, some of the surveyed family members felt the treatment they received upon presesenting to the ED was poor. One particular family took part in an in-depth interview with the Proof researcher, but did not complete a questionnaire (hence their feelings would not be reflected in the results shown in Figure 12). This family commented:

> **The first lady who met us at the emergency desk was probably the most un-empathetic, unhelpful, discourteous, patronising person. She did it with a smile as she could see I was distressed. She was smiling and just patronising. Told me to sit down and said she was unable to give any information. She was just so not equipped to be dealing with that situation which agitated me and made the whole thing worse."**
>
> 2017 – Consented to donation

It goes without saying that medical expertise and attention should be the priority for health professionals. Additionally, all interactions with family members have to be thoughtful and considered, with medical staff keeping in mind the often fragile emotional state of families. Families expect that all staff they come into contact with will be sensitive to their situation.

7.2 Delivering news of death/impending death

7.2.1 Clarity of communication

The majority (94%) of donor family members say that hospital staff made it clear that their loved one's condition was critical and that they may not survive. Findings have been consistent since Wave 1 (Figure 13).

Among families who declined donation in 2016 and 2017, 91% feel that the prognosis was clearly communicated to them, consistent with Wave 3 (Figure 13).

> **The staff were superb. Both ED and ICU doctors are very skilled in breaking bad news."**
> 2017 – Declined donation

Conversely, there were a small number of families (6% of families who consented to donation and 9% of families who declined donation) who felt that they were not fully informed of the likely outcome for their loved one. Witnessing brain death testing (as we'll see in Section 7.3) and/or being shown scans or other evidence of their loved one's condition, helps families to understand the gravity of the situation.

> **We saw the scan of our daughter's head and the doctor explained to us what we saw. He was very kind and sensitive to our situation. We saw the large blood clot in her head and we understood the situation."**
> 2017 – Consented to donation

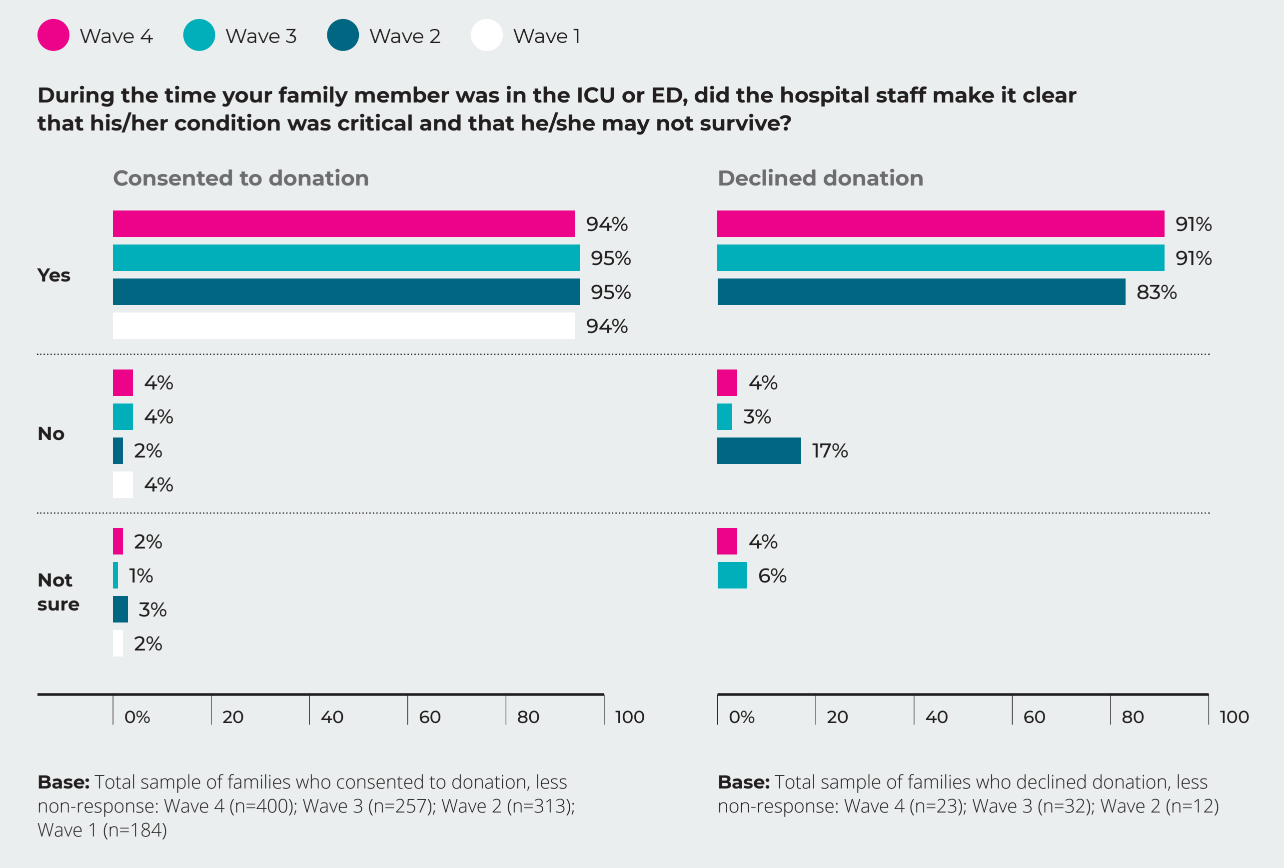
> **I think the night she first came in, the doctor, she said to me, 'her brain has gone already and the daughter you have now is gone.' And then I said, 'but how do I know... I'm not a doctor?' I said, 'can you show me something?', but she said that there's nothing she can show me that I would understand."**
> 2017 – Declined donation

Other families are given conflicting pieces of information. This can erode trust.

> **Too many times we were not able to speak with the same doctors, because of shift times and rosters. Most annoying was being told conflicting stories of 'yes, recovery is possible' and then another doctor would say to prepare ourselves for the worst."**
> 2017 – Consented to donation

> **The ICU doctors, who were amazing, were quite irritated that the information that had been given to us initially was incorrect, so we had gone through this whole 5 or 6 days with not the accurate knowledge."**
> 2017 – Consented to donation

Figure 13 Clarity of communication – prognosis



Base: Total sample of families who consented to donation, less non-response: Wave 4 (n=400); Wave 3 (n=257); Wave 2 (n=313); Wave 1 (n=184)

Base: Total sample of families who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=32); Wave 2 (n=12)

Even though the likely prognosis needs to be clearly communicated to families, the way in which this news is delivered must always be with respect and with a degree of empathy. Most times medical staff do this, but when it isn't done well, when the news is delivered bluntly and without compassion, families remember the conversation for years to come and it doesn't sit well with them.

> **The doctor said 'she is dead' in a rough way. It echoes in my brain always. I can't remember anything other than that."**
>
> 2017 – Consented to donation

> **He said to me on the phone, and that's something they shouldn't do, he said, 'your daughter had an accident and we don't know what happened yet, and it's very serious. She will not survive. Do you understand?' And he was kind of yelling."**
>
> 2017 – Declined donation

> **Doctors said they were doing everything. Nurses pointed out the good signs. They did not include us or explain examinations. They did not show x-rays or scans. It seemed that once we agreed to donate his organs when he was alive, they took steps to ensure his quick death."**
>
> 2016 – Consented to donation

Clarity of the prognosis is necessary as families need to move to a place of acceptance to 1) be open to the donation conversation, and 2) feel comfortable with their donation decision in years to come.

> **Afterwards I questioned if my daughter may have survived if taken off life support. I really struggled with this."**
>
> 2016 – Consented to donation

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

7.2.2 Treatment of families

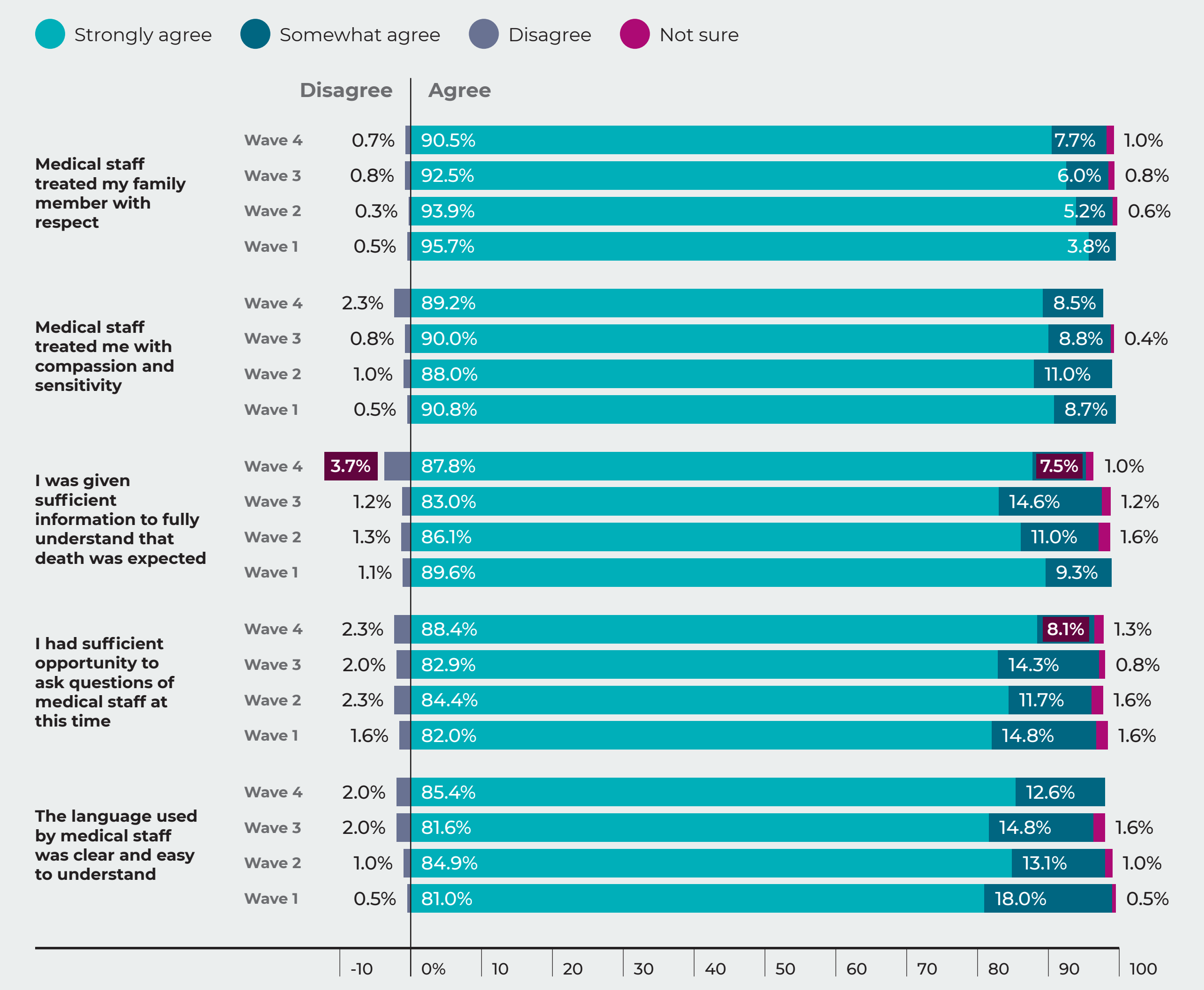
Depending on the circumstances of each patient, medical staff may have discussed with family members either testing for brain death or withdrawal of cardio respiratory support. When family members reflect on that specific time in hospital, the overwhelming majority who consented to donation (98%) recall 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 14).

While most of the five constructs measured have remained consistent over time, more families in Wave 4 feel that they had sufficient opportunities to ask questions of medical staff, while fewer families feel that they were given enough information to fully understand that death was expected.

> **Different doctors gave us hope when there probably was only a miracle."**
> 2017 – Intended

In addition, there continues to be room for improvement around the language used by medical staff (85% strongly agree that the language was clear and easy to understand).

Figure 14 Treatment of consenting families by medical staff



Base: Total sample of Wave 4 families who consented to donation, less non-response | **NB:** Base sizes vary by statement

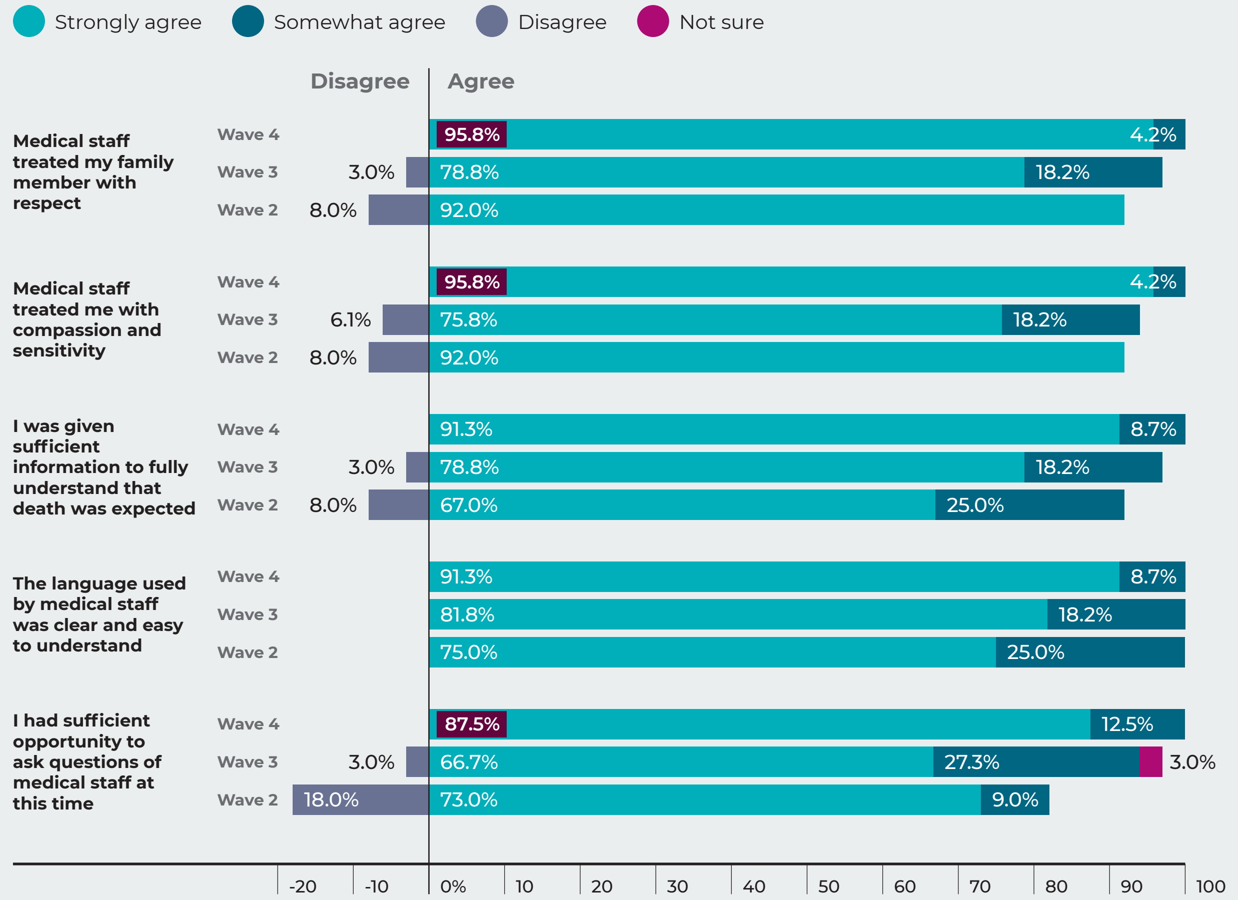
■ Denotes statistically significant difference between Wave 3 and Wave 4

Looking at families who declined donation (Figure 15), significant improvements have been made since Wave 3 with more families in 2016 and 2017 feeling that:

- Medical staff treated their family member with respect (up from 79% strongly agree in Wave 3 to 96% in Wave 4)
- Medical staff treated them with compassion and sensitivity (up from 76% strongly agree in Wave 3 to 96% in Wave 4)
- They had sufficient opportunity to ask questions of medical staff (up from 67% strongly agree in Wave 3 to 88% in Wave 4)

> **“You could ask her [the ICU nurse] heaps of questions if you wanted. Yeah, she was really good.”**
>
> 2016 – Declined donation

Figure 15 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

■ Denotes statistically significant difference between Wave 3 and Wave 4

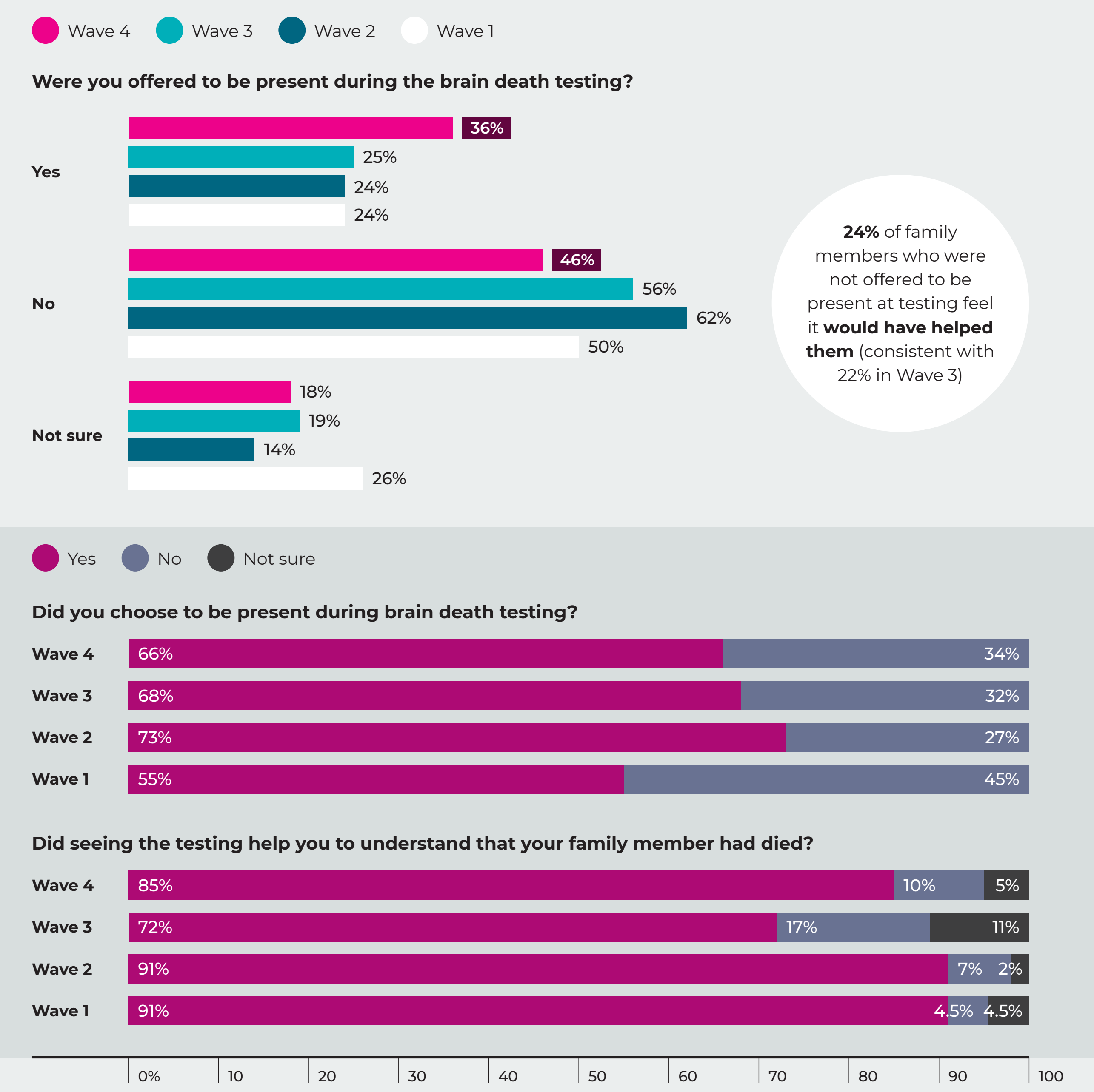
7.3 Brain death testing

7.3.1 Impact of witnessing brain death testing

During 2016 and 2017, 36% of family members who experienced the brain death pathway, were asked if they would like to be present during the brain death testing of their loved one. This is significantly higher than donor families in 2014 and 2015, when 25% of family members were given this opportunity (Figure 16).

Of those families who were invited to attend the testing, 66% opted to be present, consistent with Wave 3. Of those families who chose to be present, 85% said that it helped them to understand that their loved one had died.

Figure 16 Brain death testing – consenting families

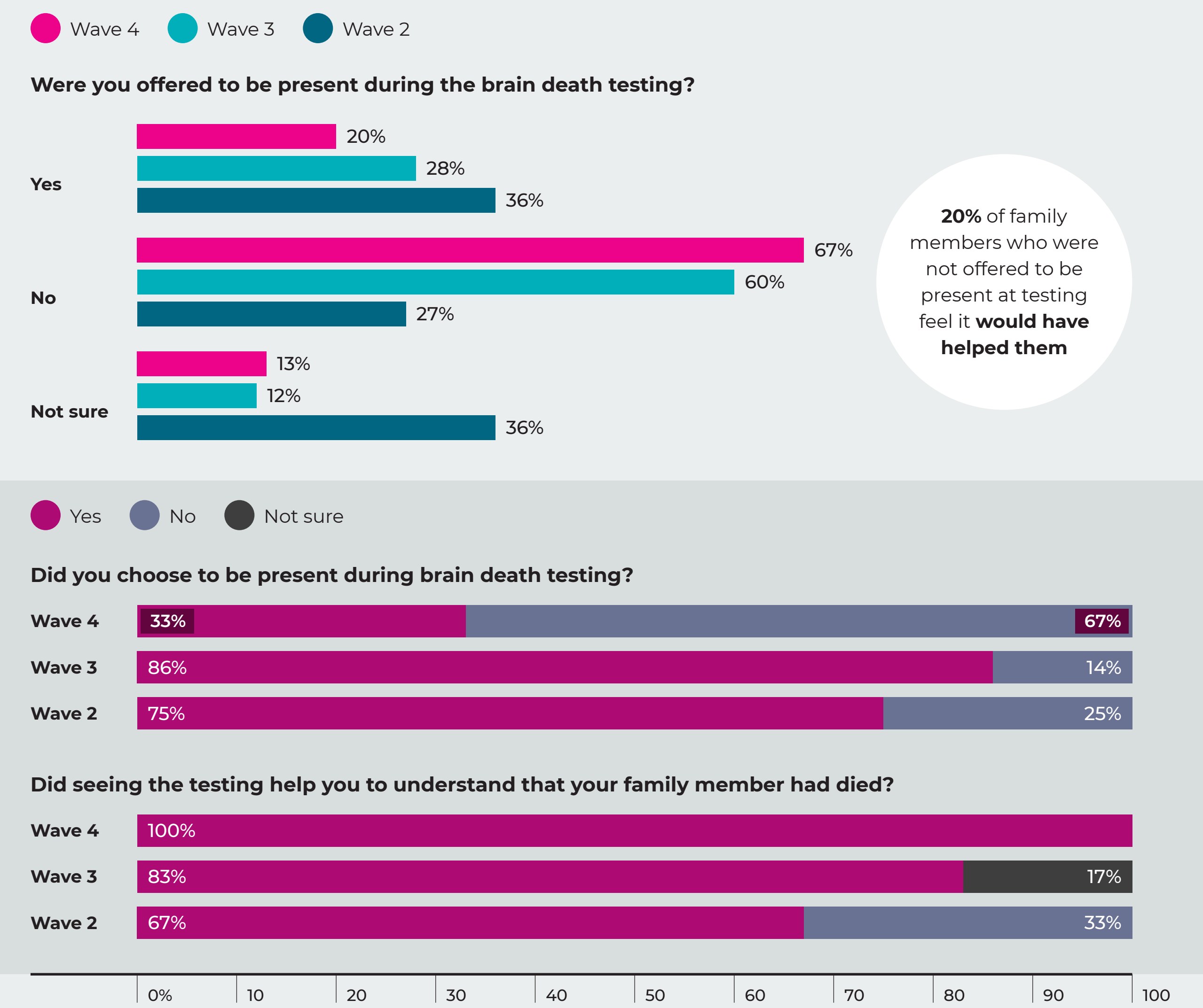


Base:
Total DBD sample, less non-response: Wave 4 (n=272); Wave 3 (n=209); Wave 2 (n=262); Wave 1 (n=163)
DBD sample who were offered to be present at testing: Wave 4 (n=96); Wave 3 (n=53); Wave 2 (n=64); Wave 1 (n=40)
Family members who witnessed brain death testing: Wave 4 (n=61); Wave 3 (n=36); Wave 2 (n=46); Wave 1 (n=22)

■ Denotes statistically significant difference between Wave 3 and Wave 4

Findings are similar among families who declined donation, with three of the fifteen families (20%) being asked if they would like to be present during brain death testing. Although base sizes are small with this analysis of families who experienced DBD, one family member of those three families chose to be present (Figure 17). That family member said that witnessing the testing helped them to understand that their loved one had died.

Figure 17 Brain death testing – declining families



20% 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 4 (n=15); Wave 3 (n=25); Wave 2 (n=11)
Families who declined donation, who were offered to be present at testing: Wave 4 (n=3); Wave 3 (n=7); Wave 2 (n=4)
Families who declined donation, who witnessed brain death testing: Wave 4 (n=1); Wave 3 (n=6); Wave 2 (n=3)

■ Denotes statistically significant difference between Wave 3 and Wave 4

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

> **The test was a formality and provided closure. Not pleasant – a hope extinguisher."**
> 2016 – Declined donation

Family experiences of witnessing brain death testing appear to be varied. Some family members recall compassionate and sensitive doctors who took the time to explain each test and who treated them and their loved one with consideration.

> **Honestly, they were amazing. They explained everything they were doing and how they were doing it. It wasn't pleasant. They would talk to [my son] as if he was awake. They were just incredible. It made me feel amazing because even though I knew he wasn't there, it made me feel like he was still getting treated with respect."**
> 2017 – Consented to donation

> **It was a positive thing. I didn't want the social worker in there so it was just me, the doctor and the nurse. He calmly explained each test and what each one's purpose was and what they were measuring."**
> 2017 – Consented to donation

Others recall a difficult situation made worse by doctors who were less than forthcoming with information and not particularly supportive.

> **We had only seen one doctor up until then and obviously he had done his test first because then he introduced us to another neurologist who was doing the second test. That one did more explaining than the one that was with him the whole time. He said, 'we do two independent tests. We then correlate our information' so he was very informative. The other one wasn't. And, it wasn't just that he wasn't informative, he was rude, he was arrogant."**
> 2017 – Consented to donation

Adding to the strain of witnessing brain death testing is who is invited into the room. This becomes important in situations where families are estranged or where there is conflict between family members, as shown in the following comment.

> **I thought it was just myself and my daughter but they told my ex-husband that he could come in, so that was really uncomfortable for all of us."**
> 2017 – Consented to donation

Where possible, family members would appreciate medical staff being sensitive to these family dynamics and clarifying with them who they would like to attend the testing. Where two family members are in conflict and both would like to attend the testing, it may be possible for one family member to sit in on the first brain death test and the other to sit in on the second test.

7.3.2 Impact of not witnessing brain death testing

From the families who experienced the brain death pathway, just under half (46%) of donor family members and two thirds (67%) of family members who declined donation were not given an opportunity to attend the brain death testing of their loved one (Figures 16 and 17 respectively). On reflection, many of these families are okay with this, but some families (24% of those who consented to donation and 20% of families who declined donation) would like to have witnessed the tests. They feel that this exercise would have helped them to better understand the situation for their loved one.

> **“Every time they sort of did a procedure with Mum we were ushered out. I didn’t like that. I wanted to be with Mum the whole time.”**
> 2016 – Consented to donation

> **“They didn’t invite us specifically to come in and witness brain death testing. I would have preferred to have been in the series of tests and understood the process and what was going on, but we weren’t asked.”**
> 2017 – Declined donation

> **“I would have liked 1) to be introduced to the 2 teams, 2) clearly explained what the test fully entailed, 3) how it is carried out, 4) be asked whether I would like to be present during the test, 5) be present during the test, 6) have the opportunity to ask questions during the test.**
>
> **Instead, I was asked to leave so the team could carry out 'the test'. To this day when I think of it, it still makes me feel that my partner was just simply a piece of meat being probed. I don't know how much dignity was exercised.**
>
> **At conclusion of the test, I would have welcomed a thank you from the teams, together with their feedback. To this day I have unanswered questions.”**
> 2016 – Consented to donation

> **“It was like a mystery. I would have liked to have known and seen more. I feel that I just had to accept that the result was as it was. Seeing it might have helped. The staff indicated that seeing the testing would prove difficult. I still wish I had been present.”**
> 2017 – Consented to donation

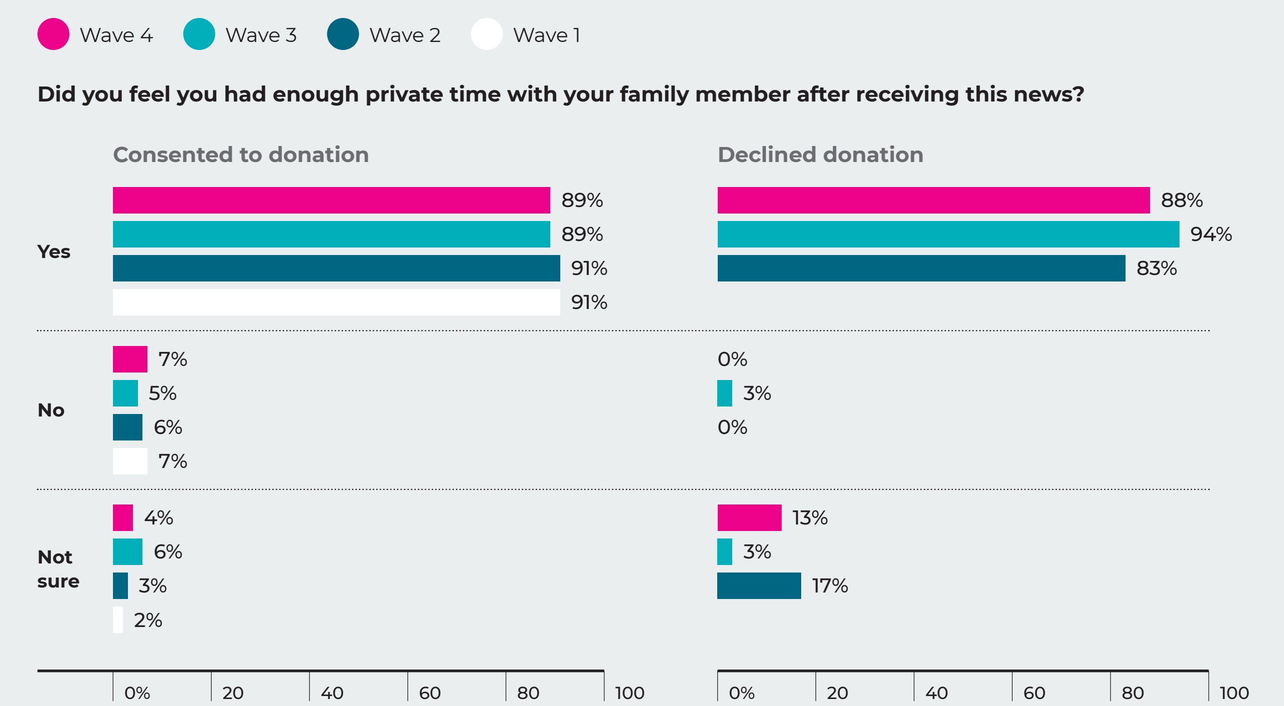
Not everyone feels the need to witness brain death testing. However, an informed decision cannot be made unless the purpose of the test is explained and family members are given an opportunity to be present during testing.

Family members who choose to attend should be emotionally supported by hospital staff during the testing. The purpose of each individual procedure and the reaction being observed should be explained as the testing progresses.

7.4 Time with family member post-prognosis

In 89% of cases, family members who consented to donation feel 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 18, this has remained consistent across previous waves. During 2016 and 2017, 88% of families who declined donation also feel that they were given sufficient time with their loved one following the prognosis. Again, this is consistent with earlier waves.

Figure 18 Amount of private time with family member post prognosis



Base: Total sample who consented to donation, less non-response: Wave 4 (n=399); Wave 3 (n=256); Wave 2 (n=313); Wave 1 (n=183)

Base: Total sample of families who declined donation, less non-response: Wave 4 (n=24); Wave 3 (n=32); Wave 2 (n=12)

> **“During the day, we were sort of left to come and go and just spend as much time as we wanted to with him.”**
> 2017 – Declined donation

Seven percent (7%) of family members who consented to donation say that they did not have enough private time with their family member after receiving news that their loved one would not survive.

Perceptions of time vary across families who consent to donation. Some say that donation gave them more time with their loved one, while others feel they were rushed because of donation.

> **“Looking back, I wonder if we had enough time with our daughter once we knew that she would not recover. It seemed like we just progressed down a pre-ordained path at a pre-ordained speed. I wish that we had been given more time.”**
> 2017 – Consented to donation

Irrespective of the *amount* of time families are able to spend with their loved one, the *quality* of time is what's valued. This often means privacy.

7.5 Improving the hospital experience

Family members were asked an open ended question "*how could your experience at this time* [before discussing donation] *have been made easier for you and your family?*" Responses have been coded into like themes and are listed in Table 15.

Table 15 Improving the hospital experience before donation is discussed

Overall, how could your experience at the hospital at this time have been made easier for you and your family?	Wave 4 consented (n=298)	Wave 4 declined (n=15)
Nothing more could have been done	40%	47% (n=7)
Positive comment about ICU/hospital staff	36%	13% (n=2)
More empathy and kindness from hospital staff towards us and loved one	7%	7% (n=1)
More privacy (private room) for – being with loved one/receiving information/family discussions	6%	**20%** (n=3)
Family comfort – more seating/somewhere to sleep/somewhere to shower/better provisions in the family/waiting room	5%	–
Regular updates and clearer information	4%	7% (n=1)
More time as a family with loved one before donation surgery/felt rushed or pressured	4%	–
More accurate time frame estimations – prolonged experience or not as much time as expected	3%	–
More support provided – counsellor/social worker	2%	–
Less paperwork, unnecessary/confronting questions and repetition of information	2%	–
Too expensive – hospital parking/accommodation/meals	2%	–
Better communication amongst staff – doctors gave conflicting information	2%	–
Allow more family members into the ICU at the same time	1%	7% (n=1)
Wish to have been allowed to be present during tests and passing	1%	7% (n=1)
More time given for family discussions	0.3%	–
Don't know/not sure	3%	7% (n=1)
Other	6%	13% (n=2)

As shown, many family members who responded to this question feel that everything that could have been done for them was done, and others talk positively about hospital staff (63% of consenting family members and 53% of those who declined donation).

In terms of areas to improve the hospital experience, they are mostly:

a Greater empathy and kindness from hospital staff

> **“During this time, I could not fault the staff attending to my son they have a beautiful nature and professionalism. However, unfortunately we had a desk clerk who was rude and inexperienced with stressed family and was not empathetic at all and escalated any situation put before her by other families as well as ours.”**
> 2016 – Consented to donation

b More privacy (for family discussions, with loved one and to receive updates)

> **“It’s such a horrible place anyway because there's no privacy. If someone had just taken us aside and spent a few minutes to explain, in a private room.”**
> 2017 – Consented to donation

> **“A private area where we could rest. We slept on the floor or waiting room chairs. Somewhere private to have a real coffee.”**
> 2017 – Consented to donation

c Improved environment for the family’s comfort

> **“We were just left in the family room and no one offered us any support. The nurses were good looking after our mum but we were just left. I feel someone should have checked on us and offered support. We had to ask for blankets and slept on the floor. It was a difficult time made even harder.”**
> 2017 – Consented to donation

> **“The chairs were hard as. It’s a pokie friggin room. There’s nothing inviting about it; it’s very sterile.”**
> 2017 – Declined donation

> **“The chairs are hard, there's no colour. You feel like you are in a morgue.”**
> 2017 – Consented to donation

d Regular updates and clearer information

> **“I had to keep asking him for information and he was getting really angry. He was getting really mad because I keep asking him.” [Family member referring to neurosurgeon]**
> 2017 – Consented to donation

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

- **Clarity of information and of the likely outcome**
- **Compassion and understanding**
- **Time to absorb the information**
- **Privacy, private time to spend with their loved one and family and a private room to hear updates.**

In addition, consideration should be given to the emotional wellbeing and physical comfort of family members during their loved one’s stay in hospital.

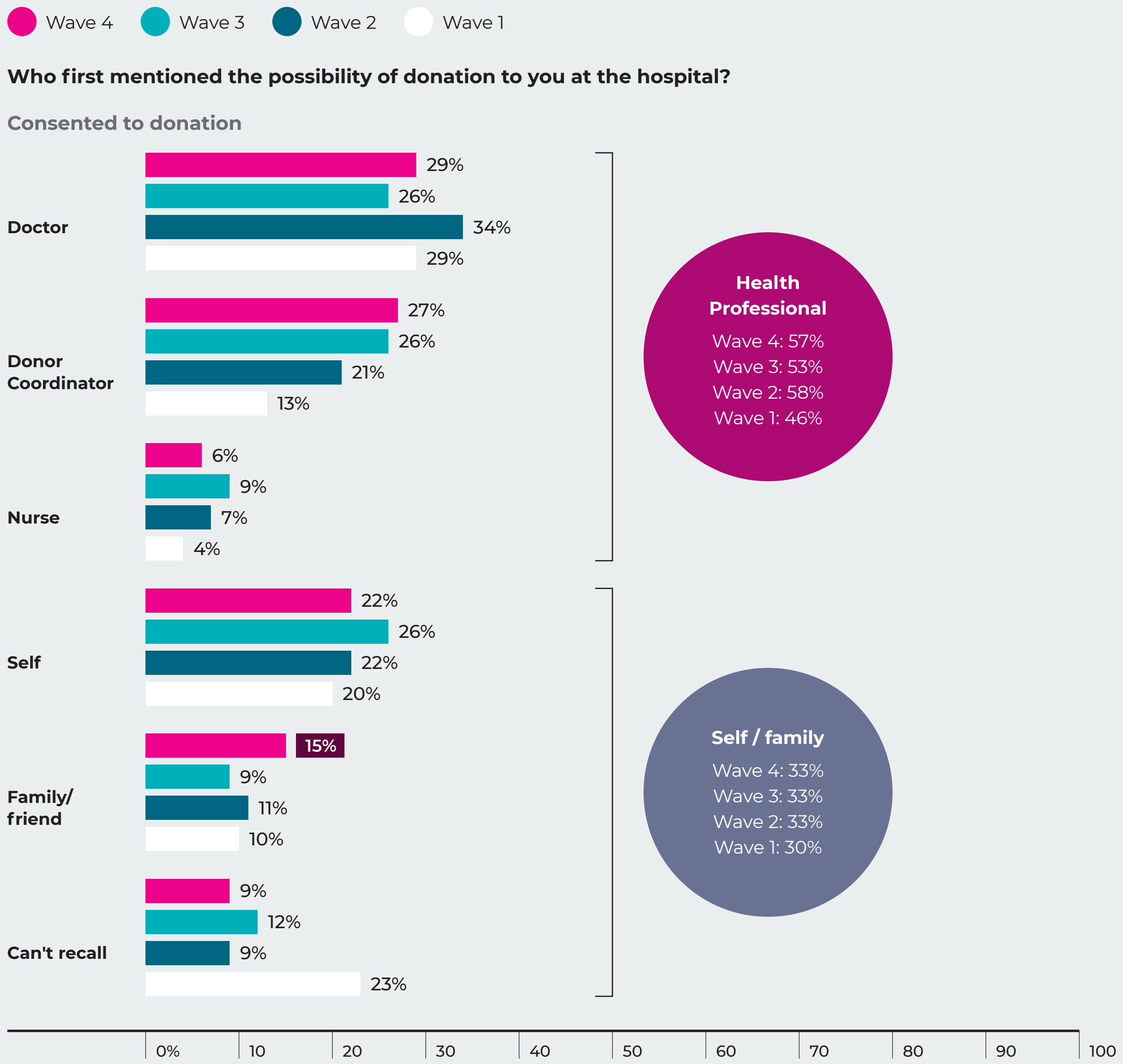
8 The donation conversation

8.1 Initiating the donation conversation – who raises it?

The possibility of donation continues to be primarily raised by health professionals (57% amongst consenting families; consistent with Wave 3). As shown in Figure 19, during 2016 and 2017, the donation conversation was initiated by doctors in 29% of cases, Donor Coordinators in 27% and nurses in 6% of cases.

During 2016 and 2017, one third (33%) of donation conversations were initiated by the next of kin or family members; consistent with previous waves.

Figure 19 Who initiated the donation conversation – consented to donation



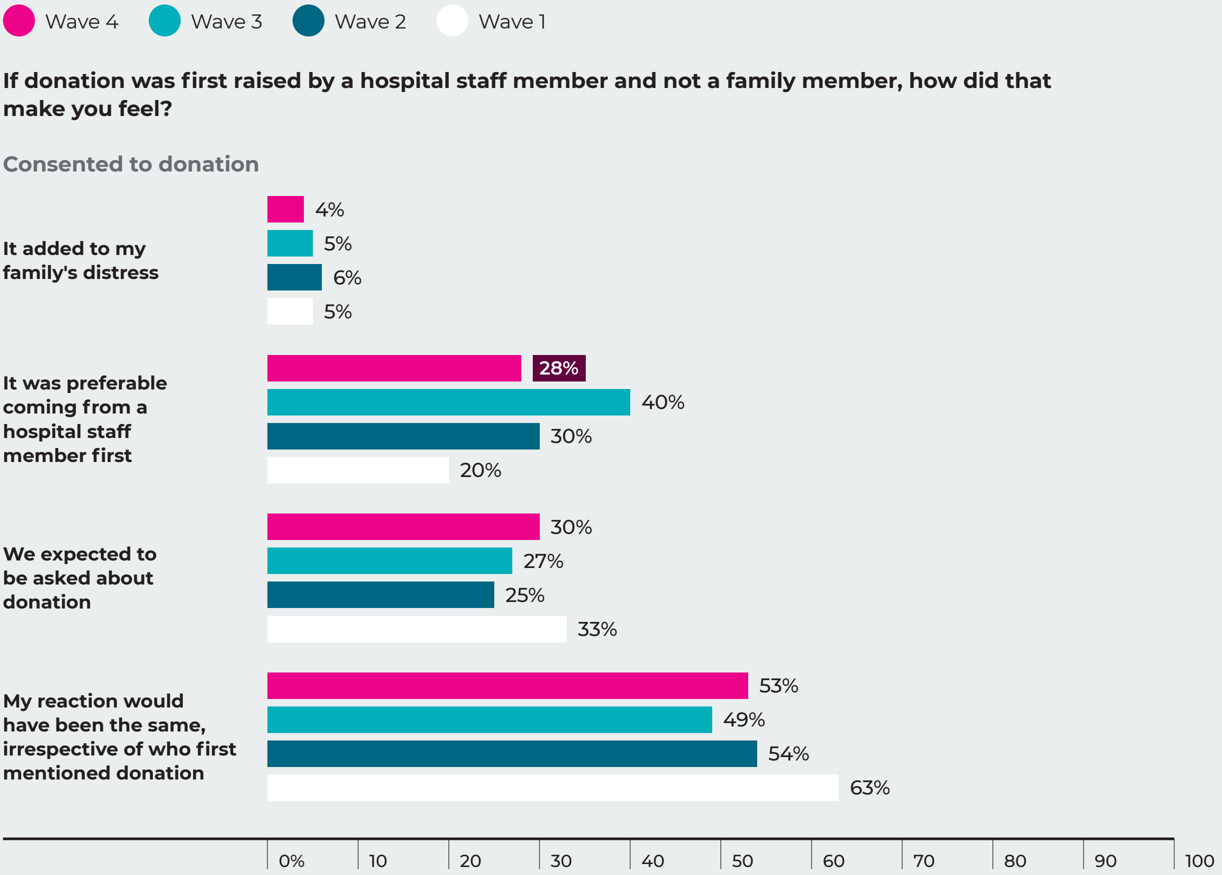
Base: Total sample of those who consented to donation, less non-response: Wave 4 (n=405); Wave 3 (n=257); Wave 2 (n=314); Wave 1 (n=184)

NB: Multiple responses allowed

■ Denotes statistically significant difference between Wave 3 and Wave 4

Amongst families where donation was initially raised by a health professional, 30% say that they expected to be asked about donation, consistent with Wave 3 findings. Fewer consenting donor families in 2016 and 2017 say it was preferable that the topic was raised by a hospital staff member first (28%), compared with families in 2014 and 2015 (40%), while half (53%) of donor family members say that their reaction would have been the same, irrespective of who first mentioned donation.

Figure 20 Reaction to donation being raised by hospital staff member – consented to donation



Base: Consenting family members who had topic of donation raised by health professional, less non-response: Wave 4 (n=213); Wave 3 (n=130); Wave 2 (n=174); Wave 1 (n=82)

NB: Multiple responses allowed

■ Denotes statistically significant difference between Wave 3 and Wave 4

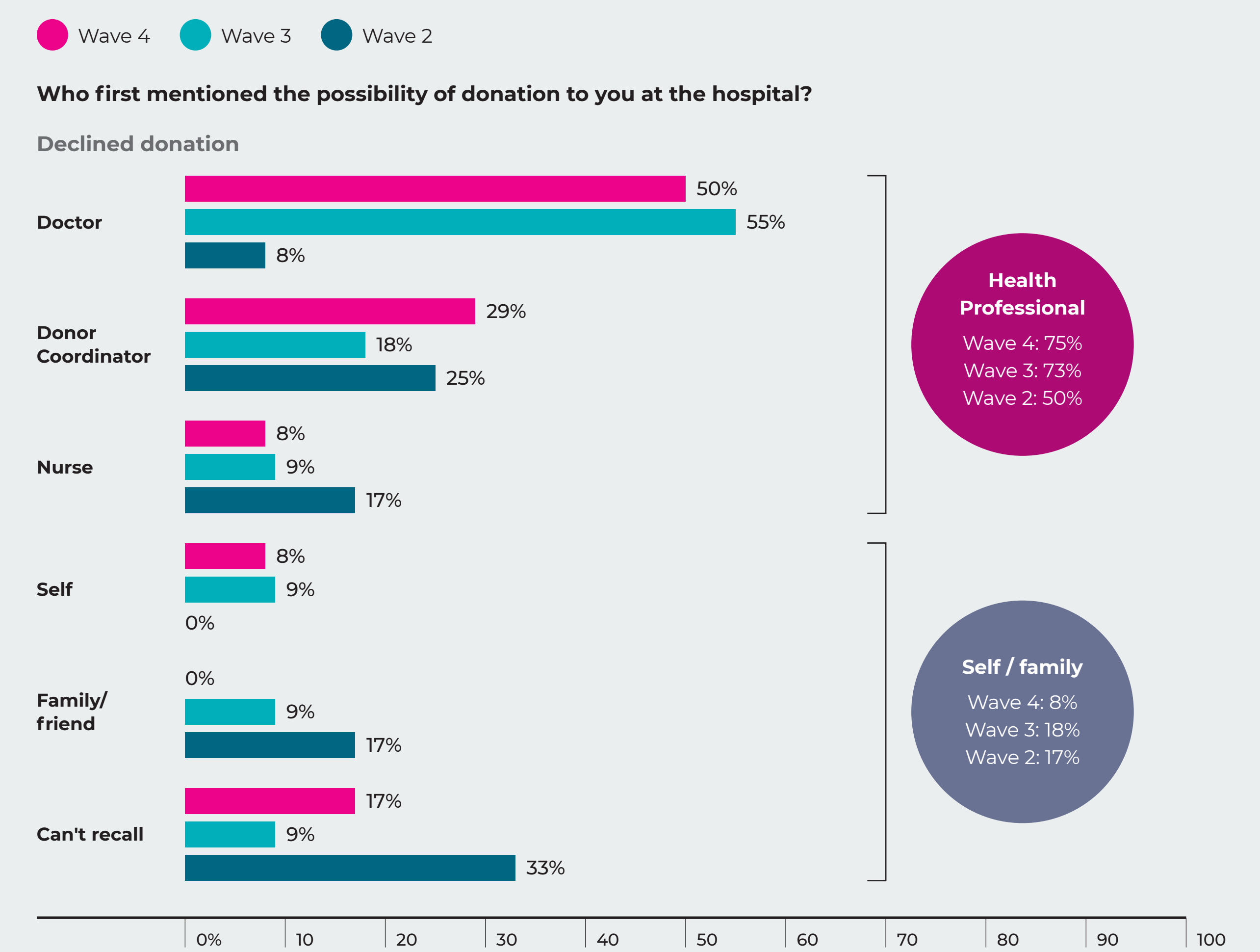
Just 4% of donor family members feel that being asked about donation by a health professional added to their family's distress (Figure 20). Looking specifically at these families, the distress appears to be brought on not so much by the fact that the conversation was raised, but by a combination of *when* it was raised, *how* it was raised and by *whom*.

> **“At first we did not understand that we were meeting with someone to discuss donation. We were told we were meeting with the ‘End of Life’ person. We thought that was just about turning off the machines.”**
> 2017 – Consented to donation

> **“I felt it was too soon. We had just been told our son would stop breathing within the next 12 to 48 hours. We were still in shock and didn't really have the time to process everything that was happening when we were asked to donate.”**
> 2017 – Consented to donation

Looking now at families who declined donation, three quarters (75%) of donation conversations were initiated by a health professional, consistent with Wave 3 findings (Figure 21) and significantly higher than consenting family member conversations.

Figure 21 Who initiated the donation conversation – declined donation

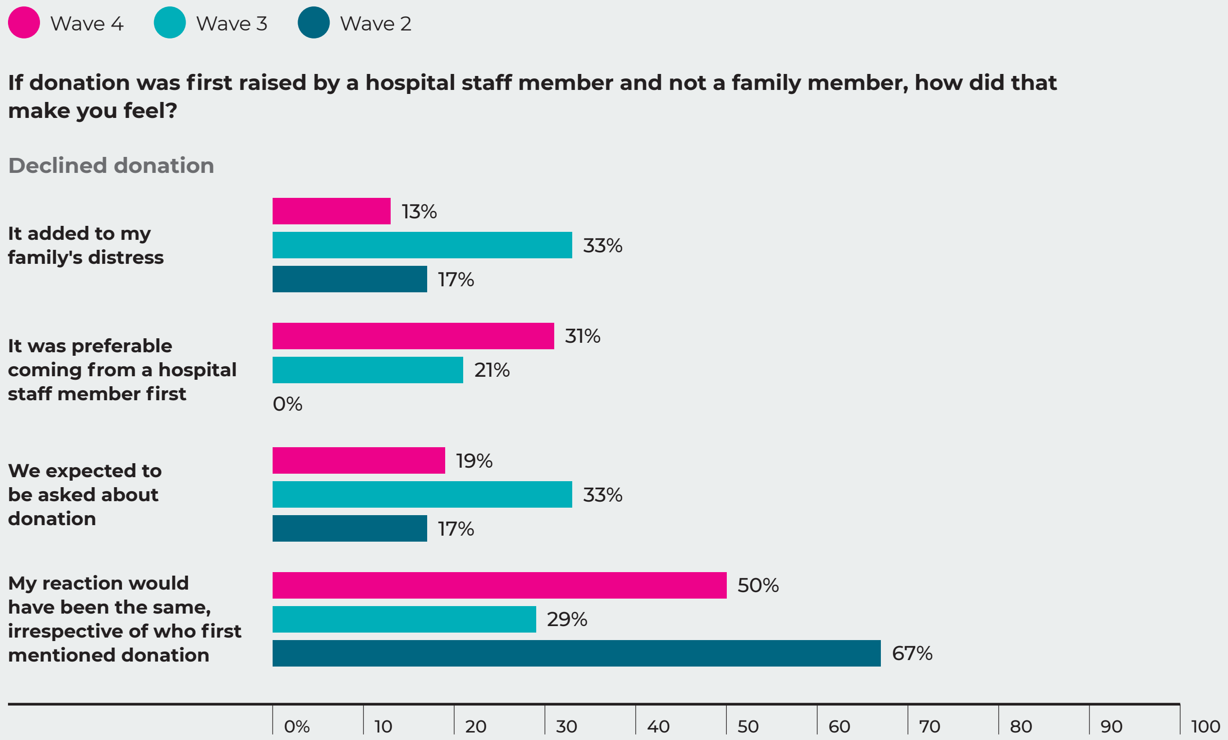


Base: Total sample of those who declined donation, less non-response: Wave 4 (n=24); Wave 3 (n=33); Wave 2 (n=12)

NB: Multiple responses allowed

Two out of these 16 families who declined donation (13%) felt that the donation conversation being initiated by a health professional added to their distress, while 5 family members (31%) said that this was preferable (Figure 22).

Figure 22 Reaction to donation being raised by hospital staff member – declined donation



Base: Declining family members who had topic of donation raised by health professional, less non-response: Wave 4 (n=16); Wave 3 (n=24); Wave 2 (n=6)

NB: Multiple responses allowed

Table 16 shows who initiated the donation conversation across waves and by donation pathway. There are no significant differences between pathways in the proportion of conversations raised by a health professional (56% in DBD cases; 57% in DCD cases).

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

Consented to donation	**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)	**Wave 4 – DBD** (n=278)	**Wave 4 – DCD** (n=127)
Doctor	**31%**	10%	34%	37% ▲	25% ▼	29%	31%	26%
Nurse	4%	5%	6%	13%	8%	16%	5%	6%
Donor coordinator	12%	20%	21% ▲	18%	26%	24%	24%	31%
Total health professional	**47%**	**35%**	**57%** ▲	**61%**	**52%**	**61%**	**56%**	**57%**
Family member/friend	10%	10%	12%	8%	10%	3%	16%	12%
Self	19%	30%	22%	24%	26%	29%	23%	20%
Total family/self	**30%**	**40%**	**33%**	**32%**	**35%**	**26%**	**35%**	**29%**
Can't recall	23%	25%	9% ▼	8%	12%	8%	8%	13%

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).

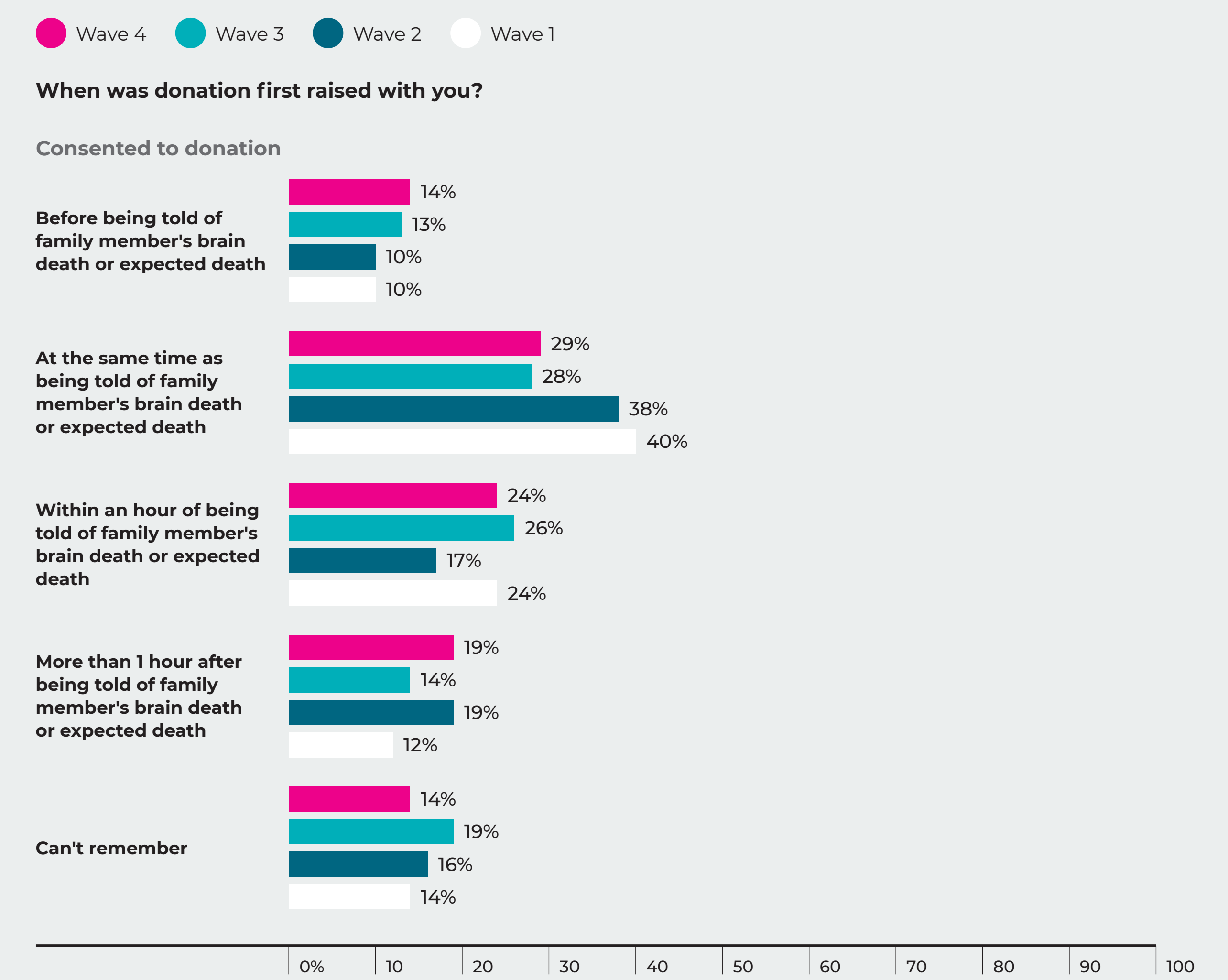
■ Denotes statistically significant difference between pathway within each wave

▲▼ Denotes a significant increase or decrease over time within each pathway

8.2 Timing of the donation conversation

In 2016 and 2017, 43% of consenting family members were asked about donation by a health professional before (14.2%) or *at the same time* (28.9%) as being told of their family member's brain death or expected death. This is consistent with Wave 3 (Figure 23).

Figure 23 Timing of the donation conversation – consented to donation



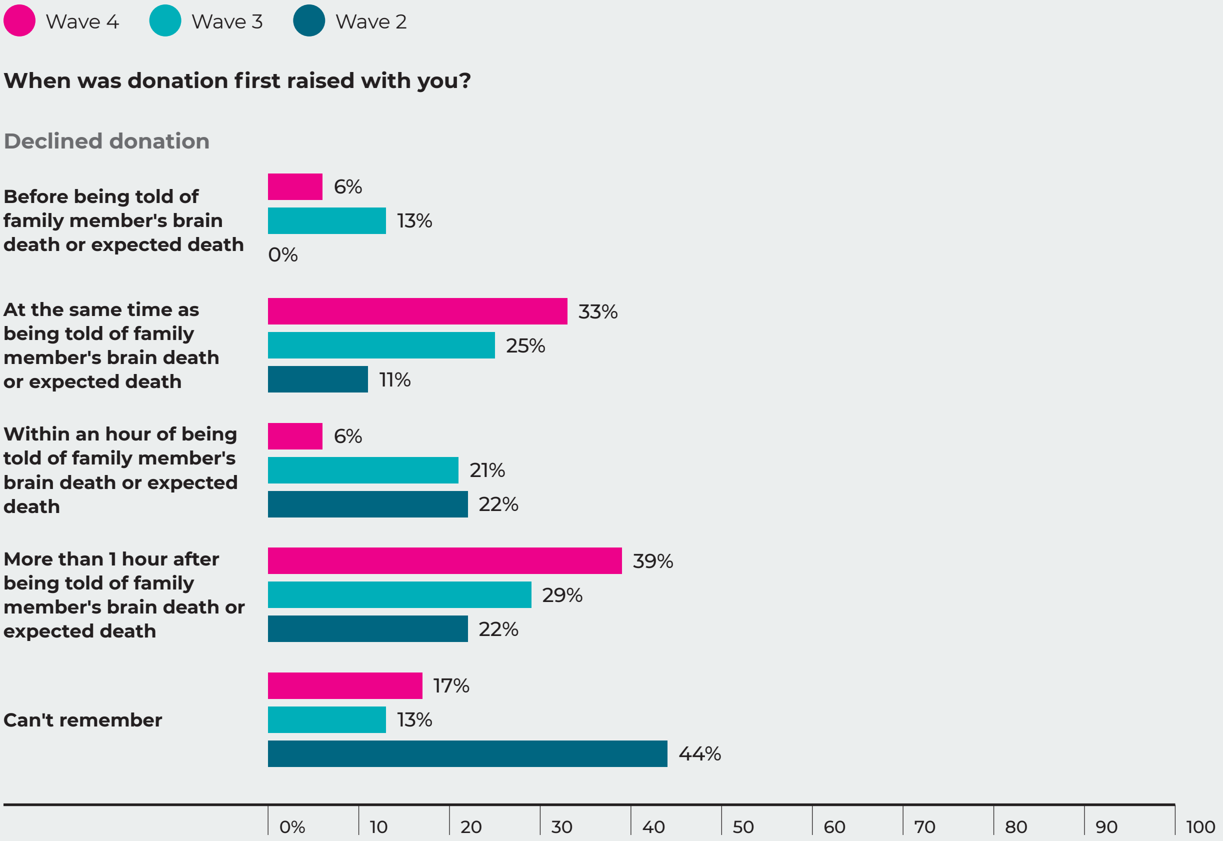
Base: Consenting family members where donation was raised by health professional, less non-response: Wave 4 (n=225); Wave 3 (n=134); Wave 2 (n=178); Wave 1 (n=84)

The timing of the donation conversation with families who declined donation is consistent with that of families who consented (Figure 24). Whilst the research tells us that families are more receptive to the donation conversation after they have had time to accept that their loved one is not going to recover, this particular quantitative finding tells us that timing is only one part of the equation – we also need to look at the approach taken.

> **“The timing was poor, very poor. I couldn't even sit down and have a coffee to even process it. My Mum was going to die that night.”**
> 2017 – Declined donation

> **“I had just lost my child and in walked the doctor to discuss donation.”**
> 2017 – Declined donation

Figure 24 Timing of the donation conversation – declined donation



Base: Declining family members where donation was raised by health professionals, less non-response:
Wave 4 (n=18); Wave 3 (n=24); Wave 2 (n=9)

Table 17 details the timing of the donation conversation, when initiated by a health professional, across states/territories. Although figures vary, any differences between states/territories are not significant. This means that throughout Australia during 2016 and 2017, the donation conversation was initiated *before* or at the *same time* as the news of death/impending death in 43% of cases and *after* the bad news was delivered in another 43% of cases.

> **They just sat there and asked us 5 minutes after we were told our son had died."**
> 2017 – Consented to donation

> **We were told of her expected brain death in the evening and discussed donation the next day."**
> 2017 – Consented to donation (timing felt to be appropriate)

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

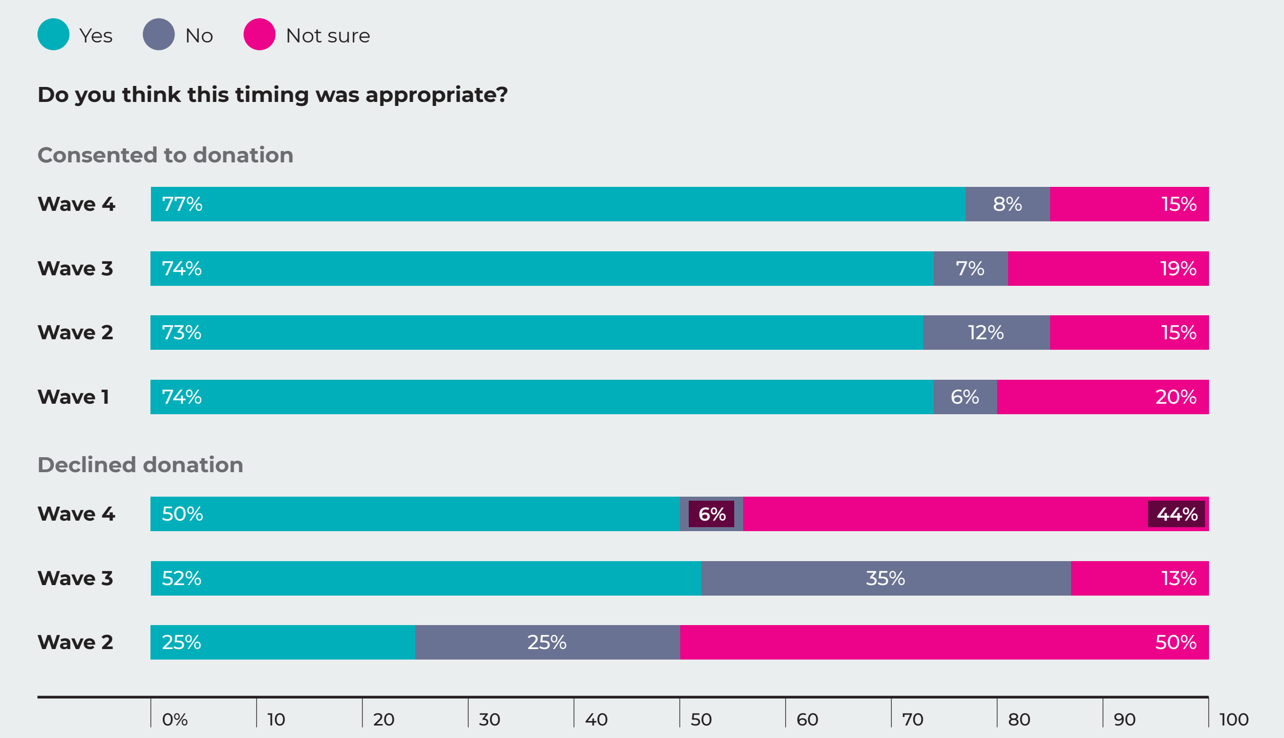
When raised by health professional	Total (n=225)	QLD (n=56)	ACT (n=10)*	NSW (n=64)	VIC (n=51)	TAS (n=10)*	SA (n=18)*	WA (n=20)*
Before	14%	13%	22%	17%	15%	–	17%	10%
At same time	29%	27%	22%	23%	35%	50%	17%	35%
Before/same time as bad news delivered	**43%**	**39%**	**44%**	**41%**	**50%**	**50%**	**33%**	**45%**
Within an hour	24%	18%	44%	34%	21%	10%	28%	10%
More than an hour	19%	23%	11%	14%	10%	40%	33%	25%
After bad news delivered	**43%**	**41%**	**55%**	**48%**	**31%**	**50%**	**61%**	**35%**
Can't recall	14%	20%	–	11%	19%	–	6%	20%

* Caution: small base

There are no significant differences between donation pathways in the timing of the donation conversation when raised by health professionals.

In total, three quarters (76%) of donor family members feel that the timing of the approach by health professionals was appropriate; 15% are not sure and 8% feel the timing was inappropriate (Figure 25). These findings are consistent with previous waves.

Figure 25 Appropriateness of donation conversation timing



Base: Consenting family members where donation was initially raised by health professional, less non-response: Wave 4 (n=221); 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 4 (n=16); Wave 3 (n=23); Wave 2 (n=8)

■ Denotes statistically significant difference between Wave 3 and Wave 4

As shown in Figure 25 above, significantly more families who consented to donation felt that the timing of the initial donation request was appropriate compared to families who later declined donation (76% of consenting families vs. 50% of declining families). Families who declined donation are more likely to have mixed feelings about the timing of the conversation (44% unsure).

Family members who felt the timing was inappropriate or who were unsure of this, needed more time to process what had happened to their loved one before being asked to consider donation, as shown in the following comments:

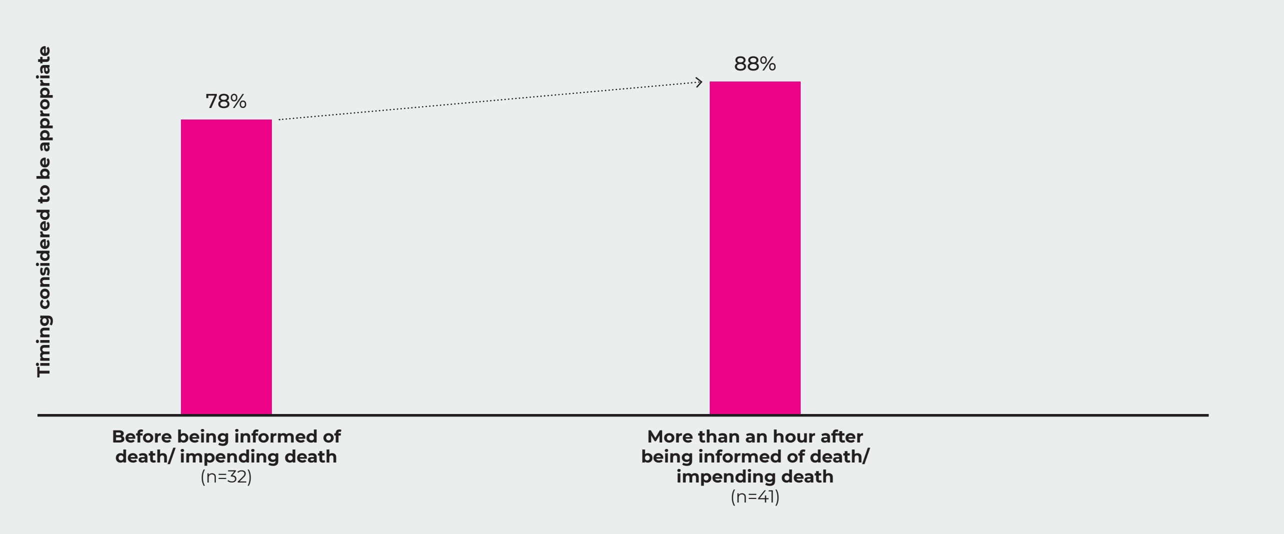
> **Don't ask [about donation] just after you are being told that he wasn't going to make it."**
> 2016 – Declined donation

> **The timing was during the family conference about the hospital's plan to turn off the machines the next day. Immediately after we were informed of this, the DonateLife people were there explaining about the organ donation option. They were very good, considerate and kind. No problems there, but it may have helped if we were warned about it and had a bit of time to consider it as a family along with everything else. It hadn't even sunk in that my husband was brain dead (I wasn't 100% sure of this) and suddenly we were expected to deal with organ donation. If my youngest daughter hadn't spoken up to all of the family so positively on organ donation, I am not sure what decision we would have made at the time- it was all so rushed and there was so much to consider."**
> 2016 – Consented to donation

> **Timing is everything, do not tell me my husband is dead and then ask me, 'have I considered organ donation?'. Allow me time to process the passing properly and grieve for a moment about my loss. Let me hold my children and catch my breath and then ask me the hard questions, because my initial response was not positive."**
> 2016 – Consented to donation

Figure 26 shows that when donation is raised by a health professional, the perceived appropriateness of the timing increases when families are given some time to process the news of impending death or brain death of their family member.

Figure 26 Appropriateness of timing when donation raised by health professional



Families have to know that their loved one has died or will soon die, before they can 'hear' any other information. They need time to digest the grave news, to grieve and to come to some level of acceptance before being asked to consider donation. Mostly, family members have to know that medical staff have done absolutely everything that can be done to help their loved one.

Consistent with previous waves, Wave 4 findings indictate that there is no golden rule for the best time to raise the topic of donation; rather medical staff are advised to use their judgement, allow some time for information to 'sink in' and be guided by how the family are responding to information.

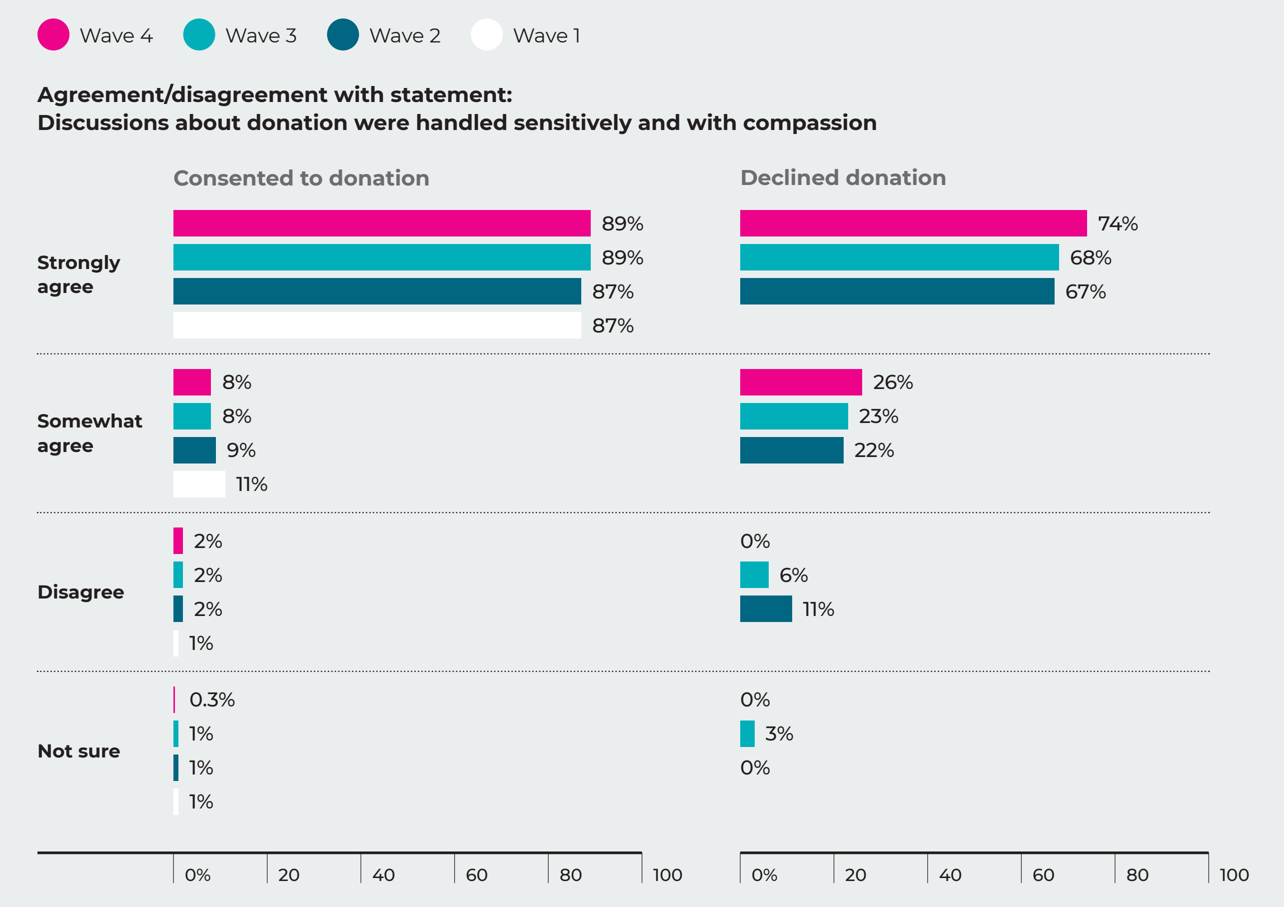
The research findings indicate that the donation conversation should not be initiated before or at the same time as delivering bad news to families; rather the timing is considered to be more appropriate when the conversations are separated and paced in line with the family's needs.

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 (74% strongly agree). Findings are consistent with previous waves (Figure 27).

Figure 27 Tone of donation conversation



Base: Families who consented to donation, less non-response: Wave 4 (n=391); Wave 3 (n=247); Wave 2 (n=301); Wave 1 (n=181)

Base: Families who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=31); Wave 2 (n=9)

> **It was good. There wasn't anything negative about any of the handling that I could say.”**
> 2016 – Consented to donation

> **I don't know her name, but I will say she was very good, very empathetic. I couldn't say a bad word about her.”**
> 2016 – Consented to donation

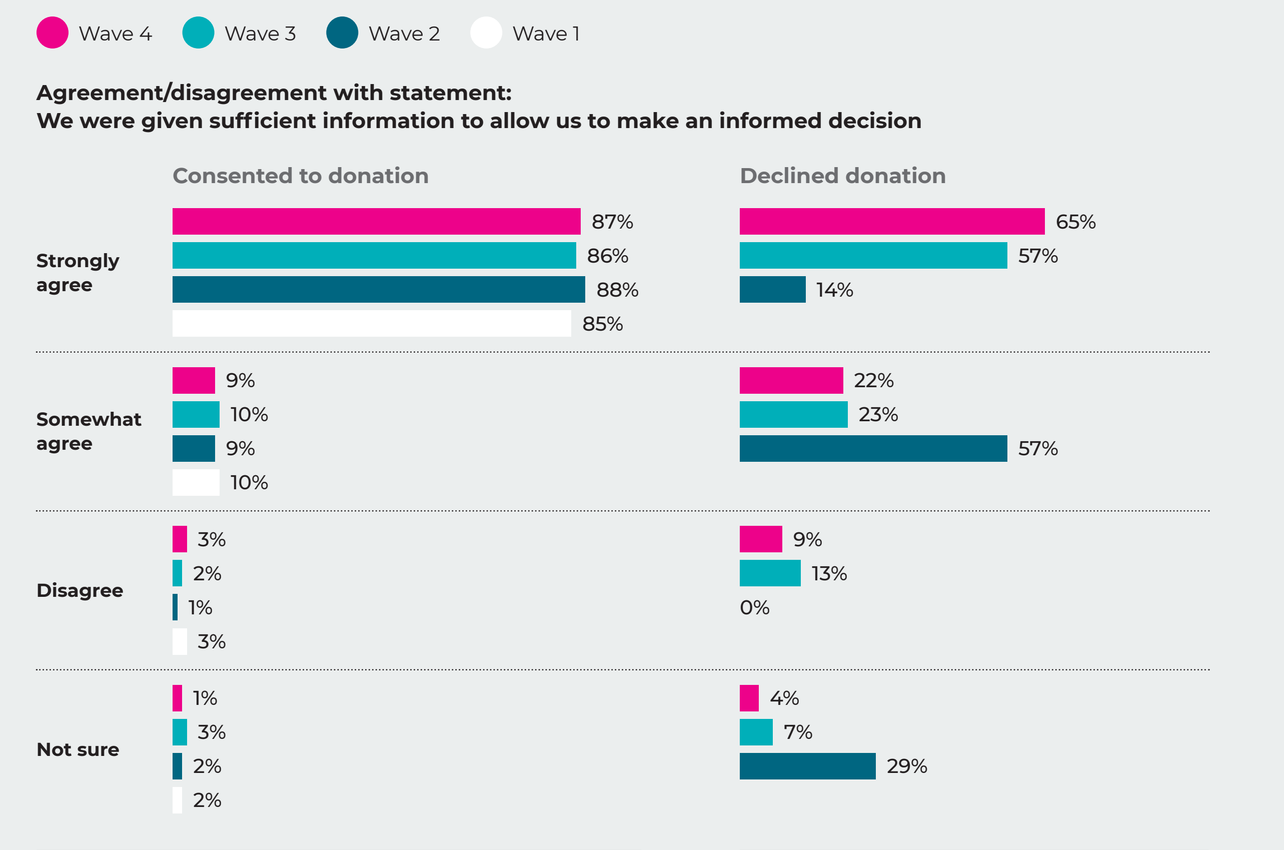
When families disagree with this statement, it tends to be not only about the tone of the conversation, but about what is said and how donation is introduced.

> **Harvested probably isn’t the right word, they need to find a kinder word.**
> **I don’t know what else she’d say but harvested just seems a little bit cold and cruel.”**
> 2017 – Consented

8.4 Information to enable an informed decision

With regards to making a decision about donation, 96% of donor family members agree (87% strongly) that they were given sufficient information to allow them to make an informed decision (Figure 24); consistent with previous waves.

Figure 28 Sufficient information to make an informed decision



Base: Total sample of families who consented to donation, less non-response: Wave 4 (n=381); Wave 3 (n=238); Wave 2 (n=290); Wave 1 (n=179)

Base: Total sample of families who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=30); Wave 2 (n=7)

> **She had a folder with her and she gave us all a brochure. I think I requested a little break there and then to let it sink in.”**
> 2017 – Consented to donation

> **It was very straightforward, no mucking around. It was just sort of like, bang, bang, bang, this is what we do, and this is how we do it. And there was plenty of time for questions if you had questions.”**
> 2017 – Consented to donation

Families who declined donation are significantly less likely to feel that they were given sufficient information to allow them to make an informed decision (65% strongly agree that they were).

> **I don't think so [they didn’t leave any information or pamphlets]. I think because his father reacted so badly, I think they perhaps wanted us to have some time to talk about it.”**
> 2017 – Declined donation

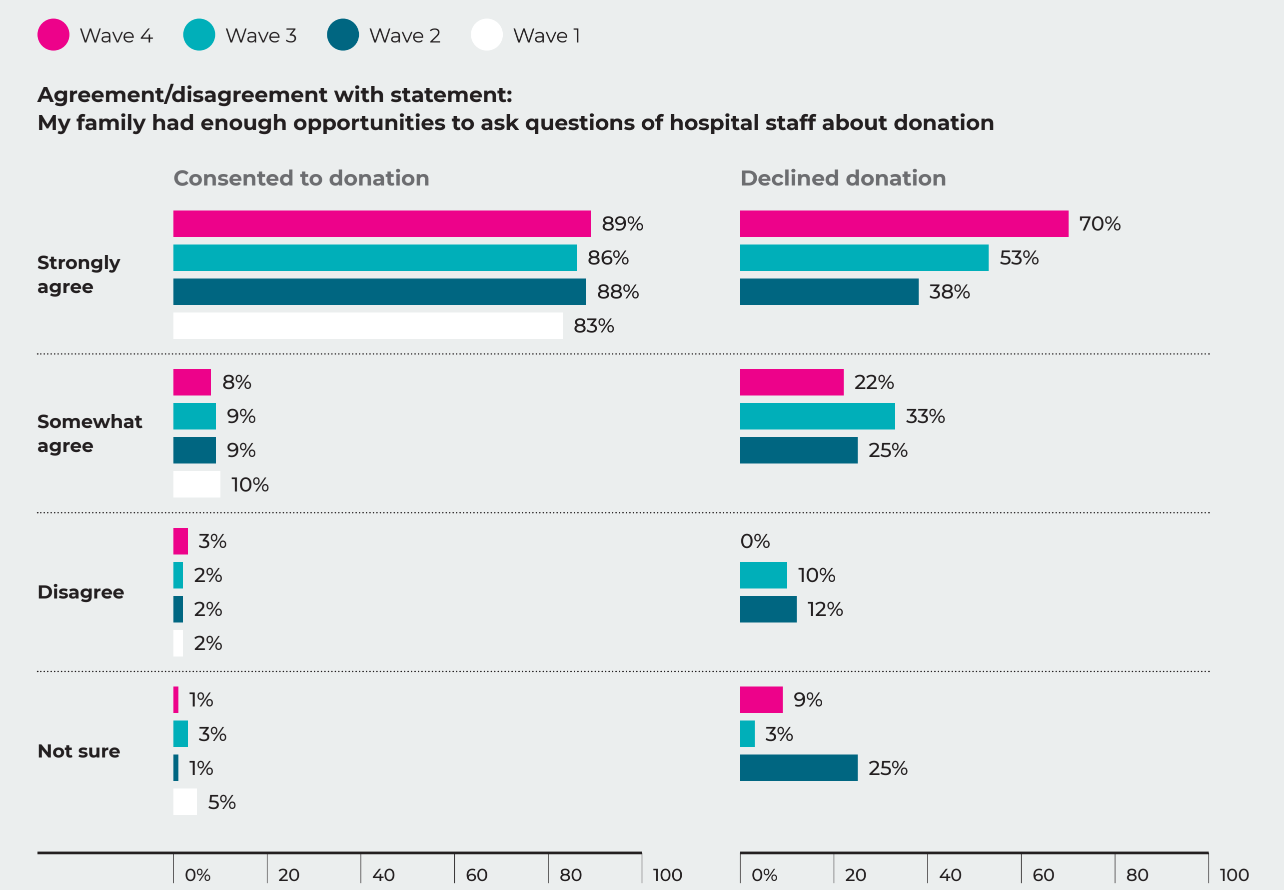
> **In terms of increasing the number of donors, I suppose maybe having some more data or information at hand to be able to talk through these complex, usually religious or ethical discussions, might have been helpful. But again, it's really hard to say because you're in a heightened emotional state and our capacity for taking in new information was reduced by that time. So, it may or may not have had an impact.”**
> 2017 – Declined donation

As demonstrated in the above two comments, it can be difficult for family members to absorb information during their time in hospital due to their emotional state. Further, if a family is against donation, hospital staff may not feel comfortable providing donation information to that family. However, in order for a family to make an *enduring informed donation decision*, it is important to provide them with an easy-to-read brochure and to also ensure that families know that the lines of communication are open should they wish to ask questions.

Regarding the latter, Figure 29 shows that 89% of donor families in 2016 and 2017 strongly agree that their family was provided with enough opportunities to ask questions of hospital staff about donation. Families who declined donation are significantly less likely to feel they were given enough opportunities to ask questions (70% strongly agree). This is a marked improvement over previous waves.

Further, 89% of donor family members strongly agree that hospital staff answered their questions. This is consistent with earlier waves, as shown in Figure 30. Again, families who declined donation are significantly less likely to agree that this occurred (70% strongly agree).

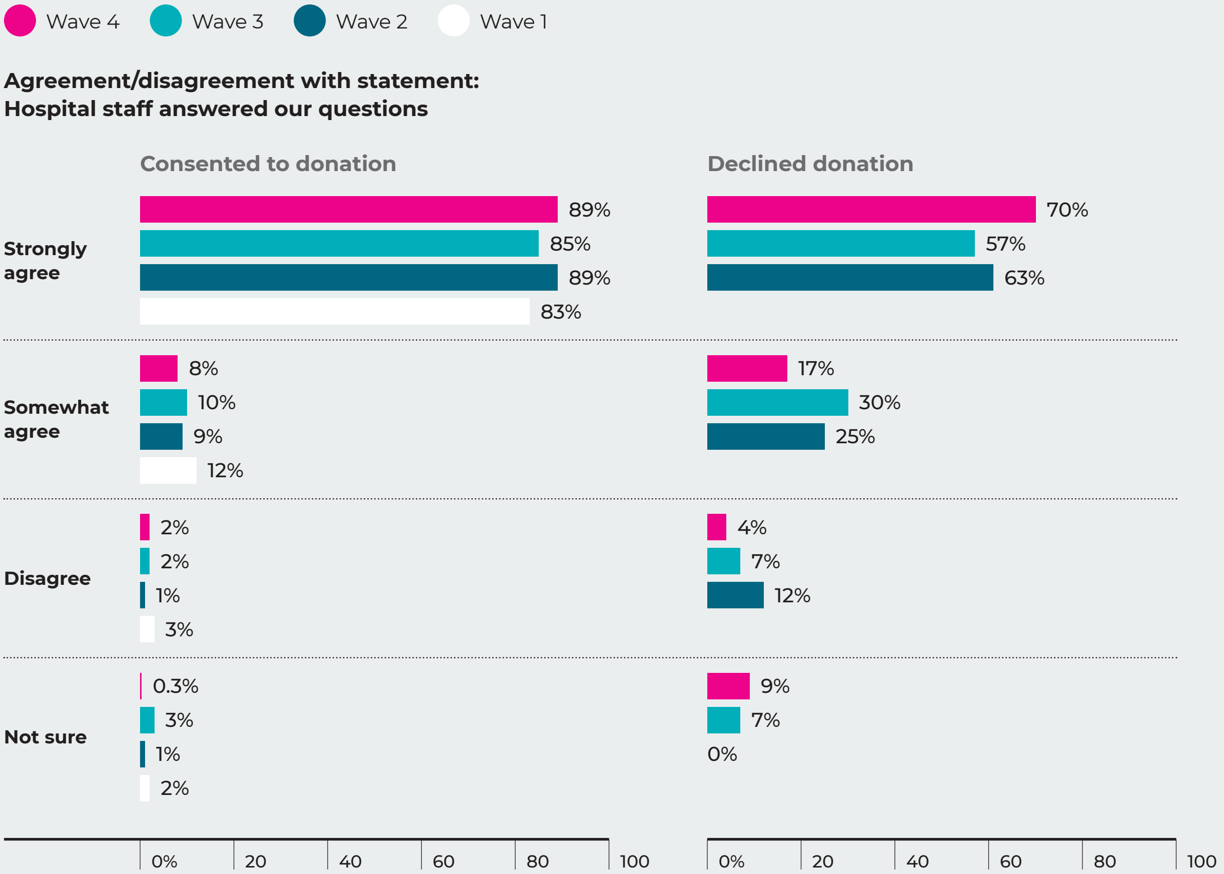
Figure 29 Opportunities to ask questions



Base: Family members who consented to donation, less non-response: Wave 4 (n=384); Wave 3 (n=244); Wave 2 (n=290); Wave 1 (n=179)

Base: Family members who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=30); Wave 2 (n=8)

Figure 30 Hospital staff answered questions



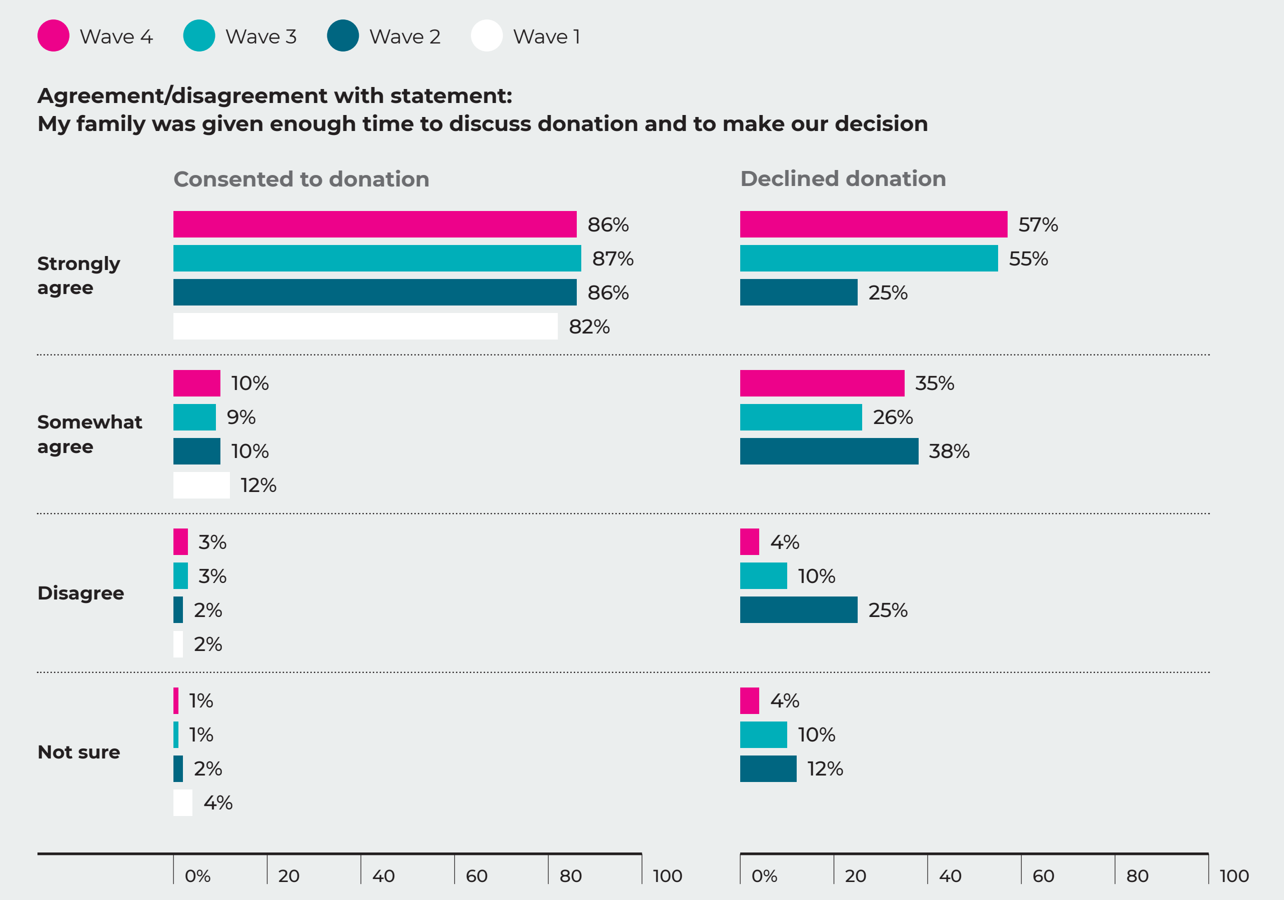
Base: Family members who consented to donation, less non-response: Wave 4 (n=381); Wave 3 (n=239); Wave 2 (n=290); Wave 1 (n=179)

Base: Family members who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=30); Wave 2 (n=8)

8.5 Time to consider donation

The majority of donor families feel that they were given enough time to discuss donation and to make their decision (86% strongly agree), as shown in Figure 31. Families who declined donation were much less likely to feel that they were given enough decision-making time (57% strongly agree; a significant difference).

Figure 31 Time to make a decision



Base: Family members who consented to donation, less non-response: Wave 4 (n=381); Wave 3 (n=238); Wave 2 (n=288); Wave 1 (n=180)

Base: Family members who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=31); Wave 2 (n=8)

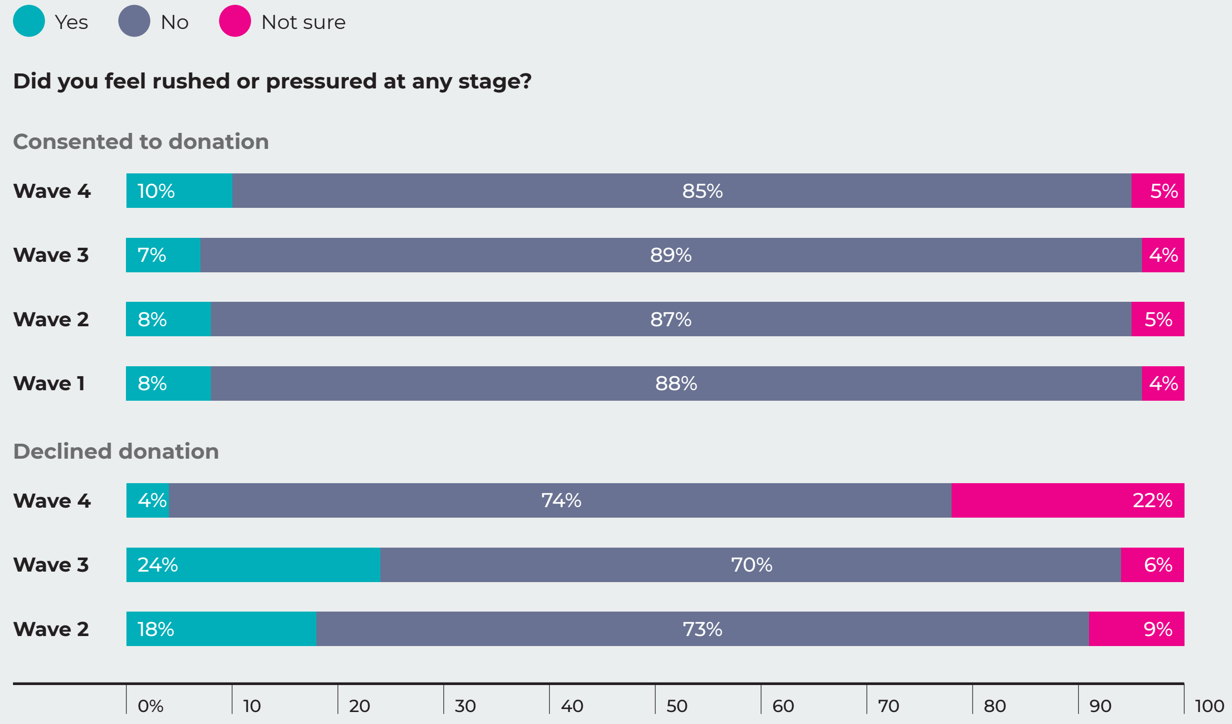
Eighty-five percent (85%) of consenting donor family members and 74% of families who declined donation did not feel rushed or pressured to make a decision about donation (Figure 32).

> **I didn't feel like I was being pushed in any one direction or the other.”**
> 2017 – Declined donation

> **I think she just asked if I would agree. I can't remember her exact words but it was just a simple question really and I said, ‘no’. And she didn't try to push me or anything.”**
> 2017 – Declined donation

Although a small sample size, significantly more families who declined donation are unsure if they felt rushed or pressured (22% compared with 5% of families who consented to donation).

Figure 32 Feeling rushed or pressured



Base: Family members who consented to donation, less non-response: Wave 4 (n=396); Wave 3 (n=254); Wave 2 (n=310); Wave 1 (n=182)
Family members who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=33); Wave 2 (n=11)

The questionnaire gives an opportunity for family members who felt pressured to provide more information which provides an understanding of where that pressure stems from. Feeling pressured can not only stem from *time constraints* placed on the family, but can also be a result of a *lack of privacy*, *what's* being said, *how* it's being said and *when* it's being said.

> **“Staff told us the faster we made our decision the better it would be. They said it would make the process easier. It would have been nice to make the decision without pressure.”**
> 2016 – Consented to donation

> **“Not well managed by the donation team. We had to ask them to leave us so as to discuss as a family.”**
> 2017 – Consented to donation

> **“They wanted me to sign before I could discuss with my family. They were pushy.”**
> 2017 – Consented to donation

8.6 Improving the donation conversation – 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**. This was an open ended question. Findings were collected verbatim and have been grouped together into similar themes and shown in Table 18.

Table 18 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)	Wave 4 (n=213)
No improvements necessary: Discussions handled well	49%	49%	48%	39%
No improvements necessary: Staff were compassionate and supportive	–	16%	9%	14%
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%	5%
Provide more information regarding timing and delays/process took too long/lengthy process waiting for donation surgery	4%	5%	7%	4%
More compassion/understanding/empathy	1%	2%	2%	4%
The timing – we felt rushed	3%	1%	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%	3%
Nothing could make it easier/difficult and confronting decision to make	3%	2%	1%	3%
Provide a better explanation of why some organs cannot be used	2%	1%	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%	2%
More discussion/don't feel it was discussed with hospital staff (on what happens after you say goodbye and the process after surgery)	–	2%	1%	1%
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%	1%
Improve timing of discussion with DonateLife staff/had to wait a long time to talk with DonateLife staff member	2%	1%	2%	–
Don't know/can't think of anything specific	6%	15%	21%	13%

NB: Table does not show 'other' one-off responses

As shown in Table 18, 52% (net) of family members feel that no improvements were necessary as the discussions were handled well and/or staff were compassionate and supportive. There is still scope, however, to improve communication with family members, to ensure that they understand the broad steps in the process leading to donation.

> **“Whilst we were made aware by the Intensive Care ward staff that our loved one's brain haemorrhage was not operable and therefore he would not survive, not one staff member was able to explain to our family what the process was for organ donation. We had to wait until the next morning until the Intensivist came on duty to explain it to us. It would have made it so much easier for us as a family if someone had been able to explain the process to us that night, particularly as one of my children was interstate at the time.”**
>
> 2017 – Consented to donation

Family members need a private room or space in which they can gather, discuss donation and make a decision that is right for them.

They should be provided with sufficient information to enable them to make an informed decision and hospital staff should ensure that families know that they can ask questions at any time.

Key pieces of information required at this stage are around the process and timelines.

9 Moving toward donation

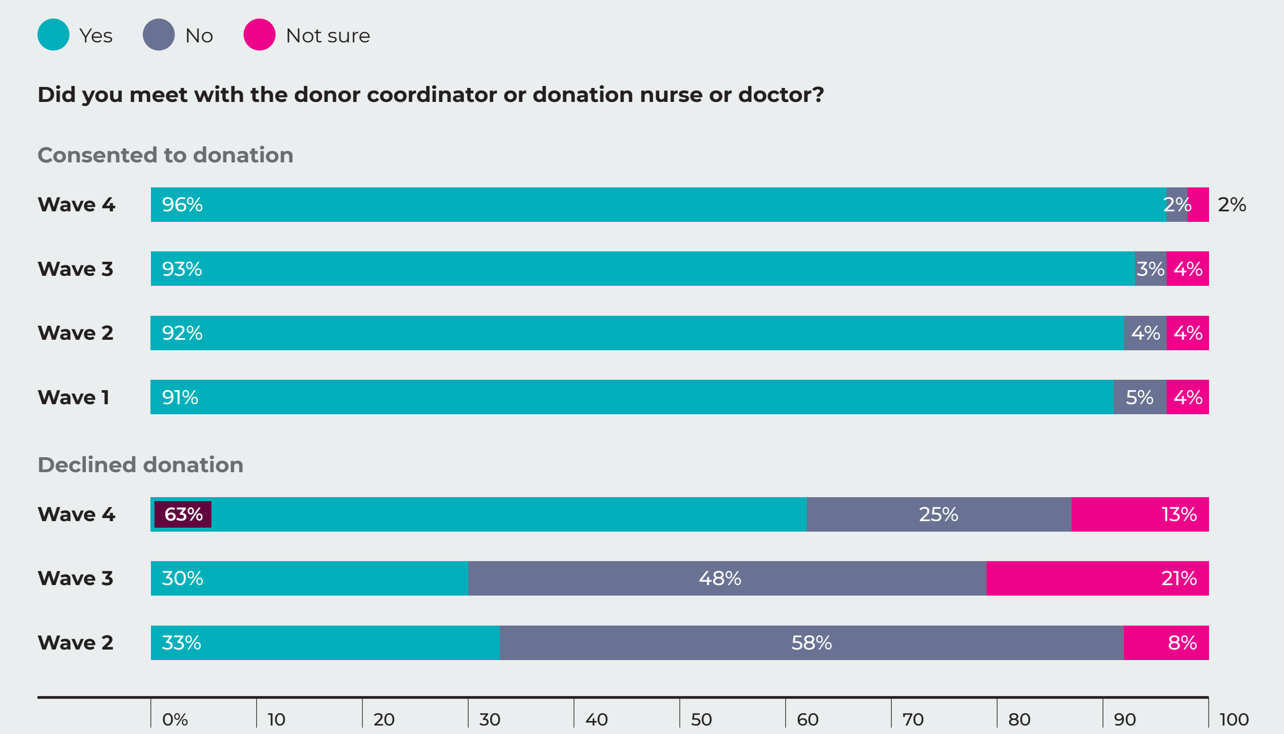
9.1 Understanding of the donation process

Most donor families in 2016 and 2017 (96%) recall meeting with the DonateLife coordinator, nurse or doctor (Figure 33). After this meeting, 84% of donor family members felt well informed; 14% still had unanswered questions and 2% left the meeting with no clear understanding of the donation process (Table 19). These findings are consistent with previous research waves.

> **Every time a different relative came, the organ donation people explained the whole process to them too, like each grandmother and grandfather. It was explained very well to all of us."**
> 2017 – Intended donor family

> **I was well informed to the extent that I could take it in while being in shock."**
> 2016 – Consented to donation

Figure 33 Meeting donation staff



Base: Families who consented to donation, less non-response: Wave 4 (n=399); Wave 3 (n=257); Wave 2 (n=317); Wave 1 (n=183)
Families who declined donation, less non-response: Wave 4 (n=24); Wave 3 (n=33); Wave 2 (n=12)

■ Denotes statistically significant difference between Wave 3 and Wave 4

As shown in Figure 33 above, significantly fewer families who went on to decline donation met with a DonateLife coordinator, nurse or doctor (63%).

Of those declining families who did meet with a DonateLife coordinator, nurse or doctor and subsequently declined donation, only 60% felt they were well informed after this meeting. The remaining families left the meeting with unanswered questions (20%) or with no clear understanding of the donation process (20%).

When families are not well informed, it can have a lasting effect and cause some regrets.

> **From when we were told she passed and organ donation was agreed to, I wasn't informed what happened next. This upset me greatly as afterwards I felt I should have been with her when she was taken off life support.”**
> 2016 – Consented to donation

To summarise, families who declined donation are significantly:

- Less likely to have met with a DonateLife coordinator, nurse or doctor (63% compared to 96% of families who consented to donation)
- More likely to *not* understand the donation process (among those who did speak with a DonateLife coordinator, nurse or doctor) (20% compared to 2% of families who consented to donation).

Table 19 Understanding of donation process after meeting with donation staff

Understanding of donation process after speaking with DonateLife coordinator, nurse or doctor	Consented to donation				Declined donation*		
	Wave 1 (n=164)	Wave 2 (n=290)	Wave 3 (n=240)	Wave 4 (n=372)	Wave 2 (n=3)	Wave 3 (n=10)	Wave 4 (n=15)
I was well informed and knew all that I needed to know about the donation process	82%	83%	80%	84%	100%	**50%**	60%
I was informed but still had some questions	16%	14%	18%	14%	–	20%	20%
I didn't have a good understanding of the donation process	2%	2%	2%	2%	–	**30%**	20%

* Caution: small base

■ Statistically significant difference compared to families who consented to donation

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 previous waves, across donation pathways and amongst intended donor families. It is important that this practice continues for all families who consent to donation, so that expectations are managed.

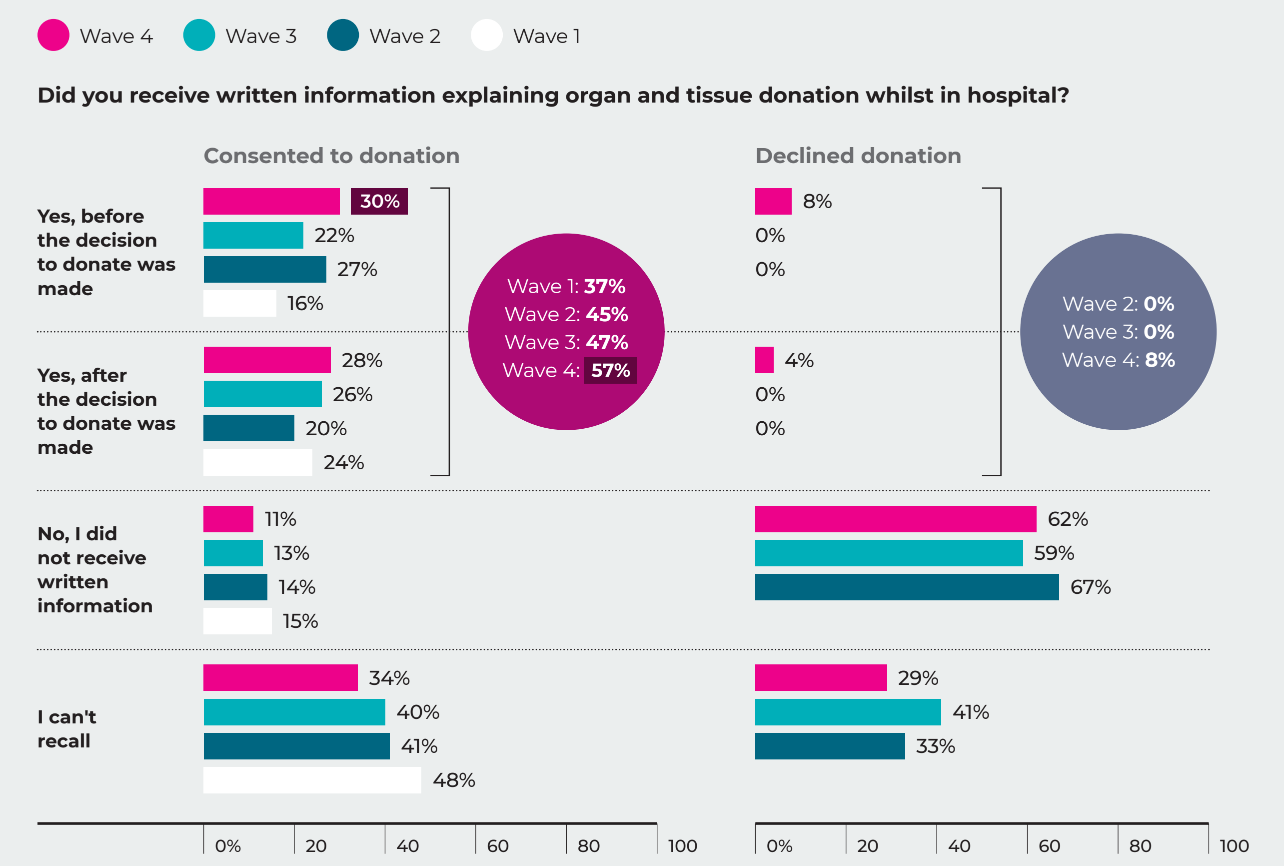
9.2 Provision of written information

In 2016 and 2017, 57% of family members recall being provided with written information explaining organ and tissue donation whilst in hospital (Figure 34), a significant improvement of 10% since the previous wave. One in nine donor family members (11%) were not given written information about donation and 34% can't recall.

Of families who declined donation, just 8% say they received written information explaining organ and tissue donation while they were in hospital. Six in 10 (62%) declining family members were not provided with written information, while 29% do not recall if they received anything.

> **We had pamphlets and I read them afterwards. They actually told us what was in the pamphlets and said when we feel the time is right, we could read up on it. They had explained a lot of it prior.”**
> 2017 – Intended donor family

Figure 34 Provision of written information



Base: Total sample who consented to donation, less non-response: Wave 4 (n=395); Wave 3 (n=254); Wave 2 (n=316); Wave 1 (n=183). Total sample who declined donation, less non-response: Wave 4 (n=24); Wave 3 (n=32); Wave 2 (n=12)

NB: Multiple response

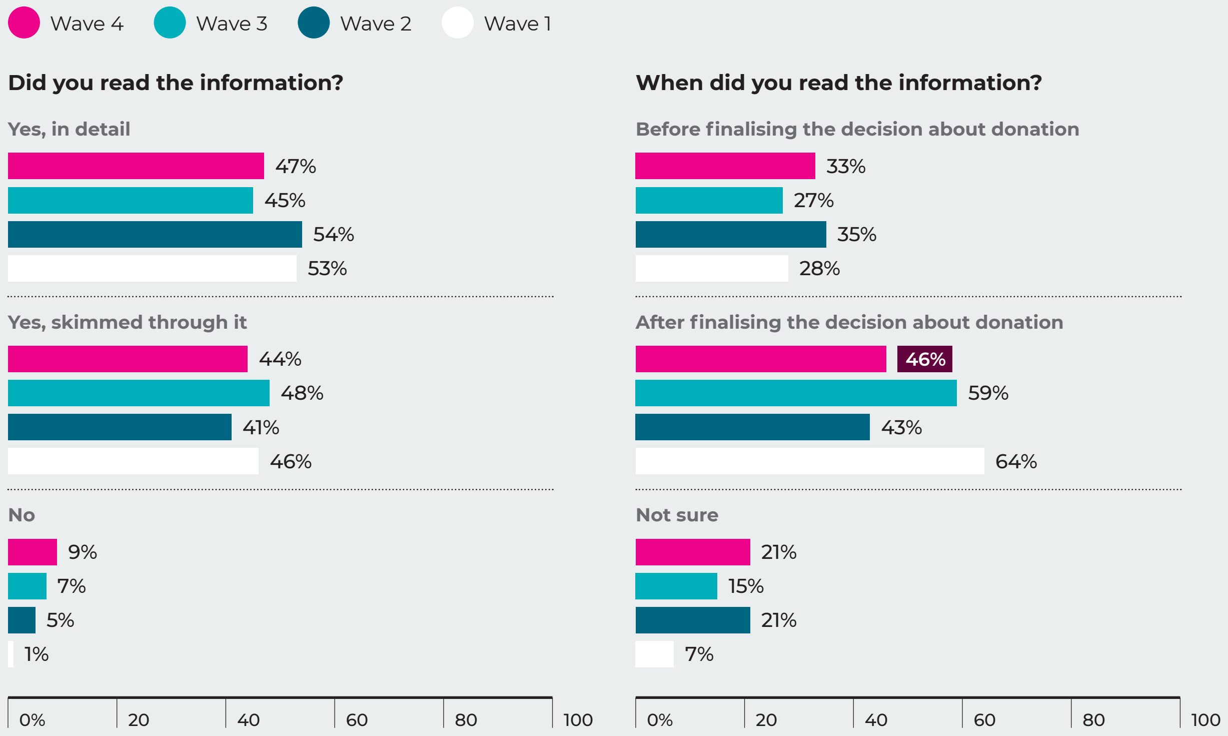
■ Denotes statistically significant difference between Wave 3 and Wave 4

For donor families who received information when in hospital, just under half (47%) read the information in detail, while 44% skimmed through it. Nine percent (9%) of families who were given information decided not to read it (Figure 35). This is consistent with previous waves.

> **"The written material was not as important to us as the decision was relatively easily made, so the detail was perhaps not as relevant."**
> 2017 – Consented to donation

> **"Our coordinator explained it well and answered our questions. I could not focus or read anything at that point."**
> 2017 – Consented to donation

Figure 35 Reading of written information



Base: Family members who consented to donation and received written information, less non-response: Wave 4 (n=224); Wave 3 (n=119); Wave 2 (n=143); Wave 1 (n=68).

Those who read the information, less non-response: Wave 4 (n=200); Wave 3 (n=111); Wave 2 (n=133); Wave 1 (n=67).

■ Denotes statistically significant difference between Wave 3 and Wave 4

For those 91% of donor family members who read the written information provided to them in the hospital, 46% read it *after* they had already made their donation decision and 33% read the information *before* finalising their donation decision.

> **“The verbal information was provided to the family; the written was to read at our leisure, then we received additional literature by mail – very helpful. Plus phone follow-up was great.”**
> 2017 – Consented to donation

As shown in Table 20, almost all (94%) family members who received and read the written information explaining organ and tissue donation whilst in hospital, found it to be useful (47% 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 (66% compared with 27%), which emphasises the importance of encouraging family members to read the information, in their own time.

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)	Wave 4		
				Total who received and read information (n=196)	Read in detail (n=103)	Skimmed through (n=93)
Very useful	54.5%	52%	42%	47%	**66%**	27%
Quite useful	41.0%	44%	53%	47%	32%	**63%**
Not useful	4.5%	2%	5%	5%	2%	**9%**
Can't recall	–	1%	–	1%	–	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 tailored to the needs of individual family members – succinct and delivered in layman's terms for ease of processing, or more detail when requested.

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

9.3 Support from health professionals – after consenting to donation

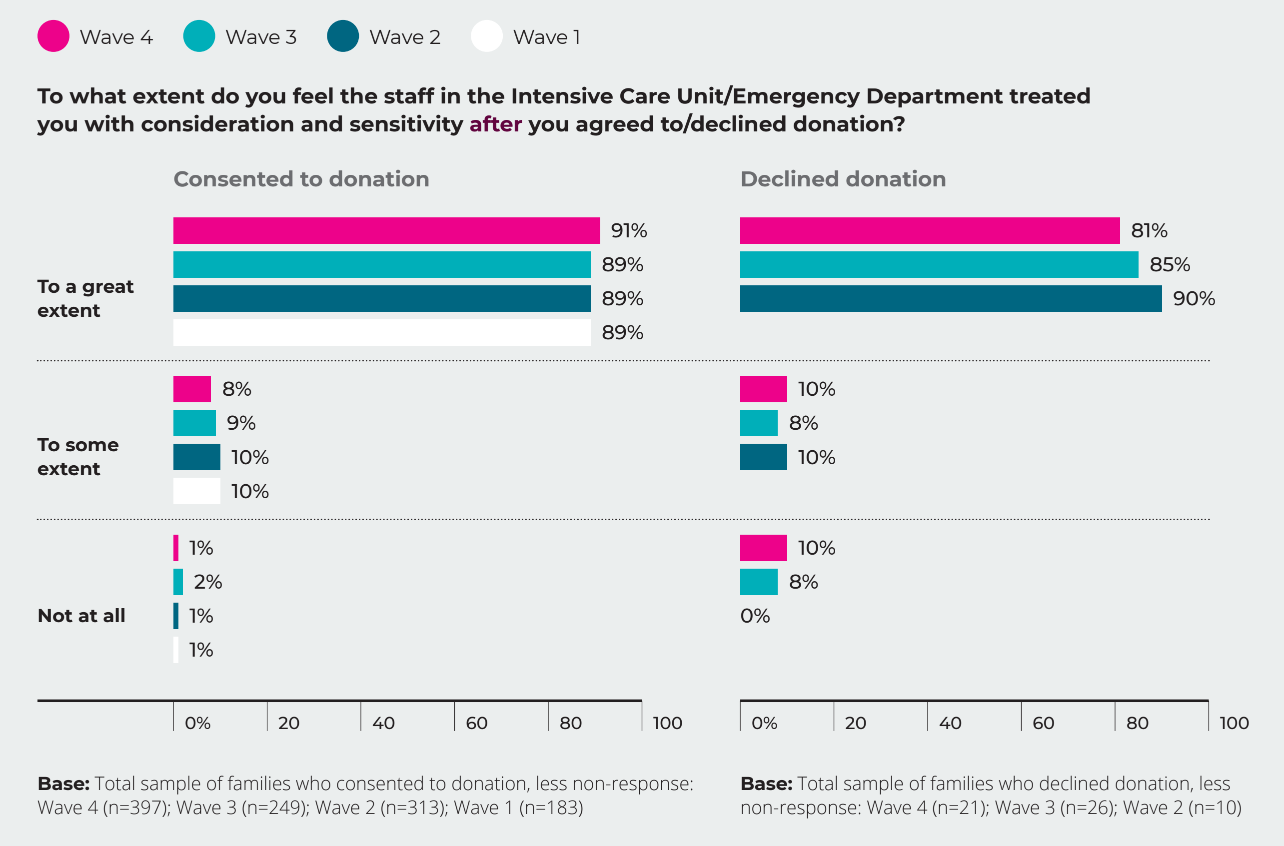
Nine in ten families (91%) feel that staff in the ICU or ED treated them with much consideration and sensitivity *after* they consented to donation. For families who declined donation, this figure drops to 81%, although the difference isn't statistically significant (Figure 36). These findings are consistent with previous waves.

> “ **The respect shown to both my family and sister was wonderful, both before and after the decision to donate was made. We were encouraged by our coordinator to take our time in the decision process.”**
>
> 2016 – Consented to donation

> “ **Staff were supportive and respectful before, during and after the process of donation.”**
>
> 2017 – Consented to donation

> “ **I imagine it's disappointing for them in their area of work saving lives, yet they remained professional and didn't treat us differently.”**
>
> 2016 – Declined donation

Figure 36 Treatment by staff after donation decision



Base: Total sample of families who consented to donation, less non-response: Wave 4 (n=397); Wave 3 (n=249); Wave 2 (n=313); Wave 1 (n=183)

Base: Total sample of families who declined donation, less non-response: Wave 4 (n=21); Wave 3 (n=26); Wave 2 (n=10)

9.3.1 Small but meaningful gestures

In defining the quality of care families receive post their donation decision, it continues to be the way medical staff care for their loved one, how they treat them with respect and use their loved one's first name whenever they are doing a medical procedure with them, and the little, human touches and gestures from hospital staff towards family members, that families remember so clearly.

These little gestures are interpreted by families as acts of great kindness. They are the things that, when reflecting on a horrible situation, are treasured.

> **The doctors and nurses were amazing, they even came and danced with me to his favourite songs."**
> 2017 – Consented to donation

Family members recall a loved one's favourite music being played in ICU; an attentive ICU nurse washing a loved one's hair; being encouraged by a nurse to rub moisturiser into their child's hands; being encouraged to place photos of happy memories around a loved one's bed; the offer of handprints, a quilt, a lock of hair; parents being allowed to cuddle their child in their ICU bed.

All of these things demonstrate complete respect for the patient and their family and importantly, they provide family members with solace during a time of great sadness.

> **The hospital staff were exemplary. They made the worst time in our lives bearable. They didn't just care for our mum, they cared for our family too. Photos of mum were printed and placed on the windows. The staff constantly kept us in the loop and even though mum had no hope of recovery they always talked to her compassionately when doing their obs."**
> 2017 – Consented to donation

> **They were very caring. They treated him like he was still alive. You know, like they were kind to him, they would be nice to him. They just talked to him like he could hear what they were saying.”**
> 2017 – Consented to donation

> **The staff were gentle and caring and kind when we needed it most. I appreciate that they took time to make my daughter look as lovely as possible. This meant a lot to me.”**
> 2017 – Consented to donation

> **The quilt we received meant the world to us during donation and the death process.”**
> 2016 – Consented to donation

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 a decline response.

Continue to demonstrate kindness and respect towards families and their loved ones, knowing that this helps families tremendously.

9.3.2 Support of social worker, counsellor or chaplain

In 2016 and 2017, 84% 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 37), which is consistent with previous waves. Three quarters (75%) of families who declined donation were also offered this type of support, statistically consistent with consenting family members.

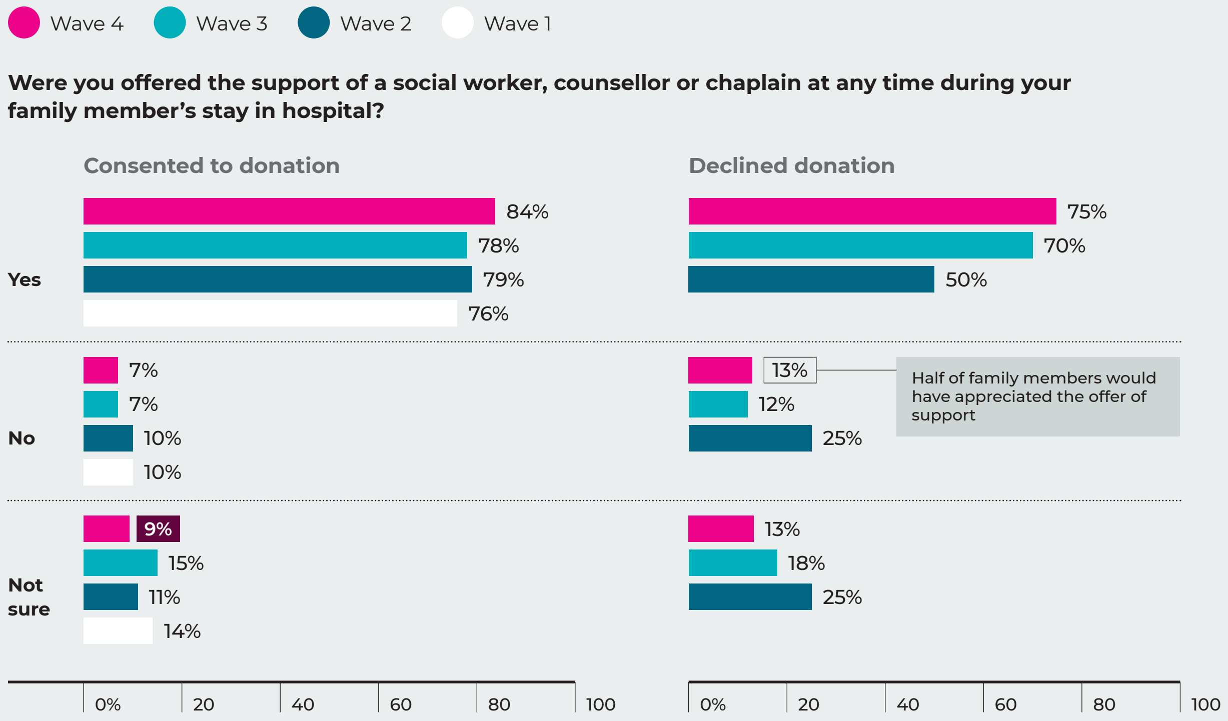
> **The social workers at the hospital were excellent and of maximum help.”**
> 2016 – Consented to donation

> **Both social workers were different in the way that they approached things but they were both very useful and very helpful.”**
> 2017 – Declined donation

Conversely, 7% of donor families and 13% of declining families were not offered support from a social worker, counsellor or chaplain during their time in hospital.

> **I was a bit disappointed with the social worker. She didn't really make contact at all. So, that was something that was quite lacking.”**
> 2017 – Consented to donation

Figure 37 Support offered during stay in hospital



Base: Total sample who consented to donation, less non-response: Wave 4 (n=395); Wave 3 (n=254); Wave 2 (n=314); Wave 1 (n=183)

Total sample who declined donation, less non-response: Wave 4 (n=24); Wave 3 (n=33); Wave 2 (n=12)

■ Denotes statistically significant difference between Wave 3 and Wave 4

The value to families of a trained and experienced social worker or counsellor in hospital doesn't end at the emotional support they provide. Families are grateful for social workers who take initiative and help with the practical things that need to be done. Examples include calling friends and family to update them on the situation, providing advice around the best places to park/arranging free parking, and sorting out accommodation when needed.

> “ **The social worker at the hospital organised it all [forms for underage sibling to fly to location of hospital]. Because you've got to email it, print it out, sign it, fax it back all that sort of stuff.”**
>
> 2017 – Intended donor family

Feedback from families about hospital social workers is mixed, with some families having a positive experience and finding them incredibly useful and supportive, and others finding their interaction with a social worker to be less than satisfactory. Consistent with previous waves, complaints appear to centre around a perceived lack of interpersonal skills.

> “ **The doctor, nurses, chaplain and donate staff did an amazing job but one of the social workers was obviously having a bad day – she should have stayed home from work that day.”**
>
> 2017 – Consented to donation

> “ **The medical staff (especially one nurse) treated us with consideration and respect. Some of the social workers did not.”**
>
> 2017 – Consented to donation

Table 21 shows findings across the four waves of research, split by donation pathway. In 2016 and 2017, 90% of DCD family members were offered the support of a social worker, counsellor or chaplain, compared with 82% of DBD family members. This is a significant difference.

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		2016/2017 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)	**DBD** (n=271)	**DCD** (n=124)
Yes	74%	**95%**	78%	84%	77%	79%	82%	**90%**
No	11%	–	10%	8%	8%	5%	8%	3%
Not sure	15%	5%	11%	8%	15%	16%	10%	7%

■ Denotes statistically significant difference between DCD and DBD family members

9.4 The donation process – from consent to surgery

Once consent to donate has been given, many things begin happening in the background to facilitate donation that families are sometimes not fully aware of. Without a basic understanding of what needs to happen and when, families can make assumptions about timelines and practices, and incorrect assumptions can lead to disappointment and frustration, as shown in Section 9.4.1.

The time between consenting to donation and donation surgery can sometimes be viewed by family members as a blessing – more time to spend with their loved one. For other families, this time can be distressing and full of second-guessing – are we doing the right thing?

Medical and nursing staff should be aware of the multitude of emotions that family members are likely to be experiencing during this time. It is important to continue to support and care for families while maintaining a consistent level of care for their loved one (not only for their organs, but for them as a person) as the time for donation surgery nears.

> **“I was surprised at how attentive they were and felt completely supported.”**
> 2017 – Consented to donation

> **“It was very stressful waiting from decision to surgery.”**
> 2017 – Consented to donation

> **“That's brutal, because you know that all the care in her room in ICU has now changed over to save the organs and keep her alive as a host, sort of thing. It’s really tough seeing that transfer of care.”**
> 2017 – Consented to donation

9.4.1 Obtaining informed consent

As part of the consent process, family members are asked to nominate which organs and tissues they agree to being donated for transplantation. When a loved one has already registered their wishes with the Australian Organ Donor Register (AODR) as to which organs and tissues they consent to donating, family members are simply asked to confirm whether or not they agree with those decisions. Invariably, families find this a much easier and less confronting process as they feel ‘guided’ by their loved one.

The meeting with DonateLife representatives to obtain informed consent is often viewed by family members as a difficult and lengthy meeting, and one in which some families feel is made unnecessarily complicated, as demonstrated in the comment below.

> **“And the lady then proceeded to walk through the whole process, ‘Do we understand this, do we understand that?’ And that wasn't a quick meeting by any stretch. It certainly felt like a long meeting, and then we had to sign. And then he [hospital lawyer] piped up and read from his clipboard, and this is the bit that really bugged me. He proceeded to go through exactly what she [the DonateLife representative] just went through, issue after issue after issue, ‘Did we understand this, did we understand that?’ Then we signed the hospital documents.”**
> 2016 – Consented to donation

Positives of the meeting

Consistent with previous waves, the DonateLife coordinators conducting the informed consent meeting are praised by families for their kindness, patience and non-judgemental attitude towards families. Many families recall being treated with respect during this meeting and to not feeling pressured into agreeing to donate specific organs or tissues that they were not comfortable with donating. DonateLife staff freely answer all questions and do their best to make families feel comfortable.

> **I mean, don't get me wrong, she was thorough, she was amazing but there was a lot to take in and it was a big process."**
> 2017 – Consented to donation

Consistent with findings from Waves 2 and 3, many donor families can more easily understand the benefit of organ donation over tissue donation. The donation of skin, bone and eye tissue is, for some, difficult to grasp. They need to know *how will this type of donation benefit others and how will it impact the appearance of their loved one post-surgery?*

Negatives of the meeting

Most donor families understand the necessity of the 'informed consent' meeting. What many struggle with, however, is:

- The duration of the meeting (as previously mentioned)
- The detailed questions about their loved one's personal life (this can make family members feel uncomfortable, especially when these questions are asked in front of other family members)
- The visual image that requesting informed consent of every organ and tissue creates in the family member's mind.

> **It's hard seeing someone figuratively cut up in front of you."**
> 2017 – Consented to donation

> **They had a questionnaire that you had to fill in about their background. I understand that you have to do it, but I was glad his Mum left. I was like, 'oh God' because they ask you all sorts of things. I'm not sure if it might have been better for me to fill it in myself with them in the room rather than it be read out loud."**
> 2017 – Consented to donation

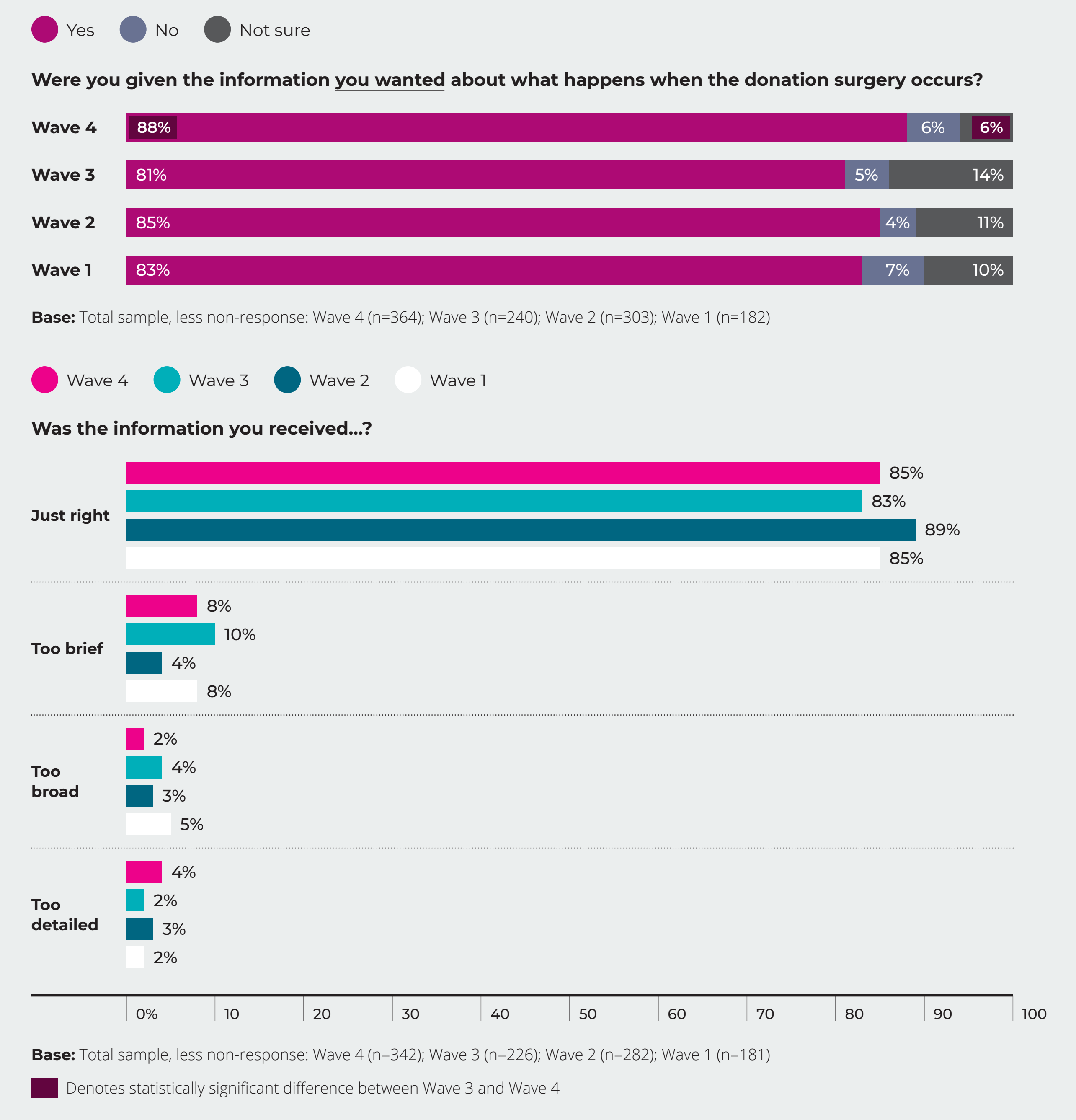
Families should be informed prior to the meeting of the expected duration of the meeting and what it involves. The meeting should be held in a private room and families offered breaks when needed.

9.4.2 Information provided about donation surgery

In terms of the information provided to families about donation surgery, 88% of donor family members feel they were given the information *they wanted* (a significant improvement over Wave 3 findings) and 85% feel that the *amount of information* they received was just right (Figure 38). One in 12 donor family members (8%) feel that the information they received about donation surgery was too brief, while 4% feel it was too detailed.

> **I got various levels of information. At each stage I felt correctly informed."**
> 2017 – Consented to donation

Figure 38 Information about donation surgery



Base: Total sample, less non-response: Wave 4 (n=364); Wave 3 (n=240); Wave 2 (n=303); Wave 1 (n=182)

Base: Total sample, less non-response: Wave 4 (n=342); Wave 3 (n=226); Wave 2 (n=282); Wave 1 (n=181)

■ Denotes statistically significant difference between Wave 3 and Wave 4

9.4.3 Managing expectations of timelines

One of the main themes emerging from the research is the negative impact that either not knowing timelines, or being misinformed of timelines, has on donor family members. Families are often given an estimate of a likely timeframe from time of consent to time of donation surgery. They cling to this timeline and prepare themselves mentally for the inevitable. When the timeline changes, families can become distressed. They can feel that precious time has been taken away from them (when the timelines are brought forward) or that their loved one's suffering is extended (when timelines are stretched).

It is necessary for hospital staff to be aware of the importance to families of providing accurate information about the timing of the donation process. Further, when things change that impact the timing, it is equally important to ensure that families are notified of the change immediately so that they can mentally re-set.

> **This is probably where they need to improve their communication, because we felt that once they had checked that yes she was on the register or no she wasn't, we were thinking that the next day it would be the day that we we're turning off her machines. But then they said, 'so tonight we will actually check which of her organs are suitable for transplanting' and I'll remember this forever, my ex just absolutely lost it. He said, 'you mean to say that we're not doing this today, we're not turning off her machines today? I have prepared myself all night knowing that I was going to be turning my daughter's machines off today, and you're telling me it's not happening today?' And he was very, very cross, he was beside himself. I think that they needed to give us a better timeline as to how the process worked."**
>
> 2017 – Consented to donation

> **We were woken at 2am and told the surgery team would be here at 5am ready to go, so machines would be turned off before then. We had to call the whole family in the middle of the night and get them in. The worst part was that we had lost very precious time with my husband. We felt that they 'stole' it. I understand that this is a difficult logistical exercise with many components and people waiting possibly all over Australia for surgery, but when you are told a certain time and have that in your mind and then 5+ hours is suddenly taken away from you, it is awful. I cannot even describe how awful. To have that time taken away when you think you are doing the right thing donating organs to save others' lives, adds another level of horror to it all. I would suggest DonateLife does not operate like that again."**
>
> 2016 – Consented to donation

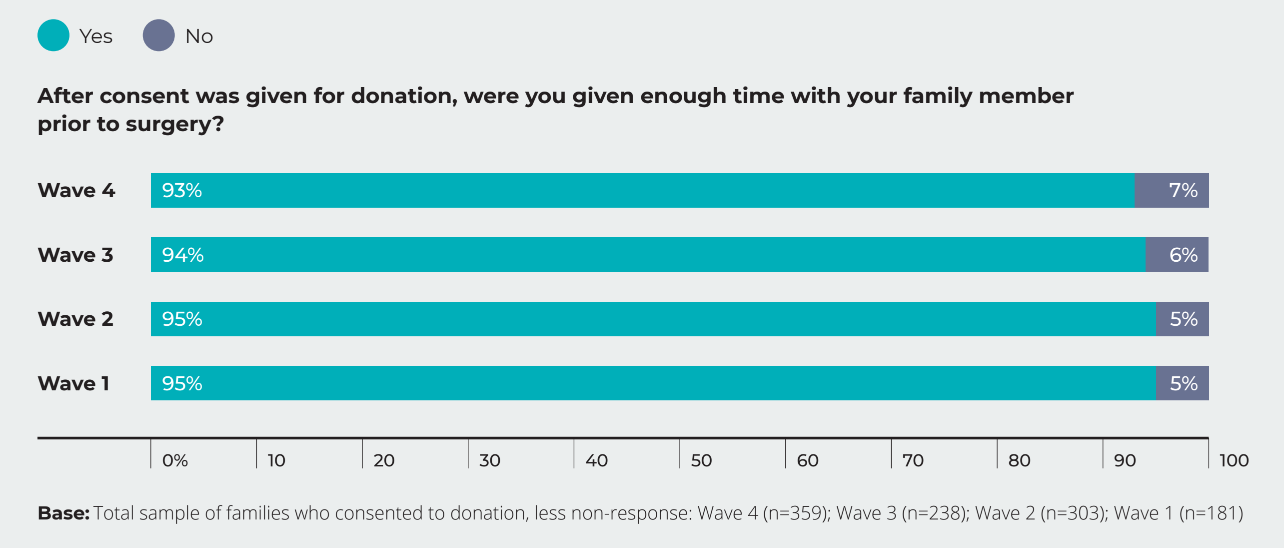
Clear communication between hospital staff and donor families can alleviate much of the stress and make families feel valued.

> **The support that was provided at the time by the organ donation team and the nurses and doctors at the hospital helped make the process of donation very easy. There was clear communication about what would happen and when, and they were always available to clarify anything or provide support if needed."**
>
> 2016 – Consented to donation

9.4.4 Time with family member prior to surgery

Just over nine in ten donor family members (93%) feel they were given enough time with their family member prior to donation surgery; 7% feel they were not (Figure 39). This is consistent with previous waves.

Figure 39 Time with family member prior to surgery



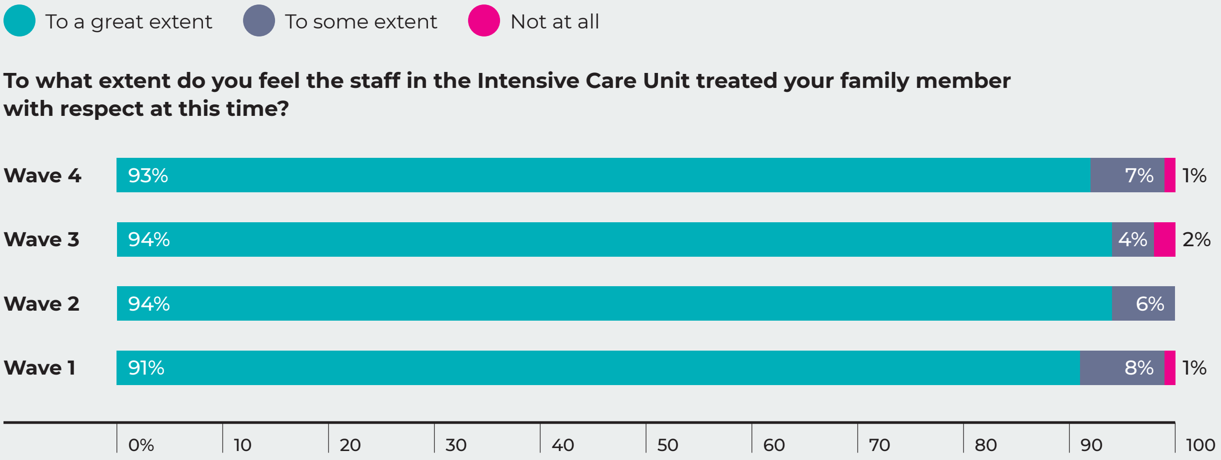
Base: Total sample of families who consented to donation, less non-response: Wave 4 (n=359); Wave 3 (n=238); Wave 2 (n=303); Wave 1 (n=181)

9.4.5 ICU staff

The vast majority of donor families have positive experiences with ICU staff. As shown in Figure 40, 93% of donor family members feel that their loved one was treated with respect by ICU staff in the lead up to donation surgery.

> **The staff were amazing – there's nothing more that could have been done. The process made a very difficult time easier to deal with."**
> 2017 – Consented to donation

Figure 40 Treatment by staff prior to surgery



Base: Total sample, less non-response: Wave 4 (n=368); Wave 3 (n=238); Wave 2 (n=300); Wave 1 (n=182)

Note: Figures may not add to 100% due to rounding

Something that families request hospital staff be mindful of is protecting them from seeing any processes that may invoke images of what happens in surgery. As much as possible, any such procedures and processes should be kept away from donor family members.

> **They could cover the eskies that they take into the hospital. We were sitting in the hospital's garden when they unloaded the eskies. That was a bit confronting."**
> 2017 – 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 their loved one with respect**
- **Being shielded from witnessing processes that directly relate to surgery**

9.5 Withdrawal of treatment/going to theatre

An upsetting but important time for families is their final moments of saying goodbye to their loved one, whether in ICU or just before their loved one goes into theatre for donation surgery. The withdrawal of life support is a painful experience for families and as such, they need knowledge (of what the process will look like), understanding, respect and privacy. For the most part, these four things are delivered by hospital staff.

> **“They were hovering in the background, very unobtrusive which was lovely. They were very conscious of just giving us the space around her. You knew they were there but they were just giving you all the time that you needed.”**
> 2017 – Consented to donation

> **“They were tremendous, absolutely tremendous. Just how they explained what would go on and how, once the life support was turned off, what would be happening. They went through it in great detail.”**
> 2017 – Intended donor

For DCD donor families, families also need to know of the time limitations and the fact that if their loved one does not die within a certain time period, donation will not happen. In instances where the timeframe of the loved one's death did not enable organ donation, families recall the sensitivity of nursing staff and this gives them some comfort.

> **“I think someone's watch beeped and then the head nurse came and said, ‘it's over the hour, I'm sorry.’ And you feel disappointed. You shouldn't feel disappointed but you feel disappointed.”**
> 2017 – Intended donor

Conversely, medical staff are also proactive in advising families that if their loved one does die within the set time period post-removal of life support, that they would immediately be rushed to theatre. Although this is difficult for families, they are understanding of the urgency and appreciate being advised of this process.

> **“They were very thorough with this and I am so pleased that they talked us through this time and time again. They told us a number of times, as soon as she has been pronounced dead she will go straight into surgery. They said, ‘You need to prepare yourself for that. You will have a quick goodbye but then that's it, we've got to get her out of there as quickly as possible.’ And they said that to us, if they said it to us twice they said it to us a dozen times. And I'm so grateful that they did because that's exactly how it happened.”**
> 2017 – Consented to donation

In one example, parents warmly recall the respect that they felt when their daughter was taken to surgery. Respect was demonstrated by medical staff forming a guard of honour either side of the corridor.

> **“We started to notice all the hospital staff coming in closer to her room, waiting in the corridor. I just noticed it behind the curtains. Then the anaesthetist came back in, he said, ‘It's time to go’. It was just beautiful. They did the guard of honour for her. People lining up either side of the corridor as they pushed her out. Yeah, it was pretty amazing.”**
> 2017 – Consented to donation

9.5.1 When the theatre doors close

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

Family members can also feel that they are now insignificant, that their loved one has been taken off to donate and save others' lives, but who is there for them? They wonder if anybody cares.

Whilst not every family member will feel like being in the company of others at this specific time, at the very least, support should be offered and ideally it should be offered by somebody the family member is familiar with/has had dealings with in the hospital. The offer could be a cup of tea, chatting to them, or simply sitting with them for as long as they need.

> “ **Then we followed the trolley to the surgery with the doctors following. It was all lovely and everyone sort of had their heads bowed, very respectful. And the surgery doors opened and everyone who had walked through the hallway went through those doors, then the doors closed.**
>
> **For 20 minutes we stood there. We didn't know what to do. We were waiting for someone to come out and say, ‘Are you guys alright? Come and sit down, let's have a cup of tea.’ And we stood there for ages. Not one person. I think the way that was done was very poor.”**
>
> 2016 – Consented to donation

> “ **Feelings of loneliness and desertion after our son was taken away to surgery. We weren't offered any comfort from staff.”**
>
> 2017 – Consented to donation

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

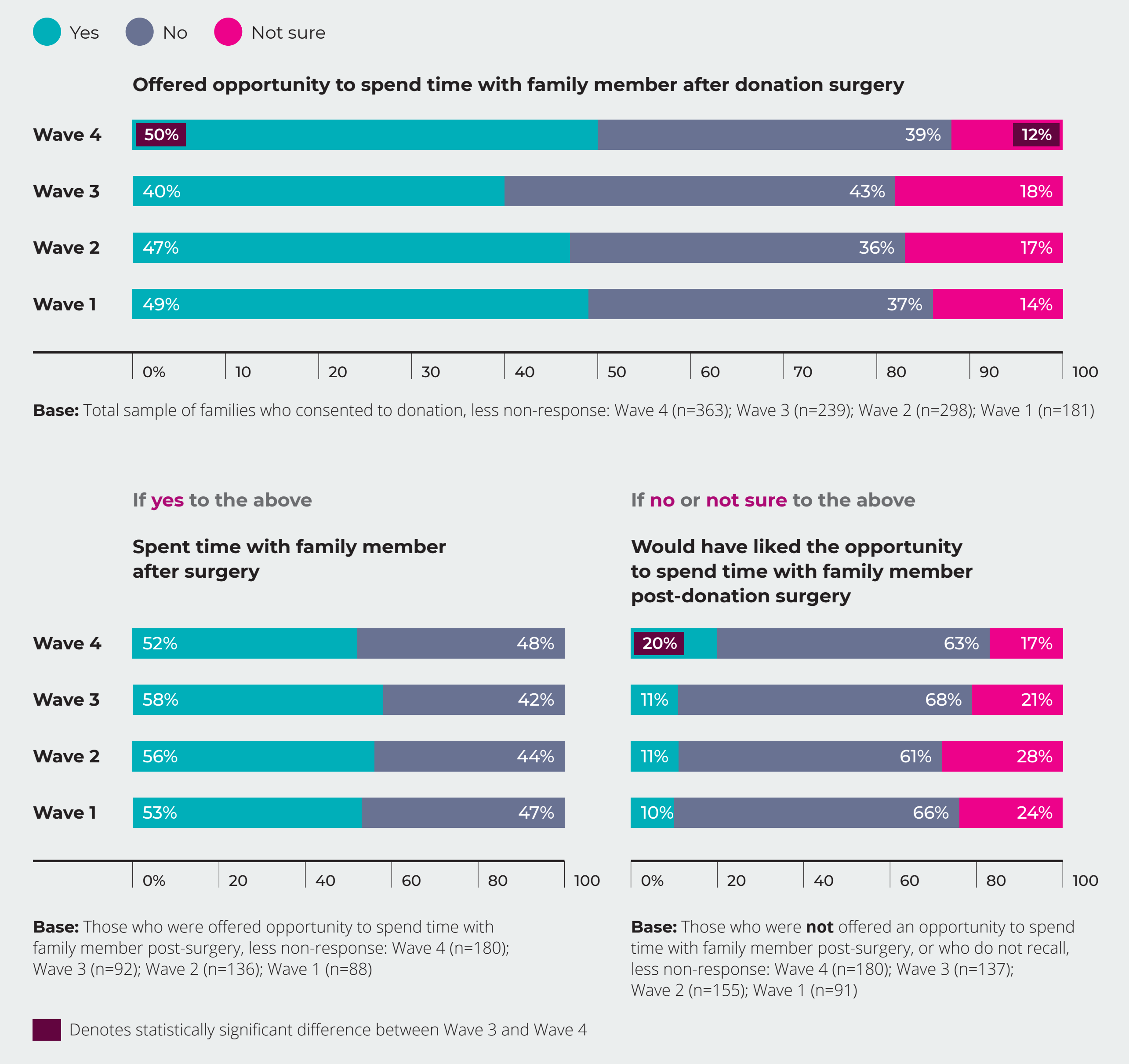
10 After donation surgery

As shown in Figure 41, half (50%) of donor family members in 2016 and 2017 were offered an opportunity to spend time with their family member after donation surgery. This is significantly more than families in 2014 and 2015.

Of those who were offered, half (52%) opted to see their family member after surgery. The majority of these family members (82%), describe the experience as a positive one; 2% describe the experience negatively, while 15% are unsure how they feel about it. This is consistent with Wave 3 findings.

> **This was an exceptionally special time."**
> 2017 – Consented to donation

Figure 41 After donation surgery



Base: Total sample of families who consented to donation, less non-response: Wave 4 (n=363); 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 4 (n=180); 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 4 (n=180); Wave 3 (n=137); Wave 2 (n=155); Wave 1 (n=91)

■ Denotes statistically significant difference between Wave 3 and Wave 4

Those who describe this experience as positive are grateful for the extra time spent with their loved one, without being rushed.

> **Being with our daughter after the donation was very important. It would have been horrible to have not seen her again to say our goodbyes. The staff were lovely and we had some special quality time with our daughter."**
> 2016 – Consented to donation

Family members who describe seeing their loved one post-surgey as a negative experience or who are conflicted about how they feel, are most distressed at how different their loved one looked, as demonstrated in the following comment. Many feel that they weren't prepared for this.

> **The medical team/donation team should have said how very dead my husband would look. It was shocking. Sounds obvious I know, but there it is."**
> 2016 – 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 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 their loved one is placed post-donation surgery. Ideally this should be in a private room in a peaceful setting (i.e. not a cold and sterile environment).

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 similar themes and detailed in Table 22.

Table 22 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)	Wave 4 (n=118)
Hospital staff compassionate/respectful/supportive/kind	11%	11%	14%	18%
Donation gave us more time to spend with loved one/opportunity to say final goodbye	8%	6%	5%	12%
Agonising/felt lost/too stressful/too upset	5%	9%	8%	9%
Received results of surgery by phone/received phone call when surgery had taken place	2%	4%	7%	8%
Didn't stay/was not present/didn't return to hospital	21%	33%	**15%**	7%
Regret not seeing family member after donation surgery	2%	6%	5%	6%
No support after surgery/didn't know where to go	–	6%	5%	6%
Was not given opportunity to see family member after surgery/had to say goodbye before/felt rushed	–	7%	4%	6%
Need preparation for what to expect after surgery/upsetting to see how family member looked after surgery	–	–	–	6%
Didn't want to see family member after surgery/wanted to remember them as they were	15%	12%	19%	**4%**
Phone calls would have been good (to check in after donation)	–	–	–	3%
Was given enough time before surgery/understood timeframe	–	–	5%	3%
Hospital staff were not compassionate/were insensitive	3%	4%	1%	3%

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)	**Wave 4** (n=118)
DonateLife team wonderful/kind/compassionate/respectful/professional	5%	6%	–	3%
Took a long time/wish it was faster/process dragged on	2%	5%	–	2%
Good experience/moving experience/tastefully handled	2%	4%	**21%**	**1%**
Had minimal time to spend with loved one pre-surgery	3%	2%	7%	**1%**
Post-donation environment – cold and sterile	–	–	7%	–
Regret seeing family member after surgery	–	2%	3%	–
We knew our loved one would be cared for and respected	5%	2%	3%	–
Experience was surreal/confronting/strange	10%	4%	1%	–
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	3%	3%	–	–
Other comments (each totalling < 1% of responses)	23%	**5%**	11%	21%

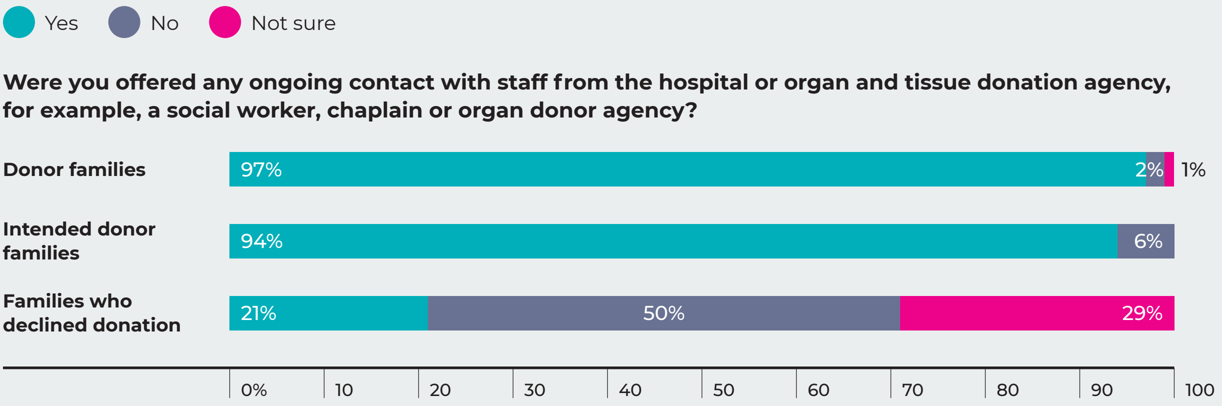
■ Denotes statistically significant difference

11 Follow-up services

In Australia, donor families are offered support through the National DonateLife Family Support Service, providing resources and access to counselling services 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 access to this support service. It is important to note that whilst participation in the Donor Family Study by all family members (not just next-of-kin) is desirable, this inclusion may skew the responses regarding family follow-up services.

During 2016 and 2017, 97% of donor family members were offered ongoing contact following donation from a DonateLife coordinator, nurse or doctor, a Donor Family Support Coordinator, hospital social worker or hospital chaplain. This is consistent with Waves 2 and 3 and is an increase since Wave 1 (85%). Further, ongoing support was offered to 94% of families of intended donors and 21% of families who declined donation. This is consistent with Wave 3 findings (Figure 42) and is likely to include support services that are not routinely offered by DonateLife and instead provided by hospital staff to meet specific circumstances.

Figure 42 Follow-up services and resources offered



Base: Total Wave 4 sample, less non-response: Consented to donation (n=346); Intended donor families (n=48); Declined donation (n=24)

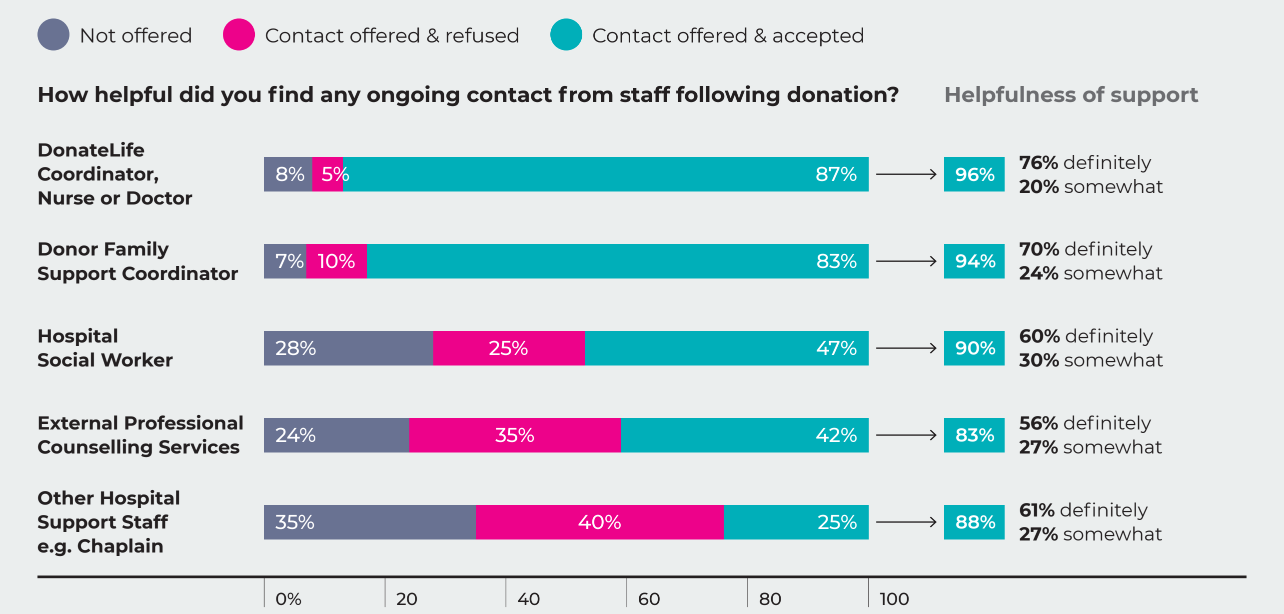
NB: Excludes any offer from an external professional counsellor

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 staff, hospital staff or external services. Findings are shown in Figure 43 below and discussed in more detail throughout this section.

Figure 43 Follow-up services and resources offered to donor families – role



Base: Total Wave 4 sample (families in 2016/2017 who consented to donation), less non-response

As stated earlier and shown in Figure 42, 21% of families who *declined donation* (5 out of 24 families) were offered ongoing contact with staff from the hospital or organ and tissue donation agency. For these 5 declining family members, most of the contact was with a DonateLife coordinator, nurse or doctor even though DonateLife support services are not routinely offered to families who decline donation. Some of these families (67%) found this useful, others did not (33%).

DonateLife coordinator, nurse or doctor

During 2016 and 2017, 92% of donor family members were offered ongoing contact from the DonateLife coordinator, nurse or doctor (95% in 2014/2015); 87% accepted and received support (consistent with Waves 2 and 3). This support was found to be helpful by 96% of donor families; consistent with findings from Waves 2 and 3.

Donor Family Support Coordinator

Ongoing contact with a Donor Family Support Coordinator (DFSC) was offered to 93% of donor family members during 2016 and 2017; consistent with the previous waves. Approximately 8 in 10 family members (83%) accepted and received support (consistent with Wave 3) and of those, 94% found the contact helpful, 70% very much so.

> **“It’s been excellent, you can't fault it. I still talk to her [the DFSC]. She called me the other day just to go, ‘I'm just checking in.’ I mean she's become like a... just a support. She doesn't have to do any of that!”**
>
> 2017 – Consented to donation

> “**DonateLife were, and still are, fabulous. They are the people that we have had the most positive experiences with. [DFSC] has contacted us a few times and she even sent a card on the day my son passed away saying that he won't ever be forgotten. That meant more to us than we can say. DonateLife were fabulous.”**
>
> 2017 – Consented to donation

> “**I had a couple of contacts from their counsellor person. That was all a bit useless, to be honest. The guy rang and it seemed a bit redundant in a way. He was being genuine but it was sort of a bit like I didn't know what to say. This has all happened, I don't know how you’re going to help me. Maybe because it's a phone call. It might have been better to be honest, to have it face-to-face, like, ‘Can we go and have a coffee somewhere or can I come and see you?’ because, I was left floundering a bit.**
>
> 2017 – Consented to donation

In some cases, families don’t feel ready to accept the offer of a DonateLife counsellor or someone to talk to immediately after the death of their loved one, although can be open to it some time later. For this reason, it is important that families know that they are able to contact DonateLife whenever they feel ready.

> “**So if it's not right for that time, don't close it off on a timeframe and say that you can only have the service for the first two years, because some people take longer than others to process trauma.”**
>
> 2017 – Consented to donation

> “**They were fabulous. I guess, and this is just nit-picking, they could contact you again down the track just to touch base. Just so you know that your child hasn't been forgotten. You just want to know that your child will be remembered by more than you.”**
>
> 2017 – Consented to donation

Hospital social workers

Ongoing contact from a hospital social worker was offered to three quarters (72%) of donor family members (consistent with Wave 3). Nearly half (47%) of donor family members did have contact with a hospital social worker (again, consistent with Wave 3) and of these, 90% found the support helpful.

External provider

Ongoing contact with an external provider, such as counsellor or psychologist, was offered to 76% of donor family members during 2016 and 2017 (consistent with previous waves). Two in five donor family members (42%) accepted this offer of support, significantly higher than in Wave 3 (28%). Of these family members, 83% found it helpful.

Hospital support staff (e.g. chaplain)

Research findings indicate that support from hospital support staff such as chaplains, is offered to, and accepted by donor families less often (65% of donor families were offered this type of support; 25% accepted). Of these families, 88% found this type of support helpful.

Table 23 details the support distribution by state, for unique donor families.

Table 23 Support offered to donor families by state/territory

Type of support offered		QLD (n=65–79)	ACT (n=11)*	NSW (n=81–90)	VIC (n=61–76)	TAS (n=13–16)*	SA (n=16–18)*	WA (n=32–38)	NT (n=1–2)*
DonateLife coordinator, nurse or doctor		94%	91%	91%	91%	81%	94%	97%	100%
Donor Family Support Coordinator		95%	91%	92%	91%	80%	88%	91%	100%
Hospital social worker		77%	73%	73%	73%	69%	56%	59%	100%
Other hospital staff (e.g. chaplain)		66%	73%	67%	64%	77%	62%	59%	100%
Total support offered	**Wave 4**	**100% ▲**	**91%**	**97%**	**95%**	**81% ▼**	**90% ▼**	**100%**	**100%**
	Wave 3	**94%**	**95% ▲**	**97%**	**99%**	**100% ▲**	**100%**	**96%**	**100%**
	Wave 2	**99% ▲**	**71%**	**99%**	**92% ▲**	**80%**	**95% ▲**	**100%**	**100%**
	Wave 1	**88%**	**100%**	**93%**	**77%**	**83%**	**70%**	**100%**	**–**

* Caution: small base

NB: Data has been filtered to include responses from unique families only. This includes where only one family member has responded to the survey (irrespective of whether or not that family member is the SNOK), and SNOK representatives, where multiple family members have responded to the survey. In the case where multiple family members have responded to the survey and neither are the SNOK, an arbitrary decision has been made as to which family member is 'closest' to the position of SNOK and that person has been included (e.g. where a sibling and a cousin have responded from the same family, the sibling has arbitrarily been designated as the NOK).

🟪🟦 Denotes significantly different from national total

11.1.1 Helpfulness of support

Families who consented to donation

Family members were asked an open ended question "*In what way was the ongoing contact helpful to you?*". Table 24 outlines coded responses to this question. As shown, ongoing contact is considered to be helpful for a range of reasons. The most common response, from 17% of donor family members, is that they find contact helpful when they receive updates on the recipients – knowing that their decision continues to help others gives them some solace.

Table 24 Helpfulness of ongoing contact

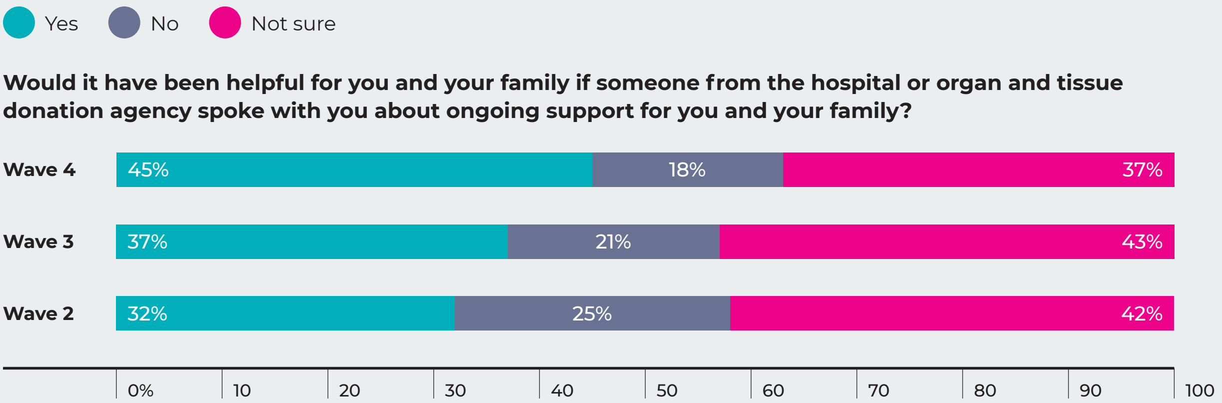
In what way was the ongoing contact helpful to you?	Wave 1 (n=122)	Wave 2 (n=161)	Wave 3 (n=128)	Wave 4 (n=220)
Found out the outcome of the donation/gave us progress updates on recipients/to know our decision was helping others	30%	19%	35%	**17%**
It provided useful information/answered our questions	9%	2%	7%	10%
Counselling/memorial services/DonateLife events helpful	4%	9%	5%	10%
Felt like we weren't forgotten/felt like we were cared for/nice to be checked up on	20%	13%	9%	9%
Helped the grieving process/gave us closure	13%	5%	9%	9%
Provided comfort and support/very compassionate	17%	11%	18%	**9%**
Follow-up calls were helpful	1%	3%	10%	6%
Ongoing contact helped us a lot (no further information)	1%	6%	2%	6%
Ongoing correspondence with recipients is very helpful	1%	7%	10%	5%
DonateLife coordinator was helpful, supportive and understood my situation	–	20%	13%	**5%**
Helped being able to talk about my family member/someone to talk to/someone external from the family to talk to	7%	8%	3%	5%
Nice to know the support is there if we need it	3%	11%	7%	4%
Private counselling/grief support group was helpful	–	6%	5%	4%
Our family member is recognised and appreciated for their contribution	16%	5%	2%	4%
The support helped validate/reinforce our decision	2%	4%	4%	2%
Keepsakes – hair and handprint was lovely/lapel pin helpful	–	2%	2%	–
Don't know/not sure	1%	1%	–	2%

> **“It was comforting to know that the care afforded us was not just whilst we were in the hospital environment but that they continued to be concerned for how we were coping and adjusting following the death of our son/brother. Having feedback and support reinforced that the correct decision to donate had been made.”**
>
> 2017 – Consented to donation

> **“We were able to update the rest of our family on the improved life and health outcomes of recipients. I think it changed their attitudes.”**
>
> 2017 – Consented to donation

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 receiving ongoing support. As shown in Figure 44, 45% of these donor family members would have found this helpful, while 18% would not; two in five (37%) are undecided. These findings are consistent with previous waves.

Figure 44 Perceived helpfulness of ongoing support, if it had been offered



Base: Donor family members who were not offered ongoing contact from one or more of hospital or DL staff following donation, less non-response: Wave 4 (n=84); Wave 3 (n=68); Wave 2 (n=59)

Families who declined donation

For the 79% of declining family members (19 out of 24 families) who were not offered ongoing contact or support, just 1 family member (6%) said that they would have liked somebody to contact them; the remaining were either unsure (28%) or said 'no' (67%).

The type of support that the majority of declining family members would find helpful is bereavement support services (71% say they would have found this useful). Around one third (36%) of declining family members say that a phone call from the DonateLife agency would have been useful, up from 14% in Wave 3.

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.

It should be made clear to all donor families that the offer of contact and support is available to them even if they initially opt out of contact from DonateLife. It is important that families know that they can reach out to someone if needed.

Particular care should be taken to ensure donor families in regional areas are supported and directed to local organisations that may be able to provide support in their area.

Support from a hospital social worker or counsellor should always be offered to families who decline donation.

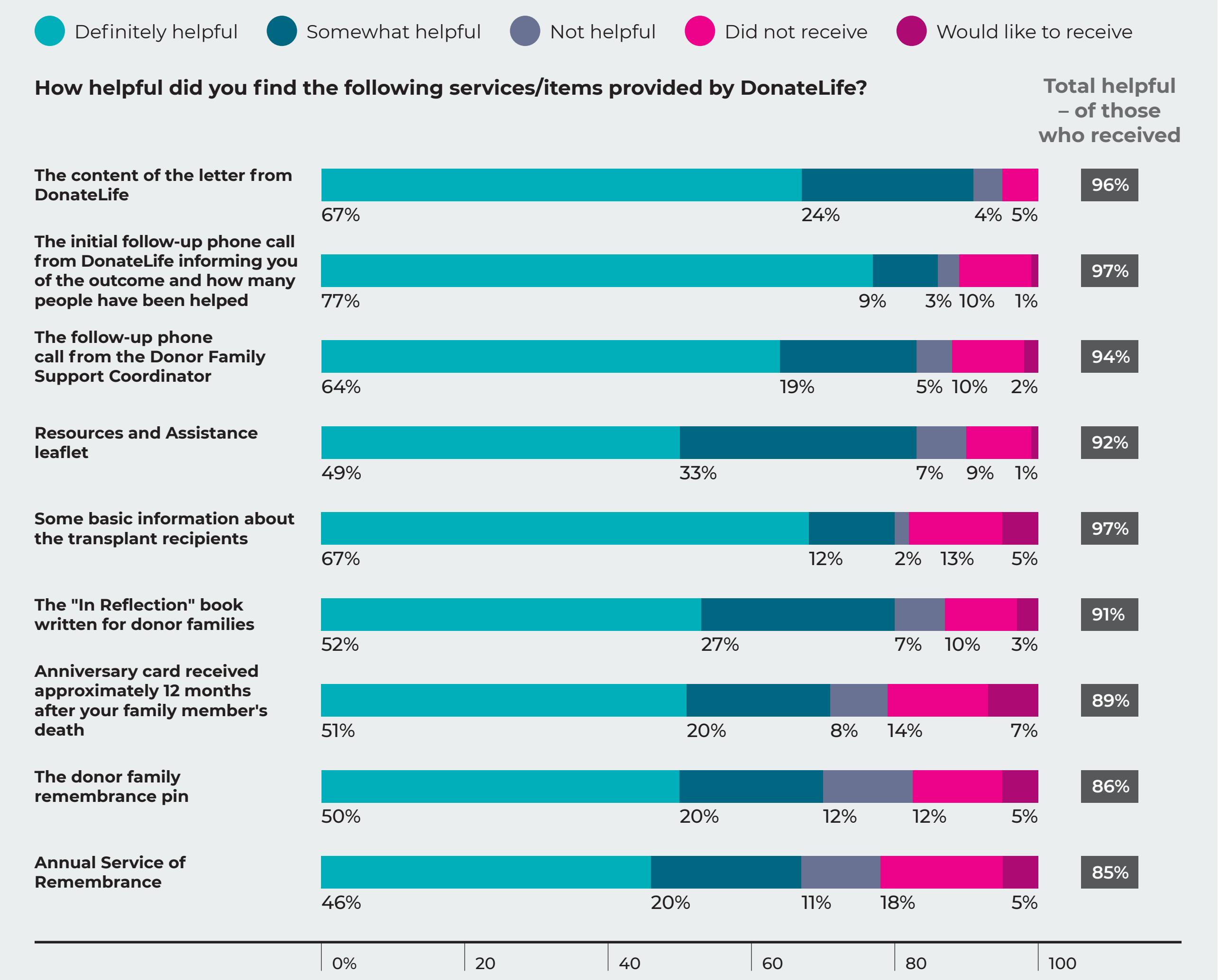
11.2 DonateLife resources

Donor family members were asked if they received any number of support services/items from DonateLife and if so, how helpful each of those were. Findings are shown in Figure 45 and compared with earlier waves in Table 25.

> **It was so touching to feel that every part of these resources were very personalised, as if I am the only person that they are dealing with, instead of just one of many cases."**
>
> 2017 – Consented to donation

> **There are several things I have realised 12 months on:**
>
> **I have used the counselling service and continued well beyond the 3 free sessions. Having the initial free sessions was wonderful.**
>
> **It was also very consoling to have some structured contact following my son's death, such as the service for donor families and recipients, contact from the Donor Family Support Coordinator, and a letter from the family of one of the recipients. Each contact or event is like a stepping stone forward from what seemed to be unbearable."**
>
> 2017 – Consented to donation

Figure 45 Helpfulness of resources provided to donor families



Base: Wave 4 families who consented to donation, less non-response. Base sizes vary (n=347 to n=385)

As shown in Table 25, the vast majority of families who receive these services find them helpful.

Table 25 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**	**Wave 4**
Initial phone call from DonateLife informing you of the outcome	99%	99%	99%	97%
The content of the letter from DonateLife	99%	98%	97%	96%
Basic information about the transplant recipients	100%	99%	99%	97%
Follow-up phone call from the Donor Family Support Coordinator	92%	**97%**	95%	94%
Resources and Assistance leaflet	Not measured	91%	86%	**92%**
Anniversary card	90%	91%	85%	89%
'In Reflection' book	93%	92%	89%	91%
Donor family remembrance pin	Not measured	88%	84%	86%
Annual Service of Remembrance	82%	83%	**76%**	**85%**

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

> **“They were beautifully presented and helpful in my need of help and assurance.”**
> 2017 – Consented to donation

> **“The presentation booklet was great. A pleasant surprise for the thought and care that had gone into it.”**
> 2017 – Consented to donation

> **“The 'In Reflection' book was my greatest tool in understanding my own grief.”**
> 2016 – Consented to donation

11.2.1 Initial follow-up phone call

Of great importance to the majority of donor family members is the **initial follow up phone call** from DonateLife informing them of the outcome of donation (89% recall receiving this call and of those, 97% found it to be helpful). This conversation is often the release for families after a stressful and highly emotional time in hospital, culminating in donation surgery. Many families eagerly await this call to inform them of the outcome. When transplantation goes well, this information provides solace to families and often reinforces their donation decision.

> **“Well they rang me on the Monday afternoon to say that the surgery had been done and what organs they had removed. Then about 2 or 3 days later they rang me and said, 'We can't tell you how anyone is just yet, but all the operations have been done.' I thought it was amazing. Then a week and a half after everything, she rang me to say that both eye surgeries went well.”**
> 2017 – Consented to donation

> **“A phone call to say surgery was completed would have been of great comfort for me personally – to complete my farewell.”**
> 2017 – Consented to donation

11.2.2 Letter from DonateLife

Similarly, 95% of donor family members recall receiving a **letter from DonateLife**. Most of these family members (96%) found the content of the letter 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.

11.2.3 Information about transplant recipients

Eight in ten donor family members (82%) report receiving basic information about transplant recipients from DonateLife (consistent with Wave 3 findings at 86%). Of these family members, almost all (97%) found the information to be helpful, consistent with previous waves.

Being told the outcome of the donation surgery, finding out that transplantation has been successful and recipients are recovering, gives many donor families a sense of relief – their loved one has made a positive difference to someone's life. Again, this solidifies their donation decision.

> **“ A week and a half after everything, she rang me up to say that the surgeries went well and they were all successful. So that was incredible.”**
> 2017 – Consented to donation

In addition to needing to know some basic information about the recipients early on, many donor families talk about the desire to be kept updated on the health of recipients. This becomes more important for those families who do not receive letters/cards from recipients.

> **“ There was a lack of follow up by DonateLife on the state of recipients, unless I prompted them. I have told my other children that I will oppose them being donors because of this.”**
> 2016 – Consented to donation

11.2.4 Annual Service of Remembrance

An invitation to attend an **Annual Service of Remembrance** was sent to 77% of donor family members in 2016 and 2017, significantly fewer than in 2014 and 2015 (86%). These figures don't change when filtering the data to unique donor families. Data is not available in the study to determine whether this reflects a family member's choice to opt-out of this service or whether an invitation was sent only to the nominated family contact.

For those who received an invitation, 85% found it helpful. This is an increase on Wave 3 findings where 76% of family members found it helpful, even if they chose not to attend.

Consistent with Wave 3, many participants in the qualitative phase of the research talk about the Annual Service of Remembrance. Some attend and some don't, either because they simply don't want to or because they don't feel ready to attend. In any case, donor family members appreciate being invited.

The Annual Service of Remembrance gives donor families a sense of appreciation for transplant recipients, provides a sense of connection to other donor families and can give family members a renewed sense of pride in their loved one.

> **“ After 12 months they probably said, ‘Look, there will be a service if you want to go along to it.’ but I don't. I don't want to extend the agony. It's life, it's happened and we move on.”**
> 2017 – Consented to donation

> **“ I went and it was the best thing I've ever done because I thought, I'm not alone, look all these people. They are here because they donate and they talk about their loved one.”**
> 2017 – Consented to donation

11.2.5 Anniversary card

Eight in 10 (79%) donor family members recall receiving an anniversary card from DonateLife 12 months after the death of their loved one. The vast majority (89%) of those who received the anniversary card found it helpful and were grateful that their loved one had not been forgotten by DonateLife.

> **We were really touched that someone would remember the anniversary. It made me want to do the same for others."**
> 2017 – Intended donor

> **Oh, it was lovely, absolutely lovely. I didn't expect it."**
> 2017 – Consented to donation

> **They sent us a 12 month anniversary card. It was lovely. I minded getting it on the day because it sort of brought it all back but then I thought, no, wrong attitude. It was lovely of them."**
> 2017 – Intended donor

11.2.6 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 is still remembered and thought of. Family members can then choose to opt in or out of communication from DonateLife as they please, noting that their preferences may change over time.

> **They are beautifully and tastefully presented. DonateLife have got it right – don't change it!"**
> 2016 – Consented to donation

> **The resources for me were a very positive part of the process. The continued contact helps remind me of my Dad's accomplishments. The books and information pack were also very useful. At first I began reading the book as a distraction from everything that was happening around me, but it ended up helping me more than I could have imagined."**
> 2016 – Consented to donation

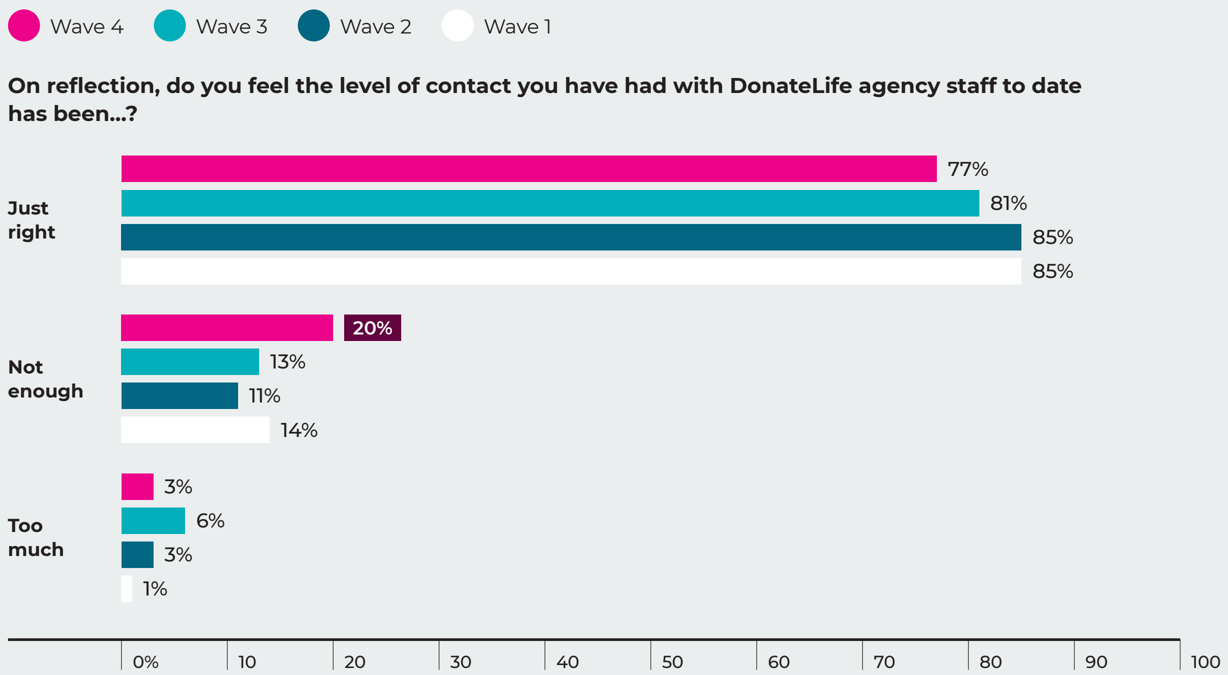
11.3 Amount of contact with DonateLife

As shown in Figure 46, most donor family members (77%) feel the level of contact they have had with DonateLife has been just right. One in five (20%) donor family members feel they've not had enough contact with DonateLife since their loved one died, a significant increase since Wave 3.

> **[The DFSC] has been very conscious of keeping me up-to-date with news of the two chaps that received her kidneys. They are both doing really well. It's very important [to be kept informed]."**
> 2017 – Consented to donation

> **DonateLife has been good. They've had their counsellor ring me, but I have asked for an update and I haven't received the update. I understand they're extremely busy, but that's been about 2 or 3 months now."**
> 2017 – Consented to donation

Figure 46 Contact with DonateLife agency staff



On reflection, do you feel the level of contact you have had with DonateLife agency staff to date has been...?

Base: Families who consented to donation, less non-response: Wave 4 (n=386); Wave 3 (n=246); Wave 2 (n=311); Wave 1 (n=177)

■ Denotes statistically significant difference between Wave 3 and Wave 4

Significant differences by state (when compared to the national result), are shown in Table 26.

Table 26 Level of contact with donation agency staff, by state/territory

Amount of information	QLD (n=96)	ACT (n=17)*	NSW (n=109)	VIC (n=83)	TAS (n=19)*	SA (n=20)*	WA (n=39)	NT (n=3)*
Just right	**89%**	59%	71%	80%	74%	70%	77%	100%
Not enough	**9%**	**41%**	28%	14%	26%	30%	18%	–
Too much	2%	–	2%	6%	–	–	5%	–

* Caution: small base

11.4 Other services

Donor family members were asked to think about other services that could be offered to better support family members. As shown in Table 27, 18% spontaneously say that they would like more updates on recipients (consistent with previous waves), while 11% request more contact from DonateLife in general.

Table 27 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)	Wave 4 (n=159)
None/can't think of any	34%	25%	23%	28%
I got all the support/information I needed	20%	**8%**	15%	12%
How the recipients are going/more updates on recipients	15%	19%	17%	18%
More contact in general/check to see how we're going	4%	8%	10%	11%
More access to social workers/counsellors/ongoing counselling	2%	6%	10%	9%
Would like to meet recipients or have more contact with them	4%	6%	7%	6%
Disappointed didn't receive letter from recipient	–	4%	1%	4%
Specific support (for children/young people/men)	2%	3%	1%	4%
Set up a donate family group in our area/online support group	3%	5%	5%	3%
More information about the donation process/raise awareness of donation	–	2%	4%	2%
Allow more than one relative to be a contact person/provide support for all family members	3%	3%	7%	**1%**
How to cope with grief	4%	3%	–	1%
Support in writing letters for both donors and recipients	–	3%	–	1%
None/prefer to source own support/rely on support from friends	–	3%	–	1%
Would like to be more involved in DonateLife campaigns/events to raise awareness	2%	1%	1%	1%
Better support in regional areas	2%	5%	9%	**–**
No longer want ongoing updates/don't want to be reminded	–	–	9%	**–**
Other one-off mentions	11%	**4%**	7%	8%

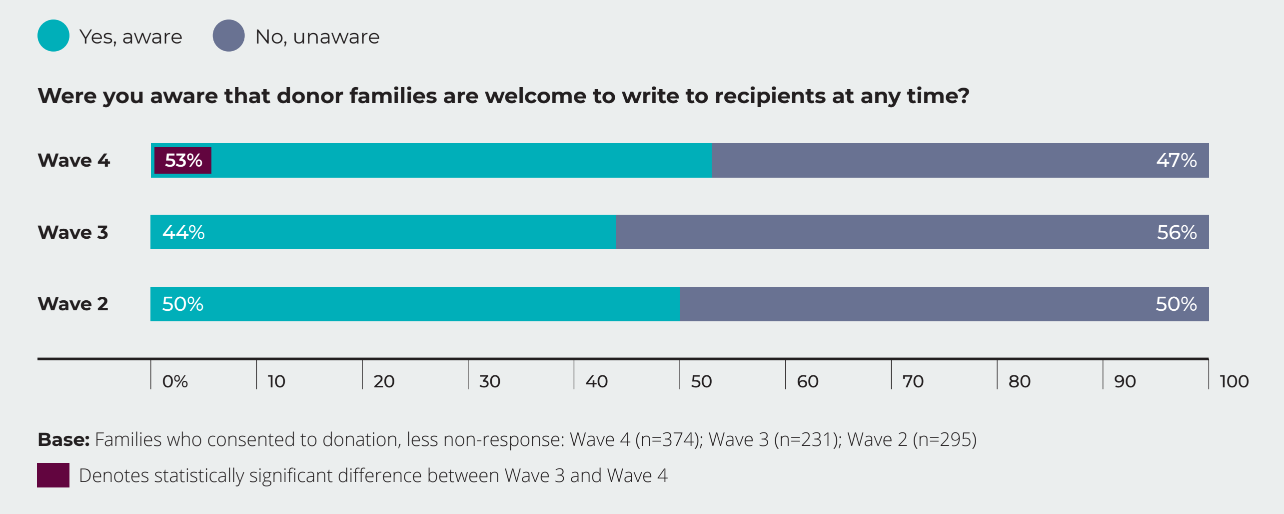
■ Denotes statistically significant difference since previous wave

12 Contact with recipients

12.1 Writing to recipients

More than half (53%) of donor family members in 2016 and 2017 know that they may write to recipients at any time. This is a significant increase since Wave 3 where 44% of families knew this (Figure 47).

Figure 47 Writing to recipients



Base: Families who consented to donation, less non-response: Wave 4 (n=374); Wave 3 (n=231); Wave 2 (n=295)

🟥 Denotes statistically significant difference between Wave 3 and Wave 4

There are mixed views from donor families about writing to recipients, but generally speaking, they agree that this option should be available. Some donor families feel that recipients should be the ones to put pen to paper; others want to write but are conscious of the feelings of recipients and do not wish to come across as pushy; others have no desire to write to recipients. In any case, DonateLife must manage expectations as donor families may be disappointed if recipients choose not to respond.

> **Picking up a bit of paper and writing to somebody? It just seems the last thing I want to do but notionally in the broader sense, I mean, I'm ashamed of myself for not writing to the person who wrote to me about how fortunate they were to have a kidney that was working."**
>
> 2017 – Consented to donation

Consistent with research findings from previous waves, some donor families find the restrictions placed upon them regarding what can and can't be said in communication to recipients frustrating. Whilst they are aware of the requirements around anonymity and privacy, some disagree with these rules and are of the opinion that they should be relaxed.

> **I kept feeling I need to write to the people who got her organs. I want them to know who she was as a person you know, and how lucky they are."**
>
> 2017 – Consented to donation

> **I've written many letters but I've never sent them because I look at them and then I think, 'Oh, that won't pass. There's too much information' and then sometimes I just cross it all out. It's very, very hard. I think they like to keep the person unknown so you can't identify too much."**
>
> 2016 – Consented to donation

As found in previous waves, some donor families have a desire to meet recipients, should the other party agree. Some take matters into their own hands and through social media, attempt to find recipients themselves.

> **After the donation happened, my husband wrote five letters and sent them to the donation people to give them to the appropriate people to say, 'This was my son, this was the person..'. So we were following the process which we thought was good where [the DFSC] said, 'If you would like to share some information, we can give it to the recipient family.' What was disappointing was he had gone to that effort and the nurse who was looking after the young girl (recipient) thought that it wouldn't be appropriate or fitting for the family to read that letter and didn't give it to them. How does she know what that family wants? She had no right to make a judgement or a call for those parents. That was the only disappointment about that process."**
>
> 2017 – Consented to donation

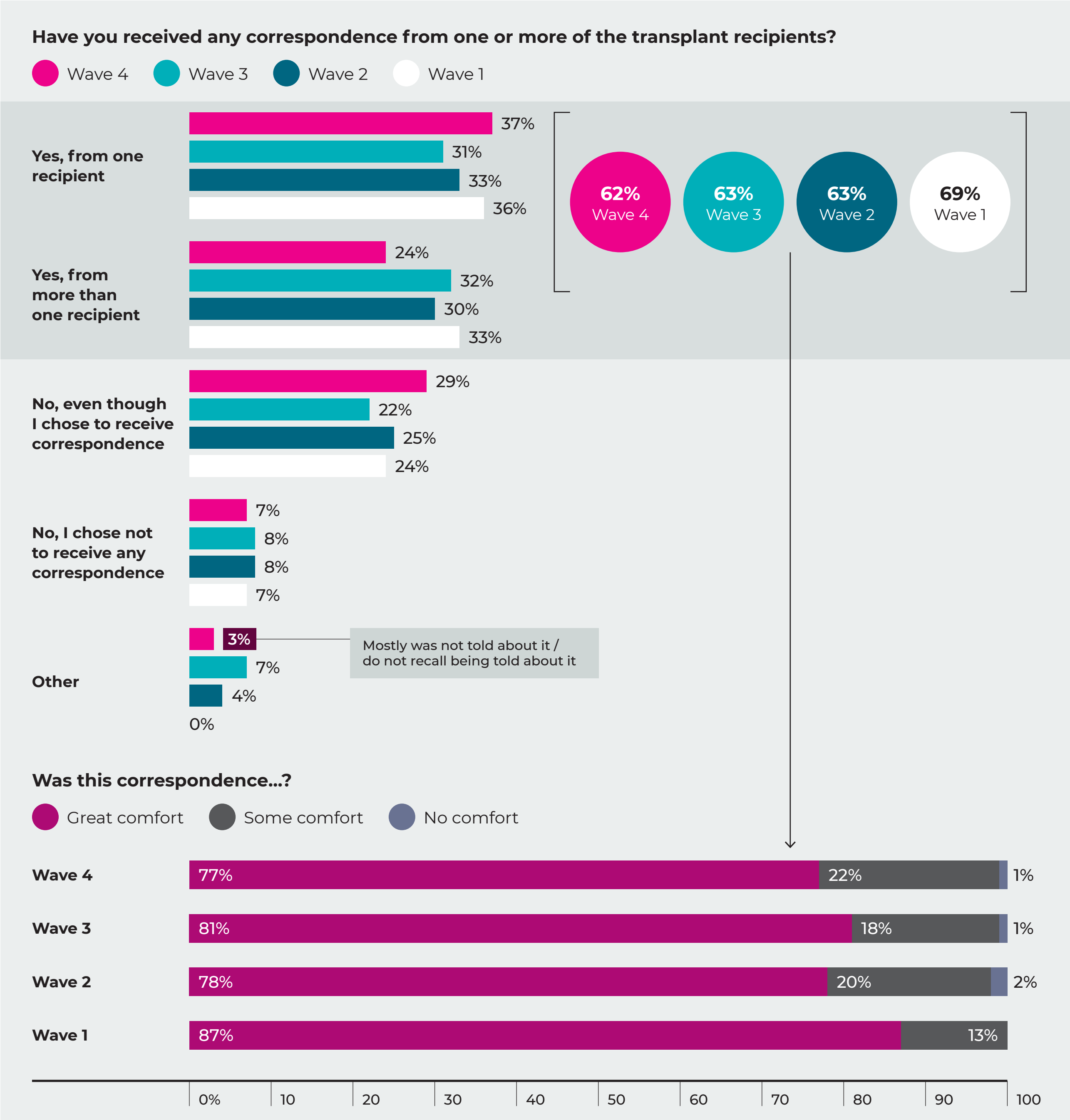
Further education is required to confirm that donor family members know that they may write to recipients at any time, should they choose to. It is important to manage expectations by not promising a response from the recipient. There is also further work required with the transplant teams to reiterate the significance for many donor families of receiving correspondence from recipients.

12.2 Deidentified contact with recipients

In 2016 and 2017, 62% of unique donor families received a letter from at least one transplant recipient (Figure 48). This is consistent with earlier waves. Receiving correspondence provides comfort to 99% of these families; again, consistent with previous waves.

At the time of the research, 29% of donor families in 2016 and 2017 had not received any correspondence from recipients, even though they chose to, consistent with previous waves.

Figure 48 Deidentified contact with recipients



Base:
Unique donor families where donation proceeded, less non-response: Wave 4 (n=276); Wave 3 (n=194); Wave 2 (n=246); Wave 1 (n=123).
Unique families who received correspondence from at least one recipient: Wave 4 (n=170); Wave 3 (n=123); Wave 2 (n=156); Wave 1 (n=84).

■ Denotes statistically significant difference between Wave 3 and Wave 4

Overwhelmingly, families who receive correspondence from recipients are grateful. They are pleased that the recipient cares enough to write to let them know of the impact of their donation. It makes them feel thankful that their loved one's gift was meaningful and that it changed a life.

> **After having received letters from the recipients and realising how it has saved their lives, I'm so glad I agreed! My son would have been so proud to know what he has done. It also is a bit of a consolation to know his heart beats on, his lungs still breathe. I wish I could meet the recipients! It would be so special."**
>
> 2016 – Consented to donation

> **I did receive about 2 weeks ago, knowing that was the anniversary of her death, I received this most beautiful letter from one of the recipients. I just sat and cried and cried and cried, he was so gracious, he was so appreciative, so thankful."**
>
> 2017 – Consented to donation

12.3 Impact of no contact from transplant recipients

Donor family members who chose not to receive any correspondence from transplant recipients (7% of donor families) are mixed in their views. Some are comfortable with not hearing from recipients but others would now like to know of their progress. Keeping the lines of communication open is therefore important, to allow family members to change their mind over time.

Families who wanted to receive correspondence from recipients but have yet to (29%), generally feel a sense of disappointment with the lack of contact (36% feel this way). Some (13%) understand that it may be difficult for recipients to write to donor families, however many more donor families who haven't received correspondence from recipients simply would like an acknowledgement of the donation and to know how the recipient is faring. This would go a long way towards healing.

> **I'd love to have contact. I'd love to just know that they're ok."**
>
> 2016 – Consented to donation

When donor families don't hear from recipients, the impact can be devastating to them emotionally. As shown in the following comments, not hearing can sour the entire donation process and can lead to family members opposing donation.

> **I wish we never did it. No contact from any family has made me withdraw my donor card. I felt my dad's body was picked off like it didn't matter to us."**
>
> 2017 – Consented to donation

Further information may be required for families of all donors, including intended organ donors who go on to donate tissue, to better manage expectations. Equally important is education for recipients on the ability to write and the benefit it can have for donor families.

> **I wouldn't do it again unless there is a greater education to recipient. They live on and my daughter doesn't. An acknowledgement would have meant the world to me."**
>
> 2016 – Intended donor / actual tissue donor

Table 28 Impact of not receiving correspondence from recipient

	Wave 1		Wave 2		Wave 3		Wave 4	
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)*	**Wanted to receive** (n=75)	**Chose not to receive** (n=16)*
Disappointed/let down/bitter/sad	33%	–	19%	–	23%	–	36%	–
Would like to receive correspondence from recipient	10%	–	14%	5%	30%	17%	25%	25%
Would like to know the progress of recipients/how donation helped/who received organs	13%	–	11%	–	26%	–	33%	13%
A thank-you would be nice/would show recipients' appreciation	10%	–	7%	–	21%	–	4%	–
Fine/ok about no correspondence	10%	63%	12%	47%	19%	33%	13%	13%
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%	–	3%	–
Ambivalent/not sure I would want it	–	–	–	–	7%	17%	1%	13%
Would have liked correspondence but didn't know it was allowed/wasn't offered this option	3%	–	2%	–	2%	–	1%	6%^
Not entirely comfortable with receiving correspondence/would rather not know	–	–	–	11%	2%	17%	–	25%
Understand if recipients aren't up to it/might not be easy/it's their decision/they will write when ready	10%	–	12%	–	–	–	13%	13%
Donation was enough/not necessary to receive correspondence/enough to know others were helped	7%	38%	2%	37%	–	–	3%	13%
Another member of the family received correspondence/another family member decided about correspondence	3%	–	2%	5%	–	8%	1%	–
Other	–	–	7%	–	5%	17%	4%	13%

* Caution with small base

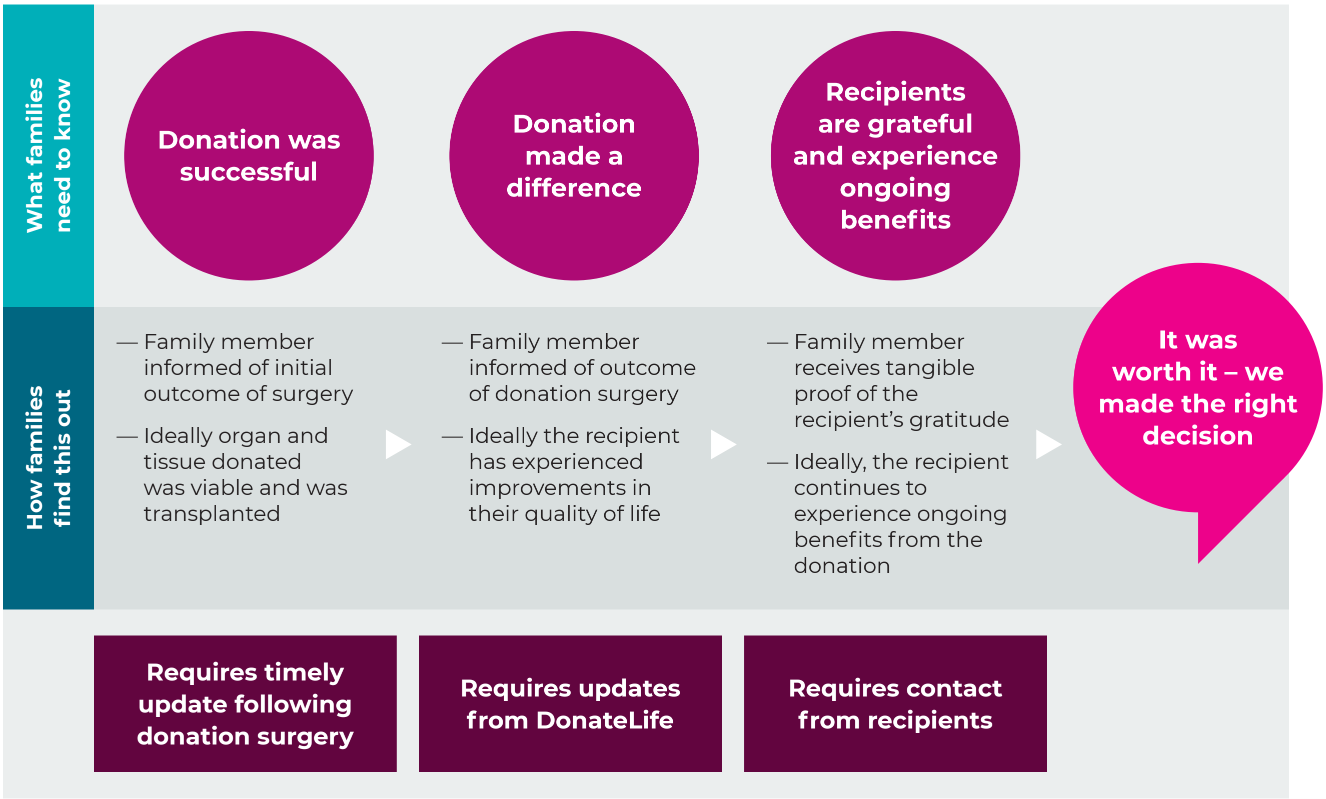
^ These family members do not recall being given the opportunity to receive correspondence

For many donor families, receiving correspondence from recipients provides great comfort and helps families to heal (Figure 49). DonateLife should work with transplant units to provide information about recipients when requested. As one donor family member suggests, it would be helpful if DonateLife staff could obtain news of recipients, if possible, before they call a donor family, just in case an update is requested.

> **I wish she would actually check up on how the recipients are going so that when she rings me she's got some news."**
>
> 2017 – Consented to donation

> **It was INCREDIBLY painful and difficult not having heard from any recipients. I needed to hear from them. I was in a pretty dark headspace until I got these three beautiful letters within a couple of weeks of each other and reading the first one, and then the others, made me feel like it was all worth it and they understood how special she was."**
>
> **I know on an intellectual level these are all ill people who need time to recover, and may also be dealing with their own emotions about getting a donation but I couldn't urge people strongly enough to write if the family wants that. The feeling of hope we wanted to give other families by making the donation is just floating around with no substance otherwise."**
>
> 2017 – Consented to donation

Figure 49 Affirming the choice to donate – the role of information about recipients for some donor families



> **The letter [from DonateLife] was really good but when I received the card from the guy who received Mum's kidneys, the sense of peace it gave me! It was the most amazing feeling. Just that card to say thank you so much. And, I don't want thanks, it's just good to know that someone's living and enjoying life."**
>
> 2016 – Consented to donation

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

13 On reflection

13.1 The decision to donate

Families who consented to donation were asked to reflect on their donation decision and their time in the hospital. In addition to responding to survey questions, they were asked if there was anything else they would like to add about their decision to donate. Responses were collected verbatim and have been coded into like themes, as shown in Table 29. The most common response from families is that donation provided comfort to them at their most difficult time of need.

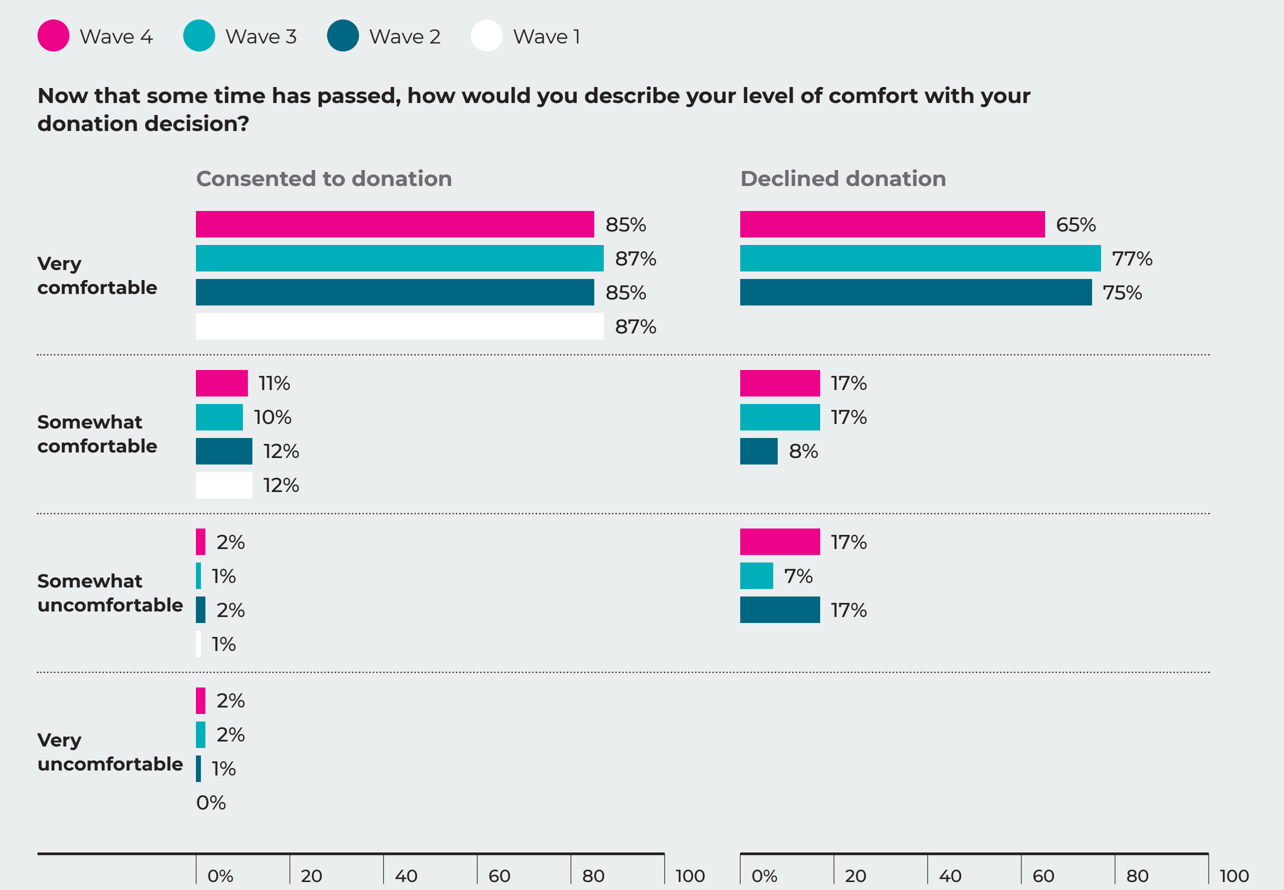
Table 29 Additional comments from donor families about donation decision

Is there anything else you'd like to add about your decision to donate?	No. of responses (n=171)	%
Donation provided comfort/some good in a bad time/knowing they saved lives made their life feel more meaningful	n=41	24%
Happy with decision to donate/thought it was the right decision/everyone in family agreed	n=23	13%
It was our loved one's wish to donate	n=19	11%
Support and contact from hospital staff and donate team was excellent and comforting	n=17	10%
We support organ donation/believe Australia should have an "opt out" system	n=10	6%
We felt by his/her nature that they would have wanted to help others	n=9	5%
Would like more information/updates on recipients	n=8	5%
Would not choose to donate again	n=8	5%
Our family wanted to help others	n=8	5%
It needs to be a faster process once the decision to donate has been made	n=7	4%
Would choose to donate again	n=4	2%
Very difficult decision	n=4	2%
Receiving updates about recipients provides comfort/makes us think that donation was appreciated	n=3	2%
Families should have the right to meet recipients	n=3	2%
Was a positive experience	n=3	2%
Hospital staff/donate team need to be better trained	n=3	2%
Other (one response each)	n=20	12%

13.2 Level of comfort in decision

For 96% of donor families (including intended donor families), the donation decision made in 2016 and 2017 still sits well with them today; 85% very much so (Figure 50). Families who declined donation are significantly less likely to feel very comfortable with their decision (65%).

Figure 50 Level of comfort with donation decision



Base: Total sample who consented to donation, less non-response: Wave 4 (n=403); Wave 3 (n=256); Wave 2 (n=317); Wave 1 (n=185)

Base: Total sample who declined donation, less non-response: Wave 4 (n=23); Wave 3 (n=30); Wave 2 (n=12)

As shown in Figure 50, 35% of families who **declined donation** are not entirely comfortable with their donation decision today. This is significantly higher than families who consented to donation where 15% of families are not entirely comfortable with their donation decision.

Some of these family members wanted to donate but there were other members of the family who didn't, and in the absence of knowledge of what their loved one would have wanted, the family opted to decline (seen as the easiest route).

Others just couldn't face donation at the time, even though they support organ and tissue donation themselves. On reflection, some feel that they may have made a different decision if they had more time.

> **Not knowing his wishes and the fact that I'd always said I'd donate our kids' organs if, heaven forbid, they died. Then I couldn't do it."**
>
> 2016 – Declined donation

> **Now two years have passed while we're still grieving. With time to reflect, maybe the decision made would have been different."**
>
> 2016 – Declined donation

Family members who **consented to donation** but who are now not entirely comfortable with their decision cite a number of reasons as listed in Table 30. A lack of contact from recipients or information about recipients (18%) continues to be a key trigger leading to some level of regret, as is the actual process of donation (16%) and the process of making the decision (12%).

Table 30 Reasons for not being entirely comfortable with decision to donate

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)	Wave 4 (n=49)
Not enough information about recipients/not enough communication from recipients/no 'thank you' from recipients	14%	15%	19%	18%
Donation process was unsatisfactory	9%	5%	4%	16%
Process of deciding is too difficult – felt rushed and pressured/emotional and exhausting time/traumatic/very long process	9%	10%	19%	12%
Difficult coming to terms with the death	9%	10%	4%	12%
Not sure if decision was right/not sure if decision was the wish of family member who donated	18%	13%	23%	8%
Upsetting that donation didn't proceed (medically unsuitable/outside of timeframe)	5%	5%	12%	6%
Fear that consenting to donation influenced clinical decisions	–	–	–	6%
Difficult to come to terms with family member's body not being 'whole'/ hard to 'give away' part of loved one	9%	10%	12%	4%
Lack of compassion and support afterwards/once decision was made/felt like donor and donor family no longer mattered	5%	5%	8%	4%
Was treated insensitively by hospital staff	5%	5%	8%	4%
Not all family members agreed, so this impacts how I feel about it today	–	–	–	4%
Was life support removed too soon?	5%	5%	8%	–
Unsure whether family member was dead at time of retrieval/wonder if family member felt pain during donation surgery	5%	10%	4%	2%
Other response	32%	13%	12%	10%

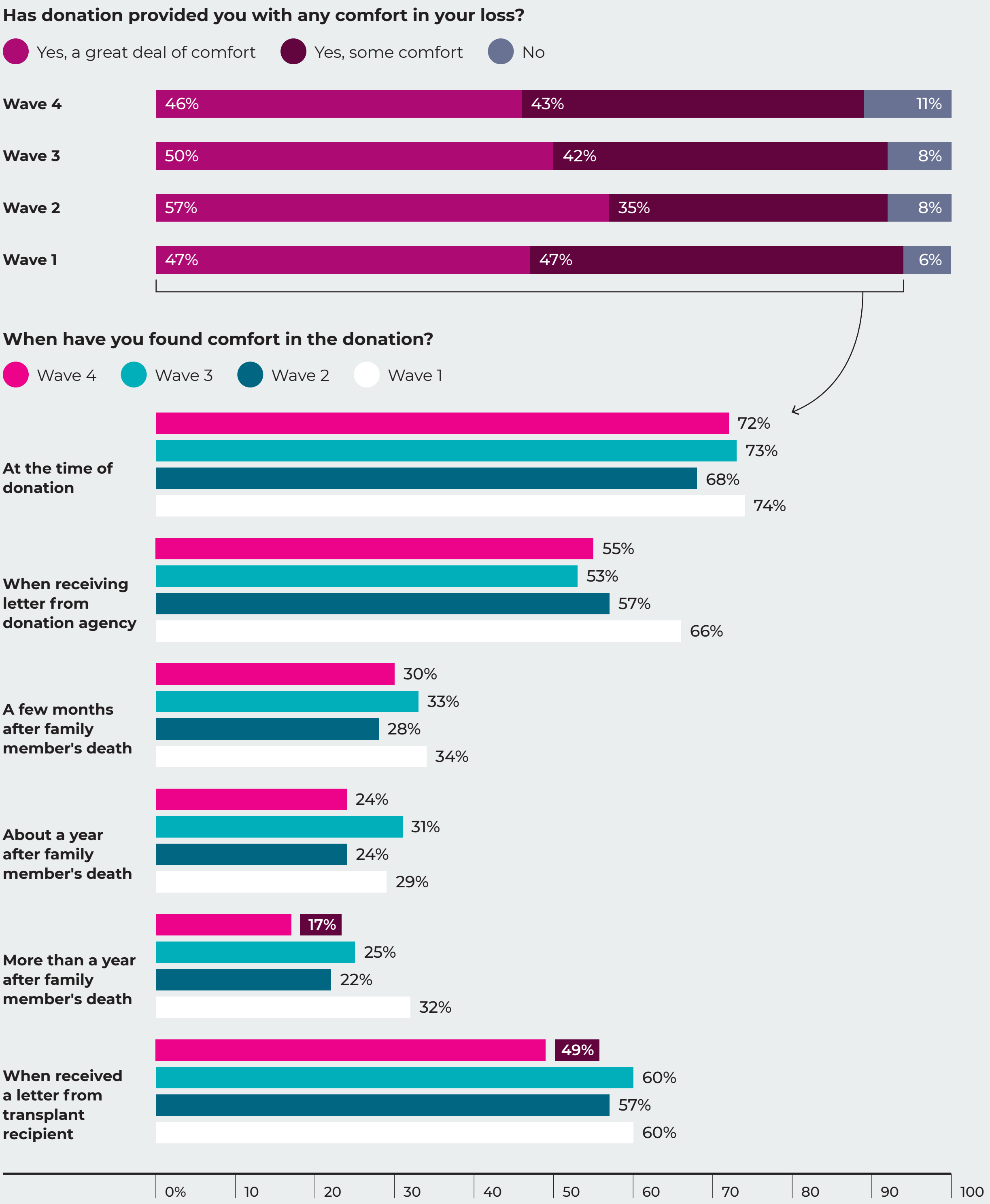
13.3 The impact of donation

Consistent with Wave 3 findings, the majority of donor families (89%) find comfort in donation; 46% finding a great deal of comfort and 43% finding some comfort. As shown in Figure 51, the times when donation provides the greatest comfort are:

- Immediately, at the time of donation – 72%
- When receiving initial letter from DonateLife – 55%
- When receiving correspondence from recipient – 49%

These findings point to the fact that donor families need to know that their donation was not in vein – that it has made a positive difference to another person's life.

Figure 51 The impact of donation



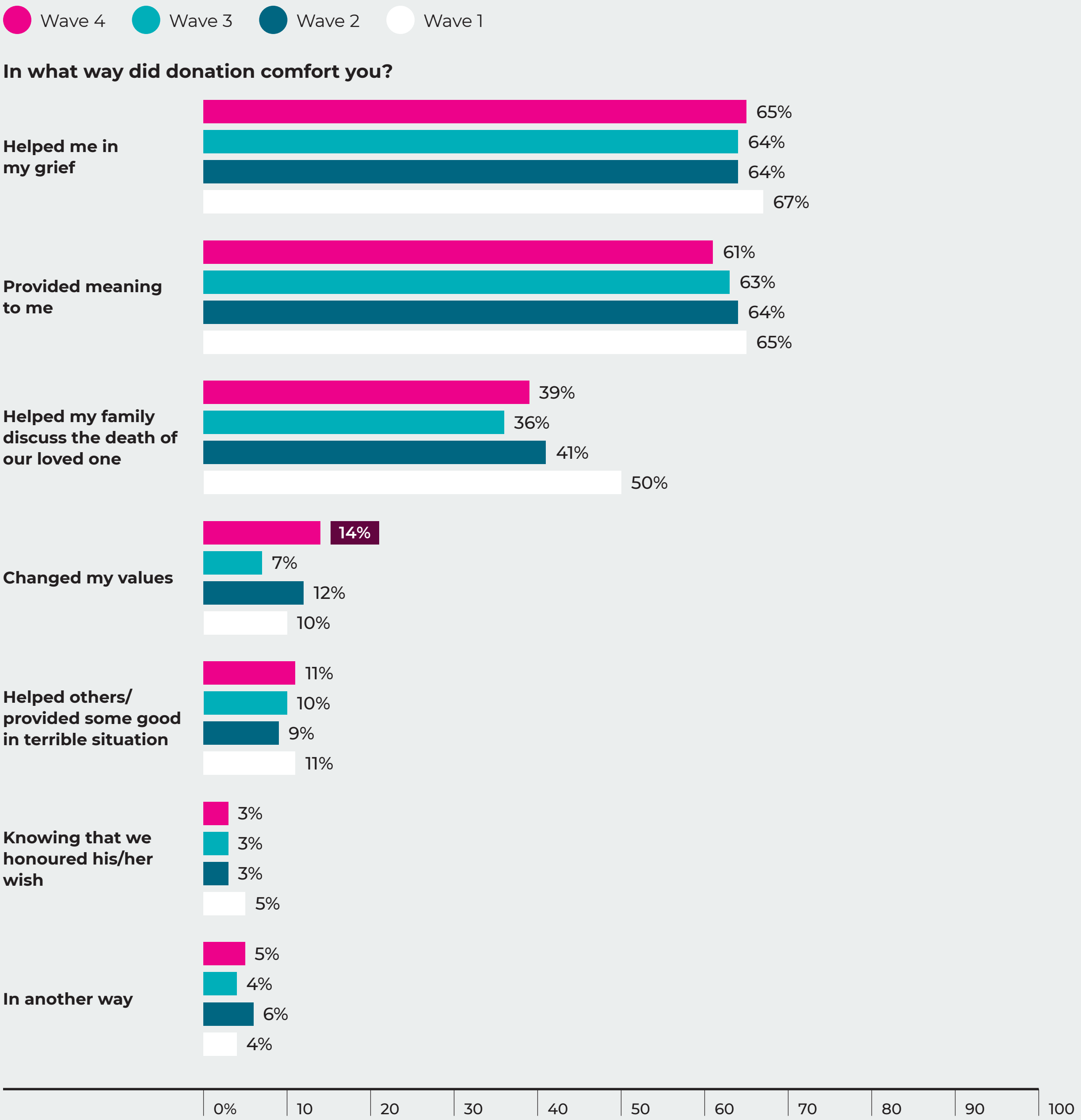
Base: Total sample, less non-response: Wave 4 (n=387); Wave 3 (n=248); Wave 2 (n=314); Wave 1 (n=180).
Those who found comfort in donation, less non-response: Wave 4 (n=336); Wave 3 (n=215); Wave 2 (n=281); Wave 1 (n=170).

Multiple responses allowed.

■ Denotes statistically significant difference between Wave 3 and Wave 4

In terms of *how* donation helps, 65% of donor families say that donation helps them in their grief; 61% say that it provides meaning and 39% say that it helps their family to talk about the death of their loved one – something that is important to do for many families to keep their loved one's memory alive. Interestingly, 14% of donor family members feel that donation has changed their values (Figure 52).

Figure 52 How donation has provided comfort



Base: Those who found comfort in donation, less non-response: Wave 4 (n=332); Wave 3 (n=210); Wave 2 (n=282); Wave 1 (n=168).

Multiple responses allowed.

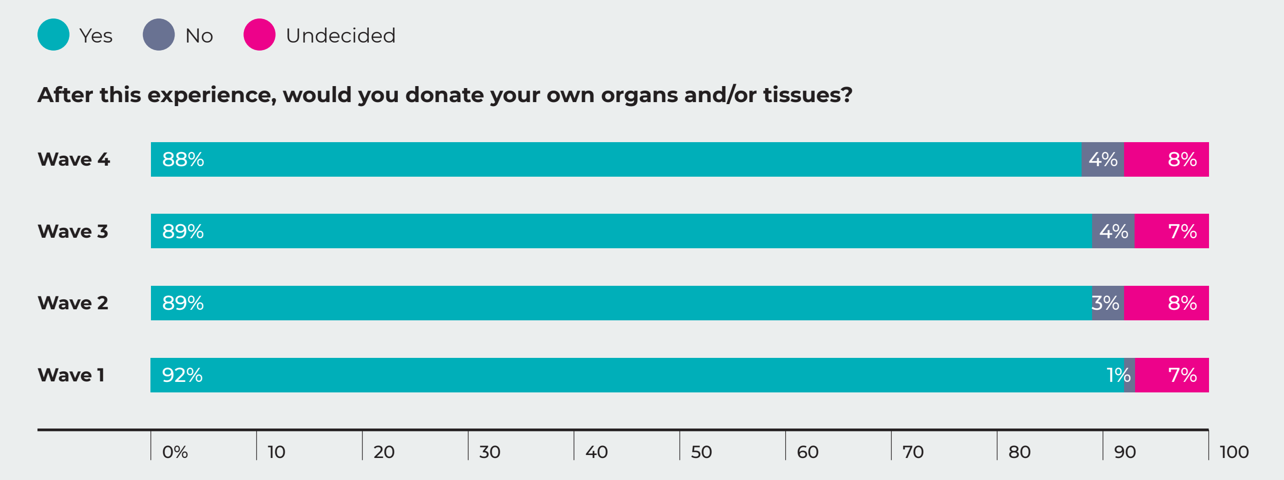
■ Denotes statistically significant difference between Wave 3 and Wave 4

> **Because it's not a life wasted. And because it's a ripple effect. So, not only has he helped two people, but it's that recipient's whole family, and then their ripple effect."**
> 2017 – Consented to donation

13.4 The impact of donation on future intentions

After the donation experience, 88% of donor family members would donate their own organs and/or tissues after death (Figure 53). There has been no significant change in this sentiment since Wave 1 of the Donor Family Study. Eight percent (8%) of donor family members are undecided, while 4% would not wish to donate.

Figure 53 Impact of experience on decision to donate own organs and/or tissues



Base: Total sample who consented to donation, less non-response: Wave 4 (n=390); Wave 3 (n=247); Wave 2 (n=316); Wave 1 (n=179)

There are no significant differences between consenting and intending donor families, as shown in Table 31.

Table 31 Impact of experience on decision to donate own organs and/or tissues – by donation pathway

After this experience, would you donate your own organs and/or tissue?	DCD (n=85)	DBD (n=260)	Intended (n=45)
Yes	82%	89%	91%
No	6%	3%	4%
Undecided	12%	7%	4%

These findings are consistent with previous waves.

Those who consented to donation but now oppose it for themselves tend to feel this way because a) they haven't heard from recipients and therefore don't feel that their gift has been valued (25%), or b) they feel they weren't treated well in hospital (25%).

> **Donation made my suffering worse. My son was chopped up for spare parts for a stranger who has not even had the decency to say thank you."**
> 2016 – Consented to donation

> **Because of how my family was treated by the donor lady was very upsetting."**
> 2017 – Consented to donation

Some have a preference for donating their bodies to science (25%), while 8% feel that their organs would not be useful because of their age or medical history. The remaining 17% who consented to donation but who now oppose it for themselves prefer not to provide an explanation other than to say that it is a personal decision.

For those who consented and are now undecided as to their own personal view of donation, the wavering appears to have been triggered by a combination of the experience in hospital (mostly feeling rushed to decide and then experiencing time delays) and a lack of acknowledgement from the recipients.

> **I felt it was too rushed and there was not enough understanding of how we were feeling.”**
> 2017 – Consented to donation

> **It was a very painful decision and one I’d probably like to spare my wife.”**
> 2016 – Consented to donation

> **It was stressful on family members. It may have been better if the recipient had made contact. That would have made us think that all was good.”**
> 2016 – Consented to donation

Among families who declined donation in 2016 and 2017:

- 83% would make the same decision again (70% in Wave 3, not significant)
- None would make a different donation decision (15% in Wave 3, not significant)
- 17% are unsure (15% in Wave 3, not significant)

> **If it was any family member other than my child, I could have consented to donation.”**
> 2017 – Declined donation

> **The decision was my daughter’s, not necessarily mine. It was her life, her death, her decision. I merely respected her wishes.”**
> 2016 – Declined donation

Table 32 shows that prior to their donation experience, 86% of family members held positive views about donation, 13% had mixed feelings and 1% held negative views. This is consistent with Wave 3 findings.

As we’ve seen in the comments above, 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 and speak favourably about donation to others, while a negative experience can cause negative word of mouth and can change a person’s mind about registering on the AODR.

It is pleasing to see that of those family members who had mixed feelings about donation prior to their loved one’s death, half (50%) would now donate their own organs.

Table 32 Impact of donation on personal views

Previously held views about donation	Total (n=404)	Would donate own organs and/or tissues?	
Generally positive (n=333)	86%	Yes	94%
		No	2%
		Undecided	4%
Mixed feelings (n=50)	13%	Yes	50%
		No	18%
		Undecided	32%
Generally negative (n=6)	1%	Yes	50%
		No	33%
		Undecided	17%

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), Wave 3 (sample size of n=257 donor family members), and Wave 4 (sample size of n=405 family members) where direct comparisons can be made.

14.1 The decision to donate

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Self-reported donation pathway (unique family units)	DBD	89%	88%	86%	85%	Figure 2B
	DCD	11%	12%	14%	9%	Figure 2B
Prior discussion – Consented to donation	Yes and knew wishes	59%	59%	63%	**54%**	Figure 9
	Yes, but unclear on wishes	9%	9%	8%	12%	Figure 9
	Did not discuss	32%	32%	29%	34%	Figure 9
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 • Wave 4: n=267	Made decision a lot easier	76%	80%	74%	70%	Table 11
	Made decision a bit easier	13%	11%	15%	17%	Table 11
	No impact	10%	8%	7%	12%	Table 11
	Made decision a bit more difficult	2%	1%	4%	2%	Table 11
	Made decision a lot more difficult	–	–	–	–	Table 11
Main reasons for agreeing to donation (top 3 reasons)	Opportunity for something positive to come out of a tragedy	81%	78%	75%	77%	Figure 11
	Family member would have wanted to help others	80%	76%	76%	77%	Figure 11
	For someone else to live a better life	74%	66%	72%	67%	Figure 11

14.2 At the hospital (prior to consenting)

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
ICU/ED staff treated family with consideration and sensitivity	To a great extent	89%	91%	90%	91%	Figure 12
	To some extent	11%	8%	9%	9%	Figure 12
	Not at all	1%	1%	1%	–	Figure 12
Hospital staff made it clear that family member would not survive	Yes	94%	95%	95%	94%	Figure 13
	No	4%	2%	4%	4%	Figure 13
	Not sure	2%	3%	1%	2%	Figure 13
Was given sufficient information to understand that death was expected	Total agree	99%	97%	98%	95%	Figure 14
	Disagree/not sure	1%	3%	2%	5%	Figure 14
Language used by medical staff was clear and easy to understand	Total agree	99%	98%	96%	98%	Figure 14
	Disagree	1%	2%	4%	2%	Figure 14

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Medical staff treated family with compassion and sensitivity	Total agree	99.5%	99%	99%	98%	Figure 14
	Disagree	0.5%	1%	1%	2%	Figure 14
Medical staff treated donor with respect	Total agree	99%	99%	98%	98%	Figure 14
	Disagree	1%	1%	2%	2%	Figure 14
Had sufficient opportunity to ask questions of medical staff	Total agree	97%	96%	97%	96%	Figure 14
	Disagree/not sure	3%	4%	3%	4%	Figure 14
Had enough private time with family member after receiving grave news	Yes	91%	91%	89%	89%	Figure 18
	No	7%	6%	5%	7%	Figure 18
	Not sure	2%	3%	6%	4%	Figure 18
Brain death testing						
Offered to be present during brain death testing	Yes	24%	24%	25%	**36%**	Figure 16
	No	50%	**62%**	56%	**46%**	Figure 16
	Not sure	26%	**14%**	19%	18%	Figure 16
Chose to be present during brain death testing (among those who were offered)	Yes	55%	**73%**	68%	66%	Figure 16
	No	45%	**27%**	32%	34%	Figure 16
Seeing tests helped in understanding that loved one had died (among those who attended brain death testing)	Yes	91%	91%	**72%**	85%	Figure 16
	No/not sure	9%	9%	**28%**	15%	Figure 16
Would have helped to have option of being present (among those who were not offered)	Yes	18%	20%	22%	24%	Figure 16
	No/not sure	82%	80%	78%	76%	Figure 16

14.3 The donation conversation

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Who initially raised donation	Doctor	29%	34%	26%	29%	Figure 19
	Donor coordinator	13%	**21%**	26%	27%	Figure 19
	Nurse	4%	7%	9%	6%	Figure 19
	Health professional – Net	**46%**	**58%**	**53%**	**57%**	**Figure 19**
	Self	20%	22%	26%	22%	Figure 19
	Family/friend	10%	11%	9%	**15%**	Figure 19
	Self/family – Net	**30%**	**33%**	**33%**	**33%**	**Figure 19**
When donation was first raised (in relation to being told of family member's death or expected death)	Before	10%	10%	13%	14%	Figure 23
	At the same time	40%	38%	28%	29%	Figure 23
	Within 1 hour	24%	17%	26%	24%	Figure 23
	More than 1 hour	12%	19%	14%	19%	Figure 23
Appropriateness of timing	Yes	74%	73%	74%	77%	Figure 25
	No/not sure	26%	27%	26%	23%	Figure 25

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Discussions with hospital staff about donation prior to donation decision being made						
Discussions were handled sensitively and with compassion	Total agree	98%	96%	97%	97%	Figure 27
	Disagree/not sure	2%	4%	3%	3%	Figure 27
Family had enough opportunities to ask questions about donation	Total agree	93%	**97%**	95%	96%	Figure 29
	Disagree/not sure	7%	**3%**	5%	4%	Figure 29
Hospital staff answered questions	Total agree	95%	98%	95%	98%	Figure 30
	Disagree/not sure	5%	2%	5%	2%	Figure 30
Given sufficient information to allow an informed decision to be made	Total agree	95%	97%	96%	96%	Figure 28
	Disagree/not sure	5%	3%	4%	4%	Figure 28
Given enough time to discuss donation and make decision	Total agree	94%	96%	96%	96%	Figure 31
	Disagree/not sure	6%	4%	4%	4%	Figure 31
Feel pressured or rushed	Yes	8%	8%	7%	10%	Figure 32
	No	88%	87%	89%	85%	Figure 32
	Not sure	4%	5%	4%	5%	Figure 32

■ Denotes statistically significant difference

14.4 Moving towards donation

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Met with DonateLife coordinator, nurse or doctor	Yes	91%	92%	93%	96%	Figure 33
	No	5%	4%	3%	2%	Figure 33
	Not sure	4%	4%	4%	2%	Figure 33
Understanding of donation process after meeting with donation staff	Well informed	82%	83%	80%	84%	Table 19
	Still had questions	16%	14%	18%	14%	Table 19
	Not a good understanding of donation process	2%	2%	2%	2%	Table 19
Made aware that donation may not happen even after consent	Yes	90%	88%	91%	91%	Section 9.1
Written information						
Received written information	Before decision was made	16%	**27%**	22%	**30%**	Figure 34
	After decision was made	24%	20%	26%	28%	Figure 34
	Did not receive written information	15%	14%	13%	11%	Figure 34
	Can't recall	48%	41%	40%	34%	Figure 34
Read information (amongst those who received it)	Yes, in detail	53%	54%	45%	47%	Figure 35
	Yes, skimmed through it	46%	41%	48%	44%	Figure 35
	Did not read	1%	5%	7%	9%	Figure 35

Experience		**Wave 1**	**Wave 2**	**Wave 3**	**Wave 4**	**Location**
When information was read (amongst those who read information)	Before finalising decision	28%	35%	27%	33%	Figure 35
	After finalising decision	64%	**43%**	59%	**46%**	Figure 35
	Not sure	7%	**21%**	15%	21%	Figure 35
Usefulness of written information (amongst those who read it)	Very useful	55%	52%	42%	47%	Table 20
	Quite useful	41%	44%	53%	47%	Table 20
	Not useful	5%	2%	5%	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%	91%	Figure 36
	To some extent	10%	10%	9%	8%	Figure 36
	Not at all	1%	1%	2%	1%	Figure 36
Offered support of a social worker, counsellor or chaplain	Yes	76%	79%	78%	84%	Figure 37
	No	10%	10%	7%	7%	Figure 37
	Not sure	14%	11%	15%	**9%**	Figure 37
Donation process						
Given enough time with family member prior to surgery	Yes	95%	95%	94%	93%	Figure 39
	No	5%	5%	6%	7%	Figure 39
Given the information you wanted about donation surgery	Yes	83%	85%	81%	**88%**	Figure 38
	No/not sure	17%	15%	19%	**12%**	Figure 38
Information about donation surgery	Too detailed	2%	3%	2%	4%	Figure 38
	Too broad	5%	3%	4%	2%	Figure 38
	Too brief	8%	4%	10%	8%	Figure 38
	Just right	85%	89%	83%	85%	Figure 38
Staff in ICU treated family member with respect	To a great extent	91%	94%	94%	93%	Figure 40
	To some extent	8%	6%	4%	7%	Figure 40
	Not at all	1%	–	2%	1%	Figure 40

■ Denotes statistically significant difference

14.5 After donation surgery

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Offered opportunity to spend time with family member after donation surgery	Yes	49%	47%	40%	**50%**	Figure 41
	No	37%	36%	43%	39%	Figure 41
	Not sure	14%	17%	18%	**12%**	Figure 41
Spent time with family member after surgery (amongst those who were offered)	Yes	53%	56%	58%	52%	Figure 41
	No	47%	44%	42%	48%	Figure 41
Would have liked the opportunity to see family member post-surgery (amongst those who were not offered)	Yes	10%	11%	11%	**20%**	Figure 41
	No	66%	61%	68%	63%	Figure 41
	Not sure	24%	28%	21%	17%	Figure 41

■ Denotes statistically significant difference

14.6 Follow-up services

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Offered ongoing contact after donation from DonateLife coordinator, nurse or doctor, a DFSC, hospital social worker or hospital chaplain	Yes	85%	**95%**	97%	97%	Figure 42
Level of contact with DonateLife agency staff to date	Too much	1%	3%	6%	3%	Figure 46
	Not enough	14%	11%	13%	**20%**	Figure 46
	Just right	85%	85%	81%	77%	Figure 46

■ Denotes statistically significant difference

14.7 Contact with recipients

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Awareness of donor families being able to write to recipients	Aware	N/A	50%	44%	**53%**	Figure 47
	Unaware	N/A	50%	56%	**47%**	Figure 47
Received correspondence from any transplant recipient (amongst unique donor families): • Wave 1: n=123 • Wave 2: n=246 • Wave 3: n=194 • Wave 4: n=276	Yes, from one or more	69%	63%	63%	62%	Figure 48
	No, even though I wanted to	24%	25%	22%	29%	Figure 48
	No, I chose not to receive any	7%	8%	8%	7%	Figure 48
Correspondence from recipients (amongst unique donor families who received any correspondence from recipients): • Wave 1: n=84 • Wave 2: n=156 • Wave 3: n=123 • Wave 4: n=170	Of great comfort	87%	78%	81%	77%	Figure 48
	Of some comfort	13%	20%	18%	22%	Figure 48
	Of no comfort	–	2%	1%	1%	Figure 48

■ Denotes statistically significant difference

14.8 On reflection

Experience		Wave 1	Wave 2	Wave 3	Wave 4	Location
Level of comfort with decision to agree to donation	Very comfortable	87%	85%	87%	85%	Figure 50
	Somewhat comfortable	12%	12%	10%	11%	Figure 50
	Somewhat uncomfortable	1%	2%	1%	2%	Figure 50
	Very uncomfortable	–	1%	2%	2%	Figure 50
Donation provided any comfort in loss	Great deal of comfort	47%	**57%**	50%	46%	Figure 51
	Yes, some comfort	47%	**35%**	42%	43%	Figure 51
	No	6%	8%	8%	11%	Figure 51
In what way donation has provided comfort (amongst those who found comfort in donation) – top 3 responses	Provided meaning	65%	64%	63%	61%	Figure 52
	Help in time of grief	67%	64%	64%	65%	Figure 52
	Helped family discuss death of our loved one	50%	41%	36%	39%	Figure 52
After donation experience, feelings towards donation	Would donate after death	92%	89%	89%	88%	Figure 53
	Would not donate after death	1%	3%	4%	4%	Figure 53
	Undecided	7%	8%	7%	8%	Figure 53

■ Denotes statistically significant difference

> **Despite my emotion surrounding it all, and constant reflection on how it is not all black and white, I believe our decision to donate was the right one.”**

2016 – Consented to donation

Appendices

A1 Glossary of key terms

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

Term	Definition
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	The organ and tissue donation agency 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	A family member of someone who is an organ or tissue donor.
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.
Intended donor	A patient who's family agreed to donation however donation was not able to occur due to medical or other reasons.
Organ and Tissue Authority (OTA)	Australian Government 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.

Term	Definition
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.
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.

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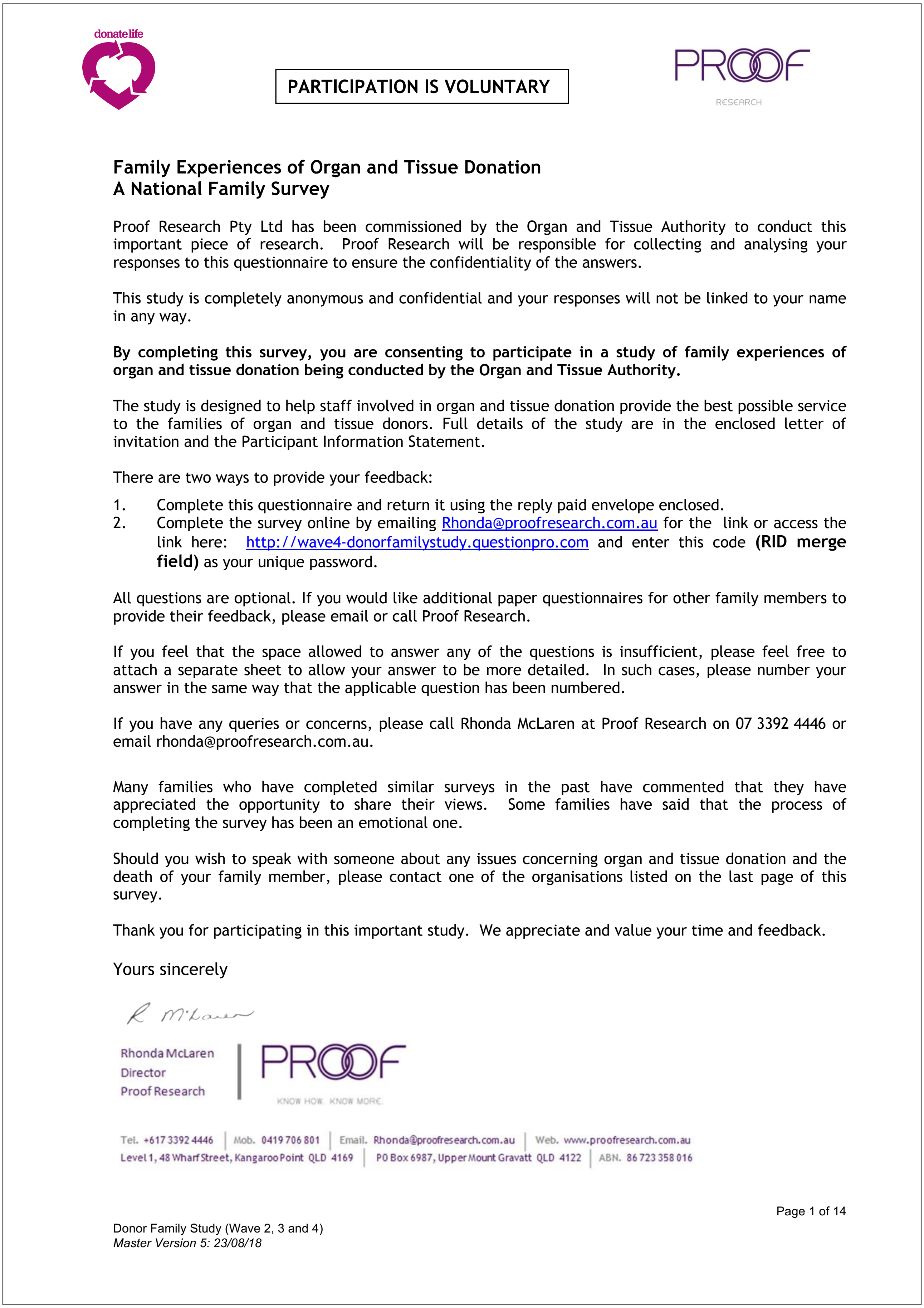
A4 Research instruments

A4.1 Questionnaire – Consenting families



PARTICIPATION IS VOLUNTARY

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://wave4-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

R McLaren

Rhonda McLaren
Director
Proof Research

PROOF
KNOW HOW. KNOW MORE.

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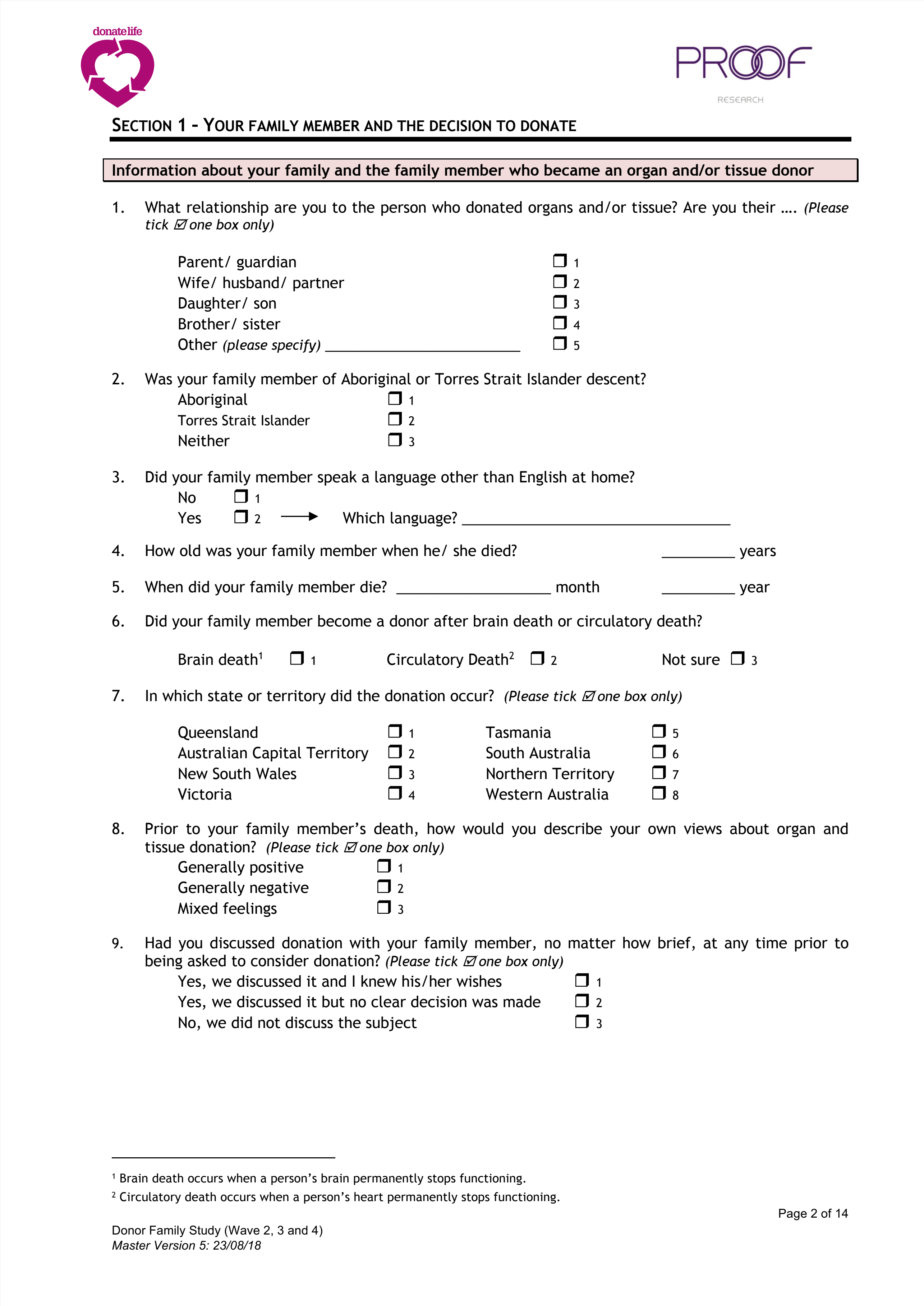


SECTION 1 - YOUR FAMILY MEMBER AND THE DECISION TO DONATE

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.

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? ✍

____

____

____

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 <u>at this time</u>? *(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

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***

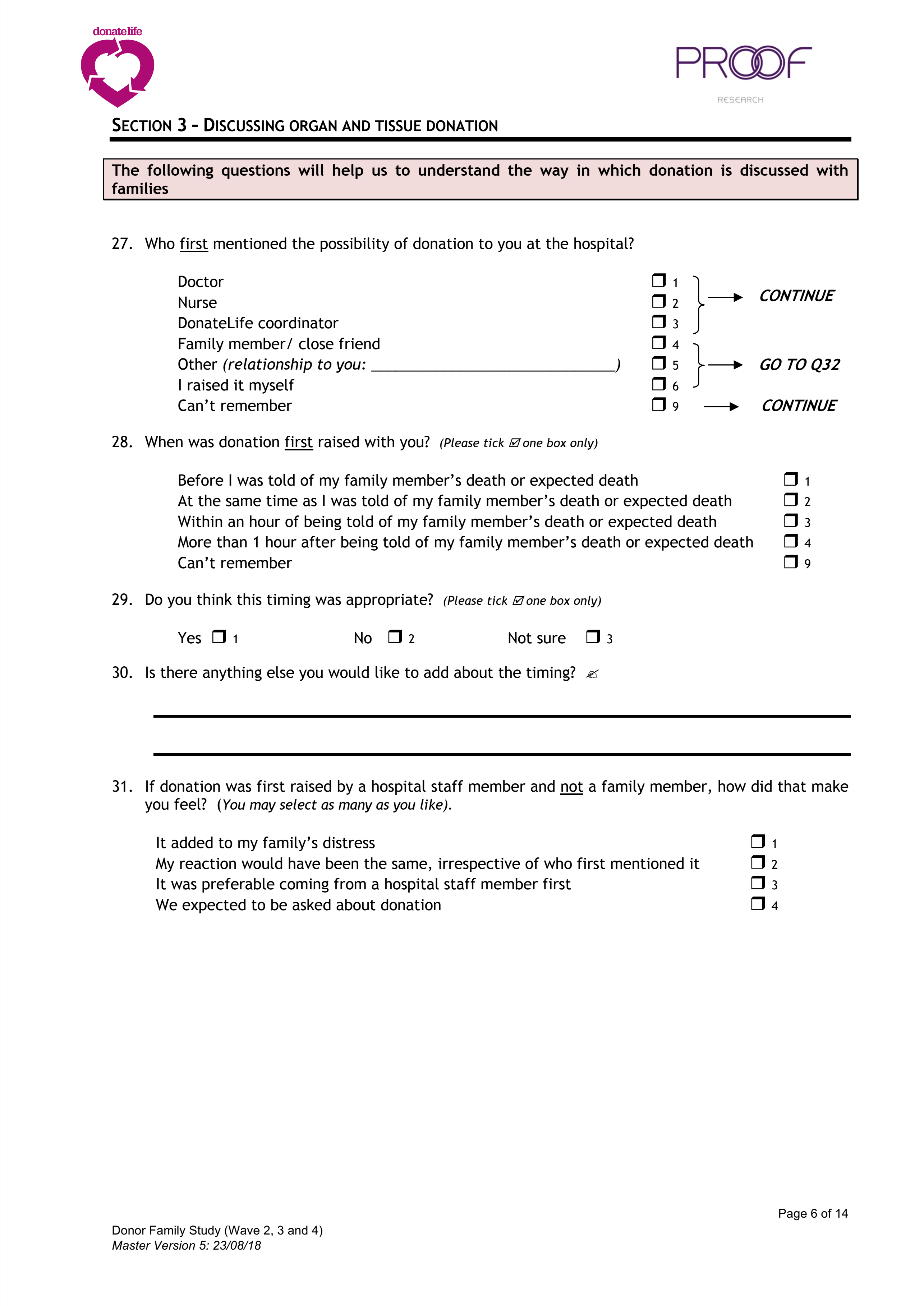
24. **If you answered 'yes' to Q23.** Did seeing the testing help you to understand that your family member had died? *(Please tick ☑ one box only)*

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? ✍



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 prior to your decision, 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 <u>after</u> 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 you 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 you wanted 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 after 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 ⟶ *GO TO Q56*

54. **If you answered 'yes' at Q53.** 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

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 <u>content</u> 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***

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 Q73***

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? ✍

____

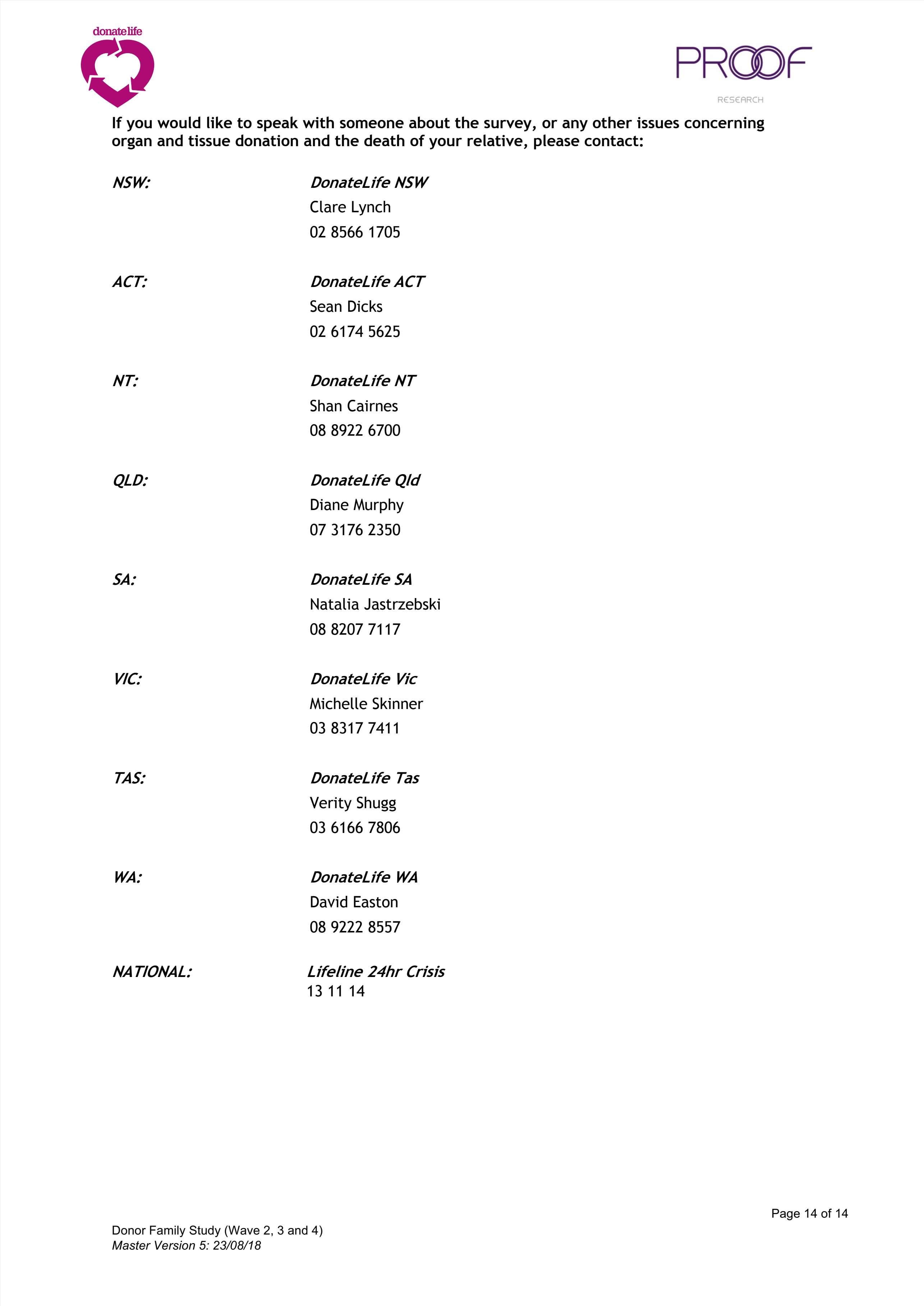
____

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:

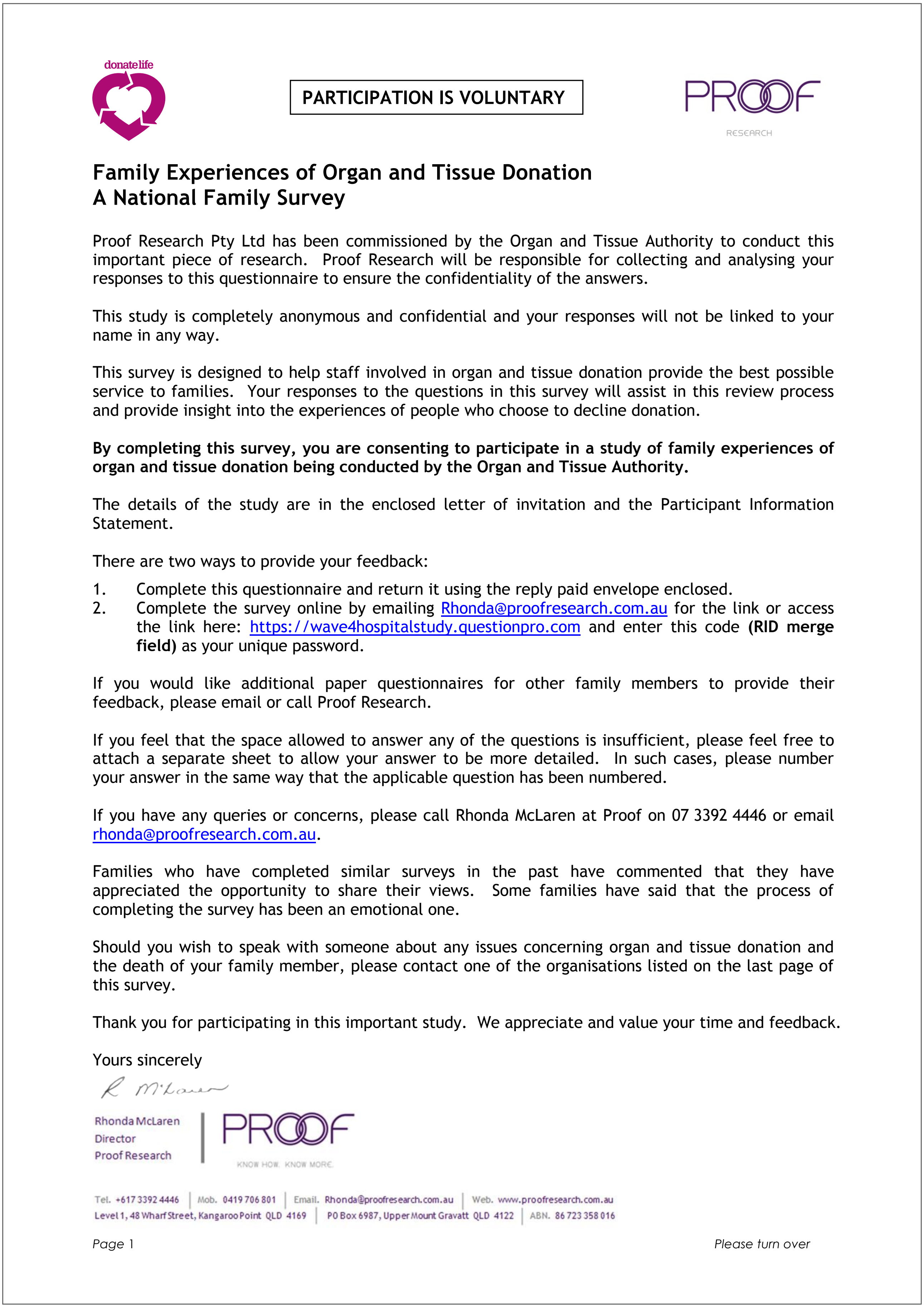
PROOF RESEARCH
REPLY PAID 85405
UPPER MOUNT GRAVATT QLD 4122



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*** Clare Lynch 02 8566 1705
ACT:	***DonateLife ACT*** Sean Dicks 02 6174 5625
NT:	***DonateLife NT*** Shan Cairnes 08 8922 6700
QLD:	***DonateLife Qld*** Diane Murphy 07 3176 2350
SA:	***DonateLife SA*** Natalia Jastrzebski 08 8207 7117
VIC:	***DonateLife Vic*** Michelle Skinner 03 8317 7411
TAS:	***DonateLife Tas*** Verity Shugg 03 6166 7806
WA:	***DonateLife WA*** David Easton 08 9222 8557
NATIONAL:	***Lifeline 24hr Crisis*** 13 11 14

A4.2 Questionnaire – Families who declined donation



PARTICIPATION IS VOLUNTARY

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://wave4hospitalstudy.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

R McLaren

Rhonda McLaren
Director
Proof Research

Tel. +617 3392 4446 | Mob. 0419 706 801 | Email. Rhonda@proofresearch.com.au | Web. www.proofresearch.com.au
Level 1, 48 Wharf Street, Kangaroo Point QLD 4169 | PO Box 6987, Upper Mount Gravatt QLD 4122 | ABN. 86 723 358 016

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)*

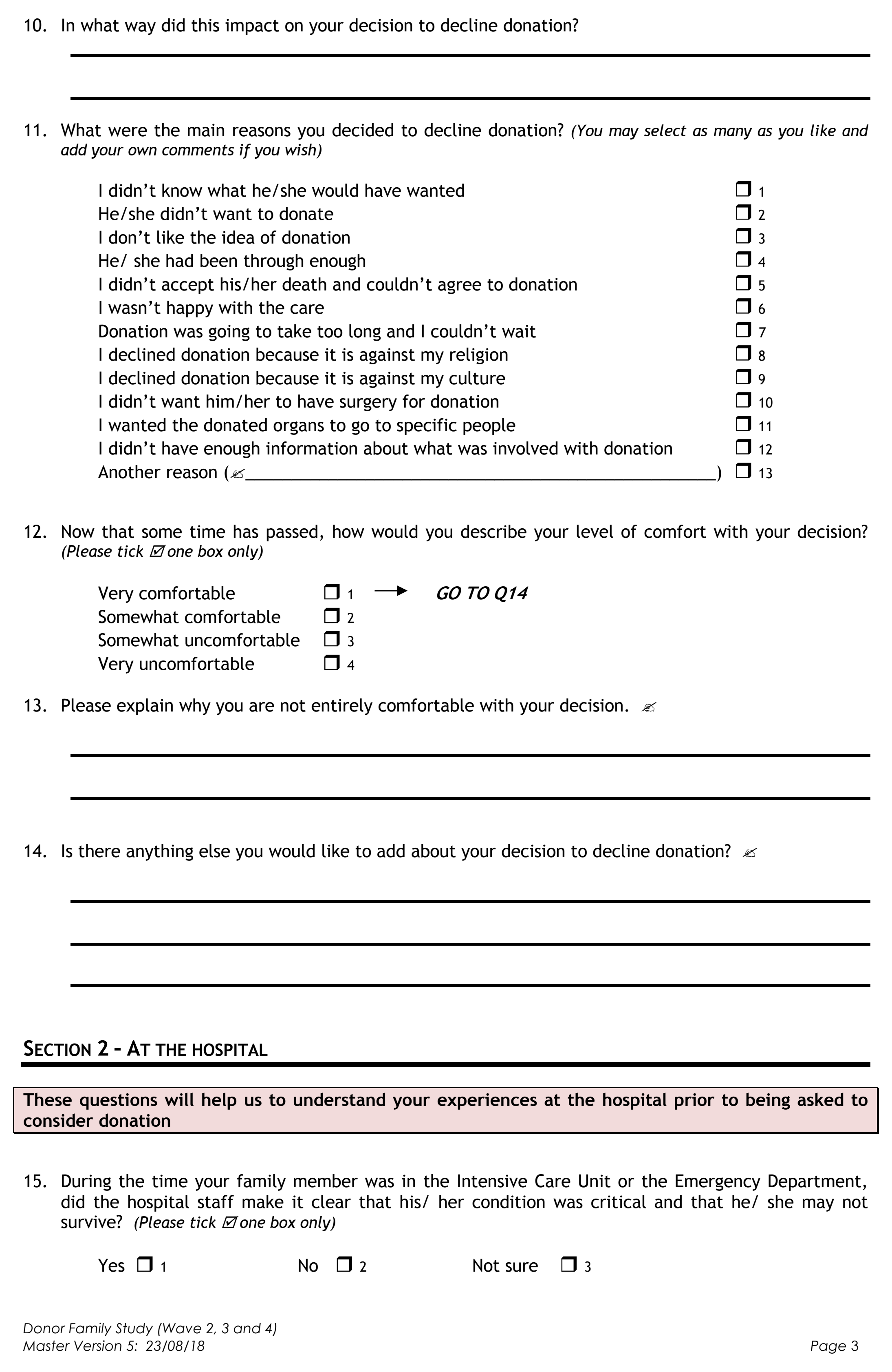
Generally positive ☐ 1
Generally negative ☐ 2
Mixed feelings ☐ 3

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 }

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 Q22.** Did seeing the testing help you to understand that your family member had died? *(Please tick ☑ one box only)*

Yes ☐ 1
No ☐ 2
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?

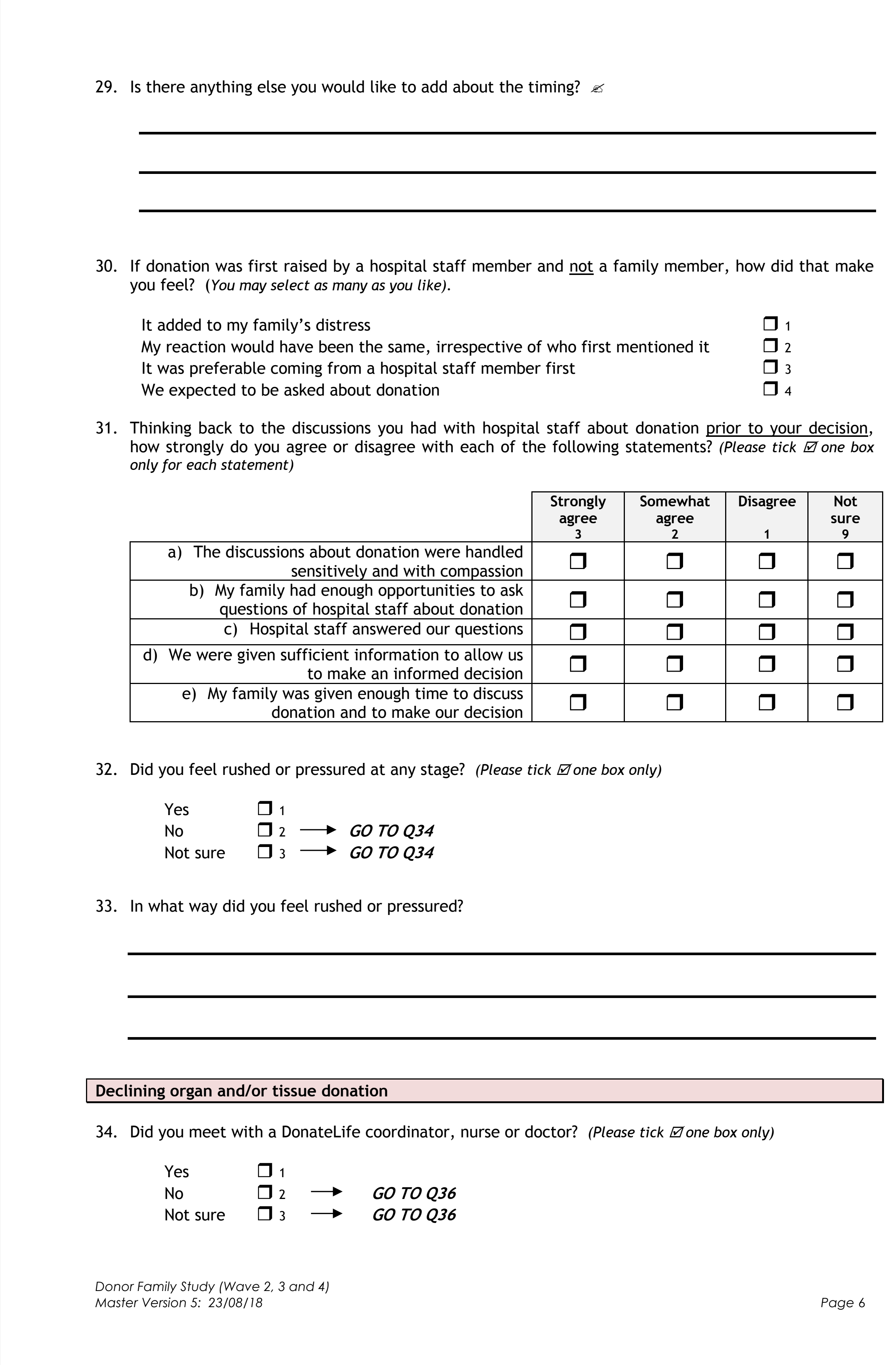
Doctor ☐ 1
Nurse ☐ 2
DonateLife coordinator ☐ 3
} → ***CONTINUE***
Family member/ close friend ☐ 4
Other person *(Relationship to you: ________________________)* ☐ 5
I raised it myself ☐ 6
} → ***GO TO Q31***
Can't remember ☐ 9 → ***CONTINUE***

27. 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 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 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

31. Thinking back to the discussions you had with hospital staff about donation prior to your decision, 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

Donor Family Study (Wave 2, 3 and 4)
Master Version 5: 23/08/18

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 } *GO TO Q49*
No ☐ 2 }
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?

____

____

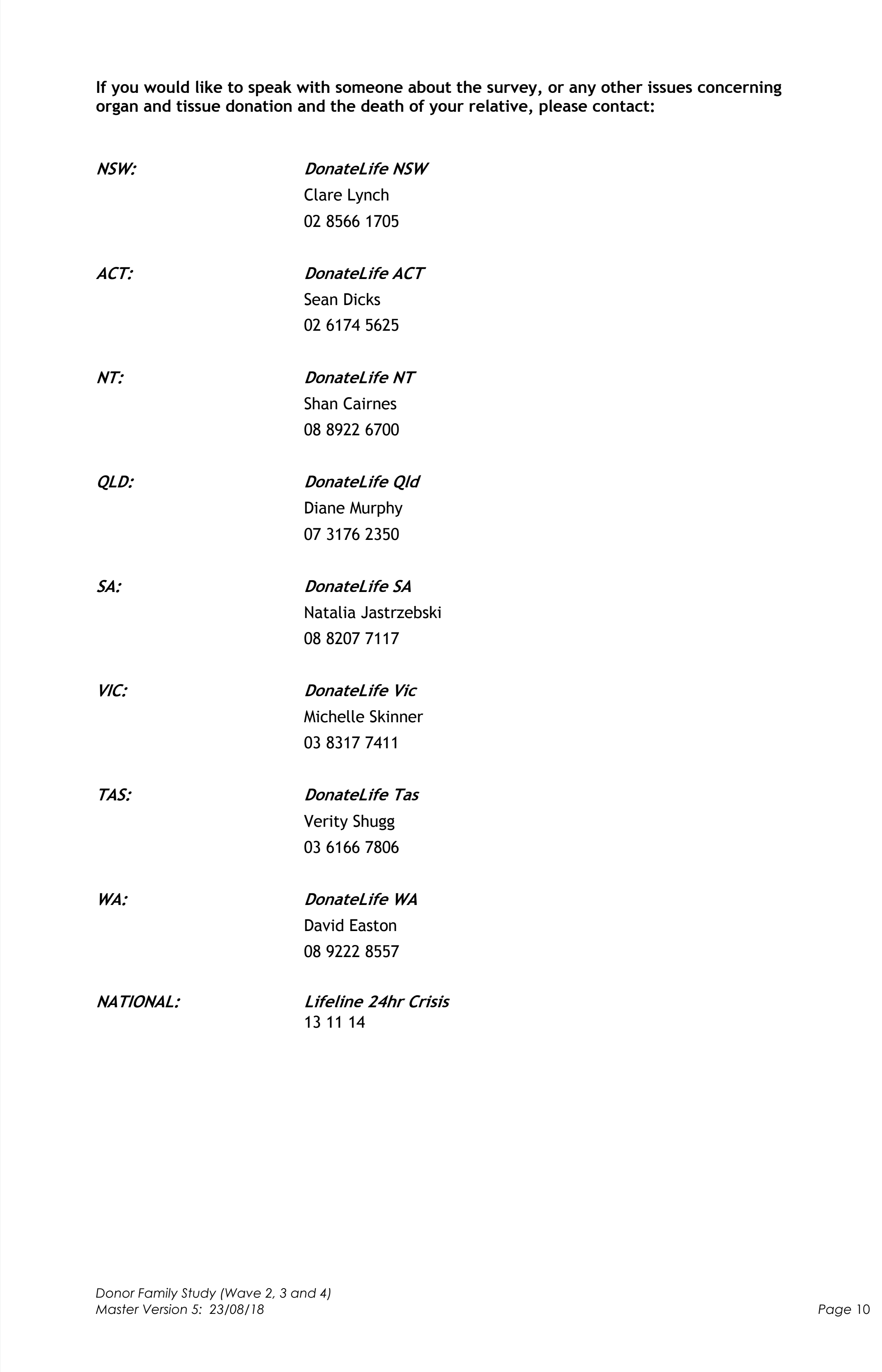
____

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*** Clare Lynch 02 8566 1705
ACT:	***DonateLife ACT*** Sean Dicks 02 6174 5625
NT:	***DonateLife NT*** Shan Cairnes 08 8922 6700
QLD:	***DonateLife Qld*** Diane Murphy 07 3176 2350
SA:	***DonateLife SA*** Natalia Jastrzebski 08 8207 7117
VIC:	***DonateLife Vic*** Michelle Skinner 03 8317 7411
TAS:	***DonateLife Tas*** Verity Shugg 03 6166 7806
WA:	***DonateLife WA*** David Easton 08 9222 8557
NATIONAL:	***Lifeline 24hr Crisis*** 13 11 14

A4.3 Participant Information Statement

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 2016 and 2017 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:

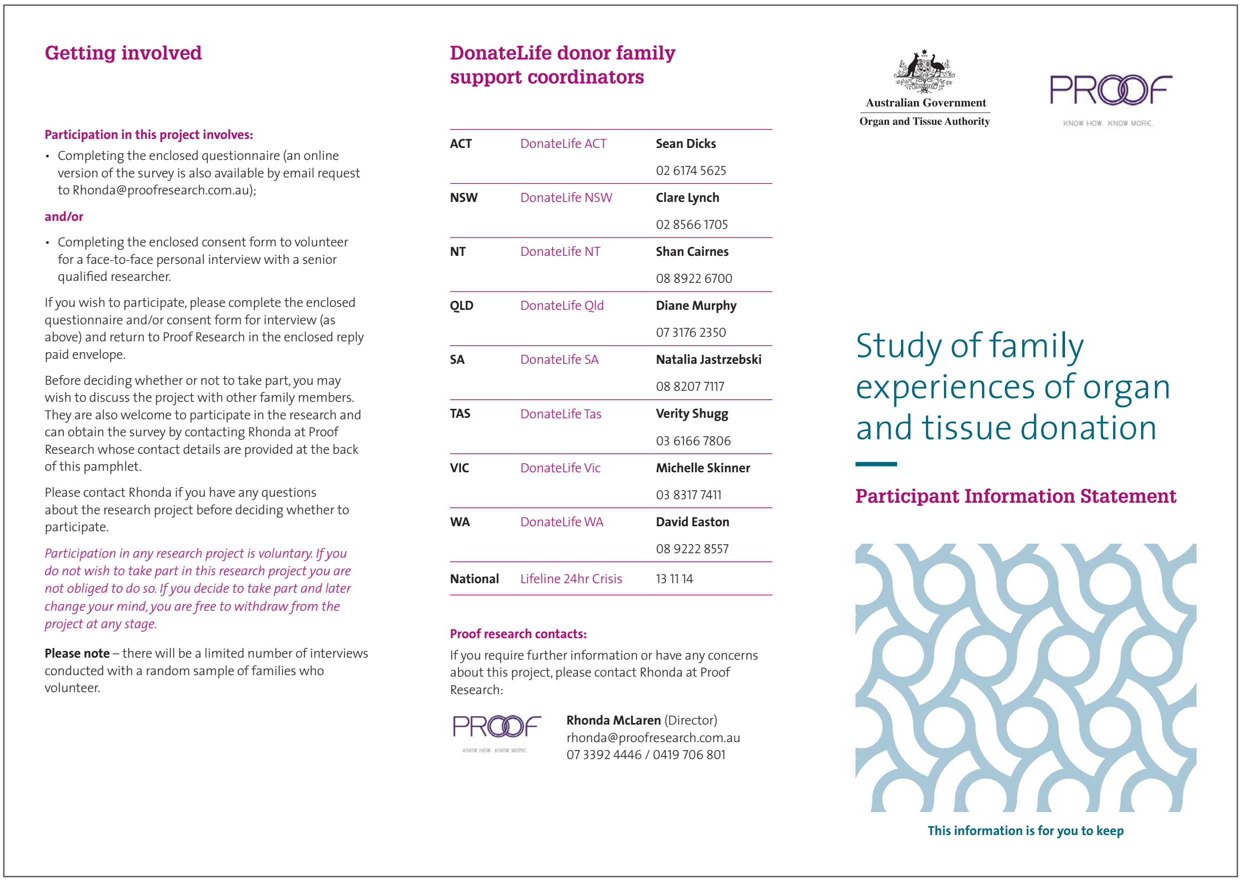
- Unique ID codes will be used to code and track questionnaire completions, maximising anonymity of your responses and data confidentiality protocols.
- All data collected will be non-identifiable. Personal details including your name will not be asked or collected in the questionnaire.

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 Amanda Bell at the Organ and Tissue Authority by email to amanda.bell@donatelife.gov.au or by phoning (02) 6198 9864.

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.



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 at Proof Research whose contact details are provided at the back of this pamphlet.

Please contact Rhonda 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	**Clare Lynch** 02 8566 1705
NT	DonateLife NT	**Shan Cairnes** 08 8922 6700
QLD	DonateLife Qld	**Diane Murphy** 07 3176 2350
SA	DonateLife SA	**Natalia Jastrzebski** 08 8207 7117
TAS	DonateLife Tas	**Verity Shugg** 03 6166 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 at Proof Research:

PROOF
KNOW HOW. KNOW MORE.

Rhonda McLaren (Director)
rhonda@proofresearch.com.au
07 3392 4446 / 0419 706 801

Australian Government
Organ and Tissue Authority

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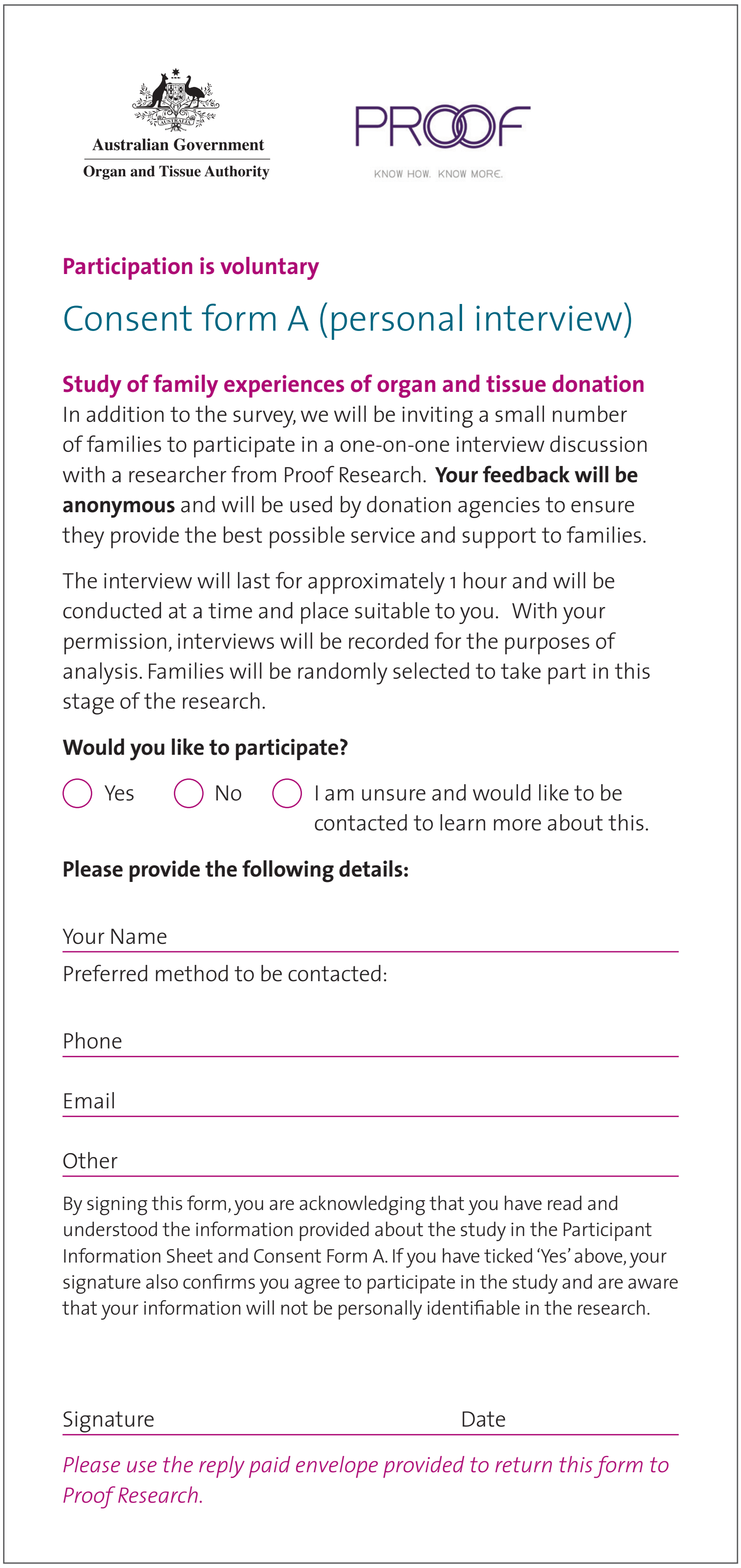
Study of family experiences of organ and tissue donation

Participant Information Statement

This information is for you to keep

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

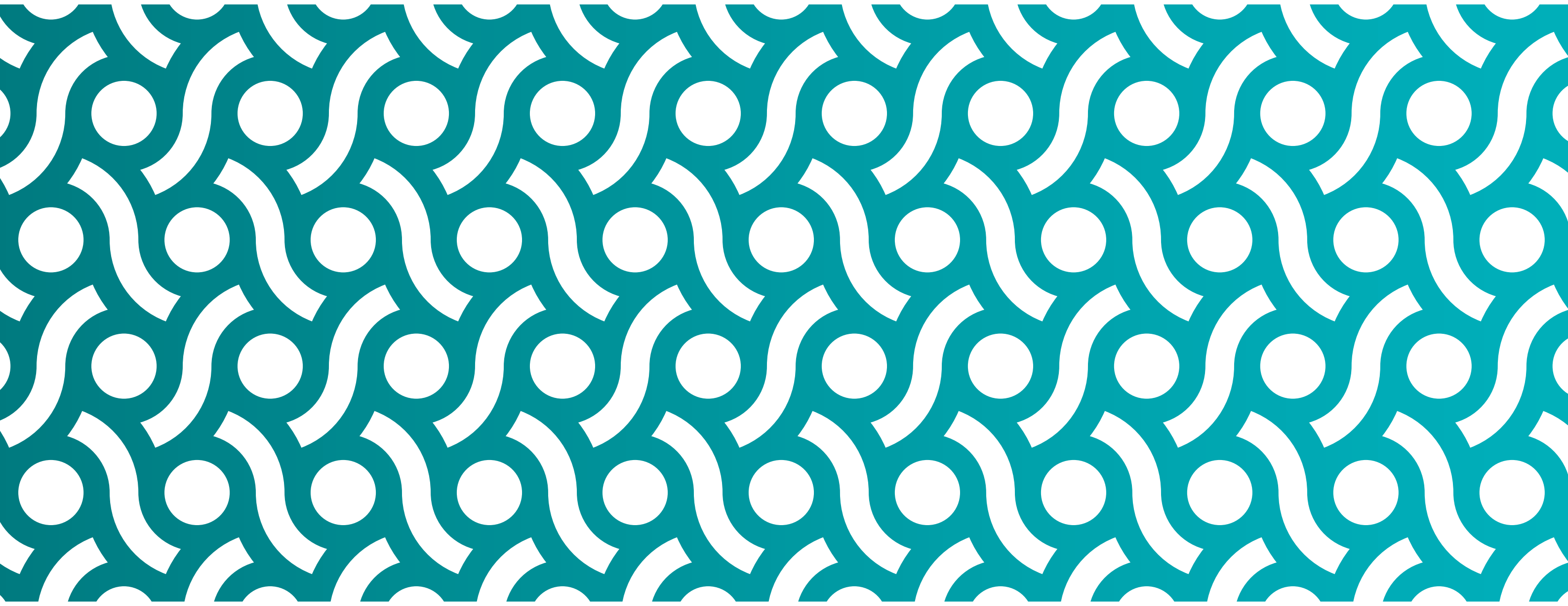
Email

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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